



FIRST PEOPLES DISABILITY NETWORK

Intersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective

**Prepared for the Expert Mechanism on the Rights of Indigenous
Peoples (EMRIP) study on ‘The Right to Health For Indigenous Peoples’.**

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About First Peoples Disability Network (Australia):

First Peoples Disability Network (Australia) is a national organisation established by, for and on behalf of Aboriginal and Torres Strait Islander people, families and communities with lived experience of disability. The Board of Directors is entirely comprised of First Peoples with disability. We are guided by the lived experience of disability in determining our priorities and our way of doing business.

FPDN is committed to research and policy development that captures and respects the knowledge, expertise and experience of disability in our communities. FPDN aims to be the interface between the First Peoples disability community, policy makers and researchers in order to generate practical measures that secure the human rights of First Peoples within a social model of disability. We have a long-standing history of advocating for the rights of First Peoples with disability through high-level policy advice to Australian Governments and in international human rights forums.

Summary of issues

1. Human right frameworks in which data collection is based on individual aspects of a person's identity (i.e. Indigenous status *or* disability) do not fully capture the composite rights of Indigenous peoples who are also marginalised due to other aspects of their identity.
2. Human rights frameworks and applied public policy should have greater sensitivity to issues of intersectional risk to ensure that the composite rights to health and appropriate care of all Indigenous peoples are secured.
3. Particular consideration should be given to intersectional aspects of institutionalised discrimination. This occurs when people are discriminated against due to multiple aspects of their identity (e.g. an Indigenous person *and* a person with disability). This is a major impediment to securing the right to health and can lead to a denial of vital health services. When it's persistent and extreme, this can result in multiple systemic failures, and can lead to catastrophic health consequences for the person affected.

What does the right to health mean for an Indigenous Person?

'Health' for Australia's Indigenous Peoples 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”¹.

The holistic definition of health incorporates broader issues of social justice, well-being and equity as key attributes of health for Aboriginal peoples and is consistent with the World Health Organisation Alma Ata Declaration of 1978:

“Health ... is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity... [it] is a fundamental human right”².

Human rights provide a framework for addressing the consequences of health inequality experienced by Aboriginal and Torres Strait Islander peoples. This includes recognising the underlying causes of health inequality as well as the inter-connections with other issues.

Embedded in the human rights approach to health is:

- Active participation by Aboriginal and Torres Strait Islander peoples in decision-making at all levels in accordance with the *United Nations Declaration on the Rights of Indigenous Peoples*; and
- Article 24 of the Declaration, read in conjunction with Article 12 of the *International Covenant on Economic, Social and Cultural Rights*, recognises the right of Aboriginal and Torres Strait Islanders “to the highest attainable standard of physical and mental health”, or the right to health.

Intersectional Dimensions on the right to health – an Indigenous Disability Perspective

Intersectionality is an emerging field of human rights research that is influencing public policy. Intersectionality acknowledges that there are multiple dimensions to a person’s identity that frame the layers in which social inequity can accumulate. This involves understanding the right to cultural inclusion as an Indigenous person, as well as the right to inclusion as a person with disability.

An Indigenous person with disability is a member of at least two communities; one pertaining to their identity as an Indigenous person and another pertaining to their disability. Addressing one aspect of a person’s rights in isolation from the composite rights can leave them excluded from another aspect of society important to their sense of identity. This theme of partial exclusion was highlighted by one respondent, an Indigenous person with disability speaking of her decision to suppress her Aboriginality, in an interview provided to FPDN:

¹ National Aboriginal Health Strategy Working Party (1989) *National Aboriginal and Torres Strait Islander Health Strategy*.

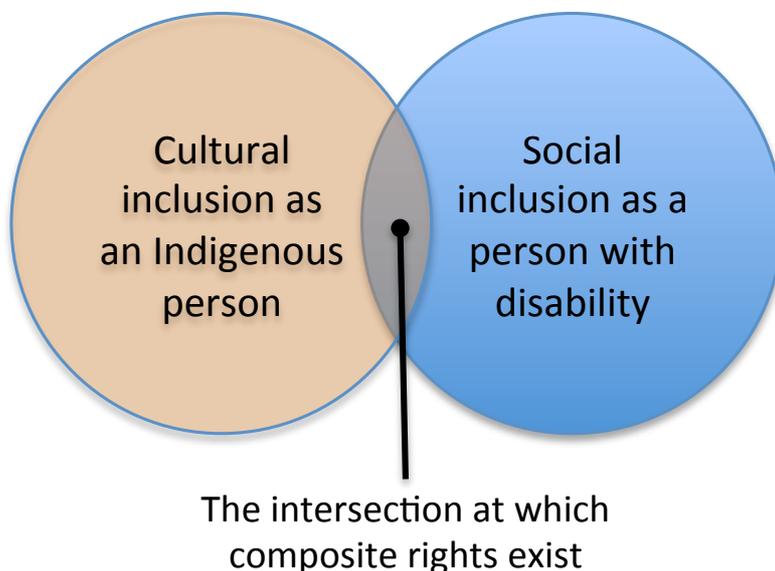
² World Health Organisation (September 1978), Declaration of Alma-Ata, International Conference on Primary Health Care, Alma-Ata, USSR

“I never used to speak about being Aboriginal. With my disability, I didn’t want another thing to have to deal with”.³

A failure to understand both dual access rights for Indigenous and the rights of a person in effect creates a minority group within a minority group. Aboriginal and Torres Strait Islander people with disability have colloquially referred to the social exclusion because of Aboriginality and disability as experiencing a ‘double discrimination’.

An intersection of rights, framed as inclusiveness in both Indigenous and disability contexts, is conceptually illustrated below:

Diagram: The composite rights for Indigenous people with disability



Whilst this particular perspective emphasises disability as an intersectional risk to the right to health for Indigenous Peoples, the concept of also applies in relation to other risk factors, which can have a cumulative detrimental impact. These risk factors can include:

- Gender
- Children and young people
- Exposure to trauma, both acute and inter-generational
- Psychiatric and mental health conditions
- Lesbian, gay, bisexual, transgender, intersex
- Drug and alcohol dependence
- Exposure to family violence
- Deprivation of liberty.

³ Participant at the Aboriginal Disability Network (NSW) ‘Living My Way’ Conference, Newcastle NSW Australia, October 2014.

The cumulative impact of intersectional risk across the life course of an Indigenous person with disability

Failures in addressing the rights of an Indigenous person in their early years can lead to a further, and often rapid, deterioration in rights over the course of a lifetime.

Here is one scenario as an example:

- An Indigenous mother living in poverty and in a community with inadequate public health facilities is more likely to have a low-birth weight baby compared to non-Indigenous people.
- Low birth weight is a known risk factor for childhood disability and learning impairment.
- The rate of removing a child from their families is significantly higher for Indigenous children compared to non-Indigenous children. In Australia, this disparity is a 10-fold increase in the rate of child removal for Indigenous children.
- Clinical protocols for the assessment for disability, particular cognitive impairments, can require a stable home environment to enable an accurate assessment. If shifting from home to home in an out-of home-care system continually disrupts a child, then an assessment of disability may not occur.
- Medical-based models of disability (not just in health, but also in education) require a diagnosis to trigger supports for a child.

So, when the barriers to access the right to health for an Indigenous person interact with those for a person with disability, the consequence for a child who is Indigenous *and* with disability is a heightened likelihood of going through their early childhood with an undetected and unsupported disability. The effect of this carries forward into their schooling years and places them on a trajectory where they are more likely to matriculate into prison than into tertiary education.

Table: The deterioration of rights across the life course of an Indigenous person

LIFE-STAGE	Peri-Natal	Early childhood	Schooling years	Young people	Justice	Health	Ageing
ASPECT							
Indigenous	Low awareness of disability Environmental factors, increased likelihood of low birth-weight	Low awareness of disability Exposure to trauma Increased likelihood of OOH – 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.

Discrimination as a barrier in securing the right to health

An intersectional approach can be applied to understand how discrimination within the health sector can work to undermine the right to health. For the purpose of this discussion, discrimination is taken to include all forms of unjust or prejudicial treatment of different categories of people, whether intentional or unintentional – i.e. including incidences of subconscious bias.

An Indigenous person with disability can potentially be exposed to at least two categories of discrimination in their interactions with health systems, which impede their right to health:

- Institutionalised racism in the health sector;
- Institutionalised ableism in the health sector.

Institutionalised racism in health service delivery

The prevalence of racism and its adverse impact on health and wellbeing is well documented⁴⁵. The ‘Experiences of Racism Survey’ in Victoria 2011-2012, funded by the Lowitja Institute, showed a relationship between mental health and reported episodes of racism⁶.

⁴ 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.

⁵ 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

⁶ 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

In 2012, the National Congress of Australia's First Peoples, Australia's representative body for Australia's Aboriginal and Torres Strait Islander peoples, conducted a broad based qualitative survey on the perceptions of Indigenous people on their interactions with the health sector. This survey found that approximately half (n=81, 49%) of those Indigenous people surveyed indicated experiencing discrimination when accessing a health service in the past.⁷

Racial discrimination presented itself in many forms (with representative narratives):

- i. Racially-based stereotyping, particularly around consumption of alcohol and drugs:

"I'd been walking and went running across the road and slipped and fell arse-over-head. When I went in there to have the x-rays and I told her what happened...She turned around and said to me, you weren't charged up were you? I just thought, well that's the last thing I expected to come out of your mouth. I thought you would have known better than that. Like, she didn't mean it badly. But I didn't say nothing." (Survey participant)

- ii. Well-meaning paternalism – i.e. making racially based assumptions about a person's health risks and status, and subsequently the provision of health care needs:

"I had my second child at another hospital; a birthing hospital. He was above birth weight, a healthy baby. The nurses were unsure about my nationality, so on my discharge day - I was there for a day and a half. The baby had no problems attaching, breast-feeding, weight, everything. I've got no issues whatsoever; I'm in a stable marriage, got a previous healthy child. I know how to look after my child, I'm ready to go home - as I'm leaving with my bag and I'm sitting on the bed and my husband is moving the car, she said, what nationality are you? I said, I'm Aboriginal and she went, oh. She goes, oh, we're allowed to keep you in here. I said, for what reason? She goes, because you're at risk. I said, and how am I at risk? How's my child at risk; please do tell me. All of a sudden, without knowing my race, everything's fine and all of a sudden..." (Survey participant)

- iii. Challenging a person's Indigenous identity on the basis of skin colour:

"She asked what nationality they were and I said Aboriginal...I said their father's from Northern Territory and I'm from Tasmania. She said - she made reference to them not being what she determined a real Aboriginal person. So to me she was saying well they're not black enough to be real Aboriginal kids." (Survey participant)

⁷ These results were presented at the Australian Institute of Aboriginal Torres Strait Islander Studies Conference, Canberra Australia, March 2014. See: http://nationalcongress.com.au/wp-content/uploads/2014/05/140324-AVERY_AIATSIS-Presentation-Member-Health-Survey-and-Racism.pdf

Institutionalised ableism in health service delivery

Institutionalised ableism, also referred to as 'diagnostic overshadowing', describes a bias which obscures undiagnosed illness amongst people with disability. This occurs when health professionals ascribe the symptoms of a patient's illness to their disability, rather than a secondary, undiagnosed illness. People with intellectual disability are particularly susceptible to having their right to health diminished through diagnostic overshadowing⁸.

First Peoples Disability Network (Australia) has a community-driven research program that collects and analyses narratives of disability from Indigenous peoples. Its preliminary results show that institutionalised discrimination, both racially based and disability based, is emerging as an issue:

- One participant interviewed for the research is an Aboriginal woman with one arm, being born without an arm and no legs. She describes going into hospital to have a baby, where the health staff in making judgments based on her disability, missed her real need for support as a first time mother.

"I had my first son, and again there was this whole barrier breaking. The hospital sent OT's [occupational therapists] around to my house, and everyone kept saying "Well, how are you going to look after your baby?" and I was saying "I don't know, I've never been a parent before"." (FPDN research participant)

- Another participant in the research succinctly describes how Indigenous people and people with disability have been viewed pejoratively in broader parts of Australian society:

"It wasn't that long ago that being Aboriginal was considered a disability in this country". (FPDN research participant)⁹

The detrimental consequences of intersectional discrimination

In whichever form, institutionalised discrimination can result in the denial of vital health services to people. When there is intersectional discrimination, or prejudice that operates on multiple layers against those who are at risk, the consequences can be catastrophic.

In 2 August 2014, a 22 year-old Aboriginal woman was arrested in Western Australia and taken into a lock lock-up for unpaid fines¹⁰. At the time, police staff made notations into their custody system that she "appears to be suffering withdrawals from drug use". Whilst the matter is subject to an ongoing coronial inquiry, the Inquest has heard that

⁸ See: Katteri R and Bywood (2001) 'Primary Health Care for People With Intellectual Disability'. *PHCRIS Research roundup*. At: <http://www.phcris.org.au/publications/researchroundup/issues/17.php>.

• These interviews were undertaken during the 'Living My Way' Disability Conference, hosted by Aboriginal Disability Network (NSW), Newcastle Australia, October 2014.

• This is the case of Ms Dhu, from South Headland Western Australia. This summary is based on various reports in Australian media. See for example: ABC News (23 November 2015) 'Police thought dying Aboriginal woman Ms Dhu was faking it, coronial inquest told' At: <http://www.abc.net.au/news/2015-11-23/inquest-into-death-of-dhu-in-police-custody/6963244>;

shortly after her arrest, she complained of pain in her ribs and taken to the local health campus. There she was initially diagnosed with 'behavioral issues' and returned to the police lock-up. On a worsening of symptoms, she was returned to the Health Campus where the initial diagnosis of 'behavioral problems' was reissued and again declared fit to be discharged to the police lock-up. Within 18 hours, she became violently ill and in extreme pain, and was again returned a third time to the Health Campus, where she died of septicemia and pneumonia related to an undiagnosed infection from an undiagnosed rib fracture.

For the record, Senior Medical Staff at the health campus denied claims of institutional racism when asked at the Coronial Inquiry.¹¹ However, the very nature of institutional discrimination is that prejudicial behaviours have become normalised over long periods of time so they are embedded in the subconscious and are taken for granted. As part of the institution, they would not be qualified to answer.

As some who was: young, Aboriginal, a woman, subject to poverty, exposed to drugs and alcohol dependency, living in poverty, exposed to family violence and deprived of liberty; this case personifies the multiple intersectional dimensions which heightened the vulnerability of the most marginalised of our marginalised Indigenous peoples. Theoretically, there were multiple opportunities for interventions to secure her right to health, and multiple conventions, treaties and human rights instruments to guard it.

But none did.

Corresponding Author

Scott Avery
Policy and Research Director
First Peoples Disability Network (Australia)
402/161 Redfern St, Redfern NSW AUSTRALIA
E: scotta@fpdn.org.au

¹¹ Perth Now (26 November 2015) 'Hedland Health Campus denies racism against Ms Dhu at Aboriginal death in custody inquest' At: <http://www.perthnow.com.au/news/western-australia/hedland-health-campus-denies-racism-against-ms-dhu-at-aboriginal-death-in-custody-inquest/news-story/078c5855077b5593a730a9fb4546dcb9>