

Friday, 1 May 2019

Commissioner Mason OAM, Commissioner Sackville AO QC  
Royal Commission into Violence, Abuse, Neglect  
and Exploitation of People with Disability  
Email: [DRCEnquiries@royalcommission.gov.au](mailto:DRCEnquiries@royalcommission.gov.au)

Dear Commissioners

**Issues paper: Health care for people with cognitive disability**

The Lowitja Institute writes to state our support for the work of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – and provide for your consideration materials relevant to the *Issues paper: experiences within the health care system for people with cognitive disability*. Our response puts forward suggested practices in primary healthcare and workforce that can be looked at to improve the cultural and clinical safety for Aboriginal and Torres Strait Islander people with cognitive disability, however these must be accompanied by increased measures to protect against discrimination within the health system.

The Lowitja Institute is Australia's National Institute for Aboriginal and Torres Strait Islander health research. The Institute is an Aboriginal and Torres Strait Islander organisation working for the health and wellbeing of Australia's First Peoples through high impact quality research, knowledge translation, and by supporting Aboriginal and Torres Strait Islander health researchers.

Over the years we have funded a range of research work aimed to create knowledge around the health and wellbeing of Aboriginal and Torres Strait Islander People with disability. This includes research projects on:

- engagement of Aboriginal and Torres Strait Islander people under the National Disability Insurance Scheme (NDIS) in *Understanding disability through the lens of Aboriginal and/ or Torres Strait Islander people – challenges and opportunities*<sup>i</sup>
- the protective health factors of participation in cultural and community activities in *Wellbeing through culture: Aboriginal and Torres Strait Islander people with disability*<sup>ii</sup>

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- developing a culturally secure rehabilitation approach for Aboriginal and Torres Strait Islander peoples after brain injury in *Yarning together: Culturally secure rehabilitation for Aboriginal and Torres Strait Islander peoples after brain injury*<sup>iii</sup>.

Our current research themes of *Empowerment, Sovereignty, Connectedness and Cultural Safety and Respectful Systems* also cover a number of areas of relevance. Primarily the theme of *Connectedness* prioritises the topic of '*Structures and networks that will connect Aboriginal and Torres Strait Islander people living with disability with researchers, services and policymakers within values and cultures that promote their inclusion*'.

Based in this experience we offer the following comments on the questions raised in the issues paper *Health care for people with cognitive disability*.

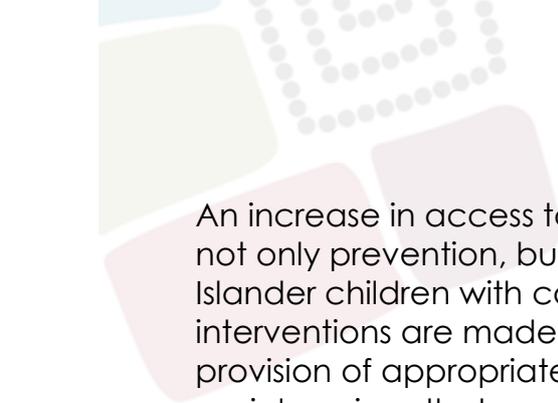
**Q. What do you think of the quality of health care for people with cognitive disability?**

**Q. Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?**

The current health system is not doing enough to ensure access and safety for Aboriginal and Torres Strait Islander people with a cognitive disability. The NSW Coroner's Report on the investigation into the tragic passing of Ms Hookey offers good insight into the multiple barriers that exist for Aboriginal and Torres Strait Islander people with cognitive disability in accessing health care. From the training and experience of the health and disability workforce, to the culture created by under-resourced health systems and importantly the bias of health system staff in treating patients with a cognitive disability, all are examples of factors that can combine and result in system failure.<sup>iv</sup>

#### Preventative care and early intervention

An important indicator of system failure is the higher prevalence of preventable health conditions, and lack of early assessment amongst Aboriginal and Torres Strait Islander people. This is a major contributor to the gaps in health outcomes, and higher incidence of cognitive disorders and co-morbidities amongst Aboriginal and Torres Strait Islander people. While there is an inherited genetic element to some cognitive disabilities, preventable health conditions such as chronic disease, injury and poisoning (including self-harm and violence), nutrition, exposure to environmental toxins (eg. mercury, lead), substance abuse and psychological stress contribute to higher levels of cognitive disability amongst Aboriginal and Torres Strait Islander people.



An increase in access to, and quality of, primary health care could assist in not only prevention, but also early assessment of Aboriginal and Torres Strait Islander children with cognitive disability ensuring important health interventions are made available in a timely manner. Early diagnosis assists in provision of appropriate interventions in areas such as health, education and social services that could help prevent and manage the development of more complex co-related conditions such as psychological illnesses.

While we have seen an increase in relevant health care services (such as maternal and infancy programs) under the Closing the Gap agenda more can still be done. Key expert bodies such as the National Aboriginal and Community Controlled Health Organisation (NACCHO) and First Peoples Disability Network (FPDN) emphasise the importance of investing in community-controlled health and disability services to ensure accessibility, both in terms of geographical proximity and cultural and linguistic relevance.

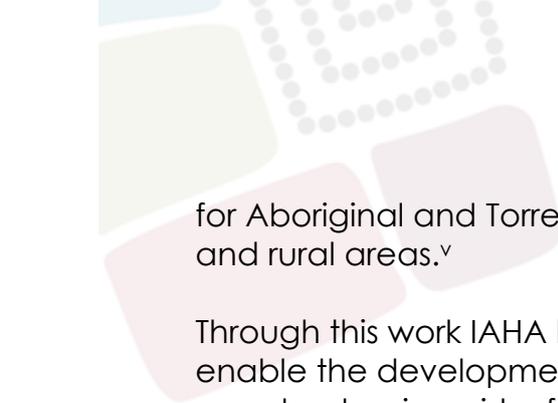
#### Addressing complex care

One of the success factors of Aboriginal and Torres Strait Islander community-controlled organisations is that their culturally based definition of health and wellbeing is reflected in holistic services. This is particularly relevant to Aboriginal and Torres Strait Islander people with a cognitive disability who often have complex health needs, including co-existing activity disabilities. One of the ways that these needs are met are through employment of multi-disciplinary teams (ie Doctor, Nurse, Aboriginal Health Workers, Occupational Therapists, Psychologists and Social Workers) to appropriately assess and manage a range of health, cultural and social and emotional needs.

Workforce, especially in regional and remote areas, is currently a key barrier to such services and it is important that we continue to invest in creating knowledge on how this problem can be addressed.

*Yarning together: Developing a culturally secure rehabilitation approach for Aboriginal and Torres Strait Islander peoples after brain injury* is a research project that looked at rehabilitation for Aboriginal and Torres Strait Islander people with and acquired communication disorder derived from brain injury from stroke or trauma. It looked at the application of a culturally tailored model of rehabilitation (speech pathology) both in person and by telehealth and found that both models were well received by participants who felt their communication improved across the treatment.

Indigenous Allied Health Australia (IAHA) has also undertaken work funded by the Department of Social Services (DSS) and the National Disability Insurance Scheme (NDIS) to inform improved workforce models for remote and rural areas. The Remote and Rural Indigenous allied health workforce development project (RIAHP) in Tennant Creek and Palm Island identified the need for a culturally safe allied health workforce to increase access to NDIS



for Aboriginal and Torres Strait Islander people with disability living in remote and rural areas.<sup>v</sup>

Through this work IAHA have highlighted that the NDIS is an opportunity to enable the development of quality, cost effective and accessible services for people at serious risk of exclusion from the health system. Part of the approach has been ensuring that Aboriginal and Torres Strait Islander people are central to identifying their community needs and priorities.

While there is much ground to be made in health and wellbeing outcomes through improved services in areas such as primary health care, focus on health services alone overlooks the importance of social and cultural determinants such as environment and housing, poverty and cultural expression and exchange that are all critical considerations in upholding a human rights-based approach to health.

**Q. Are experiences of violence, abuse, neglect or exploitation in health care different for First Nations and culturally and linguistically diverse people with cognitive disability?**

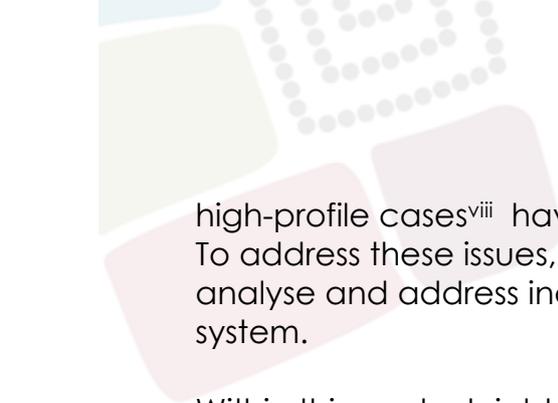
**Q. What could prevent people with disability experiencing violence, abuse, neglect or exploitation in health care?**

The FPDN have stated that that 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 are secured.<sup>vi</sup>

Analysis within the *Understanding disability through the lens of Aboriginal and Torres Strait Islander people* reported that overall Aboriginal and Torres Strait Islander people living with disabilities were more likely than other Aboriginal and/ or Torres Strait Islander people to experience unfair treatment. Based on these findings the report emphasises the importance of considering safety issues, including in engagement with initiatives such as NDIS.

Interwoven with this are systemic issues that may drive individual acts of violence or abuse, and foster institutional cultures of negligence and exploitation. For example substandard housing and infrastructure in Aboriginal and Torres Strait Islander communities can lead to people being at increased risk of injury hazards (including inter-personal violence) where secure housing and community facilities are not available. Further, racism within health or disability care settings may interact and compound experiences of violence, abuse, neglect and exploitation.

Increasingly evidence is indicating that experiences of inter-personal racism has a negative impact on health, including anxiety, depression and suicide risk.<sup>vii</sup> Within the healthcare system statistics on courses of treatment show that Aboriginal and Torres Strait Islander people are treated differently and recent



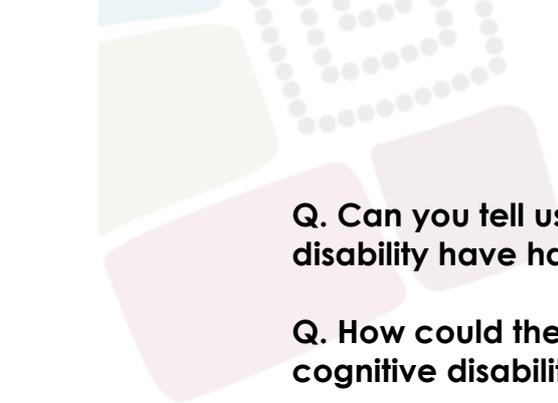
high-profile cases<sup>viii</sup> have linked racism to deaths in the health care system. To address these issues, comprehensive measures need to be put in place to analyse and address individual and systemic racism within the healthcare system.

Within this context rights education for people with disability, their carers' and community, is important and there must be measures to ensure that these rights are exercised and protected. Including access to legal services as part of complex health care models is an example of an initiative that could support this. Health Justice Partnerships are one such model that place lawyers in health and wellbeing services to work with health care professionals.<sup>ix</sup> The approach recognises the health harming impact of unaddressed legal needs, particularly relevant to the considerations by the Commission given the alarmingly high levels of incarceration of Aboriginal and Torres Strait Islander people with cognitive disability.

*Wellbeing through cultural participation: An affirmative strategy for the inclusion of Aboriginal and Torres Strait Islander people with disability* conducted research that explored the role of culture as a determinant of health for Aboriginal and Torres Strait Islander People with a disability. The project looked at the high levels of participation in cultural and community activities by Aboriginal and Torres Strait Islander people with disability and how this acts as a protective factor for health and wellbeing.

This theme was further explored in the 2020 Close the Gap Report '*We nurture our culture for our future, and our culture nurtures us*'. Authored by the Lowitja Institute on behalf of the Close the Gap Steering Committee, the Report explored a theme of Culture using narratives of Aboriginal and Torres Strait Islander people. The work of the Nuuna Ron group of Aboriginal and Torres Strait Islander artists living with disability looked at the power of cultural expression and exchange in providing a safe place for community members living with disability to come together and build resilience, connect to culture, and support each other in keeping strong.

A component of this is the cultural safety of the health system, and the freedom of cultural expression (or inversely the freedom from assault on identity) that one feels within it. While the health system is moving towards cultural safety through regulations around health practitioners and health services, this must be coupled with broader service reforms such as ensuring provision of services on-country, facilitating traditional medicines and healing practices within mainstream services and building community-controlled health and wellbeing services. There must also be measures around system integrity that ensure the experiences of Aboriginal and Torres Strait Islander people with cognitive disability are privileged when issues of accessibility and discrimination occur.



**Q. Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?**

**Q. How could the NDIS and health systems work better for people with cognitive disability?**

*Understanding disability through the lens of Aboriginal and/or Torres Strait Islander people – challenges and opportunities* examined the implantation of the NDIS Aboriginal and Torres Strait Islander Engagement Strategy, interaction between the National Disability Insurance Agency (NDIA) and Aboriginal Community Controlled Health Services and the experience of Aboriginal and Torres Strait Islander people in accessing the NDIS (note that it does not differentiate information on people with cognitive disability).

Key barriers that the study identified to accessing the NDIS for Aboriginal and Torres Strait Islander participants included:

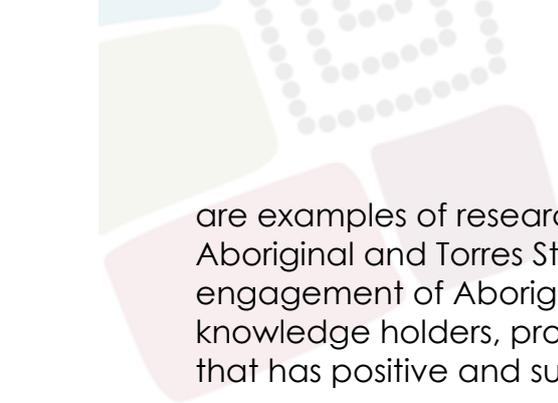
- The language of disability (eg no related word or concept) and under-identification leading to under-identification and under-utilisation.
- Kinship systems that preference reliance on family as carers, rather than external support workers or provider.
- Geographical and logistical access to services are rated as significant for people living with disability in regional, remote and very remote areas. This may also involve limited access to transport, inadequate housing and over-crowding.
- Lack of registered providers in many rural and remote communities.
- Linguistic and cultural accessibility.

The report makes 13 Recommendations for improving access to the NDIS for Aboriginal and Torres Strait Islander people that are available in the Report and Policy Brief. These include implementation and expansion of the Aboriginal and Torres Strait Islander Engagement strategy, expanding, strengthening and supporting community connectors, development of resources for participants and their families, strengthening the local Aboriginal and/ or Torres Strait Islander workforce and developing hybrid models for support provision for remote areas.

The Project Policy Brief has been attached for further information.

### **Q) Other Considerations**

*Both the Wellbeing through cultural participation and Understanding disability through the lens of Aboriginal and/ or Torres Strait Islander people*



are examples of research projects that have been co-designed with Aboriginal and Torres Strait Islander people and organisations. The engagement of Aboriginal and Torres Strait Islander people with disability as knowledge holders, producers and users is important to undertaking research that has positive and sustainable impact within their communities.

One of the *Ten Priorities to Address Disability Inequity* advocated for by the FPDN is resource for a community-directed research strategy which specifically focuses on Aboriginal and Torres Strait Islander disability.<sup>x</sup> We support that such an investment is required to better understand the journey through the health system by Aboriginal and Torres Strait Islander people with cognitive disability, and measure where and how meaningful reforms are made.

We thank you for the consideration of the matters raised in this paper, please email [Leonie.Williamson@lowitja.org.au](mailto:Leonie.Williamson@lowitja.org.au) or call M. 0431 950 537, if there is any further information that we can provide on this matter to assist the work of the Commission.

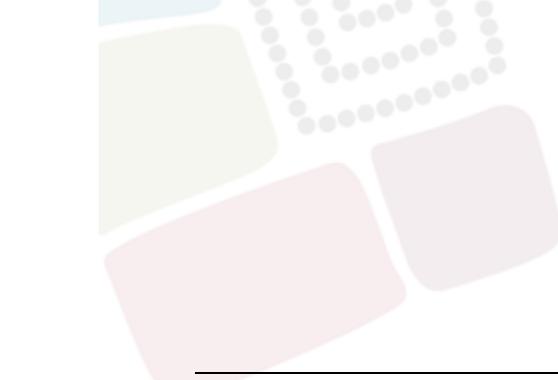
Kind regards



Dr Janine Mohamed  
CEO, the Lowitja Institute

ATTACHMENT

Policy Brief: Understanding disability through the lens of Aboriginal and Torres Strait Islander people – challenges and opportunities.



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<sup>i</sup> Ferdinand, A. et al 2019. available at <https://www.lowitja.org.au/page/research/research-categories/cultural-and-social-determinants/disability/completed-projects/ndis>

<sup>ii</sup> Avery, S., Dew, A & Dowse, L. 2019. available at <https://www.lowitja.org.au/page/research/research-categories/cultural-and-social-determinants/culture-for-health-and-wellbeing/projects/wellbeing-cultural-participation>

<sup>iii</sup> Ciccone, N. 2019. available at <https://www.lowitja.org.au/page/research/research-categories/cultural-and-social-determinants/disability/completed-projects/yarning-together-culturally-secure-rehabilitation-for-aboriginal-and-torres-strait-islander-peoples-after-brain-injury>

<sup>iv</sup> State Coroner's Court New South Wales. 2016. *Inquest into the death of Shona Hooker*, available at <http://www.coroners.justice.nsw.gov.au/Documents/Hookey%20findings%20FINAL%2022%20Dec%2016.pdf>

<sup>v</sup> IAHA. 2019. Rural and Remote Allied Health Workforce Development <https://iaha.com.au/policies-and-research/projects/>

<sup>vi</sup> First Peoples Disability Network. 2016 *Intersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective* (submission to the Expert Mechanism on the Rights of Indigenous Peoples study on 'The Right to Health for Indigenous Peoples', available at

<https://www.ohchr.org/Documents/Issues/IPeoples/EMRIP/Health/FirstPeoplesDisabilityNetworkAustralia.pdf>

<sup>vii</sup> Priest, N. et. al. 2011 Racism as a determinant of social and emotional wellbeing for Aboriginal Australian youth Naomi C Priest, Yin C Paradies, Wendy Gunthorpe, Sheree J Cairney and Sue M Sayers *Med J Aust* 2011; 194 (10): 546-550.

Available at <https://www.mja.com.au/journal/2011/194/10/racism-determinant-social-and-emotional-wellbeing-aboriginal-australian-youth>

<sup>viii</sup> see *Inquest into the death of Naomi Williams*

<http://www.coroners.justice.nsw.gov.au/Documents/Naomi%20Williams%20findings.pdf> and *Inquest into the Death of Ms Dhu* <https://www.coronerscourt.wa.gov.au/1/inquest-into-the-death-of-ms-dhu.aspx>.

<sup>ix</sup> P.20 Close the Gap Steering Committee. 2020. *We Nurture Our Culture For Our Future, And Our Culture Nurtures Us*. available at [www.humanrights.gov.au/social\\_justice/health/index.html](http://www.humanrights.gov.au/social_justice/health/index.html)

<sup>x</sup> First Peoples Disability Network *Ten Priorities to Address Disability Inequity* available at <https://fpdn.org.au/wp-content/uploads/2018/10/FPDN-ten-priorities-2018.pdf>