17.0
Health and wellbeing

This chapter provides an overview of health and wellbeing in the communities, and examines some key service delivery issues influencing health outcomes.

The Commission has not undertaken a full review of health and wellbeing services—rather, the findings reflect a focus on significant issues impacting on remote and discrete Aboriginal and Torres Strait Islander communities.

Key points

- Indigenous people in remote Queensland experience a burden of disease and injury 2.4 times the non-Indigenous rate—mainly chronic disease, mental disorders, cancers and intentional injuries.

- Socioeconomic determinants (education, income, overcrowding), racism and discrimination play a significant role in the health gap, along with behavioural and environmental risk factors.

- The health system is a multifaceted network of services and settings, involving a variety of public and non-government providers, funding arrangements, participants and regulatory mechanisms.

System issues

- The 'silo' approach to service delivery is problematic for communities. It is difficult to ensure services are adequate, appropriate, coordinated and not unnecessarily duplicated, and meet community priorities and user needs.

- Mainstream mental health services do not meet the cultural needs of Indigenous people, who view social and emotional wellbeing as incorporating individuals, their families and communities.

- Service providers and institutions are not well-equipped to respond effectively to the distress Stolen Generations can experience when using those services—distress that arises from the role of those institutions in past injustices.

- Anecdotally, Foetal Alcohol Spectrum Disorder is prevalent, and access to diagnosis limited.

- Access to healthcare can be problematic—issues include ineffective, nil or confusing referral pathways, lower screening rates and limited access to renal care and rehabilitation centres. There are significant gaps in the Indigenous health workforce.

What is working

- Aboriginal and Torres Strait Islander community-controlled health services provide effective, culturally appropriate and multidisciplinary models of comprehensive primary healthcare.

- Family Wellbeing is an example of a cultural healing program that has been found to increase the capacity of participants to exert greater control over their health and wellbeing.

The reforms proposed by this inquiry can provide an enabling environment for stakeholders to develop collaborative and flexible solutions to these challenges.

17.1 High-level outcomes

Aboriginal and Torres Strait Islanders experience more ill-health and disability than non-Indigenous Queenslanders and are more likely to die at a young age. This disparity is known as the 'health gap'.

Aboriginal and Torres Strait Islander Queenslanders living in remote and very remote areas experience a burden of disease and injury 2.4 times the non-Indigenous rates, compared to those living in major cities (1.9 times) (QH 2017a, p. 13).

In remote areas, the largest broad-cause contributors to disease and injury burden in 2011 were chronic disease, mental disorders, cancer and intentional injuries. Diabetes was the leading specific cause of burden of disease and injury, followed by ischaemic heart disease, anxiety and depression, chronic obstructive pulmonary disease, and suicide and self-inflicted injuries (QH 2017b, p. 28). Compared to the Queensland non-Indigenous rate, Aboriginal and Torres Strait Islander people living in remote areas experienced 3.5 times the expected burden for injuries, and four times the expected burden for communicable diseases, maternal and neonatal conditions (QH 2017b, p. 81).

Chronic disease

Chronic diseases accounted for the greatest burden of disease of remote Aboriginal and Torres Strait Islanders in Queensland. These are non-communicable diseases that evidence has demonstrated could be better prevented and managed in remote locations.

Chronic disease risk factors

Addressing the range of health risks that contribute to chronic disease is a challenge (NRHA Inc n.d., p. 1). Known health risk factors include smoking, drinking and other drugs, family dysfunction, inactivity, poor health literacy, passive welfare, economic and employment disadvantage, gambling, and physical environmental factors including inadequate housing, overcrowding, inadequate food storage and cooking facilities and inadequate public health infrastructure. These can contribute to high rates of injury, obesity, poor nutrition, preventable infections, high sexually transmissible infection (STI) rates, and low personal resilience—resulting in chronic disease and other poor health outcomes (Tsey et al. 2006, p. 24). People in remote areas have poorer oral health, which has also been linked to a greater risk of developing cardiovascular disease, diabetes and respiratory illnesses (NRHA Inc n.d., p. 2).

Reducing exposure to behavioural and physical risk factors could reduce the burden of disease and injury in Queensland's Aboriginal Torres Strait Islander people by up to 37 per cent (QH 2017a, p. 11). For example, more than half of the diabetes, cardiovascular disease and cancer burden (74 per cent, 68 per cent and 50 per cent respectively) could be avoided through the elimination of selected risk factors including obesity, smoking, and physical inactivity. (QH 2017a, p. 43)

Mental disorders

Together in 2011, mental disorders and intentional injuries (including suicide, self-harm, homicide and violence) were the second greatest contributors to disease and injury burden in remote areas, particularly among adolescents and young adults. According to the 2016 Overcoming Indigenous Disadvantage report, wellbeing and resilience problems of young Indigenous people have seen no improvement—these include family violence, psychosocial distress, hospitalisations for self-harm and juvenile detention (SCRGSP 2016 in CQUniversity sub. 7, p. 3).

Australia's Indigenous men have the highest rate of suicide in the world—of this group, the most prevalent rates of suicide manifest in the Cape York and Torres Strait communities (CYI sub. 26, p. 4).

The impacts of mental health and wellbeing issues are felt at the community and individual levels:

> especially when it comes to dealing with a systemic core problem of socio-economic disparity and 'mental health crisis' that is prevalent in remote and discrete communities … the composition of chronic infestation is enshrouded within an invisible film of complex trauma that is filtered through the networks of community settlement bringing a scourge of a silent epidemic that is spreading with no real form of crisis management that is creating social disharmony and dysfunction within our society especially across the greater Mount Isa & Gulf regions. (NWQICSS sub. 23, p. 6)

A study of treated psychotic disorders in the Indigenous populations of Cape York and the Torres Strait found a higher prevalence in the Aboriginal population (2.05 per cent) than in the Torres Strait (0.95 per cent). Male Aboriginal Australians were found to bear the greatest burden of psychosis in these populations. High rates of alcohol and cannabis use were found, and comorbid intellectual disability was common (Hunter et al. 2012).

17.2 Factors affecting health service delivery

Economic and social determinants of health

Between one-third to half of the health gap between Indigenous and non-Indigenous Australians is estimated to be attributable to social determinants (AHMAC 2015), meaning that much of the work to improve health inequalities lies beyond the health sector. For example, chronic disease is best addressed 'upstream' before it has the chance to develop, with a focus on determinants of health including the social and physical environments (Tsey et al. 2006, p. 24).

Increased disadvantage in more remote areas suggests that social determinants would have an even greater impact on health outcomes. Poorer access to services, medications and healthy food sources due to environmental, geographical and cultural factors contribute to higher rates of disease and injury burden in remote parts of Queensland (QH 2017a, p. 13). Households are more likely to be overcrowded, and services such as sewerage, and facilities for food preparation and washing, are more likely not to be working (NRHA Inc n.d., p. 8). Employment and incomes tend to be lower, impacting on the ability of remote living Indigenous people to access health and community services, including transport and communication (NRHA Inc n.d., p. 8).

Health and wellbeing issues are compounded by the effects on the Stolen Generations and their immediate family and descendants. This group:

> are around 50 per cent more likely to have been charged by police, 30 per cent less likely to report being in good health, 15 per cent more likely to consume alcohol at risky levels and 10 per cent less likely to be employed compared to other Indigenous people in Australia (Anderson & Tilton 2017, p. 19)

In some cases, trauma is passed down to future generations (Box 17.1).

Box 17.1 Intergenerational trauma definition

The subjective experiencing and remembering of events in the mind of an individual or the life of a community, passed from adults to children in cyclic processes as 'cumulative emotional and psychological wounding'.

Source: Anderson & Tilton 2017, p. 22; Atkinson 2013, p. 5.

These challenges contribute to many of the issues faced in communities, including family violence, substance abuse and self-harm (Anderson & Tilton 2017, p. 4). Misdiagnosis can result in ineffective therapeutic interventions (Nadew 2012, p. 3). A holistic approach is needed to address the full spectrum of stressors at the community and individual levels, and to tackle mental illness and substance-use disorders (QH 2017b, p. 32).

A holistic view of health and wellbeing

Aboriginal and Torres Strait Islander culture has a holistic view of health that includes physical health, mental health, and other factors such as cultural, spiritual and social wellbeing.[66] The wellbeing of communities and families is as important as that of individuals (QMHC 2016, p. 6).

Social and emotional wellbeing and empowerment are key components of a holistic view of health. Social and emotional wellbeing can be defined as:

> *being resilient, being and feeling culturally safe, having and realising aspirations and being satisfied with life. (QMHC 2016, p. 6)*

Social and emotional wellbeing is a significant protective factor against the worst impacts of stressful life events. It protects against some mental illnesses, suicide and problematic alcohol and other drug use, and supports recovery. Social and emotional wellbeing improves life outcomes including educational, employment and economic participation, physical health and mental health (QMHC 2016, p. 6).

Empowerment involves people assuming control and mastery over their lives. Recognised by the World Health Organisation as a viable strategy for improving individual and community health outcomes and quality of life, empowerment must be promoted across all service areas if success is to be possible (Wallerstein, in Tsey et al. 2006, pp. 10–12).

> A key lesson from the COAG Indigenous community coordination trials and the Northern Territory Emergency Response is that engagement with Indigenous Communities is essential to achieve measurable improvements in economic, health and social indicators. (SCRGSP 2009, p. 71)

17.3 The health system

The health system is defined as 'all the activities whose primary purpose is to promote, restore and/or maintain health' (WHO 2000, p. vii). Major types of health care include primary and secondary care (Box 17.2).

Box 17.2 Primary and secondary health care

Primary health care includes health promotion, prevention and early intervention, treatment of acute conditions, and management of chronic conditions.

Secondary care is medical care provided by a specialist or facility (such as a hospital) upon referral by a primary care physician.

Source: AIHW 2016, p. 2.1

Health services to rural and remote Aboriginal and Torres Strait communities are a complex arrangement of providers, funding, and regulatory mechanisms. An overview is provided at Box 17.3.

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[66] Wellbeing is defined as a state of health or sufficiency in all aspects of life, including health, social well-being, economic well-being, environmental well-being, life satisfaction, spiritual or existential well-being, and other characteristics valued by humans (Tsey et al. 2006, p. 12).

Box 17.3 Health system roles and responsibilities

Australian Government funds and commissions:

- universal public health insurance (Medicare), subsidising medical services and pharmaceuticals

- population health programs, community health services, health and medical research

- jointly funds public hospitals; Aboriginal and Torres Strait Islander health services

- outreach health programs including chronic disease, hearing, optometry.

Queensland Government:

- manages and jointly funds public hospitals; delivers and commissions primary health care services

- funds and delivers chronic disease prevention and management services (including dental services) through community health centres, public hospitals (outpatient units, outreach programs, inpatient services) and Aboriginal Community Controlled Health Services.

Local governments deliver:

- community-based health and home care services; public health and health promotion activities including immunisation services

- environmental health-related services (for example, water and sanitation services, food inspection).

Community controlled health organisations:

- culturally appropriate and multi-disciplinary models of primary healthcare, with a social and emotional wellbeing focus and a view of the individual as part of the family and community

- services include Indigenous health practitioners, outreach midwives, podiatrists, audiologists, physiotherapists, dietitians and nutritionists, diabetes nurse educators, paediatricians and GPs.

Apunipima Cape York Health Council:

- the largest remote community controlled health organisation in Queensland, delivering integrated wellbeing and primary health care services to 11 Cape York communities.

Royal Flying Doctor Service:

- grant funded by the Australian Government to deliver emergency retrieval, essential health care and general practitioner services in remote and very remote locations

- contracted by Queensland Government to deliver some services in Cape York communities.

Private sector:

- private hospitals; medical practices; pharmacies; allied health services

- limited presence in the remote and discrete communities.

Sources: AIHW 2014, p. 2.1; QH 2015; Tsey et al. 2006, p. 9.

A good health system is one that 'delivers quality services to all people, when and where they need them' (WHO 2015). However, stakeholders have advised that the effectiveness, efficiency and equity of health services for communities is hampered by duplication and gaps, inappropriate service delivery models, and a mismatch with community priorities. Access is hindered by cultural and language barriers, lower levels of service availability and distance. These issues are discussed in the following section.

Duplication and gaps

Communities have multiple local, state and Australian government providers visiting to provide specific services. For example, in Coen—a small community of around 400 people—there are two primary health care facilities less than 100 metres apart: 'two separate buildings, each separately staffed, delivering primary health services and using separate patient records in one small community' (CYP sub. 26, p. 9). A lack of coordination and communication between services gives rise to issues including duplication and gaps in service delivery, over-servicing, sub-optimal referral pathways, and no shared tracking of outcomes. CheckUP provided an example that typified broad concerns:

> (CheckUP) … facilitated a stakeholder meeting between a local discrete Aboriginal and Torres Strait Islander community medical centre, the local HHS facility, the State run Healthy Hearing program, a Commonwealth Hearing program, the regional HHS tertiary hospital ENT service and CheckUP's funded visiting audiologist. Although all of these providers were linked together in their goal to improve the hearing health of Aboriginal and Torres Strait Islanders, some providers were not aware that there were other services visiting, or of the range of services currently being provided. They were also not aware that they were able or how they could refer to others; not aware that their own referral criteria could restrict external organisations' access; were servicing some groups multiple times while other groups inadequately; and finally there was no shared database or way of tracking whether patients entering the system were progressing through to achieve an outcome. One provider commented that they had waited five years for a meeting like this to occur. (CheckUP sub. 10, p. 9)

Another stakeholder observed that:

> Much of the money seems to go to duplicating organisational infrastructure, head offices, HR etc. and duplicated services from multiple organisations. It has also become very political and competitive with funding given out in lots of little bucket for organisations to fight over … you go to a remote community all of a sudden there's conditions on using certain staff and funding streams only for certain conditions. Real people don't work like that. (Wieland sub. DR21, p. 1)

Gap: suicide prevention

Submissions to this inquiry suggest a mismatch between services and community priorities, such as addressing the root causes of suicide. For example, there are concerns that:

> suicide and criminal activity are disproportionate amongst youth in Doomadgee … there is 'nothing for them to do'—with no facilities or effective programs; and that the solution is on-country education programs that have previously been proposed but not support or funded … concern that funding is spent on a plethora of duplicated externally provided services, rather than capacity building and employment opportunities within the local Indigenous community. (Burke Shire Council sub. 25, p. 1)

In Yarrabah:

> suicide prevention funding which employed staff in Yarrabah was reallocated to Lifeline, and is now absorbed into their overarching funding. Previous local support has been replaced by the 1800 phone number which is insufficient and unacceptable for Yarrabah's specific and highly acute needs. (YASC sub. 11, p. 10)

Suicide is a significant health challenge in communities. Cultural continuity has been recognised to be an important protective factor, giving a sense of ownership of the past and the future:

> *If, owing to some train of personal or collective mishaps, single individuals or whole communities lose track of themselves in time and thus suffer some disconnect with their past or future, life becomes cheap. (Lalonde & Chandler 2008)*

Research among Canada's First Nations found suicide rates were largely unrelated to measures of poverty and isolation, but strongly related to measures of cultural continuity. Measures of cultural continuity include efforts to regain forms of self-government and legal title to traditional lands, reassert control over community and social services, and to preserve and promote traditional cultural practices (Lalonde & Chandler 2008).

The Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project identified potential success factors for Indigenous suicide prevention programs, led by communities (Box 17.4).

Gap: Disabilities and Foetal Alcohol Spectrum Disorder

Concerns were raised by stakeholders about gaps in the diagnosis of disabilities and delivery of disability services. Aboriginal and Torres Strait Islander people have substantially higher rates of disability than non-Indigenous Australians (AIHW, 2011b). However, many living in remote communities are reluctant to identify as having a disability and may not receive the support services. Remoteness further impacts on the availability of disability support services (Griffis 2012; Queensland Government sub. 27, p. 5).

National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is being progressively rolled out across Queensland–it is already available in the Gulf region, with other regions including Cape York and Torres Strait to follow in 2018 (NDIA 2017). The NDIS provides individualised packages of support to eligible people with disability, and creates increased opportunity for disability services to be delivered by Aboriginal and Torres Strait Islander organisations. There are challenges that need to be overcome in the remote and discrete communities for the full potential of the NDIS to be realised (Box 17.5).

Box 17.4 Community led suicide prevention programs

Primordial prevention[67]:

- addressing community challenges, poverty, social determinants of health

- building identity, social and emotional wellbeing (SEWB) and healing

- Reducing alcohol/drug use.

Primary prevention:

- gatekeeper training—Indigenous-specific

- awareness-raising programs about suicide risk—use of DVDs with no assumption of literacy.

Young people:

- peer-to-peer mentoring, and education and leadership on suicide prevention

- programs to engage/divert, including sport and connecting to culture/country/Elders.

Clinical elements:

- access to counsellors/mental health support—24/7 availability

- awareness of critical risk periods and responsiveness at those times

- crisis response teams after a suicide/postvention.[68]

Community leadership, including:

- community empowerment, development, ownership—community-specific responses

- involvement of Elders and cultural elements in programs.

Provider:

- partnerships with community organisations and ACCHOs

- employment of community members/peer workforce.

Source: ATSISPEP 2016, p. 3.

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[67] Primordial prevention is the prevention of risk factors themselves, beginning with change in social and environmental conditions in which these factors are observed to develop, and continuing for high risk children, adolescents and young adults.
[68] A postvention is an intervention conducted after a suicide, largely taking the form of support for the bereaved (family, friends, professionals and peers).

Box 17.5 NDIS challenges

Barriers to accessibility

- Limited understanding amongst communities and remote health services about what the NDIS is, what it is for and how to access and use it.

- It is difficult to navigate the NDIS system and information is not culturally accessible.

- The use of inappropriate language – some communities have no local words for 'disability', making it hard for them to understand what a disability is, or to feel comfortable using the word or identifying as a person with a disability. The terms 'insurance' and 'carer' can be misleading and confusing.

- There is a lack of disability services in remote communities.

Service providers

- Limited support is available to assist local Aboriginal and Torres Strait Islander organisations to understand and register under the NDIS.

- There is a shortage of Indigenous disability workers, who can play an important role in encouraging and supporting community members to understand and sign up for the NDIS.

Source: ADA Australia sub. DR6, p. 2.

Foetal Alcohol Spectrum Disorder

Foetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a range of impacts caused by exposure to alcohol in the womb. The consequences vary along a spectrum of disabilities including physical, cognitive, intellectual, learning, behavioural, social and executive functioning disabilities, and problems with communication, motor skills, attention and memory.

Concerns about the prevalence of FASD in the remote and discrete communities were raised in submissions. For example:

> Amnesty International has heard repeatedly from communities, service providers and government about limited access to diagnosis for FASD. The effects that this has on ATSI [Indigenous] children, particularly as an identified contributing factor towards the overrepresentation in the justice system, must be taken into consideration in the delivery of services in remote and discrete Indigenous communities. (Amnesty International Australia sub. 13, p. 3)

The need for some form of antenatal intervention was canvassed:

> FASD is prevalent in remote Aboriginal communities. Some form of ante-natal intervention is warranted. Current legislation does not provide services any opportunity for intervention in situations where pregnant mothers-to-be are clearly consuming alcohol at levels harmful to the unborn foetus. At what point does this activity constitute knowledgeable and avoidable harm such that some loss of liberty is warranted. Consideration could be given to prioritising family rehabilitation for families with expectant mothers at venues such as the Cape York Family Centre near Cooktown. (Hannan sub. 24, p. 4)

FASD can have adverse, life-long consequences including inappropriate sexual behaviour, crime, psychiatric problems and alcohol and drug abuse. Lack of early diagnosis (before 12 years of age) has been indicated as one of the strongest correlations with adverse outcomes (Streissguth et al. 2004).

The prevention of FASD can improve mental health of children including intellectual, cognitive and learning abilities, speech and language, and behaviour and emotional wellbeing. This requires working with communities to inform and underpin interventions with an understanding of the complexities of alcohol consumption during pregnancy. Early detection of FASD to prevent secondary disabilities such as mental health problems and chronic diseases is also important.

What works: Community health assessment

Remote and discrete Aboriginal and Torres Strait Islander communities are highly diverse, suggesting a one-size-fits-all approach is unlikely to be successful. A way to manage this is for local people to be engaged in the development of measures so that they reflect local needs and characteristics. Good information is needed about the current health status of the community, and factors that will influence that health status, to effectively plan and prioritise services. An assessment of a community's health can help the community to work with professional organisations and service providers in prioritising appropriate prevention activities and response services. Community health assessments are outlined in Box 17.6.

Box 17.6 Community health assessment

A community health assessment is a process of community engagement including:

- collection and interpretation of data on health outcomes, correlates and determinants

- identification of health disparities

- identification of resources that can be used to address priority needs.

The assessment is informed by a common set of health status metrics to:

- facilitate comparisons across populations

- promote collaboration between organisations conducting assessments

- assist in establishing a shared understanding of the factors that influence health

- help to galvanise residents to work collaboratively to improve community health.

Source: CDCP 2013, p. 1.

A partnership approach informed by a community health assessment can address existing problems in an effective and prioritised way that makes the best, most cost-effective health choices possible (CDCP 2013, p. 1).

Accessibility

Access to primary health care is critical for improving health outcomes. Mortality data suggests that in remote areas, fewer chronic diseases are detected before advanced presentation, representing significant inequality in access to appropriate and timely diagnostic and treatment services (NRHA Inc n.d., p. 1). Issues with access to health care lead to poorer health outcomes as diagnosis and management of conditions is delayed.

> *When Indigenous people are diagnosed with cancer, it's usually late stage cancer, which means survival rates are lower. Screening rates are a lot lower for Indigenous people. (Dr Al-Yaman, in Hunter & Gordon 2017)*

Models of health care are needed that maximise participation by Aboriginal and Torres Strait Islander people. Even though remote living Aboriginal and Torres Strait Islander people suffer a burden of disease 2.4 times greater than the non-Indigenous Queensland population, their access to many services is significantly lower than for the general population (QAIHC 2011, p. 9). The accessibility of health services to communities is influenced by the effectiveness of the health workforce, barriers to cultural safety, the level of involvement of communities in planning and program design and delivery, and the degree to which services are effectively integrated (Queensland Health 2015, p. 9).

Health workforce

Organisations delivering services in remote areas have specific workforce challenges, including attracting and retaining people with the skills and experience needed to deliver complex services, connectivity and access to training (Queensland Government sub. 27, p. 9). Because of workforce shortages across many health professional groups in remote and discrete communities, people are frequently unable to access the health care they need at the time they need it—if at all. Combined with greater health need and socioeconomic disadvantage, poorer access to primary care leads to increases in hospitalisations that might have otherwise been preventable.

Workforce challenges have two aspects—the relatively small number of Indigenous people in the health workforce and the shortages of workers, particularly health professionals. An overview of the health workforce and issues of shortages in remote communities is at Box 17.7.

Box 17.7 Health workforce

General practitioners (GPs)

- GPs in very remote areas are half the number per capita compared to major cities.

- Remote GPs work longer hours and perform a broader range of tasks due to fewer other health professionals being available.

- Limited access to quality and timely primary care through a local GP leads to a higher prevalence of chronic disease.

Nurses

- They are often the first point of contact for a range of primary care functions that would normally be provided by GPs, specialists and allied health professionals.

- They are often the sole primary care provider in the community.

- Nurses are frequently required to extend their skills due to the diverse health needs of their community and the lack of any other form of health personnel support.

Aboriginal health workers (AHW)

- AHW comprise only 1.4 per cent of the health workforce, while Aboriginal and Torres Strait Islander people make up 3.5 per cent of the population (Qld).

- They are often the first point of contact in the primary care setting.

- AHW are critical and integral to ensuring culturally appropriate, effective health services.

Allied health professionals

- They play a vital role in the prevention and management of chronic disease.

- Examples of these professionals are dietitians, diabetes educators, exercise physiologists.

- There are less than half the number of allied health professionals in remote/very remote areas compared to major cities.

Dental professionals

- Dentists, dental hygienists, dental therapists, dental prosthetists and oral health therapists are classified as dental professionals.

- People living in remote/very remote areas have significantly poorer oral health and limited access to dental services—around one-third the number of dentists compared to major cities.

- Poorer oral health has been linked to a greater risk of cardiovascular disease, diabetes and respiratory illnesses.

Source: NRHA Inc n.d., pp. 3–5.

The need to 'train and recognise an Indigenous health workforce and a workforce for Indigenous health, and up-skill our health workforce to provide culturally appropriate services' has been identified by the Health and Hospitals Reform Commission (QAIHC 2011, p. 19). Existing training is also unlikely to support health, mental health providers and institutions (such as aged-care facilities) to respond effectively to the increasing distress Stolen Generations and their descendants might experience by coming into contact with these services, often agents of harm from their past (Anderson & Tilton 2017, p. 30).

Greater Indigenous representation in the health workforce would go a long way to solving these issues. Indigenous health workers are recognised to be immensely important to the health and wellbeing of Aboriginal and Torres Strait Islander people and their communities. Their significance to the engagement of communities in their own primary health care is recognised nationally and internationally (QAIHC 2011, p. 10). Substantial gaps in Indigenous participation in the health workforce pose a major challenge to achieving health outcomes.

What works—increase the workforce capacity

The National Rural Health Alliance identified innovative chronic disease prevention and management programs being trialled or run in rural Australia that could complement initiatives to increase workforce capacity. For example, upskilling local staff, usually nurses, so that they could provide pulmonary rehabilitation to local patients, was found to be effective—rural and remote patients with chronic lung disease were able to access treatment previously unavailable to them, and patient outcomes were improved (NRHA Inc n.d., p. 16).

Other options include: recognition of lived experience or life skill where formal qualifications do not exist; support and incentives for current workers to access higher education including traineeships and on the job training; and increased opportunities for Aboriginal and Torres Strait Islander people to apply for identified positions (ADA Australia sub. DR6, p. 3). Person-centred care (below) that enables more people to self-manage chronic conditions would have the combined benefits of better outcomes for patients and freeing up health workforce capacity.

What works—interventions outside the health system

Significant health benefits also stand to be gained through interventions outside the health system. For example, involving Aboriginal people in land management has been found to improve health outcomes and reduce the costs of primary care. After adjusting for relevant sociodemographic factors and health behaviours, it was found that Aboriginal people involved in land management had significantly less chance of developing diabetes, kidney disease and high blood pressure (NRHA Inc n.d., p. 17).

Barriers to cultural safety

Research has shown that in Australia, culturally unsafe healthcare practices contribute to negative health outcomes for Indigenous Australians.

Where "business as usual" health care is perceived as demeaning or disempowering – that is, deemed racist or culturally unsafe – it may significantly reduce treatment adherence or result in complete disengagement, even when this may be life threatening. (Laverty et al. 2017, p. 15)

A high rate of hospital discharge against medical advice (8 times higher in Aboriginal peoples than non-Indigenous Australians) is an indirect indicator of the cultural responsiveness of hospitals.

Barriers to cultural safety in the Australian healthcare sector include an inadvertent reliance on stereotypes, language difficulties and the inherent power imbalance between provider and patient. Aboriginal peoples have been found to have fewer opportunities to voice their concerns, and limited opportunity to engage as partners in decision-making about their care (Couzos & Delaney Thiele 2016). These factors are often exacerbated by, or occur alongside, a lack of understanding about Indigenous concepts of wellness.

Cultural safety results where recipients are empowered in their interactions with the health care system, and there is a patient-centred approach involving them in decision making as part of a team effort. Culturally safe care is mindful of and responsive to difference (Laverty et al. 2017). For example, Schultz (in Laverty et al. 2017) notes that the connection between Indigenous Australians and their country has long been overlooked in healthcare settings. Issues of cultural safety and the accessibility of renal care were raised by stakeholders to this inquiry, and echoed in the work of the Menzies School of Health Research (Box 17.8).

Box 17.8 Renal care

Stakeholders to this inquiry have raised issues about access to renal care.

Diabetes is prevalent in the remote and discrete communities, and can lead to chronic kidney disease (CKD) and renal failure. Most haemodialysis[69] services are far from community.

A study by the Menzies School of Health Research (MSHR) found that many Indigenous kidney disease patients abandon dialysis due to the difficulty of dislocation from their community, culture and country —they think that dying would be a more satisfactory option (Marks 2017).

The MSHR reported that patients and carers did not believe the current models of renal care were fit-for-purpose. Patients identified the tremendous healing provided by being in their lands, in those places where they have real status as persons (as opposed to 'factory line' patient). They called for:

- renal care close to home that must provide cultural safety and include a workforce membership from their own community

- a strengthened partnership with primary health care and meaningful health promotion in relation to chronic disease awareness and education (Hughes et al. 2017).

The MSHR recommends an overhaul of the system. Better patient outcomes would be achieved by locating dialysis chairs in communities, and teaching patients how to manage their disease themselves.

There is potential to reduce costs—peritoneal, home or even satellite haemodialysis could all deliver savings compared to haemodialysis delivered in hospitals (KHA 2016).

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[69] Haemodialysis is a medical procedure to remove fluid and waste products from the blood and to correct electrolyte imbalances. This is accomplished using a machine and a dialyzer, also referred to as an "artificial kidney". Haemodialysis is used to treat both acute (temporary) and chronic (permanent) kidney failure.

Recommended responses are to increase Aboriginal and Torres Strait Islander representation in governance and in the health workforce and move to more community control of primary health. Increased public accountability for Indigenous health outcomes, and mandated standards of organisational change may be necessary to overcome barriers thrown up by institutional resistance, evident in gatekeeping, marginalisation or underfunding (ADCQ 2017; Laverty et al. 2017).

Community control and integration of services

Many Aboriginal and Torres Strait Islanders in remote and discrete communities have complex health needs requiring access to multiple services in a wide range of areas including health, housing and community supports. The Commission was told that having to retell their story to multiple service providers and workers is difficult, and creates barriers to access and effective service delivery. Some services do not wish to collaborate with others, for example by referral, due to concerns regarding access to funding. Services could better work together in a collaborative approach that puts the needs of the service user at the centre (QMHC 2016, p. 13).

Primary health care

Increased community control in the design, delivery and monitoring of primary health care services can lead to innovative service delivery and is recognised to be a key factor for improving Indigenous health indicators (Reeve et al. 2015; Tsey et al. 2006). Culturally effective programs designed and delivered by the local community have demonstrated improved uptake and outcomes. For example, Lavoie et al (2010) found that communities with better local access to primary health care consistently show lower rates of Ambulatory Care Sensitive Conditions (ACSC),[70] and the longer community health services have been under community control, the lower its ACSC rate.

By accessing better primary health care services, communities may achieve better prevention, early intervention and management of health conditions, fewer preventable hospital admissions and long-term health gains (Queensland Government 2011, p. 7). The importance of an increased focus on primary health care in the remote and discrete communities is evident in the following examples (Box 17.9).

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[70] Ambulatory Care Sensitive Conditions are defined as "those diagnoses for which timely and effective outpatient [primary] care can help to reduce the risks of hospitalization by either preventing the onset of an illness or conditions, controlling an acute episodic illness or conditions, or managing a chronic disease or condition" Billings et al. 1993, in Lavoie et al. 2010, p. 2.

Box 17.9 The importance of primary health care (PHC)

Effective primary health care can help prevent:

- Acute rheumatic fever/rheumatic heart disease. It starts as a Group A Streptococcal infection of the throat (and perhaps skin) which may result from overcrowding and poorly functioning health hardware in housing. Lack of access to appropriate PHC limits early preventive treatment and facilitates the development of acute rheumatic fever. Continuing lack of access to appropriate PHC further exacerbates this issue culminating in rheumatic heart disease, an expensive and complex disease that contributes to the life expectancy gap in ATSI communities.

- Chronic kidney disease (CKD). If CKD is detected early and managed appropriately, then the otherwise inevitable deterioration in kidney function can be reduced by as much as 50% and may even be reversible.

- Persistent and recurring ear infections, which may lead to hearing loss if not appropriately followed up in PHC. They can result in learning difficulties and involvement with the criminal justice system/incarceration. The Deadly Ears program delivers culturally effective hearing and ear health services for Aboriginal and Torres Strait Islander children in Queensland.

- Syphilis. A syphilis epidemic that started in North Queensland Indigenous population in 2011 has since spread to the Northern Territory, Western Australia and South Australia. It has caused congenital deaths and abnormalities, and has been linked to rising Human Immunodeficiency Virus (HIV) rates. Syphilis is preventable and controllable; the epidemic signals a failure in the PHC system.

Sources: AIHIN 2017; KHA 2016; QAIHC sub. DR16.

The Australian Productivity Commission (PC 2017d, p. 11) recently highlighted the importance of a shift to patient-centred care (PCC):

> *All Australian governments should re-configure the health care system around the principles of patient-centred care, with this implemented within a five-year timeframe.*

Health care providers who are orientated to PCC can enhance their patient's capacity for chronic disease self-management, and are more likely to satisfy their patients, and improve the quality of life. PCC can deliver concomitant reductions in mortality, improved shared decision-making to reduce antibiotic overprescribing, and reductions in hospitalisation (Coxeter et al. 2015; Heneghan et al. 2016; Ory et al. n.d.).

Aboriginal and Torres Strait Islander Community Control Health Services deliver patient-centred, primary health care (PHC) through their community-controlled health service model.

Aboriginal and Torres Strait Islander Community Controlled Health Organisations

Aboriginal Community Controlled Health Organisations (ACCHOs) have demonstrated the effectiveness of the community-controlled model (Box 17.10).

Box 17.10 Aboriginal Community Controlled Health Organisations

More than 150 ACCHOs across Australia are responsible for managing and delivering comprehensive and culturally appropriate primary health services to their communities. The ACCHO model of integrated care is in keeping with the philosophy of Aboriginal holistic health.

An assessment of the Aboriginal community controlled health services found they have reduced unintentional racism and barriers to access to health care, and are progressively improving individual health outcomes for Aboriginal people.

Primary health care data show the ACCHOs are consistently improving performance in key performance on best-practice care indicators, and demonstrate superior performance to mainstream general practice.

ACCHOs also play a substantial role in training the medical workforce and employing Aboriginal people.

ACCHOs are funded by the Commonwealth through the Medical Benefits Scheme and block grant funding, though they have faced a loss of funding for their policy role which is seen to be a critical element of their success.

With commensurate and secure funding arrangements, ACCHOs are an effective model for all levels of government to re-think the way they work with Indigenous communities.

Source: DPMC 2015; Panaretto et al. 2014.

ACCHOs play a critical role in supporting community decision making, participation and engagement in health care. This is fundamental to effective primary health care and ensures that services are provided to meet community needs in a holistic and culturally appropriate way (QAIHC 2011, p. 28). The model of care is team-based more so than general practitioner-focused. Care is patient-and-family-focused, with significant physician input and integration with allied health specialists, mental health professionals and community services (Panaretto et al. 2014, p. 649). Broader benefits of community controlled health services include greater local participation in the health workforce, and improved self-determination and empowerment of Aboriginal and Torres Strait Islander people and communities.

The Queensland Government and Apunipima Cape York Health Council are progressively transitioning some Cape York primary health care services to community control (Chapter 8). Effective transition of healthcare services to community control is critical to ensure constancy of care. In Australia, unrealistic timeframes, underdeveloped change management processes, inflexible funding agreements and distrust have complicated the implementation process (Lavoie & Dwyer 2016). The transfer of clinical or patient notes, and retention of at least some of the health care staff after transfer to community control are important to ensure continuity (Lavoie et al. 2010). Stakeholders to this inquiry have highlighted such issues in relation to the transfer of some primary health care services to community control in Cape York, for example:

> just the way it's set up and the politics behind it and what they've been allowed to take over or what they've been allowed to get funding for has not allowed them to provide comprehensive primary health care … some of the organisations really did get set up to fail and they don't get given the resources they need to do the job properly … (Wieland sub. DR21, p. 2)

Lessons from Canada point to the need for a firm long-term commitment to transition, adequate resourcing of communities to support change management, and accountability frameworks tailored to the Indigenous primary health care context (Lavoie & Dwyer 2016).

Mental health care accessibility

Stakeholders to this inquiry have raised issues with the accessibility of some mainstream mental health services. Barriers include inappropriate models of care, and a lack of clear funding processes for preferred community-controlled models of care (Anderson & Tilton 2017, p. 43). Concerns regarding mental health services accessibility were raised by the Lockhart River Aboriginal Shire Council (Box 17.11).

Box 17.11 Accessibility of mental health services

The CEO of Lockhart River Aboriginal Shire Council believes there are problems with accessibility and raises the issue of a mental health counselling service where the three practitioners fly in on a Monday and fly out on a Friday. Their office is located within public view near to the local store.

The CEO indicated:

> To be effective mental health counsellors you need to mix with and get to understand the community … where the risks might lie … you need to get out of the office and do the vital outreach needed for a vibrant health service … not sit in an office and wait for community members to come to you … people feel shamed and don't want to be seen entering the office.

He also raised the concept of 'efficiency dividend', questioning the cost of fly in, fly out counsellors (for example, $1,100 return airfare per person every week) and asking at what point in time it becomes more efficient to fund a full-time mental health counsellor living within the community.

> Lockhart River Aboriginal Shire Council has experienced significant trauma, a suicide, rape, and domestic violence in recent months, and needs a commitment to "on the ground" service provision. Mental health issues do not just arise on Tuesday to Thursday of each week. This community has been traumatised and needs support.

Source: LGAQ sub. 14, p. 8.

The National Centre for Family Wellbeing describes wellbeing as:

The concept of social and emotional wellbeing (SEWB) merges the population health paradigm and an Indigenous Australian worldview in which spirituality is recognised as a key element of health. SEWB is premised on Indigenous views of health as holistic, involving spiritual, social, emotional, cultural, physical and mental wellbeing, and issues related to land and way of life. It supports the view that Indigenous health inevitably relates to colonisation, history, racism and social factors, all of which need to be addressed as part of effective service delivery. (NCFW sub. 16, p. 1)

Examples of SEWB protective factors include:

cultural continuity, self-determination and community control, good mental health and wellbeing, social support, resilience, problem solving skills and strategies for coping with stress. (NCFW sub. 16, p. 2)

Risk factors include:

cultural or religious conflicts, no social support networks, at risk mental status, recent interpersonal crisis, loss or trauma, family breakdown, child custody issues, influence of alcohol or drugs, difficulty accessing help; financial difficulties, unemployment, legal prosecution, illness. (NCFW sub. 16, p. 2)

Early intervention and management of mental health and substance use are critical to prevent exacerbation of symptoms (Queensland Health 2017b, p. 31). Yet it is recognised that the provision of mental health services for Aboriginal and Torres Strait Islander people is both inadequate and inappropriate (NMHC 2012, in Dudgeon et al. 2014, p. 2).

Conventional mental health services may not fully meet the Aboriginal and Torres Strait Islanders' holistic view of health and wellbeing, incorporating differing cultural values and needs than the mainstream. This means that even where mental health services are physically available in a community, the level of access by Aboriginal and Torres Strait Islanders is unlikely to reflect the level of need (Queensland Health 2017b, p. 32).

The accessibility of rehabilitation services was also raised as an issue:

Rehabilitation centres are difficult to access. Centres servicing Cape York are in Yarrabah and Townsville and this requires a long and expensive journey. Also the removal from country impacts the individual emotionally. A rehab centre located more centrally on Cape York and near bushland rather than the trappings of large cities would have benefit … (Hannan sub. 24)

What works—mental health and wellbeing

Effective strategies to strengthen the mental health and wellbeing of Aboriginal and Torres Strait Islander people are identified in Box 17.12.

Box 17.12 Characteristics of mental health programs that work

Programs that show promising results for Indigenous social and emotional wellbeing are those that encourage self-determination and community governance, reconnection and community life, and restoration and community resilience.

- Important features include a holistic approach; focus on recovery and healing; empowering people to regain a sense of control and mastery over their lives; strategies that are Indigenous-led, family-focused, culturally responsive, and context-specific; interdisciplinary approaches that provide outreach services and transport; partnerships with ACCHOs and local communities.

- There is evidence that both mainstream and Indigenous-specific programs and services that adhere to principles of engagement, access, integration and accountability are more effective.

- Programs that involve Indigenous families and communities in developing, implementing and evaluating programs tend to foster a more culturally responsive and safe environment for users.

- engaging in cultural activities is an indicator of positive cultural identity that is associated with better mental health among Indigenous Australians.

Source: Dudgeon et al. 2014, p. 2.

Health and wellbeing services that are designed and delivered either in a real partnership with communities, or wholly by communities, have been recognised to effectively improve the social and emotional wellbeing of Aboriginal and Torres Strait Islanders. Models demonstrated to be effective include the Cape York Wellbeing Centres, integration of wellbeing and primary health care services, and the Family Wellbeing Program.

Cape York Wellbeing Centres

Jointly funded by the Australian and Queensland Governments, the four Wellbeing Centres (WBCs) were established to contribute to the change in behavioural and social norms, through culturally appropriate services that assist individuals and their families to maintain or return to positive social and emotional wellbeing. The WBCs focussed on issues such as drug and alcohol misuse, gambling, mental health and wellbeing, and family violence. Activities were guided by Local Advisory Groups, local staff members, Elders and other community stakeholders to reflect the specific community needs.

An evaluation commissioned by the Australian Government found that the WBCs had a clinically and statistically significant positive effect on the mental health on their clients. Anecdotally, individual change was having a positive effect on some families within the communities. However, the evaluation noted 'there can be no quick fix to rectify challenges that have been decades in the making'. It was considered unlikely that sustained significant change would be observed at the community level unless there was another significant positive enabler of change in the communities, for example the availability of employment. The evaluation report recommended that the WBCs be integrated within a primary health care setting, to improve service delivery and client referral, reducing service duplication and improving performance monitoring (HOI 2014).

In 2017 the WBCs were transitioned to Apunipima to be delivered under a community controlled model of care.

Family Wellbeing Program

The Family Wellbeing Program (FWB) was initially started in 1998 in South Australia by a group from the Stolen Generations. It has been adapted by the Apunipima Cape York Health Council to meet the specific needs of Cape York communities. FWB is premised on the concept that efforts to close the gaps should start with personal development and capacity enhancement (The Lowitja Institute 2015). Participants learn a range of practical techniques that can be applied to everyday living and develop the confidence to address their personal, family and community wellbeing.

Efficacy of the FWB program has been established in an evaluation by the University of Queensland and James Cook University. Most participants were better able to manage change, support others and remain focused on the future:

> we can help them now, we've got the strength back – some of it.

> [FWB]… helps you understand yourself you know to take one thing at a time – you can't just take a big sledge hammer and smash the rock. You've got to chip away be chipping away at it. It's the same in life. FWB will help you to understand that. (Tsey et al. 2006, pp. 37–38)

Positive individual, family and community outcomes were identified, with reductions in domestic violence, alcohol and drug abuse, suicide, school absenteeism and welfare dependence, and improved education and employment outcomes. Health and wellbeing improvements included diet, physical activity, alcohol and smoking.

17.4 Conclusion

Up to half of the health gap between Indigenous and non-Indigenous Australians is estimated to be attributable to social determinants, meaning that much of the work to improve health inequities lies beyond the health sector. Closing the health gap requires simultaneous effort to address socioeconomic determinants of health including housing, education and employment. While some progress is being made, there is an opportunity to change practices to better meet the needs of communities, families and individuals.

A localised planning and delivery approach is more likely to achieve health and wellbeing improvements. Community health assessments would enable better planning of health services, reduce duplication and enable gaps to be identified and addressed. Effective prioritisation of services would make more cost-effective health choices possible. Improved access to local primary health care services, with a patient-centred care focus, can deliver better prevention, early intervention and management of health conditions, fewer preventable hospital admissions and long-term health gains. Cultural accessibility of services can be enhanced by attracting and retaining an effective workforce, with career pathways for Aboriginal and Torres Strait Islander staff.

Aboriginal and Torres Strait Islanders can have complex health needs that require access to multiple services in a range of areas including health, housing and community supports. Services could be better integrated to improve service delivery and client referral, reduce duplication and improve performance monitoring. Increased collaboration between government and non-government service providers would also promote better integration of services, for example, by improving transition care arrangements such as discharge planning, transfer of patient records and follow-up care.

Improving Indigenous wellbeing means tackling more than just physical illness. Accessibility and effectiveness of health services can be improved with models of service delivery that include social and emotional wellbeing services in a primary health care setting. The Aboriginal and Torres Strait Islander Community Controlled Health Organisations demonstrate an effective model providing effective, culturally appropriate and multidisciplinary models of comprehensive primary healthcare.

The reforms proposed by this inquiry can provide an enabling environment for stakeholders to develop collaborative and flexible solutions to these challenges.

Recommendation 22

All stakeholders should address opportunities to improve health and wellbeing services through:

- a greater focus on prevention and early intervention, including strategies to address: socioeconomic determinants of health, suicide, Foetal Alcohol Syndrome Disorder and disabilities

- individual and community input to prioritise, design and deliver services, based on data-informed community health assessments to address:

  - accessibility, cultural appropriateness and effectiveness

  - attraction and retention of an effective health workforce, including growing and supporting the Aboriginal and Torres Strait Islander health workforce

  - better integration of services through increased collaboration with non-government health service providers (particularly Aboriginal Community Controlled Health Organisations (ACCHOs)) and improved transition care arrangements

  - improved pathways and access to mental health and substance services

  - gaps in responses to suicide, disabilities and Foetal Alcohol Syndrome Disorder.