Transgender Health

Briefing to the Incoming Minister of Health 2020
from the Professional Association of Transgender Health Aotearoa

Transgender people in New Zealand experience serious health inequities, and significant rates of mental distress. These occur because of stigma, marginalisation, discrimination and inadequate access to gender-affirming healthcare. Demand for gender-affirming healthcare is increasing, and provision of local and national services are inadequate. Leadership and resourcing are needed to build on emerging models of good practice.

Additionally, transgender people face barriers to accessing services across the wider healthcare system because of limited training of healthcare providers in trans competency, and environments, policies and systems that are not designed to be inclusive of transgender people.

While these issues have long been recognised, there is currently no targeted national approach to ensure health equity for transgender people. A strategy is needed across three priority areas:

1. Reliable public access to gender-affirming healthcare
2. A wider health system that delivers safe, equitable, effective care for transgender people
3. Addressing discrimination against transgender people as a social determinant of health

This briefing provides more detail on each of these areas, and recommendations for action.

The Professional Association for Transgender Health Aotearoa (PATHA) is committed to improving the health of transgender people in Aotearoa. We have prepared this briefing to outline the situation with transgender health in Aotearoa, and what transgender people need from New Zealand's public health system.

PATHA has written this paper based on our expertise as an interdisciplinary professional organisation working to promote the health, wellbeing, and rights of transgender people. We have more than 100 members, who work professionally for transgender health in clinical, academic, community, legal and other settings.

Our vision is that all transgender people have full access to appropriate healthcare, and that all healthcare providers have access to information and resources which enable them to provide appropriate healthcare.

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Background: transgender people and health inequity

We use **transgender** as an umbrella term, covering tāhine[1], takatāpui[2] and other Māori gender minorities; other indigenous genders such as fa'afafine, fa'atama, leiti and akava'ine;[3] non-binary and genderqueer identities; transsexual people and others whose current sex or gender is different from their sex assigned at birth. This includes some people who are intersex – those who also identify as transgender. Not everyone who uses these identity terms would describe themselves as transgender, but we are using this term for brevity.

Transgender people are part of every community, culture and whānau

Transgender identities, lives and experiences are diverse, crossing every age, ethnicity and cultural background, geographical location and socioeconomic status. Some transgender people are disabled, some have experience of being a refugee or asylum seeker, or of migrating to New Zealand. Transgender people are part of every other population group, while also being their own marginalised population group that has specific health needs.

It is likely that around 1% of New Zealand's population is transgender

There are no clear data on how many transgender people live in Aotearoa. Work is just starting on collecting such information through New Zealand's Official Statistics System, with the last Minister of Statistics committing to counting transgender people in the next Census[4] and questions about gender identity being trialled in the Household Economic Survey.[5] Stats NZ is currently updating its Sex and Gender Standards, which will guide the collection of data about transgender people in the Census and other population surveys.[6]

In national survey data from secondary school students in the Youth'12 study,[7] 1.2% of students reported that they were transgender, and 2.5% were not sure of their gender. In other countries, population surveys have found between around 0.5 and 5%[8] of people identify as transgender, depending how the question is framed. For example, the United States Behavioral Risk Factor Surveillance System found that 0.6% of adults aged 18 or over self-identify as transgender.[9]

Transgender people experience serious health inequities

Transgender people have the same potential to live healthy, flourishing lives as everyone else. However, evidence shows that transgender people experience poorer overall health and lifetime higher risk of health problems compared to the total population. For example:

- the University of Waikato's *Counting Ourselves* survey[10] heard from 1178 transgender and non-binary respondents aged 14-83. It found 71% of transgender people were currently experiencing high levels of psychological distress (compared with 8% in the general population).[11] More than half of those surveyed (55%) had seriously thought about suicide in the past 12 months, and 37% had ever made a suicide attempt.

- The University of Auckland's *Youth'12* study[12] found one in five transgender secondary school students had attempted suicide and nearly half had self-harmed in the previous year. Around 40% were currently experiencing significant depressive symptoms.

Higher risks of health problems are related to discrimination

These higher risks are not inherent to transgender people, but are linked to social exclusion and discrimination.[13] Those who experience discrimination related to other aspects of their identity,[14] including Māori[15]; Pacific, disabled and migrant people, have even higher risk of poor health outcomes. Conversely, acceptance, inclusion, social support and access to gender-affirming healthcare are all protective factors that contribute to lower rates of health problems. For example, *Counting Ourselves* participants who were supported by at least half of their family or whānau were almost half as likely to have attempted suicide in the last 12 months.[16]

For many transgender people, accessing gender-affirming healthcare is necessary to ensure their wellbeing and to address any discomfort or distress caused by incongruity between their body and their gender or sense of self (gender dysphoria). *He Ara Oranga*, the Report of the Government Inquiry into Mental Health and Addiction, recognised that limited access to gender affirming healthcare "has a negative effect on the mental health and wellbeing of people seeking to access them".[17] Timely access to appropriate gender-affirming care reduces such impacts resulting in better patient-centred care and lower health costs acrosss a person's life span.

Action is needed across three priority areas

To ensure equitable health outcomes for transgender people, **a national strategy on transgender health** is needed which encompasses action across three priority areas:

1. Reliable public access to **gender-affirming healthcare**
2. A wider health system that delivers **trans-competent healthcare** that is safe, equitable, effective care for transgender people
3. A targeted approach to **addressing discrimination against transgender people** as a social determinant of health

Over the next seven pages, we have provided more background on each of these areas, and specific recommendations for action.

1. Reliable public access to gender-affirming care is essential

The term **gender-affirming healthcare** refers to any healthcare that affirms a person's gender and increases congruence between their body and their gender or sense of self. This covers a wide range of interventions including counselling and psychosocial support, hair removal, voice therapy, puberty blockers, gender-affirming hormones and surgeries.

Each person has their own individual needs, and best practice gender-affirming healthcare is guided by the principle of Te Mana Whakahaere - trans people's autonomy of their own bodies, represented by healthcare provision based on informed consent.[18] For many transgender people, accessing gender-affirming healthcare is essential to their wellbeing.

Access is inadequate and demand is growing

In Aotearoa, access to gender-affirming healthcare is limited and generally inadequate. In 2008, the Human Rights Commission's *Inquiry into Discrimination Experienced by Transgender People*[19] found significant gaps and inconsistencies in the availability, accessibility, acceptability and quality of health services, with most transgender people not receiving the gender-affirming healthcare they needed.

Ten years later, *Counting Ourselves* in 2018 found significant levels of unmet need for gender-affirming healthcare. This ranged from 19% for hormone treatment to 67% of transgender men with an unmet need for chest reconstruction surgery. Around half of transgender women had an unmet need for voice therapy (50%) and feminising genital surgery (49%).

Demand for gender-affirming healthcare has increased significantly in recent years (for example, as seen in this Auckland[20] and Wellington[21] data) as transgender people have become more aware of healthcare options and as support increases for people affirming their gender. The true picture of demand is unclear, as many services are unavailable, unmet need is not documented, and people often face barriers to understanding what services are available or how to access them.

Transgender people are burdened with significant individual healthcare costs. Where healthcare is not accessible through the public system, this can involve private specialist appointments, surgery (which may require travelling overseas) and unfunded medications. Within public healthcare, transgender people taking gender-affirming hormones incur regular and life-long co-payments for general practice visits and pharmacy prescriptions. Private health insurance explicitly excludes coverage for most gender-affirming healthcare.[22,23,24] This results in many people being unable to access the care they need. Others may fundraise for essential healthcare through donations from friends, whānau and transgender communities.

Provision varies significantly between DHBs and is not treated as essential

Although DHBs are responsible for meeting the health needs of their population including gender-affirming care,[25] there is no agreement about the minimum standard of care that this must include. The only reference to gender-affirming healthcare within the Crown Funding Agreement between the Minister of Health and DHBs relates to fertility preservation services for transgender people.[26] Similarly, gender-affirming care is not stipulated as an essential primary health care service in DHBs' PHO service agreements.

Public information about what each DHB provides is limited. A 2019 survey of clinical colleagues[27] and a study based on Official Information Act requests in 2018[28] both documented a significant "postcode lottery", with many services unavailable in most DHBs.

Gender-affirming healthcare is provided across a range of services (e.g. general practice, sexual health, endocrinology, surgical services, allied health services such as physiotherapy or speech therapy, and mental health support). Many DHBs do not have a clearly identified pathway for transgender people seeking gender-affirming care. It can be difficult to find clear information about what services are available and how they can be accessed, and transgender people often need to self-advocate to receive essential medical care to which they are entitled.

Even when services are available, the number of people who can access them is insufficient because of funding and capacity limitations. For example, long waiting lists for public endocrinologists or psychologists can delay access to hormone treatment for unacceptable lengths of time or require individuals to pay for private consultations. Another example is chest reconstruction surgery – while many DHBs have the ability to provide this, limited oversight of demand and capacity issues mean delays or denials are common and there is no coordinated plan to address significant unmet need.

Nationally-provided services are not funded to meet need

The Ministry of Health manages the national provision of gender-affirming genital surgery.[29] This service received new funding in the 2019 Budget,[30] and is starting to refer people for specialist appointments ahead of potential surgeries.[31]

This service is not funded at a level that will meet population need, with a current estimated waiting list that remains decades long. No psychosocial support is provided for people waiting for these essential procedures.

The level of need for these surgeries is even greater than the waiting list suggests. In the *Counting Ourselves* survey, only 46% of participants knew that this funding existed and only 15% of those wanting genital surgeries had applied to the publicly-funded list. The most common reason for not applying was because of the length of the waiting list (74%). 40% did not know how to apply for it and 28% did not have the money to pay for the assessments needed to apply.[32]

There are promising models of good practice emerging

The following initiatives are some examples of good practice designed to reduce barriers to accessing gender-affirming care. Initiatives like these are likely to create more efficient and cost-effective healthcare services and lead to better physical and mental health outcomes.

Co-design of services with transgender people

Co-design of services with transgender people has enabled some DHBs to develop and improve services more effectively. For example, in Canterbury DHB, a working group of transgender people and primary care leaders collaborated to redesign local gender-affirming healthcare services,[33] and in the Northern Region, a Clinical and Consumer Advisory Group[34] informed the development of the Hauora Tāhine pathways.[35]

Access through primary care

In some DHB areas, there has been a shift towards primary care to better meet increased demand and the needs of transgender communities. It is more cost effective for trans people and the health system when primary health providers are confident to do assessments and prescribe gender affirming hormones within the primary care setting. For example in Canterbury, a group of GPs is supporting each other to prescribe hormones in primary care and better coordinate services. In Wellington, a pilot study at Victoria University found benefits in providing gender-affirming hormones through student health services.[36]

In line with the recommendations of the Health and Disability System Review,[37] there are significant benefits in providing gender-affirming healthcare in the primary care setting where possible. This allows people to access care in a timely way and in a supportive setting that is closer to people's homes and communities.

Peer support and service navigation

Peer support and navigation services are essential components of gender-affirming healthcare. These services have long been provided informally by transgender communities and peer-led support organisations. In the Northern Region, peer support roles for transgender people and their whānau are resourced as part of gender-affirming healthcare through a contract with RainbowYOUTH[38] and OUTLine.[39] A transgender health key worker employed by Auckland DHB specifically helps people navigate access to gender-affirming health services. This role has helped reduce waiting times for endocrinologist and other specialist appointments and reduce the number and cost of missed appointments.

How COVID-19 is affecting reliable access to gender-affirming healthcare:

Gaps in healthcare provision have been amplified as health resources are redirected to the pandemic response. Delays, cancellations and uncertainty about whether care will be provided has increased anxiety and distress for many transgender people.[40]

To achieve reliable public access to gender-affirming healthcare, we recommend:

- **National leadership and clear responsibilities** to ensure equitable access to gender-affirming healthcare for all transgender people across the lifespan. This should be developed in partnership by transgender and cisgender experts in the field and be transparent and accountable to transgender communities.

  PATHA believes that national coordination of a distributed model of care would best serve the increasing demands for gender-affirming care being placed on our healthcare system. National coordination could draw on specialist expertise in current hubs within DHBs to:
    - provide clinical guidelines, peer navigation and support, and care for transgender people where specialist clinical knowledge is needed, including for specific transgender populations such as children and youth
    - coordinate national gender-affirming genital surgeries and provide psychosocial support for transgender people receiving or waiting for these surgeries
    - provide education and supervision for healthcare practitioners, with a focus on developing capacity in primary care
    - promote person-centred care based on informed consent and tailored to individualised gender-affirming care needs and goals
    - develop and promote Māori and Pacific models of care, and ensure culturally-competent services for transgender people from all cultural backgrounds
    - create a workforce development plan to ensure a sustainable pool of experts in gender-affirming healthcare

  - **Clear requirements and resourcing for DHBs** to provide and fund local gender-affirming healthcare services, including in the Crown Funding Agreement with DHBs and associated documents such as the Service Coverage Schedule and National Service Specifications, and in DHBs' PHO Service Agreements, where applicable. This should include:
    - clear expectations about providing timely access to a range of services including at minimum: puberty blockers, fertility preservation, gender-affirming hormones, psychosocial support, hair removal, voice therapy and gender-affirming surgeries including chest reconstruction, breast augmentation, laryngeal shave, hysterectomy and orchiectomy
    - clear direction to resource primary care, including Māori and Pacific health providers, to deliver appropriate gender-affirming services (including psychosocial support, hormones, and referrals to secondary gender-affirming services) as a core part of the model of care
    - a requirement to provide clear, up to date, publicly available information on pathways to access gender-affirming healthcare
    - guidance on engaging transgender people in the process of designing, developing and improving services

- Adequate funding and support for the **national gender-affirming genital surgery service** to meet the transgender population's needs.

2. The wider health system should be safe, equitable and effective for transgender people

Beyond gender-affirming healthcare, transgender people have the same range of healthcare needs as others in New Zealand. However, compared with others, transgender people are less likely to be able to access healthcare when it is needed, more likely to delay or avoid access because of anticipated discrimination, and more likely to receive unsatisfactory care.[41,42,43]

Health services may be ineffective or unsafe for transgender people because of inadequate staff training, exclusionary policies and environments, or lack of service availability. Cost and difficulties accessing transport cause additional barriers.[44] These issues occur across all areas of healthcare: primary care, mental health, sexual and reproductive health services, and other forms of medical care. For example:

- *Youth 2012* found that transgender high school students were more than twice as likely to be unable to access health care compared with their non-transgender peers.[45]
- In *Counting Ourselves*,[46] over a third of participants (36%) had avoided seeing a doctor when they needed to because they were worried about disrespect or mistreatment as a trans or non-binary person. Almost half (46%) had to teach a healthcare provider about transgender people so that they could get appropriate healthcare, and less than half (46%) reported having GPs who consistently used the correct names and pronouns when referring to them or who supported their gender-affirming healthcare needs (47%). Compared to the overall New Zealand adult population, transgender people were more than twice as likely to have not visited a GP in the last 12 months because of cost.
- The *Out Loud* project collected the stories and wishes of transgender and other rainbow people around Aotearoa's mental health and addiction services and system.[47] Experiences include privacy breaches, mental distress being used as a reason to gatekeep access to gender-affirming healthcare, and racism and ableism adding additional barriers to accessing support. Other studies have reported similar experiences.[48,49,50,51]

Health professionals need more access to professional development

One of the reasons for these barriers is because transgender identities have until recently been defined as mental health issues.[52] This framing is now understood as incorrect and harmful, but many health professionals have not had access to up-to-date professional training to learn about transgender people's healthcare needs, lives and experiences, and to understand their role in enabling transgender people to make informed choices about their healthcare.[53] Training in both trans cultural competency and technical, clinical competency is essential.[54]

Learning opportunities are becoming more available within professional degree programmes and from professional bodies, but these are still limited. For example, preclinical medical training includes some limited content, and there is potential to integrate this more effectively.[55] Some

professional programmes, for example the Auckland Training Programme for Psychiatrists, have incorporated teaching on transgender health for psychiatrists to develop specific skills and knowledge to support transgender people. Similar content is required across all professional training programmes, and ongoing professional development opportunities need to be provided for all health practitioners.

Health services and systems need to be designed for inclusion

Other barriers to accessing effective healthcare can be due to environments, policies and systems that are not designed to be inclusive of transgender people. For example, gender-segregated spaces in healthcare settings such as bathrooms and wards can be unsafe or stressful for transgender people. Simple service design considerations such as providing gender-neutral bathroom options and clear guidance that transgender people can use gendered bathrooms, can significantly reduce barriers for transgender people accessing a service.

Another example is the collection and management of patient data and personal information. Work is needed to improve data management systems so that an individual's name and gender are recorded appropriately and consistently, and to ensure private information such as details about an individual's body is protected within the confidential relationship between a healthcare practitioner and patient. Currently the National Health Index (NHI), patient management systems and other electronic platforms used across the health system do not enable best practice in capturing and managing this information. For example, guidance about how to update the name and gender on an NHI record is limited and contradictory.[56]

How COVID-19 is affecting transgender people's health and healthcare:

Transgender people are more likely to have poor physical health and less likely to be able to access safe, effective healthcare when needed. This means that transgender people have particular vulnerabilities to COVID-19 infection.

To achieve a safe, equitable and effective healthcare system for transgender people, we recommend:

- **DHBs to be resourced and required to include compulsory training** on providing respectful, non-discriminatory care to transgender people for all staff, including primary care providers and other organisations contracted by the DHB to provide services.
- **The Ministry of Health, working with DHBs, PHOs, PATHA and transgender community expertise, to undertake a review of health systems and service design**, to identify opportunities for national and local systems, environments and policies to be more inclusive of transgender people.
- **Targeted quality improvement programmes** to shift practice and systems, and improve transgender people's experience of accessing health services.

3. A targeted approach is needed to address discrimination as a social determinant of health

Stigma, marginalisation, and discrimination are key social determinants of health[57] which cause significant health inequities. Transgender people in New Zealand experience these pervasively: in healthcare settings and through inadequate access to gender-affirming healthcare; in interpersonal relationships such as whānau; within wider communities or institutions such as schools, workplaces or religious settings; through discriminatory laws[58]; and through exposure to trans-negative rhetoric in media and politics.

Stigma, marginalisation and discrimination against transgender people impact on health by:

- creating minority stress[59] - that is, persistent underlying stress from living in a hostile environment, which directly affects transgender people's physical and mental health
- leading to lower income levels, lower employment, and more risk of unstable housing and poverty,[60] which are all recognised as social determinants of health, and
- creating barriers to accessing healthcare, so that transgender people are less likely to receive healthcare when they need it.

For Māori, and others who experience racism or discrimination related to other aspects of their identity, these effects can be compounded. Taking a public health approach means addressing discrimination at all levels: across society, in communities, in public institutions and in whānau.

How COVID-19 is affecting the social determinants of transgender people's health:

Transgender people face higher rates of unemployment and housing insecurity. They also experience discrimination when accessing social support services. The economic impact of COVID-19 will only exacerbate these inequalities. There has been no targeted response to transgender community needs in the COVID-19 recovery response to date.

To address discrimination as a social determinant of health, we recommend:

- **Commitment to a programme of cross-government action** to address discrimination and improve health outcomes for transgender people (similar to the Child and Youth Wellbeing Strategy and the Suicide Prevention Strategy). This would include actions across education, the justice sector, social services (including Work and Income, social housing and homelessness services and Oranga Tamariki), Te Puni Kōkiri and population-based agencies (Ministry for Pacific Peoples, Office for Ethnic Communities, the Office for Disability Issues).
- **A national anti-discrimination initiative** to recognise gender diversity and reduce stigma, marginalisation and discrimination against transgender people.
- **A programme of law reform** to address gaps in protections for transgender people, including legal gender recognition, unlawful discrimination and hate speech provisions.

Recommendations: priorities for transgender health

Transgender people experience significantly poorer health outcomes than other people in New Zealand. While these issues have long been recognised, there is currently no targeted national approach to ensure health equity for transgender people. PATHA would welcome the opportunity to work with you as Minister of Health to address these health equity issues.

To ensure equitable health outcomes for transgender people, we recommend that you develop:

1. A **national strategy on transgender health**, which aims to improve access to gender-affirming healthcare, ensure the wider healthcare system is trans-competent, and includes a targeted approach to reducing discrimination and recognising gender diversity.

We recommend that this overarching strategy guides action across the following three priority areas to improve the health and wellbeing of transgender people.

Reliable public access to gender-affirming healthcare

2. **National leadership** and clear responsibilities to ensure equitable access to gender-affirming healthcare for all transgender people.
3. **Clear requirements for DHBs** to provide and fund local gender-affirming healthcare services, including through primary care.
4. Adequate funding and support for the **national gender-affirming genital surgery** service.

A wider health system that delivers safe, equitable, effective care for transgender people

5. DHBs to be resourced and required to include **training on providing respectful, non-discriminatory care** to transgender people.
6. A **national review of health systems and service design**, to identify opportunities for national and local systems, environments and policies to be more inclusive.
7. Targeted **quality improvement programmes** to shift practice and systems.

A targeted approach to addressing discrimination against transgender people as a social determinant of health

8. Commitment to a **programme of cross-government action** on addressing discrimination and improving transgender health outcomes.
9. A **national initiative to reduce discrimination** against transgender people.
10. A **programme of law reform** to address gaps in legal protections for transgender people.

[1] Tāhine is a new word in te reo Māori that means transgender, which was community developed and has been endorsed by Te Taura Whiri i te Reo Māori / Māori Language Commission. The history of this kupu is shared in Oliphant, J., Veale, J., Macdonald, J., Carroll, R., Johnson, R., Harte, M., Stephenson, C., & Bullock, J. (2018). *Guidelines for gender affirming healthcare for gender diverse and transgender children, young people and adults in Aotearoa New Zealand*. Transgender Health Research Lab, University of Waikato, 2018.
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[14] Robertson, S. (2017). *All of Us: Minority Identities & Inclusion in Aotearoa New Zealand.* Retrieved from: https://theallofusproject.net/
[15] "As takatāpui, we experience a unique combination of discrimination, based on being Māori and having diverse gender identities and sexualities. As Māori, we share the legacy of colonisation, where systemic racism has resulted in poor outcomes in education, health, employment, social services and justice. In these contexts, takatāpui often find that our gender and sexuality is ignored, minimised or considered shameful. Even within Rainbow communities, the importance of being Māori to takatāpui and the appropriate use of tikanga or Māori protocols is not well understood." From Kerekere, E. (2015) *Takatāpui: Part of the whānau.* Auckland: Tīwhanawhana Trust and Mental Health Foundation.
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