CULTURE IS INCLUSION

A narrative of Aboriginal and Torres Strait Islander people with disability

Scott Avery

FIRST PEOPLES DISABILITY NETWORK (AUSTRALIA)

An initiative of First Peoples Disability Network (Australia)

First Peoples
Disability Network
Australia

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Aboriginal and Torres Strait Islander readers are advised that this narrative includes the voices of people who have passed away.

Aboriginal and Torres Strait Islander people are further cautioned that this research contains personal testimony and content that some people may find distressing.

PROLOGUE

THE MISSING CHAPTER

Back in my younger days, I remember reading the classic Australian novel *Picnic at Hanging Rock*. I love my Australian history and I'm always up for a good mystery, and this book did not miss. The lingering question of what happened to the schoolgirls who vanished from their picnic without a trace, its historical setting, the whole 'Australian-ness' came together in one story, captivating in a way that was truly special. Later made into a classic Australian movie, the haunting image of Miranda and her friends walking up the crevasse in the rock, never to be seen again, sucked me right into a timeless mystery of 'What on earth happened to them?'

Some years later and I was at the University of Wollongong library, searching the sorting shelf for a textbook. Sitting right on top of the shelf is a paperback book, begging to be picked up. It is *The Secret of Hanging Rock*, claiming to be the missing chapter that unveils the mystery of Hanging Rock. There's a missing chapter?! As the story behind the story goes, it claims that the author Joan Lindsay had removed this final chapter from her original piece at the request of her publisher, as a device to create the literary effect of an unanswered mystery. My economics assignment could wait, I took it back to my desk and read it from cover to cover. It gives the game away. Now I had an answer, if not the answer. But when I finished reading, I was torn. Whilst the unsolved mystery introduced the mystical to the original book, there also came a sense of betrayal that there was another part to the story that had been kept from me from the start. But now I know.

Much older again, and I have since discovered that there is another chapter of a story that has been ripped out of a much larger, grander book. It's the story of people with disability in Aboriginal and Torres Strait Islander communities. This is a story that has been excised from the book of Australia's social history. If you go hunting for the disability story amongst the realm of material on the impact of colonisation on Aboriginal and Torres Strait Islander people, then you'll find that the chapter is missing. The history of people with cognitive impairments locked up in mental institutions from the mid 1800s onwards is also hidden. In modern times, the pages on disability have been excluded from the book of Australian Indigenous policies, such as Closing the Gap. And whole chapters on disability have been ripped from every single inquiry into why so many Aboriginal and Torres Strait Islander people end up in prison. Within Australia's social record, Aboriginal and Torres Strait Islander people with disability have similarly just disappeared.

The ambition of this book is to be that missing chapter. It aims to unveil a mystery unknown to many Australians – the story of Aboriginal and Torres Strait Islander people with disability. It goes directly to the source for its material, Aboriginal and Torres Strait Islander people with disability themselves.

How to read this document

This publication, *Culture is Inclusion*, is an outcome of a research project that promotes the voices of Aboriginal and Torres Strait Islander people with disability within research and policy. The research project, which commenced under the working title, *Living our Ways*, is an exploratory study into the issues that affect Aboriginal and Torres Strait Islander people with disability, as told by them through their testimony.

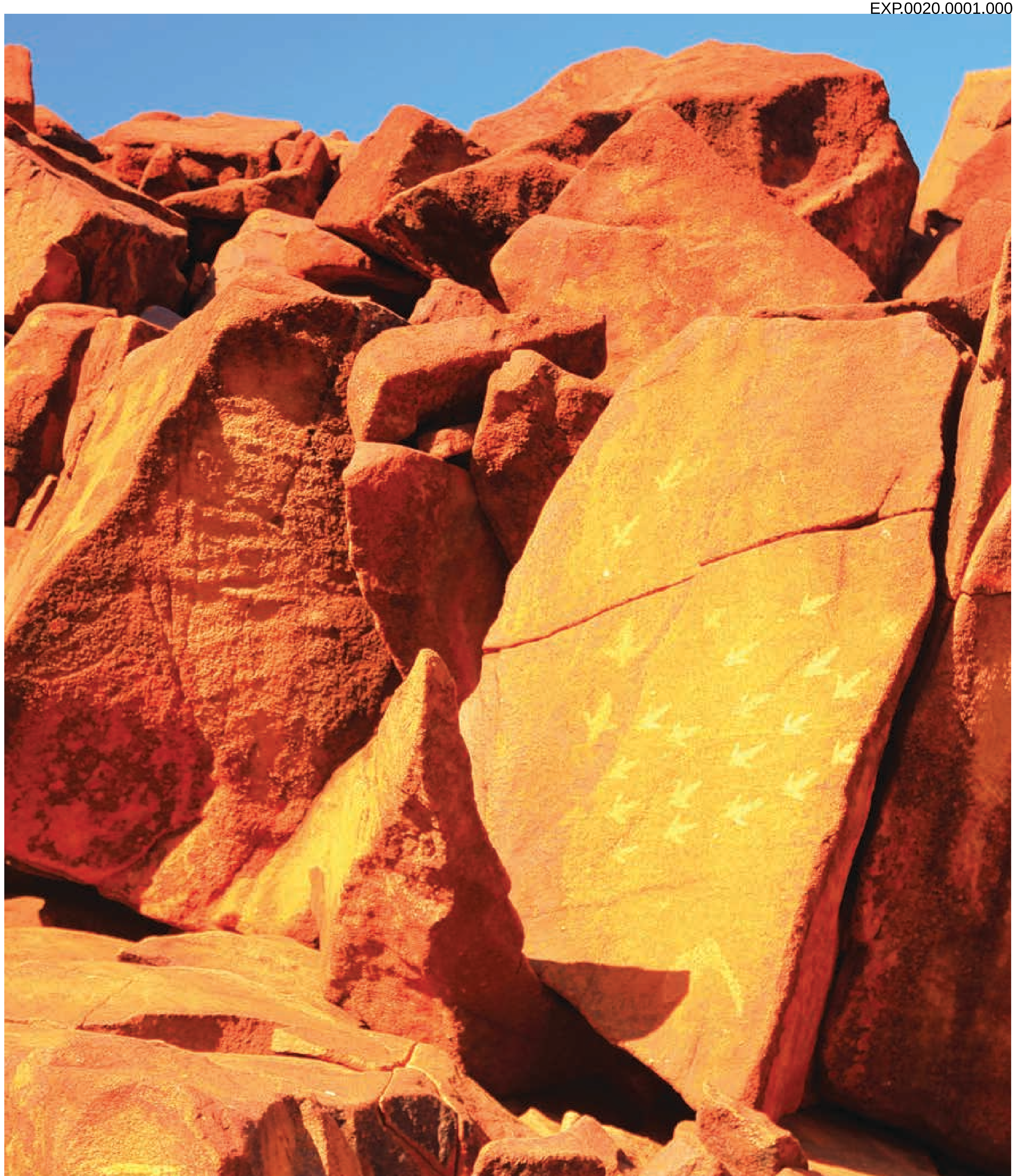
Led by the First Peoples Disability Network, a community-controlled Aboriginal and Torres Strait Islander disability organisation, it creates a 'narrative' of Aboriginal and Torres Strait Islander people with disability by combining their personal testimony gathered through interviews with statistical data sourced from Australian Bureau of Statistics. This data is brought to life with the distinctly Aboriginal concept of 'yarning', where vignettes are extracted from the testimony to show how many issues come together in the daily life of one person. The research is presented in ten chapters.

Chapter 1 introduces the cultural and social background to the research. It entails a brief history of inclusion and disability in Indigenous cultures going back to ancient times. It then provides a snapshot on the impact of colonisation from a disability perspective. It concludes with the emergence of the rights-based movement to draw attention to the marginalisation of Aboriginal and Torres Strait Islander people with disability in Australian society.

Chapter 2 outlines the key concepts and terms used throughout the research. It includes definitions for the use of some common terms within this research. It conceptualises how the 'narrative' was developed, by integrating the testimony from interviews with participants, statistical data, and 'yarnings'. It establishes a vocabulary of new concepts where existing terminology could not adequately explain the experiences of Aboriginal and Torres Strait Islander people with disability. 'Intersectional inequality' and 'apprehended discrimination' are two concepts that have been described in this chapter, and are used in later chapters to explain the research.

Chapter 3 builds on the conceptual model of community-directed research by outlining how the principles for participatory research were put into research practice. It describes the role of an Academic Advisory Panel providing academic guidance on the conduct of the research. It then discusses a relational approach with the Australian Bureau of Statistics in securing technical advice on the statistical data that was used in the research, and outlines the factors that have made this relationship a benchmark of engagement between an Aboriginal and Torres Strait Islander community organisation and a government agency.

Chapter 4 commences the presentation of the research findings. This chapter presents the statistical data on the prevalence and profile of disability in the Aboriginal and Torres Strait Islander population. It also draws upon the testimony of research participants for a focussed discussion of issues that emerged from the statistical data analysis. These issues include: the availability of disability diagnoses in Aboriginal and Torres Strait Islander communities; the 'overshadowing' of co-occurring disability; and the intersection of gender and remoteness in Aboriginal and Torres Strait Islander disability data.



Chapter 5 exposes the discrimination faced by Aboriginal and Torres Strait Islander people with disability attributable to racism, ableism and a unique form of 'intersectional discrimination'. Using illustrative quotes from the testimony of participants, it explores the concept of 'apprehended discrimination' to describe the pathway in which an expectation of discrimination can lead people into avoiding situations where they might be exposed to discrimination.

Chapter 6 is an analysis of the social, health and wellbeing inequalities experienced by Aboriginal and Torres Strait Islander people with disability. The statistical data and participants' testimony have been presented thematically and organised according to the priorities of the Australian Government's National Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability.

Chapter 7 is dedicated to the implementation of the National Disability Insurance Scheme (NDIS) in Aboriginal and Torres Strait Islander communities. Whilst implementation of the NDIS in Aboriginal and Torres Strait Islander communities was in its formative days when this research was conducted, several concerning issues emerged that warrant a further focussed investigation.

Chapter 8 details the staggeringly high detrimental impact that accumulated experiences of discrimination, trauma and social exclusion have on the mental health and wellbeing of Aboriginal and Torres Strait Islander people with disability. It can make for difficult reading, even harder for the people living it. But within the testimony, there still glows embers of hope.

Chapter 9 shifts the tone from social exclusion to a culture of inclusion. It presents a crucial finding of the research: that despite the inequalities experienced in other aspect of their life, Aboriginal and Torres Strait Islander people with disability participate in community and cultural activities at the same rate as other Aboriginal and Torres Strait Islander people. It discusses the implications of a 'culture of inclusion' as a moderating force on the health and wellbeing of Aboriginal and Torres Strait Islander people with disability, and prescribes a model for inclusive policy and practice.

Chapter 10 brings the themes and issues discussed in the previous chapters together to form a concise First Peoples disability research agenda and a direction for further research activity and policy development. This is the ultimate deliverable for the research project and its concluding recommendation.

The first stop in the narrative journey of Aboriginal and Torres Strait Islander people with disability is Lake Mungo in Far West New South Wales, where footprints of a one-legged man on a hunt with his tribe were discovered. More than twenty thousand years old, these footprints have survived the harshest elements.

These footprints survived for a reason.

They survived to tell us a story.

Executive Summary of research findings

1. Disability in Aboriginal and Torres Strait Islander communities is twice as prevalent, more complex in terms of co-occurring disabilities, and compressed within a shorter life expectancy compared to other Australians.
2. Aboriginal and Torres Strait Islander people with disability experience unique form of 'intersectional discrimination' and social inequality that is an interaction of discrimination that is both Aboriginal and Torres Straits Islander and disability related.
3. Frequent exposures to various forms of discrimination can have cumulative impact and can manifest into 'apprehended discrimination'. This is a pathway in which a fear of discrimination transforms into a rational expectation of discrimination, and it can lead to a person avoiding social situations where they could be exposed to possible discrimination.
4. The statistical data and testimony of participants show that intersectional inequality is acute and pervasive across all supports for Aboriginal and Torres Strait Islander people with disability; including disability services, health, education, employment housing and transport.
5. The impact of intersectional inequality as a detrimental impact upon the social health and wellbeing of Aboriginal and Torres Strait Islander people with disability.
6. The sole category that is an exception to the inequalities experienced by Aboriginal and Torres Strait Islander people with disability is their social participation within their own communities. Rates of participation by Aboriginal and Torres Strait Islander people in cultural and community activities are on par with other Aboriginal and Torres Strait Islander people.
7. A culture of inclusion is a moderating force on the social health and wellbeing and has a mitigating impact on intersectional inequality.

1.1 CONTENTS

1

CULTURAL AND SOCIAL PRESENTATIONS OF DISABILITY BY ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

1.1 'NO WORD FOR DISABILITY' IN ABORIGINAL LANGUAGES

To understand 'disability' in Aboriginal and Torres Strait Islander communities today, you need to cast your mind back 20,000 years to ancient times.

The archaeological site at Lake Mungo, part of the Willandra Lakes Heritage site in south west New South Wales, contains the oldest footprints found in Australia, giving insight into Aboriginal society in ancient times[1]. Amongst the collection of footprints is a single track-line of one right footprint deeply impressed into the clay, but no corresponding left footprint was discovered. Trackers from the Pintubi people of Central Australia, traditional custodians of the land, were sought for their advice on what this meant. Looking at the track, they told the archaeological research team, "yes, this is definitely a one-legged man"[2]. Using sophisticated scientific modelling techniques, further analysis by the archaeological team indicated that the one-legged man was possibly moving as part of a hunting pack and moving at pace, upwards of an incredible twenty kilometres an hour.[3] Using traditional knowledge, the Pintubi people, skilled in reading the nuances in the track-lines, suggested that the one-legged man simply threw away his walking stick and hopped at speed to keep pace with the hunting pack.

The story of the one-legged Mungo man actively participating in a hunting group is symbolic of the diversity and inclusion in First Peoples cultures. It is derived from a belief system and worldview of humanity in which biological, physical and intellectual differences are accepted as part of the fabric of society.

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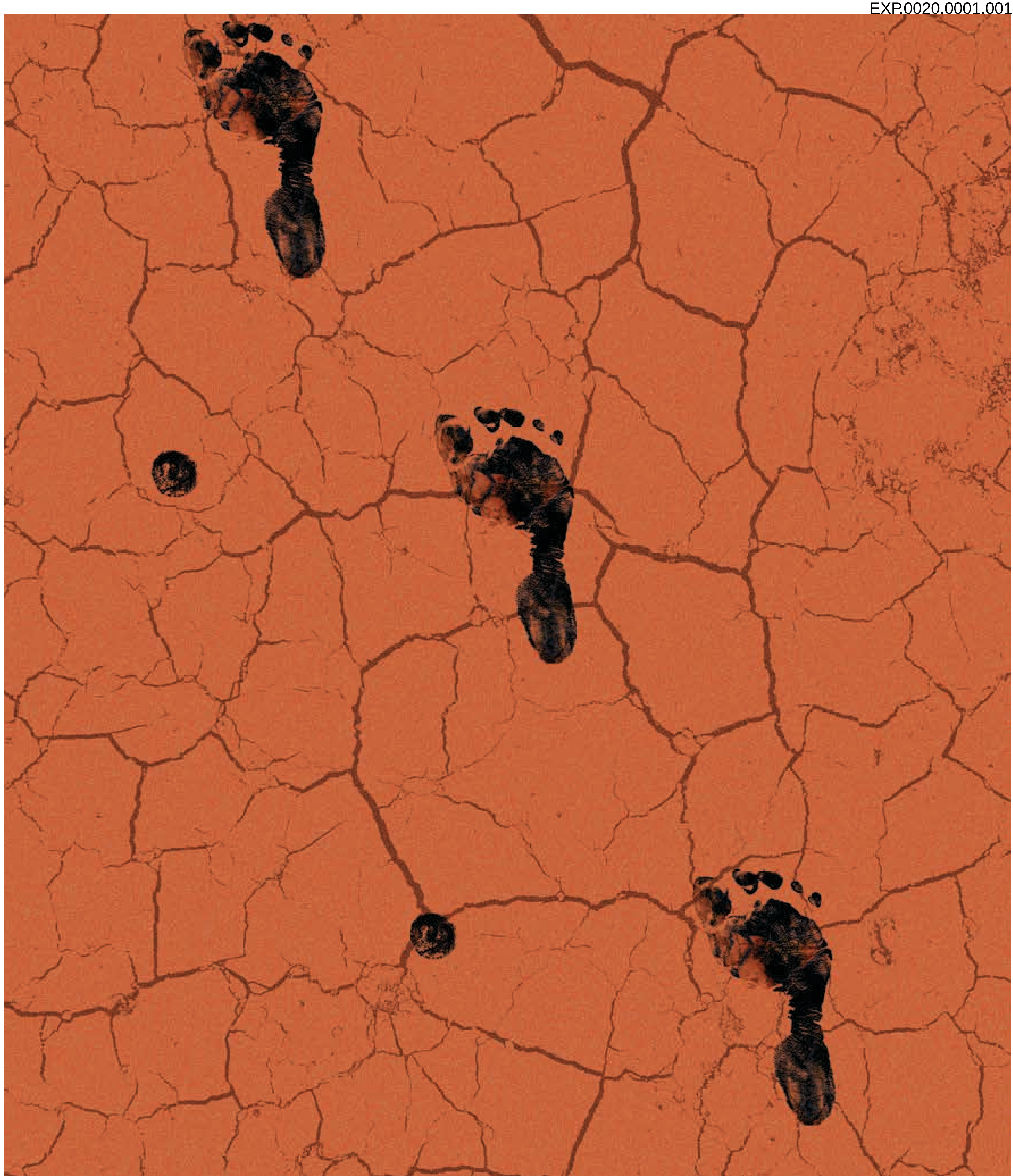
1 Webb S. (2007), 'Further research of the Willandra Lakes fossil footprint site, southeastern Australia' Journal of Human Evolution 52, 711-71

2 Markey S. (2016), ' Australia's 200,00 year old human footprints'. National Geographic, 24 May 2016

3 Webb S.(2007).



The small amount of published research on disability in Aboriginal and Torres Strait Islander communities all settle on a conclusion that 'disability' is not a concept that readily translates in Aboriginal languages and cultures. Ariotti's study observing the Anangu people of the Northern Territory describes a community where there is no word for 'disability' in their native Pitjantjatjara language[4]. Instead, there are words in the native language which describe various impairments, such as blind ('kuru pati'), deaf ('pina pati'), to hobble around ('lurpani') or to have back pain ('witapijara'). It was observed that the Anangu people did not use these words in a pejorative way. Instead, these words are factual references to a person's functioning capacity within a community in which there is an acceptance of diversity and difference.

Another study by King et al involving Aboriginal people working in an urban Indigenous-specific respite centre for people with diabetes-related disability speaks of "invisibility of their disability experience"[5]. This phrase makes reference to a society in which the centrality of Indigenous culture, being a person who is Aboriginal, overshadows the physical, objective nature by which an impairment may be viewed. Accordingly, the Aboriginal people involved in the study did not readily accept the categorisation of being a person with disability, as disability was viewed as a non-Indigenous concept. The hierarchy of Aboriginal identity above disability in an Aboriginal person's sense of belonging is paraphrased by a participant in the study as being "Indigenous first, disabled second"[6]. Gilroy et al[7] studied services providers' attitudes towards Aboriginal and Torres Strait Islander people with disability and concluded that there were diverse conceptualisations of disability in the Aboriginal population, often described as "normal" and "part of living", and that an acknowledgement of disability, or lack thereof, was a key influencing factor in whether Aboriginal people accessed disability services.

There are parallels to Aboriginal and Torres Strait Islander people's worldview of human capability and diversity with other Indigenous peoples worldwide. Culturally, there were no equivalent words in the Maori language for disability or many diagnostic labels that apply, such as autism. The Te Pou o te Whakaaro Nui [8] is a project to update and create Māori language used in the mental health, addiction and disability sectors with language that is not judgmental, and uses Maori's words 'whaikaha', meaning 'to have strength, otherly abled' as an equivalent for 'disabled'; and 'takiwatanga', meaning 'his or her own time and space' as an equivalent word for 'autism'. In another hemisphere, the Navajo Indigenous people of North America lacked a word for 'disability' until an acculturalisation through western influences, instead living by a concept of 'Honzo' to describe someone who is walking in harmony with all that is around them[9].

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4 Ariotti L. (1999) 'Social Construction of Anangu Disability', Australian Journal of Rural Health. Vol. 7, 216-222.

5 King J.A., Brough M., and Knox M (2014) 'Negotiating disability and colonisation: the lived experience of Indigenous Australians with a disability' Disability and Society. Vol 25. No.5, 738-750.

6 King et al (2014) at 744.

7 Gilroy J., Donelly M., Colmar S., Parmenter T. (2016) 'Twelve factors that can influence the participation of Aboriginal people in disability services'. Australian Indigenous Health Bulletin 16(1).

8 Te Pou o te Whakaaro Nui (2016) Te Reo Hāpai – The Language of Enrichment. Accessed at: https://www.tepou.co.nz/initiatives/te-reo-hapai-the-language-of-enrichment/169

9 Kapp S.K. (2013) 'Navajo and Autism: the beauty of harmony'. In: Moving Beyond Boundaries in Disability Studies: Rights, Spaces and Innovations. Moore M. Ed, p77-90, Routledge, at p 82-83.

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.

The contemporary dilemma for Aboriginal and Torres Strait Islander people is that their culture and belief system of human functioning and diversity is so radically different from the Western construct of disability dominant in Australia and other Westernised nations. The Western system constructs disability as a deficit against a perceived 'normal level of functioning, and "an individual deficit/problem that has to be fixed, rehabilitated or prevented."[10] Philosophical reflections aside, the cultural dichotomies present a contemporary dilemma for Aboriginal and Torres Strait Islander people. 'Do you have a disability?' is a question that is culturally insensible for Indigenous peoples.

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10 Berghs, M., Atkin, K., Graham, H., Hatton,C., and Thomas C. (2016), 'Implications for public health research of models and theories of disability: a scoping study and evidence synthesis, Public Health Research, No. 4.8.

Yarning piece

The understatement of disability

He comes from a town where there has been a spate of young people who have recently died by suicide. The local community is stunned, they can't explain it. An Aboriginal organisation that specialises in healing and wellness programs, are running a community session to try to work through the trauma.

He had turned up for two days running, one day for the healing session and the day prior for a yarn-up that focussed on disability. There's a small group of about ten or so people, and he has come with someone. Judging by the emotion that surrounds him, it is someone who is close to him, perhaps his wife or partner, but the deal is it's his story and I don't want to intrude by asking.

He starts the interview by saying that he had "sort of had a motorbike accident", twelve months ago nearly to the day of the interview. It was the 'sort of' motorbike accident that had left him with a broken neck, broken, leg, and spinal cord injury that means that he cannot use one arm. It was the 'sort of' accident that had kept him in bed for six months and he lost about twenty kilos of muscle.

Twelve months after the accident, he is still trying to get his life on track. It's been six months since he has been able to stand at all, and he's now at the stage where he is starting to walk up and down stairs. He is still unsteady on his feet and at high risk of falling over. Something as simple as a stick on the ground, or carrying a bottle of milk, becomes a major obstacle.

Despite the nature of the injuries he remains upbeat. He says that he doesn't have access to any formal rehabilitation, and what he does, he does himself. "I haven't had any rehab or anything. I had a little bit of rehab at hospital but I don't have rehab now. I'm supposed to still go to it, but I just get up and walk." Despite not using these words, he is inferring that he does his own rehab, even despite the traumatic nature of his injuries. Given the nature of his injuries, both visible and self-described, I double-check that he is not receiving specialised rehabilitation and ask what he does on his own. "[I] Get up and walk, and walk, and walk, and that's my exercise for the whole day, you know. I just – that's the only thing I think that's going to build my leg back and build all the muscle back."

He is back working at the local school where he was working prior to the accident. I ask how that came about "Well, went and asked them, "Can I come back?" And, they was happy to bring me back so, I thought, [I can come] back a little, a little bit, as much as I can." The headmaster at the school worked his schedule around so he could get back to work in a safe and accessible workplace. "[The headmaster said] I've got to stay on the bottom level for the first term that I was back, so that was pretty good, so I didn't have to climb any stairs or anything like that. He knew where I was coming from, I suppose." There's a sense that feeling valued and understood by people around him has had as much therapeutic value as any physical therapy he had received. "He's – he's excellent. He's – my employer's a really, really good person. Yeah. I – I enjoy working over there."

The 'he' in this story is not just him personally, it has had a tremendous impact on those closest to him. His companion is visibly distressed during the healing workshop. His healing is driven by a strong obligation to family, and he speaks of his children. "One's away playing footy, so – yeah. Better get back to work to support him down here".

We finish our discussion. I turn off the recorder and we walk back to the community healing session. On the way back, we talk about how it would have been nice to have had more people turn up to the healing session and disability workshop, especially given the recent events in the community. With me lamenting the researcher's peril of turning off the recorder too early, he responds with a succinct comment embodying the hope that exists in the face of trauma, and survival in the in face of obstacles. "It's like throwing pebbles in the pond. Throw them in, and it will all ripple out".

1.2 DISPOSSESSION OF COUNTRY AND BODY: A POST-COLONIAL HISTORY OF TRAUMA EXPERIENCED BY ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DISABILITY

European colonisation caused catastrophic shocks in Aboriginal and Torres Strait Islander societies[11].

The process of colonisation has had multiple and continuing impacts on the Aboriginal and Torres Strait Islander population[12] [13]. First, massacres and the introduction of foreign diseases drastically reduced the Aboriginal population in the first decade following European contact. Second, the imposition of guns, alcohol, tobacco and sugar as agents of colonisation resulted in hugely increased levels of disablement among the surviving population and their future generations, which has had a long-term impact on population health status. Third, the colonisation itself was founded on the imperial legal doctrine of 'terra nullius', literally meaning 'nobody's land'[14] [15]. To morally justify the dispossession of the native inhabitants from their land, Aboriginal and Torres Strait Islander people were treated as subhuman and viewed as inferior by their European conquerors. The humanity of Aboriginal and Torres Strait Islander people was effectively denied, and the impact of racial discrimination affecting the rights, inclusion and social structure of Aboriginal and Torres Strait Islander people is still evident in Australia today.

Colonisation had a particular impact upon Aboriginal and Torres Strait Islander people with disability, centring them at a convergence of armed aggression dispossessing them from their land as Aboriginal people, alongside their social 'othering'[16] as people with disability. Colonisation commenced in period in history known as the Enlightenment, an intellectual and political movement which emerged in Europe in the late 18th and early 19th century, characterised by scientific thought, reasoning, and the promotion of personal liberty[17]. An influential thinker in Britain at the time was Scottish economist Adam Smith, whose book the Wealth of Nations[18] included a theory of market economics. Amongst the key ideas of the theory of market economics is a concept of 'human capital', which equates people to physical resources in a production proces. A corollary of 'human capital' is the notion of a 'disabled person', an idea that was socially constructed to categorise those people that were perceived to be unable to participate in the market economy, or raw materials in a production process and discarded as not meeting a standard specification. These were the emergent ideas at the time and became the foundation for the social and political economy of the new colony.

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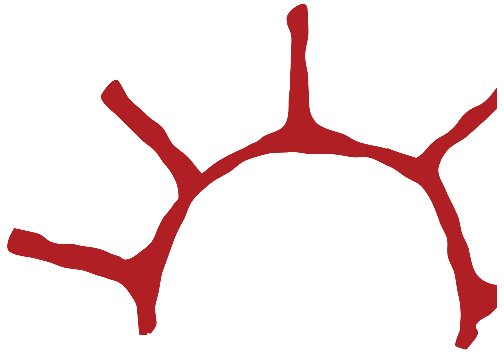
11 (David, Barker and McNiven; Hocking, 2005; Kidd, 1997)
12 Trudgen, R. (2000). Why warriors lay down and die. Darwin: Aboriginal Resource & Development Services.
13 Johnston, E. (1991). Report of the Royal Commission into Aboriginal Deaths in Custody. Canberra: Australian Government Publishing Service.
14 Frost, A. (1981). 'New South Wales as terra nullius: The British denial of Aboriginal land rights.' Australian Historical Studies, 17(777), 513-523.
15 Reyonds, H. (1987) The Law of the Land. Penguin Books Australia.
16 Mik-Mayer, N. (2016) 'Othering, ableism and disability: A discursive analysis of co-workers' construction of colleagues with visible impairments'. Human Relations. Volume: 69 issue: 6, page(s): 1341-1363
17 Reeves, C. (Ed) (2010) A Cultural History of the Human Body in the Enlightenment. Berg Publishers
18 Smith, A. (1776) The Wealth of Nations. Public domain.

Hence, the native population of Australia faced cultural upheaval on multiple fronts. Over and above the violent aggression of colonisation was the establishment of a social order completely at odds with their cultural values of diversity and inclusion.[19] Some Aboriginal people, already subjugated by armed force[20] and the pejorative influences of the early colonial press[21], also acquired a new label of 'disability', adding another dimension to their dehumanisation, further marginalising them even amongst their own people. In the two and a half centuries since, Aboriginal and Torres Strait Islander people with disability have been vulnerable to the worst of the worst in the social engineering that has taken place post-colonisation: whether it is the over-incarceration of Aboriginal and Torres Strait people [22]; the institutionalisation of people with disability in mental asylums and institutions, and the structural violence that occurred within them[23]; the removal of children from their families during the Stolen Generations and beyond[24] [25]; or exclusion from equal participation in a market economy[26]. In appreciating how enshrined the forces of their exclusion have become, the current status of Aboriginal and Torres Strait Islander people with disability is a reminder that the echoes from a distant past still resonate loudly today.

The magnitude of the impact of colonisation upon Aboriginal and Torres Strait Islander people with disability cannot be covered in the scope of this project. It is, however, important to note here the history of colonisation and its impact on Aboriginal and Torres Strait Islander people with disability. The exclusion, dispossession, violence, racism and discrimination has caused, and continues to cause, significant trauma and suffering. These experiences of trauma were pervasive and sustained, and have been passed down and compounded through generations. In essence, the 'trauma story' of Aboriginal and Torres Strait Islander people with disability is an impairment uniquely experienced by Aboriginal and Torres Strait Islander people who have been dispossessed from both Country and body.



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19 Hollinsworth, D. (2006). Race and racism in Australia. Melbourne: Cengage.
20 Gilroy, J., Ragen, J. and Meekosha, H. (2018) 'Decolonizing the dynamics of media power and media representation between 1830 and 1930: Australian Indigenous peoples with disability'. In: Ellis, K., Goggin,G. and Haller, B.(eds.), Routledge Companion to Disability and Media. New York: Routledge.
21 Reynolds, H. (2013). Forgotten War. Sydney: NewSouth Books.
22 Johnston, (1991).
23 Sweet, M. (2017). Acknowledgement: A social journalism research project relating to the history of lock hospitals, lazarets and other forms of medical incarceration of Aboriginal and Torres Strait Islander people. PhD thesis. Canberra: University of Canberra
24 Human Rights and Equal Opportunities Commission. (1997). Bringing them home: National Inquiry into the separation of Aboriginal and Torres Strait Islander children from their families. Sydney.
25 McGlade, H. (2012). Our greatest challenge: Aboriginal children and human rights. Canberra: Aboriginal Studies Press.
26 Hunter, B. (2000). Social exclusion, social capital, and Indigenous Australians: Measuring the social costs of unemployment. Canberra: ANU.

To morally justify the dispossession of the native inhabitants from their land, Aboriginal and Torres Strait Islander people were treated as subhuman and viewed as inferior by their European conquerors.

The humanity of Aboriginal and Torres Strait Islander people was effectively denied, and the impact of racial discrimination affecting the rights, inclusion and social structure of Aboriginal and Torres Strait Islander people is still evident in Australia today.

1.3 ABORIGINAL AND TORRES STRAIT ISLANDER DISABILITY IN PUBLIC POLICY

Aboriginal and Torres Strait Islander disability policy sits at the nexus of two strategic policy frameworks:

- 'Closing The Gap on Indigenous Disadvantage' framework[27]; and
- the National Disability Strategy[28].

The prevalence of disability in the Aboriginal and Torres Strait Islander population is significantly higher than in the general population. If you are an Aboriginal or Torres Strait Islander person, you are 2.1 times as likely to have disability than if you are not an Aboriginal or Torres Strait Islander person[29]. The latest data from the 2014-2015 National Aboriginal and Torres Strait Islander Social Survey (NATSISS), shows that 45% of Aboriginal and Torres Strait Islander people are living with disability or a long-term health condition. The reported prevalence of severe and profound disability is 7.7% of the Aboriginal and Torres Strait Islander population aged over 15 living in private households[30].

Given the high prevalence of disability amongst Aboriginal and Torres Strait Islander people and its significance in both social and economic terms, not enough is known about the true extent and nature of disability. Whilst data on social and health outcomes have been available for Aboriginal and Torres Strait Islander people, and people with disability as discrete populations, disaggregated data to understand the unique experiences of people who are both Aboriginal and/or Torres Strait Islander and have disability have historically not been accessible. The unavailability of disaggregated data has meant that there has been a limited awareness of disability as a determinant of social and health outcomes for Aboriginal and Torres Strait Islander people, and disability is largely absent from the Australian Government's Closing the Gap Framework to address Indigenous Disadvantage and related Indigenous policies such as the National Aboriginal and Torres Strait Islander Health Plan. Similarly, the unique needs of Aboriginal and Torres Strait Islander peoples have only recently been formally acknowledged within the National Disability Strategy with the release of the Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability in November 2017[31]. This Plan provides an impetus for focussed responses to the unique needs of Aboriginal and Torres Strait Islander people with disability, and the presentation of evidence on what drives the social inequalities they experience is organised according to the five priority areas for action under the Plan.

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[27] Coalition of Australian Governments (2007) National Indigenous Reform Agreement (Closing the Gap). Accessed at: http://www.federalfinancialrelations.gov.au/content/npa/health/_archive/indigenous-reform/national-agreement_sept_12.pdf

[28] Coalition of Australian Governments (2010) National Disability Strategy 2010-2020. Accessed at: https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf

[29] Australian Bureau of Statistics (ABS) (2016) National Aboriginal and Torres Strait Islander Social Survey, (NATSISS) 2014-15 (Release 4714.0).

[30] ABS (2016), NATSISS 2014-15.

[31] Commonwealth of Australia - Department of Social Services (2017) Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability. Accessed at: https://www.dss.gov.au/sites/default/files/documents/10_2017/dss0001_atsi_disability_plan_accessible_v1.pdf

The 'Closing the Gap' framework is an overarching policy monitoring and evaluation framework that the Australian government devised to reduce the difference in life expectancy and other social outcomes between Aboriginal and Torres Strait Islander people and other Australians within a generation. The framework that initiated 'Closing the Gap' as a Government policy initiative included targets for reducing the gap in:

- life expectancy;
- mortality rates in children;
- school attendance;
- literacy and numeracy;
- year 12 attainment; and
- employment outcomes[32].

The significance of targets under the Closing the Gap framework is that they were negotiated and agreed between the Commonwealth and State and Territory Governments through the Coalition of Australian Governments (COAG), with the intent to align the policy efforts of all Australian governments in a given priority area. Closing the Gap targets are underpinned by National Partnership Agreements which contain performance related funding measures. Despite the impact of disability in attaining other Closing the Gap indicators, there is at the time of writing no stand-alone target to reduce inequality in disability related outcomes under the Closing the Gap Framework. Instead, disability is grouped with chronic disease as a 'headline indicator', which is a second-tier priority under the Closing the Gap Framework[33]. This recognises that a long-term whole of government response is required to address a determinant of inequality in life expectancy, health and social outcomes, but not to the extent that there is an overarching performance measure and aligned funding stream.

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[32] Coalition of Australian Governments (2007) National Indigenous Reform Agreement (Closing the Gap)

[33] Productivity Commission (2016) Overcoming Indigenous Disadvantage Key Indicators Report.. Report Accessed at: http://www.pc.gov.au/research/ongoing/overcoming-indigenous-disadvantage/2016/report-documents/oid-2016-overcoming-indigenous-disadvantage-key-indicators-2016-report.pdf. Refer Headline Indicator 4.9, S4.4

1.4 THE COMMUNITY BASED ORIGINS OF THE 'LIVING OUR WAYS' DISABILITY RESEARCH PROGRAM

The purpose of the research program reported here is to understand the issues affecting Aboriginal and Torres Strait Islander people from their viewpoint. The program was given the working title: 'Living our ways' to reflect this.

The project began at the First Peoples Disability Network (Australia) (FPDN), which is a community-based representative disability organisation established by and for First Peoples with disability, their families and communities. As a First Peoples disability organisation, FPDN's governance is unique in Australia because it is governed by a board and executive of Aboriginal and Torres Strait Islander people with an intimate experience and knowledge of disability, either through having a personal experience of disability, through supporting a close family member with disability or as a leader within the Aboriginal and Torres Strait Islander community with a history of dedicated support to people with disability. The housing of the research program in a community-controlled disability organisation is instrumental in keeping the research program grounded to the needs, values and decision-making practices of the community.

The concepts and principles used in this research can be traced to the emergence of a focused First Peoples disability rights movement. In 1991, Uncle Lester Bostock, esteemed Aboriginal Elder and leader of the First Peoples disability rights movement, presented the Meares Oration in which he spoke of the 'double disadvantage' that people who were both Aboriginal and living with disability experienced. As a person with a physical disability, Bostock noted that "when we look at access and equity to service agencies and access to the workforce, Aborigines are at the lowest rung of the servicing ladder."[34] The concept of 'double disadvantage' as observed by Bostock forms a basis for the framing of issues of access by First Peoples with disability as 'intersectionality' in this report.

The First Peoples disability rights movement emerged as a distinct community when the Aboriginal rights movement and disability rights movement converged. In 1999 there was a gathering of Aboriginal people with disability in Alice Springs with representation from all States and Territories. An agreed priority at the gathering was for those present to return home and to establish States and Territory based representative Aboriginal disability organisations. Some state-based organisations survived on the back of fledgling funding, notably the Aboriginal Disability Network in New South Wales, but most attempts to establish disability organisations in other States and Territories floundered because of a lack of tangible support from governments. The Aboriginal Disability Network New South Wales (ADNNSW) became an incorporated entity in 2002. ADNNSW was the precursor to the nationally constituted First Peoples Disability Network (Australia) incorporated in 2010.

Between 2004 and 2005, the Aboriginal Disability Network New South Wales undertook a broad-based community consultation on the needs of Aboriginal and Torres Strait Islander people with disability. Bostock, now the inaugural chair of an incorporated Aboriginal Disability Network, and Damian Griffis, current CEO of FPDN, visited 33 Aboriginal communities across New South Wales to produce the seminal report, 'Telling it Like it is',[35] which chronicled high levels of unmet need, a lack of service provision and extreme poverty in Aboriginal communities. Consulting directly with Aboriginal and Torres Strait Islander people with disability, and a fiduciary obligation to the First Peoples disability community to 'tell it like it is', are two core ethical principles that this research project has inherited from this original work.

Despite a distinct First Peoples disability rights agenda emerging through a process of development led by the community, the research to support the rights agenda was being conducted parallel to, and not within community. An audit of disability research in 2014 located 39 papers in scientific literature and 30 papers in 'grey' literature[36], the majority of which constituted bio-medical disability research conducted in Aboriginal and Torres Strait Islander communities. The search inclusion criteria failed to incorporate the knowledge and expertise of the First Peoples disability community and its leaders, highlighting the gaps in scientific searching techniques to identify research activities and the priorities identified by the community.

The failure of research institutions to appropriately recognise and respond to the voices of those being researched increasingly frustrated the efforts of the First Peoples disability community seeking to have their rights acknowledged and respected. While well-meaning, research that amplified the voices of outside researchers, service providers and other intermediaries over the voices of First Peoples with disability themselves rendered invisible their expressions of real need. In asserting their dual rights of participatory decision-making and self-determination, enshrined in the Convention of the Rights of Persons with Disabilities[37] and the United Nations Declaration on the Rights of Indigenous Peoples[38], the First Peoples disability community determined it was no longer content to be a subject of the research priorities and projects of others, but would instead assume the leadership role in the progression of research that affected them. In December 2014, the Board of the First Peoples Disability Network declared its strategic intent to own the First Peoples disability research agenda in partnership with its community[39]. The 'Living our ways' research program is an outcome of this strategic commitment to undertake research by the community for the community. This report is its inaugural publication.

> As a person with a physical disability, Bostock noted that "when we look at access and equity to service agencies and access to the workforce, Aborigines are at the lowest rung of the servicing ladder."[34]

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[34] Bostock L. (1991) *Access and equity for people with a double disadvantage,* Australian Disability Review, Vo1. 2, pp. 3-8.

[35] Bostock L., and Griffis D. (2005) *Telling it Like it Is: A report on community consultations with Aboriginal people with disability and their associates throughout NSW, 2004-2005.* Aboriginal Disability Network New South Wales.

[36] Centre for Disability Research and Policy (2014). *Report of Audit of Disability Research.* University of Sydney, Supplement at p.21.

[37] United Nations (2006) *Convention on the Rights of Persons with Disabilities* (A/RES/61/106)

[38] United Nations (2007) *United Nations Declaration on the Rights of Indigenous Peoples* (A/RES/61/295)

[39] First Peoples Disability Network (2015) *Strategic Directions* 2015-2020.

1.5 THE RESEARCH BRIEF

First Peoples Disability Network received funding under the Commonwealth Government's National Disability Research Development Scheme to fund one full-time researcher for two years to listen to and record the lived experience of Aboriginal and Torres Strait Islander people with disability through their narratives.

First Peoples Disability Network was the community base for the project and provided additional services for the project in-kind. The University of Technology Sydney and University of New South Wales have provided ongoing support for this project and supported the intent for genuine community leadership and partnership, including in-kind support.

There are six deliverables of the 'Living our ways' research program:

i. Establish a genuine model of co-production in disability research which is driven by Aboriginal and Torres Strait Islander people with disability.

ii. Improve the interpretation of quantitative data collected through the NATSISS, Survey of Disability Ageing and Carers (SDAC) and related instruments through a complementary qualitative knowledge base.

iii. Produce a national research agenda for prioritising the future Aboriginal and Torres Strait Islander Disability Research Project.

iv. Incorporate community-based capacity building for greater participation by Aboriginal and Torres Strait Islander disability research.

v. Invite groups of Aboriginal researchers to build their capacity in disability studies.

vi. Summarise the analysis in a report for NATSISS, SDAC and Research and Data Working Group.

The research proposal included three core principles for conducting the research:

- The first principle referred to an intersectional approach to reflect the uniqueness of Aboriginal and Torres Strait Islander disability rights and research.
- The second principle referred to an authentically grounded approach to reflect the perspectives of Aboriginal and Torres Strait Islander people with lived experience of disability.
- The third principle referred to establishing a genuine community-directed model of co-production in Aboriginal and Torres Strait Islander disability research.

As the research progressed, these principles firmed into a distinctive First Peoples disability research philosophy, which culminates in the presentation of a First Peoples disability research agenda that is sourced directly from the voices of Aboriginal and Torres Strait Islander people with disability.

The purpose of the research program reported here is to understand the issues affecting Aboriginal and Torres Strait Islander people from their viewpoint.

2

KEY TERMS AND CONCEPTS

2.1 THE DEVELOPMENT OF CONCEPTS AND TERMS

The purpose of this chapter is to outline the key terms and concepts that appear in this research, providing definitions of the key ideas and concepts developed and used throughout. These concepts have been categorised as follows:

i. Aboriginal and Torres Strait Islander people with disability and their community;

ii. defining disability and functional impairment;

iii. the processes of research production; and

iv. the multiple forms of discrimination experienced by Aboriginal and Torres Strait Islander people with disability.

As disability within Aboriginal Torres Strait Islander communities incorporates clinical, social, cultural and human rights dimensions, its language and terminology can be imprecise and often contested when used in multiple contexts:

- In some cases a single word can have different meaning in different contexts. An example in this research is the word 'Community'.
- In other cases there are multiple words or phrases used to describe a single context, the choice of which reflects the user's knowledge, preferences or values. An example here is the interchangeability between 'Aboriginal and Torres Strait Islander people' and 'First Peoples'.
- In some cases, a concept has been explained in one way within an existing body of research, but has been extended within this research to explain findings in a different setting. An example here is the concept of 'overshadowing' applied in this project in a new way.
- In some case, new concepts have been devised to explain phenomena which could not adequately be explained by terminology presently in use. An example here is the explanation of 'apprehended discrimination' to describe the absolute breakdown of trust that occurs when a person is continually exposed to discrimination.

The relationship of language to the stigmatisation of Aboriginal and Torres Strait Islander people, and people with disability means that the choice and use of terms and phrases is made with great care relative to the context of this research in which these terms and concepts are used.

2.2 CONCEPTS RELATED TO THE FIRST PEOPLES DISABILITY COMMUNITY

'Community'

In the broadest sense, a 'community' is a group of people with shared beliefs, values and experiences.

The shared experiences of Aboriginal and Torres Strait Islander people mean the 'community' has a special connotation for them. It is not only a term that describes physical connection of a group of people, but also a spiritual sense of belonging.

In Aboriginal and Torres Strait Islander affairs, there are a variety of contexts in which 'community' can be used. Two prevalent examples of contrasting contexts in the use of 'community' are:

- **Spatial references to 'community':** In this context, 'community' is used to locate a person's sense of belonging which is place-based or geographical. For example, people may identify as belonging to an Aboriginal nation, and/or a town or locality.
- **Non-spatial references to 'community':** In this context 'community' is used independent of geographical markers and used to locate a person's sense of belonging based on their shared experiences with other people. In this sense, Aboriginal and Torres Strait Islander people with disability may be viewed as a 'community' based on shared experiences of disability, that transcends geographically based markers.

Notably, an individual may have multiple affiliations with different communities. For example, an Aboriginal or Torres Strait Islander person with disability may identify as a member of the disability community as well as a member of an Aboriginal nation.

On another point of clarification, 'First Peoples disability community' is used to refer to the group of Aboriginal or Torres Strait Islander people with a shared experience of disability; whereas the 'First Peoples Disability Network' is used to specifically refer to the community-based representative organisation established by the First Peoples disability community.

For the purposes of this project:

- 'Community' is used to refer to the First Peoples disability community. This is to convey the focus of the project, which is to narrate the shared experiences of Aboriginal and Torres Strait Islander people with disability.
- To avoid confusion within this report, place-based names are referred to as 'research sites'.

'Aboriginal and Torres Strait Islander people' and 'First Peoples'

'Aboriginal and Torres Strait Islander people' and 'First Peoples' are used interchangeably in the document, and reflects varying preferences based on the context. For example, the Australian Bureau of Statistics (ABS) incorporates the identifier 'Aboriginal and Torres Strait Islander' in the description of the NATSISS, which is a primary dataset used for statistical analysis; whereas the First Peoples Disability Network, a national community disability organisation, prefers the terminology of 'First Peoples' when referring to its community. Ultimately, they are different identifying terms used to refer to the same population group.

For the purposes of the inclusion criteria as an Aboriginal and Torres Strait Islander person, the research applies the criteria of self-identification. This is consistent with the 'Standard Indigenous Question' used by the ABS in its data collection and many other government agencies, which states that "An Aboriginal or Torres Strait Islander is a person of Aboriginal and Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives."[40]

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[40] Department of Aboriginal Affairs (1981). Report on a review of the administration of the working definition of Aboriginal and Torres Strait Islander, Canberra: Commonwealth of Australia. Department of the Parliamentary Library, 2003. Defining Aboriginality in Australia, Canberra. Commonwealth of Australia.

2.3 CONCEPTS RELATED TO DISABILITY AND IMPAIRMENT

Medical, social and cultural presentations of disability

‘Disability’ is an overarching term which is subject to various interpretive models which explain its nature and effect. The two dominant models of disability covered extensively within the research literature are the ‘medical model’ of disability and the ‘social model’ of disability.

Medical model of disability: The medical model of disability is characterised by clinical diagnoses of impairment. Within a medical model, a focus is one of curing disability, and a disability diagnosis serves as a trigger for biomedical supports for an individual.

Social model of disability: A social model of disability emerged in the late 1970’s as a reaction to the limitations of a medical model in addressing disability as a human right issue[41]. In contrast to the medical model, a social model of disability views disability as a social construct, in which disability is created by barriers in the physical environment and negative social attitudes and low expectations of those who have impairments. In the social model of disability, the focus is on accommodating people who experience an impairment by removing their barriers to access and social participation.

Despite the differences in their perspective, both the medical and social models have been framed from a western belief system of disability as a deficit in human functioning, either caused by a biomedical condition (the medical model), or a deficit in the social and physical environment (the social model). For Aboriginal and Torres Strait Islander people whose cultural practices are based on inclusion, these concepts of disability as a deficit are a foreign concept. Having ‘no word for disability’, the language of disability, including all the diagnostic labelling, is a language that Aboriginal and Torres Strait Islander people have had to learn out of necessity so they can negotiate the western disability systems intended to support them and improve their quality of life.

As the western concepts of disability differ from Aboriginal and Torres Strait Islander ontological understandings of human capability, this research explores a third model of disability – a ‘cultural model of inclusion’ – which is more consistent with the culture and beliefs of First Peoples. It further explores how in a post-colonial nation, the western models of disability can come together with culture within a single individual who can exhibit an integrated medical, social and cultural presentation of disability.

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[41] Shakespeare, T. (2010) ‘The Social Model of Disability’. In Davis, L.J. (Ed.) The Disability Studies Reader. New York:Routleledge. 266.273.

A working definition for ‘disability’ and ‘functional limitation’

The World Health Organisation’s International Classification of Functioning, Disability and Health (ICF) sets a standardised framework for disability terminology which integrates the biophysical and social factors affecting a person. In the framework, ‘disability’ refers to a specific condition or impairment rated against their health, whereas functioning relates to the capacity to undertake a task as a consequence of having an impairment:

> “Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person’s health condition(s) and that individual’s contextual factors (environmental and personal factors).
>
> Functioning is an umbrella term for body function, body structures, activities and participation. It denotes the positive or neutral aspects of the interaction between a person’s health condition(s) and that individual’s contextual factors (environmental and personal factors).”[42]

The ICF framework frames disability and human functioning within a limited concept of health, which means that other factors which may inhibit social participation, such as racial discrimination, are outside its scope[43]. This limitation in scope presents another gap in its application to what are significant disabling factors affecting Aboriginal and Torres Strait Islander people.

The ABS adopts the ICF Framework within its statistical dataset, and describes disability in terms of severity of the functional limitation. It categorises four levels of severity in functional limitation:

Profound – the person is unable to do, or always needs help with, a core activity task.

Severe – the person sometimes needs help with a core activity task, and/or has difficulty understanding or being understood by family or friends, and/or can communicate more easily using sign language or other non-spoken forms of communication.

Moderate – the person needs no help, but has difficulty with a core activity task.

Mild – the person needs no help and has no difficulty with any of the core activity tasks, uses aids and equipment and has difficulty in general mobility.[44]

The ABS datasets used for the research adopt a self-identification method in identifying the severity of functioning limitation.

For the purposes of the research, the inclusion criteria is based on a self-identification process in which the participant self-identifies with the First Peoples disability community. This maintains consistency with the self-identification of Aboriginal and/or Torres Strait Islander status, and the self-identification approaches used by the ABS in the dataset used in the statistical analysis.

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[42] World Health Organization (2001) The International Classification of Functioning, Disability and Health (ICF). Geneva: WHO.
[43] World Health Organization (2001) Ibid.
[44] Australian Bureau of Statistics (2016) Disability, Ageing and Carers, Australia: Summary of Findings, 2015. Rel. 4430.0. Glossary. At: http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4429.0Main+Features100232009

2.4 CONCEPTS RELATED TO RESEARCH PRODUCTION

‘Narrative’

“Narrative’ is an overarching term meaning the use of story-telling in messaging. Narrative inquiry is a recognised approach within disability research through which the voices of people with disability are made central in shaping an understanding of the issues that affect them individually and socially.[45]

Within this research, the ‘narrative’ of First People with disability has come together by combining three elements:

Testimony

The research collected first-hand oral testimony from Aboriginal and Torres Strait Islander people with disability on their life experiences of disability. The testimony was obtained through:

i. Personal interviews with 47 people with disability; and
ii. Participation at a forum of Elders.

The testimony was given orally, or in the case of Deaf Aboriginal people via a verbal translation from Auslan, and recorded digitally. The oral testimony was then transcribed verbatim into text form for analysis. The testimony is presented as verbatim quotes used to provide context and illustration in the thematic analysis.

Statistical data

The research was conducted on secondary analysis of statistical data collected independently by the ABS. The two principal data sources used for obtaining quantitative data were the National Aboriginal and Torres Strait Islander Social Survey (NATSISS) and Survey of Disability Ageing and Carers (SDAC). The processes for analysing and presenting the quantitative data within the model of co-production developed for the research is described further in Chapter 3.

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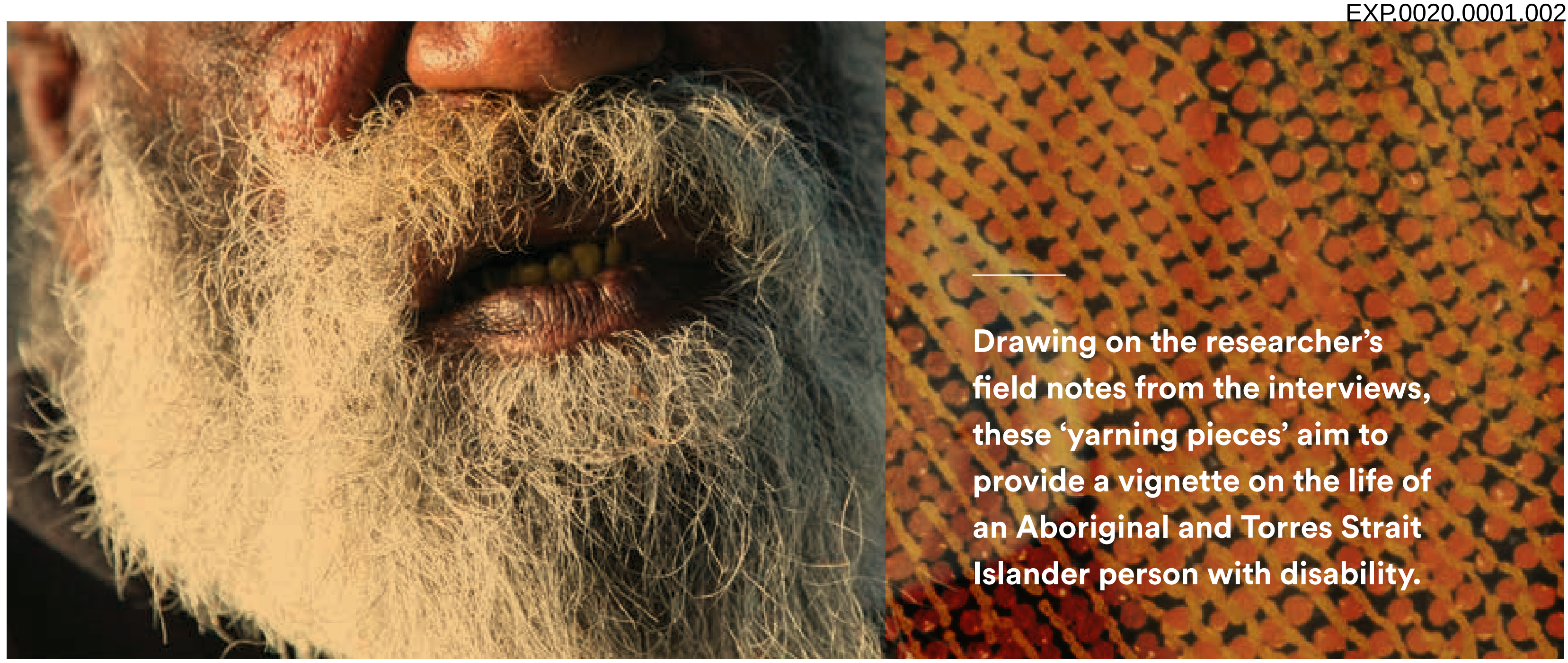
[45] Smith-Chandler, N. and Estelle Swart (2014) ‘In Their Own Voices: Methodological Considerations in Narrative Disability Research’ Qualitative Health Research, Vol. 24(3) 420–430.



Drawing on the researcher’s field notes from the interviews, these ‘yarning pieces’ aim to provide a vignette on the life of an Aboriginal and Torres Strait Islander person with disability.

‘Yarning pieces'

Whilst the presentation of testimony with statistical data together provided both scope and context in the analysis of thematic issues covered by the research, these two elements of the narrative could not provide a complete picture in isolation. What was missing from the verbatim transcription of the testimony was the human experience, particularly how many of the issues come together in the life of each person. To complete the narrative, a concept of ‘yarning pieces’ was created to connect themes as they presented within the life of each person.

Whilst testimony and statistical data can be generated and analysed using westernised methodologies for qualitative and quantitative research, the yarning pieces draw upon the Aboriginal concept of ‘yarning’ through which oral histories are transmitted in harmony with time and place.[46 47] This is achieved by asking people: “What is your story?”, and allowing them to recount it at their own pace, on their own terms, and within their own safe space. No judgment was made, nor boundaries placed upon what they could or could not say. The yarning pieces are not adjuncts that complement the testimony or statistical data, they are the mechanism through which otherwise disparate themes are drawn together in a cohesive narrative.

Drawing on the researcher’s field notes from the interviews, these ‘yarning pieces’ aim to provide a vignette on the life of an Aboriginal and Torres Strait Islander person with disability. They are designed and written in a way that aims to place the reader in the chair of the interviewer, watching and listening to the person’s story as it unfolds, and encompassing experiences beyond the spoken word.

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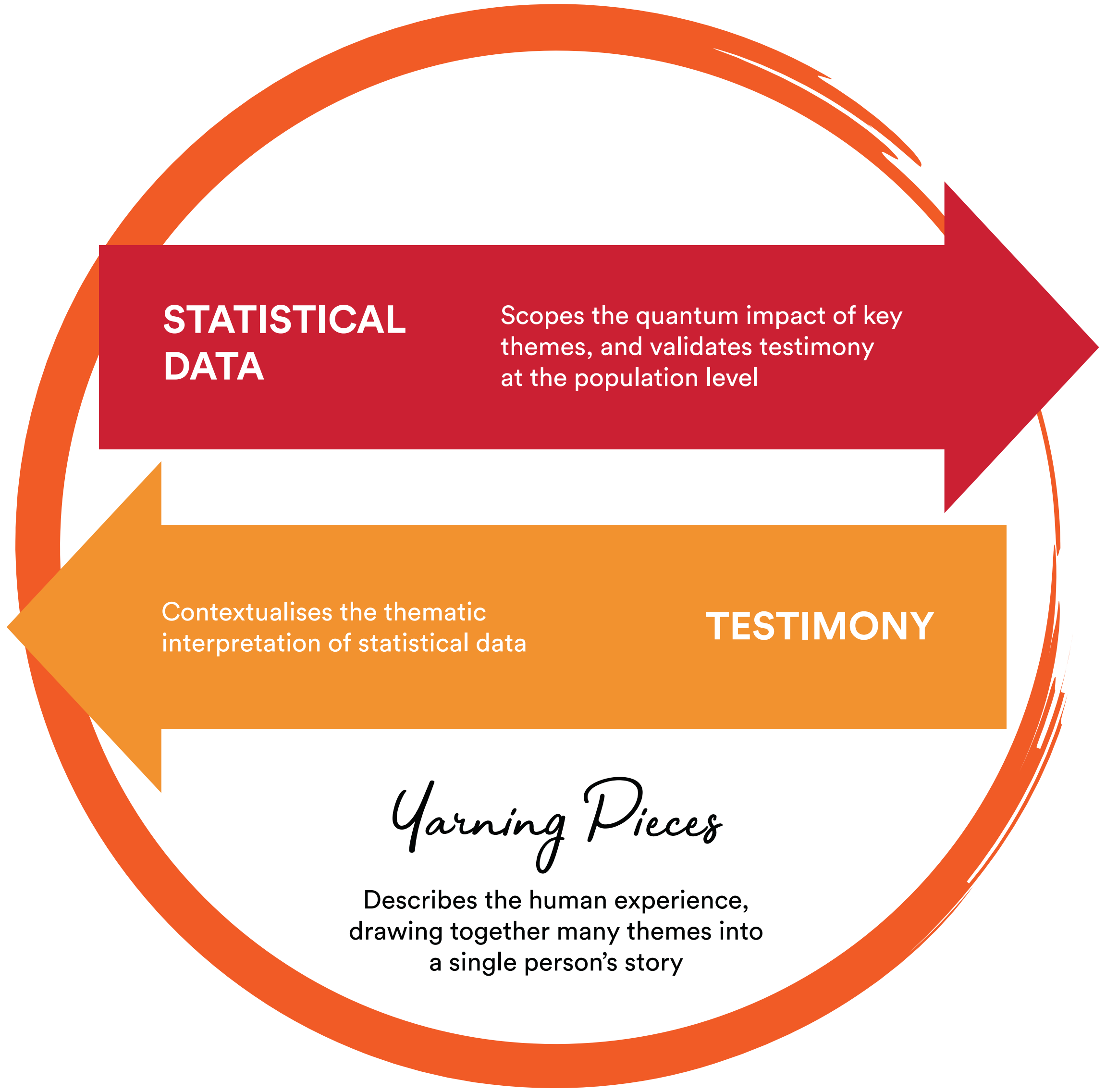
[46] Rogers, J. (2017). ‘Photoyarn: Aboriginal and Maori Girls Researching Boarding Experiences.’ Australian Aboriginal Studies Journal. Vol 1, pp. 4-14.

[47] Bessarab, D. & Ng’andu, B. (2010), ‘Yarning about Yarning as a Legitimate Method in Indigenous Research’, International Journal of Critical Indigenous Studies, vol. 3, no. 1, pp. 37–50.

The synergies between testimony, data and a culturally grounded analytic has taken the research from an exercise in statistical analysis to an immersive process of 'data whispering'. The data speaks a story, has patterns and flows, much like dots on a painting speak to an artist, the topography of the landscape speaks to a tracker, or stars to a night-time navigator. Together with the spoken word, the statistics and the stories have fused to deliver a dynamic narrative of disability in Aboriginal and Torres Strait Islander communities.

Chart 2.3 (1): Elements of the Narrative



STATISTICAL DATA

Scopes the quantum impact of key themes, and validates testimony at the population level

TESTIMONY

Contextualises the thematic interpretation of statistical data

Yarning Pieces

Describes the human experience, drawing together many themes into a single person's story

A community-directed model of 'research co-production'

The promotion of the rights of the Aboriginal and Torres Strait Islander disability community is the rationale for doing this research and the inherent value underpinning its design. Core to the rights-based foundation of the research is the right to self-determination for the Aboriginal and Torres Strait Islander disability community, as it applies within the research domain. The right to self-determination is expressed by the United Nations Declaration on the Right Of Indigenous Peoples "the right to freely pursue their form of economic, social, and cultural development".[48]

This research applies the right of self-determination as a participatory principle, a distinction to its conventional use as a political or legal construct. As a participatory principle, self-determination is compatible with the philosophies of emancipatory disability research[49 50], with the added dimension of providing cultural surety over and above the active participation of marginalised populations.

There are implications in promoting self-determination as a participatory right with models of research co-production. By logical inference, the right of self-determination can only be optimised when research that affects the economic, social and cultural development of Aboriginal and Torres Strait Islander people with disability is led by their community. This puts the Aboriginal and Torres Strait Islander community in a position of sovereignty over the research, its aims, methods and translation. By contrast, Aboriginal and disability researchers who are highly regarded within Australia and internationally, act as technical advisors providing their expertise on academic quality to community. The effect of establishing community as the ultimate decision-making authority over the research inverts the "unequal power relationships between researchers and researched"[51] that emerge when research is institutionally led.

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[48] United Nations (2007) United Nations Declaration on the Rights of Indigenous Peoples, Article 3.

[49] Barnes, C. (2003) 'What a difference a decade makes: Reflections on doing 'emancipatory disability research.' Disability in Society 18 (1).

[50] Albert. B (ed) (2006) In or out of mainstream? Lesson from research on disability and development cooperation. The Disability Press. Leeds.

[51] Hanley B. (2005) Research as Empowerment? Toronto Seminar Group.

Influenced by decolonising research methodologies[52] and an Indigenous relationship approach to “research is ceremony”[53], this research is a nexus with self-determination through several touch points:

- **First Peoples disability community as ‘researcher’ and host:** At the highest conceptual level, it addresses the power imbalances that can occur in co-production between ‘researcher’ and ‘community’[54] by fusing these roles into one. In other words, ‘community’ is the ‘researcher’. This is operationalised in this research by the First Peoples Disability Network adopting the role of host organisation for the research, and designating a member of its community as lead researcher.
- **Participants as owners:** ‘participants’ are more than just subjects of research, they are fully acknowledged as participant-owners of the research and its outcomes. This safeguards the cultural and intellectual property on behalf of the research and minimises the leakage of property rights outside the community.
- **The researcher as a ‘message stick’ for community wisdom:** the researcher has a custodial role over the testimony that is shared by the participants. Community wisdom stays with the community, and cannot be appropriated by the researcher, even in its conversion into formal forms of knowledge. During the research, the researcher acted as an agent of the participants, or a ‘message stick’ upon which the participants could write their story. The researcher acted with the assent from within the First Peoples disability community, and hence was accountable to community structures of authority as well as academically based research ethics. Having a lead researcher that was based within the First Peoples disability community was pivotal to ensuring that all stages of the research co-production proceeded in harmony with community values.
- **Consent as a form of ceremonial form of permission:** The roles and relationship of the participant and individual researchers alters the nature of obtaining consent to participate. By contrast, consent takes on a role in which consent designates the passing of permission from the participant to share their wisdom and their testimony, to the research as a trusted custodian who accepts a responsibility to care for the testimonies as artefacts of the cultural history of Aboriginal and Torres Strait Islander people with disability.
- **Academics and knowledge translators are trusted technical advisors:** Within this model academics are advisers to community on technical matters of research methods, data management, academic rigour and quality and knowledge translation. They work respectfully within a model of community-directed research and the inherent principle of self-determination, and do not over-reach by asserting a decision-making authority. They give expert guidance.

Diagram 2.3 (2): Community directed model of research co-production

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[52] Tuhiwai Smith, L. (2012) Decolonizing Methodologies: Research and Indigenous Peoples. 2nd Ed. Zed Books: London and New York.

[53] Wilson, S. (2008) Research is Ceremony: Indigenous Research Methods. Fernwood Publishing: Halifax and Winnipeg.

[54] Filipe A, Renedo A, Marston C. (2017) The co-production of what? Knowledge, values, and social relations in health care. PLoS Biol 15(5): e2001403

Intersectional discrimination is not a point-in-time concept. The detrimental consequences of intersectional discrimination at one point in life can be life-long, as it increases the likelihood of being exposed to future experiences of exclusion and discrimination.

2.5 CONCEPTS RELATED TO DISCRIMINATION AND INEQUALITY

‘Inequality’ in social outcomes

Chapter 6 uses statistical data to illustrate 'inequality' in social, health and wellbeing outcomes experienced by Aboriginal and Torres Strait Islander people with severe and profound disability compared to Aboriginal and Torres Strait Islander people with disability. ‘Inequality’ in this usage refers to the variation in the outcomes comparing the two sub-groups that can be objectively measured and shown to be not equal.

It should be noted that the statistical data is used empirically, and no statistical tests were used to determine where any variation was statistically significant. It should be further noted that a statistical analysis in and of itself does not imply correlation or causation on its own. For this expanded analysis, the statistical data on inequality, and the patterns in the data, combine with the testimony and yarning pieces to form a more complete narrative on the experiences of Aboriginal and Torres Strait Islander people, as described above.

‘Intersectionality’

‘Intersectionality’ is an explanatory framework that explains how relativities in the empowerment and disempowerment of Aboriginal and Torres Strait Islander people with disability generate and maintain inequalities for people who intersect two (or more) marginalised population groups.

‘Intersectionality’ was devised by critical race theorist Kimberlé Crenshaw[55] to explain the effect of race and gender upon the incidence and impact of family violence against African American women. Crenshaw’s observations of intersectionality showed that an explanation of race or gender in isolation from each other did not fully describe the experiences of African American women in their exposure to violence, and instead they constituted a marginalised group within a marginalised population. Intersectionality explores the dynamics in the power relations that exist between and within marginalised populations[56], and explains how inequalities in the power relationship between groups can create and sustain inequality[57]. As a foundational framework for the research, intersectionality shows that to fully understand the unique experiences of Aboriginal and Torres Strait Islander people with disability, the research must recognise that they are a discrete group at an intersection of two marginalised populations.

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55 Crenshaw K. (1991) ‘Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color’ 43. Stanford Law. Review. 1241 1990-1991.

56 Cho S., Crenshaw K.W., McCall L. (2013) ‘Towards a Field of Intersectionality Studies: Theory Application and Praxis’ Signs: Journal of Women in Culture and Society 38, No 4: 785-810.

57 Choo H.Y, and Ferree M.M. (2010) ‘Practicing Intersectionality in Sociological Research: A Critical Analysis of Inclusions, Interactions, and Institutions in the Study of Inequalities’ Sociological Theory 28:2.

‘Racism’, ‘Ableism’ and ‘Intersectional discrimination’

The theory of ‘intersectionality’ can be applied to explain the social experiences and life outcomes for people who are both Aboriginal and Torres Strait Islander and have disability. Crenshaw’s explanation of intersectionality is consistent with Bostock’s observation of “double disadvantage” [58], in which she drew upon her personal experiences as an Aboriginal leader and disability scholar and addressed the issue of multi-faceted discrimination that affects Aboriginal people who also have a disability. In pointing to a hierarchy in access and social equality, Bostock stated that Aboriginal people with disability were “at the lowest rung on the service ladder”[59].

> Bostock’s concept of double disadvantage aligns with the theory of intersectionality. As people with identities traversing two marginalised groups, Aboriginal and Torres Strait Islander people with disability experience both racially based discrimination (‘racism’) and disability related discrimination (‘ableism’). The prevalence of racism and its adverse impact upon health and wellbeing of Aboriginal and Torres Strait Islander people is well documented.[60] [61] [62]

In addition to racism and ableism as discrete forms of discrimination, the research detected a third experience – ‘intersectional discrimination’ – which is a unique interaction of race and disability-related discrimination experienced by people who are both Aboriginal and/or Torres Strait Islander and have disability. An example from the testimony is an account of an Aboriginal man with cognitive impairment who is harassed at a shopping centre by security guards who assume he is drunk. In this example, the physical presentation of a person with cognitive impairment interacts with populist prejudices about Aboriginal people and drinking which exposes a person who is Aboriginal and has cognitive impairment to a heightened vulnerability not adequately explained by racism or ableism alone. These three forms of discrimination are represented in Diagram 2.4.1

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58 Bostock (1991), Ibid, at p.7

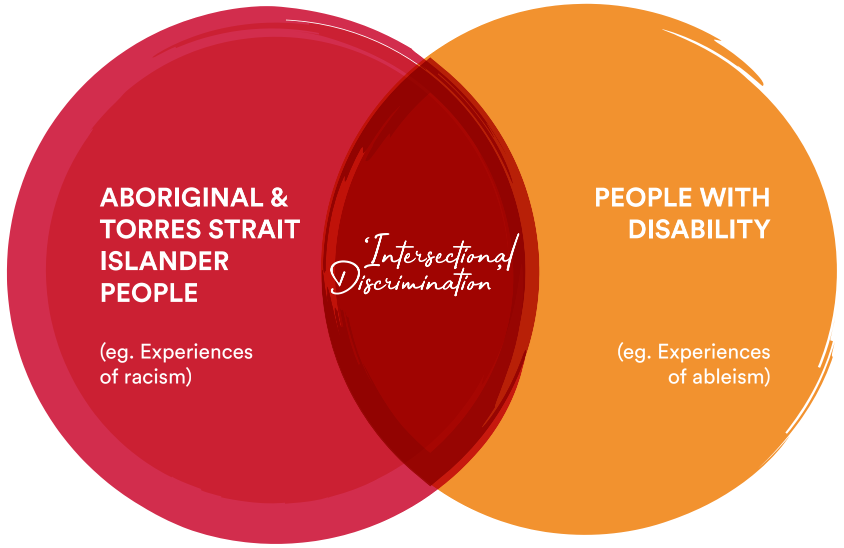
59 Bostock (1991), Ibid at p.6.

60 Larson, A.; Gillies, M.; Howard P.J; and Coffin J., (2007) ‘It’s enough to make you sick: the impact of racism on the health of Aboriginal Australians’ Australian and New Zealand Journal of Public Health Vol. 31, Issue 4, pp 322–329.

61 Priest N.; Perry R.; Ferdinand A.; Paradies Y.; Kelaher M. (2014) ‘Experiences of racism, racial/ethnic attitudes, motivated fairness and mental health outcomes among primary and secondary school students’, Journal of Youth and Adolescence, 43(10):1672-87.

62 Ferdinand, A., Paradies, Y. & Kelaher, M. (2012) Mental Health Impacts of Racial Discrimination in Victorian Aboriginal Communities: The Localities Embracing and Accepting Diversity (LEAD) Experiences of Racism Survey, The Lowitja Institute, Melbourne.

Diagram 2.4 (1): Racism, ableism and intersectional discrimination for people at the intersection of two marginalised populations



‘Intersectionality’ across the life trajectory; A ‘matriculation pathway into prison’

Intersectional discrimination is not a point-in-time concept. The detrimental consequences of intersectional discrimination at one point in life can be lifelong, as it increases the likelihood of being exposed to future experiences of exclusion and discrimination. The following table shows how inequality experienced by Aboriginal and Torres Strait Islander people with disability accumulates over the course of their lives. Even before they are born, the social circumstances into which Aboriginal and Torres Strait Islander people are born can add to the burden of disability. The impact of undetected and unsupported disability in their early childhood carries forward into the schooling years. This compounds into greater inequalities in later life, effectively placing them on a ‘matriculation pathway into prison’[63], as opposed to further education and employment. Whilst an intersectional analysis of the life trajectory presents a bleak picture of the opportunities that Aboriginal and Torres Strait people with disability are currently presented with, it can be transposed for positive impact. In addition to an explanatory model for understanding the impact of accumulated disadvantage, it can be further developed using knowledge translation strategies to identify the pivot points which can alter the life trajectory by providing timely supports to their disability.

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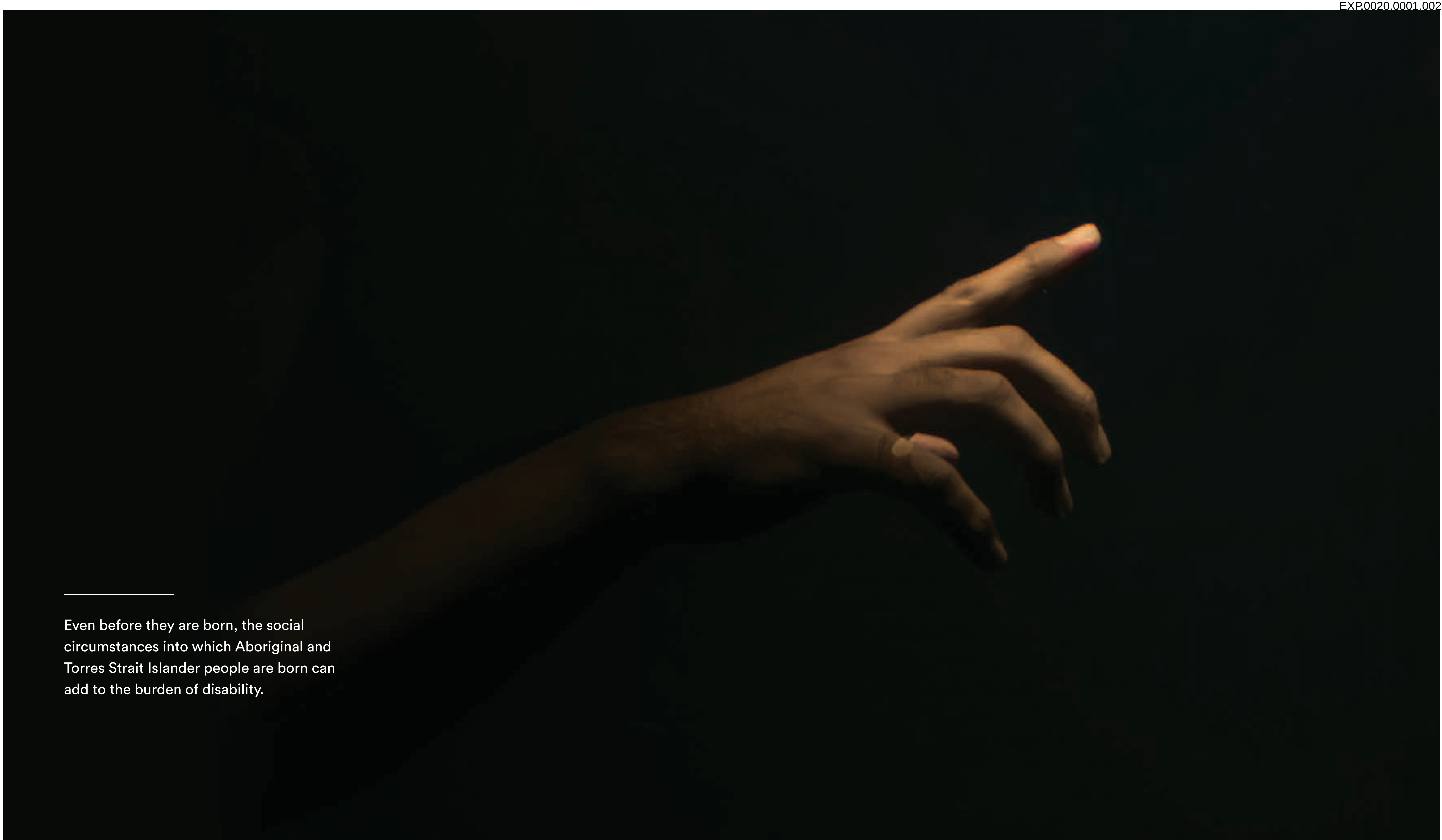
63 Avery S. (2016) ‘The life trajectory for an Aboriginal and Aboriginal or Torres Strait Persons with disability’. In: Aboriginal and Torres Strait Islander Perspectives on the Recurrent and Indefinite Detention of People with Cognitive and Psychiatric Impairment. First Peoples Disability Network



Even before they are born, the social circumstances into which Aboriginal and Torres Strait Islander people are born can add to the burden of disability.

Table 2.4 (1): Intersectionality across the life trajectory of an Aboriginal or Torres Strait Islander person with disability[64]

LIFE-STAGE ASPECT	Peri-Natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
Aboriginal and Torres Strait Islander	Low awareness of disability Environmental factors, increased likelihood of low birth-weight	Low awareness of disability Exposure to trauma Increased likelihood of OOHC – off country, unstable home setting	Low awareness of disability "Bad black kid syndrome" – punitive schooling over supported disability	Less likely to secure employment Increased likelihood of police contact	Denial of rights – over incarceration	Subconscious bias – institutional racism	Reduced life expectancy Disability happens earlier in life and with more co-morbidities.
Disability	Low birth weight and environmental factors in developmental disability	Disability assessments aren't carried out to the extent that they need to be	Undiagnosed and unsupported disability	Less likely to secure employment Communication impairments, reduced capacity to negotiate conflict	Denial of rights – indefinite detention and fitness to plea for people with cognitive and psychiatric disability	Subconscious bias – diagnostic over shadowing	Inadequate public infrastructure especially in remote communities.

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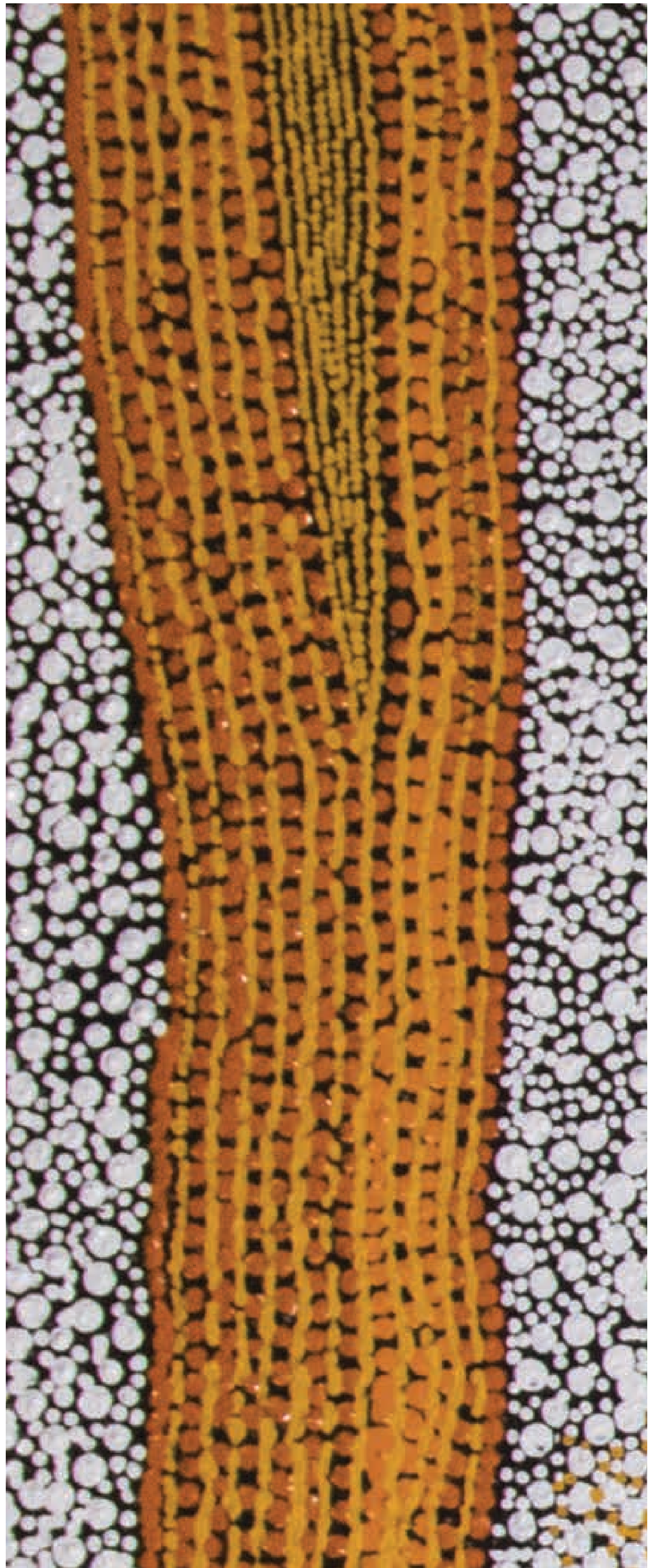
[64] Avery S. (2016) 'The life trajectory for an Aboriginal and Aboriginal or Torres Strait Persons with disability'. In: Aboriginal and Torres Strait Islander Perspectives on the Recurrent and Indefinite Detention of People with Cognitive and Psychiatric Impairment. First Peoples Disability Network



‘Apprehended discrimination’

Participants in the study revealed exposures to racism, ableism and intersectional forms of discrimination. The frequency of their exposure across multiple forms of discrimination was so great that one of the discoveries of this research is that a pattern in the psychological responses to the threat of discrimination can be determined. In particular, the participants demonstrated a sequence of psychological responses to discrimination across a continuum. This continuum begins as an intuitive fear of discrimination, and develops into an increasingly rational understanding of discrimination that is acquired through increasingly frequent personal exposures to discrimination. This pathway from fear of discrimination to avoidance could not be adequately explained within existing terminology and concepts. To overcome the limitations in existing terminology, a concept of ‘apprehended discrimination’ has been devised to describe the rational fear of discrimination, which can ultimately lead to an avoidance of social situations in which a person could expect to be discriminated against.

The concept of ‘apprehended discrimination’ expands upon other research that signifies ‘trust’ and ‘engagement’ as vital components in the effective service delivery to Aboriginal and Torres Strait Islander people[65]. In understanding apprehended discrimination as a continuum or pathway in the psychological responses to discrimination, there are a number of phases through which the participants progressed in describing the impact of discrimination in their testimony.

FEAR OF DISCRIMINATION: The pathway commences with an intuitive understanding of discrimination. In the early stages of understanding, discrimination is externalised, in that the participants are drawing from a perceived understanding of discrimination which happens to others, distinct from their own personal exposures to discrimination.

APPREHENDED DISCRIMINATION: As they become more personally exposed to discrimination, their understanding of discrimination transitions from an intangible judgment to an increasingly rational thought process, in the sense that every incident adds weight of evidence to their rational judgment of discrimination, its frequency and its impact upon them. Apprehended discrimination is the ‘a-ha’ moment when they realise that their perception of discrimination has become their reality, a psychological realisation that invokes an unpleasant physiological reaction.

AVOIDANCE OF DISCRIMINATION: There comes a threshold point at which the accumulated exposure to discrimination is so great that the participant expects to be discriminated against, as distinct from being assessed as a chance encounter. Their response is self-exclusion, that is, to avoid situations in which they can be exposed to any further discrimination. The psychological response of avoidance is a rational choice, to avoid further harm by being further exposed to discrimination.

Illustrations of apprehended discrimination drawn from the testimony are provided in Chapter 5.2 in relation to everyday encounters of discrimination experienced by Aboriginal and Torres Strait Islander people with disability, and in Chapter 6.5 which provides a focussed discussion of apprehended discrimination in job-seeking and employment programs.

As an explanatory concept in describing avoidance as a psychological response to a rational fear of discrimination, ‘apprehended discrimination’ could also help other situations in which a fear of being discriminated against outweighs the potential benefit of seeking help. Such contexts might include:

- The mother of a child with Foetal Alcohol Spectrum Disorder, considering whether she should reach out seek support;
- The reason some Aboriginal and Torres Strait Islander people do not fill in the Census and other statistical reporting; and
- Whether the Aboriginal and Torres Strait Islander women are less likely to report incidents of family violence to the police, out of a fear that they themselves will instead will be picked up for minor infringements.

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[65] Dew, A., McEntyre, E., Vaughan, P., Coony, E., Dillon Savage, I., & Dowse, L., UNSW (2018). No More Waiting: A Guide for Organisations to Plan with Aboriginal People with Disability. UNSW: Sydney. At p

3

A COMMUNITY–DIRECTED RESEARCH METHODOLOGY

3.1 OVERARCHING DESIGN

This research is an exploratory scoping study and was primarily designed to promote the voices of Aboriginal and Torres Strait Islander people with disability in setting the agenda for future research. Its purpose was to canvass issues and generate ideas using an authentically grounded approach, using a research question that was distilled into four words: 'What is your story?' In keeping with the participatory aims of the research, Aboriginal and Torres Strait Islander people with a lived experience of disability were deemed the people most qualified to answer this question.

The grounded approach drew upon both the well-established grounded theory[66] approach to research following the grounded theory and sampling guidelines. The research commenced with firmly set values about how the research would be conducted as a community-directed approach to disability research, but without a pre-determined theoretical framework or hard-wired set of methods. Whilst influenced by the purposive, convenience sampling techniques of grounded theory, it is noted that these concepts were developed from a Westernised approach to research, and that these concepts would need to be adapted and extended for the research to be authentically grounded within the Aboriginal and Torres Strait Islander disability community.

The authentically grounded approach was operationalised into research practice through a number of design principles:

Principle 1: The research is philosophically, methodologically and operationally aligned to the control and direction of the First Peoples disability community.

Principle 2: The research continues the rights-based movement of the First Peoples Disability Network to advance the rights of Aboriginal and Torres Strait Islander people with disability.

Principle 3: The research is inclusive of all people who wish to participate, subject only to their self-identification as a member of the First Peoples disability community.

Principle 4: The research is discrimination and trauma informed, acknowledging the unique sensitivities of conducting research that includes people who are both Aboriginal and/or Torres Strait Islander and have disability.

Principle 5: The research meets both (i) international standards of ethical research practice and quality, and (ii) ethical standard for conducting research in Aboriginal and Torres Strait Islander communities.

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[66] Charmaz, K. (2006) Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. SAGE Publications. London.

3.2 SCOPE AND CONTEXT

Before progressing to a detailed discussion of how the research was conducted and its findings, it's important to highlight what the research was not designed to do.

Firstly, as an exploratory scoping study aimed at generating issues and ideas, it is not intended or designed to be an evaluation of any specific disability services or support programs. This is a particularly important note for how the research should be interpreted when referencing specific disability support systems, such as the chapter on the National Disability Insurance Scheme. The aim of this research was to solely identify issues for further exploration, and in doing so highlights some focused areas of concern in relation to the equity and quality with which support programs are provided to Aboriginal and Torres Strait Islander people with disability. However, no definitive conclusions about program or service evaluation can be drawn from this research, other than to demonstrate a need for further focused evaluation on the issues of concern that have been identified.

Secondly, the testimonial data has the capacity to report on the quality of the personal experience. There was insufficient sample size in the qualitative survey to provide any inference on the prevalence of issues from the testimonial data alone. The research has attempted to overcome this limitation by using a mixed methods approach[67] in which the statistical data interacts with testimonial data to generate the cohesive 'narrative' addressing quality and prevalence.

Thirdly, the inclusion criterion for all data was self-identification as an Aboriginal and Torres Strait Islander person with disability. The research was promoted through the First Peoples disability community as inclusive of all disability types. By adopting an 'inclusive of all' approach the research was conducted consistent with the values of Aboriginal and Torres Strait Islander culture, segregation by disability types or clinical diagnoses of disability in the inclusion criterion and analysis was not relevant to the research.

Finally, this research has started a process of activating participation by Aboriginal and Torres Strait Islander people in research, and has been successful in reaching people who have never had an opportunity to speak on issues that affect them. Nonetheless, it should not be presumed that this process has comprehensively captured all the views of the dispossessed and marginalised. There are particular gaps within the Aboriginal and Torres Strait Islander disability community whose views appear to be underrepresented. These groups include the views of children and young people; people who are in detention; people who are homeless and sleeping rough. In this respect, this research is a starting point for further exploratory studies on the narrative of the even 'harder to reach', not merely to incorporate their story as a perspective within research, but in positioning it as central to the purpose for conducting social impact research in the first place.

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[67] Leech N, Onwuegbuzie A, (2008) A typology of mixed methods research designs, Quality and Quantity, 43(2), March, pp. 265-275.

3.3 SETTING UP STRUCTURES AND RELATIONSHIPS FOR RESEARCH CO-PRODUCTION

Academic Advisory Panel

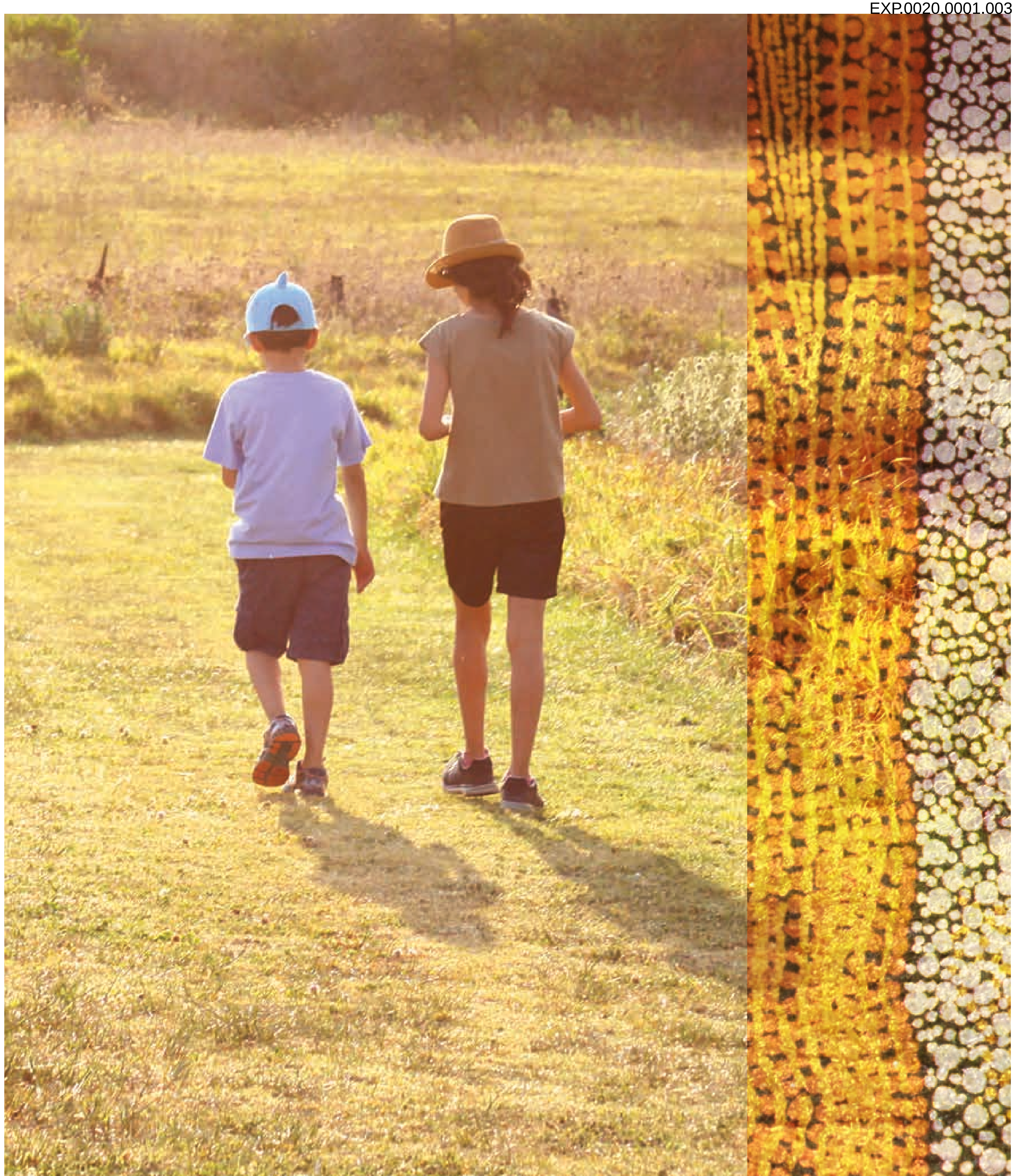
The 'Living our ways project' established an Academic Advisory Panel (AAP) comprising Aboriginal and disability researchers from two universities. The AAP is the core structure through which co-production of this research project occurs. That is, the research progresses through the connection between First Peoples Disability Network and the academic community, through the AAP.

The AAP interacts with the community-based researchers at regular review meetings, and through weekly communication with the lead academic researchers. The AAP established a community-led structure in that FPDN sets the AAP's agenda aligned to the 'Living our ways' research aims and objectives. These aims and objectives were set by the First Peoples disability community in the design of the research. The AAP contributes its governance expertise and advice to ensure the highest standard of academic rigour is met and that the research aims are achievable. In its advisory capacity, the AAP provides support and advice in decisions about participant recruitment, data analysis, and the ethical conduct of the research, including direct participation in interactions with Aboriginal Research Ethics Committees.

Relationship strategies with the Australian Bureau of Statistics: A model of constructive engagement between Community and Government

The absence of disaggregated data has been a long-standing impediment to understanding the specific needs of Aboriginal and Torres Strait Islander people with disability. At the commencement of the project, even the number of Aboriginal and Torres Strait Islander people with severe and profound disability was contested, due to the lack of direct access to the data and rigour in estimation practices.

The First Peoples Disability Network recognised access to disaggregated Aboriginal and Torres Strait Islander disability data as a driver of social change and prioritised a strategic partnership with the ABS. This provided the third angle to the triangular model of research co-production referred to above. A strategic partnership for research was a natural extension of the long-standing interactions that First Peoples Disability Network had as contributors to expert advisory groups convened by the ABS, with the lead researcher personally appointed to Expert Advisory Groups for the NATSISS, the SDAC, and National Aboriginal and Torres Strait Islander Health Survey.



The aim of the partnership was to complete a narrative on the profile of disability in Aboriginal and Torres Strait Islander communities as told through the data. This required a mixed methods approach to the research in which:

- The qualitative data generated through the interviews contextualises the quantitative data, and reciprocally;
- The independence of the quantitative dataset provides scope to the issues raised by participants of the research in the qualitative interviews.

The source of the quantitative data used is the NATSISS and SDAC. Whilst the data for the two survey instruments is publically available, the technical expertise provided by the ABS assisted the disaggregation of Aboriginal and Torres Strait Islander disability specific data from the responsive whole of population datasets. Ongoing advice and review also ensured that the community-based researchers at First Peoples Disability Network interpreted the data with integrity to the collection methodologies and limitations of both surveys.

The relational approach between a government data collection agency and a community organisation has produced data driven analysis on the social inequalities experienced by Aboriginal and Torres Strait Islander people with disability with unprecedented scope. The first output of the strategic partnership was the publication of an occasional paper entitled Social and Economic Wellbeing of Aboriginal and Torres Strait Islander People with Disability,[68] in which the ABS acknowledged its partnership with and the contribution of First Peoples Disability Network. The presentation of narrative and the numbers side by side in this report builds on this collaborative approach.

There are several attributes to the strategic partnership which have contributed to its success as a model of cooperation between a community organisation and a government agency:

- It is fundamentally a relational approach in which goodwill and respect accumulates over continued engagement and interaction.
- Both share a vision for social change. The First Peoples Disability Network has an expressed desire to use data and evidence to improve the social circumstance of Aboriginal and Torres Strait Islander people with disability, and the ABS has an expressed desire to get data into the hands of people who strive to make a difference.
- The strategic relationship is a 'whole of organisation' approach with breadth of support in each organisation and access to structures within the ABS for the collection of Aboriginal and Torres Strait Islander data and disability data.
- The whole of organisation commitment is reinforced by strong interpersonal relationships between a number of staff at First Peoples Disability Network and within the ABS, providing continuity.
- Each organisation acknowledged the other's particular expertise. The ABS is recognised for its expertise on the access and interpretation of quantitative data through its statistical collection. First Peoples Disability Network is recognised for its expertise on the access and interpretation of qualitative data through the collection of testimony from community. This has facilitated privileged access to the other's data and expertise.
- Once established the goodwill allowed for trust-building discussion. It is a notional concept of 'safe space' in which any issues around the access and interpretation of sensitive data could be addressed and worked through with mutual respect.
- The strategic relationship extended beyond initial aspirations to 'listen to the voices of Aboriginal people' because it provides a tangible contribution to a project that has been prioritised by community.
- There is a common language to communicate, which in this partnership is the language of data.

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[68] Australian Bureau of Statistics (2017) Social and Economic Wellbeing of Aboriginal and Torres Strait Islander people with disability. National Aboriginal and Torres Strait Islander Social Survey 2014-2015. (Feature article) Rel. 4714.0.

3.4 A PLAYBOOK FOR COMMUNITY DIRECTED RESEARCH

STAGE 1: PREPARATION AND CONCEPT DEVELOPMENT

(January 2015–December 2015)

Research activity: Developed the concept of a community-directed approach to disability research and the core principles for its implementation

Reason for the approach chosen

The essential purpose of the research was to elevate and promote the voices of Aboriginal and Torres Strait Islander people with disability, but it needed in principle support.

As an innovation in social impact research, there was no precedent to guide how this would be done. Hence there needed to be a firm set of principles which would direct how the research would progress which kept integrity. with its intent.

How this was implemented in the research

The FDPN Board of directors formally endorsed a community-directed approach to research as part of its Strategic Directions in December 2015. This positioned FPDN as the lead organisation for the research activity, guided by a set of principles through which the community-directed model of research would be conducted.

Research activity: Established a research team to reflect the community directed model of co-production.

Reason for the approach chosen

FPDN's core strength is its connection and access to the disability community, but it required access to technical expertise on academic research and technical advice of statistical data.

FPDN had long-standing but informal relationships with key Aboriginal and disability researchers, and the ABS. This research applied a project focus to these relationships.

How this was implemented in the research

A research team was established comprising:

- **Community:** represented by FPDN, who designated the researcher from its community to lead the research.
- **Research:** represented by an Academic Advisory Panel comprising leading Aboriginal and disability researchers to provide research and academic oversight to the project.
- **Policy:** Represented in this model by the ABS, who facilitated access and provided technical advice on statistical data.

Research activity: Secure the resources to undertake the project

Reason for the approach chosen

The research reflected a bold ambition for change coming from the First Peoples disability community. It needed a sufficiently secure base of core funding to continue.

How this was implemented in the research

Core two-year funding was received from the Australian Government's National Disability Research Development Scheme. The process of securing funding commenced in January 2015 with a formal Expression of Interest, proceeded through a Request for Tender stage, and was finalised with the signing of a funding agreement in November 2015.

Core funding was complemented by expertise-in-kind support from its academic partners at UTS and UNSW, and the ABS.

The lead researcher also received additional support from the Lowitja Institute as part of a PhD project related to this research to enable him to undertake knowledge translation activities that were not funded through the core funding.

Research activity: A data strategy was developed utilising a mixed methods approach

Reason for the approach chosen

The research foresaw that the impact of the participants' testimony might be diminished on the basis of an insufficient sample size.

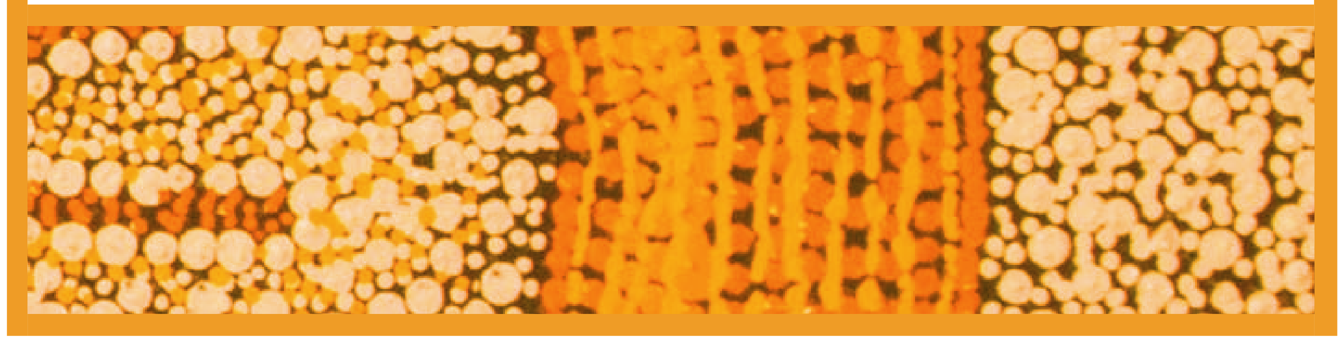
Therefore it was recognised that qualitative data would be required to contextualise the quantitative data that affects Aboriginal and Torres Strait Islander people, to complement the personal insights garnered through interviews.

How this was implemented in the research

A data strategy was developed to obtain:

- **Quantitative data:** Through the NATSISS and the SDAC
- **Qualitative data:** generated through interviews with Aboriginal and Strait Islander people with disability.

Field notes of the interview process were also kept by the lead researcher as an interpretive guide during later stage analysis.



STAGE 2: PROJECT DESIGN

(July 2015–March 2016)

Research activity: Developed a relationship strategy with the ABS to facilitate access to qualitative data and obtain technical advice on its interpretation.

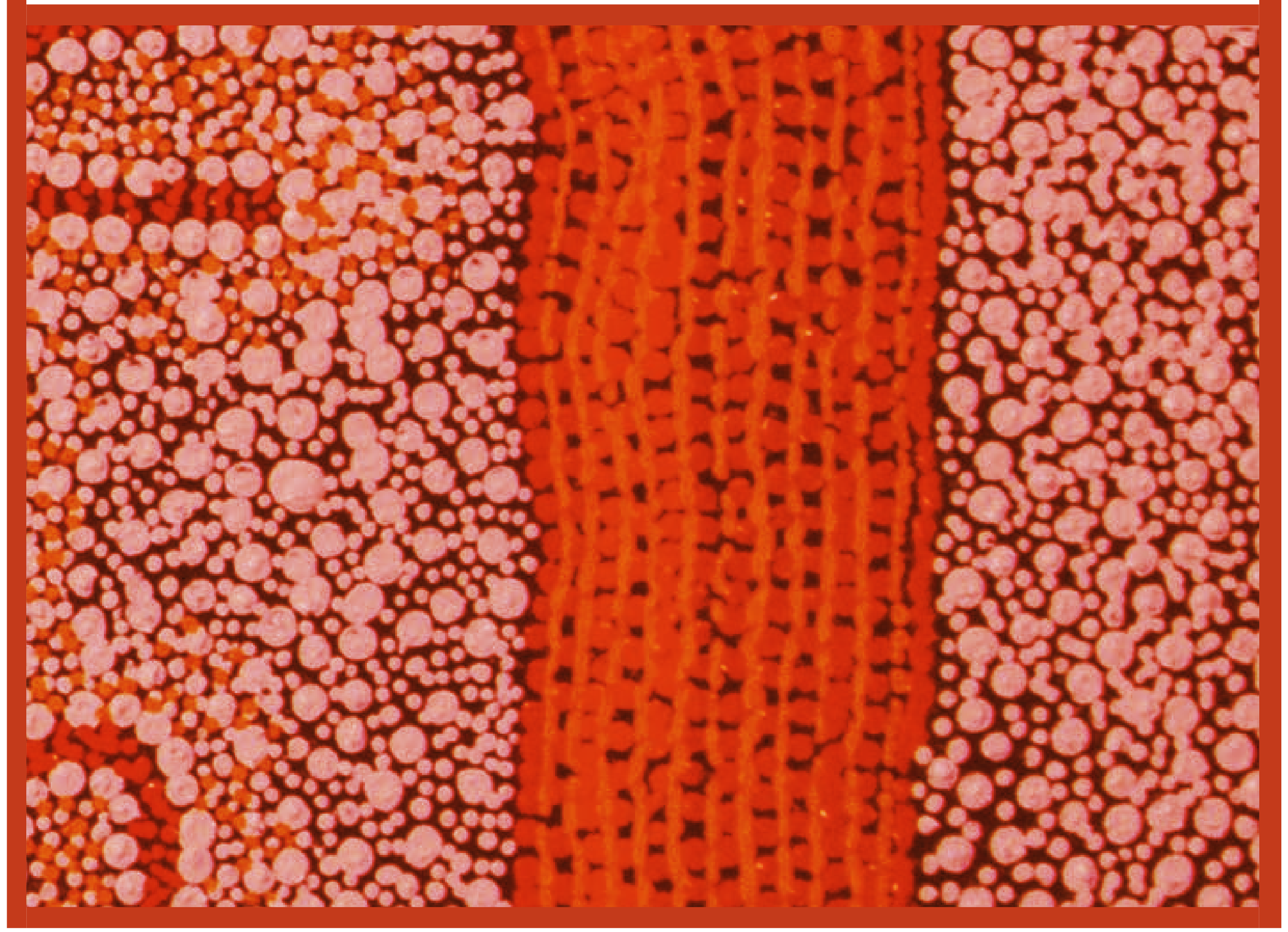
Reason for the approach chosen

As Aboriginal and Torres Strait Islander disability data was available but fragmented across various data sets, it was determined that the most qualified agency to assist in sourcing the data and accurately interpreting it was the source agency that collected it.

How this was implemented in the research

The lead researcher was invited by the ABS to join Expert Advisory Groups for the NATSISS and the SDAC. This facilitated access to both data as well as technical experts on the various datasets within the ABS.

In addition to participating on Expert Advisory Groups, the research and the ABS met on numerous occasions during the course of the project.



Research activity: Community consent was obtained from local Aboriginal communities in which the qualitative component of the research would be conducted.

Reason for the approach chosen

A convenience sampling method was used for the selection of research sites and individual participants due to the exploratory nature of the research combined with the limited resources available relative to its scope and purpose.

Community consent started with the lead researcher's existing community network, then expanded to FPDN's established network, then, as the research built a track record with community, expanded again into FPDN's emerging networks.

Within the convenience sampling approach, the research nonetheless aimed to obtain participation from a cross section of metropolitan, regional and remote areas. This was needed to enable some exploration of the comparative experiences of Aboriginal and Torres Strait Islander people living in urban, regional and remote locations.

How this was implemented in the research

The community consent pathway was leveraged from FPDN's existing community engagement activities, in that the research was considered an extension of the rights and disability awareness activities conducted in Aboriginal communities.

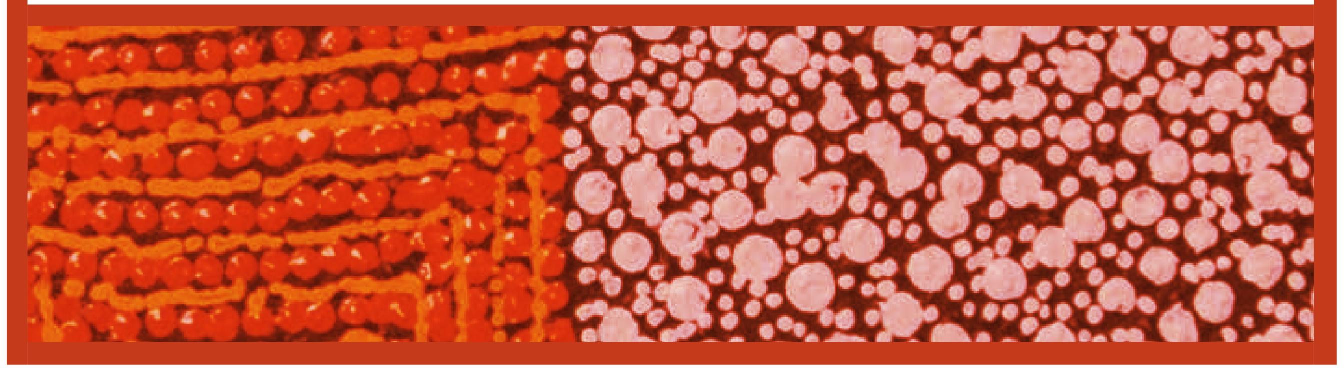
Community consent- Deadly Deaf Mob (Commencing site): The first cohort providing their consent to participate was the Deadly Deaf Mob, a social network of Deaf Aboriginal people. This came about when one of the conveners of the Deadly Deaf Mob learned about the research, and asked the lead researcher who is also a Deaf Aboriginal man whether the Deadly Deaf Mob could participate.

Community Consent – Disability community NSW: Community consent was then secured through members of the Aboriginal Disability Network (NSW).

Community consent- Barkly Shire, including Tennant Creek and Utopia: The research then followed the community engagement activities of FPDN into the Barkly Shire in the Northern Territory. Noting that the research was a non-sequential, staggered process, the community consent in the Barkly Shire was happening concurrently with interviews in NSW.

Community consent – Deadly Deaf Mob (second site): The convener of the Deadly Deaf Mob subsequently invited the lead researchers to continue interviews with the Deaf community at a second research site.

During the course of the project, the process of obtaining community consent commenced in Northern Australia and regional South Australia, but these were discontinued due to the resource constraints of both the project and the community organisations approached to facilitate access to research sites.



Research activity: Create an interview style and protocol that was based upon deep listening and sensitive to trauma.

Reason for the approach chosen

The interview protocol was designed to create a 'safe space' in which Aboriginal and Torres Strait Islander people with disability could give their testimony on their terms and in their own time.

How this was implemented in the research

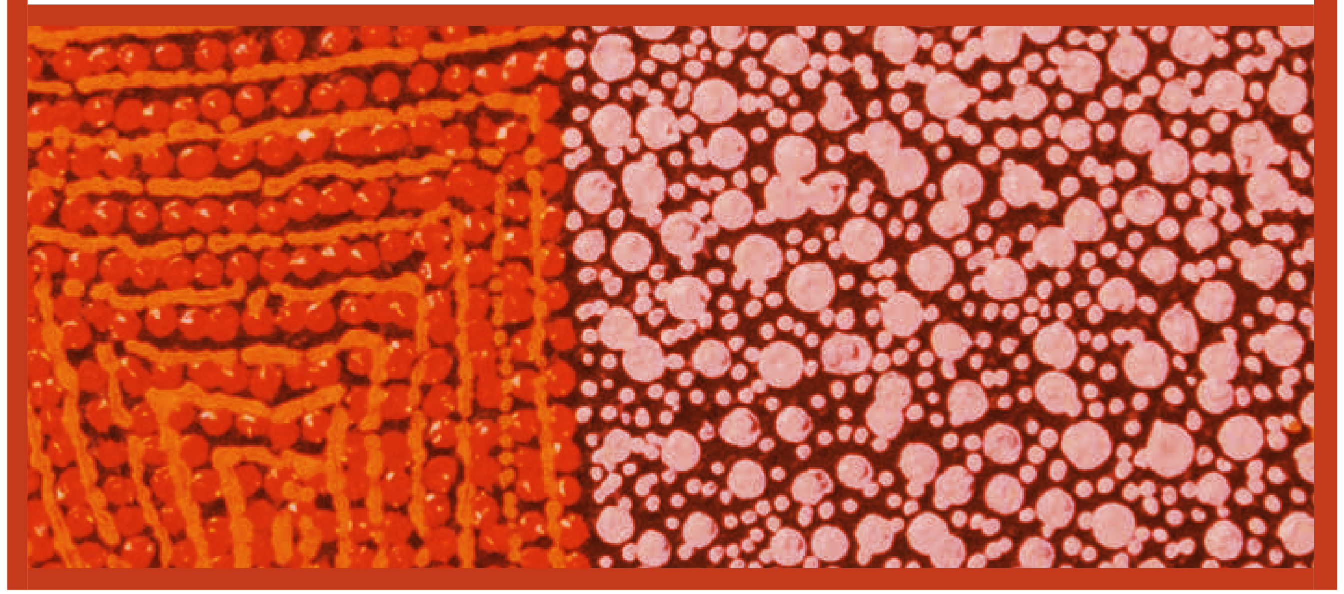
Interview style: An unstructured interview technique was utilised to enable participants to tell their story on their terms and at their own pace.

Discussion prompts: As opposed to questions, five discussion prompts were woven into the interview to facilitate the telling of testimony. It commenced by asking a general question: "What is your story?", designed to situate the participant at the centre of the interview from the outset, rather than the researcher. It then proceeded to prompt discussion of barriers, strengths and sources of personal support. It then concludes with a question around what matters to them in regard to their future.

Discussion prompts:

1. What is your story?
2. What barriers and obstacles have you faced in getting the help you need?
3. Who do you turn to when you need help?
4. What are some of the good things you have been able do?
5. What matters to you regarding your future?

The discussion prompts did not contain any reference to 'disability'. Other than introducing the researcher as from the First Peoples Disability Network, which set the general domain for discussion, references to 'disability' were otherwise avoided unless introduced into the discussion by the participant. This was consistent with one of the aims of the study that was to understand how Aboriginal and Torres Strait Islander people with disability intuitively identify with their disability.



Research activity: A study protocol around the collection of testimonial data

Reason for the approach chosen

The study protocol maintained the aim of promoting the voices of Aboriginal and Torres Strait Islander people living with disability. International standards for research quality and ethical protocols for research in Aboriginal and Torres Strait Islander communities were used as a minimum standard point, and democratised to facilitate the inclusion of First Peoples with disability.

The use of the term 'inclusion criteria ' to determine participation is a choice to reflect the participatory aims of the research, and to distinguish it from a 'selection criteria' which may be taken as limiting.

How this was implemented in the research

An 'Inclusion criteria': The inclusion criteria for participant was:

Self-identification as an Aboriginal and/ or Torres Strait Islander person; and

Self-identification as a person living with disability.

As the research was introduced as an extension of FPDN's community engagement activities, the inclusion criteria in practice became self-identification with the First Peoples disability community.

Consistent with the aim of promoting the voices of Aboriginal and Torres Strait Islander people living with disability, service providers and other people operating in a professional capacity were not considered within the inclusion criteria (although on occasions, some were present during the interviews in a role of support person to the participant).

Participant information and consent form: A two-page (one single sheet, double sided) was drafted from scratch in the personal presence of an Aboriginal person with disability as a representative of the participant group, and separately reviewed by another Aboriginal person with disability. The final version of the participant's information and consent form incorporated the following advice provided during the drafting:

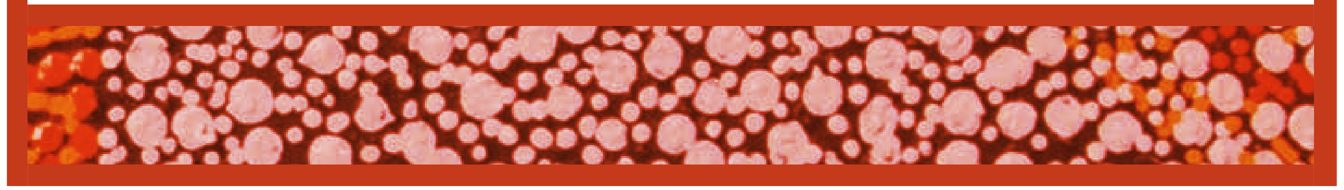
They found comfort in knowing the research was being led by an Aboriginal non-government organisation, rather that Government or a University, although this was not an immediate realisation. This was reinforced by including FDPN's logo on the form.

- They wanted an iron-clad assurance that their personal story would not be handed to a Government agency.
- They found lengthy, technically worded consent forms intimidating, and would be reluctant to sign them.

Data Management: The research conformed to ethical guidelines for secure data management and the presentation of the participants' confidentiality. This included the identification of raw testimony during its transcription into text form, and secure storage of data in electronic format.

Safety protocols: Protocols were established to encourage awareness of signs that the participant was affected by trauma. These protocols included:

- stopping the interview if the safety of the participant was of concern, and
- making sure a support person was available at all times.



STAGE 3: ETHICS

(January 2016–June 2017)

Research activity: Ethics approval was sought and obtained from the Aboriginal Heath Research Ethics communities with jurisdiction over each research site.

Reason for the approach chosen

As an Aboriginal community controlled organisation, FPDN respects and promotes the role of the Aboriginal Research Ethics Committees as an independent barometer of ethical conduct in Aboriginal communities.

An iterative process which enabled research to commence in sites where community consent was readily obtainable, whilst allowing more time to obtain community consent in other sites.

How this was implemented in the research

As with the community consent process, the ethics approval was variable, reflecting slightly different approaches and requirements from each of the Aboriginal Health Research Ethics Committees in each of the regions where the research was conducted:

- The New South Wales Aboriginal Health and Medical Research Council (Approved April 2016, with annual renewal). This was prioritised as FPDN's domicile state, and where the community consent process was most advanced.
- Central Australian Human Research Ethics Committee (Approved April 2017, with end of year renewal): This covered the Barkly region in the Northern Territory and the Elders forum in Alice Springs
- South Australian Aboriginal Health Research Ethics Committee (Approved June 2017):

A separate ethics process also commenced for potential research sites in the northern regions of Northern Territory. However, this process coincided with the timing of the Royal Commission into the Protection and Detention of Children, and sensitive to the resource constraints that would be placed upon supporting community controlled organisations at this time, it was decided not to proceed.

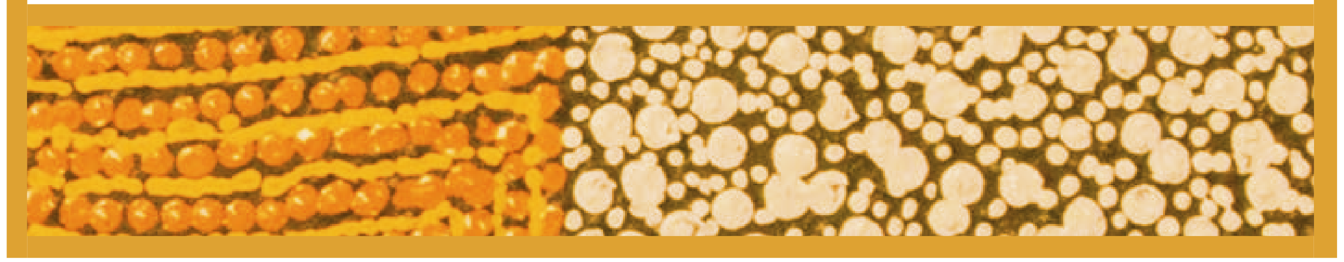
Research activity: Meet with Elders and FPDN Board for their endorsement to proceed with the research.

Reason for the approach chosen

In addition to obtaining ethics approval from the relevant people the research obtained 'spiritual assent' from Elders of the First People disability community and the FPDN Board before proceeding with any interviews.

How this was implemented in the research

Assent of Elders: The research was presented to Elders from the First Peoples disability community and FPDN's Board in March 2016, who endorsed the research approach and recommended that the research begin.



STAGE 4: DATA COLLECTION

Research activity: Secure access to disaggregated statistical data on disability in Aboriginal and Torres Strait Islander communities.

Reason for the approach chosen

Statistical data was needed to:

Scope the population-wide prevalence and profile of disability in Aboriginal and Torres Strait Islander communities, and

i. Interrogate intersectionality as a foundational assumption in the social, health and wellbeing outcomes experienced by Aboriginal and Torres Strait Islander people with disability compared to others in the population.

ii. As there was no single data source containing a discrete population, it was anticipated that the statistical analysis would require polyangulation of data across multiple data sets.

How this was implemented in the research

Prevalence and Profile: Statistical data on the prevalence and profile of disability amongst the Aboriginal and Torres Strait Islander population was sourced from;

i. The NATSISS, disaggregated by people self-identifying as having disability;

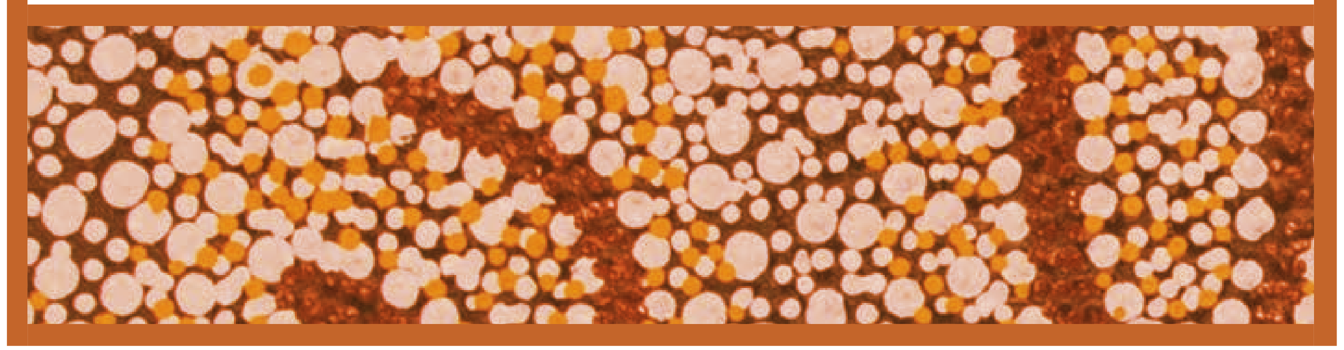
ii. The SDAC, disaggregated by people who self-identify as Aboriginal and / or Torres Strait Islander.

This data is reported in Chapter 4.

Social, health and wellbeing inequality: Statistical data which compared the social, health and wellbeing outcomes of Aboriginal and Torres Strait Islander people with severe and profound disability to Aboriginal and Torres Strait Islander people without disability was sourced exclusively from the NATSISS. This data is reported in:

- Chapter 6 with respect to social health and wellbeing iniquities;
- Chapter 8 in respect to trauma and mental health; and
- Chapter 9 in respect to cultural participation.

All statistical data sourced from the ABS was collected by the ABS independently of this research project and is available on their public website. ABS staff from the National Centre for Aboriginal and Torres Strait Islander Statistics and Disability, Ageing and Carers Section provided technical advice and assistance on the extraction of data from publically available data tables, and on the correct interpretation of the data with reference to the limitations on the survey instruments used to collect the data.



Research activity: A ‘rock-up recruitment’ approach to facilitate participation that worked within the communication channels preferred within each research site.

Reason for the approach chosen

To bridge the communication gap in which the language of research discourse was seen as alienating within community, the researcher coined the phrase ‘rock-up recruitment’ to convey a flexible, non-threatening manner in which the researcher would ‘rock up’ to community, sit with the people, understand and then utilise the community communication structures to communicate the purposes and objectives of the research. The objective was to position the researcher within communities as available to take people’s testimony, but not so obtrusive as to be seen as pressuring people to participate.

How this was implemented in the research

‘Rock-up recruitment’: The flexible recruitment approach generated participation through a variety of means including:

- direct referrals of participants from community members;
- unsolicited request by participants who had heard about the research through the Koori grapevine (word of mouth);
- promotion on the Deadly Deaf Mob social media sites;
- guest speaking spots on community radio;
- community barbecues;
- an invitation by a Men’s group; and
- attendance at Aboriginal gatherings and community meetings to which the researcher was invited.

Research activity: Conducted interviews with participants to collect testimonial data

Reason for the approach chosen

The interview schedule was staggered, which was a consequence of the staggering of the community consent and ethics reviews processes.

There was a secondary purpose of staggering in that it enabled testimonial data to be collected in FPDN’s home state of NSW whilst community consent and ethical review was taking place in sites outside NSW.

This strategy generated some testimonial data as runs on the board for a community directed model of research as safeguard in the event that resources were suddenly withdrawn for whatever reason.

Interviews continued until the qualitative data reached saturation point using the purposive convenience sampling techniques.

How this was implemented in the research

All interviews were conducted by the lead researcher. This maintained a consistency in the style of interview throughout.

All testimonies were given verbally and digitally recorded. Interviews with the Deadly Deaf Mob were conducted with the assistance of an Auslan interpreter, in which the verbal response from the interpreter was recorded. As an additional precaution for the Deadly Deaf Mob interviews conducted in Auslan, the signed responses of the participant were also video recorded in case they were needed for verification during the transcription of the interview, although this proved to be unnecessary.

The interviews generated a participant profile shown in Table 3.3.1.

Research activity: Elders Forum

Reason for the approach chosen

The purpose of the Elders forum was twofold:

- First, it provided an opportunity for Elders to speak on their own behalf on their views of how disability is seen within their communities through recorded testimony.
- Second, it provided their assent to how the research was conducted during the interviews, before it proceeded to analysis and reporting

How this was implemented in the research

There were 11 participants at the Elders Forum, which was conducted at Alice Springs, Northern Territory in September 2017.

STAGE 5: DATA MANAGEMENT

Research activity: Testimonial data was de-identified and securely stored

Reason for the approach chosen

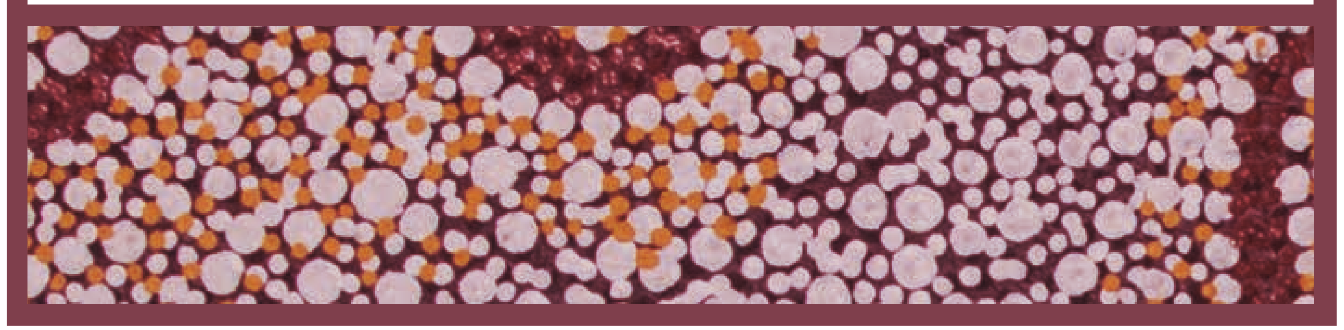
Data management practices for the de-identification of raw text and storage of data were put in place to comply with best practice ethical standards for protecting participants' confidentiality and the secure storage data.

How this was implemented in the research

De-identification: Once an interview was completed, the audio recording was transcribed verbatim into text form. The lead researcher then screened the raw text and removed any identifying attributes including references to names (whilst retaining a gender reference), city or town name (whilst retaining a reference to urban, regional or remote setting) or specific names of organisations that provided them with support. The exception to this rule was the retention of references to Aboriginal nations, as it is improbable that a person could be identified by that attribute alone, and it is an important data in understanding how Aboriginal and Torres Strait Islander people choose to identify themselves.

An additional screening for attributes or quotes that could potentially identify participants was also conducted during the writing and review stages of the draft (see stage 7).

Storage: The de-identified narrative texts were then stored on a secure server at First Peoples Disability Network's office, after which the audio and video recordings were permanently destroyed.



STAGE 6: ANALYSIS

Research activity: De-identified testimonial data was imported into NVivio software for a two-staged categorical and thematic analysis.

Reason for the approach chosen

The use of Nvivio software enabled an iterative analysis of the testimonial data, involving:

- a categorical screening of all testimonial data
- a deeper thematic analysis; and
- capacity for key word searching

How this was implemented in the research

Categorical screening: As an initial stage, all de-identified texts were screened by the researcher to identify key themes

Thematic analysis: once key themes were identified, texts relating to a particular theme were collated from all texts for an analysis of key messages and issues.

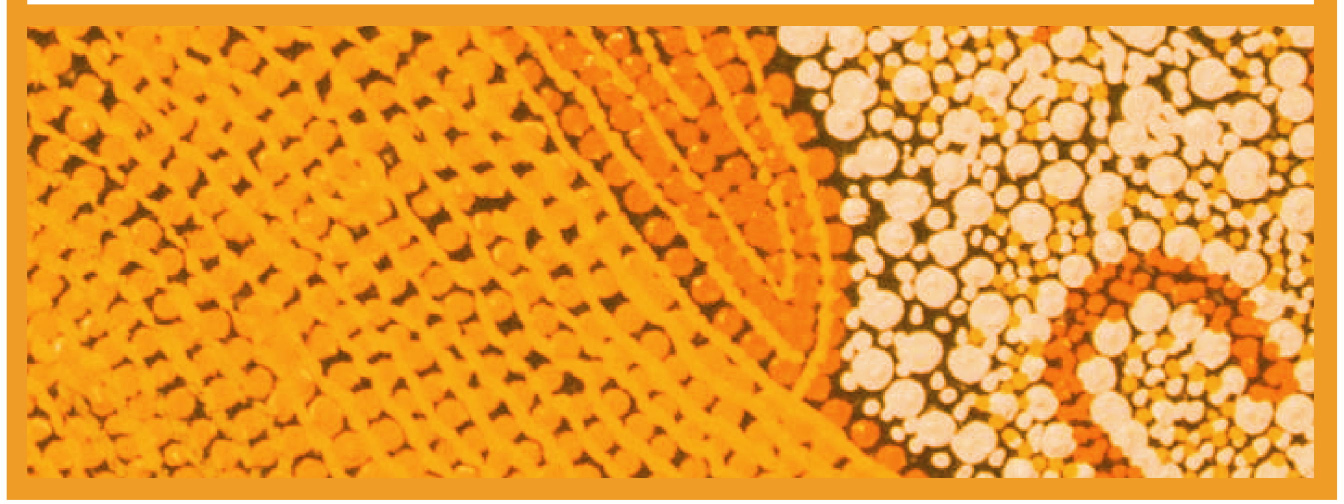
Research activity: Single testimonies were integrated with field notes to generate ‘yarning pieces’

Reason for the approach chosen

During the writing of the analysis using statistical and verbatim quotes from the testimonial data, it was clear that those two types of data alone could not fully convey a comprehensive narrative.

How this was implemented in the research

Creation of yarning pieces: At the conclusion of the categorical and thematic analysis, the researcher revisited the field notes from some of the interviews, which when combined with verbatim quotes from testimony, morphed into the yarning pieces.



STAGE 7: COMMUNITY AND ACADEMIC REVIEW

Research activity: The research was subjected to a multi-layered process of community and academic review prior to its publication.

Reason for the approach chosen

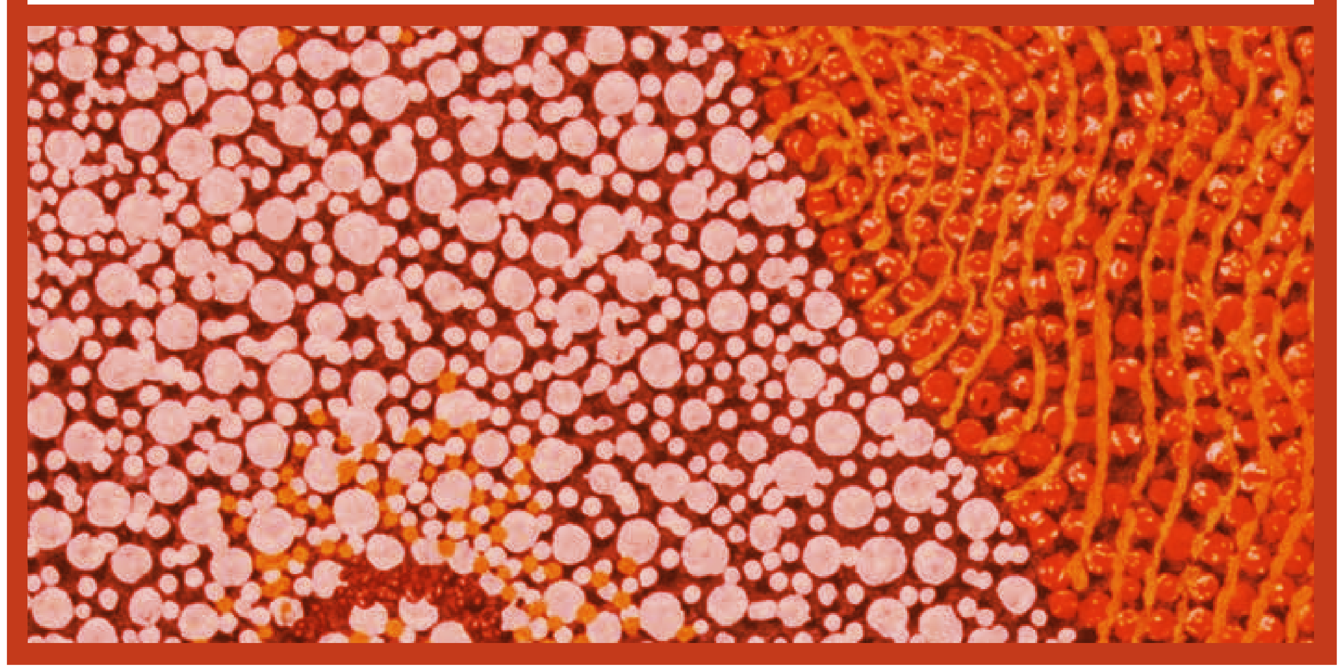
A review process by both the First Peoples disability community and leading academics was built into the project governance, so the end product satisfied the dual requirements of being community and culturally compatible research, and of high academic quality.

In addition to internally established review processes, a final draft of the research was submitted to the Aboriginal Health and Medical Research Council in compliance with the conditions of ethics approval; and the providers of research funding, in compliance with the research funding agreement.

How this was implemented in the research

Community and academic review: Prior to final publication, the research has been reviewed by:

- Representatives from the First Peoples disability community, as affirmed by a resolution of the Board of Directors at FPDN;
- The Academic Advisory Panel;
- Representatives of the ABS (exclusively relating to the technical accuracy of the presentation of statistical data).
- The Aboriginal Health and Medical Research Council, as affirmed by their formal approval to publish.
- The Research Data Working Group as administrators of the National Disability Development Research Scheme through which research funding was provided.



STAGE 8: RESEARCH TRANSLATION

Real time translation

Reason for the approach chosen

As the researcher was a first-hand witness to acute inequality and unnecessary suffering, there was a duty of care to draw attention to issues as they arose, rather than wait until the completion of the research project.

The real-time translation also helped build the research as a rights-based movement, which in turn encouraged greater participation of Aboriginal and Torres Strait Islander people, supporting a key deliverable of this project.

How this was implemented in the research

Real-time translation into policy advice: The findings of the research were incrementally infused into the policy advice and advocacy work of the lead researcher and FPDN in meeting their obligations as systemic advocates on behalf of community. This advice was unfunded and provided on call to:

- Community members,
- Aboriginal and Torres Strait Islander organisations,
- University and research institutions, and
- A number of Government agencies at the Commonwealth, State and Territory levels.
- Working groups and roundtables on the Closing the Gap framework, the Indigenous Advancement Strategy, National Disability Strategy and a number of state-based programs.

Create a publication which can act as a resource for planning, training and teaching

Reason for the approach chosen

There is need for a comprehensive resource to support community organisations seeking to set up services and train a workforce to meet the needs of Aboriginal and Torres Strait Islander people with disability.

The publication needs to be able to reach a broad range of people. It needs to be in a style and format accessible to those in the Aboriginal and Torres Strait Islander sector who want to know more about the disability sector who want to know more about Aboriginal and Torres Strait Islander people.

How this was implemented in the research

'Culture is inclusion' is the first publication from this research.

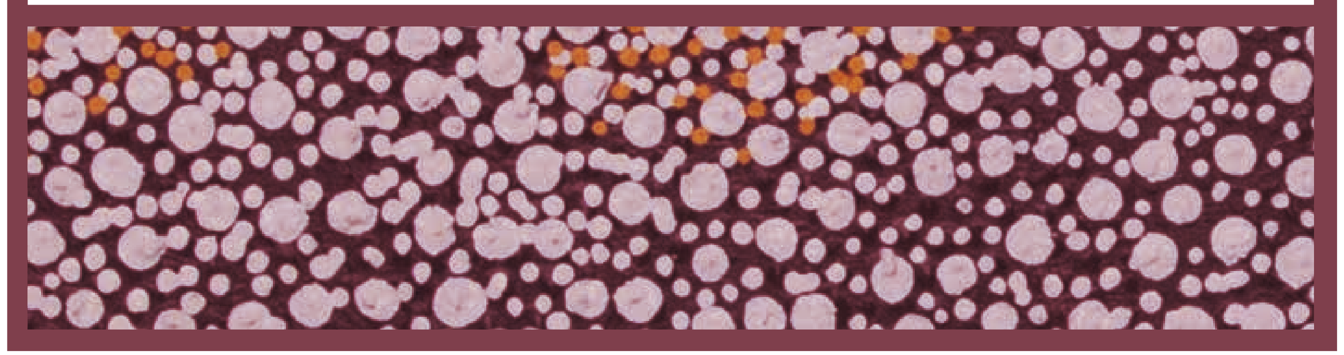
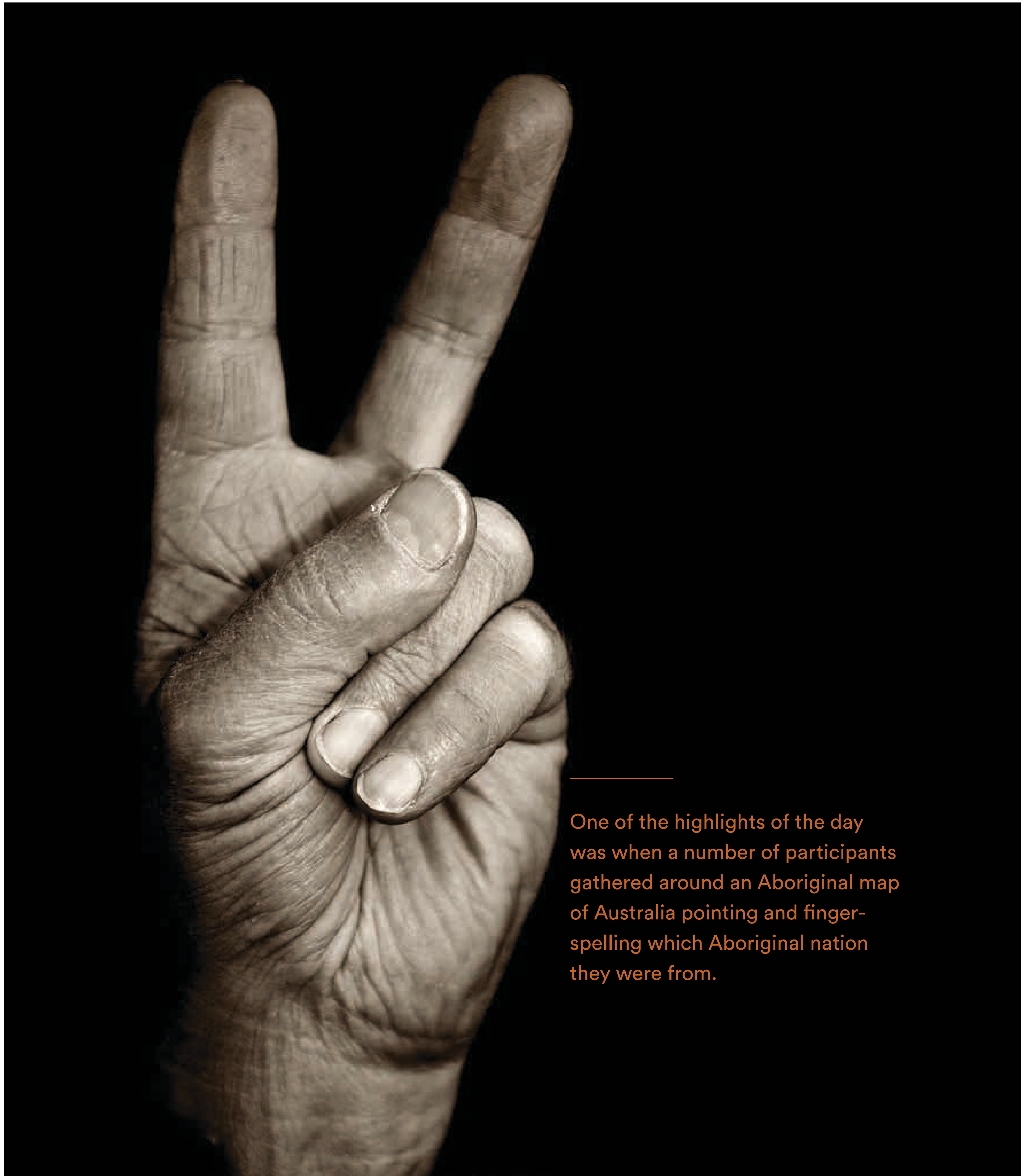


Table 3.3.1 Participant Profile

Total number of participants	
47	
Total Number of interviews	
41	
Average time per interview	
31.01 minutes	
Participants by gender	
Female	25 (53.2%)
Male	22 (46.8%)
Participants by cohort	
Deadly Deaf Mob (two sites)	11
Urban – NSW	11
Non-urban – NSW (regional and remote)	15
Non-urban – Northern Territory	10
Elders Forum	
Number of Participants	11
Areas represented	NSW Remote Northern Territory Barkly Shire. Northern Territory Torres Strait Islands Queensland South Australia North-west Australia



One of the highlights of the day was when a number of participants gathered around an Aboriginal map of Australia pointing and finger-spelling which Aboriginal nation they were from.

Case Cohort: Deadly Deaf Mob

The Deadly Deaf Mob is the name of a social network of Deaf and hearing impaired Aboriginal and Torres Strait Islander people. FDPN and its lead researcher have an extensive history of supporting the Deadly Deaf Mob, who reciprocally view this research as an opportunity to document their experiences in a research context – a form of participation they have not previously had the opportunity to be involved in.

The Deadly Deaf Mob research project was initiated by a cohort of Deaf Aboriginal people. In February 2015, the lead researcher of the 'living our ways' project was invited by three members of the Deaf Aboriginal community, connected through social media as 'the Deadly Deaf Mob' to assist them in preparing a grant application under the 'My Choice Matters' grant scheme. The funding application was being prepared under each of the individual's names, which would be consolidated to convene a gathering of Deaf and hearing impaired Aboriginal people. The grant application was successful, and the Deadly Deaf Mob convened a gathering in Western Sydney from 30 September to 1 October 2015. The conveners then invited the lead researcher to prepare a video on the research which was shown at the Conference, and this was later placed on the Deadly Deaf Mob Facebook page. One of the conveners of the Deadly Deaf Mob provided a letter of support for the purposes of obtaining ethic approval.

The first round of interviews with the Deadly Deaf Mob were conducted at FPDN's Head Office in Redfern NSW on 16 September 2016. The interviews were conducted in Auslan, and a number of the participants stayed after their interview to keep yarning as a group. One of the highlights of the day was when a number of participants gathered around an Aboriginal map of Australia pointing and finger-spelling which Aboriginal nation they were from.

After the Redfern interviews, a few members of the Deadly Deaf Mob moved interstate. They spoke positively of their experience with others from the Deaf community in their area, which resulted in an invitation to visit and conduct some further interviews. Again, these interviews were conducted in Auslan, but with a difference. A last-minute withdrawal of the interpreter who had been booked to attend the second day meant that arrangements were made for two interpreters who were based interstate to do the interpretation via Skype using the researcher's laptop.[69]

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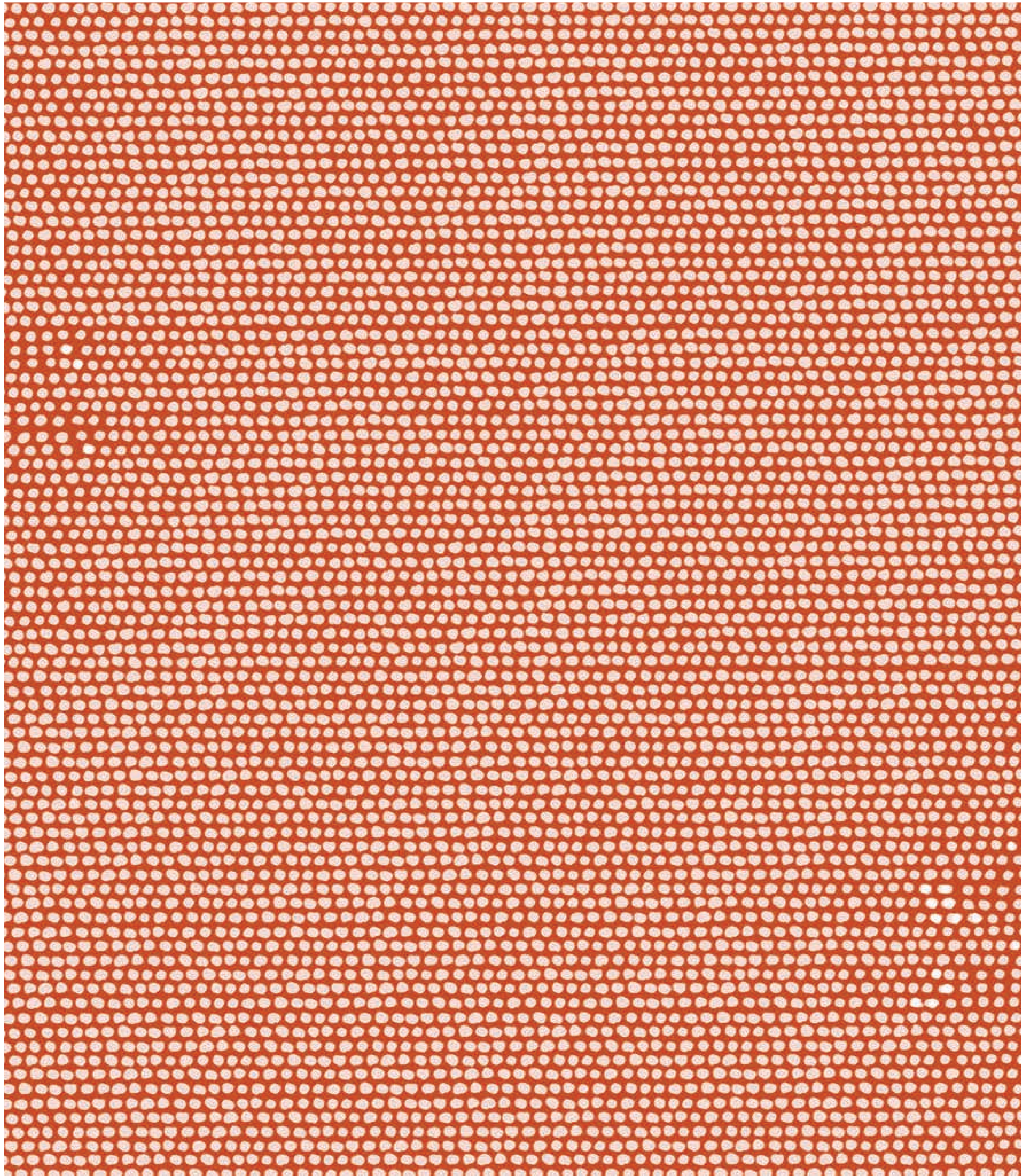
[69] Photo taken with express permission.

4

PREVALENCE AND PROFILE OF DISABILITY AMONGST THE ABORIGINAL AND TORRES STRAIT ISLANDER POPULATION



KEY FINDINGS:

Prevalence and profile: Disability in Aboriginal and Torres Strait Islander communities is twice as prevalent, more complex in terms of co-occurring disabilities, and compressed within a shorter life expectancy compared to other Australians.

Severe and profound disability: The number of Aboriginal and Torres Strait Islander people with severe and profound disability, using the best available data, is estimated to exceed 60,000 people.

Disability diagnoses: The high reporting of unspecified disability indicates that disability diagnoses are either not available or not known by the individuals, which can act as a barrier to them accessing adequate support for their disability.

Overshadowing of co-occurring disabilities: For people who experience multiple disabilities, a focus on supporting just one disability may overshadow the adequate recognition and support for other co-occurring disabilities.

Gender and remoteness: There are variations in the prevalence of severe and profound disability within Aboriginal and Torres Strait Islander communities when prevalence data is disaggregated further by gender and remoteness.

4.1 DATA SOURCES AND LIMITATIONS IN ESTIMATING THE PREVALENCE AND PROFILE OF DISABILITY IN ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITIES

There is no focussed population-based instrument to capture prevalence, profile and outcomes for Aboriginal and Torres Strait Islander people with disability.

Two primary sources of population data collected by the Australian Bureau of Statistics which allow a depth of analysis of disability amongst Aboriginal and Torres Strait Islander people are:

i. The NATSISS, a sample survey of Aboriginal and Torres Strait Islander people which includes disability questions; and

ii. The SDAC, which is a sample survey of people with disability and their carers which includes an identifying question for Aboriginal and Torres Strait Islander people who complete the survey.

There is also the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)[70] which collects data on disability. However, the NATSISS is more appropriate for exploring some of the social components of Aboriginal and Torres Strait Islander people's experiences with disability that are relevant to this project and its qualitative findings. The Australian Census does not expressly collect data on disability, but does so indirectly through a general question on a person's 'need for assistance'. Unlike the NATSISS and the SDAC, both of which collect data from a sample of their target populations, the Census aims to collect data for the entire Australian population.

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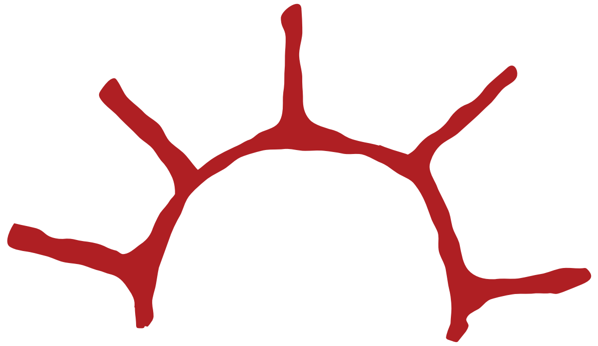
[70] Australian Bureau of Statistics (2013) Australian Aboriginal and Torres Strait Islander Health Survey: First Results, Australia, 2012-13 Rel. 4727.0.55.001.

Whilst both surveys include Aboriginal and Torres Strait Islander disability, subtle differences in the methodological approach used make it difficult to make a direct reconciliation, a point that is acknowledged by the ABS.[71] Both surveys generate data that provides useful insights, yet each survey has relative strengths and limitations as a scientific tool compared to the other.[72]

A comparison of the methodologies and their structural limitations is outlined in Table 4.3.1 as an aid to interpreting the data. Notably, both the NATSISS and the SDAC collect data from Aboriginal and Torres Strait Islander people with disability living in private dwellings. In other words, neither survey collects data on people living in institutional settings, such as prisons or in out of home care. Neither collects data on people who are currently homeless, or 'living rough'. There is otherwise of dearth of data to estimate the homelessness rate of Aboriginal and Torres Strait Islander people with cognitive impairment. [73] This population cohort represent some of the most isolated and excluded people in society, and due to the nature of their social isolation, accurate data on the disability prevalence amongst this group does not exist. In an absence of data, the understanding of intersectionality makes it reasonable to assume that the prevalence of disability amongst Aboriginal and Torres Strait Islander people not living in private dwellings is significantly higher than those living in private dwellings.

In addition to limitations due to the design features in each survey, there are underlying cultural factors to consider when interpreting the data. Chapter 1 of this report, 'No word for disability', highlighted a belief system of Aboriginal and Torres Strait Islander people in which disability is normalised, and in which disability discourses and diagnostic terminology are not always understood or accepted, and hence there is a dispensation to under-disclose disability on cultural grounds. Similarly, if Aboriginal and Torres Strait Islander people do not trust the way data is used, or fear that they may be discriminated against by disclosing a disability, then this may also lead to an Aboriginal and Torres Strait Islander person not disclosing disability. Taken together, the design, cultural and social limitations in collecting data on disability from Aboriginal and Torres Strait Islander people means that, whilst data is improving, under-reporting of disability in Aboriginal and Torres Strait Islander communities in the official statistics is likely.



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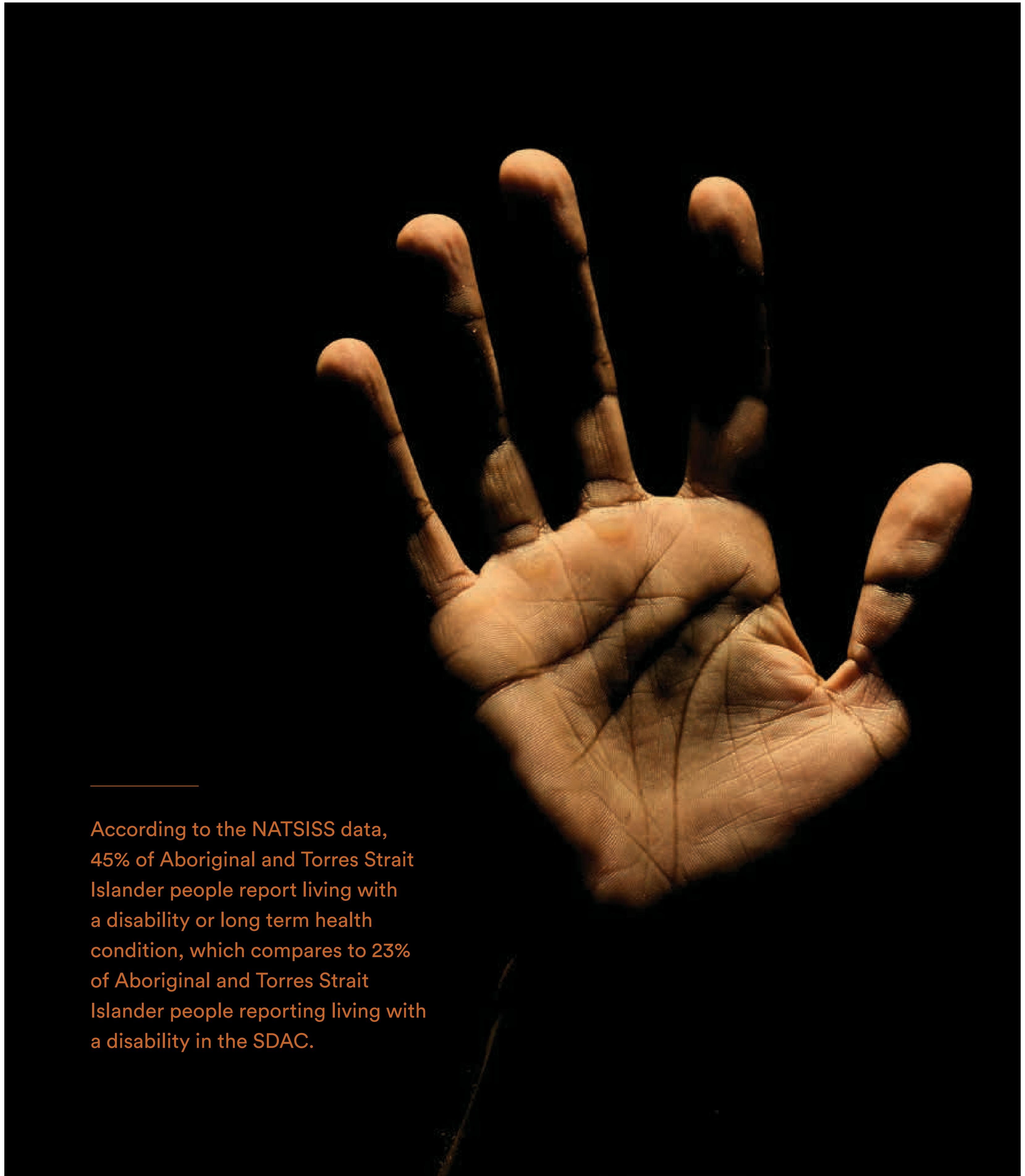
[71] See 'Technical note.' Australian Bureau of Statistics (2017) Aboriginal and Torres Strait Islander People with a Disability, (SDAC) 2012. Rel. 4433.0.55.005.

[72] Biddle, N., Al-Yama, F., Gourley, M., Gray, M., Bray, J.R., Brady, B., Pham, L.A., Williams, E., & Montaigne, M. (2012). Indigenous Australians and the National Disability Insurance Scheme: The extent and nature of disability, measurement issues and service delivery models. Commonwealth of Australia: Canberra. At p.34.

[73] Townsend C., White P., Cullen J., Wright C., & Zeeman, H. (2017). 'Making every Australian count: Challenges for the NDIS and the equal inclusion of homeless Aboriginal and Torres Strait Islander Peoples with neurocognitive disability', Australian Health Review, Mar 30.



According to the NATSISS data, 45% of Aboriginal and Torres Strait Islander people report living with a disability or long term health condition, which compares to 23% of Aboriginal and Torres Strait Islander people reporting living with a disability in the SDAC.

4.2 NUMBER OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DISABILITY

Differences emerge between the NATSISS and SDAC in estimating the prevalence of disability amongst Aboriginal and Torres Strait Islander people. Using the NATSISS data, 45% of Aboriginal and Torres Strait Islander people report living with a disability or long term health condition, which compares to 23% of Aboriginal and Torres Strait Islander people reporting living with a disability in the SDAC. The principal point of difference between the two surveys is the recording of 'long term health conditions' in the NATSISS, but not in the SDAC.

However, the differences in the scope of statistical data collected does not in itself explain the discrepancy between the two surveys, and there is still an amount of unexplained difference. Possible factors in the discrepancy in the disclosure of disability by Aboriginal and Torres Strait Islander people in the survey may include the way the questions are framed, with respect to the cultural and systemic factors affecting how an Aboriginal or Torres Strait Islander person might interpret the question; and the level of involvement that Aboriginal and Torres Strait Islander people had in collecting the data.

4.3 PREVALENCE OF SEVERE AND PROFOUND DISABILITY

Importance of statistical data on severe and profound disability

Both the NATSISS and SDAC enable further analysis on the prevalence of disability by the severity of functional impairment that is self-assessed by the respondents to the surveys. People with severe and profound disability are included in the total population of Aboriginal and Torres Strait Islander people with disability. The rationale for further disaggregating disability data by severity recognises that disability exists on a spectrum, and how severity of disability can contribute to a higher determination of need.

Quantifying the prevalence of severe and profound disability among Aboriginal and Torres Strait Islander people is critical to modelling the support requirements to meet the need.

The number of Aboriginal and Torres Strait Islander people with severe and profound disability has particular relevance to the implementation of the National Disability Insurance Scheme (NDIS) in Aboriginal and Torres Strait Islander communities. The NDIS provides support packages to people with a severe and profound disability that meet the Scheme's disability requirements[74] including, but not limited to:

- Having a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments, or to one or more impairments attributable to a psychiatric condition;[75]
- is, or is likely to be, permanent;[76]
- results in a substantially reduced functional capacity to undertake, or psychosocial functioning across a number or areas.[77]

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[74] Commonwealth of Australia (2013) National Disability Insurance Act. Section 24
[75] Ibid, (section 24(1)(a))
[76] Ibid, (section 24(1)(b))
[77] Ibid, (section 24(1)(c))

Whilst the NDIS eligibility criteria does not expressly reference 'severe and profound' in relation to the disability requirements for accessing a support package, estimates of Aboriginal and Torres Strait Islander severe and profound disability using the ABS datasets serve as an independent population-based measure from which to model access to the NDIS by Aboriginal and Torres Strait Islander people.

As highlighted by the data presented in the following chapters, Aboriginal and Torres Strait Islander people with severe and profound disability have unmet needs for support across a range of sectors which is over and above their access to the NDIS. An emergent workforce of Aboriginal and Torres Strait Islander disability professionals will require improved data which better describes the unique and complex support requirements of Aboriginal and Torres Strait Islander people with disability, both in number and its nature.

Accurately estimating the number of Aboriginal and Torres Strait Islander people with severe and profound disability is critical to defining the size of the sector and the market for support services, from which further modelling can be built.

Estimates on the prevalence of severe and profound disability amongst Aboriginal and Torres Strait Islander people

There is convergence on the estimated rate of severe and profound disability amongst the Aboriginal and Torres Strait Islander population that is recorded through the NATSISS and the SDAC. The NATSISS found that 7.7% of Aboriginal and Torres Strait Islander people reported having severe and profound disability. This result compares to a prevalence rate of severe and profound disability of 7.3% of the Aboriginal and Torres Strait Islander population using SDAC data. Using age-adjusted comparators, the SDAC and the NATSISS respectively estimate that the prevalence of disability is between 1.8 and 2.1 times the prevalence rate of severe and profound disability in the non-Indigenous Australian population. These relativities in the prevalence of disability for the Aboriginal and Torres Strait Islander population and non-Indigenous population have been age adjusted by the ABS to consider differences in the age composition of the two populations. This is illustrated by the material differences in the life expectancy between Aboriginal and Torres Strait Islander people and the rest of the Australian population. Aboriginal and Torres Strait Islander men experiencing 10.6 years lower life expectancy compared to other Australian men and Aboriginal and Torres Strait Islander women experiencing 9.5 years lower life expectancy compared to other Australian women[78]. The significance of this is that not only is disability more prevalent amongst Aboriginal and Torres Strait Islander people, the economic burden of disability is compressed into a shorter life.

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[78] Australian Bureau of Statistics (2013) Life Tables for Aboriginal and Torres Strait Islander Australians, 2010-2012 . Rel. 3302.0.55.003

In the absence of a focussed census of disability in the Aboriginal and Torres Strait Islander population, extrapolating the prevalence rates of severe and profound disability in the Aboriginal and Torres Strait Islander population estimates provides an expected value on the number of Aboriginal and Torres Strait Islander people with severe and profound disability. The expected value is calculated using the following formula:

$$\text{Ex}\ (S\&P) = \alpha\ (S\&P) \text{ x Population}$$

Where:

- *Ex(S&P) is the expected number of Aboriginal and Torres Strait Islander people with severe and profound disability;*
- *α (S&P) is the estimated prevalence rate (probability) of severe and profound disability; and*
- *'Population' is the estimated Aboriginal and Torres Strait Islander population.*

The estimated Aboriginal and Torres Strait Islander population as at 2018 is 781,091 people. This is sourced from the post-enumeration projections of the Aboriginal and Torres Strait Islander population from the 2011 Census[79]. Population projection from the 2011 Census are used as they include statistical adjustments for an undercount in the number of Aboriginal and Torres Strait Islander people who complete the Census, which is needed to accurately project the Aboriginal and Torres Strait Islander population. This differs from the Aboriginal and Torres Strait Islander population data from the 2016 Census which was released in June 2017, as the 2016 Census data count only records people who have identified as Aboriginal and Torres Strait Islander and completed the census (649,200 people)[80]. The statistical adjustment for an expected undercount in the 2016 Census had not been completed at the time of this report, and as the Census count alone could under-estimate the number of Aboriginal and Torres Strait Islander people with disability by as much as 15% to 20%, it is not used in this estimation.

Based on the current Aboriginal and Torres Strait Islander population estimates, the best available estimate of Aboriginal and Torres Strait Islander people with disability is 60,144 people using the prevalence rate derived from the NATSISS, and 57,019 using the prevalence rate derived from the SDAC.

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[79] Australian Bureau of Statistics (2014) Estimates and Projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026. Rel. 3238.0.

[80] Australian Bureau of Statistics (2017) 'Census: Aboriginal and Torres Strait Islander population.' Media Release, 075/2017

Table 4.3.1: Estimates of the prevalence of disability amongst Aboriginal and Torres Strait Islander people with disability, comparing the NATSISS to the SDAC.

	NATSISS	SDAC
Scope and methodology		
Date of latest survey data	**2014-2015**	**2015**
Survey approach.	Self-reported quantitative sample survey.	Self-reported quantitative sample survey.
Designed to be completed by.	Aboriginal and Torres Strait Islander people.	People with disability and their carers.
Question set used.	The NATSISS uses Short Disability Module which applies the same criteria as the SDAC to identify people with disability and determine their severity of restriction. However, it uses only a short question set and a series of prompt cards to establishes the presence of effects of any long-term health conditions, limitations or restrictions, and then ascertains the extent to which these require the person to be assisted to carry out various core activities.	The SDAC contains over 140 questions designed to identify disability and underlying impairments causing disability. The SDAC includes a set of 39 questions that are designed to exclude people if their need for assistance is not the direct result of disability.
How Aboriginal and Torres Strait Islander disability is identified within the data collection.	Disability questions are included within the survey and asked of people aged 15 years and over[1].	The survey contains an Aboriginal and Torres Strait Islander identifier.
Inclusion criteria for survey respondents.	Aboriginal and Torres Strait Islander people living in private dwellings.	People with disability, – all ages living in private households.
Geographical limitations.	Some coverage of remote Aboriginal and Torres Strait Islander communities.	The SDAC does not include those living in very remote and discrete communities.
Data on the prevalence of disability		
Percentage of Aboriginal and Torres Strait Islander population reporting as living with disability *and/or* long term health condition.	45%	
Percentage of Aboriginal and Torres Strait Islander population reporting as having some disability (without including long term health conditions).		23.9%
Data on the prevalence of severe and profound disability		
Percentage of Aboriginal and Torres Strait Islander population reporting as having severe and profound disability.	7.7%	7.3%
Comparator: Percentage of people reporting as living with severe and profound disability in the Australian population.	4.6%	5.8%
Age adjusted ratio: Likelihood of severe and profound disability occurring in Aboriginal and Torres Strait Islander people compared to other Australians.	2.1 times	1.8 times
Estimated number of people with severe and profound disability when prevalence rate is extrapolated to Aboriginal and Torres Strait Islander population (using 2018 population projections).	60,144	57,019

The most common category of disability reported by Aboriginal and Torres Strait Islander people is physical disability, which includes mobility impairments, experienced by 6.2% of the population.

4.4 PROFILE OF DISABILITY BY DISABILITY TYPE

Table 4.3.1 highlights the prevalence of disability types that have been self-reported by Aboriginal and Torres Strait Islander people through the NATSISS. Restating the limitations of the survey methods, this data presents an indicative profile of disability by type in Aboriginal and Torres Strait Islander communities, from which a number of insights can be drawn for further focussed investigation.

The most common category of disability reported by Aboriginal and Torres Strait Islander people is physical disability, which includes mobility impairments, experienced by 6.2% of the population. The second most commonly reported disability category was sensory impairment, reported by 3.6 % of the population. The sensory category of disability includes sight, hearing and speech impairments. Third on the list of most prevalent disability categories for people with severe and profound disability is psychological disability, reported by 2.5% of the Aboriginal and Torres Strait Islander population. The reported prevalence of severe and profound physiological disability equates to approximately one in three of all Aboriginal and Torres Strait Islander people with severe and profound disability. The effects of trauma generated by multiple exposures to social isolation that accumulate over the life a person who is both Aboriginal and/or Torres Strait Islander and has disability are explored further in Chapter 8.

4.5 UNSPECIFIED DISABILITY AND THE UNAVAILABILITY OF DISABILITY DIAGNOSES

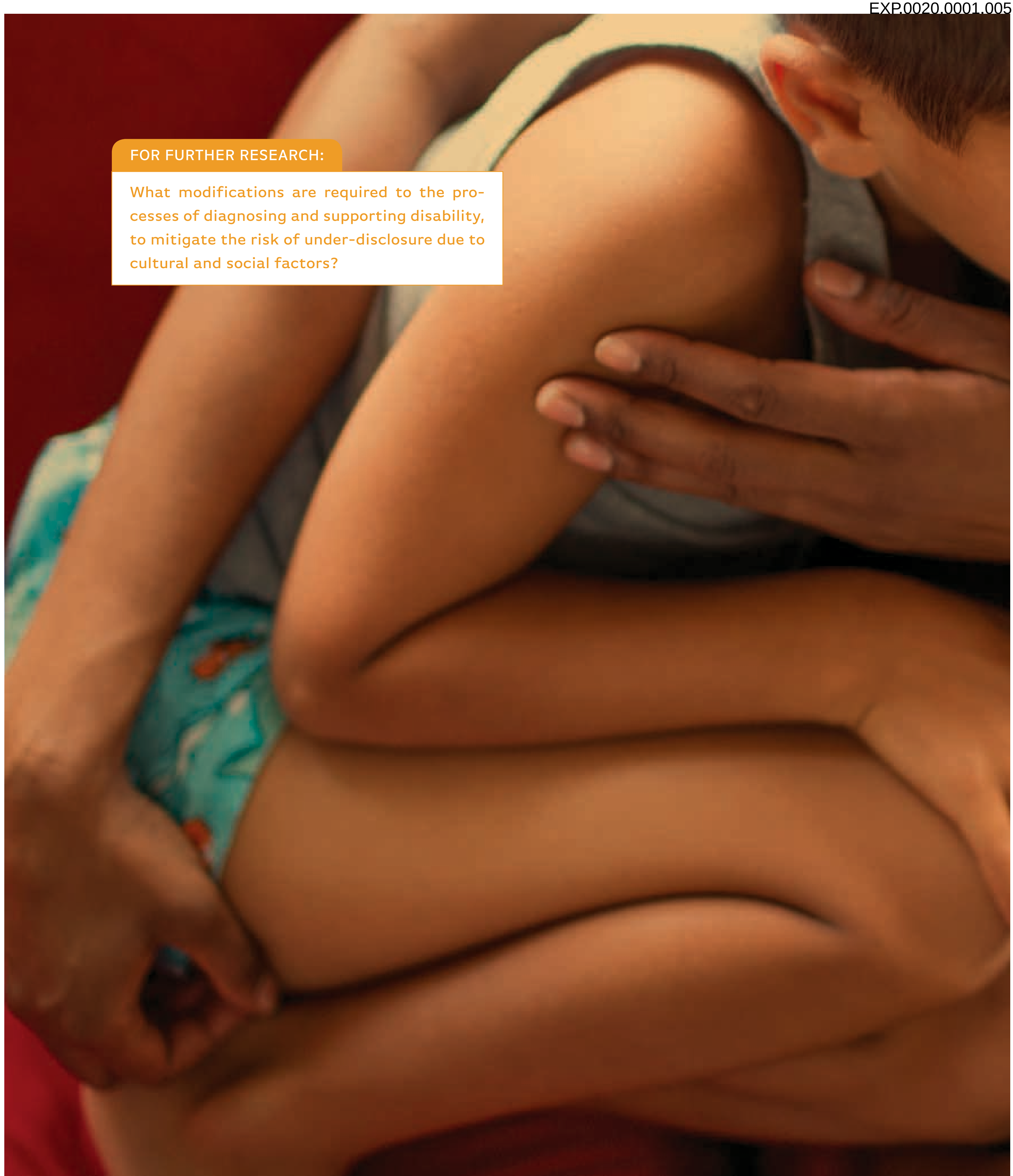
In addition to specific disability categories, 3.6% of the Aboriginal and Torres Strait Islander population have been included in the category 'Other not specified'. To place the size of the 'other' category in context, it is equal to the second highest category of severe and profound disability by type. That people are reporting an unspecified disability indicates that the impact of complex disability is well understood within Aboriginal and Torres Strait Islander communities, even if disability cannot be expressed using diagnostic labels.

The testimony from the research showed that people with disability are not clear on the role that having a specific diagnosis has in being able to access supports for disability. The distinction between 'disability' and 'diagnosis' is not clear to Aboriginal and Torres Strait Islander people within the communications and practices of disability services providers. Having a disability diagnosis is understood to be vital in driving the systems of support for disability, and further, people with disability are concerned that those that need support but do not have a diagnosis will fall through the cracks. This concern is expressed by a support person who attended an interview with one of the participants who did not have a diagnosis for her disability:

> *"The doctor hasn't given her a diagnosis....They're not even doing the tests. So, I wouldn't know how to, myself, to get the help. You know, to get [her] diagnosed without costing a lot of money"*

Accessing a diagnosis is further complicated by living in a remote community, as pointed out by one of the participants, a mother speaking about her long battle to obtain a diagnosis for her daughter who is non-verbal, uses a wheelchair, and has profound disability:

> *"We was going to [the city, from a remote community] but I had to change because we was down there for about four years, travelling down there, and we been down there and they couldn't tell me what she was diagnosed with. And so, all that time we were back and forward they couldn't find right genes for her. And, so when we went to [a hospital a in a different city] and then we made a big change. So, there was a bit of trouble getting a diagnosis in the start. They just didn't know or they had it wrong. Well, she got all the tests done that many times in [the city] and every time we go back they couldn't find anything. And, they switching her, like, changing medication and so went to [the city] and then she had scan done on her brain and changed her medication and slowed her seizures right down.*
>
> *[INTERVIEWER]: So, you've got a diagnosis now. Is that right?*
>
> *Yeah. But, I don't know what [it is] – but I leave it all up to Doctor"*



FOR FURTHER RESEARCH:

What modifications are required to the processes of diagnosing and supporting disability, to mitigate the risk of under-disclosure due to cultural and social factors?

4.6 THE OVERSHADOWING OF CO-OCCURRING DISABILITIES

Co-occurring disability refers to a person with disability experiencing more than one disability type. In other words, a person with a disability affecting their mobility may also have a sensory disability such as hearing or vision impairment, and/or have a cognitive disability, and/or a psychological disability.

Amongst Aboriginal and Torres Strait Islander people with severe and profound disability, the rate of co-occurring disability is on average 2.5 disability types per person with disability, as shown in Table 4. This means that every person experiencing one disability type will most likely have at least an additional one or two other disability types.

Co-occurring disability is an important consideration in ensuring that support for people experiencing multiple disability types is adequate. If the focus of support is exclusively based upon a primary presenting disability, there is a risk that it may 'overshadow' the presence of a co-occurring disability. This is a variant of 'diagnostic overshadowing',[81] [82] [83] a term used to describe an under-diagnosis of health needs because symptoms are attributed to a person's disability rather than a serious illness, which is discussed further in Chapter 6.6. In this extension to the concept of 'over-shadowing', the comprehensive needs of people with disability are under-diagnosed because a focus on one disability obscures the support requirements for other disabilities. Given the issues that Aboriginal and Torres Strait Islander people face in accessing even a primary disability diagnosis, there is a risk that co-occurring disability will remain invisible in their assessment of need. As such, 'overshadowing' warrants further focussed exploration beyond what could be achieved through this research, with particular attention to the practices of assessing needs by disability specialists and service providers.

FOR FURTHER RESEARCH:

What are the compounding effects of the over-shadowing of co-occurring disability upon the health and wellbeing of people with disability?

How can the risk and detrimental impact of over-shadowing be mitigated through improvements to the diagnostic practices of disability specialists, health care professionals and service providers?

Table 4.6.1: Incidence of disability by type, and rate of co-occurring disability amongst Aboriginal and Torres Strait Islander people with severe and profound disability (NATSISS, 2014-2015)

Disability type (Severe and profound disability)	Numbers (Australia)	% of Aboriginal and Torres Strait Islander population
Physical	27,800	6.2%
Sensory (sight, hearing, speech)	16,100	3.6%
Physiological	11,300	2.5%
Intellectual	11,200	2.5%
Head injury, stroke	3,400	0.8%
Other not specified	16,200	3.6%
Number of disability types per person with severe and profound disability	2.5	

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81 Jones, S., Howard L., and Thornicroft, G. (2008) ''Diagnostic overshadowing': Worse physical health care for people with mental illness.' Acta Psychiatrica Scandinavia, 118: 169–171.

82 Mason, J., and Scior, K. (2004) ''Diagnostic Overshadowing' Amongst Clinicians Working with People with Intellectual Disabilities in the UK.' Journal of Applied Research in Intellectual Disabilities. Vol 17:2, 85-90.

83 Katteri, R. and Bywood P. (2011) 'Primary Health Care for People With Intellectual Disability'. PHCRIS Research Roundup. Issue 17.

4.7 INTERSECTING GENDER, REMOTENESS AND THE PROVISION OF 'ON-COUNTRY' SUPPORT

The prevalence of disability is higher among Aboriginal and Torres Strait Islander women (47.0% reported living with disability, with 8.4% experiencing severe and profound disability) than Aboriginal and Torres Strait Islander men (42.9% reported living with disability, with 7.1% experiencing severe and profound disability).[84]

There are also differences in the reported prevalence by remoteness. 45.4% of all Aboriginal and Torres Strait Islander people living in non-remote areas (metropolitan and regional) reported having some disability, and 7.8% reported having severe and profound disability. The prevalence of disability in remote areas is comparatively lower, with the prevalence of some disability 44.0% and severe and profound disability 7.5% among Aboriginal and Torres Strait Islander people living in remote locations.

Aboriginal and Torres Strait Islander disability is further disaggregated by gender and remoteness in Table 4.7.1 below:

Table 4.7.1: Prevalence of Aboriginal and Torres Strait Islander disability by gender and remoteness (as a percentage of the total Aboriginal and Torres Strait Islander population), NATSISS 2014-15[85]

By Gender		By Remoteness		Total
Female	**Male**	**Non-remote**	**Remote**	**Total**
Living with disability or restrictive long term health condition				
47.00%	42.9%	45.4%	44.0%	45.1
Severe or profound disability:				
8.4%	7.1%	7.8%	7.5%	7.7%

An interesting observation is the relative prevalence when looking at the combined effect of gender and remoteness. Among Aboriginal and Torres Strait Islander women living in remote communities, the reported prevalence of severe and profound disability is 6.1%. The reported prevalence for Aboriginal and Torres Strait Islander men is 9.2%, or 1.5 times the prevalence rate amongst women. However, when looking at the same statistics for non-remote areas, the result is the reversed. The reported prevalence of severe and profound disability among Aboriginal and Torres Strait Islander men living in non-remote areas is 6.4% of that population cohort, where the reported prevalence for Aboriginal and Torres Strait Islander women in non-remote areas is 8.9%, or 1.4 times the prevalence rate amongst men in non-remote areas.

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[84] Australian Bureau of Statistics (2016) NATSISS. Rel 4714. See Table 11.2

[85] Australian Bureau of Statistics (2016) NATSISS. Rel 4714. See Table 12.3 'Health and Disability'

Table 4.7.2: Prevalence of severe and profound disability

Intersecting gender and remoteness (as a percentage of the total Aboriginal and Torres Strait Islander population), NATSISS 2014–2015

	Remote	Non-remote
Female	6.1 %	8.9 %
Male	9.2%	6.4%

4.8 HIERARCHIES IN THE SEGMENTATION OF THE ABORIGINAL AND TORRES STRAIT ISLANDER DISABILITY MARKET

Who gets what they need in a market approach to disability services?

The prevalence of disability detailed in the chapter contests an emerging description of the Aboriginal and Torres Strait Islander disability market as a 'thin market'. The 'thin market' description has emerged from a Productivity Commission report, in the context of its report on National Disability Insurance Scheme (NDIS) Costs (Productivity Commission, 2017),[86] and is increasingly used to describe the market conditions for Aboriginal and Torres Strait Islander people with disability[87]. The Productivity Commission report does not provide a working definition for what constitutes a 'thin market'. In the jargon of financial markets, where the term originated, a thin market is a market where there are few buying options and low demand, and is characterised by low trading volume, and high volatility.[88]

A 'thin market' analysis and its assumptions cannot be applied to the context of Aboriginal and Torres Strait Islander disability without critical review, as the data on the prevalence of disability show that a number of assumptions inherent in a 'thin market' description do not apply. First, a 'thin market' description appears to conflate issues affecting the delivery of disability services and supports to people living in remote communities with issues affecting the delivery of services to Aboriginal and Torres Strait Islander people as a whole. In breaking down the population prevalence by remoteness, 78.7% of all Aboriginal and Torres Strait Islander people with a disability and restrictive long term health conditions live in non-remote areas, compared to 21.3% who live in remote areas[89]. This profile of disability does not match the assumptions within a 'thin market' analysis.

By equating issues affecting services to Aboriginal and Torres Strait Islander people solely with remoteness, 'thin market' analysis effectively excludes the substantial component of people living in non-remote areas from the view of policy and service design. As outlined in Chapter 1, large swathes of Aboriginal and Torres Strait Islander people who have needed support for their disability have been historically marginalised from accessing the various disability support schemes that have existed in the past. From an economic viewpoint, a market demand curve that draws a straight line from what has occurred in the past as the basis for future demand projections will continue to isolate the 'buyers' that have been hidden from the market due to institutionalised access barriers. From a social viewpoint, a 'thin market' description carries forward into policy the implicit biases which reinforce an historical legacy of unmet demand. In this sense, language matters.

The data and analysis highlights the fact that the Aboriginal and Torres Strait Islander disability market is larger than has generally been accepted in public disability policy, and therefore warrants significant investment to build a comprehensive large scale market infrastructure. While the Aboriginal and Torres Strait Islander disability market is made more complex by the geographical disparities of where people live, the main issue that needs to be confronted is the high level of unmet demand for disability support. Responding to the prevalence and profile of Aboriginal and Torres Strait Islander people with disability will require a service model which is realistic to issues in remote service delivery, where there may be a small number of people with disability living in any given remote community, but also characterised by a cultural model of disability support which can benefit all Aboriginal and Torres Strait Islander people with disability regardless of where they live.

FOR FUTURE RESEARCH:

What are the design principles of a core cultural model of disability support that can be applied to benefit all Aboriginal and Torres Strait Islander people with disability regardless of where the live?

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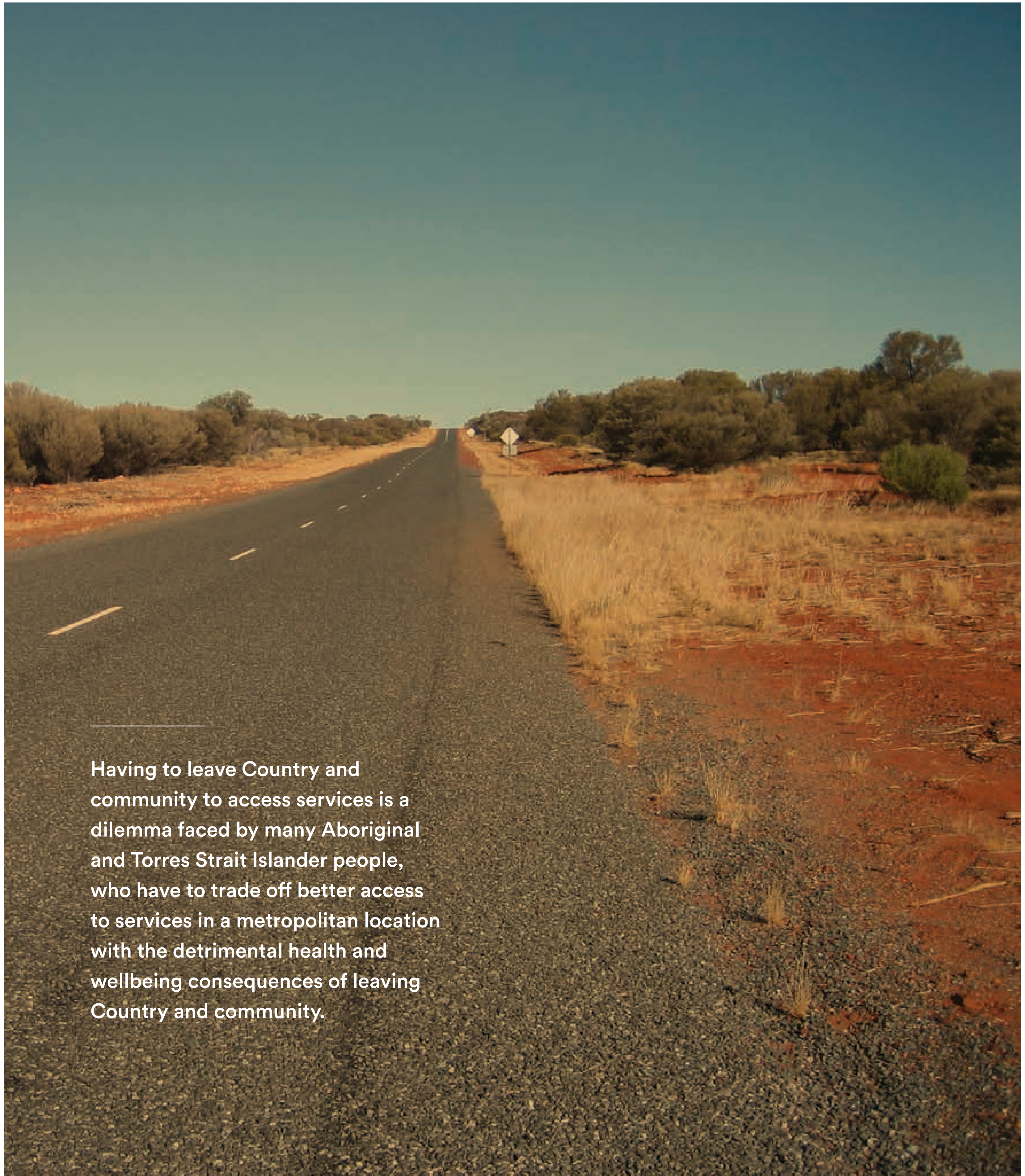
[86] Productivity Commission (2017) National Disability Insurance Scheme (NDIS) Costs, Study Report, Canberra.

[87] Productivity Commission report has categorised Aboriginal and Torres Strait Islander people disability supports as a 'thin market', alongside other defined demographic cohorts, including: people who live in outer remote or very remote areas; have complex, specialised or high intensity needs, or very challenging behaviours; are from culturally and linguistically diverse backgrounds; and have acute and immediate need. Ibid, at p 37.

[88] Rostek, R. and Weretka, M. (2008). 'Thin Markets'. In: Durlauf, S.N. and Lawrence E. Blume L.E. (eds). The New Palgrave Dictionary of Economics. Palgrave Macmillan.

[89] ABS (2016) NATSISS. See Table 12.1 Table 12.1 'Health and disability, by sex and remoteness'.



Having to leave Country and community to access services is a dilemma faced by many Aboriginal and Torres Strait Islander people, who have to trade off better access to services in a metropolitan location with the detrimental health and wellbeing consequences of leaving Country and community.

The provision of 'On Country' disability support

An interesting interpretation of the gender and remoteness data is that women with severe and profound disability living in remote communities have a greater likelihood of leaving their Country and community and moving to a metropolitan area to access disability support services whilst men in remote communities are more likely to stay in community, as women undertake traditional carer roles that compensate for the limited access to structured disability support services in remote communities.

Furthermore, men who acquire a disability, say through accident or injury, whilst living away from their Country are able to return to their Country, as Aboriginal and Torres Strait Islander women assume carer duties, even if informal and without systemic support. Women, on the other hand, do not benefit from informal carers roles provided by men to the same extent that they provide them to men, and hence they may be forced to leave their communities to access the degree of service required to support their disability. What prevails is an inherent gender inequity in which the burden of compensating for the lack of services of remote communities falls predominantly upon Aboriginal and Torres Strait Islander women, either: in the quantum of care they provide to others; or in being forced to leave their Country when they themselves require access to disability support services.

Having to leave Country and community to access services is a dilemma faced by many Aboriginal and Torres Strait Islander people, who have to trade off better access to services in a metropolitan location with the detrimental health and wellbeing consequences of leaving Country and community. This data shows that if you are also an Aboriginal or Torres Strait Islander woman with disability from a remote community, this dilemma becomes more acute. Whilst this might be intuitively understood by many Aboriginal and Torres Strait Islander people in remote communities, the significance of the data is that the gravity of the inequality experienced by Aboriginal women can be acknowledged, quantitatively measured, and ultimately addressed.

There is a positive, however that Aboriginal and Torres Strait Islander men choose to return to Country and receive informal care through their community rather than access systemically supported services in non-remote areas. This points to the inherent competitive strength of culturally competent community care, even if it is not fostered through structured support. The strengths of Aboriginal and Torres Strait Islander community care should be explored further through sector development and research.

In terms of building upon a conceptual model that explains the compounding inequalities in health and social outcomes experienced by people who are both Aboriginal and Torres Strait Islander and have disability, this finding that the theory of 'intersectionality' continues to hold true once gender and remoteness are added.

FOR FURTHER RESEARCH:

How does gender inequality compound inequalities experienced by Aboriginal and Torres Strait Islander women with disability?

How can disability service models be sensitised to address these inequalities, especially for people living in remote communities?

5

DISCRIMINATION EXPERIENCED BY ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DISABILITY

KEY FINDINGS:

Aboriginal and Torres Strait Islander people with disability frequently experience discrimination in multiple forms:

- Racism, related to being an Aboriginal and/or Torres Strait Islander person;
- Ableism, related to being a person living with disability; and
- A unique form of 'intersectional discrimination' that is an interaction of discrimination, that is both Aboriginal and Torres Straits Islander and disability related.

Frequent exposures to discrimination throughout the life of an Aboriginal and Torres Strait Islander person can have cumulative impact which manifests into 'apprehended discrimination'. This is a pathway in which a fear of discrimination transforms into a rational expectation of discrimination. An effect of apprehended discrimination is that it can lead to a person avoiding social situations where they could be exposed to possible discrimination.

Frequent exposures to discrimination throughout the life of an Aboriginal and Torres Strait Islander person can have cumulative impact which manifests into 'apprehended discrimination'.

5.1 EVERYDAY EXPERIENCES OF RACISM, ABLEISM AND INTERSECTIONAL DISCRIMINATION

As people intersecting two marginalised population groups, Aboriginal and Torres Strait Islander people with disability can experience discrimination that is both race and disability related. Chapter 2 discussed in conceptual terms how racism and ableism can occur of their own accord, but also interact which each other to generate a unique experience of discrimination which is referred to in this research as 'intersectional discrimination'. This chapter builds upon the concepts described in Chapter 2 by presenting how multiple forms of discrimination appeared in the testimony of the Aboriginal and Torres Strait Islander people who were interviewed for the research.

In reviewing the testimonial data on discrimination, it should be noted that participants were not directly asked during the interview if they had been discriminated against. Instead, the participants' recounting of their experiences of discrimination came as a result of this more general discussion prompt on what barriers they faced in their lives.

Below are two examples drawn from the testimony that illustrate the 'everyday' nature of discrimination as it appears in the lives of Aboriginal and Torres Strait Islander people with disability. The first example comes from a group of participants who live in an Aboriginal Housing complex on the outskirts of a regional centre. This example highlights how one form of structural discrimination (in this example, a lack of access to transport), can compound with other personally directed forms of discrimination (in this example, racial vilification). The participant lives in a community group of about thirty people, all are Aboriginal, none with access to transport. The centre of town is a few kilometres away and buses don't come out their way, so he says that he walks into town when he needs something. He says that he sees a counsellor for an hour or so every few weeks for a mental health condition, "as I am supposed to". He then mentions that on the walk back from seeing his counsellor, he is often racially abused by people in the street and driving past, instantly undoing any benefit of his therapy.

A second example highlights how race and disability can interact to accentuate the risk of discrimination for people who are Aboriginal and Torres Strait Islander and have disability. The testimony comes from an outer metropolitan area, involving an Aboriginal woman with a cognitive disability and possible undiagnosed hearing impairment, and her son, an Aboriginal man who also has an intellectual disability. The support person, attending with the participant, said that he works at a local disability place. "He's a supervisor now. He's been there a long time," and she comments that "as he is getting older, he's losing his, you know, his fine motor skills", which causes him to lose his balance and fall. She recalls an incident during a shopping trip:

> *"Because he's, you know, his balance is off. And, the other day – we'll put this on the issue, is that [the participant and her son] went to go shopping. And, the security guard at the Shopping Centre... stopped [the son] and said, "No. We don't like – you can't come in because you're intoxicated." And, he wasn't intoxicated. That's just how he is.*
>
> *And, they told Woolworths not to let him in. And, I was there. I ripped them. I said, "If you can't tell between a person living with a disability and a person that's intoxicated." I said, "You shouldn't be working here." I said to the security guard. And, I said, "As for you, [speaking about the Shopping Centre], you can't discriminate. Can't discriminate against people living with a disability." So, then they let him do the shopping. And, then they came and apologised to [the mother]. I said, "Don't apologise to her. You need to apologise to that young man." I said, "Because you stopped him."*

She mentioned that this type of incident happens regularly. The participant said that when she goes to the club.

> *"They say, 'That's enough. You've had enough to drink.' [But] I don't drink."*

The support person follows up

> *"And, they put her out."*

Direct references to discrimination contained within the participants' testimony spanned a range of ordinary day activities

Whilst these two testimonies highlight how racism and ableism interact to generate a unique form of intersectional discrimination, the participants consistently relayed experiences that could be directly attributed to either racism, ableism or an intersectional form of discrimination in response to the prompt, "What barriers have you faced?" Their testimony included exposures of to a range of discriminatory behaviours, which included:

- being subjected to prejudicial assumptions about what they could or could not do because they were Aboriginal or Torres Strait Islander and/or have a disability;
- not being believed, because their life experiences were seen as contradictory what professionally trained people were taught;
- being viewed as a burden when they had asked for accommodations to be made to enable them to participate in a social activity; and,
- being called a racist or ableist name out of frustration by the person that they were speaking with at the time of the incident.

The type of daily routines that the participants were undertaking at the time they encountered this highlights how their day to day lives are constantly interrupted by casual exposure to discrimination. Direct references to discrimination contained within the participant's testimony spanned a range of ordinary activities such as:

going to the doctor;

going shopping;

going out for a meal;

taking a phone call at work;

catching a plane;

asking to attend or participate in a community group meeting; and

applying for a job.

5.2 ‘APPREHENDED DISCRIMINATION’ AND THE PATHWAY TO AVOIDANCE

‘Apprehended discrimination’ was introduced as a concept in Chapter 2 to describe a pathway in which repetitive exposures to discrimination transforms an intuitive fear of discrimination into a rational expectation of discrimination, which in turn leads to an avoidance of situations where discrimination could possibly occur. The concept of ‘apprehended discrimination’ is illustrated through three examples drawn from the testimony.

The first example is a single construction of the sequential pathway from a fear of discrimination to a personal avoidance of discrimination. It involves an Elder with a physical disability, whose status in community meant that he was regularly invited to meetings to talk on Aboriginal issues and culture:

Phase 1 **Fear of discrimination:** His initial reference to a fear of discrimination is described intuitively and is externalised: “Most of the [meeting] organisers don’t have a disability, …so they make the bookings on their own ability.”

Phase 2 **‘Apprehended discrimination’:** The next sequence in his testimony describes his personal experiences of being unable to access buildings because of disability, which helps form his rational thinking on the likely threat of discrimination: “When I get to the meeting, it’s not accessible or the lifts are out.”

Phase 3 **Avoidance:** The third sequence describes his response which pre-empts an expectation of discrimination: “So, that’s why I don’t bother to go to a lot of meetings.”

A second example shows how multiple exposures to discrimination accumulate and lead to avoidance, as exhibited through a single person’s testimony. The participant in this example is an Aboriginal woman living in a remote location who has a son with a cognitive disability:

Phase 1 **Fear of discrimination:** She initially speaks of a historical legacy of distrust of police by the local Aboriginal community. She speaks of past injustices which have framed her intuitive thinking on discrimination: “[The] police hung someone here before. The police killed a black person, they hung him in jail here.” She then makes reference to a recent incident where an Aboriginal man from her community was assaulted by police, and then makes a direct connection to her son: “[My son] has a disability and I’m scared for my son.”

Phase 2 **‘Apprehended discrimination’:** The testimony progresses along the continuum when she raises that she had approached the Department of Education and the police to get help for her son who had been “interfered with” at school. This request for help went unheeded, and the undercurrent of her testimony is that it is because they are Aboriginal.

Phase 3 **Avoidance:** The apprehension of discrimination has progressed into avoidance – she has withdrawn her son form school for fear for his personal safety, and he is currently not receiving formal education.

A third example relates to the employment of people with disability, which is discussed in connection to employment inequality in Chapter 6. This is a construction of apprehended discrimination and involves piecing together various components of narrative across a single issue:

Phase 1 **Fear of discrimination:** First, the statistical data demonstrates that there is inequality in employment outcomes experienced by Aboriginal and Torres Strait Islander people with disability compared to the rest of the population, setting a data-based foundation for fear of discrimination.

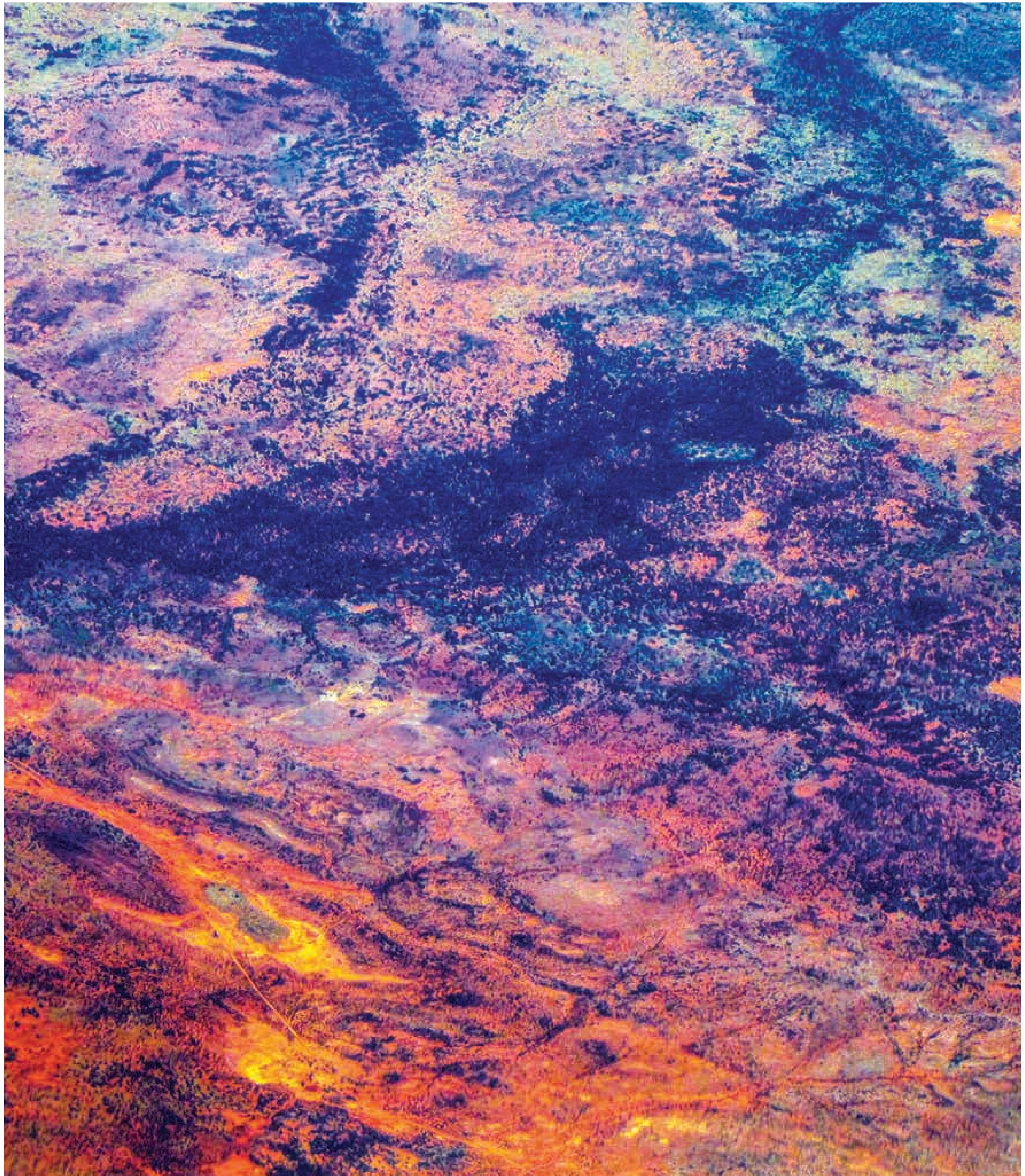
Phase 2 **‘Apprehended discrimination’:** Within the testimonies, the participants who referenced discrimination in employment had progressed the intuitive fear of discrimination, and spoke extensively of their personal exposure to discrimination in employment, including a yarning piece in which a young woman with disability says that she is told that she is unable to secure causal employment with high profile corporations as she “does not fit the brand”.

Phase 3 **Avoidance:** The pathway from apprehended discrimination progresses to avoidance, illustrated by an example when a vision-impaired person says that he no longer applies for jobs that have holding a driver’s license in the selection criteria. He puts his reasoning down to an expectation that not meeting this criteria, which is a function of having disability, would be used to reject his application without any further consideration, regardless of his merit in meeting all other aspects of the selection criteria.

The personal experiences from participants are used to expand the concept of ‘apprehended discrimination’ in the following diagram.

Diagram 5.2.1: Apprehended discrimination: A pathway from fear of discrimination to avoidance

	Phase 1	Phase 2	Phase 3
	FEAR OF DISCRIMINATION	**APPREHENSION OF DISCRIMINATION**	**AVOIDANCE OF DISCRIMINATION**
	Understanding of discrimination is intuitive. Cognition of discrimination is influenced by: • personal values and morals • Media and discourses on discrimination in society (eg. its prevalence and how it is seen to be resolved)	Their intuitive fears are realised, with increased personal exposure to discrimination, which reinforces their intuitive understanding and adds weight to their rational judgment. May still be participating in social functioning, but becoming anxious about the outcome.	The accumulated personal exposure to discrimination has reached a point where they have formed fear and expectation of discrimination which is rationally formed. Their rational response is to avoid situations where they may be exposed to discrimination, effectively self-excluding from social participation.
EXAMPLES FROM THE TESTIMONY:			
1. Disability access	"Most of the [meeting] organisers of organisations don't have a disability, ...so they make the bookings on their own ability."	"When I get to the meeting, it's not accessible or the lifts are out."	"So, that's why I don't bother to go to a lot of meetings."
2. Personal safety	Police are seen to have a reputation for violence against Aboriginal people in town. "[My son] has a disability and I'm scared for my son."	Police are contacted to help resolve allegations of her son being "interfered with" whilst at school, without resolution	The son is withdrawn from school, and is not presently receiving an education.
3. Employment	People with disability have low visibility in employment	People with disability are told that they "don't fit the brand" when they are overlooked for jobs.	People stop applying for jobs where they expect they will be discriminated against by potential employers.



6

INTERSECTIONAL INEQUALITY: THE NUMBERS AND NARRATIVES

KEY FINDINGS

Intersectional Inequality: The statistical and testimonial data shows that as a group intersecting two marginalised groups, Aboriginal and Torres Strait Islander people with disability experience greater social, health and wellbeing inequalities relative to other population cohorts. The inequality that they experience is greater than the inequalities that Aboriginal and Torres Strait Islander people, and people with disability, experience as discrete population groups.

Acute and pervasive inequalities: The intersectional inequalities that Aboriginal and Torres Strait Islander people with disability experience are acute and pervasive across all the systems which are intended to support disability; including the provision of disability services, health, education, employment, housing, and transport.

Barriers to inclusive communities: Aboriginal and Torres Strait Islander people, particularly those living in remote and regional communities, are susceptible to living in inaccessible housing and physical environments unsuitable for people with disability. The inaccessibility in the living environment is compounded by a lack of accessible transport, which is vital to a person with disability's self-esteem and independence. This has the effect of reducing their capacity for social interaction in their communities, and in extreme cases becoming prisoners in their own houses.

Education: Aspirations for further education are high, including a strong appetite for further cultural education, but these aspirations are often unfulfilled due to systemic barriers in the education pathway. Limited access to Auslan interpreters creates a specific educational barrier for Deaf Aboriginal people due to access.

Employment: Prejudicial attitudes towards people with disability by prospective employers curtail the employment opportunities for people with disability. Sustained exposure to discrimination in the job market increases the prospect of apprehended discrimination leading to people with disability ceasing to seek employment.

Health: Aboriginal and Torres Strait Islander people with disability experience stark inequalities in their access to health care compared to other population groups. Institutionalised ableism and racism in the health systems, overshadows their clinical and health care requirements, which leads to suboptimal health care and a heightened the risk of adverse health care events.

6.1 PATTERNS IN THE DATA

The NATSISS produces population-wide data on social, health and wellbeing outcomes for Aboriginal and Torres Strait Islander people, which can be disaggregated by disability status. To enable a comparison to the social, health and wellbeing of other Australians, select indicators are compared to responses to ABS's General Social Survey[90] which is a sample survey of the whole Australian population.

In Table 6.1.1 overleaf, there are five population groups where the selected social, health and wellbeing indicators are compared:

i. The general population that does not have disability (which may include Aboriginal and Torres Strait Islander people with disability within the data collection source);

ii. People with disability (which may include Aboriginal and Torres Strait Islander people with disability within the data collection source);

iii. Aboriginal and Torres Strait Islander people that do not have disability;

iv. People who are both Aboriginal and/or Torres Strait Islander and living with disability that is not severe and profound; and

v. People who are both Aboriginal and/or Torres Strait Islander and living with severe and profound disability.

TABLE 6.1.1: Percentage of population experiencing selected social, health and economic outcomes, by population group (General Social Survey[91] and NATSISS[92])

Percentage of population experiencing outcome

INDICATOR	(i) General population	(ii) People living with disability	(iii) Aboriginal and Torres Strait Islander people with no disability	(iv) Aboriginal and Torres Strait Islander people living with disability that is not severe and profound	(v) Aboriginal and Torres Strait Islander people living with severe & profound disability
Self-assessed health as excellent/very good	69.0%	32.0%	53.4%	22.9%	13.9%
Had problems accessing health care services	2.8%	11.4%	11.3%	19.5%	27.0%
Total experienced one or more stressors	59.2%	69.8%	62.6%	75.3%	82.7%
Feelings of safety walking alone in local area after dark	55.9%	43.9%	58.6%	47.5%	37.5%
Participation in the labour force	83.0%	53.0%	68.1%	51.8%	31.1%

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[90] Australian Bureau of Statistics (2014) General Social Survey: Summary Results, Australia. Rel. 4159.0. Table 11: 'Disability'.

[91] The General Social Survey is used as the data source for: (i) General population; and (ii) People with disability.

[92] The NATSISS is used as the data source for: (iii) Aboriginal and Torres Strait Islander people with no disability; and (iv) Aboriginal and Torres Strait Islander people living with disability, and (v) Aboriginal and Torres Strait Islander people and with severe & profound disability.

There is a pattern in the data that illustrates intersectional inequality across the indicators:

- Aboriginal and Torres Strait Islander people experience greater inequality in their social and health outcomes compared to other Australians.
- Aboriginal and Torres Strait Islander people who also live with disability experience greater inequality when compared to:
  - Aboriginal and Torres Strait Islander people without disability, and
  - non-Indigenous people with disability;
- Aboriginal and Torres Strait Islander people with severe and profound disability experience greater inequality in social, health and economic outcomes than Aboriginal and Torres Strait Islander people with disability that is not severe and profound.

Relating this to the concepts of intersectionality and intersectional discrimination introduced in Chapter 2, the data can be used to categorise social inequality into three types:

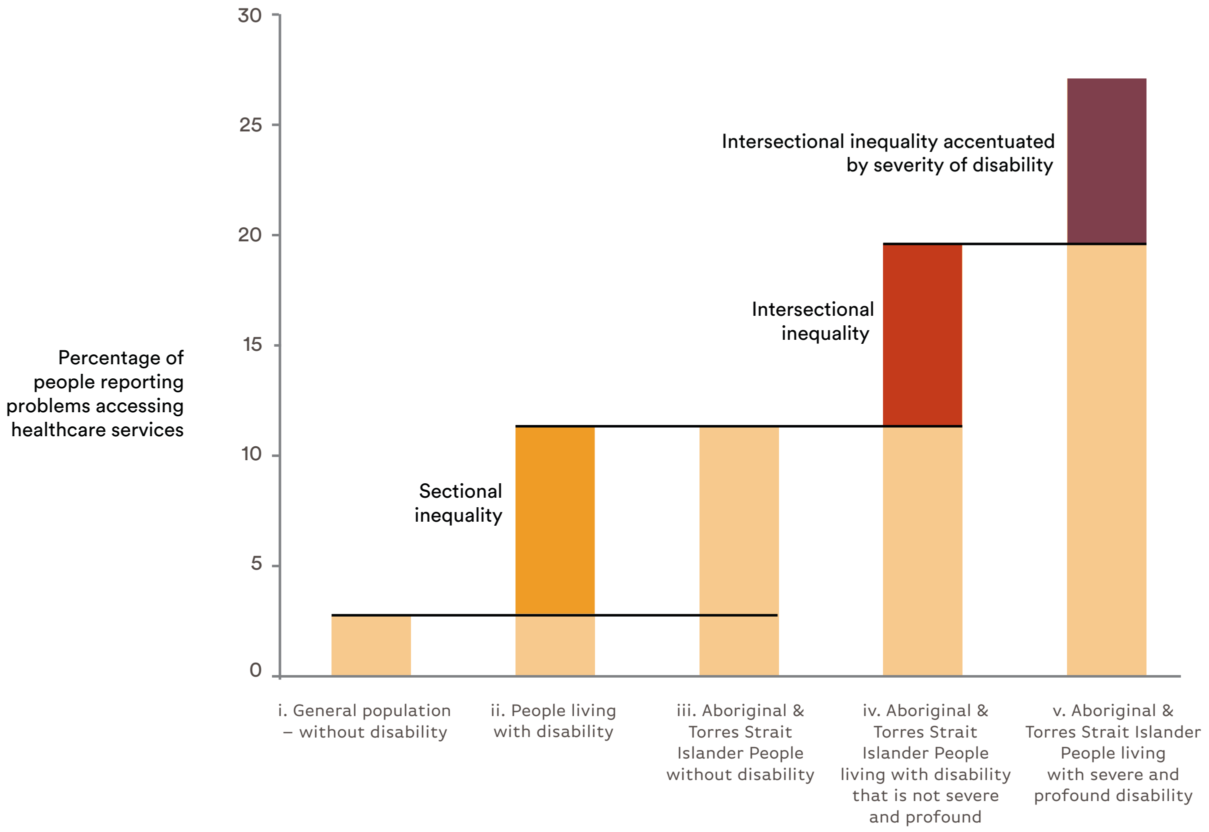
Sectional inequality This is inequality that affects the one marginalised group as a discrete population, ie. the population of people living with disability (group ii), and Aboriginal and Torres Strait Islander people without disability (group iii). This is referred to as 'sectional inequality' to provide a point of contrast to 'intersectional inequality'.

'Intersectional inequality' This is the compounding of inequality that affects those people who are members of two or more marginalised groups, ie. Aboriginal and Torres Strait Islander and live with disability (group iv).

'Intersectional inequality' accentuated by severity of disability Separating populations who report having any disability (group iv) and people reporting severe and profound disability (group v) recognises that disability exists on a spectrum, and hence highlight how the severity of disability can further accentuate intersectional inequality.

The clearest example of intersectional inequality presented in table 6.1 relates to problems in accessing health services. This is represented diagrammatically in Figure 6.1.1 below:

Figure 6.1.1: Sectional and intersectional inequality in accessing healthcare services. (General Social Survey 2014, NATSISS 2014-15)



The remainder of the chapter explores inequalities that exist within the Aboriginal and Torres Strait Islander population using a more detailed investigation of thematic issues. It uses the NATSISS as the source for statistical data, which is brought together with testimony and yarning pieces in order to align it to policy priorities.

To facilitate the translation of this research into policy, the data is organised to align with the priority areas outlined in the National Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability.[93]

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[93] Commonwealth of Australia – Department of Social Services (2017) Australian Government Plan to Improve Outcomes for Aboriginal and Torres Strait Islander People with Disability.

There was a broad range of topics raised within the theme of inaccessible housing: from disability access, to housing affordability and experiences in accessing social housing.

6.2 INCLUSIVE COMMUNITIES

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 1: Aboriginal and Torres Strait Islander people with disability have access to appropriately designed shelter and live in accessible, well designed communities that are fully inclusive of all their residents.

The data collected through the NATSSIS and the SDAC are limited in scope and do not record the environment Aboriginal and Torres Strait Islander people with disability are living in or public infrastructure. For example, the NATSISS asks whether a person has daily face to face contact with family and friends, but has no capacity to assess if geographic location is a factor. The SDAC asks questions like "do you have trouble climbing stairs?", but does not address whether the stairs should be there in the first place.

Disability accessible housing:

Neither the NATSISS nor the SDAC can provide insights into rates of homelessness amongst Aboriginal and Torres Strait Islander people with disability, as they only survey people living in private dwellings. The NATSISS does collect data on previous experiences of homelessness. This shows an intersectional effect: Aboriginal and Torres Strait Islander people with severe and profound disability have experienced homelessness at 1.9 times the rate of Aboriginal and Torres Strait Islander people without disability (41% compared to 22%).

Accessible housing was raised as a major issue for participants in the interviews, with 10 of the 47 participants referencing it as an issue. There was a broad range of topics raised within the theme of inaccessible housing: from disability access, to housing affordability and experiences in and accessing social housing. This was particularly the case in the remote sites visited, where according to participants housing providers included disability accessibility at best as an afterthought, and at a worst case a wilful oversight:

> *"It's disgusting how... our housing company is treating these disability people in their homes. You've got her son can't get no help, you've got another man who –, he's got to walk up steps and he's nervous because there's no rail for him to get into his house, there's no rails for him to hang onto in the bathroom"*

The picture below[94] illustrates the issues of disability accessible housing in remote communities. Taken in a very remote community, it shows the entrance to a house which had recently been built as part of a remote housing project. The occupants had been on a waiting list for seven years before the house was built, and were not consulted during its construction. What is shown below is a steel ledge, approximately five centimetres high, at the main entrance to the house. The occupants said that when people with disability come over, they have to lift them over the ledge so they can come into the house.

Another of the participants at the Elders forum is a wheelchair user living in an apartment with standard height shelves which she could not reach. There was also a raised ledge at the entrance which made it difficult for her to enter. She had been asking for some time for modifications with the NDIS, but had not heard back from them at the time of the interview.

A few participants spoke of experiencing homelessness or a direct threat of homelessness, although they did not necessarily describe it using those terms. One participant, a deaf Aboriginal woman, spoke of difficulties in finding housing when she moved to a city area to better access other services:

> *"In [other cities], there's lots of Aboriginal organisations whereas in [the city I live in] the access is limited. When I came here, I couldn't get a house here, because here the [Housing organisation] have merged with – like, single mothers or abused mothers, deaf, disability, it's all in one. So, there's a ten-year waiting list to get a home. I had nowhere to stay. So, [my female friend] she's bought her home, so luckily she allowed me to stay with her, and she doesn't mind me living with her until I can get a home."*

Another participant from a remote area described his current living situation as "living rough" in a town camp, unable to secure any form of housing:

> *"We tried [talking with someone about getting housing]. We tried. Nothing happened. It's just overcrowding what existing houses are there. There was some houses bought, [a person from the Government] bought those houses, didn't they? But, they never connected them up. They're just sitting there in a paddock."*

There is an apparent hierarchy to the provision of housing support:

1. The first-tier issue is provision of any housing at all;
2. The second tier is the issue of incorporating disability accessibility into the design and construction of new housing; and
3. The third tier is the modification of existing housing to make it accessible. The evidence from the site visits to remote communities indicates the issue of providing core housing is seen as so great in magnitude, that disability access and home modifications are at the end of a very long queue.

Over and above the functional aspect of houses providing shelter, there is a psychosocial dimension of living in a place you can call your own. When a person who is living rough was asked what having a house would mean to him, he replied:

> *"I want to go home. That's all."*

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[94] Taken with express permission from the community.

'Fit for purpose' disability aids:

A second core issue contributing to the (non) inclusiveness of people with disability in communities is the suitability of the disability aids that they are provided with in the physical environment. The deterioration and lack of suitability of available wheelchairs in remote communities was observed consistently.

This issue is illustrated in the following photograph. This photo was taken in one of the research sites during the initial stages of the research. It shows a standard issue foldable wheelchair, which in an urban environment where there are footpaths, would be consider light and portable because it can be folded up and put into a car boot. The same wheelchair, when put into a different physical environment, may cease to be suitable. The wheelchair in this photo's rubber wheels have melted off because of the extreme heat, making it completely unusable.

The photo below left[95] was not an isolated observation. One of the participants at the Elders forum travelled from a regional centre to Alice Springs with a manual wheelchair. It was broken at the seat support which made it rub against the wheel, requiring such physical exertion to make the wheelchair function that people had to take turns to push her. At another regional centre, a participant mentioned living only few streets form the Town Centre, said that they rarely went into town or too far from home, as if their wheelchair broke down, they would be stranded.

Indeed, it was rare for the researchers to see a fully functioning wheelchair in any remote communities visited, and this made a distinct impression upon their social visibility within communities. In some of the remote communities, a graveyard of discarded wheelchairs was the only outwardly visible sign of people with mobility impairment living in that community. For people who rely on wheelchairs, the lack of suitable and well maintained chairs could leave them isolated within their own homes.

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[95] Photo taken with express permission from community.

Transport:

A third core obstacle to inclusive communities is a lack of access to transport. This has a particular impact on inclusion, as a lack of access to transport creates knock-on access problems, such as getting to school, getting to a job interview, or getting to medical appointments:

> *"Transport is another failure because there's no transport to get to hospital and appointments, because if you go to your local doctor and you get a referral to go to the Women's and Children's. I had my grandson, nobody could transport me, so I had to get up at four o'clock in the morning, catch a bus to Women's and Children's to have an MRI, you know."*

One participant living in a regional centre said that transport was a major problem, and that there was only one disability access taxi in the region where she lived:

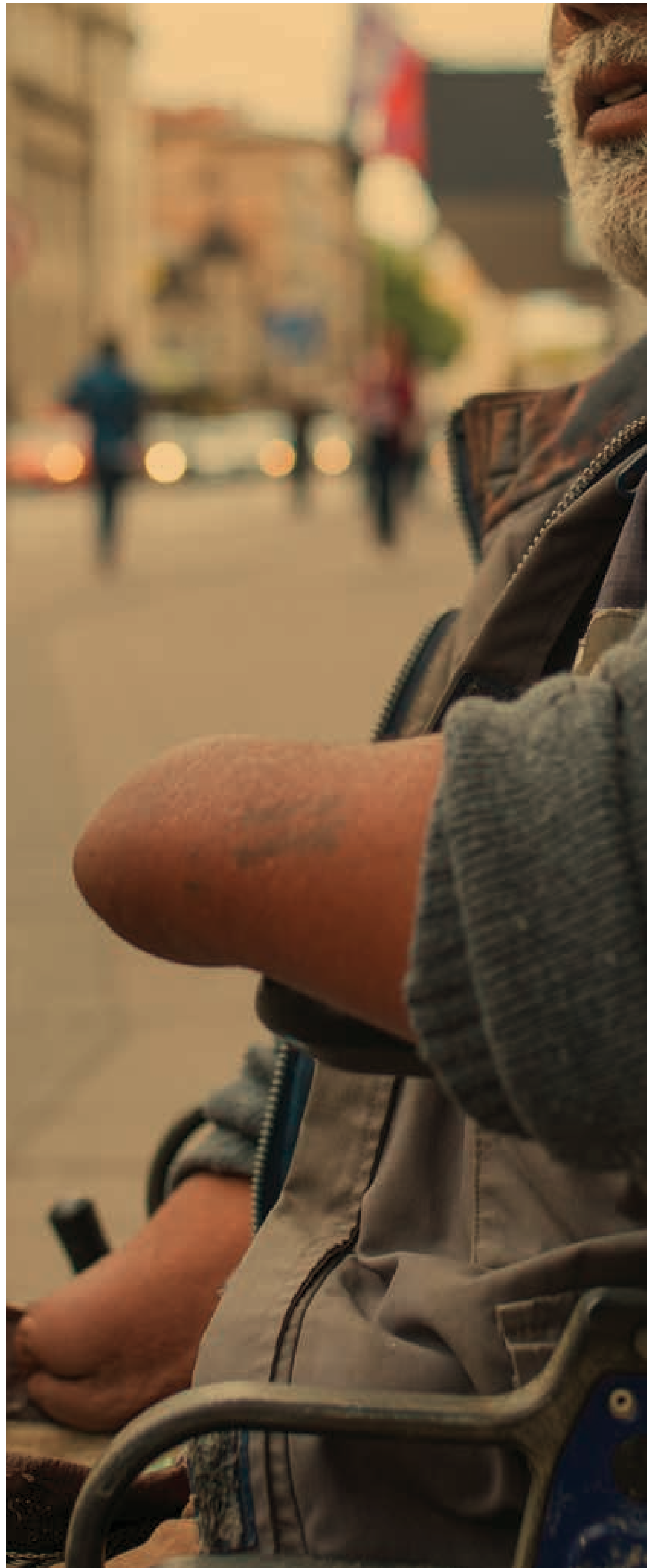
> *"Well, there isn't much transport here. There's only one taxi. And, it's only going till like, morning, till six o'clock in the afternoon. Which, isn't really right at all. You know? Like, other people that walk everywhere or push themselves, yeah."*

When asked how she gets around, she captured a lifetime's experience in three words:

> *"I push everywhere."*

Much like housing, transport has both a functional dimension and a psychosocial dimension. Whilst there is a practical requirement for people with disability to get from point A to point B, the ability to do so without being made to feel a burden is a vital aspect of a person with disability's sense of independence. This is where promoting and providing inclusive transport can be as significant as the logistical aspects of transport, and the testimony pointed to Australian airlines as poor performers in this regard:

> *"So, with some of the barriers that I've met would be with just, say, one to tick off would be transport and a couple of years ago I flew with [an airline]. And, they – their whole disability policy, that which my wife went through to make sure that we knew what steps were in place. Then we went through the whole system of going to the airport... that was blown out of the water. Nothing was in place. There was no transfer equipment. The people didn't know how to use it properly.*
>
> *They took apart my chair completely when it hadn't ever been taken apart before, and when I got to [the destination] had to put the whole thing back together. And, just the whole experience with the crew on board was negative and – and especially then when we come back to [the city] and had a really rude altercation with one of the [airline] staff because we couldn't find my wheelchair and the lady was going off at my wife, which brought [her] to tears. And, we ended up eventually finding my wheelchair that was, not in pieces, but it wasn't right. So, we had to sort of put it back together."*



The structural limitations of a personal agency approach to social change:

The issues of housing, disability aids and transport highlight the impact that the structural limitations in the physical environment place upon a personal responsibility approach to improving someone's social, health and wellbeing status.

Simply put, people with disability can't go to school and can't go to work if they can't get there. The barriers created by inaccessibility are also relevant in the coming sections on the inequalities experienced by Aboriginal and Torres Strait Islander people in education, employment and in health.

There are practical consequences when public disability policy is devoid of the impact of structure on personal agency. A case in point is the implementation of the National Disability Insurance Scheme, which is discussed further in Chapter 7. This is a model of disability support in which the design principles are exclusively about fostering personal agency. Whilst it might not be within the remit of a National Disability Insurance Scheme to fix the public infrastructure problems that exist in remote communities, inclusion strategies that are dependent upon a personal agency model will fall short of their optimal effectiveness if the structural limitations cannot be accommodated within public policy that aims to be inclusive of disability.

6.3 JUSTICE

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 2: Aboriginal and Torres Strait Islander people with disability have the right to be free from racism and discrimination, have their rights promoted, and a disability–inclusive justice system.

Exposure to threatened or actual violence

Exposure to violence or a traumatic death of a close family member or friend was referenced by participants in 9 of the 41 interviews (22%). The types of violent and traumatic episodes referred to included: references to close family members who had been murdered or 'lost'; women alluding to seeking respite from gender based violence; being subjected to a violent attacks with a weapon; deaths by suicide; a young child dying because of medical neglect; and an extensive and detailed account of being exploited by a human trafficking ring.[96] There is a clear gender bias in the responses, at least with respect to the person making the disclosures, with 7 of the 9 recounts of violence made by women.

It is worth remembering at this point that participants were not directly asked whether they had been exposed to violence. These incidents were voluntarily disclosed by the participants in response to a general invitation to share their life story.

The quantitative data collected by the NATSISS suggests an intersectional effect, with the data showing that Aboriginal and Torres Strait Islander people with severe and profound disability are approximately twice as likely as Aboriginal and Torres Strait Islander people without disability to have been either threatened with or exposed to violence within the past year.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Experienced threatened violence in past year	25%	14%	1.8
Experienced physical violence in past year	19%	11%	1.7
Felt safe at home	71%	87%	0.8

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[96] The details of these events have been redacted as a measure of privacy to the participants, and to reduce the risk of excessively trauma to Aboriginal and Torres Strait Islander people who might read this report.

Imprisonment of Aboriginal and Torres Strait Islander with disability

Intersectional, quantitative data on Aboriginal and Torres Strait Islander people with disability in detention is not available from the data sources used in this study. The NATSISS is a survey that is confined to private households so it excludes people who are currently in detention or other forms of institutional care from its inclusion criteria.

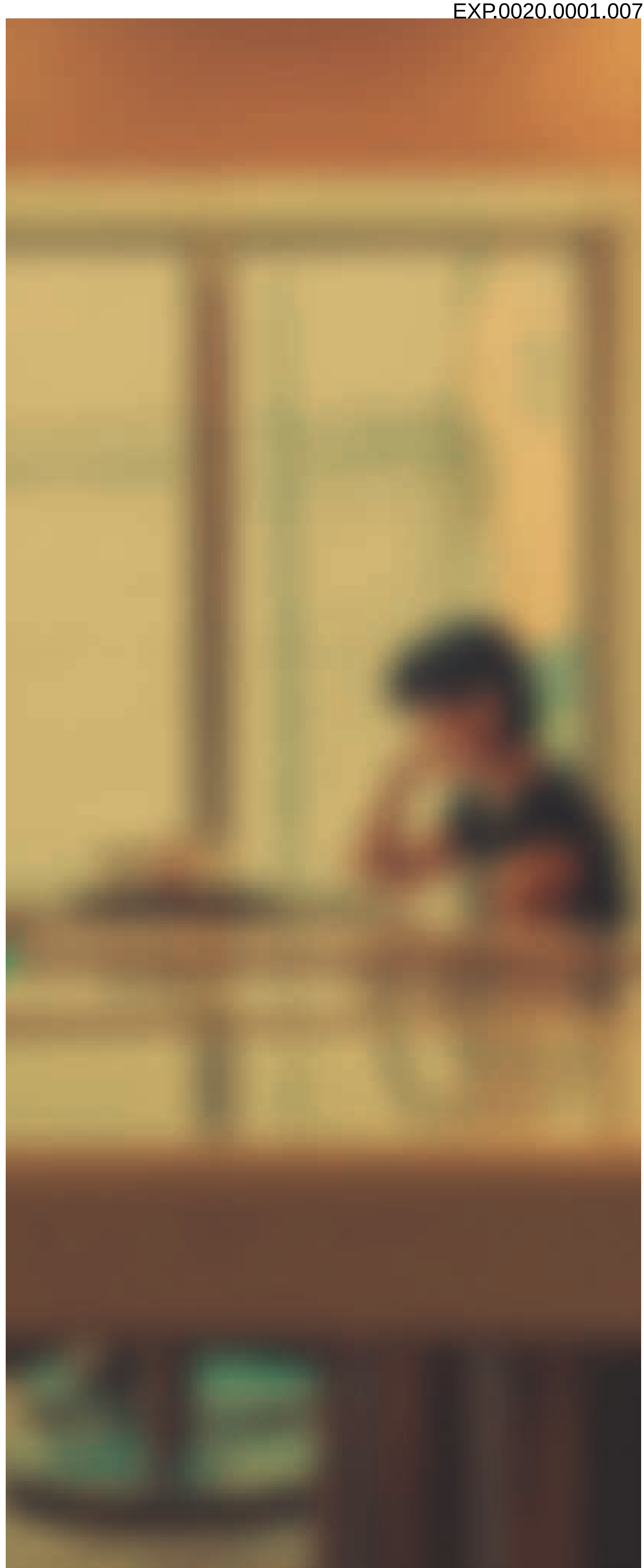
The ABS publishes data from the National Prisoner Census which includes data demographic and legal characteristics of prisoners such as age, sex, country of birth, Indigenous status, legal status, prior imprisonment, most serious offence/charge and length of sentence being served. The most recent report, Prisoners in Australia (2017)[97] shows that incarceration rate for Aboriginal and Torres Strait Islander people was 2,434 prisoners per 100,000 of the Aboriginal and Torres Strait Islander population. By comparison the imprisonment rate for other Australians was 160 prisoners per 100,000 non-Indigenous population. As data on disability is not reported, it is not possible to quantify the intersectional impact if disability upon the rate of imprisonment of Aboriginal and Torres Strait Islander people using the national data set.

However, jurisdictional data from New South Wales on the health and wellbeing status of people in the juvenile justice system shows that the prevalence of complex disability and multi-faceted disadvantage is higher amongst Aboriginal young people compared to other young people[98]. It paints a bleak picture of who ends up in juvenile detention:

54%	54% of young people in juvenile detention are Aboriginal or Torres Strait Islander.
23.8%	Of young Aboriginal people, 23.8% scored extremely low and 39.6% were borderline on the tests used to assess intellectual ability.[99]
87%	87% of young Aboriginal people met the threshold criteria for at least one psychological disorder, and 69% met the criteria for two or more.[100]
25%	25% of young people had a past head injury resulting in loss of consciousness, with females more likely than males to have sustained a head injury (52.6% vs. 22.5%)
68.2%	68.2% of young people in juvenile detention reported experiencing at least one form of childhood abuse or neglect, with more than one-quarter (28.1%) experiencing some form of severe abuse or neglect.

Within this study, one participant referred to being placed in detention, and another participant mentioned a family member who had spent time in person. As there was insufficient data drawn from the qualitative research, it is not possible to draw any definitive conclusions on the experiences of people with disability in the justice system, nor reasons for its omission from the narrative. However, it is reasonable to expect that Aboriginal and Torres Strait Islander people with disability are imprisoned at higher rates than other people with disability and at higher rates than Aboriginal and Torres Strait Islander people without disability and have poorer experiences and outcomes when interacting with the justice system, as identified in other research.

Outside this study, a 2015 report by University of New South Wales report entitled 'A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system'[101] provides a comprehensive account of Aboriginal and Torres Strait Islander people with cognitive impairment in the criminal justice system. Another investigation by international human rights agency Human Rights Watch in 2018 has also chronicled an account of abuse and neglect of prisoners within the Australian prison system[102].



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[97] Australian Bureau of Statistics (2017) Prisoners in Australia. Rel. 4517.0

[98] Justice Health & Forensic Mental Health Network and Juvenile Justice NSW (2017) 2015 Young People in Custody Health Survey: Full Report. NSW Government.

[99] This is using a FSIQ indicator. Ibid, at Table 148, p 81. (Note that this is not an assessments of cognitive impairment)

[100] Ibid, at Table 117 page 65

[101] Baldry, E., McCausland, R., Dowse, L. and McEntyre, E. (2015) A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system. UNSW, Sydney.

[102] Humans Rights Watch (2018) I Needed Help, Instead I Was Punished: Abuse and Neglect of Prisoners with Disabilities in Australia.

6.4 EDUCATION

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 3: Aboriginal and Torres Strait Islander people with disability achieve their full potential through participation in an inclusive high quality education system that is responsive to their needs. People with disability have opportunities for lifelong learning

Unfulfilled aspirations for education

Aboriginal and Torres Strait Islander people volunteered high aspirations for their personal advancement through education:

> *"There's one thing I want to do before I leave this earth is to have my degree in human rights law and then I'll be happy with that."*
>
> *"I'm studying social welfare and psychology at [University] and my main goal is to go on and do neuroscience and be able to become a neuroplastician and work in that field."*

Education was an important factor in the life journey of the participants in the research, with 36 of the 41 interviews (88%) including some reference to 'school'. Further, 23 of the interviews (56%) indicated some current or previous experience with the higher education system, with 14 making some reference to 'University' education (34%), and 16 making some reference to 'College' or 'TAFE' (39%). These reflected high levels of participation in the education system by the participant group. Whilst noting the difficulties in making a direct correlation between the statistical data and the testimonial data used for the study, references to undertaking higher education from the participant group interviewed appear substantially higher than the rates of participation in education for Aboriginal and Torres Strait Islander people within the NATSISS (see Table 6.4.1 below). This suggests the possibility of a positive education bias amongst the participants in the study.

Whilst Aboriginal and Torres Strait Islander people with disability express high aspirations for education, statistical data on education outcomes show that these aspirations remain unfulfilled. Population wide, Aboriginal and Torres Strait Islander people with disability attain educational outcomes at half the rate of Aboriginal and Torres Strait Islander people without disability.

Table 6.4.1: Education Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014-15.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
EDUCATIONAL ATTAINMENT			
Currently studying	14%	25%	0.6
Certificate III qualification or higher	19%	34%	0.6
Educational attainment below Yr 10	42%	18%	2.3

Yarning piece

"It's all about the boxes"

Note that school age children were not interviewed as they were outside the selection criteria. As the voices of school age children are not present in the research, there is likely some understatement of the issues around education. Based on this limitation alone, it is recommended that there is more focused education research that encompasses the voices of children and young people.

However, there were some interviews with parents of Aboriginal children with disability. One participant drew attention to the compartmentalised approach to education where programs for Aboriginal and Torres Strait Islander children run independently of programs for children with disability; as opposed to flexible, coordinated programs which are both culturally inclusive and disability inclusive. In this case, the mother of an Aboriginal child with Autism described being compelled to choose which aspect of support to prioritise through a selection of boxes to tick (which is assumed to drive school funding support). Reduced to its core facts, the case study reads as a farce:

"And, you know, I was filling out the school form and it came to the, "Do you identify as an Aboriginal Torres Strait Islander person? Please tick this box. "Does your child have any special needs?" And, I thought, well, this is going to go two ways. I'm going to tick that Aboriginal box and they're going to focus on that. And, I'm going to tick that Autism box and then going to focus on that. Which one are they going to prioritise?"

I made the decision that I would prioritise [my son's] Autism and – do you know what I mean? Like, that was a really hard decision for me. Because, I've always identified [as being Aboriginal] and, you know, that's our heritage.

I had to pick a box... I just felt if I focus on this they're going to focus on that and then he's going to become a statistic and at the exclusion of the other. So, if I pick this box and not that box they'll focus on the autism and not the other part. And, if I did it the other way that's all they would focus on.

So, I made that choice. And, it was probably the wrong choice at the time. But, you know, I was so scared for him to go into school in general and my experience with the education system down the track is that Aboriginal students are, you know, sort of, put into a group and, sort of, excluded and, you know, the way they manage it is they might not even have an achievement. But, every week they go to the principal with some sort of work that they've done and they're removed from the class and put in a special group and that's how they're treated.

And, the question came up with Aboriginality again when [my daughter] enrolled. Because, of course I ticked the box for her. I'm, like, yes, that's who we are. Tick the box. Don't even think twice about it.

And, then [the school] questioned [my son's] parentage. Whether there was the same father. You know, how they were related. If he was not Aboriginal and she was Aboriginal. So, then I was called up to the school and I had to give an explanation... So, I explained to them and I said, "Look, this is why I did it." So, the box got ticked again and everybody was happy. Because, if there's a box to tick everybody's happy.

It's all about the boxes. See, if there's no box to tick everything falls apart."

Interrupted pathways in further education

The participants tended to describe an interrupted pathway, in which they built their education in piecemeal blocks, rather than as a continuous pathway of matriculation. This observation relates to the excess demands of managing their disability (such as transportation issues, campus access, interpreters, and health issues) concurrently with the demands of study.

One of the people interviewed mentioned that they aimed to complete a succession of certificate level qualifications, as that could be managed within the physical and logistical demands of his disability. Another participant said:

> *"I've always started courses. I never finish them. No, I didn't finish the first course I was doing".*

Later in the interview, the person revealed that the reason she did not complete her first course at University was that she suddenly acquired a disability mid-way through completing her degree. The combined physical and psychological trauma caused her to withdraw from her studies. Having had the flow of her educational pathway interrupted by acquiring a disability, her subsequent attempts to re-enter the University system have faltered.

Many University and higher learning institutions have equity strategies to promote inclusion of both Aboriginal and Torres Strait Islander students, and students with disability. There narratives say that the presence of social factors for both groups of students make educational journeys unpredictable, and do not always conform with the lock-step curricula in many educational institutions. Whilst highly motivated and capable, there are groups of students who have not been able to navigate their way into higher education system, and their actual attainment is lower than what is possible. This knowledge would not be readily available to higher education institutions, as this prospective cohort of students are currently sitting outside the system, but the lived experience knowledge could be tapped to improve the quality and effectiveness of educational equity strategies.

Customised support for individual learning requirements

There were good models of learning support which were provided by the participants who had undertaken further study. As the nature of disabilities and hence needs for learning support are diverse, the key to effective support to establish clear lines of communication between a dedicated support unit and the student to establish their specific support needs, and have the support in place prior to the first lesson:

> *"So, education has been really good because I did my Cert 4 and I had scribes put in place which was really helpful. I've only got limited wrist control but I can read a text book but I'm really slow at opening the pages. So, I'd have a scribe in place going through text books, opening up the books, highlighting passages, when the teacher's going through the notes. And, that's in TAFE. It's supposed to be a lot harder in university, I've been told, to obtain scribes."*

Whilst it might appear obvious that having support in place prior to the commencement will improve outcomes, it is not always the case that Aboriginal and Torres Strait Islander students with disability know who to go to for their cultural support and disability support. This is a particular barrier for students commencing study at large complex institutions. This can cause them to fall behind in their academic work from their commencement, and may lead to their withdrawal from studies.

One gap in support that emerged through the testimony is support for students with mental health conditions. Whilst it was mentioned that access for students with physical disabilities was a focal point of disability support units in educational institutions, issues of access for students with psychosocial disability have not been fully integrated. One participant spoke of the impact a mental health condition, which is episodic and requires periods of hospitalisation, has had on her capacity to complete her academic studies and the unavailability of support within the institution:

> *"Staying at university has been really hard for me, in terms of keeping up with assignments and, in the beginning, there was lack of support at the uni, in terms of mental health support. Like, I find that they have a disability centre, but it's not really catered to people with mental illness."*

Additional educational barriers experienced by Deaf Aboriginal and Torres Strait Islander people

The Deadly Deaf Mob interviews generated rich and extensive data on the specific educational issues for Deaf Aboriginal and Torres Strait Islander people, which is summarised in this section. Education was far and away the dominant issue raised by the Deadly Deaf Mob participants, with all participants citing their experiences being a Deaf person learning in a hearing world.

Three core issues emerged from the Deadly Deaf Mob educational experiences. The first issue is the transitory nature of accessing education, with people having to shift around from school to school, and often going from one school with a Deaf pedagogy which promoted sign language to the next school with different pedagogy that favoured verbal education. Difficulties in accessing specific Deaf education, particularly (but not limited to) in non-metropolitan area meant whole families had to move:

> *"Mum moved to [the city] because of my education, because of the barriers that I had out in the country, because there were no resources out there that were available."*

The second issue was access to Auslan interpreters. Access to interpreters is not universal, yet as the two contrasting experiences show, is pivotal to the educational experience of Deaf students:

> *"I had a hard time in my education because I was in a mainstream school and in that period I didn't have any interpreters available for my education. I didn't have a support worker. So, my – my English – my written English is okay, but it's not the best, you know, it's not at that standard that it should be at."*
>
> *"I had a good experience, I didn't miss out on anything, I had an interpreter. The teachers were hearing and I had an interpreter, so I had a really positive experience."*

As is the case with many other needs of people with disability, it is family and community who bear the load of compensating for a lack of interpreter services through systems:

> *"I've got a brother and a sister and my eldest brother who was always my interpreter, I grew up with him, he's four years older than me, he always interpreted to me."*

The third theme from the Deadly Deaf Mob is their strong desire to learn more about their own Aboriginal cultural heritage. They described an approach to their education which was dedicated to making them proficient learners in a western hearing world. However, a general lack of access to Auslan within Aboriginal and Torres Strait Islander communities has left them isolated from the depth of cultural knowledge that is taught to hearing Aboriginal and Torres Strait Islander people. This has left them with a sense of longing for further cultural learning.

6.5 ECONOMIC SECURITY AND EMPLOYMENT

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 4: Aboriginal and Torres Strait Islander people with disability, their families and carers have opportunities to gain economic security through employment and business ownership, enabling them to plan for the future and exercise choice and control over their lives

Undervaluing the contribution of Aboriginal and Torres Strait Islander people with disability through employment

Table 6.4.1 shows that Aboriginal and Torres Strait Islander people with severe and profound disability are almost twice as likely as Aboriginal and Torres Strait Islander people without disability to be unemployed (1.8 times), and half as likely to participate in employment (0.5 times).

Table 6.4.1: Education Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
EMPLOYMENT PARTICIPATION			
Participation rate	31%	68%	0.5
Employment rate	19%	55%	0.3
Unemployment rate	34%	19%	1.8

The testimony reflected the unfulfilled aspirations for employment held by the participant group. 24 of the 41 interviewees (58.5%) referenced 'jobs' during their interview, and the overwhelming majority of their testimony centred on their inability to get them. The issue of employment was particularly significant for Deaf Aboriginal people, with employment issues raised in every one of the interviews with the Deadly Deaf Mob.

Many participants had indicated that they had undertaken study or a training course to improve their employment prospects (refer 6.4), but this had not advanced their long-term employment prospects:

> *"So when I finished school I went to TAFE and study hairdressing. And that was a one year apprenticeship. And there were so many barriers. I thought it would be fantastic. But – no. The whole industry and the area was full of people who can hear. So I know how to cut and shampoo and do everything. But everyone was hearing and they all spoke, so we had to communicate through writing and paper...I did love that job but ended up leaving."*

In most cases, the barriers and discrimination that the participants faced in their job-seeking experiences could be traced back to their disability, rather than being an Aboriginal or Torres Strait Islander person. However, some participants held an expectation that they would be discriminated against because they were Aboriginal and Torres Strait Islander, and this is the point 'apprehended discrimination' filtered into the testimony:

> *"It's difficult to get jobs. And, that's the main issue. And, it's difficult to get accepted in mainstream societies. And, a lot of people with – who are wheelchair bound have a – found it difficult to get into employment and they still can't – there's a lot of them still having problems with disabilities with employment. And, being accepted. Then the other disadvantage is if you're an Aboriginal person – well, my experience was that if you're an Aboriginal person you can't get a job... I was brought up during the old racist Australia days and the white Australia policy and all of that. And, that's another disadvantage. Trying to make your way in – in that world."*

It's as much about the job giver as it is the job seeker

Improving employment prospects is a policy priority of both the Closing the Gap strategy and the National Disability Strategy. However, outcomes data on employment show that the intersectional impact of disability on outcomes for Aboriginal and Torres Strait Islander people have not been adequately addressed in either strategy. There is a dominance of employment programs, bundled under the euphemism, 'capacity-building' which target the upskilling of the job-seeker, on the assumption that 'capacity' is where the problem lies. By contrast, little consideration is given to problems with the job-giver.

Yarning piece

Not fitting 'The Brand'

I had met this person through a friend of a friend, in early 2016 not long after we had started the research program, and had not yet commenced interviews. When we first met, she told me that she couldn't get any of the "Westfield type jobs" as when she turned up for an interview, she would be told that she "didn't fit their brand". Hearing this, and the sheer arrogance that some big brand employers show people with disability leaves me with white-knuckled fury. I made a mental note to follow up down the track to ask whether she would be prepared to go on record and be interviewed for the research.

By the time of the interview, just over a year after we first met, I already knew much of her background. I know of her disability diagnosis, although she doesn't mention it once during the recorded interview. Growing up in an urban area, she is young, currently at University, and comes across as softly spoken, and highly intelligent. The thing that I notice most is how extremely polite she is.

> *"I grew up with a lot of, kind of, discrimination due to my disability, but not only that, within my high school, because I was of Torres Strait Islander descent, I actually got extra support. So the other student would get jealous in a sense that I would get extra support, and they would kind of discriminate against the group of us that were Indigenous."*

During her high school years, being 'Indigenous' was more a label than an identity. Things started to change at University. "Up until then, I didn't understand why I was getting extra support. And, like, what it meant to be Indigenous. I didn't really understand until I actually got to Uni, actually did a subject on Indigenous studies... and I kind of got to connect with other people that were Indigenous." She tells me that she entered University through a pathway scheme for Indigenous students, and that she has a private tutor which is sponsored by the Uni.

"With my disability, I obviously face a lot of barriers, especially with getting a job. That is a big one. The employment side of things is a big obstacle in the way that, like, I can't get a normal job at Maccas for example, because if I was to work at a check out they would need to do is put a chair there for me to sit on. But they don't like to make these alterations. So it is hard for me to get a job, and for people to look past, get to know the 'who I am', instead of looking at the disability."

The stigmas and false assumptions that other people hold around her and her disability is a constant source of frustration for her. In her case, it is the conflation of her physical disability with intellectual impairment. "Because I've got a physical disability, [people assume] that I must be intellectually impaired. So when I tell them, no, I actually go to University and actually work [in a policy research support role]... they actually get quite shocked." She gives an example of an experience she has had the employment agency that has her on its books.

> "I had an interview with this one agency and this was just to see if I was going to work with them or not. And the person that was actually interviewing me talked to my mum instead of me because she thought that I couldn't communicate. And mum was like 'She can talk. You don't need to talk to me. She's fully capable of communicating."

"Just a horrible experience", as she describes it, it is one example of many in her life. She is yet to meet an agency, or a person in an agency who has helped her find a job. It has soured her view on whether employment agencies will ever be able to help her. "They are amazing at helping you fill out a resume and all that sort of stuff. But when it actually come to finding you a job they can't do it".

Her education experience, at least at University, appears in contrast with her attempts at getting some work. Despite the occasional hiccups, usually due to a lack of communication, her education experiences "have actually been great". She gets a regular disability service plan with exam adjustments, and has access to a participation assistant which helps out. She is doing two degrees, and her goal is to become a neuroplastician and become a researcher in neuroscience. I jot down a note to look up what a neuroplastician does when we're done with the interview.

The discussion comes back again to employment. The inability for "people to actually look past the disability" is clearly dispiriting for her. Her current casual job has irregular hours, and she would like to be able to get some extra money in. "I would just love to get a normal job, like a check out chick...All I would need is a chair. Like, just to put those little minor alterations in place so I could do the job...Just get to know me, instead of judging what is on the outside."

What keeps her strong is converting her lived experience of disability into resilience and a source of motivation. "What keeps me strong is knowing that I can use my personal experiences to make a difference to the world, to inspire others, no matter how small... Just use all my negative experiences and hardships and turn them into positive. That's what keeps me going".

She describes her greatest achievement as getting a casual job where the wisdom of her experiences are valued. "I was just over the moon when I was accepted to work, so empowered that I'm able to make a difference and educate people."

The disconnect between policy and the lived experience of seeking employment

Whilst the people involved in the study uniformly expressed their desire to participate in employment, they also conveyed the high expectations of them. In some instances, the high expectations were self-imposed, typically born from a previous bad experience in which their skills and qualifications were belittled. Regardless of whether the high expectations were internally or externally imposed, an undercurrent filtered through the narrative that people with disability are constantly having to prove themselves in the workplace in a way that is over and above what is required of people without disability.

> *"I thought to myself, you know, if I do something completely different, like, move to another city, go to school, you know, try and get a good job or whatever, you know, get involved in TAFE and study and finish year 12 and achieve those goals, and then people would you know, give me the credibility and say 'Wow, you can do it.'*
>
> *"I'm in my fourteenth job now since I've come to [the city]. And, I've always been successful in finding jobs and – and, now I – I'm doing a traineeship and I'm getting more and more confident, I'm learning more, I'm going out to do lots of courses and training and – and, especially events."*

On one hand Aboriginal and Torres Strait Islander people are expressing their desire to advance themselves through education and employment, on the other they are subject to simplistic job seeker program and policy slogans around 'capacity building' and telling them to 'go to school and get a job'. The clear message coming from the research is that Aboriginal and Torres Strait Islander people with disability are willing and able to go to school and get a job, but they can't gain or sustain regular employment because of barriers which are both physical and attitudinal.

Herein lies the dangers in reductionist policy discourse. Policy messaging around 'capacity building' targets people in what behavioural change theorists might describe as the precontemplative stage of change.[103] They are short and sharp messages, aimed at motivating people who are currently unmotivated in changing their behaviour with a short, sharp call to action (ie.'upskill yourself, go to school and get a job'). The issue is that this assessment is not grounded in their lived reality of trying to find secure employment, completely misreading where people are at in the stage of change continuum. The people in this study have moved beyond the precontemplative stage and are motivated. In failing to acknowledge the core structural impediments in securing employment, motivational styled messaging paradoxically becomes acutely demotivational, as its exclusive contribution is to fuel the negative stigmatisation for those who can't secure employment.

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[103] Prochaska, J.O., and Velicer W.F. (1997) 'The Transtheoretical Model of Health Behavior Change'. Am J Health Promotion 1997;1211]:38-48.)

Apprehended discrimination and the avoidance of participating in employment

Apprehended discrimination, or self-exclusion because of a rational fear of being discriminated against, can help explain the pathway in which people go from being motivated, to demotivated, and on to not participating in the employment market. The concept of apprehended discrimination as it applies in employment is practically illustrated with the following hypothetical: There are many client-stakeholder engagement styled jobs that are advertised on job seeker websites which include a driver's licence as an essential criterion. From a functional viewpoint, visiting clients and stakeholders might be an essential part of a job. What the requirement of a driver's licence as an essential criterion does is not only stipulate that you must visit stakeholders, it also prescribes how that function must happen (ie. self-drive in a car). As there are many people with disability unable to hold a driver's licence they are, as a consequence, locked out applying for that position because of one seemingly innocuous job stipulation. An Aboriginal and Torres person with disability might be qualified in every other aspect of the position, but sensitised to the multiple forms and detrimental health effects of discrimination that they have been routinely exposed to, choose not to even apply to avoid putting themselves in a position where they could be further discriminated against because of their disability. The fear of discrimination is enough to contribute to inequality in the outcomes.

Rather than subject themselves to the possibility of being discriminated against based on that one job criteria, they will not apply for the position, even if they see themselves as qualified in every other way.[104]

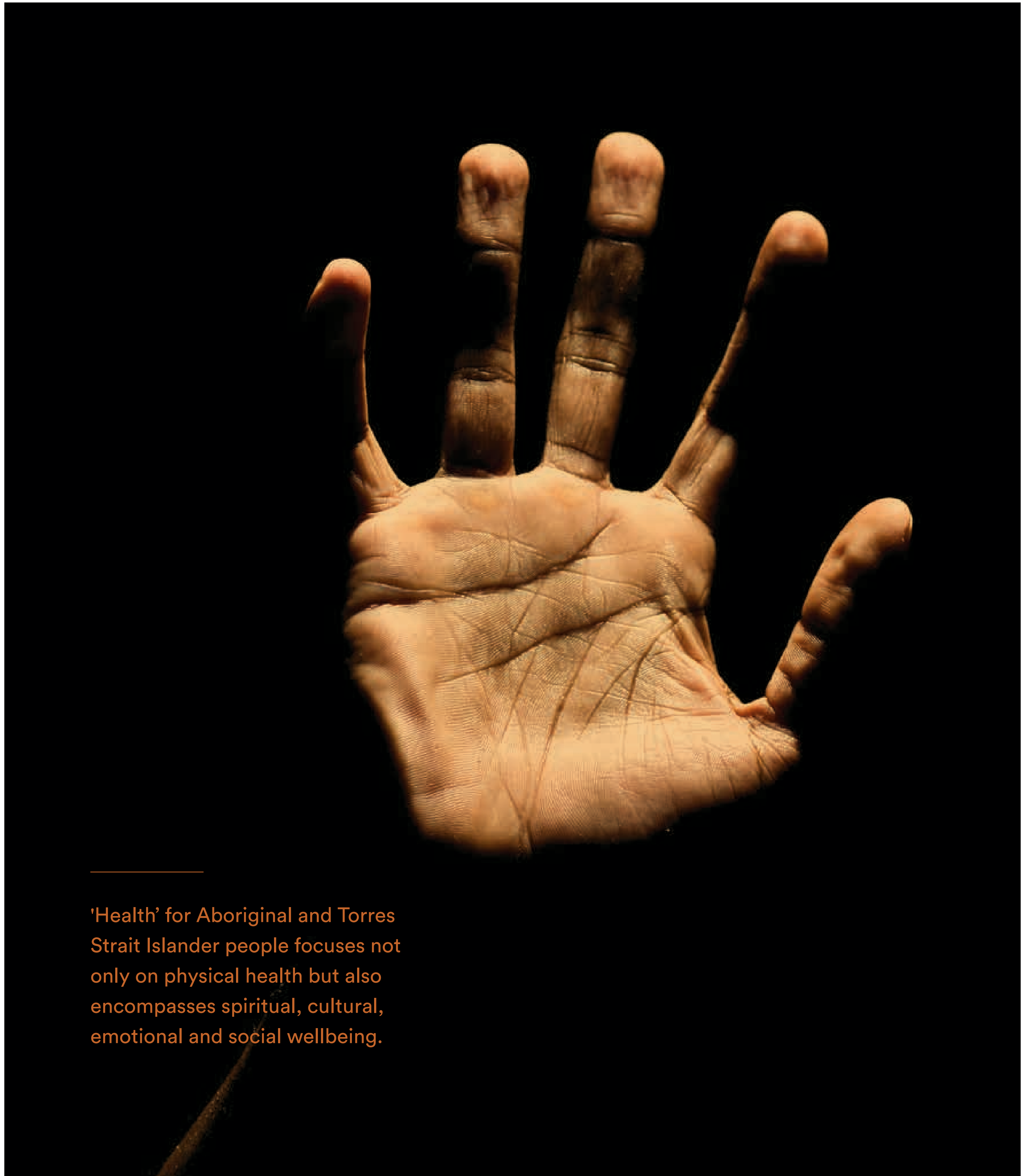
When a person is constantly looked over for employment, the effect on personal confidence is debilitating. When someone has their heart set on a career and their life-long ambitions are cast aside because of their disability, it can be dream-shattering:

> *"I've applied for [a major Australian airline] as a [flight steward] and so I asked, you know – I got an interpreter in to help me fill out the forms and – so, we sent that off. And, it failed. And – because, I only had one issue and that was the – the inability to hear. So – and, that's the problem. You must be able to hear to work on the planes. And, it really pissed me off. You know, I can do that. I know – I know I can do that. I've travelled all over the place. I've been overseas continuously. I've travelled all over the world. And, I thought to myself, you know what? I would like to work for [the airline]. And, you know, that was my dream and that's what I wanted to do and I couldn't do it. It was only because I'm deaf and I couldn't hear.*
>
> *So, you know what job I'm doing now? I'm working as a cleaner."*

Multiply this single experience by many, and you have apprehended discrimination.

---

[104] This hypothetical is drawn directly from a real life experience of a vision impaired Aboriginal person, who had told the researcher that he no longer bothered applying for jobs which included having a driver's licence as a standard criteria, regardless of whether it was relevant to the job or not. As this experience was shared informally with the researcher at a break during a community forum, it is presented in this report as a hypothetical rather than a fully documented narrative interview. Nonetheless the researcher wishes to acknowledge the source of this hypothetical as coming from the Aboriginal and Torres Strait Islander disability community.



'Health' for Aboriginal and Torres Strait Islander people focuses not only on physical health but also encompasses spiritual, cultural, emotional and social wellbeing.

6.6 ACCESS TO HEALTH CARE SERVICES

Reference to the Australian Government's Plan to Improve the Outcomes of Aboriginal and Torres Strait Islander People Living with Disability:

Area 5: Aboriginal and Torres Strait Islander people with disability attain the highest possible health and wellbeing outcomes throughout their lives, enabled by all health and disability services having the capability to meet their needs.

Access and the psychosomatic dimensions of healthcare

There are multiple dimensions to Aboriginal and Torres Strait Islander health and wellbeing. 'Health' for Aboriginal and Torres Strait Islander people focuses not only on physical health but also encompasses spiritual, cultural, emotional and social wellbeing. Health is more than the absence of sickness; it is the relationship with family and community, providing a sense of belonging and a connectedness with the environment:

> *"Aboriginal [and Torres Strait Islander] health means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total well-being of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life"*[105].
>
> *"Health ... is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity"*[106].

All of the above aspects of health were raised through the testimony in one way, shape or form. Given the breadth of coverage, this section focuses on access to health services, particularly those related to the somatic aspects of health. Issues of trauma, mental health and psychosocial disability were so pervasive that they warranted a dedicated discussion in Chapter 8, which follows.

In many respects, health status is where the impact of discrimination and inequality in other aspects of life materialises. Life expectancy data for Aboriginal and Torres Strait Islander people is not disaggregated by disability status, so the statistics on self-assessed health status is the best available summary proxy for the overall quality of health experienced by Aboriginal and Torres Strait Islander people with disability. It is here in health that the inequalities experienced by Aboriginal and Torres Strait Islander people with disability are at their starkest.

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105 National Aboriginal Health Strategy Working Party (1989) National Aboriginal and Torres Strait Islander Health Strategy.
106 World Health Organisation (September 1978), Declaration of Alma-Ata, International Conference on Primary Health Care, Alma-Ata, USSR

Approximately one in seven Aboriginal and Torres Strait Islander people with severe and profound disability assess their health as excellent or very good (14%). By comparison, approximately one in two Aboriginal and Torres Strait Islander people without disability assess their health as excellent or very good (53%); and for people without disability the self-assessment rating of excellent or very good health is more than two in three (69%)[107]. Based on this data, the likelihood that an Aboriginal and Torres Strait Islander person with severe and profound disability would assess their health as excellent or very good is one-fifth as likely as someone in the general population assessing themselves as having health which is excellent or very good.

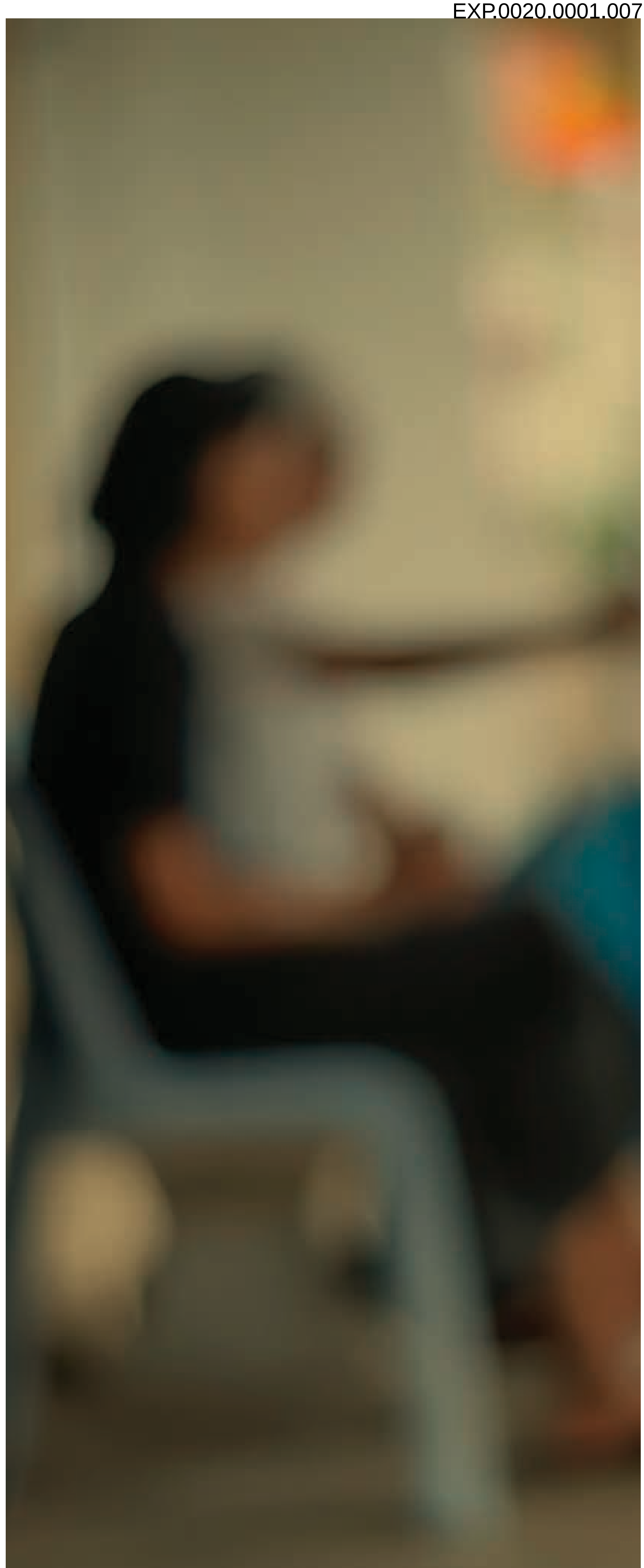
Table 6.4.1: Health Status and Access Indicators,
Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
HEALTH			
Self- assessed as excellent or very good	14%	53%	0.3
Difficulty in accessing health services	27%	11%	2.5
Trust in own doctor	76%	82%	0.9
Trust in hospital	54%	70%	0.8

The statistical data on accessing health care in Table 6.6.1 show that Aboriginal and Torres Strait Islander people with disability experience difficulty in accessing health care services at 2.5 times the rate of Aboriginal and Torres Strait Islander people without disability. It is not clear whether this is because of the high frequency of trips to a health care provider (ie. high frequency of health care visits means there are more opportunities for something to go wrong), or despite it (ie. whilst high frequency of visit means there are more opportunities to get things right there is some other significant factor which is an impediment to access).

Trust is the other psychosomatic variable in the provision of health care. Aboriginal and Torres Strait Islander people with disability have trust in their own doctor at a slightly lower rate than other Aboriginal and Torres Strait Islander people (76% compared to 82%), with a greater gap in the comparative levels of trust when it comes to hospitals (54% compared to 70%). On balance the participants in the research spoke about their relationship with their personal doctor casually, although there was one participant for whom a trusting relationship with her doctor was critical to their sense of personal empowerment:

> *"The doctor who prescribed me all this medication...but then at the age of 16 he said, "All right. You've got a choice". He said, "It's your choice now to get off the medication or continue with it". And, so I said that I'm getting off it. A few weeks after he asked to see me again just to see how I was going. He said it was the best decision I ever made.*
>
> *So, I felt like finally I had a voice, you know, I feel like I could say what I wanted."*



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107 Australian Bureau of Statistics (2014) General Social Survey.

Diagnostic overshadowing and the intersection of institutional ableism and racism in health

Chapter 4.6 presented the body of research which has found that 'diagnostic overshadowing' can apply in the provision of health care services to people with disability when symptoms of an illness are attributed to a person's disability rather than the presenting undiagnosed condition. The disability 'over-shadows' or obscures the serious illness, and the serious illness remains undiagnosed. As a version of institutional ableism, it occurs when a treating healthcare practitioner's clinical judgement is subconsciously biased by preconceptions, prejudices and assumptions about disability. At a minimum, the quality of care to the patient with disability is compromised, but it also heightens the risk of a catastrophic health event.

The concept of 'diagnostic overshadowing' is extended by this research, which found that access to health care by Aboriginal and Torres Strait Islander people with disability is adversely affected by institutional racism as well as institutionalised ableism. One participant, a quadriplegic wheelchair user, spoke extensively on how the quality of healthcare had been compromised through diagnostic overshadowing, citing a series of incidents across a range of health care settings where practitioners did not demonstrate a working knowledge of how disability related to their area of clinical practice.

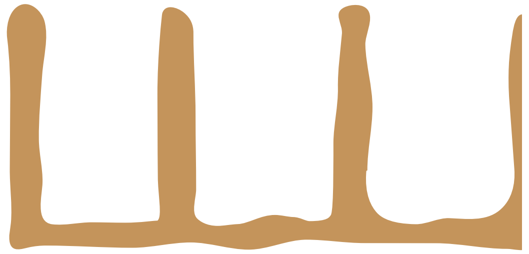
"I've had a lot of ups and downs with the health system. So, just a little interaction that I had a couple of weeks ago. Like, because a lot of people just presume, even within the health system, because I'm a quadriplegic. I can't feel from the chest down. And, I went to a podiatrist and, you know, he's mucking around with my – with my toes and he's like, "You can't feel that. You can't" – and he's just presuming that's, you know, perception of people in wheelchairs. They can't feel from here down. But I can feel everything bar my right leg sensation wise...

And that's even in hospitals as well. Like, I've had interactions with nurses that say, "You can't feel this" or, "You can't do that." I'm like, "Hey, no. I can feel my left leg. I know what you're doing down there. Like, take it easy, all right?" "Just don't take the mickey and think you know?" So, I've had some good experiences but some bad ones as well, just because of what people presume and so forth."

Power relations between the clinician and the patient play a role. Intersectionality, which is framed in terms of power hierarchies between people in power and vulnerable population, is also relevant. The power relationship between a clinician and a patient with disability can be greater than between a clinician and a patient without disability. This narrative shows that systemically generated practice trumps patient experience in a westernised model of health care, and ultimately it is the believability of the person with disability that is contested. When institutional ableism intersects with institutional racism, as is the case with Aboriginal and Torres Strait Islander people with disability, the power differential between clinician and patient is greater again. An example of the intersection between ableism and racism, and the heightened risk of catastrophic health event, is an Aboriginal or Torres Strait Islander people person with disability whose health concerns are dismissed as being alcohol related, when the clinical assessment of a health practitioner is biased because of the negative stereotyping of Aboriginal and Torres Strait Islander people and alcohol consumption.

During community consultations for this research, the researcher was informed of a critical incident involving a young Aboriginal man who required emergency treatment for severe dehydration and hypothermia. The man involved has Aboriginal tattoos and uses a motorised wheelchair, thus visibly projects his dual identity as an Aboriginal person and person with disability. He was returning home in his motorised wheelchair from an Aboriginal community meeting held outside on a hot day when his body started overheating. As his condition started to deteriorate, he made his way to a bottle shop attached to a pub, being the only place in the vicinity with ice and air conditioning. By the time the ambulance arrived, he was in a state of semi-consciousness, and whilst he could hear what was being said, he was immobile and unable to communicate with them. Even though there was no presence of alcohol in his system and a bottle of water on him that he could not open, he was under-triaged as suffering from excess alcohol consumption, as opposed to dehydration. He recalls vividly perceiving "the looks of disgust from the paramedics, all the way through the hospital, the doctors and the nurses". It was not until he "started coming to" that the exact nature of his medical emergency was correctly diagnosed, and as soon as they realised that alcohol was not a factor, the medical staff "started backtracking".

Whilst the conditions of this case are a perfect storm for institutionalised ableism and racism, it does highlight the adverse health consequences of failing to follow through with diagnostic protocols in full when vulnerable patient groups are concerned. This is not an isolated incident. There is at least one coronial inquiry where a critical incident resulted in the death of a young Aboriginal woman, in which "premature diagnostic closure" by medial staff was found to have been present.[108]



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[108] This refers to the coronial inquest into the 2014 death in police custody of Ms Dhu, a young Aboriginal woman in Western Australia. Whilst the Coroner did not rule Ms Dhu's death as avoidable, the Coroner did find various errors and omissions in the diagnosis and treatment of her condition in her various presentations to a medical facility. Testimony was provided to the inquest that "premature diagnostic closure", the legal term used by the Coroner, had occurred after police told medical staff that the patient was "faking it". See: Coroner's Court of Western Australia (2016). Inquest into the Death of Ms Dhu.

I want to go home… for my own blood family”

Towards the end of the morning, one of the community workers came in and asked whether one more of the men could come in and tell their story, as someone had been waiting a long time. “Of course”.

In came an elderly man, with a walking stick. He was softly spoken with a gentle demeanour. He said he was sixty, but he looked considerably older. By my reckoning, he had waited about an hour and twenty minutes to speak with us whilst other men from the community centre had come in to tell their story.

Very early in the interview, I got the sense that he was lonely, and just wanted to talk to someone. He started his story by talking about how he worked on a station when he was younger, then came into town with his family. “That’s where I got disability, down here”, he said. He started to describe what happened, but talking about it was clearing making him uncomfortable. “It’s hard to talk about. Yeah. Yeah.”, he said. “Okay. That’s fine. You don’t need to talk about it.”

We switched tack to talk about his family, then talk about some of the barriers he had faced in his life. At this point, he mentioned that he was sleeping rough. “I live at bush… Just around the town area. Just down – [pause] – we’ve got nowhere to sleep”.

About ten minutes into the interview, the story drifts back to his health.

INTERVIEWER (I): Do you see a doctor about any health issues?

PARTICIPANT (P): Yeah. I went up there [to a regional hospital]. I’ve got to go – I’ve got to go back too. I’ve got this operation… I’ve got some pins down here.

At this point the man lifts his trouser, and points to his leg. There is a diagonal bulge covered by a scar which looks to be covering a pin, which is about an inch long and clearly visible. It was quite stark, reminding me of those flat-topped mountains that pop up out of nowhere you can see when you go driving in the outback.

I: Okay.

P: I’ve got a walking stick down here. That’s why I can’t work. Can’t do anything.

I: So, you’ve had an operation recently. Okay. I can see the scar over your knee.

P: Yeah. Bit sore up here.

I: It’s swollen. Is it sore now?

P: Just – I’m right to walk around.

I: Yeah. Yeah. Just got to take it easy. And, how long ago was that operation?

P: Well, that was one month back, with – what’s the date today? That was last month.

I: And, were you in hospital for very long?

P: Yeah. Down at [the regional hospital].

I: And, how long were you actually in hospital for?

P: I’ve been there for two weeks…Just everything got healed up. They put – – –They put pin down here.

I. Okay. I can see the size of the pin over your knee cap there. Have you got to keep going to see the doctor regularly to make sure it’s all right?

P: Yeah. Yeah.

I: And, it’s working good?

P: Yeah. Yep. They’ll – they’ll be – they’ll be calling me up here.

I: Do they come and see you or do you got to go into town?

P: No. I’m going to the big hospital, talk on these video links down to a doctor. Yeah. They’ll be calling me maybe after this month. I’ll be going back there to have another operation to take – take the pins out…in a month.

I: One month. All right. And, when do you go… does someone come and get you? Or – – –

P: No. They put me on a bus.

Yarning piece

I: They put you on a bus. Okay.

I make a mental calculation that this would be about a six or seven hour bus ride.

I: From out there? From – – –

P: From the hospital.

I: Right. From the hospital. Okay. And, how do you get to – from where you're sleeping at? Because, you said you were sleeping rough. Is that right?

P: Yeah.

I: How do you get there?

P: I walk.

I: You walk?

P: Yeah. Walk slowly.

I: And, how – how many – how long would that take you to walk?

P: Well, the hospital's a couple of blocks in. Yeah. Be about 500 metres.

At this point, I'm registering that an Australian health care system would discharge a sixty-ish year old man from hospital after a significant knee operation into a situation when he is on own his own and sleeping rough.

He then spoke of what it was like "living bush". He described it as safe, but it was cold and there was no bathroom or running water. He has to get water for himself with a bucket from the local rodeo ground, which is across the road from the camp site. Stating the obvious, I point out that this might be tough going with a crook knee, to which he laughs ironically and readily agrees.

He speaks of a common bond between him and others who live bush, and says that they all look out for each other. I ask what would happen if he needed urgent help, and he said that the people he lived with would call the ambulance to come and get him, as some of them have their own phones, He makes the point he is not the only one in his situation. "So, we need to tell the government that we've got men with a disability, living bush."

But despite sharing a common bond with his 'living bush' community, he speaks with a tinge of regret at his lack of personal space and the infringements upon his dignity. These are basic acts of living that many Australians might take for granted. He said "you can't get breakfast...because when you put it [fresh food] out there you've got to hang them up a tree and the crows come and eat, or dogs around there [if it is left on the ground]."

His family checks on him regularly and brings him food and fire wood. It is clear by his demeanour when he speaks of them that his family is his strength. But they live too far away. I ask him why he doesn't stay with them, and he replies "it's just overcrowded. There's too many people in kid's house, can't fit in". These are the words of a humble man who doesn't want to be a burden.

Despite being relatively young by Australian standards – by my reckoning, he is some twenty five years younger than the national average life expectancy - there is already a sense of a final destiny creeping into his story. What matters to him in his future is simply a roof over his head and his family around him. When I asked are there things that he would like that would make things better for him, his response was a dignified request. "I want to go home. That's all. Yeah. Get – get my family to come. For my own blood family. My daughters."

Elevating the voice of Aboriginal and Torres Strait Islander people with disability in health care research

Healthcare research which centres the service provider as the exclusive source of knowledge cannot, by definition, detect the influence of subconscious bias upon the care provided to Aboriginal and Torres Strait Islander people with disability and other vulnerable groups. Whilst it may be suitable to centre practitioners in clinical research, the sociology of health can only be understood though promoting the voices of vulnerable patient groups as a check and balance to implicit biases that are taught, practiced and recreated through clinical education and training.

The National Aboriginal and Torres Strait Islander Health Plan provides an avenue through which the lived experience of the Aboriginal and Torres Strait Islander patient can be integrated into research, policy and practice. If it is to be held true to its vision of a health system free of racism, then by logical inference, it must hypothecate a place for Aboriginal and Torres Strait Islander people as a frame of reference for further health research, as only they are positioned to provide a critical reaction to the inherent biases built into the system that provides services to them.

The data, both quantitative and qualitative, present a compelling case that disability has a material impact on the health outcomes of Aboriginal and Torres Strait Islander people. The National Aboriginal and Torres Strait Islander Health Plan is considering the impact of racism in health, however it is completely silent on the impact of ableism. Indeed, the only activities relating to disability contained within the current implementation plan are cross references to the National Disability Strategy[109] and to the implementation of the NDIS[110]. This is not enough. Neither the disability sector nor the NDIS has responsibility for the provision of care within Australian health care systems. If anything, the significance of the NDIS in relation to health is as the future cost bearer of an increased and avoidable burden of disability that occurs because of institutionalised ableism, diagnostic overshadowing, and sub-optimal health care practices provided to Aboriginal and Torres Strait Islander (and other) people with disability. The current status quo can be addressed through an ongoing intersectional approach to health research for people with disability, emphasising Aboriginal and Torres Strait Islander people and other vulnerable groups.

The avoidance of suffering has an impact on quality of life and an economic benefit. The impact on quality of life is revealed in the narratives in this chapter. The economic impact will be realised in disability service provision and the full implementation of the NDIS if it becomes a cost bearer for failings in the health system

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[109] Commonwealth of Australia – Department of Health (2017) Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan 2013–2023. At p. 12

[110] Ibid, at p14

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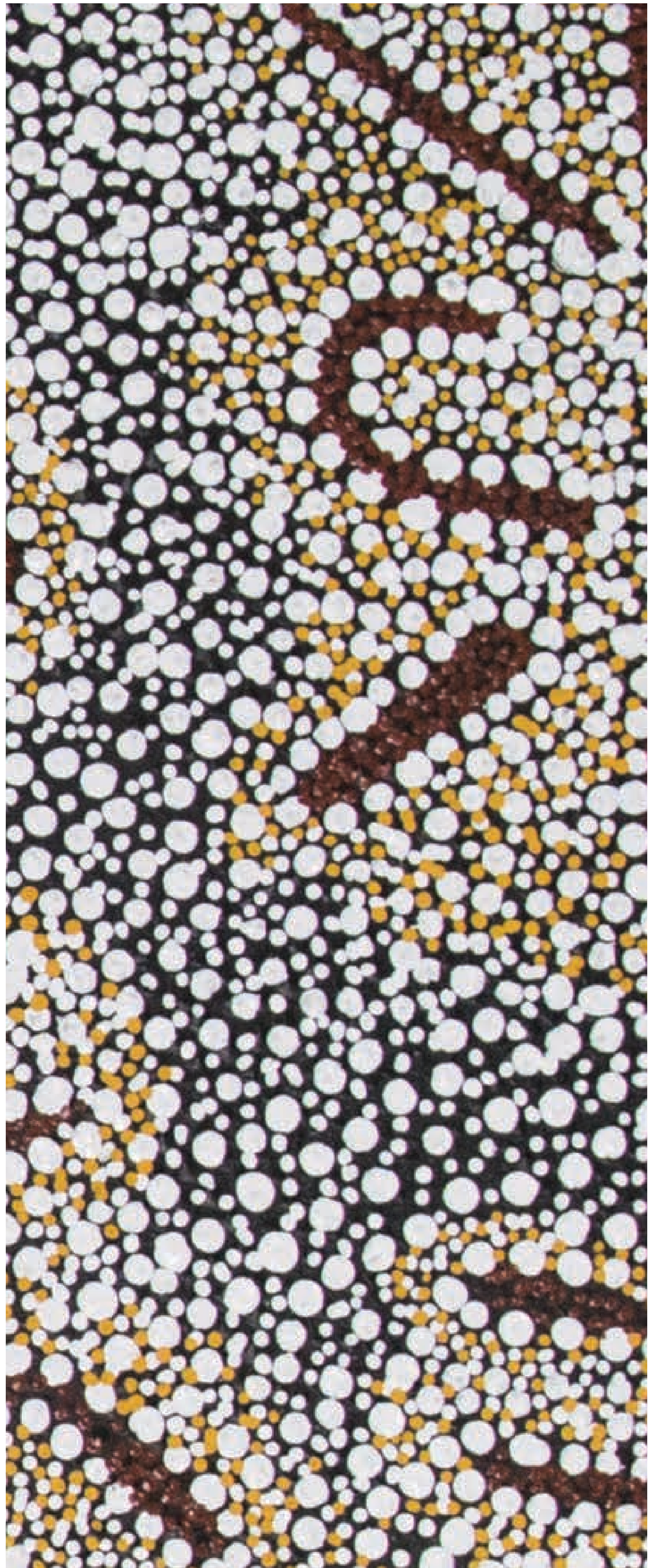
ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE AND THE NATIONAL DISABILITY INSURANCE SCHEME



The National Disability Insurance Scheme was launched in July 2013 in a number of trial sites. One of the trial sites was the Barkly Shire, Northern Territory, which coincided with one site where research interviews were conducted. While acknowledging that it is still early days in the implementation of the NDIS, it was found to have had relatively little impact on the lives of the participants in the personal research interviews. The 'NDIS' or related words[111] were referenced in 11 of the 41 interviews (26.8%), for a total of 27 mentions by participants.

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[111] The text search included: 'NDIS'; 'insurance'; 'scheme'; and 'package'.

7.1 NARRATIVE DATA ON THE NDIS

In referencing the NDIS, not all participants mentioned having direct personal interaction with the Scheme. Two of the participants spoke about their anticipation of the Scheme's contribution to a system-wide approach to communication and support for people with disability.

One participant expressed an aspiration that the NDIS would help them navigate 'the system' in positive terms:

> *"There's no one to guide Deaf Aboriginals now into the wider community. And – and, really, that's what the NDIS should be about and making sure that everybody is provided with the individual needs that are needed for them."*

Another expressed frustration that the NDIS would merely add to the systemic complexity, and highlighted a need for independent sources of communication and personal advocacy:

> *"Well, the system like it currently is, with NDIS. That's another story. Another long story. It's unbelievable."*

Other participants who referenced the NDIS did so with varying degrees of personal engagement, and varying experiences with the Scheme and its processes. Nonetheless, there was not a single participant from within the research cohort who had conveyed that they have completed, or that they understood, the process of getting a package, having a package activated, and being satisfied with the outcome.

One research participant from a metropolitan area attended the interview with a support person who acted as a personal advocate. At the time of the interview, she was not on a plan, and is best described as having just started the process. She did not have a formal disability diagnosis, and her support person was concerned that the absence of a diagnosis would be a barrier to accessing the Scheme:

> *"The doctor hasn't given her a diagnosis of what's wrong with [her]. And, I'm frightened that [she] is going to fall through the cracks and not going to be entitled to a package."*

The support worker was concerned that the participant did not fully understand the importance of the correspondence that came from the NDIS and that some letters sent to her directly may have been inadvertently thrown out.

During the interview, it emerged that there were two members of her immediate family living in the same household, with intellectual disability, neither of whom had been contacted by the NDIS, and that they too would fall through the cracks:

> *"I understand that the NDIS is individual. But, from what I hear, they can be flexible, as well. And, I honestly think that [she] and her two boys are going to fall through the cracks. And, they would need a package that kind of – I know they're individual, but link into each other. Because if anything happens to [her], what's going to happen to her boys? You know what I mean? They need something in their home. A structure."*

Another research participant from a remote area, had secured a package for one of her sons who has a severe cognitive disability. In prefacing her discussion on the NDIS, she had spoken extensively of the difficulties that her son faced in getting an education, and due to a series of bad experiences including abuse, was not attending the only local school in the area. Despite securing a specific dollar package from the NDIS for her son, she remains highly distrustful that the package would be spent on her son and in a way that would benefit him:

> *"People with disability {don't) get the money that the NDIS or the government that sends them out here, you know....And, now my son missed out on an education. .. All I want is for someone to come up there, at least twice or three times a week and – and give my son an education, you know, just – well, he knows a lot but at least teach him some other things that he need to know. He's got a right to have a one-on-one teacher. I've been trying to fight for that for years.*
>
> *When people get us funding there's only certain things they can use that funding for. I'm not allowed to even use that – their funding to take me and my son over there for that. I want – I want a big easel, I want some paintbrushes, I want some – all these paint things so my son can sit up there and do these things, that'll be good for his hands."*

Other participants said that they were on plan that had helped them personally. Two participants had said that they met with NDIS representatives – "they've got my story there", said one – and had a plan. Whilst they felt that the NDIS had provided what they needed, they nonetheless appeared more as passive participants to a process that was happening around them, rather than being fully empowered and in control. With regard to navigating the NDIS processes, they turned to someone from within their community, not an NDIS employee for help:

> *"Then, I had that artificial leg for eight years, maybe. And then, 2008 I don't feel like using the artificial leg anymore. Yeah. I had to send it back to town and – and that – and, now I start – I didn't know about NDIS. I didn't know about it. Only in 2015 I know about NDIS. When I was walking around no – with the crutches now, for that many years. And, 2015, I got myself a new scooter now and I've got the scooter back home there. Yeah. About – about 2015. Then I – then I know – I realise – they told me about NDIS and that they help me out with – I get that new scooter. I didn't know – I didn't know about NDIS that many – that many years. Only 2015 and now. I didn't know – they told me – someone from NDIS want to see you. I'm thinking, who? I don't even know NDIS. This was 2015, I know NDIS.*
>
> *...Sometimes I go next door here. I talk to [a male community worker]."*

Another participant had said that she had had a planning meeting in relation to her two sons. She had said that she had just attended a community organisation's information session, and that was helpful:

> *"Where I'm – yeah. Yeah. I'm in a good place right now and I just want to move forward and hopefully get everything I can out of the NDIS. That's going to be helpful for myself and the boys. But, mainly for them. I want them to live life like everyone else.*
>
> *I've had I've had my plan done and, yeah. I have to hear – I'm – I'm thinking about, oh my god, I want a review ASAP. There's some things I want to change already in there. Just learnt some stuff that I can – oh, I didn't know I can do that."*

Some participants reported extended time lapses between initial planning meetings and further communications from the NDIS, leaving them wondering what was going on with their case. One participant with a mobility impairment needing a wheelchair reported long delays in responding to modifications to her unit "not physically made for disability people but 'elderlies'" to make it more accessible. An Elder from a regional centre also said that they had had a meeting with the NDIS and asked for a new wheelchair. She was promised this, although she had not heard anything further in the month since the meeting had taken place.

Communications with local Aboriginal people are hit and miss. When one Elder was asked whether the NDIS people she had dealt with acknowledged and respected her role as Elder in the community, she replied "yes". Within the same place, another Elder was asked about disability support in the region, to which he replied "Nothing". When pressed on whether the NDIS had come to speak with him, he said, "No, they don't even speak to me. This the first time we have you mob here – [to talk disability]" (with reference to the FPDN community engagement team and researchers).

One Elder from a remote area in Central Australia said that there were people in their community who have received packages, some valued upwards of $50,000, which they can't spend because there aren't any services in the community.

7.2 ELDERS' VOICES ON THE NDIS

Speaking on behalf of their communities, the participants at the Elders' Forum spoke more directly to their concerns about the implications of the roll-out of the NDIS in Aboriginal and Torres Strait Islander communities. At the heart of their narrative is a deep suspicion that the NDIS is yet another government stratagem that will only serve to undermine self-determining capacities within their communities.

It is not just the further infringements of self-determining capacity that concerns the Elders. They cited examples where the application of the market-based model of the NDIS is inconsiderate of the social circumstances of Aboriginal and Torres Strait Islander people with disability. These considerations do not include cultural ways of doing business, but also go to an understanding of the core living conditions that exist in some Aboriginal communities. As one example, an Elder from one remote community spoke of an absurd situation where people have been approved for substantial packages from the NDIS, but are starving and homeless. One Elder from a remote area in Central Australia said that there were people in their community who have received packages, some valued upwards of $50,000, which they can't spend because there aren't any services in the community. But the families are going hungry, and need shelter, but they can't buy food and blankets because food and blankets are not seen as 'reasonable and necessary'.

> *"And the other thing that people ask for is really – we call it proper help, and proper help for our families is food – because sometimes we arrive out there, family's got no food, so we need to be able to get food for people, and that's something that the NDIS says is not a reasonable or necessary support. But if you arrive and that family's got no food, that's what you've got to deal with. You can't be talking about that physio that's coming out here in three months' time or – you've got to – it's totally counterintuitive not to respond to what's going on for that family that day..."*
>
> *"Because the other thing [our Elders] pointed out to me is swags and blankets is something that our families ask for all the time, help with making sure that they've got somewhere warm and safe to sleep at night, and that's a really practical thing and we've done that for years. Like, I've been since 2004 providing swags and blankets to families, and now the NDIS is coming and they're saying, 'No', they're saying, 'We don't buy swags and blankets for people. That's' not reasonable or necessary.' But if you've got nowhere to sleep, of course swags and blankets are reasonable and necessary, so we're having – we've been having lots of arguments with NDIA and saying that they need to change the way that they do business. In Aboriginal communities, it's different, and they need to be able to respond to that difference, because otherwise, in five years' time we're all going to be sitting at a table saying, 'The NDIS didn't help much, did it?' and we don't want that. The NDIS is an opportunity and we want to make sure that Aboriginal people can access that opportunity and get the best out of it."*

7.3 IMPLICATIONS

There are barriers to accessing the NDIS which even amongst the Aboriginal and Torres Strategy Islander population can differ markedly. Whilst differing cultural practices are a consideration, the main difference observed during this research was lack of homogeneity in the communication and policy application by the NDIS. Communications on what the NDIS is and how it operates have been shown within this research as hit and miss. This has led to anomalies in accessing the NDIS, where in some regional areas, the difference between inclusion and exclusion could be as little as living one street further away from the town centre.

There is also evidence that the NDIS is being implemented as a transactional process, in which eligibility and supports are determined through a bureaucratic assessment using a dichotomous 'yes' or 'no' criterion. Whilst this may lead to more Aboriginal and Torres Strait Islander people receiving physical supports than they otherwise may have had access to, they are nonetheless being positioned as passive participants in the process, particularly in the absence of a strong and trusted local member of their community who can help them navigate the NDIS system. This could be alternatively described as the NDIS happening *to* Aboriginal and Torres Strait Islander people, which is falling short of the NDIS's promise of empowering people by giving them 'choice and control'.

At the community level, there appears to be some recognition of the status of Elders in communities within the implementation of the NDIS, although this level of recognition is not being received as universal. Elevating and promoting the status of Elders within the disability community is a strength-based pillar for the implementation of the NDIS which has positive benefits in promoting a community-wide version of choice and control. The testimony from Elders on how they have seen their role gradually eroded over time is a reminder that the NDIS is operating in an historical and policy context which has seen a diminution of control by Aboriginal and Torres Strait Islander communities over affairs that affect them, and the erosion of their natural leadership structures.

The interpretation of what is 'reasonable and necessary support' in Aboriginal and Torres Strait Islander communities requires a much deeper interrogation. If people are starving, then food is necessary. If people are homeless, then shelter if necessary. These observations relate to the essential foundations of survival.

The observations emanating from the Elders Forum reiterate that without a basic public health infrastructure, the market-based model of the NDIS cannot operate. There needs to be a reconsideration of the assumptions that do not fit the reality, in order for the NDIS to make any sense for people with disability living in communities affected by poverty and a lack of basic utilities. Secondary implications of chronic hunger and homelessness on the future burden of disability, especially relating to childhood development, are not withstanding, and yet to appear on the NDIA's or other government agencies policy radar.

FUTURE RESEARCH:

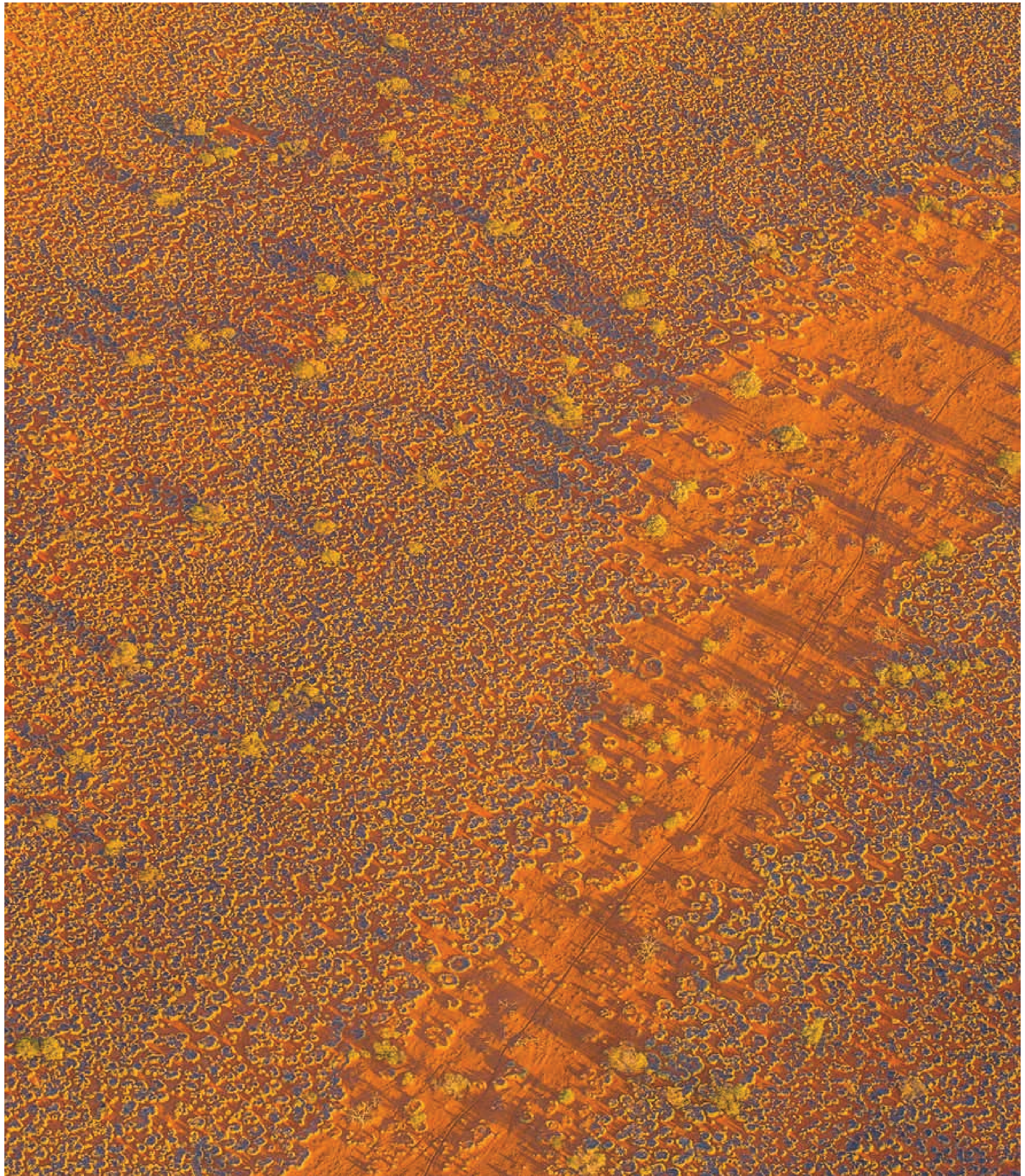
What is the role of Elders as natural leaders of strategies for the greater inclusion of people with disability?

What aspects of a community version of choice and control are vital for personal choice and control to be operationalised in Aboriginal and Torres Strait Islander communities?

How should the concept of 'reasonable and necessary support' be interpreted in an Aboriginal and Torres Strait Islander disability context?

What will be the impact upon the future burden of disability borne by the NDIS attributable to chronic hunger, homelessness and poverty? What early mediation strategies can be put in place to reduce this burden, measured in terms of economic cost and social impact?

There needs to be a reconsideration of the assumptions that do not fit the reality, in order for the NDIS to make any sense for people with disability living in communities affected by poverty and a lack of basic utilities.



8

MENTAL HEALTH AND WELLBEING – TRAUMA AND HEALING

KEY FINDINGS

- Aboriginal and Torres Strait Islander people with disability experience social isolation at far higher rates than other population groups. This manifests in acquired mental health conditions, which occur at five times the rate of Aboriginal and Torres Strait Islander people without disability.
- The high rates of mental health and psychological distress can be explained by the nature of social isolation that Aboriginal and Torres Strait Islander people with disability experience, which is both constant and acute. As people with disability, the daily barriers to their social inclusion (ie. access to transport, housing, education, employment, awkwardness in social interactions with others) are a constant reminder of their social exclusion. As Aboriginal and Torres Strait Islander people, the racial discrimination they experience has a nastiness attached to it, giving acuity to their negative feelings of personal isolation. As people with disability who are also Aboriginal and Torres Strait Islander, they experience constancy and acuity in their social exclusion.
- Exposure to trauma was observed in multiple variations: intergenerational trauma; exposure to acute traumatic experiences; and repeated micro-retraumatisations through constant exposures to various forms of discrimination.

- When trauma is clustered in small tight-knit communities, psychological distress is like a contagious disease. In these situations, individually focussed cognitive behaviour therapies are rendered useless in the absence of strategies that address the community-wide trauma and psychological distress.
- Without looking to attach further labels or stereotypes, testimony on the psychosocial status reflected two distinct cohorts within the participant group:
    - Aboriginal and Torres Strait Islander people with disability living in remote communities spoke of their connectedness to their community as an affirming factor in their psychosocial status, and were less likely to experience symptoms of trauma and distress compared to Aboriginal and Torres Strait Islander people with disability living in metropolitan areas. This is despite having notionally inferior access to and choice of health services
    - Aboriginal and Torres Strait Islander people living in metropolitan areas were more likely experience symptoms of trauma and distress, despite notionally having greater access to health services. This correlated with being separated from relational bonds with their community and Country.

8.1 METRICS OF SOCIAL EXCLUSION AND ISOLATION

Social inclusion is not explicitly defined through the NATSISS data, but there are several indicators that are illustrative of the social inclusion or exclusion of Aboriginal and Torres Strait Islander people with disability. For illustrative purposes, data on the likelihood that they or someone close to them has been removed from family, the likelihood of living alone, have daily contact with family and friends, experience homelessness and have limited or no access to communications via the internet have been includes within the category of social inclusion outcomes. The data on outcomes on social inclusion are presented in Table 8.1.1 below.

Table 8.1.1: Social Inclusion Indicators, Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	Aboriginal and Torres Strait Islander people		
	With severe and profound disability	Without disability	Rate (x times likely)
Live alone	14%	8%	1.8
Daily face to face contact with family or friend	35%	45%	0.8
Homelessness	41%	22%	1.9
Access the internet at home	58%	78%	0.7

In each of the indicators presented, Aboriginal and Torres Strait Islander people with disability experience greater social isolation than Aboriginal and Torres Strait Islander people without disability. Notably, they are almost twice as likely to be have experienced homelessness in the past[112], and 1.8 times more likely to live alone.

Whilst conceivably less of an impact on the quality of life compared to other indicators, internet access at home by only 58% of Aboriginal and Torres Strait Islander people with disability is particularly significant. Many communications strategies for disability services and other social programs hinge on website based mechanisms to promote access, particularly during the start-up stages, but can inadvertently miss large cohorts of the people it is targeting who do not access the primary communication platform used.

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[112] The NATSISS does not measure current rates of homelessness, as it only surveys people living in private households.

8.2 A CENTREPOINT OF SOCIAL AWKWARDNESS

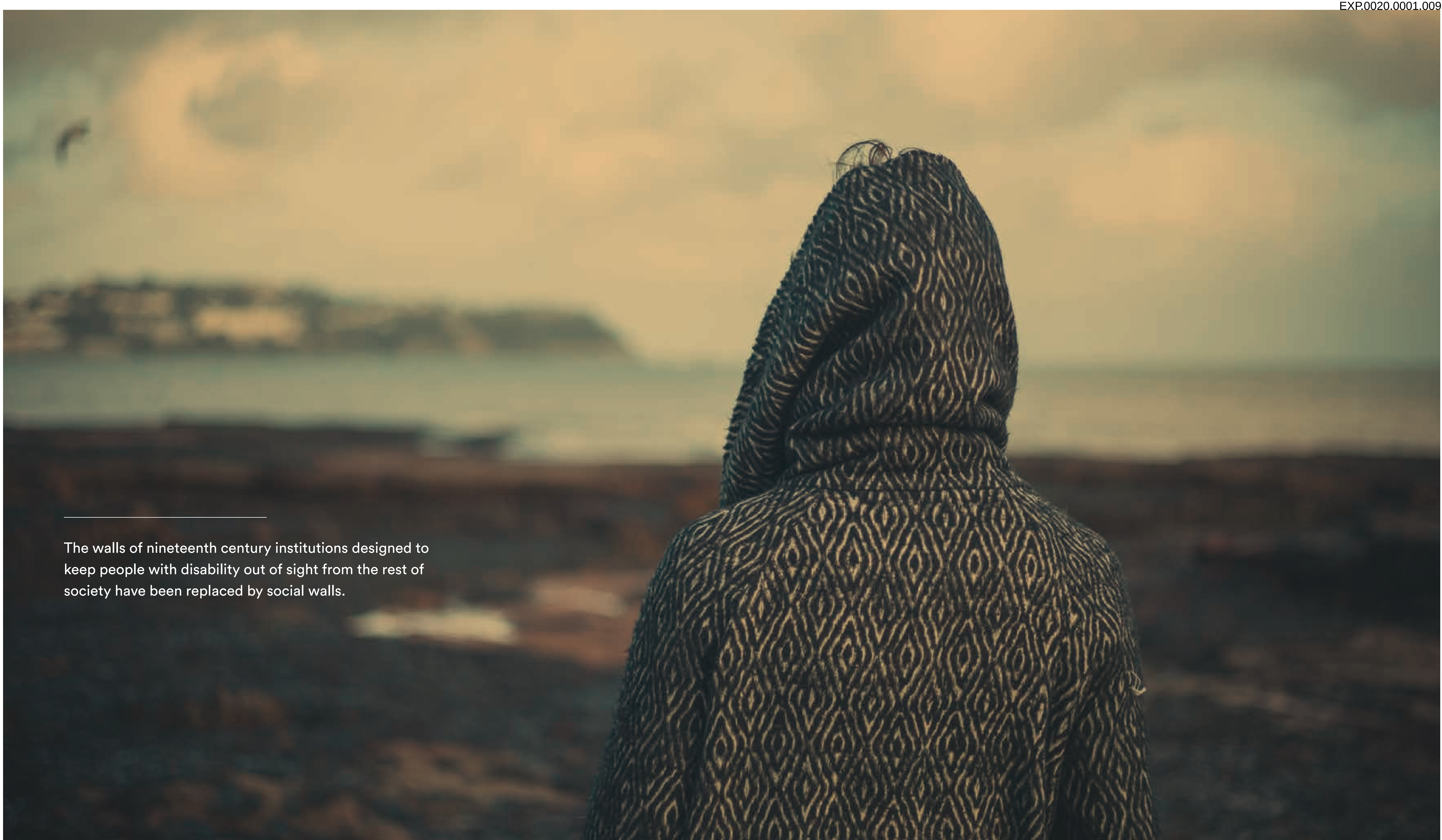
People with disability face constant reminders in their daily lives of their social isolation. From the moment they wake up, they encounter environmental and physical barriers to their active participation in society, as documented in Chapter 6.2 on inclusive communities.

In addition to the physical and environmental barriers, there is a social awkwardness talking about disability, and people with disability become the centrepoint of this social awkwardness. This was evident in the testimonies from many of the participants in describing how they interacted socially with other people, citing everyday conversations where people ignored them and talked to their companions, seemingly because they were uncomfortable talking directly to the person with disability. The social awkwardness of others around people with disability was evident in professional settings, with specific examples provided when doctors and employment agents spoke to a person accompanying a person with disability rather than addressing the person directly. This was also evident in social settings, as described by a wheelchair user who commented that people felt uncomfortable talking directly with him:

> *"But – and, in general public as well, you know? Because, I get people, sometimes when I'm with my wife, like they won't even talk to me. Like, that might be in a restaurant or another setting, because sometimes they'll get the idea that mentally I don't have the capacity."*

The social awkwardness points to a positioning of people with disability within society, which some disability scholars, as referred to in Chapter 1 call 'othering', is a constant for people with disability. The walls of nineteenth century institutions designed to keep people with disability out of sight from the rest of society have been replaced by social walls. People with disability might be physically present, but not valued as equal participant in social functioning. The sadness and frustration that the constant isolation causes people with disability is summarised by one young female participant, who at the conclusion of her interview said:

> *"I just want to be normal."*



The walls of nineteenth century institutions designed to keep people with disability out of sight from the rest of society have been replaced by social walls.

8.3 VARIANTS OF TRAUMA

Whilst social isolation through 'othering' is essentially a disability story, the nature of trauma experienced is unique to Aboriginal and Torres Strait Islander people.

Exposure to trauma presented itself in various ways in the participants' testimony. First, there were citations that could be classified as intergenerational trauma, in which the historical hurt that has been inflicted on Aboriginal and Torres Strait Islander people has been passed down to subsequent generations. Second is personal exposure to traumatic events. Third are micro-retraumatisations, in which exposure to everyday discrimination triggers negative thoughts.

Intergenerational trauma is the historical legacy in a person's narration of their own contemporary history. The two unresolved traumas, both associated with colonisation, and very current, which continue to loom large in the lives of Aboriginal and Torres Strait Islander people are the threats of incarceration and death in police custody, and the Stolen Generations and removal of children from their families by the State.

> *"That's straight out because he's Aboriginal and because the police are taking the law into their own hands here. The police hung someone here before. The police killed a black person, they hung him in jail here. Not only that, there was other unexplained deaths here."*

> *"I'm very proud of my great-grandmother. She was a part of the Stolen Generation, and she [has severe mental heath issues]".*

> *"You know, we've had bad experiences with the Stolen Generation where – you know, the white Australians came in and they took all our children and they took them to the Mission and that's where my uncle was from. And, I remember once – you know, with the stolen generations one of my uncles had disappeared and I remember all the families being really upset during that time."*

> *"Like, and I've always gained, like, my confidence from, like, because my grandfather from the Stolen Generation and you know, he – the hardships that he went through when he grew up."*

> *"I did not know I was an Aboriginal descendant until I was 24. My dad was nearly a Stolen Generation. His mum died after their last sibling was born.... So, that was really, really scary when Dad told me. So, they tried to be as white as they possibly could."*

> *"So, basically, how to do I start? So, I'll start with my mum, 'cause it sort of stems from there. So, my mum was part of the Stolen Generation. And, she spent, from the age of four until she was 18 in the homes. So, growing up with my mum, sort of, impacted me, as a person."*

The second variant of trauma that was evident through the interviews is a personal exposure to traumatic events. As Chapter 6.3 highlighted, there is an extraordinarily high personal exposure to traumatic episodes amongst the participant group. More than one in five of the participants referenced a personally traumatic event in their life, which included people close to them being murdered; the unexplained death of a child; sexual assaults; and being subject to violent assaults with a weapon.

The ever-present threat of child removal provides a nexus between the intergenerational traumas of the past and the traumatic events of the present. One participant provided a detailed and frank account of raising two sons with autism and intellectual disability as a single mother. The pathway of this testimony incorporated the range of aspects previously mentioned in relation to social isolation that she encountered as a carer of two young men with disability: from communication barriers her boys experienced in their education; avoidance of public transport; trouble in getting suitable accommodation; inappropriate schooling; experiences of her sons' fear of going to the doctor, or getting their hair cut; to wheelchair inaccessible housing. This has manifested into mental health issues of her own, with periodic treatments in a rehabilitation facility. The escalation of her own distress, and in the telling of her testimony, came when the state based community services agency arrived without notice to remove her children from her care. She spoke of being "so frightened" and "they just intimidated me and I was just frightened and I just – I didn't know what my rights were really." Summarising her emotional response to the removal of her children from her care, and her subsequent interactions with the state government agency, she said:

> *"Basically, because they were taking the kids away. And then – so, that happened which was very traumatic. Yeah. It was like someone had – it was like my boys had died."*

Statistically, there is an intersectional effect in the incidence of traumatic event that Aboriginal and Torres Strait Islander people are exposed to. They are fifty percent more likely to have been removed or had a close family member removed from their family, or death of relative or close friend; and twice as likely to have experienced a serious health issue.

Table 8.3.1: Trauma Exposure Indicators,
Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	**Aboriginal and Torres Strait Islander people**		
	With severe and profound disability	Without disability	Rate (x times likely)
Removed and/or family member removed from family	50%	37%	1.4
Death of family member or close friend	37%	25%	1.5
Serious illness	26%	8%	3.3

The chapter on intersectional discrimination noted the high frequency with which Aboriginal and Torres Strait Islander people were exposed to various forms of discrimination in their everyday life. In one example, a young Aboriginal man described being racially abused on his walks home from the town centre. Others spoke of being asked to leave shopping centres and eating places. These everyday incidents of racism and ableism, happening as frequently as they do, act as a succession of micro re-traumatisations, which accumulate and keep people in a state of despondency.

How people spoke of being isolated because they were Aboriginal and Torres Strait Islander person differed to how they spoke of being isolated as a person with disability. As a person with disability, they spoke of being ignored, as if their existence did not matter. As an Aboriginal and Torres Strait Islander person, they were recognised, but in being so were subject to intense racial vilification. The disability dimension of isolation is omnipresent, in that it is built into their environment that they could not avoid or escape. Whilst the racial dimension was more episodic, when it arose, it did so with an intensity that was personal. However, for an Aboriginal and Torres Strait Islander person with disability, the disability and Aboriginal and Torres Strait Islander dimensions to their isolation co-exist, hence there is both constancy and acuity to their social isolation.

The ever-present threat of child removal provides a nexus between the intergenerational traumas of the past and the traumatic events of the present.

8.4 THE MANIFESTATION OF PSYCHOLOGICAL DISTRESS

The cumulative effect of discrimination and trauma exposure manifests into various stages of psychological distress, which can be equally or more debilitating than the impact of disability. What disables Aboriginal and Torres Strait Islander people most is not broken ears, broken eyes or broken limbs, it is a broken spirit.

The pattern of intersectionality continues when it comes to mental health outcomes, outlined in Table 4.1. Aboriginal and Torres Strait Islander people with disability are 5.2 times more likely to experience mental health distress compared to Aboriginal and Torres Strait Islander people without disability, and also elevated rates of alcohol and substance misuse.

Table 8.4.1: Mental Health Indicators,
Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	**Aboriginal and Torres Strait Islander people**		
	With severe and profound disability	Without disability	Rate (x times likely)
Mental illness	26%	5%	5.2
Drug related problems	9%	3%	3.0
Alcohol related problems	8%	5%	1.6

The majority of participants reported experiencing trauma or distress, either currently or in the past:

> *"I go through my ups and downs, my phases of depression with it and – but, you don't let it control your life. It's hard. There are days when I – I don't want to face the day. I'll just get up, have my shower and I'm going back to bed."*

In exploring the relationship between community ties and wellbeing, the participant group can be categorised into two distinct cohorts; one cohort are living in remote communities, the other cohort are living in metropolitan areas. For people living in remote areas, the access to health services was relatively low compared to metropolitan areas, so appeared as concentrations of people with physical disability which could be attributed to mismanaged healthcare (eg. clusters of people with amputations attributable to diabetes). However, these group of participants tended to speak more positively about their ties to community and how their community looked after each other. This sentiment is evident in the yarning piece with an elderly man living rough in Chapter 6.6.

For people living in metropolitan areas, access to health services is greater, but this cohort of participants was more likely to report more acute signs of psychological distress. They were also more likely to assert their Aboriginal identity by stating the Aboriginal nation they identified with in their introduction, (whereas people in remote communities were more likely to mention what town or area they were from rather than their Aboriginal nation), display Aboriginal tattoos, or wear clothing which would identify them as Aboriginal. These symbols were portrayed as a source of pride by the participants, and may be reflective of their seeking psychosocial proxies to their Aboriginal heritage to compensate for a lack of direct physical, connection to their home community.

8.5 LIMITATIONS OF CLINICAL MODELS OF MENTAL HEALTH

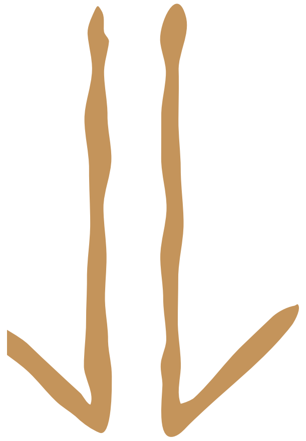
It was rare for participants to use clinical diagnostic terms when describing their mental health status. Despite the high rates of traumatic episodes that the participants were exposed to, only four of the forty-one interviewees used the terms 'depression' or 'anxiety'.

Indeed, clinical models of mental health appear grossly inadequate in describing the prevailing sense of sadness and abandonment. Many people maintained that they were seeing counsellors, "as they are supposed to", but found them ineffective in relating to their experience, both as an Aboriginal and Torres Strait Islander person and as a person with disability:

> *"If that person – psychiatrist was a deaf person, or if they understood me or understood Indigenous people, it might be better. But at the moment I'm trying to work my way back into the Deaf community. I just resigned from work three weeks – a month ago because it was really affecting my mental health. I had anxiety attacks. I ended up in hospital because of anxiety. It became too much for me."*

Others mentioned seeking to compensate for gaps in the clinical model of mental health service provision by sourcing cultural models of healing:

> *"So, on the coast there's an organisation called Cultural Healing. It's an Aboriginal organisation and within that team they have mental health workers. So, I go to them if I need help. But they're not part of the unit? [disability support unit], they're separate."*



8.6 TRAUMA AS AN INFECTIOUS DISEASE

The research also noted the presence of 'trauma clusters', where there were large proportions of people in a small community who displayed signs of trauma. The tight-knit nature of these communities meant that everyone within that community has had some personal or community exposure to trauma.

Scientific literature is inadequate in explaining the overwhelming sense of sadness and abandonment that is felt in communities. Not only was it felt by all of the people within the community, the overwhelming sadness and despondency was also felt by the researchers when visiting those communities. This experience of 'catching trauma' can't be described using the normal vocabulary of a researcher. The most apt description of the personal experience that came with witnessing intense concentrations people affecting by trauma during the research is crossing a boundary line and entering another world.

The vicarious nature of trauma was observed in these small communities as operating more like an infectious disease within a community than a bio-medical condition of an individual. In these cases, daily re-traumatisations are almost guaranteed. In effect, individuals who have experienced personal trauma are in a community engulfed by trauma.

Despite the prevalence of community-wide trauma, and its contagious nature, the interventions that people spoke of were individually focussed psychotherapy. The dominance of cognitive behavioural therapies as a solution to trauma are again an example of personal agency taking the place outside the environment in which the individual exists. The environmental context in which people live renders their individually focussed therapies useless. In this respect, depression and alcohol misuse become trauma suppressants, (as opposed to clinical diagnoses as they might be regarded in a clinical model of mental health). Further, the evidence in this research, both statistical and narrative, suggests that depression and alcohol misuse appear to have greater efficacy as a coping strategy than clinical models of cognitive behavioural therapy.

8.7 EMBERS OF HOPE

Alongside a sense of despondency in many communities, there is a strong narrative of resilience and survival. This presented itself through a variety of emotions, ranging from anger, defiance, and even humour.

There were embers of hope which shined through. The holding of hope was captured by one participant from a community in which there were excessively high rates of trauma, who said:

> *"There is something stronger in here",*
>
> *pointing to his heart,*
>
> *"but I've just got to get there."*

All the communities and the people who participated welcomed the research. People wanted to tell their story. In some places, the participants lined up and waited, some for more than an hour, to share their life experiences through the research. Some of the participants even expressed their gratitude at being able to share their experience.

The response by the Aboriginal and Torres Strait Islander disability community as participant-owners of the research reinforces a process in which 'lived experience' as testimony, being heard and being believed, is critical in the process of healing and transformation. Narrative models of social transformation as used in this research have reach beyond the Aboriginal and Torres Strait Islander disability community, and can be applied more broadly to address vulnerability in other marginalised populations.

Yarning piece

Not ruined by the sadness

The interview is approaching the half hour mark, and with some idle chatter, the discussion is starting to peter out. I look to close out the interview by providing an opportunity to put on the record what she hasn't already spoken about. Then comes a bombshell disclosure.

INTERVIEWER: So, this is your story, and I'm just wondering if there's anything that you wanted to say for the record, that you feel like, you haven't spoken of already. You don't have to say anything, but if there's something that you just kind of go, 'I want to be able to say this', given that we're collecting your story. Is there anything over and above what you've spoken about already?

PARTICIPANT: There is one thing. Like, the main thing that keeps me going is, like, my girlfriend actually committed suicide five months ago.

The revelation and its timing come as a bolt from the blue, as we had already covered so much personal terrain – education, employment, health, transport – during the interview. It has only comes at the last moment when things appeared to be winding up, yet it was sitting there all along. It speaks to the intensely personal nature of suicide and trauma, and how its impact can remain buried, despite feeling that you are in on an open and transparent discussion.

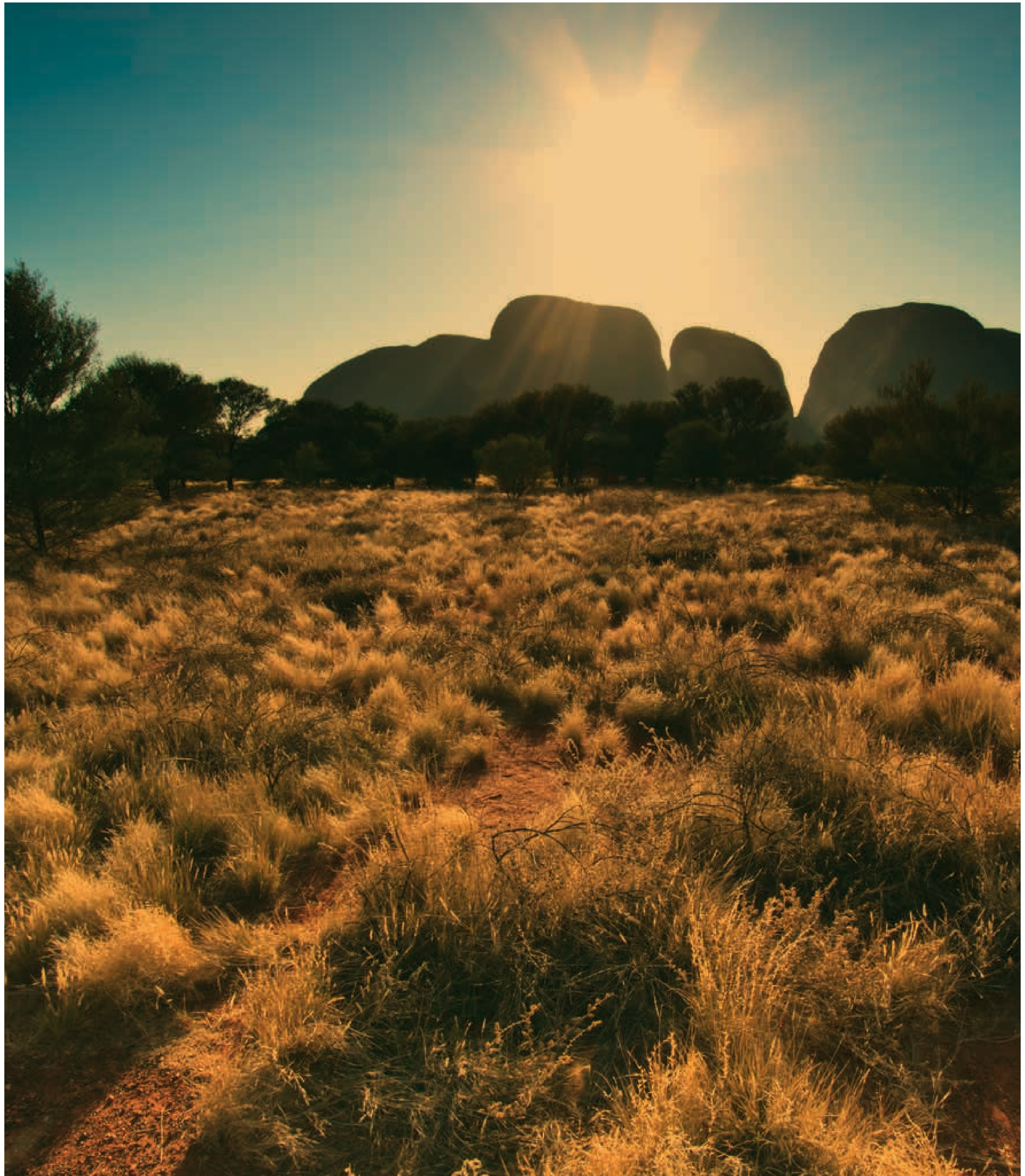
The discussion re-opens again. It's like we start over again.

She reveals the closeness of their relationship, and how it had impacted upon her at a time she was having her own health concerns. I remind her that it's okay for her to stop if it's making her feel uncomfortable talking about it, but she says it is something she wants off her chest.

"It's like there's a lot of stigma around suicide as well and I think, it needs to be talked about a lot more and a lot more people need to be educated about not only suicide, but mental illness and the whole, like, aspect and everything about it as well. And, just the whole treatment needs to be improved, no matter if it's public or private. It all just needs to be improved."

In the face of the personal impact of multi-faceted discrimination and trauma, she has transformed her personal experiences into a source of strength. It is the authenticity of her lived experience of disability and trauma that shines through as a penetrating insight into how resilience is made intrinsic to people with disability. It does not come across as a belligerent 'stuff you' to the world. Instead, it is a desire that her experiences of distress are a beacon to circumvent the unnecessary distress experienced by others. It is representative of a worldview of humanity that I come across in the disability community, time and time again.

"It really did show me that, like, instead of letting it, like, ruin me with sadness, I just really want to use it to change peoples' lives and to motivate me to get my degree, to get out there and to make change happen to improve the system, and to prevent this from happening to other people...It has really inspired me just to continue and just to continue to improve the system and just to keep going and, yeah. Not only for myself, but for her."



9

CULTURE IS INCLUSION: A FIRST PEOPLES CULTURAL MODEL OF DISABILITY

KEY FINDINGS

- Aboriginal and Torres Strait Islander people with disability participate in social activities and events within their community at the same rate as Aboriginal and Torres Strait Islander people without disability.
- The parity in social participation by Aboriginal and Torres Strait Islander people with disability within their communities is the categorical exception to the inequalities that they experience in their interaction with systems and supports outside their community structure.
- Inclusive participation in cultural and community events has a positive impact on social health and wellbeing and moderates the harm of inequalities experienced in daily life.
- This finding is a contemporary expression of a culture of inclusion that has survived despite other disruptive influences upon community functioning.

9.1 PARITY IN CULTURAL AND COMMUNITY PARTICIPATION

Parity in cultural and community participation by Aboriginal and Torres Strait Islander people within their communities is reflected quantitatively through data drawn from the NATSISS, as presented in Table 9.1.1.

For all indicators on cultural and community participation collected by the NATSISS, from general indicators, Aboriginal and Torres Strait Islander people reported participation in cultural and community events, including involvement in ceremony, speaking an Indigenous language, and other cultural activities, at the same rate as other Aboriginal and Torres Strait Islander people. Parity in the participation of cultural and community activities is reflected in the indicators by participation rate of Aboriginal and Torres Strait Islander people with disability which is 1.0 to 1.1 times that of Aboriginal and Torres Strait Islander people without disability.

Table 9.1.1: Cultural Inclusion Indicators,
Aboriginal and Torres Strait Islander people – by disability status, NATSISS 2014–15.

INDICATOR	**Aboriginal and Torres Strait Islander people**		
	With severe and profound disability	Without disability	Rate (x times likely)
Participated in cultural activities	62%	65%	1.0
Involved in ceremony	67%	62%	1.1
Identifies with clan, tribal or language group	67%	61%	1.1
Speaks an Indigenous language	20%	19%	1.1

The parity of cultural and social participation by people with disability in Aboriginal and Torres Strait Islander communities is the categorical exception in the data on the inequalities that Aboriginal and Torres Strait Islander people with disability experience with respect to their access to ‘mainstream’ services, such as access to disability services, healthcare, employment and education referred to in Chapter 6. As a population wide result, Aboriginal and Torres Strait Islander people with disability experience social inclusion within their community structures, but regress towards social isolation upon leaving the protective forces of their community structures and start interacting with systems outside.

9.2 NARRATIVES FROM A LIFE OF CULTURAL INCLUSION

A longing for traditional Aboriginal and Torres Strait Islander cultures seeped through into the narratives.

For some, cultural longing took a form of reminiscing the 'good old days' when traditional cultural values dominated social life:

> *"Sharing and caring was with our people before white people came to this country. Responsibility was with the family and the community."*

For others, the reminiscence was far more personal, recalling days when they could do things that they physically could no longer do, but had managed to maintain a spiritual connection with cultural life, just by being there. One of the participants, an Aboriginal woman using a wheelchair, spoke of her younger days when she was a hunter-gatherer for her family:

> *"Hunting. Camping out. Hunting. Always. Then we lived and we raised – I raised my first son so we didn't go out – we did go out just for a day, come back, go out the next day, go and get bush turtles. Go at night time shooting kangaroo."*

Nowadays, her mobility impairment means that she doesn't get into the thick of the hunting, and that role has now has passed to her husband, (who, by her account, isn't as good at sourcing traditional foods as she was, so sometimes they just have to go to the shop and buy things). However, she maintains a spiritual and emotional connection to the traditional life, which is one of inclusion:

> *"We go hunting together. He goes out, I sit in the car and wait when he goes out hunting."*

The operative pronoun in this narrative is the use of the collective 'we', not the singular 'he'. "*We* go hunting". Despite not being the one who physically throws the spear, she is emotionally and spiritually connected to the activity. She is included.

Art has a particularly special place in cultural life of people with disability as a facilitator of their inclusion. In some cases, art was presented as a means of communicating between generations, and between Deaf people and the hearing world:

> *"[My grandmother], she used to teach me a lot of things. You know, she taught me all about Aboriginal art, and she didn't know how to sign, and I didn't know how to communicate with her, but I've become very successful with my Aboriginal art, so I'm really proud of my grandmother."* [113]

The affirming properties of art as 'story-telling' emerged as people spoke of their art as a way that they could personally connect with their own personal Aboriginal and Torres Strait Islander heritage:

> *"I've worked in disability for the last ten years specifically with Indigenous disabilities. So, about eight years ago I started painting. And, I'd always liked painting but, kept saying to my partner at the time, I've got these paintings in my head I want to start doing some stuff.... For my 50th birthday she bought me a canvas and paints and said, "Look, stop talking about it, just do it." And, that totally had a whole new chapter in my life with the art. [I gravitated to] the dot style painting. Traditional stuff. Telling stories."* [114]

Others had extended their personal connection with culture through art by promoting it as a medium to connect to others and to their community and culture:

> *"So, some of the good stuff I'm doing now is part of [an Aboriginal] Art Group, that Uncle runs. So, it's an art group for people with disabilities. So, I've done a lot of, like, paintings and stuff that have gone on exhibition so that, sort of, keeps me strong. Because I like my art and I look forward to doing it. I find it really helps with stress."*[115]

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[113] TR5
[114] TR26
[115] TR28

“Sharing and caring was with our people before white people came to this country. Responsibility was with the family and the community.”

There is a risk of over-romanticising the culture of inclusion, as it is not perfect. A small number of cases emerged, particularly within the Deadly Deaf Mob, where their aspirations for cultural inclusion had not been realised. One Deaf Aboriginal person spoke of wanting to participate in the local Land Council, but had been denied access to an Auslan interpreter, with funding constraints cited as the reason. His self-advocacy for his right to participant came as a shock to them "because they'd never heard about people with disabilities wanting to be involved", but through persistence he is now a member and an active participant.

> *"But, the issue I have is the communication and sometimes they do struggle with the fact that I'm a deaf person. I would like to have an interpreter turn up to NAIDOC week. Maybe we could have a deaf organisation represented at NAIDOC week because it represents all the deaf Aboriginals."*

This experience serves as a point of reflection for Aboriginal organisations who are the service providers, representative bodies and advocates for Aboriginal and Torres Strait Islander people, that they remain grounded in the culturally inclusive traditions that are innate in the social life of communities. There is a temptation for Aboriginal organisations to mimic the non-inclusive systems and structures they are required to interface with, but cultural authenticity will come through, grounded in the traditions of inclusiveness.

9.3 A FIRST PEOPLES CULTURAL MODEL OF DISABILITY AND INCLUSION

The narrative opens up the prospect of culture as an affirming and inclusive force in the health and wellbeing of First Peoples with disability.

The metaphysical dimension of cultural inclusion upon wellbeing is unintelligible to orthodox science, which is not yet able to observe or explain how it works as a phenomenon. However, the presence of culture is real and it is there in the narratives. Narratives such as "we go hunting together" all point to a higher conceptualisation of social participation, one that is over and above the physical undertaking of a particular function or activity, albeit one in which western scientific thought does not yet have the capacity to explain. It is a phenomenon which happens innately in Aboriginal and Torres Strait Islander communities, and for an Aboriginal and Torres Strait Islander person, it is logical and rational, and the evidence shows it to be as effective as any other disability aid that the disability support system has to offer.

Rather than being rebuked for its unknown, abstract qualities, divining the metaphysical properties of culture into a practice and policy model of support for people with disability presents something of a new frontier of scientific enquiry. It may take ten, twenty or even one hundred years to understand the phenomena of culture using the language of western science. It may also be that we are never meant to know. But in looking at the current state of the evidence, connecting people with their First Peoples culture is most likely to rapidly improve their quality of life.

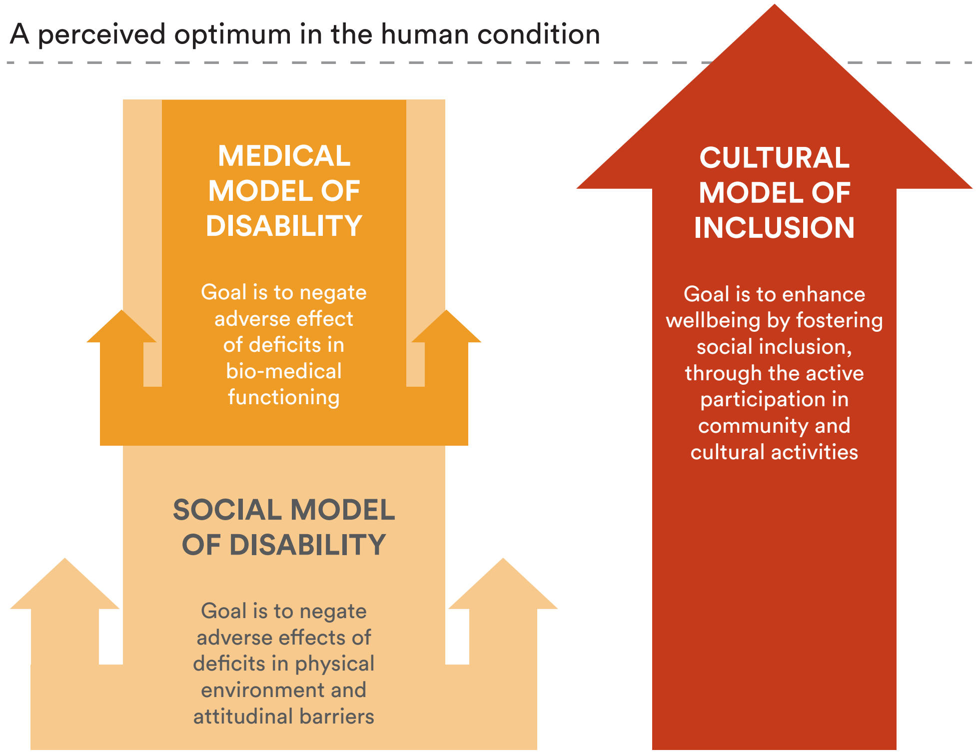
Aboriginal and Torres Strait Islander people with disability will still walk in 'two worlds', their Aboriginal and non-Aboriginal world. The numbers and the narratives presented in earlier chapters show that on balance Aboriginal and Torres Strait Islander people with disability experience the worst of both worlds, in that their cultural normalising of disability means they do not access services at the level they need, yet they still suffer from the ill effect of negative stereotyping, labelling and discrimination. Aboriginal and Torres Strait Islander people with disability face a conundrum in trying to improve their position – in order to access the services they need in a non-cultural model, they effectively have to disable themselves, a concept that is antithetical to their core cultural beliefs.

The therapeutic potential of a cultural model of inclusion is illustrated by contrasting it to other interpretive models of disability, namely the medical model and the social model of disability, mentioned in Chapter 2. Both the medical and social models frame disability as a deficit against a perceived optimum human condition. As an interpretive model, the medical model presents disability as a deficit in bio-medical condition. The medical model of disability aims to mitigate the adverse bio-medical impact of what is perceived as a negative cognition, and the utopian end-point is cure. As an interpretive model, the social model of disability presents the deficit in terms of the environment, which may be either the built environment (eg. housing, footpaths in remote communities) and/or the social environment (eg. attitudes barriers, stigmas and discrimination). As an interpretive model, the goal of the social model is to overcome the defects in the environment, and its utopian end-point is to accommodate people within a fully inclusive community in which negativity in the environment does not exist.

To reiterate, in both the medical and social models of disability, the goal is to reduce the impact of a perceived negativity against a perceived optimum.

A First Peoples cultural model presents a philosophically different approach based on the premise that there is 'no world for disability', hence negativity is not observed. In this respect the utopian end-point of the medical and social models of disability – cure and accommodate – is the starting point of an Indigenous cultural model of inclusion. By contrast, the First Peoples model is the only model that seeks to improve the human condition through positive affirmation, as distinct to merely negating the adverse impact of difference. The affirmative philosophy of a First Peoples cultural model of inclusion, and how it can co-exist with medical and social models of disability, is illustrated in Figure 9.3.1 below:

Figure 9.3.1: Comparative philosophies of medical and social models of disability and a First Peoples cultural model of inclusion.



As stated early in the chapter, the status of the research is not sufficiently advanced to be prescriptive on how this translates into policy and practice. Instead, a model of cultural inclusion is presented as a vision and direction for a future Aboriginal and Torres Strait Islander disability research agenda.

10

A FIRST PEOPLES DISABILITY RESEARCH AGENDA

Establishing a cultural model of inclusion sets a positive direction for advancing the health and wellbeing of Aboriginal and Torres Strait Islander people within a research, policy and practice development agenda.

There are steps to get there. As extensive as the issues covered in this report have been, it is a synoptic overview and further depth in the knowledge base is needed. Issues such as the social and cultural foundations of inclusion, and the impact of colonisation from a disability perspective, have only been touched on in the opening chapter. Chapter 4 provided an initial screening of the data to establish baseline prevalence and profile of Aboriginal and Torres Strait Islander disability, but the data is rich and further iterations and analysis will bring greater insights.

Chapters 5 and 6 showed how Aboriginal and Torres Strait Islander people suffer greatly from the effects of multiple forms of discrimination, both in people's attitudes and in the systems that provide support to them. Much of the discussion has focused on the detrimental impact of institutionalised bias and discrimination. Exposing the harm that Aboriginal and Torres Strait Islander people with disability are exposed to is only an initial step in elevating awareness of bias from the unconscious to the conscious. The next step is a collective focus from researchers, public service agencies and practitioners on reform of delivery systems to stem the flow of harm.

The other area of research development is continuing a First Peoples disability research philosophy. This is the work program on the community-led research processes which underpin each of the thematic research areas. Community-directed research is an emerging area in social policy research, and the participatory method utilised for this research sets a precedent for continued innovation in community-based research. As a model of research, it could conceivably be exported into a project involving other marginalised groups within Australian society, and taking an international perspective, other Indigenous peoples worldwide.

There are four research streams proposed to set the direction for future First Peoples disability research.

Stream 1:

The Cultural Foundations of Inclusion

This research provides a snapshot of the contemporary narrative from Aboriginal and Torres Strait Islander people with disability, but the historical narratives are still unaccounted for. The introductory chapters only provide a fleeting reference to the cultural and social context of Aboriginal and Torres Strait Islander disability and serve as a pointer to a fields of further inquiry, such as the cultural dimension of inclusion and a disability perspective of colonisation.

This research has avoided using scholarly theories of colonisation as this is not the language that the participants used. However, looking forward, critical theories of colonisation theory can be used to segment this stream into three perspectives:

- **Pre-colonial perspectives:** This perspective entails a further understanding of how disability and diversity has evolved within Aboriginal and Torres Strait communities, including nuanced variations amongst Aboriginal and Torres Strait Islander cultures, from the time of the one-legged Mungo man until colonisation.
- **Post-colonial perspective:** This perspective entails a further exposition of the legacies of colonisation, how the importation of a western model of disability has pejoratively affected Aboriginal and Torres Strait Islander people, and the collision in the histories of the incarceration of Aboriginal and Torres Strait Islander people and the institutionalisation of people with disability.
- **Neo-colonial perspectives:** this perspective is a future focused perspective of how Aboriginal and Torres Strait Islander peoples with disability can be empowered as a minority in a post-colonial nation, encompassing questions such as; What does reconciliation, treaty and restitution means for a people with disability as a marginalised group within a broader marginalised population?; and How do political strategies for empowerment interface with wellness and healing approaches to empowerment?

Stream 2:

Mitigating Systemic Harm

Chapters 5 and 6 revealed a consistent pattern of discrimination within the support system and consistent and acute forms of discrimination and inequality that Aboriginal and Torres Strait Islander people with disability report experiencing. In summary, to positively progress the quality of life for Aboriginal and Torres Strait Islander people, strategies need to be developed to mitigate the harm that they are currently exposed to.

Exposing the discrimination and its institutional nature has been a key outcome of this research. One of the defences of institutionalised discrimination is unconscious bias, or 'I did not know'. This research has elevated awareness on the incidence and nature of discrimination from the unconscious to the conscious. So now you know.

The next steps in the research stream are how to dismantle the discrimination within the system. This will require collaboration and critical reflection with those who run the systems. The Australian Government's Plan to Improve Outcomes for Aboriginal and Torres Strait Islander people with disability provides a structure for this, and the future focussed studies building upon this research can be organised accordingly:

Inclusive communities	**Justice**	**Education**	**Economic security and employment**	**Health**

Whilst this research has extensively discussed racism and ableism as forms of discrimination, these two forces alone appear to fall short in explaining why there has been so little systemic reform responding to the substantial evidence of unequal access. If it is accepted on face value that there is a critical mass of people working within the system who as individuals are well-meaning and capable, then this leaves the question: why is it that so many well-meaning and capable people are unable to change an inherently racist and ableist system?

This reflection points to a potential third category of bias over and above considerations of racism and ableism – the "too hard basket". There is support for this hypothesis coming from recently released neuroscience research, which shows the perception of difficulty in performing a task has as much impact upon cognitive bias as the actual difficulty of performing a task.[116] In other words, just thinking something is too hard to begin with is enough to avoid action, even if the action is not actually as hard as it looks. Working within siloed systems of support, ill-equipped to deal with complexity, the issues within this report may appear imponderable. Further research is needed in how to undertake meaningful reform of complex systems that is sensitive to issues of intersectionality. There are two suggested aims for this research focus:

- to untangle the unnecessary complexity in the inter-connectivity of disability support systems; and
- to directly address the subconscious perception of complexity in the administration of social programs, where it does not exist.

In solving these problems, the community-directed methods used in this research can make a different type of contribution to research activity. This research has positioned the First Peoples disability community as unique holders of 'insider' knowledge on their own lived experience. This is a position that can be transposed to providers of an independent 'outsider' perspective in research that critiques the support systems which they do not run, but are served by.

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116 Hugura N., Haggard P., Diedrichsen J., (2017) 'Perceptual decisions are biased by the cost to act' eLife 2017;6:e18422.

Stream 3: A cultural model of inclusion for policy and practice

This stream of research involves the translation into policy frameworks and practice models. This stream of research closely aligns to stream 4 of the research agenda, which is the ongoing infusion of a First Peoples disability research methodology in the development of practice standards and protocols.

The size and scale of the implementation of the National Disability Insurance Scheme in Aboriginal and Torres Strait Islander communities is enough to warrant its own line in a research agenda.

Whilst this research project was not designed as an evaluation of the NDIS, it nonetheless provides baseline data on issues requiring closer scrutiny in future evaluations. It has also unearthed a number of significant limitations to its establishment design principles, particularly around what constitutes 'reasonable and necessary support' in regard to the social circumstances of Aboriginal and Torres Strait Islander people with disability. It also noted that there is no apparent attention to avoidable costs within the research, and what early interventions are required to relieve future cost burdens upon the Scheme that will otherwise be inherited through failings in systems that are antecedent pathways to the NDIS.

The chapter on inclusive communities showed that access to technology in the provision of fit-for-purpose disability aids is particularly poor in remote Aboriginal and Torres Strait Islander communities, who are currently reliant on work-arounds which mask failings in support systems. Increased use of technology, particularly when driven by Aboriginal and Torres Strait Islander people's cultural knowledge, provides exciting potential for innovation research with rapid advancements in social impact.

Finally, the continued development of an Aboriginal and Torres Strait Islander disability information strategy, which is commensurate with the size of the sector, runs parallel to policy practice development. This project has shown how putting data in the hands of community is a form of empowerment which can drive social change. Beyond the transformative power of data and knowledge from a social perceptive, it serves a practical function in providing the tools for business planning and risk management to support the economic development of a sector in growth.

Stream 4: First Peoples disability research methodology

This research has redefined what grounded research looks like in practice, when led by community. Its legacy is a First Peoples disability research philosophy, underpinned by ethical principles for research in marginalised and traumatised populations, respectful of community protocols, and capable of delivering research outcomes.

There is an increasing desire coming from within the research community to become involved in research with populations that experience vulnerability, but there is not a lot of knowledge that exists on how to do it safely and respectfully. Within the published academic literature, community based research methodologies are sparse.

There is a sense that aspects of the First Peoples disability research philosophy can be replicated, but the organic pathways that this project took will need to be critiqued and refined to assess how and in what circumstances this can be transported into research methods involving other marginalised groups.

The four streams proposed for the First Peoples disability research agenda are presented in the attached diagram.

Elevating a vision of culturally-led inclusion

Whilst there was a research brief to be met, the underlying motive for this study was always about elevating and promoting the voices of Aboriginal and Torres Strait Islander people with disability. In pursuing this research agenda, it is important not to lose sight of the vision and aspirations expressed by Aboriginal and/or Torres Strait Islander people with disability, which is for a life in which they can freely embrace their Aboriginal and/or Torres Strait Islander identity and/or their disability identity as they so choose, strengthened by family, culture and community. It is a vision for the best of two worlds, one which provides access to support they need, but without the labels.

Keeping with the spirit of this document as a narrative owned and told by the First Peoples disability community, a final word on this vision goes to one of the participants of the research:

> *"Look, I'm very proud because I've got two identities of who I am. And I want to say thanks to Mum for moving to the city to give me a better education. And, thanks to my dad for, you know, making me who I am today. So – and the positive and being, you know – my life experience of the main culture and the cultural changes that I've experienced... I've learned to accept diversity, you know, of all different communities. I've learned to accept that. And, the positive... to what I've achieved to now is because of my parents. If it wasn't for my parents – I've got a good job now. I've got good qualifications. And, I've got a beautiful family. And, what more can I have? That's why I'm happy."*

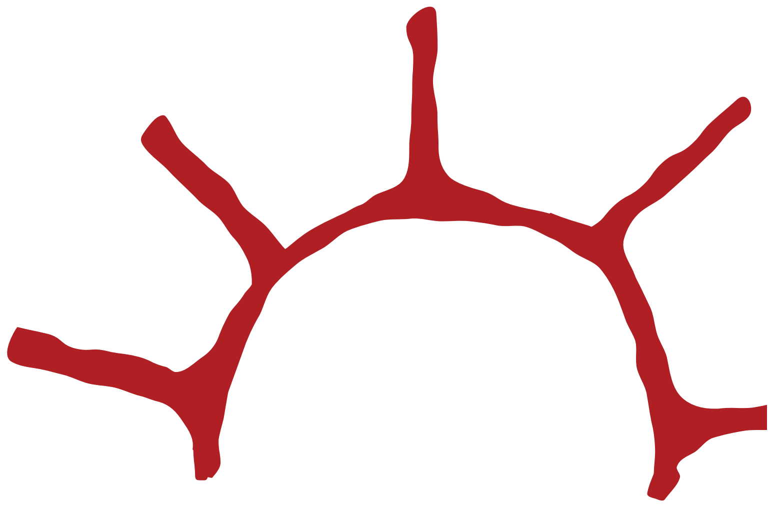


Figure 10.1 A First Peoples Disability Research Agenda

THE SPIRIT FORCE DRIVING CULTURAL INCLUSION RESEARCH:

To elevate and promote the voices of Indigenous people with disability within research and its translation into policy and practice.

CULTURAL FOUNDATIONS OF INCLUSION

(Conceptual framing)

Precolonial: Cultural traditions of diversity and inclusion (the one-legged Mungo man)

Postcolonial: Historical impact of colonisation on the institutionalised exclusion of Aboriginal and Torres Strait Islander people with disability

Neo-colonial: Restitution and re-animation though healing

MINIMISING SYSTEMIC HARM

(Problem exposition and isolation)

Addressing intersectional inequality in systems which support people with disability

Apprehended discrimination and the restitution of trust

Public discourses and stigmatisation

System complexity and connectivity

CULTURE IS INCLUSION: MODELS OF POLICY AND PRACTICE

(Problem solving and transformation)

Narrative based disability support programs and protocols

The implementation of the NDIS in Aboriginal and Torres Strait Islander communities

Technology driving social change

Data driving social transformation – performance frameworks and Aboriginal and Torres Strait Islander disability informatics

RESEARCH THAT:

Is grounded in community as ‘participant owners’ of the research

Addressees ‘intersectionality’ in the unique experiences Aboriginal and Torres Strait Islander people with disability

Advances the rights of inclusion for all

Is sensitive to experiences of discrimination and trauma

Meets international standards of ethical conduct and research quality

Honours our Elders, history, traditions and customs

EPILOGUE

A prospectus for community-directed service development

As an exploratory study, this research has laid out a business case to address the specific needs of Aboriginal and Torres Strait Islander people with disability. The issues have been laid bare with honesty by Aboriginal and Torres Strait Islander people with disability themselves.

It is also a prospectus for doing business the way of the First Peoples Disability community. The First Peoples disability community members are the custodians of this research and are therefore the rights-holders for commercialising this research through its translation into policies and services.

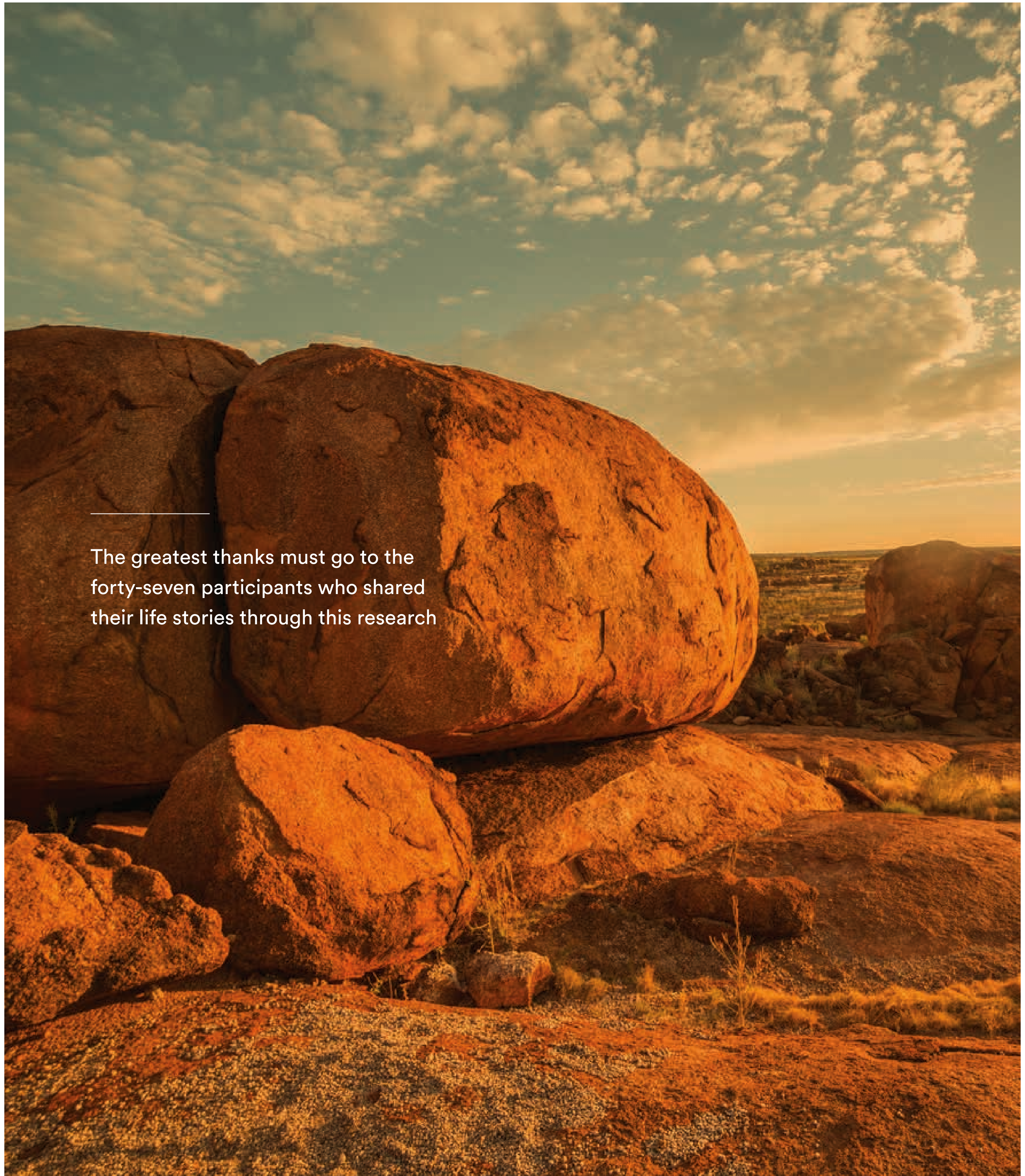
The models of co-production and collaboration used in this research are now established. The next step of the research is to translate these concepts and models into sustainable community-directed services and practice.

A culture of inclusion is a way of life for all

One of the things that has stayed with me over the past two years is how the research has brought people together, enabled their participation and assembled a bigger picture. I can vividly recall many times when people were lining up, keen to tell their story. I'm sure that part of this was because they wanted someone to hear – and believe - their story, but for others my sense is it was because they were lonely and wanted someone to talk to. But, that is a reflective paper for another day.

There is a bigger message that comes from the research, beyond what to do next. It is about the power of research to build communities. It is when we come together and stick together, we can get things done that have a sense of purpose. It is when people are isolated and go it alone that they find themselves struggling.

So, with a culture of inclusion comes a message that connects the people that make up the First Peoples disability community, and also reaches out to others. The message of inclusion is: You are not alone. You are our community, and we are yours. If we can come together and stick together, then nothing can divide us.



The greatest thanks must go to the forty-seven participants who shared their life stories through this research

ACKNOWLEDGEMENTS

Firstly, I pay respect to the Elders past, present and future, of the many Aboriginal nations that I have visited while undertaking this research. I also acknowledge the nations of those who have been part of this research, either as participants, helpers or cheer squad.

There's a saying that it takes a village to raise a child, and that is very much the case for this book. I had had a great privilege to work on this book from the First Peoples Disability Network. It is a truly uplifting experience to be part of a community organisation that fights the good fight day in, day out. Everyone I have met through First Peoples Disability Network carries themselves with grace, humour and tenacity, and it is this character I've consciously tried to recreate when writing for this this book. To Damian, June, Paul, Lisa, Sara, Lai Ha, Aunty Gayle, Aunty Kay, Aunty Maureen, Uncle Lester, Jake, Mel, Donna, Michelle, Ben, Mikayla Sereako, Dianne and an ever growing First Peoples disability community - you made this book come to life, and its story belongs with you. A special thanks to Lisa Hindman and Sara Irvine for your dedication in getting this book to print.

Thank you also to our designers Tracy James and Fleur Feller for amazing me with the way you have brought the words to life with your creative and beautiful imagery.

I am fortunate to work with some of the most open-minded and creative researchers within the academy. Our Academic Advisory Panel began with Professor Joanne Travaglia, Dr Megan Williams and Professor Melissa Haswell, who were soon joined by Professor Leanne Dowse and Dr Ruth McCausland, along with Dr Deborah Debono, who I regard as an honorary member of the Academic Advisory Panel. You have all pushed us to make this research as good as it possibly could be, while allowing the members of the First Peoples disability community to speak for themselves.

This also could not have been possible without the generous advice and support from my friends and colleagues at the Australian Bureau of Statistics. With special thanks to wonderful people at Centre of Excellence for Aboriginal and Torres Strait Islander Statistics, and Disability, Ageing, Carers and Mental Health Section, you have set the bar in showing our organisation respect.

It is also not possible to do a research of this scope on goodwill alone. I'm grateful to the Lowitja Institute for supporting Aboriginal and Torres Strait Islander disability research. They jumped on board early when this project was just a dream and I'm very proud to call myself a Lowitja Scholar. I also acknowledge the funding support that came through the National Disability Research and Development Agenda that has enabled something much grander in scope than otherwise would have been possible.

There was a time when this research journey felt more like walking through a bindi patch. This is where my family came in. Alison, Zoe and Tegan, you were always there, and always will be.

Of all, the greatest thanks must go to the forty-seven participants who shared their life stories through this research. Each interview was a personal tuition in humanity, gifting me with a sense of honour and responsibility. Through your testimony, each of you have added to the knowledge of this nation, and the scholars who carry this research agenda forward will forever be in your debt.

Scott Avery

July 2018.

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