QAIHC

Queensland Aboriginal and
Islander Health Council

QAIHC SUBMISSION TO THE

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability

SUBMISSION

Health care for people with cognitive disability

April 2020

QAIHC

Queensland Aboriginal and
Islander Health Council

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QAIHC receives funding support from the Australian and Queensland Governments

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SUBMISSION

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About the Queensland Aboriginal and Islander Health Council (QAIHC)

QAIHC was established in 1990 by dedicated and committed Aboriginal and Torres Strait Islander leaders within the community-controlled health sector.

Originally established as QAIHF (Queensland Aboriginal and Islander Health Forum), the organisation provided a voice for the community-controlled health sector in Queensland. This organisation was self-funded until 1996, when the Commonwealth Department of Health commenced funding support. QAIHC has experienced considerable growth in membership and the scope of services provided to those members since its establishment.

In 2004, the organisation was reconstituted under the Australian Investment and Securities Commission (ASIC) and assumed its current form as QAIHC.

Today, QAIHC represents 28 community-controlled health services and 14 associate members who share a passion and commitment to addressing the unique health care needs of their communities through specialised, comprehensive and culturally-appropriate primary health care.

QAIHC is the peak body representing the Aboriginal and Torres Strait Islander Community Controlled Health Organisation (ATSICCHO) sector in Queensland at both a state and national level. Its membership comprises of ATSICCHO's located throughout Queensland. Nationally, QAIHC represents the Community Controlled Health Sector through its affiliation and membership on the board of the National Aboriginal Community Controlled Health Organisation (NACCHO) and is regarded as an expert in its field.

QAIHC, as the peak of Queensland's ATSICCHO's, wish to express the collective views on behalf of our state-wide members, on the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability's consultation on health care for people with cognitive disability.

QAIHC CONTACT REGARDING THIS SUBMISSION:

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1. Opening statement

QAIHC believes that all Aboriginal and Torres Strait Islander peoples with a disability should have equitable access to the health system. This means that all Aboriginal and Torres Strait Islander peoples across Queensland with a disability should have access to holistic, culturally safe, timely, affordable disability support and health services on country, regardless of where they live, which meet their aspirations and needs. In addition, all Aboriginal and Torres Strait Islander peoples with a disability should have proficient health literacy to enable informed and confident decision making for themselves and their family.

Across all areas of the health sector, Aboriginal and Torres Strait Islander peoples face significantly disproportionate health challenges compared with those faced by other Australians. This is intrinsically linked with disability where improperly treated or continuing illness may result in, or further complicate, lifelong disability. Aboriginal and Torres Strait Islander peoples are 1.8 times more likely to have a disability compared with non-Indigenous Australians, and it is nearly twice as likely to be severe.[1]

Despite consistent and repeat attempts to ask the NDIA to work with the community-controlled sector,[2] and despite multiple formal funding requests,[3] QAIHC continues to be unfunded to provide disability-related support to our Members. There is a monumental failure of the National Disability Insurance Agency (NDIA) and other Government departments to respond to the needs voiced by QAIHC and our Members.

The result of this lack of investment by the NDIA is that Aboriginal and Torres Strait Islander peoples with cognitive disability (and any disability) are not receiving the level of disability related support that they may need, or would benefit from, from their local ATSICCHO. This includes supporting individuals to understand what a disability is and how the NDIS may apply to them, providing assistance through the application and planning process and with accessing or delivering services once a plan is approved.

This submission addresses questions 1, 2b, 3b and 4b that were put forward by the Disability Royal Commission in the consultation paper entitled “Health care for people with a cognitive disability”:

In considering the questions and feedback from our Member Services, QAIHC provides the following recommendations to the Royal Commission on how the NDIS and health systems could work better for people with a cognitive disability:

1. The Commonwealth Government implement constitutional recognition of Aboriginal and Torres Strait Islander peoples, as requested in the Uluru Statement from the Heart: “*We seek constitutional reforms that will empower our people and to take a rightful place in our own country. When we have power over our destiny our children will flourish. They will walk in two worlds and their culture will be a gift to their country*.”
2. The Commonwealth and State government increase investment in community controlled and community-driven, local, place based preventative health initiatives (including healing initiatives) to try to reduce the number of Aboriginal and Torres Strait Islander peoples with potentially preventable cognitive disabilities.
3. The NDIA, Department of Social Services (DSS) and the Queensland Department of Communities, Disability Services and Seniors, the Department of Health and Queensland Health formally recognise, incorporate into disability service delivery, and mandate for:

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[1] Aboriginal and Torres Strait Islander Health Performance Framework 2017 report, section 1.14 Disability.

[2] QAIHC has invested at least $30,000 in staff time since October 2018 in understanding Member needs, facilitating workshops including the NDIS and the ATSICCHO Sector workshop attended by NDIA Branch Manager for Communities of Practice, National Disability, Acting Director for Workforce Policy, NDIS Market oversight branch, Commonwealth Department of Social Services and the NDIA Director of Queensland Provider and Market Engagement. QAIHC has also worked with the NDIA Director of Community and Mainstream Engagement Branch, contributed submissions to the Thin Market pricing review and supported NACCHO’s submissions to NDIA.

[3] In January 2019 QAIHC applied for $421,000 in the jobs and market fund round 1 to build the capacity and capability of Queensland's Aboriginal and Torres Strait Islander Community Controlled Health Services (ATSICCHSs) to provide NDIS related support to people with a disability. This application was rejected. In October 2019 QAIHC applied for $1.9 million through the Information, Linkages and Capacity building Mainstream Capacity Building Grant to provide targeted activities to support Aboriginal and Torres Strait Islander peoples with a disability and to support ATSICCHOs with resources and tools to assist people with disability in their communities. This application was also rejected.

   a. the vital role of the ATSICCHO holistic Model of Care and self-determination in disability service provision.
   b. ATSICCHOs and QAIHC as preferred providers of NDIA service delivery, either a restrictive selection process or a non-competitive restrictive selection process.
   c. Improvements to care coordination between, and amongst, health and disability services.

4. The NDIA conduct a thorough review of NDIS systems (policy, procedures, programs and funding models) in partnership with Aboriginal and Torres Strait Islander peoples and QAIHC to understand where gaps are present, and address institutional racism failings in a timely manner.
5. The NDIA fund QAIHC to (a) conduct a community needs assessment (data review, consultations with ATSICCHOs, stakeholders and consumers) (b) drive pilot projects to improve NDIS access by peoples with a disability (c) support ATSICCHOs to develop their capacity to provide NDIS services (d) establish an ATSICCHO best practice disability network and to (e) support ATSICCHOs to implement innovative responses to providing disability supports that meet the needs of their communities, including through increasing community awareness, supporting individuals with access to the NDIS, providing NDIS services and workforce development.
6. The NDIA and DSS fund the ATSICCHO sector to develop culturally safe and suitable resources to help individuals understand the NDIS and disability, including cognitive disability. This could include training for health staff on working with an Aboriginal and Torres Strait Islander person with disability. Training must be culturally safe and would aim to address barriers to healthcare access such as unconscious bias, stigma, understanding abilities and communication skills.
7. Health Workforce Queensland, working with the NDIA, QAIHC and other peak bodies, establish a Queensland Aboriginal and Torres Strait Islander disability workforce target and support the development of new and existing disability workforce within ATSICCHOs.

Question 1: What do you think about the quality of health care for people with cognitive disability?

Access to high quality, culturally safe and holistic health care for Aboriginal and Torres Strait Islander peoples with a disability is available through Queensland's ATSICCHOs who operate under a holistic Model of Care:

> *The Queensland ATSICCHO Model of Care[4] incorporates community control, engagement and cultural safety, clinical services that are patient and family centred, the integration of population health and social and environmental determinants into everyday service delivery, research and advocacy on behalf of the individual, community or from the ATSICCHs sector to influence system-wide change and operational systems that are driven by community priorities and a commitment to high quality care, compliance and accountability.*

ATSICCHOs are recognised as a best practice approach to improving the health and well-being of Aboriginal and Torres Strait Islander Australians and are increasingly considered to operate a best practice model for health care for all Australians. Aboriginal and Torres Strait Islander peoples with a disability can encounter stigma in the mainstream health system which makes access to health services more difficult. ATSICCHOs are designed to reduce these barriers of access and ensure that no further trauma is incurred through health care. ATSICCHOs encourage community participation and ownership of their health and wellbeing, adopting a bespoke model of care which expresses self-determination and the collective goal to deliver high quality comprehensive healthcare for Aboriginal and Torres Strait Islander peoples, by Aboriginal and Torres Strait Islander peoples, in their community.

ATSICCHOs have a broader experience and deep understanding of what works best to address local health and wellbeing needs of all local Aboriginal and Torres Strait Islander peoples, based on the mutually trusted working relationship. This sets ATSICCHOs in a unique position and enables them to work with the community and deliver the best possible holistic primary health care services.

As recommended in the 2020 Close the Gap Report, investing in community control and "upholding the role of Aboriginal and Torres Strait Islander Community Controlled Health Organisations as a fundamental component of the Australian health system"[5] is essential so that Aboriginal and Torres Strait Islander peoples can be in control of the decisions that affect them. This applies to disability and health, where the quality of health care for Aboriginal and Torres Strait Islander peoples with a disability could be improved by better supporting ATSICCHOs to provide services to their communities.

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[4] QAIHC Model of Care (2019)

[5] Close the Gap Report 2020, https://www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-islander-social-justice/publications/close-gap-2020, page 6

Question 2b: Can you tell us about any barriers that people with cognitive disability have experienced in accessing health care?

Our Members have highlighted four barriers that people with cognitive disability experience in accessing health care: (1) poor health literacy leading to late presentation to health care; (2) a lack of culturally safe holistic health services that recognise the importance of all elements of health; (3) the lack of availability of any health service; and (4) unwillingness to identify as having a disability due to stigma. Each is discussed in greater detail below.

1) Poor health literacy leading to late presentation to health care:

ATSICCHOs in Queensland have reported that it is common for people with a cognitive disability to present late for health services and the presentation may only be because a carer has suggested or supported them to attend. This means that disease may have progressed to a chronic stage and is no longer preventable (which could be interpreted as a form of neglect by the system). The solution to late presentations is to improve health literacy and facilitate preventative health checks. Further details on each are below.

a) Increase the health literacy of the person with a disability, and of their carer

There are many health promotion activities that are run by and for Aboriginal and Torres Strait Islander peoples such as the Tackling Indigenous Smoking (TIS) program, nutrition and healthy lifestyle programs, and sexual health programs. However, QAIHC is not aware of any that are specifically targeted to peoples with a disability, or which have been designed with the input of peoples with a disability. QAIHC would be interested in discussing this further with the Commission.

Some Aboriginal and Torres Strait Islander peoples with a cognitive disability may not have the capacity to develop their health literacy to a necessary standard. In these circumstances, it is important that the carers, including respite carers, have good health literacy and have a level of familiarity with the client so they can spot changes in their health.

Case study: Carbal Medical Services, Toowoomba.

Carbal Medical Services (Carbal) is an ATSICCHO that is a registered NDIS provider. Carbal have found that a large proportion of their new NDIS clients have chronic disease. Carbal's NDIS services are embedded within their ATSICCHO Model of Care and disability carers are often qualified Aboriginal and Torres Strait Islander Health Workers or Practitioners (AHW) who are trained to consider health needs. Because of this, they are able to notice potentially preventable health needs earlier. Carbal also understand and reported on the importance of the carer being able to form a meaningful relationship with the client which enables them to spot changes in their health which the client might not recognise themselves. As Carbal's NDIS and health services are interlinked, clients are able to be referred to the General Practitioner quickly and efficiently.

b) Facilitate regular preventative health checks.

In Aboriginal and Torres Strait Islander health there is a specific Medicare item called MBS Item 715: Medicare Health Assessment for Aboriginal and Torres Strait Islander people.

> *"The health assessment includes an assessment of the patient's health, including their physical, psychological and social wellbeing. It also assesses what preventive health care, education and other assistance should be offered to the patient to improve their*

> *health and wellbeing. It complements existing services already undertaken by a range of health care providers.*[6]*”*

This MBS item is used largely by ATSICCHOs who are experts in delivering the item in meaningful and effective ways, due to their understanding in the reasoning and value of the assessment in preventative health, including health literacy. It’s use, however, relies on individuals presenting to the clinic for their health assessment. One suggestion to address this is to facilitate annual health checks for all peoples with disability to prevent unintentional neglect through failing to identify health concerns prior to the progression into chronic disease.

2) Lack of culturally safe holistic health services that recognise the importance of all elements of health

Aboriginal and Torres Strait Islander peoples experience a disproportionate burden of illness and social disadvantage when compared with non-Indigenous Australians. Also, Aboriginal and Torres Strait Islander peoples experience much higher levels of racism and discrimination.

To overcome these issues, cultural safety must be embraced at all levels of health care planning and delivery (programs, services, policies and strategies) in order to provide the best possible health care for Aboriginal and Torres Strait Islander peoples.

Cultural safety is about respecting the cultural rights, values, beliefs and expectations of Aboriginal and Torres Strait Islander peoples while providing services that meet their need[7]. Cultural safety is distinguished from cultural ‘awareness’ as it relates to embedding culturally sound practices into all elements of delivery, rather than merely recognising that cultural differences exist.

QAIHC recognises Aboriginal and Torres Strait Islander culture as a source of strength, resilience, happiness, identity and confidence, which has a significant impact on the health and wellbeing of Aboriginal and Torres Strait Islander peoples. QAIHC believe that to improve health outcomes for Aboriginal and Torres Strait Islander peoples, health service provision needs to be responsive to cultural differences and the impacts of conscious and unconscious racism. It is clearly understood that Aboriginal and Torres Strait Islander peoples are more likely to access, and will experience better outcomes, from services that are respectful and culturally safe. Integrating cultural safety in health care is the best way to improve equitable access to the health services and programs.

The lack of culturally safe, holistic health care services extends beyond primary health care to include the justice system and tertiary health care systems. As the Royal Australian and New Zealand College of Psychiatrists (RANZCP) state in their submission to the Queensland Productivity Commission’s report on imprisonment and recidivism:

> *“There is a significant body of evidence documenting the links between mental health issues and incarceration, as well as between childhood trauma and future psychosocial problems.”*[8]

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[6] https://www1.health.gov.au/internet/main/publishing.nsf/Content/F55BEF7B8F46193DCA257BF0001F95FF/$File/715%20-%20Medicare%20Hlth%20Assmnt%20Aboriginal%20Torres%20Strait%20Islander%20People.pdf

[7] Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice

[8] The Royal Australian & New Zealand College of Psychiatrists, quoted from Queensland Productivity Commission report page xiv https://qpc.blob.core.windows.net/wordpress/2020/01/FINAL-REPORT-Imprisonment-Volume-I-.pdf

Case study: Difficulty accessing culturally safe health care in prisons

There are high levels of FASD and acquired brain injury amongst young people who are in the child protection and youth detention systems. 72 per cent of people in the Queensland youth detention system are Aboriginal or Torres Strait Islander young peoples.

Health care in prison is the responsibility of each state. In Queensland, the Hospital and Health Services (HHSs) run prison health services. Despite the high representation of Aboriginal and Torres Strait Islander peoples in the criminal justice system, prison health care services do not operate under the holistic model of care that ATSICCHOs operate. The result is that people in the criminal justice system with cognitive disability are frequently unable to access appropriate health care due to being in the justice system.

An example of difficulty accessing appropriate health care in prisons can eb found in Townsville prison where 86 per cent of the women in prison are Aboriginal and Torres Strait Islander peoples. The local ATSICCHO, Townsville Aboriginal and Islanders Health Service (TAIHS), finds it is common for women to be prescribed mental health medication by the prison doctors rather than being offered healing services which might be more medically appropriate for the women. This reliance on medication might be reduced if the prison health service were able to offer holistic health services in line with the ATSICCHO Model of Care.

QAIHC has been working with Queensland Health to reduce institutional racism. Reducing institutional racism within the Department of Health and HHSs should, in turn, improve the cultural safety of the tertiary health care services that are provided by HHSs to Aboriginal and Torres Strait Islander peoples with a cognitive disability.

Institutional racism is evident in the Australian health care system and has a profound impact on improving health and wellbeing outcomes of Aboriginal and Torres Strait Islander peoples. Institutional racism is distinctive and separate to personal racism where racist features are directly or indirectly linked with the policies, program, structures, attitudes, hierarchies, practices and perspectives of the organisation. Also, institutional racism may appear in different forms within the system. It is characterised as the absence or insufficiencies of appropriate considerations intentionally or unintentionally which leads to racial disadvantages[9,10]. Systemic racism greatly influences Aboriginal and Torres Strait Islander peoples' access to health care as well as limits individuals from receiving the same quality of healthcare services available for non-Indigenous Australians.[11]

Discussions about how institutionalised racism may be present within all Australian Government departments, not just health departments, and how it may be present in all policies and practices, are essential to addressing disparities between Aboriginal and Torres Strait Islander peoples and other Australians. Such conversations must be de-stigmatised in order to objectively understand how inequalities may be unconsciously perpetuated by institutions intended to support minority groups.

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[9] Australian Indigenous Doctors' Association (AIDA). Policy Statement https://www.aida.org.au/wp-content/uploads/2017/08/Racism-in-Australias-health-system-AIDA-policy-statement_v1.pdf

[10] Institutional racism in Australian healthcare: a plea for decency. Barbara R Henry, Shane Houston and Gavin H Mooney. MJA Vol 180 17 May 2004

[11] Purdie, Nola; Dudgeon, Pat; and Walker, Roz, "Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice (First Edition)" (2010). https://research.acer.edu.au/indigenous_education/24

Case study: Queensland government legislating to reduce institutional racism

In December 2019 a Bill that paves the way for the elimination of institutional racism in Queensland's HHSs was introduced by the Labor government into Queensland Parliament. If passed, the Bill will make a number of the recommendations that QAIHC has been calling for legally binding on HHSs.

The Health Legislation Amendment Bill 2019 recommends that the Hospital and Health Boards Act 2011 should be updated in three ways:

1) Guiding principles will be embedded into the foundation of the Act:
    a. "a commitment to achieving health equity for Aboriginal and people and Torres Strait Islander people"
    b. "a commitment to the delivery of responsive, capable and culturally competent health care to Aboriginal people and Torres Strait Islander people"
2) All HHSs will be required to develop and publish a "Health Equity Strategy" – a plan to ensure that equitable health services are provided to Aboriginal and Torres Strait Islander peoples. The legislation states that the strategies must be developed through consultation with Aboriginal and Torres Strait Islander peoples.
3) All HHS Boards must have one or more members who are Aboriginal and Torres Strait Islander peoples.

Consideration of Aboriginal and Torres Strait Islander peoples' holistic nature of health and whole-life-view is essential in the development of effective health services. A particularly damaging factor is the assumption within government and public health that past injustices have been resolved and are non-consequential for health policy. Numerous accounts and research, including ethnographic research conducted in Brisbane among Aboriginal and Torres Strait Islander peoples, refute this assumption by confirming an ongoing impact. It is therefore necessary to critically analyse the continuing presence of colonial legacies within the lives of Aboriginal and Torres Strait Islander peoples, as well as implications for the construction of policy, governance, and service provision according to the dominant culture.

Profound intergenerational impacts of trauma inflicted by racist policies, state sponsored discrimination and violence, forced institutionalisation of individuals by government medical officers, the removal of children from families and social marginalisation are visible within the prevalence of mental illness such as depression, violence and self-harm, substance misuse, imprisonment, and inharmonious family relationships.

It is important to consider the relationship and connectedness aspect of Aboriginal and Torres Strait Islander peoples to each other and to the environment as a key determinant for improved health outcomes. The ATSICCHO's evidence-based integrated Model of Care is the true reflection of this approach which further incorporates the holistic concept of Aboriginal and Torres Strait Islander peoples' health and wellbeing. It is essential that the sustainability of ATSICCHOs is ensured so they can continue to deliver and meet community need through the support of capacity development.

3) Lack of availability of any health service, including allied health services:

Australians living in rural and remote areas of Queensland tend to have shorter lives, higher levels of disease and injury, and poorer access to, and use of health services compared to people living in metropolitan areas. 41 per cent of Aboriginal and Torres Strait Islander peoples live outside of Queensland's capital and 17 per cent of Aboriginal and Torres Strait Islander peoples live in Queensland's rural and remote areas.[12]

People living in rural and remote Queensland face a significant range of third world conditions that other parts of the state and country do not have to endure. The health disparities of Aboriginal and Torres Strait Islander peoples amongst rural and remote populations out-weighs non-Indigenous populations. Life expectancy decreases with remoteness; in 2015 people living in *remote and very remote* areas had

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[12] Australian Bureau of Statistics (ABS) 2016 Census data

a mortality rate 1.3 times that of people living in major cities[13]. Aboriginal and Torres Strait Islander men live 6.2 years less, and women live 6.9 years less, than their Aboriginal and Torres Strait Islander urban counterparts[14]. The Closing the Gap Report 2020 states that the target to Close the Gap in life expectancy by 2031 is not on track. The leading causes of death in remote and very remote areas compared with major cities in 2015 were: Coronary heart disease (mortality rates 1.3 times higher); diabetes, (mortality rates 2.3 times higher); suicide (mortality rates 1.7 times higher) and road transport accidents (mortality rates more than 5 times higher)[15]. This doesn't account for the additional challenges experienced by people with a cognitive disability.

Case study: The availability of mental health services in Cape York region.

A study by Hunter et al. in 2012 found that there is a high burden of psychosis in the Aboriginal and Torres Strait Islander populations of Cape York and the Torres Strait Islands, particularly for males. There are stark differences in prevalence rates of psychosis between Aboriginal and Torres Strait Islander populations in the Torres Strait and Cape York regions and urban centers in Queensland. Nationally, 7.7% of Aboriginal and Torres Strait Islander people over 15 years of age have an intellectual disability, however the study showed a substantial difference between rates of intellectual disability between Aboriginal (38.9%) and Torres Strait Islander (6.9%) patients.

Despite the high levels of psychosis in the Cape York region, the amount of outreach specialist psychology services is severely limited compared with demand and split between the HHS, Royal Flying Doctor Service (RFDS) and the ATSICCHO. For example, in Mapoon and Napranum (populations of 300 and 1200 respectively), Torres and Cape HHS provide outreach services from Weipa and a psychologist visits only monthly. Further information on the availability of services in remote Northern Queensland can be provided. on request.

[16]

Health services are not available to the same extent in rural and remote areas compared with more urban settings. More needs to be done to support the HHSs and ATSICCHOs to co-commission, co-design and co-locate services for Aboriginal and Torres Strait Islander peoples within ATSICCHOs and to transition services to community control.

4) Unwillingness to seek support by peoples with a disability:

Past policies and actions continue to influence present day behaviours. For example, poor relationships with child protection and the police, and the ongoing prevalence of intergenerational trauma and institutional racism, have an impact on how families reach out for support.

These barriers mean that individuals and family members may not seek medical or disability related support that they are eligible to receive and which would likely benefit the individual with a disability.

Case study: The normalisation of Fetal Alcohol Syndrome Disorder (FASD)

In the Cape York region of Northern Queensland, FASD is often normalised by community and people with FASD are integrated into community. Families can be reluctant to seek help because of a fear of child removals. Families and the ATSICCHO provide support to individuals which has great benefit, as people are often best cared for by their family. However, the burden of disability-related care that community members carry on a daily basis could be reduced if funding and services were available to help them optimise their lives.

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[13] The Australian Institute of Health and Welfare (AIHW)

[14] Closing the Gap report 2020 - https://ctgreport.niaa.gov.au/life-expectancy

[15](AIHW unpublished analysis of National Mortality Database). ABS (Australian Bureau of Statistics) 2015. National Health Survey: First Results, 2014–15. ABS cat. no. 4364.0.55.001. Canberra: ABS

[16] Hunter et al., (2012). Psychosis in Indigenous populations of Cape York and the Torres Strait, MJA 2012; 196: 133–135 doi:10.5694/mja11.10118 https://www.mja.com.au/system/files/issues/196_02_060212/hun10118_fm.pdf; and Australian Bureau of Statistics; Australian Institute of Health and Welfare. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2008. Canberra: AIHW, 2008. (AIHW Cat. No. IHW 21.)

Question 3b: Can you tell us about any problems that people with cognitive disability have had with the NDIS and accessing health care?

Issues with the NDIA

Disability services have traditionally been a state-responsibility. However, in 2011 the Productivity Commission released an Inquiry Report which spearheaded national reform of the way in which disability services were provided. A Bilateral Agreement between the Commonwealth and Queensland for transition to a National Disability Insurance Scheme (NDIS) was signed in June 2016. Since then, the Commonwealth National Disability Insurance Agency (NDIA) commenced NDIS rollout in Queensland, which was completed in June 2019.

There is a large disparity between known and projected NDIS statistics.[17] These are indicative of major issues that disadvantage an already disadvantaged sub-set minority group of Aboriginal and Torres Strait Islander peoples. Factors impacting on engagement of this sub-set minority group with services include community understanding of the term ‘disability’, remoteness and the availability of culturally safe service providers.

The following barriers are known challenges experienced by many ATSICCHOs when working with people with disability:

- **System level barriers:** unknown population group (poor data and evidence); lack of care coordination opportunities; lack of awareness of obstacles; lack of awareness of systems and supports available; lack of capacity within ATSICCHOs, lack of funding, unconscious bias.
- **Thin market barriers:** insufficient funding to provide culturally safe services, particularly in rural and remote areas; poor access to allied health care services; poor access to health specialist services; lack of infrastructure.
- **Individual barriers:** lack of understanding of ‘disability’; poor engagement with mainstream systems; lack of support available to access NDIS.

QAIHC has consistently advocated to the NDIA about the need for culturally safe, specific disability services and the ongoing low level of representation of Aboriginal and Torres Strait Islander participants in the NDIS. QAIHC has also been supporting our members: most notably, in 2015 QAIHC released guidance for ATSICCHOs on how to prepare for the NDIS[18] and in 2019, QAIHC hosted an NDIS and the ATSICCHO Sector workshop to enable ATSICCHOs to congregate and share best practice ideas to overcome substantial barriers they were experiencing[19].

Despite consistent and repeat attempts to ask the NDIA to work with the community controlled sector[20], and despite multiple formal funding requests[21], QAIHC continues to be unfunded to provide disability-related support to our Members. There is a monumental failure of the National Disability Insurance Agency and other Government departments to respond to the needs voiced by QAIHC and our Members.

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[17] COAG, Disability Reform Council Performance Report – National, 31 December 2019.

[18] QAIHC Guidance for ATSICCHOs on how to prepare for the NDIS (link)

[19] NDIS and the ATSICCHO Sector (link)

[20] QAIHC has invested at least $30,000 in staff time since October 2018 in understanding Member needs, facilitating workshops including the NDIS and the ATSICCHO Sector workshop attended by NDIA Branch Manager for Communities of Practice, National Disability, Acting Director for Workforce Policy, NDIS Market oversight branch, Commonwealth Department of Social Services and the NDIA Director of Queensland Provider and Market Engagement. QAIHC has also worked with the NDIA Director of Community and Mainstream Engagement Branch, contributed submissions to the Thin Market pricing review and supported NACCHO’s submissions to NDIA.

[21] In January 2019 QAIHC applied for $421,000 in the jobs and market fund round 1 to build the capacity and capability of Queensland's Aboriginal and Torres Strait Islander Community Controlled Health Services (ATSICCHSs) to provide NDIS related support to people with a disability. This application was rejected. In October 2019 QAIHC applied for $1.9 million through the Information, Linkages and Capacity building Mainstream Capacity Building Grant to provide targeted activities to support Aboriginal and Torres Strait Islander peoples with a disability and to support ATSICCHOs with resources and tools to assist people with disability in their communities. This application was also rejected.

The result of this lack of investment by the NDIA is that Aboriginal and Torres Strait Islander peoples with cognitive disability (and any disability) are not receiving the level of disability related support that they may need, or would benefit from, from their local ATSICCHO. This includes supporting individuals to understand what a disability is and how the NDIS may apply to them, providing assistance through the application and planning process and with accessing or delivering services once a plan is approved.

Case study: Institute for Urban Indigenous Health's nationally significant NDIA pilot project

The NDIA has funded the Institute for Urban Indigenous Health (IUIH) to pilot a project of national significance in South East Queensland. The pilot is in response to major design flaws in the current 'mainstream' NDIS rollout, which, as recently pointed out in the NDIS Tune Review, continues to manifest substantive fragmentation and lack of cultural safety experienced by Aboriginal and Torres Strait Islander peoples in attempting to access the NDIS. The pilot represents a complete 'recast' of the current Local Area Network access model through the establishment of alternate teams of Aboriginal and Torres Strait Islander staff engaging with potential NDIS Participants through the eligibility testing, pre-planning and Plan build stages. Critically, this new approach is built on cultural integrity, trusted relationships and complete integration with the health care, family support, aged care and disability systems operated by IUIH.

Case study: Gaps between health and disability services for PHaMS clients

A number of mental health support programs are transitioning to the NDIA. These include the Personal Helpers and Mentors Scheme (PHaMs). Apunipima has experienced difficulties with the transition. The type of service provided under PHaMs which suited the needs of individuals with cognitive disability, such as drop in social gathering opportunities, are no longer available under the NDIS.

Case study: Lack of Early Child Early Intervention (ECEI) services in the Cape York region

The Cape York region has not had an ECEI program operational since the ECEI started in 2018. This means that children who may have been eligible for the ECEI, are no longer in the age bracket and may no longer be eligible for ongoing NDIS support. If the ECEI service had been available in their region, the children may have been assessed as needing ongoing support and would have transferred onto the NDIS. The result is that children who require disability support are not eligible to access it because the NDIA failed to provide the necessary infrastructure for the service to exist.

Case study: Availability of specialist and allied health services

On the Sunshine Coast of Queensland, the North Coast Aboriginal Corporation for Community Health (NCACCH) receives high volumes of enquiries from parents needing assistance to get their child/ren into a state special school or to receive additional assistance at a Queensland state school. Often the schools require a paediatric assessment and there is currently an 18-month public waiting list for appointments and no alternative options. NCACCH tries to provide support, however unless clients are eligible for Integrated Team Care (ITC) funding, there is no access to other (private) paediatricians for cognitive assessment. Clients find the waiting process for the paediatrician burdensome and stressful. While waiting for an assessment, the child is not able to access the specialist education or to adequate support.

Apunipima were advised by the NDIA that applications for NDIS Psychosocial disability supports would meet NDIS access requirements with GP evidence sign off and that it was not essential for this signoff to be undertaken by a Clinical Psychologist. Despite this advice, evidence has shown that during the transitioning of Apunipima’s PHaMs client to NDIS, all of the 16 PHaMs clients that had a Specialist Mental Health sign off/assessment had ‘access met’ whereby the 11 that were signed off by the GP were deemed ineligible for NDIS supports. The GP evidence did not carry the weight of a Specialist Mental Health Professional in providing evidence of functional impairment resulting from a permanent disability.

Apunipima does not employ a clinical psychologist, so in order for the organisation to support clients to obtain the necessary functional evidence, clients need to be referred to the Queensland Health Mental Health team for assessment. Existing Queensland Health mental health services are limited and already at capacity providing mainstream services. Access to a specialist mental health professional for assessment is likely to take a significantly long time. Added to this it takes many visits for any health professional in community to develop sufficient trust with the client to obtain an accurate assessment of their functional needs.

There is also a shortage of allied health services, particularly in rural and remote Queensland. Further information on the challenges ATSICCHOs are experiencing in providing allied health services to NDIA clients can be provided on request.

Question 4b: How could the NDIS and health systems work better for people with cognitive disability?

There is a need for the NDIA to work with the Community Controlled health sector to support the development of successful whole-of-journey strategies for Aboriginal and Torres Strait Islander peoples with a disability, including those with a cognitive disability. Disability services for Aboriginal and Torres Strait Islander peoples must be holistic, incorporating the physical, social, emotional, and cultural wellbeing of individuals and their communities.

QAIHC's view is that the Australian Government and other stakeholders should work collaboratively with ATSICCHOs and support to develop ATSICCHO's capability to co-commission, co-design and co-locate disability support services for Aboriginal and Torres Strait Islander peoples within ATSICCHOs. ATSICCHOs are governed by an Aboriginal and Torres Strait Islander board that is elected by members of the local community and they deliver services that build, strengthen and enable self-determination for Aboriginal and Torres Strait Islander communities and peoples.

There is also a need to consider the cause of cognitive disability for Aboriginal and Torres Strait Islander peoples and to invest in preventative projects to reduce the number of peoples with a cognitive disability. While some cognitive disabilities cannot be prevented or are difficult to prevent, many experienced by Aboriginal and Torres Strait Islander peoples are caused by the environment. Cognitive disability could be cause through: prenatal infection, exposure to substances prenatally, prematurity at birth, low oxygen at birth and accidental trauma and asphyxiation as a child and adult. The underlying cause of these causes must also be acknowledged – the history of trauma, loss of culture, lack of self-determination and abuse leading to high risk behaviour and poor mental health. Focusing purely on the flaws of the existing system will not change the system. A fundamental shift is required if real change is to be achieved and this shift must recognise the right of self-determination for Aboriginal and Torres Strait Islander peoples.

For Aboriginal and Torres Strait Islander peoples in Australia, the right to self-determination has been of fundamental importance in improving health and wellbeing outcomes. Self-determination is a principle preserved in international law. According to law, all peoples have the right of self-determination and "*by virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development*".[22] Similarly, according to the United Nations Declaration on the Rights of Indigenous Peoples, "*Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions*".[23]

Transferring responsibility and decision-making power to Aboriginal and Torres Strait Islander communities, so that they can make decisions on matters that affect them, must be central to change that takes place.

Two case studies are provided, which are projects that have been developed by community for community to improve the health and wellbeing of community. These two projects have been highlighted because of their potential to reduce the number of Aboriginal and Torres Strait Islander peoples who have a cognitive disability in the future.

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[22] Article 1 of the International Covenant on Civil and Political Rights (ICCPR) and Article 1 of the International Covenant on Economic, Social and Cultural Rights

[23] Article 23; United Nations Declaration on the Rights of Indigenous Peoples (Resolution adopted by the General Assembly on 13 September 2007) https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf

Case study: Maternity Services Integration Project (MSIP)

The MSIP was born out of QAIHCs involvement in the development of the Queensland Health Growing Deadly Families Strategy which opens by saying "*Aboriginal and Torres Strait Islander babies have a better chance of a healthy start to life when their mothers are healthy, before and during pregnancy, increasing the likelihood of full-term pregnancies and babies being born at a healthy birthweight. Investing in the health of mothers and babies is one of the best ways to improve Aboriginal and Torres Strait Islander health outcomes and prevent chronic disease throughout life".*

Throughout the consultation process, three key issues for improvement were identified. In the words of consumers and stakeholders, these key issues were:

"we want a say in how maternity services are designed and delivered:"

"we don't want to keep telling the same story to different people"

"we want more of our people providing our maternity care"

The MSIP was designed to address the deliverables associated with achieving progress towards the three key identified issues. The project is funded to connect ATSICCHOs with their local hospital, working together to provide streamlined integrated care and an improved maternity experience for mothers birthing Aboriginal and Torres Strait Islander babies.

Case study: Development of the Queensland Aboriginal and Torres Strait Islander Youth Health Strategy

In addition to navigating the transition from child to adult, Aboriginal and Torres Strait Islander youth in Queensland face greater challenges than non-Indigenous youth and do not always enjoy the same opportunities and health and wellbeing outcomes. In Queensland, 70 per cent of the Aboriginal and Torres Strait Islander population is under 34 years old. QAIHC recognises that it is imperative that we listen to our young people to ensure they, and their families, are able to thrive with strong bodies, calm minds and resilient spirits.

The Youth Health Strategy is being developed with Queensland's Aboriginal and Torres Strait Islander young people to address the trauma, disproportionate levels of representation in youth justice facilities, high levels of suicide, high levels of potentially preventable deaths, and challenges of poor social and cultural determents of health that young people struggle with today.

Creating a strong, calm and resilient youth will reduce the levels of cognitive disability amongst the Aboriginal and Torres Strait Islander population in the future and enable advocacy for appropriate, effective disability services.

Conclusion

In order to improve the health system and NDIS for people with a cognitive disability, QAIHC recommends:

1. The Commonwealth Government implement constitutional recognition of Aboriginal and Torres Strait Islander peoples, as requested in the Uluru Statement from the Heart: *"We seek constitutional reforms that will empower our people and to take a rightful place in our own country. When we have power over our destiny our children will flourish. They will walk in two worlds and their culture will be a gift to their country*."
2. The Commonwealth and State government increase investment in community controlled and community-driven, local, place based preventative health initiatives (including healing initiatives) to try to reduce the number of Aboriginal and Torres Strait Islander peoples with potentially preventable cognitive disabilities.
3. The NDIA, Department of Social Services (DSS) and the Queensland Department of Communities, Disability Services and Seniors, the Department of Health and Queensland Health formally recognise, incorporate into disability service delivery, and mandate for:
   a. the vital role of the ATSICCHO holistic Model of Care and self-determination in disability service provision.
   b. ATSICCHOs and QAIHC as preferred providers of NDIA service delivery, either a restrictive selection process or a non-competitive restrictive selection process.
   c. Improvements to care coordination between, and amongst, health and disability services.
4. The NDIA conduct a thorough review of NDIS systems (policy, procedures, programs and funding models) in partnership with Aboriginal and Torres Strait Islander peoples and QAIHC to understand where gaps are present, and address institutional racism failings in a timely manner.
5. The NDIA fund QAIHC to (a) conduct a community needs assessment (data review, consultations with ATSICCHOs, stakeholders and consumers) (b) drive pilot projects to improve NDIS access by peoples with a disability (c) support ATSICCHOs to develop their capacity to provide NDIS services (d) establish an ATSICCHO best practice disability network and to (e) support ATSICCHOs to implement innovative responses to providing disability supports that meet the needs of their communities, including through increasing community awareness, supporting individuals with access to the NDIS, providing NDIS services and workforce development.
6. The NDIA and DSS fund the ATSICCHO sector to develop culturally safe and suitable resources to help individuals understand the NDIS and disability, including cognitive disability. This could include training for health staff on working with an Aboriginal and Torres Strait Islander person with disability. Training must be culturally safe and would aim to address barriers to healthcare access such as unconscious bias, stigma, understanding abilities and communication skills.
7. Health Workforce Queensland, working with the NDIA, QAIHC and other peak bodies, establish a Queensland Aboriginal and Torres Strait Islander disability workforce target and support the development of new and existing disability workforce within ATSICCHOs.

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