Aboriginal Patient Advocacy Training

Pre-Reading Booklet







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Aboriginal and Torres Strait Islander people – please be aware that some of this reading contains information around dispossession and colonisation and may be distressing to read.

This information is background knowledge only – if you feel that you have sufficient knowledge on any of these topics, please feel free to skip them

Aboriginal and / or Torres Strait Islander History

For more than 40,000 years prior to the arrival of Europeans, Aboriginal and / or Torres Strait Islander people inhabited the whole of the Australian continent and its nearby islands. They were self-sufficient and harmonious, and resources were abundant. They moved through the country in accordance with the seasons, and developed rich and complex rituals – languages, customs, spirituality, and the law. At the heart of this was connection to country.

1788-1900

This was changed with the arrival of the first fleets in 1788. Great Britain took possession of Australia without negotiation, and declared the continent *terra nullius* – empty land, or land that does not belong to anyone (ignoring the fact the land was owned by over 400 different nations at the time of claim). Since this European Invasion of Australia, Aboriginal and / or Torres Strait Islander peoples have been oppressed.

Settlement of new colonies was not peaceful and led to the dispossession of land and killings of mass numbers of Aboriginal and / or Torres Strait Islander people through battles or hunting parties. With colonisation also came the introduction of alcohol and diseases such as measles and tuberculosis and as the Indigenous Australian's had no resistance to the deadly viruses this devastated the Aboriginal and / or Torres Strait Islander people. By 1900 there was a 90% reduction in the Indigenous population, and this deteriorated Aboriginal and / or Torres Strait Islander people's physical, emotional, and spiritual wellbeing.

1900-1950

On 1 January 1901, the Australian Constitution took effect, and the Commonwealth of Australia was formed. Under the laws of the Australian Government, Aboriginal and / or Torres Strait Islander peoples were not included as citizens and were instead treated as foreigners in their own land.

After another decade of dispossession, killings, and change; new policies of segregation and protection were introduced for Aboriginal and / or Torres Strait Islander people. These policies supported the Government's theory to 'Breed the Race Out' and allowed for the forced relocation of Aboriginal and / or Torres Strait Islander people onto reserves with no citizenship rights, no voting rights, no access to social services, imposed curfews within city regions when visiting and working, child removal from families to missions, and Government control of intermarriages. They were also not allowed to own property, be the legal guardian of their own children or drink alcohol. Aboriginal and / or Torres Strait Islander people were also contracted to work, but never received payment for their work.

1950-1966

After 60 odd years of segregation and protection policies, new assimilation policies were developed to merge Aboriginal and / or Torres Strait Islander people into the new European Australia where they were to 'live like the white man'. Even though the theory was to assimilate into the white community, and some Aboriginal children were allowed to attend school, Aboriginal and / or Torres Strait Islander people had no citizenship rights, were forced to discard their own culture, were segregated from the rest of town, required a certificate of exemption to move around town freely, still had some curfews and were still having children removed from families.

But rights movements were happening during this time regarding social justice issues for Aboriginal and / or Torres Strait Islander people, including citizenship, maltreatment, removal of children, access to traditional lands, and rights to practice culture. All Aboriginal and / or Torres Strait Islander peoples finally gained the right to vote in Federal Elections in 1962, and state elections in 1965.

1967-2007

On 27 May 1967, the Australian Government held a referendum which was a momentous turning point in Australian history, altering the Australian Constitution. 90% of all Australians voted for Aboriginal and / or Torres Strait Islanders to have Citizenship rights. The Government could then make laws applied to Aboriginal and / or Torres Strait Islander peoples that could assist in addressing inequalities. This period also saw 'Land Rights' movements and claims being established through the courts, allowing Aboriginal and / or Torres Strait Islanders to claim their traditional lands, or access to other significant lands; and the Royal Commission into Aboriginal Deaths in custody established. In 1971 the first Aboriginal Community Controlled Health Organisation (ACCHO) was established to provide accessible health services for the Aboriginal population in Redfern

Although the Racial Discrimination Act was implemented in 1975, in 2007 the Government suspended it to put in place the Northern Territory Emergency Response (NTER), after an inquiry into child sexual abuse. The intervention involved placing restrictions on Aboriginal communities in the Northern Territory, including on alcohol, pornography, welfare payments and education. This was heavily criticised as findings confirmed that statistics did not appear to support the allegations. It was amended shortly after, although some restrictions remain in place. ¹

2008-Today

Aboriginal Community Controlled Health Organisations have continued to increase and expand, and have become key services for not just health, but community development, engagement, empowerment and education.

A Government Apology in 2008 brought a wave of emotional release as the recognition of experiences through historical exposures to Aboriginal and / or Torres Strait Islanders was acknowledged. Closing the Gap was also established in 2008, which is an Australian Government strategy that aims to reduce the disadvantage and inequity between the Aboriginal and / or Torres Strait Islander peoples and non-Indigenous Australians'. This is based on multiple targets, and the aim is to 'Close the Gap' within a generation. After ten years, six of the seven targets had not been met so in 2020 there was a refresh of the agenda which now puts more focus on partnerships between Governments and Aboriginal and / Torres Strait Islander people.²

Although progress has been made, it is important to note that these improvements have not ended discrimination. Extreme hardships have and are being faced, ranging from forced removal of children to loss of culture and homelands. Aboriginal and / or Torres Strait Islander children are nearly ten times more likely to be in out-of-home care,³ and inequity, racism and discrimination are still happening to this day.

¹ Australian Aboriginal peoples - Aboriginal peoples in Australian society | Britannica

² Closing the Gap Report 2020 (niaa.gov.au)

³ FamilyMattersReport2020 LR.pdf

Cultural Awareness

Cultures are about ways of everyday living, ways of understanding the world and our origins, relationships with families and other people, relationships with environments, personal and group values and rules, communication (including languages) and the way we adapt to change. Culture helps us make meaning of our everyday experiences

Dominant Cultures

This refers to the main culture that is shared or accepted in society without opposition from the majority. It is created by establishing social norms for language, values, laws, rituals, customs, as well as by oppressing or marginalising other cultures. Dominant cultures privilege members of that culture.

In Australia, dominant culture dictates the design and delivery of every policy, program, and service that we receive, so it is primarily influenced by non-Indigenous benchmarks – even looking at the idea of closing the gap, Aboriginal and / or Torres Strait Islander peoples are measured against non-Indigenous Australians, hence the term gap is used. This dominant culture is seen through the education system, the health system, community, and workplace policies & procedures.

Constant moving between cultures can be challenging for many, which is why Aboriginal and / or Torres Strait Islander organisations are so essential – because they are driven by identity, way of working, doing, and knowing, and what is important and recognised.

Aboriginal Culture

Aboriginal culture is holistic and is fundamental to wellbeing and identity. ⁴ It is often centred around family, community and nation groups, and there are complex kinship structures. There are also complex networks of knowledge, faith and practices which come from stories of creation. Language, ceremony and rituals like dance, song and arts are kept alive by passing them down from one generation to the next.

Aboriginal identities usually relate to language groups or traditional country and being on country is central as it holds stories, religion, customs, and ancestors. Acts on country such as hunting or building shelter are carried out sustainably, and in balance with the surroundings.

Land, family, lore (law), ceremony and language are all interconnected with one another. Families are connected to the land through the kinship system, and this comes through specific responsibilities that are observed through ceremony and lore requires you to follow. All these cultural factors determine societal structures, behaviour, and ceremonies.

These connections to culture are critical for emotional, physical, and spiritual wellbeing and identity, and understanding them can help us understand how colonisation caused so much damage. The disconnection from culture had a deep impact on sense of identity and belonging, which is what gives meaning to people's lives. This being understood and considered when making decisions is a good way to help overcome disadvantage

Click here for more information about the kinship system

Click here for more information about Noongar Lore

⁴ Aboriginal people in Australia - Creative Spirits

Torres Strait Islander Culture

Torres Strait Islanders have distinct cultures which vary between islands.⁵ The culture is complex and has Australian and Papuan element combined into it, but many identify strongly with their island roots. Torres Strait Islander people often use the names of their islands to identify themselves, even if born in mainland Australia, and sea rights for them are as important as land rights.

Like the Aboriginal people, Torres Strait Islanders are traditionally agriculturalists and cooking and hunting is taught from a young age. There is a long history of developing stories, crafts, and games, and these are passed down between generations.

Torres Strait Islander peoples also have complex kinship systems, where the children do not always stay with their birth parents but might be adopted to someone else in the same bloodline.

Why is it important for us to recognise cultural differences?

Aboriginal and / or Torres Strait Islander peoples each have their own laws, traditions, and customs, but the interconnected perspective of both is extremely different to Western Culture. Understanding their complex culture and how interconnected all the aspects are can help prevent causing more pain from colonisation.

A lack of understanding of the kinship system of a client, patient of community can impede engagement and effectiveness. It is the responsibility of the service provider to understand the local kinship practices and will help with understanding who makes decisions and how to arrange meetings to accommodate practices. A doctor may need to ask questions that are only biological family could answer but be unaware that the accompanying person is a relative but not the parent/sibling. This practice is common all over, whether it be in cities through to small communities. Everyone is expected to fulfil their responsibilities to their family

In mainstream services, unless providers are conscious of the barriers that exist between them and the communities they're servicing and take the necessary action to engage with them effectively, the services are unlikely to properly address the issues impacting the client. Culture needs to be considered first and foremost when actions are taken which intend to overcome any disadvantage, and for this reason Aboriginal and / or Torres Strait Islander people must be involved in the decisions that affect them.

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⁵ Torres Strait Islander culture - Creative Spirits

Aboriginal and / or Torres Strait Islander Health

For Aboriginal and / or Torres Strait Islander Australians, good health isn't just the absence of disease, and doesn't just include physical and mental health. It includes social, cultural, ecological, and spiritual wellbeing for not just the individual, but the whole community. These factors play a large part in determining someone's health and are all interconnected with one another.

The conditions in which you are born, grown and live can have a massive impact on your health. Social circumstances such as employment, education, housing, remoteness and income have a massive effect on health, and Indigenous Australians are disadvantaged in all of these areas due to many years of social exclusion. Even things like addiction, incarceration, domestic violence can lead to poor health.

In the holistic Aboriginal view of health, cultural factors also have the ability to determine one's health. Colonisation and dispossession has resulted in a loss of culture for many, tarnishing their wellbeing. However although invasion and exclusion from society has led to poor outcomes, Aboriginal people are extremely self-determined and drawing on this and connectedness with family, community and country can have a positive impact on the health and wellbeing of Aboriginal people

This trauma has left the Aboriginal community more vulnerable to health issues which is why there is a big gap in health. All of the determinants above can be linked to trauma which gets passed down through generations. This is a systemic problem which need to be changed through the whole of Australia, but interventions can take many years to action, and it can take many more years to see positive outcomes.

Intergenerational Trauma

Indigenous people in Australia have experienced trauma as a result of colonisation, including the associated violence and loss of culture and land, as well as subsequent policies such as the forced removal of children. In many Indigenous families and communities, this trauma continues to be passed from generation to generation with devastating effects. Research shows that people who experience trauma are more likely to engage in self-destructive behaviours, develop life-style diseases and enter and remain in the criminal justice system.

The high rates of poor physical health, mental health problems, addiction, incarceration, domestic violence, self-harm, and suicide in Indigenous communities are directly linked to experiences of trauma. These issues are both results of historical trauma and causes of new instances of trauma which together can lead to a vicious cycle in Indigenous communities and families.

Click here for a short video about intergenerational trauma

The Health System

How do Doctors make a diagnosis?

Presenting Symptoms → Assessment → Tests → Diagnosis → Medication → Follow up

- Assessment: done off the best practice guidelines
- Tests: these may need to be repeated or additional tests might be needed depending on results
- Diagnosis: made from test results
- Medication: what is prescribed is usually what is most used to treat the condition, but it might not necessarily be the best thing for the patient
- Follow up: This is to ensure the treatment has been effective, if side effects are seen it might be best to try another brand

National / Federal Health System

Click here to read about the Australian Government health system

Aboriginal and / or Torres Strait Islander Health in Australia

The Indigenous Australians' Health Programme (IAHP) funds Aboriginal and / or Torres Strait Islander health programs. They work across 4 areas, which are primary health care services (such as immunisation and prevention services), improving access to primary care (such as outreach services), targeted health activities (such as managing chronic conditions) and capital works (such as managing infrastructure). The program aims to ensure that Aboriginal and / or Torres Strait Islander people get high-quality care, no matter where they live.

They implement Australian Government health policy commitments such as the National Aboriginal and Torres Strait Islander Health Plan (2013-2023) by funding of Aboriginal Community Controlled Health Organisations.⁶

State / Territory Health System:

WA is the largest area in the world covered by a single health authority. Each area is responsible for the public services in their own area – We have 6 areas in WA who all have their own boards and manage their own budgets.

- Child and Adolescent Health Services Perth Children's Hospital, Child and Adolescent Mental Health Service, Child Development Centre & includes school and community nurses.
- East Metro Health Service Royal Perth hospital, Armadale Hospital, St John of God Midland, Kalamunda Hospital and Bentley Health Service
- North Metro Health Service Sir Charles Gairdner Hospital, Osbourne Park Hospital,
 Joondalup Hospital, Graylands Hospital, and some King Edward Memorial Hospital services
- South Metro Health Service Peel Health Campus, Fiona Stanley Hospital, Fremantle
 Hospital, Rockingham General Hospital
- West Australian Country Health All of the regional hospitals & The Patient Assisted Travel
 Scheme

⁶ Aboriginal Community Controlled Health Organisations (ACCHOs) (naccho.org.au)

PathWest Laboratory Medicine

Health gets the most money from the state budget of anything – in 2021, 30% of the WA state budget was allocated for Health & Mental Health.

Aboriginal Health in Western Australia

As Aboriginal and / or Torres Strait Islander peoples have the greatest needs of anyone in the state, WA Health have an office who are responsible for improving health outcomes of the Aboriginal and / or Torres Strait islander peoples in Western Australia. They are responsible for seeking opportunities in WA Health to attend to the areas set out in the WA Aboriginal Health and wellbeing Framework 2015-2030.

There are many bodies who aim to improve the care of Aboriginal and / or Torres strait Islander peoples in Western Australia, such as the Aboriginal Health Council of Western Australia, which is the peak body for Aboriginal Community Controlled Health Services in Western Australia. Their purpose is to support the Aboriginal Community Controlled Health Services (ACCHS) in WA. Click here to look for local ACCHS

Mental Health System

The Mental Health Act 2014 is the law around mental health treatment in Western Australia. It sets out when a person can be given treatment, the criteria for referring someone for examination, how inpatient treatment orders operate, when someone can be made an involuntary patient, and the rights of people with mental illnesses and their support persons.⁷

Click here for a flow chart for Referring Practitioners

Voluntary Patients

A voluntary patient is someone receiving treatment for a mental illness voluntarily. They will get admitted if a psychiatrist believes they could benefit from treatment in hospital. However, even if they are a voluntary patient, if they want to leave against medical advice, they might be referred to a psychologist on a form 1A. They can be held up to 6 hours for them to see a psychiatrist, and this cannot be extended. After assessment, if you do not meet the criteria for needing to be an involuntary patient, they will be allowed to leave.

Involuntary Inpatients

An inpatient treatment order (Form 6A or 6B) will be issued if a psychiatrist examines them and decides that there is a risk to themselves or others if they don't have treatment, they are not well enough to make decisions about their own treatment and there is not a less restrictive option.

An inpatient treatment order means they will be admitted to and receive treatment for mental illness at the hospital named on the order and that they will not be allowed to leave the hospital until the inpatient treatment order ends (or unless you are granted leave). These orders can last up to 21 days for adults, but can be extended for up to 12 weeks, and they can last up to 14 days for children but can be extended for up to 28 days. These orders can be repeated for as long as necessary until they are well enough to no longer need inpatient treatment

Involuntary Community Patients

A Community Treatment Order (Form 5A) can also be issued if a psychiatrist examines them and decides that there is risk to themselves or others if they do not have treatment, that they aren't well enough to make decisions about treatment at the moment, and they do not need to be admitted to a hospital but there is no other less restrictive way of providing treatment

A community treatment order means they can continue to live in the community, but they must accept the treatment that has been planned. There will be an examination at least once a month that must be attended, and if orders are not complied with and the psychiatrist has taken all reasonable steps then a notice of breach will be issued – if this is not complied with the police may become involved. These can last up to 3 months but can be repeated as many times as necessary until the consumer is well enough to no longer need treatment. The CTO ends when it expires and isn't renewed, if its decided the patient is well enough for it to be cancelled, if its decided the person needs inpatient treatment or when the Mental Health Tribunal decides a CTO is not necessary

⁷ Consumer Handbook to the Mental Health Act 2014 (mhc.wa.gov.au)

Advocacy

What is it?

Health consumers have always been active in influencing the delivery of programs, and advocacy is another part of this. It is working with a person who needs support, to represent their rights and welfare in a way that benefits the individual. If you are advocating for someone else, even if your beliefs and opinions do not coincide with theirs, you must be on their side and no-one else's. It often involves dealing with challenging situations, and issues may arise around independence, best interests, and conflicts of interest, so as an advocate you must consider whether you can remain loyal and accountable to the consumer.

Why is it important?

Advocacy and health advocacy specifically, can seem daunting. People having problems accessing or receiving treatment that is failing them can be scared, frustrated and may be quite unwell. The health system is large and complex and can be very difficult to negotiate, and consumers issues can be multiple and varied.

Advocacy empowers consumers and their advocates to actively participate in decision making around their healthcare and the broader health system. When advocacy is done effectively it ensures that there is accountability and transparency for the consumers, which ensures their needs and rights are met, which can empower them and instil confidence in the way health services are operating. Resolution of issues as they arise can mitigate escalation and lengthy issues.

Furthermore, it can open doors for more people to participate, can address injustice, and improve health services. Effective advocacy ensures that services are continuously improving, with consumer views being considered when developing and implementing policies and decisions. Health advocacy can contribute to positive changes to legislation, policies, practices, and delivery. It can also raise awareness of the impacts of social and environmental factors, and facilitate systemic change.

Why is advocacy important for Aboriginal and / or Torres Strait Islander Health?

Without advocacy, certain groups would miss out on health services and support, which results in poorer health outcomes, so advocacy plays an important role in ensuring Aboriginal health consumers can access and receive fair and equal treatment from health services. There have been many cases of inadequate care of Aboriginal and / or Torres Strait Islander people in the health system. Even recently, we have seen <u>deaths after being dismissed from hospital</u> and <u>deaths in police custody</u>.

Advocacy is a powerful way of supporting Aboriginal patients to have their voices heard within the health system and improves the accountability of services by shining a light on issues that otherwise may not have been raised. It can also allow for people to be connected to support networks, to learn their rights, to learn self-advocacy skills.

Types of advocacy

Advocacy can be applied broadly and differently by consumers, community, government, and non-government sectors.

Individual advocacy is around helping individual consumers maintain their rights and promote their needs. This is sometimes referred to as patient advocacy. This usually involves things like supporting the consumer to represent their own interests and empowering them to voice their perspectives.

Systemic advocacy seeks to produce long term positive changes to policies, systems, attitudes and ensure the collective rights and interested of health consumers are upheld. This would involve things like encouraging changes to laws, policies, and community attitudes, and influence the social structures that sustain injustice and equality.

Who can be an advocate?

There are a range of advocacy approaches. Where possible, self-advocacy should be the starting point. There are many benefits of this such as avoidance of conflict of interests and building up the confidence to analyse and communicate decisions.

However, when ill or vulnerable, you might need to seek the support of someone else. It may be helpful having a friend of family member advocate, but an impartial third party can ensure conflicts are avoided and that they can act in the best interest of the consumer. However, nothing is fixed and the method will be specific to the nature of the issue.