Health and Disability System Review

Summary of Submissions

August 2019

New Zealand
HEALTH AND DISABILITY System Review
HAUORA MANAAKI ki Aotearoa Whānui

Acknowledgement from the Chair

Heather Simpson | Chair

The New Zealand Health and Disability System Review (the Review) has been fortunate to receive the insights and ideas from many New Zealanders to guide this work.

This report summarises the voice of submitters received through our online and email processes and demonstrates what we heard. These submissions have provided the Review with a deeper understanding of current and future issues, and what is important to design a more equitable health and disability system.

Many thanks for taking the time to share your views.

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Executive Summary

This summary of submissions provides a thematic overview of the 646 submissions the Review Panel received between 1 February 2019 to 31 May 2019 via email, online and telephone.

Submitters were invited to comment on values, issues, and changes that would help improve health and wellbeing for all New Zealanders. Submitters were however free to make comments on any issues they believed to be relevant.

A total of 477 individuals and 169 organisations provided submissions to the Panel. Submitters were diverse and provided a broad range of views. Their submissions have informed the Review's Interim Report and will guide the next phase of design.

In addition, the Review held workshops, wānanga, and met with many individuals and groups during its Phase One work. However, this report does not include the discussions or views from these methods of engagement.

Summary of themes

Submitters described a set of societal and system values that are important for the future Health and Disability System to guide decision-making, behaviours and activities. Included within these was a desire for the system to be founded on the principles and rights within te Tiriti o Waitangi (the Treaty). Submitters highlighted other important values including equity, fairness, inclusion, collaboration, holistic views of health, self-determination, flexibility, compassion, and quality.

Submitters proposed a shift away from deficit-based biomedical approaches towards wellbeing, prevention, and more holistic models of care. Some believed that mainstream adoption of relevant cultural frameworks and approaches might benefit all service users and whānau.

Social determinants were identified as major contributors to achieving equity in health outcomes. Submitters also acknowledged that many of these remain outside the control of the health and disability system. To cohesively address these upstream factors, submitters proposed sectors and services work collaboratively with clearer accountabilities to drive action.

Submitters overall supported stronger, more unified national leadership and stewardship, with longer time horizons and a more collaborative, less competitive approach. They expressed many and varied ideas on who should lead, which entities should be responsible for which functions, how decision-making should be shared across the system, and whether and how restructuring should occur.

Funding was recognised as a key driver of behaviour across all levels of service delivery. Some submitters indicated that some areas of health were under-funded and under-resourced, but consistently supported more being invested in prevention and earlier intervention activities. Some said that commissioning approaches needed to shift away from narrow fee-for-service models to more comprehensive, person-centred, and integrated models. Submitters' views on how this might be approached varied, with some proposing a single national purchaser while others suggested more localised purchasing. Funding approaches to overcome financial barriers, such as copayments, were identified as important to improve equity of access.

There were consistent service-level themes across population health, Tier 1, Tier 2, and disability services. Submitters sought the involvement of service users in the planning and design of services; a more consistent and robust approach to quality and governance; and mechanisms to foster innovation, share and promote learning to continuously improve services.

To prevent disease, and protect and promote the health of the population, submitters wanted stronger population health (public health) governance mechanisms and accountability, and greater co-ordination within and across sectors. They requested focus and investment in population health infrastructure, workforce, policies, monitoring and surveillance, and activities to promote wellbeing and reduce the downstream consequences of detrimental factors.

The configuration and integration of Tier 1 services (delivered within the community and home) was recognised by submitters as being critical to restore equity within New Zealand’s health and disability system. Submitters wanted timely access to high quality and culturally appropriate services regardless of where people live, their culture, or their income. Submitters described a desire for flexible, people and whānau centred services that meet more holistic needs. They suggested different ways to overcome access barriers including using remote and digital technology, one-stop-shops, and options to deliver services in environments outside general practice (such as schools, marae and churches).

Submitters wanted to ensure that disabled people can participate at all levels of society and that their rights are upheld by the health and disability system. Additional barriers that disabled people must overcome to access many health and disability services were also highlighted by submitters. A more equitable system that can: recognise and adapt to each person’s unique circumstances; provide adequate support to enable maximal vocational and social participation; and empower disabled people to make their own choices - was seen as important for disabled people.

The location and integration of Tier 2 services was highlighted by submitters as being critical to providing effective and fair services. Submitters wanted clear transitions between hospitals and community and primary healthcare, improved accessibility to specialist services by reconfiguring how and where services are provided, and fairer access to elective procedures.

Submitters were concerned with the ability of the health and disability workforce to cope with increasing future demand. Many indicated that the workforce needed to change the way in which it works to address these challenges. Improved cultural and technological competence and practice, and a more representative and empowered workforce that is valued and paid fairly were important for many submitters.

Many submitters identified opportunities to have a consistent approach to govern and access health and disability data. Submitters wanted integrated data and systems to streamline and improve the quality of service delivery. Clarity of data ownership and central guidance to navigate modern data challenges was also important. Submitters recognised the potential of both data and digital technology to change the way health and disability services are delivered, and wanted greater investment to improve the capabilities of the workforce and infrastructure to capitalise on these opportunities.

1. Submission process

1.1. Submission capture process

The New Zealand Health and Disability System Review ran an online process from 1 February 2019 to 31 May 2019. The Review asked nine open-ended questions and responses were received online, via email, mail and phone. This report provides a summary of these submissions.

Online questions

1. What are the most important values for our future public health and disability system?
2. Think about how the best health and disability system for New Zealand might look in 2030. How would that be different from the system we use today?
3. What changes could make our health and disability system more fair and equal for everyone?
4. What changes could most improve health for Māori?
5. What changes could most improve health for Pacific peoples?
6. What changes could make sure that disabled people have equal opportunities to achieve their goals and the life they want?
7. What existing or previous actions have worked well in New Zealand or overseas? Why did they work, and how might they make things even better in the future?
8. What are the most important changes that would make the biggest difference to New Zealanders?
9. Is there anything else you wish to add?

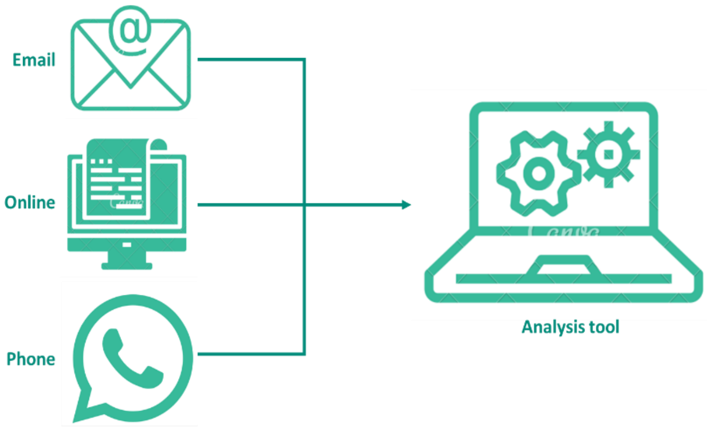
Submitters were also able to attach up to three documents to support their response. While not required, submitters who completed online responses typically responded to some or all of the above questions. Some submitters chose to provide responses using their own format via online attachments or submitting via email.

Key demographic information about the respondent was requested when submitters completed the online response. Email submitters did not routinely include demographic data, but in cases where we could infer demographic data from their submission, it was added. An analysis of this information is provided in Section 2.

Submitters had the opportunity to complete their online response in English, Te Reo Māori, plain English, and Sign Language.

1.2. Submission analysis process

Submissions were stored and analysed on a digital feedback platform.

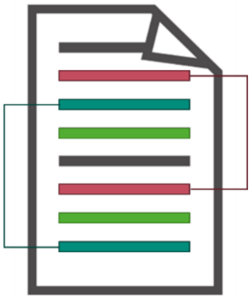


Coding & Analysis

Submitters had valuable things to say across many different topics. This meant that each submission needed to be split into smaller parts (what we have called ‘**excerpts’**) so they could be grouped and analysed with submissions that were also about a similar topic. The analyst attributed a ‘**code’** (or multiple codes) to these smaller parts that indicated the relevant topic areas mentioned.

Once all submissions were coded, analysts examined all the responses related to a specific topic together to gain a clearer understanding of its main themes.

The analysts then summarised the main themes in the body of this report (see Sections 3-7).



Identifying topics

With the breadth and complexity of the health and disability system, submitters responded across numerous topic areas to varying levels of detail. To keep this report more concise, it does not include every topic identified by each submitter. Instead, it summarises the key themes that were more frequently discussed.

This report has used a similar structure to the Interim Report to provide consistency between the two documents. However, the subheadings of this submission summary have been driven by the content and themes from the submissions. The Review is focused on future changes, but many submitters described current issues. In this summary, the current system issues have been briefly summarised, and greater emphasis is placed on possible solutions.

Quotes taken directly from submissions have been included in this report. They were selected from different individuals and organisations to illustrate a range of submitters’ voices. To promote privacy, quotes and sources were de-identified. Some submitters chose to keep their submissions private, and quotes from these submitters have not been included in the report.

This report provides a summary of the most consistent submitter comments grouped by theme under topics.

Included in the summary of themes are comments regarding topics that are defined by the Review’s Terms of Reference. Submitters’ comments on out-of-scope topics have not been summarised.

1.3. Overview of coded submissions

As described above, each submission was broken into smaller segments (excerpts) to 'code' the comments based on topic.

Across the 646 submitters there were:

4,762

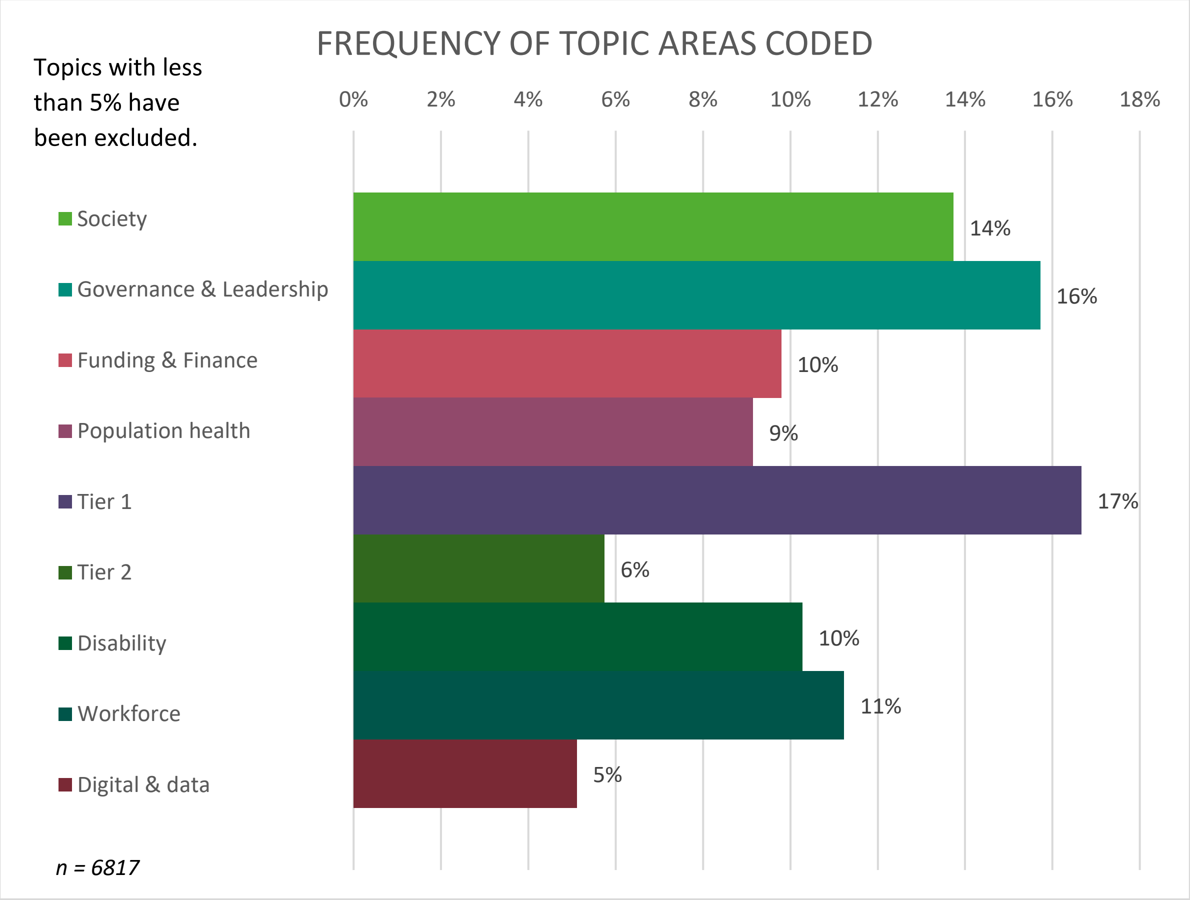
unique excerpts coded

Each excerpt could be coded to multiple topic areas, so in total there were:

10,165

codes applied

Below is an overview of the main topic areas submitters discussed, based on the number of times the topic was coded (excluding population and case example codes). Tier 1 and the Governance and Leadership sections were the most frequently coded topics, while infrastructure was coded the least.



2. Demographic analysis

2.1. Types of submitters

Submitters could identify (or were categorised) as one of two types: individuals or organisations. This identified whether a submitter responded on behalf of an organisation, or responded independent to an organisation. An 'individual' submitter may represent a single respondent or a combined response from multiple people but does not represent an organisation's views.

Each category was analysed using specific demographic variables:

Individual submitters

- Age, gender, ethnicity, location, and rural or urban
- Whether they consider themselves disabled or not
- Whether the submitter works or volunteers in the health and disability system, and in what capacity.

Organisation submitters

- Type and focus of the organisation
- Which geographic areas the organisation services and the location of the head office
- The number of employees

2.2. Notes regarding the demographic analysis

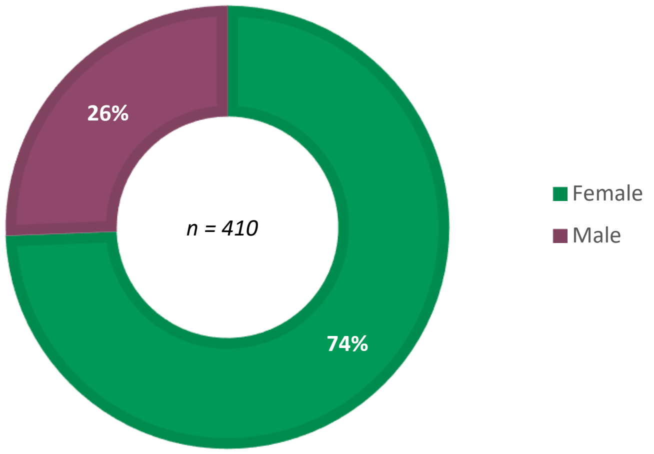
The following demographic analysis includes only the demographic data when it was provided directly by the submitter (if they completed their submission online), or when it was inferred in the content of their submission. The totals for each table and chart differ as not all submitters provided responses.

For some data, it was possible to select more than one response (it was possible to select more than one ethnicity, or organisation focus). Each instance is counted separately, with no weighting applied. Some submitters provided more than one submission (via online and email). These have been counted only once.

2.3. Number of submitters

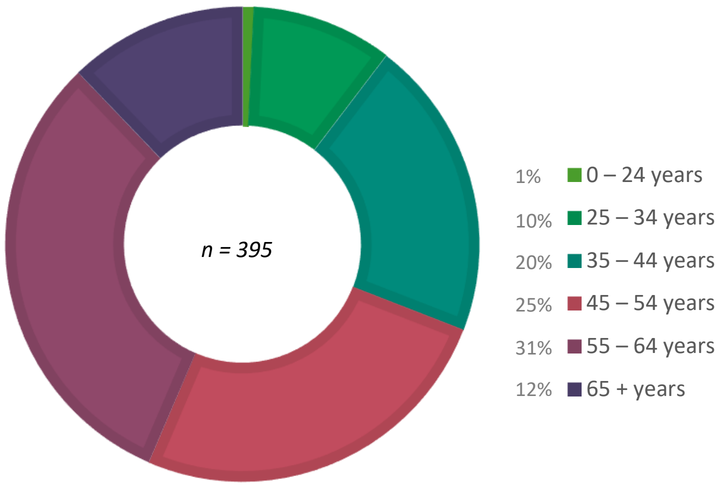
In total, there were 646 unique submitters who provided a submission via the online response form, via email, or via phone discussion. 74% of submissions were from individuals and 26% of submissions were from organisations.

2.4. Individual submitter analysis



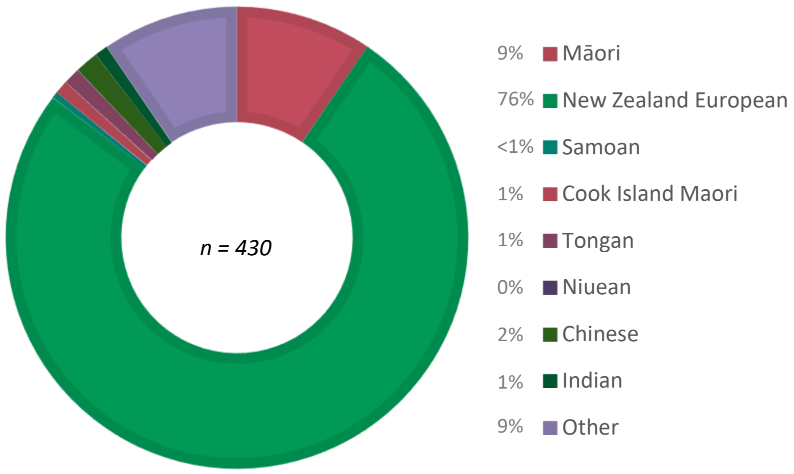
Gender

Almost three quarters of individual submitters were female.



Age

Only 11% of individual submitters were below the age of 35. Nearly one third (31%) were from the 55-64 age group.

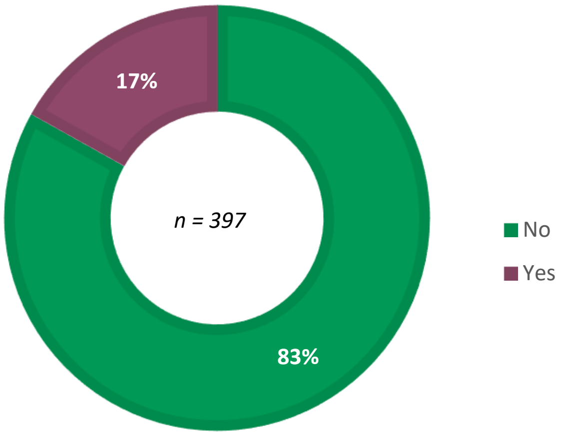


Ethnicity

Just over three quarters of individual submitters were New Zealand European. 9% were Māori, and few individual Pacific people submitted. The ‘other’ category made up about 10% of all individual submitters.

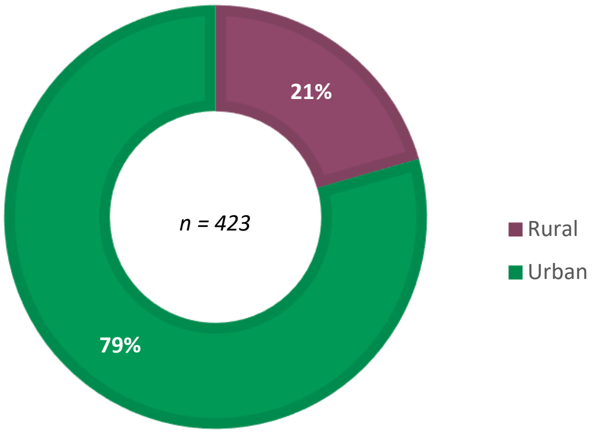
Disability

Just over 1 in 6 individual submitters identified as being disabled.

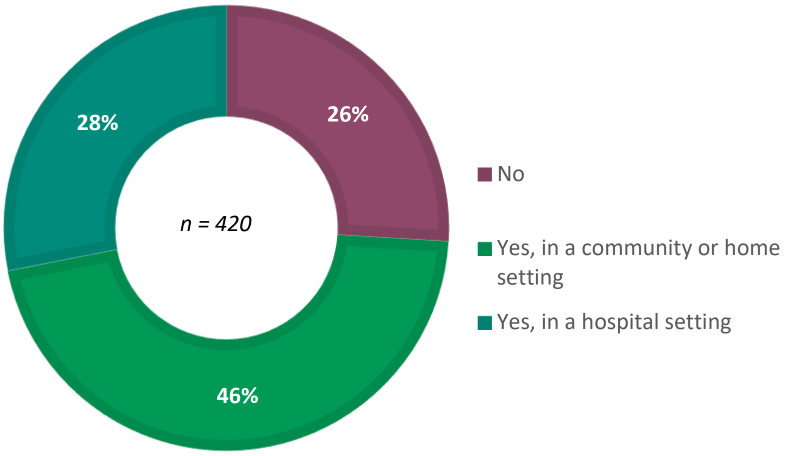


Rural or urban

Most individual submitters live in urban areas.

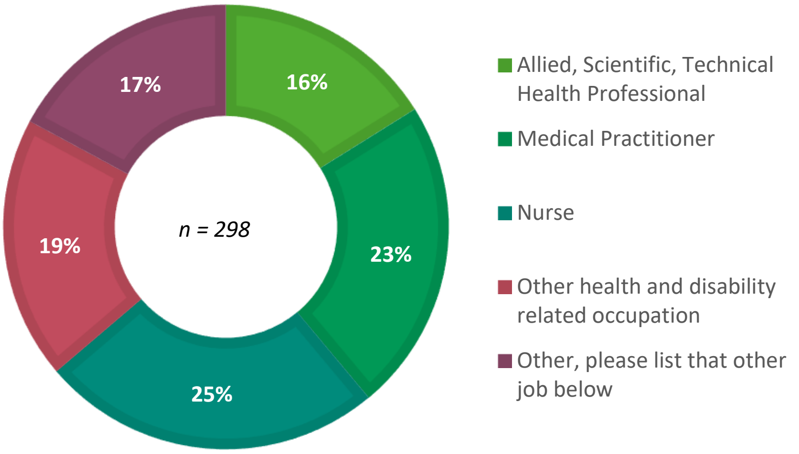


Auckland and Wellington had the highest number of individual submitters. There were more submitters from regions in the lower South Island relative to their population.



Work in the Health and Disability System?

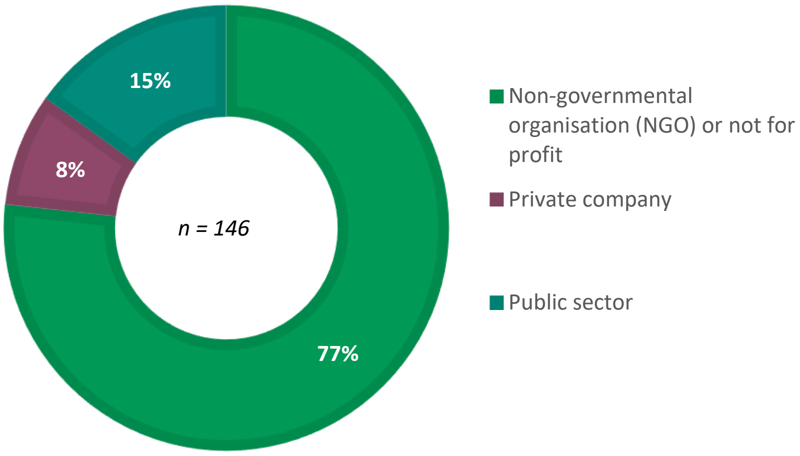
Nearly three quarters of individual submitters work in the health and disability system. Most of these people work in a community or home setting.



Occupation in the Health and Disability System

Individual submitters had broad representation across different occupations.

2.5. Organisation submitter analysis



Type of organisation

Over three quarters of organisations that provided a submission were from the NGO or not-for-profit sector.

3. People and Communities

3.1. System Values

During the submission process, the Review asked people: *"What are the most important values for our future public health and disability system?"*. Submitters identified a broad range of values for the future health and disability system, however, most submitters described a system that:

- **Embraces the principles of te Tiriti o Waitangi / the Treaty of Waitangi**. A system that embraces and commits to rangatiratanga (authority, ownership, leadership). Cultural leadership and governance is across all aspects of the system.
- **Fosters equity, fairness, and honours the human rights of all people**. The system distributes its resources fairly to eliminate inequalities and ensure the rights of people are upheld.
- **Builds relationships, collaborates, fosters trust and works together for the benefit of all New Zealanders**. There are closer partnerships across sectors and organisations to plan and achieve better health outcomes.
- **Includes and respects diversity, enabling all people to live free from the burden of bias and discrimination**. The system is built to include rather than exclude, systemically addressing discrimination at all levels. People with diverse perspectives are involved in the planning and design of services.
- **Embraces holistic perspectives of health and wellbeing.** It supports and empowers people to prevent, minimise or delay poor health and includes aspects such as connection, belonging, participation, culture, and wairuatanga (spirituality).
- **Gives service users the autonomy to make their own treatment decisions.** People are fully informed of their choices, have self-determination, and can include the right support people for them. It actively works to avoid institutional racism, and build cultural leadership and governance across all aspects of the system.
- **Regards people and their circumstances as unique**. It provides person-centred, flexible support based on specific needs, rather than a single or standardised approach.
- **Is built on compassion, fairness, manaakitanga (reciprocity and support), and respect**. All people, including the health and disability workforce, have positive interactions with the health and disability system, feel listened to, understood, and confident that health services are provided with genuine empathy for service users.
- **Is integrated, collaborative, and connected**. It consistently provides a cohesive and well-co-ordinated experience that makes it simple and quick to access the services people need, and transition between them seamlessly.
- **Supports excellence, integrity, and innovation:** An evidence-based system that makes best use of available resources for all New Zealanders and strives for quality of care in all it does. This includes using data effectively and ethically across the system, valuing the expertise of communities in service delivery, trusting and valuing the workforce, and welcoming fresh thinking and innovation.

In addition, other values and principles that came through in submissions built on or complemented those above, including a health and disability system that had strong leadership, transparency, affordability, accessibility, and timeliness. Other submitters also acknowledged the need for a sustainable system to value cost-effectiveness and efficiency.

3.2. Social determinants of health

3.2.1. **What issues were raised?**

Many submitters described the need to address upstream social, economic, and environmental factors that significantly affect the health of the population including:

- Income and poverty;
- Domestic violence and abuse;
- Social connectivity;
- Education and employment;
- Housing and healthy environments; and
- Access to transport and healthy food.

Submitters commented on the need to reach whānau experiencing inequity of access and reduce the impact of the social determinants of health and lifestyle risk factors on vulnerable populations, including children, Māori, Pacific people, pregnant women, and disabled people. Submitters noted that disabled people have unique socioeconomic needs (e.g. education, employment and income, healthcare, transport, housing, and social inclusion) that must be addressed as they are interconnected and mutually reinforcing.

Many submitters stated reasons for reducing socioeconomic inequalities, including improved health of individuals and society, benefits to the health system, and economic benefits to society.

> *Concerted effect needs to be placed on reducing socioeconomic inequalities. Reducing socioeconomic inequalities benefits not just the individual's concerned but the wider society […]. Reducing avoidable disease and premature death by addressing socioeconomic factors has economic benefits.* (Individual submission)

3.2.2. **Suggested solutions to addressing the issues**

Submitters acknowledged that health inequities cannot be addressed solely through the health sector and may be driven by other areas of government. Submitters considered that strong population health leadership and intersectoral government (national, regional and local) approaches are required to address socioeconomic inequalities and influence change outside of the health sector. Submitters suggested:

- Regulating the housing market;
- Providing healthy lunches and growing fruit and vegetables in schools;
- Regulations for warmer and drier rental and state housing;
- Providing physically and culturally accessible housing;
- Increasing incomes/benefits/paid parental leave to meet the changing cost of living; and
- Reducing liquor stores and fast food outlets in low socioeconomic areas.

Some submitters also suggested increased taxation as a means of addressing socioeconomic inequalities, but while some described the need for greater taxes in some areas, others cautioned the use of taxes (including fuel and carbon tax) due to the burden it places on individuals and families experiencing high deprivation.

3.3. Key objectives of the future health and disability section

Submitters thought that a system focussed on wellbeing, more broadly than health, would result in better population health in the long term. They wanted system leaders to be influencing broadly across government and society, as well as having a primary focus on running health services. They sought

> *A strong cross-government focus on the social, economic and structural determinants of health. There should be a strong focus on addressing poverty and ensuring adequate safe, healthy and secure housing.* (Organisation submission)

> *Pressing issues that are impacting on whānau and community health include: housing affordability and quality, energy insecurity, food insecurity, zero hour contracts, living wage, unliveable benefit levels, paid parental leave entitlement well below the minimum wage, and unaffordable child care, climate change and ecological degradation.* (Organisation submission)

Submitters wanted a strategic approach to wellbeing, coherent across sectors, under which the health and disability strategies would fit. At present, some submitters thought there was little connection between these strategies, and they did not add up to an easily understood approach.

There was strong support for a focus on equity, especially for Māori and also for other communities who are disadvantaged in the current system. Submitters emphasised work across Government to provide the foundations of social and economic necessities and to build the abilities of people, whānau and communities to live well and look after their own health.

> *More resources directed towards enabling people to live healthier lives - focussed on disadvantaged groups.* (Organisation submission)

As well as broader wellbeing and cross sector approaches, submitters wanted a longer term horizon and national approach to system planning and investment. Submitters stated that long term national planning would require coordination between organisations responsible for workforce, resources and infrastructure planning. They wanted public reporting on health that would show changes over the long term. They wanted accountability to the public, and to iwi, for infrastructure, wellbeing and health outcomes that would provide assurance of health, and provision for ill-health, for future generations. They wanted a higher-level public conversation about what sustainability means in the context of urbanisation, globalisation and climate change.

> *The health care system must also be held accountable for improving Māori health, with transparent monitoring, reporting and evaluation. This is part of honouring the Māori right to monitor the Crown's progress and should include consequences for non-performance in relation to Māori health outcomes.* (Organisation submission)

> *work with a mid-term planning horizon. High level planning parameters, including budgets, should ideally be set out at least indicatively over a three to five-year period in order to enable a more strategic approach to services and to financial management.* (Individual submission)

3.4. Population perspectives

Submitters provided many comments that were from, or about some specific population groups, including Māori, Pacific peoples, disabled people, rural, older people, women, children, and young people. Many of the issues and suggestions for these population groups are discussed within subsequent sections of this report where relevant to that section. In many cases, there is a lot of consistency across population groups and wider submitters with regards to what is important in the future health and disability system.

The following sections contain a broad summary of submitter comments regarding each population group listed below, and any specific or unique elements that differ from other populations. A detailed view of Māori perspectives is provided in Section 4.0, and disabled people's perspectives is provided in Section 6.4.

3.4.1. Pacific peoples

Many submitters discussed the need for mainstream health services to be culturally responsive to Pacific peoples, as well as providing tailored services to meet the diverse needs of various Pacific population groups. Submitters indicated that Pacific peoples faced a unique set of challenges which included a large proportion of Pacific peoples living in lower socioeconomic areas, language barriers (if English is a second language), low levels of understanding of traditional Pacific health approaches, and fewer Pacific health professionals in the workforce.

> *Pacific want to be recognised as unique, not only as a population group but by individual nation e.g. Tongan, Samoan, Fijian, Niuean, Cook Islanders, Tokeluan, Tuvaluan etc. They want health and social services that recognise their diversity and which develop services that fit them, not the other way round. Pacific want to understand their health, in language that is relatable to their situation and level of health literacy. They want to be involved in the decision-making around their health, and to design solutions that fit their needs and aspirations. In a number of instances, they want to deal with people who are Pacific, who speak their language or, at the very least, identify with and acknowledge their cultural, spiritual and philosophical outlook and reflect it during their interactions. This includes an acknowledgement that traditional healing has a place within this sphere.*
> (Organisation submission)

Submitters described the characteristics of a more effective health and disability system for Pacific peoples which included:

- Improved understanding and support to navigate between the Pacific worldview of health and wellbeing with the Western view of health;
- Recognition of the importance of relationships between Pacific people and service providers;
- Support to reduce language barriers;
- More time for Pacific people when engaging with health professionals
- Fairer funding for services more suitable for Pacific peoples. For example, better funding for family-based support options for disabled. Many Pacific communities prefer for the

family to be responsible for care; however, residential care services can be better funded; and
- Enhanced population health approaches that target improved health outcomes for Pacific peoples.

Some submitters expanded upon population health approaches. They stated that more resources needed to be directed towards enabling people to live healthier lives, targeted on issues of relevance to Pacific people, such as:

- A sustained commitment to improve social determinants of health, including improvements to housing and income inequality;
- Providing interventions that cater to Pacific peoples' risk factors;
- Targeted health promotion and health literacy initiatives to Pacific communities;
- Clear pathways and service provision in New Zealand to support Pacific peoples displaced by climate change, suffering consequent health impacts; and
- Incorporate the Pacific community in the population health system through churches.

Submitters described a Pacific people-focused model of care (Fanau Ola) as an example of an approach to providing health services. The key components of the model that submitters spoke favourably of is the re-engagement of Pacific people with their primary healthcare team while in the hospital, case management from Pacific nurses or social workers, delivery in a Pacific language, and including family members in the healthcare plan.

3.4.2. **Older people**

Submitters noted the increased pressures that the ageing population will place on the health and disability system.

> *Older age cohorts are rapidly increasing and by 2030 the 65 years + age group will account for one fifth of the total population and the population aged 85 years or over will have tripled.* (Individual submission)

Submitters acknowledged that older people are more likely to have more healthcare needs due to age-related illnesses and disabilities. These submitters therefore called for more proactive planning and resourcing towards the needs of this growing population group.

> *We have an aging population and those with disabilities only increasing we need a system that can be flexible to adapt to any age, stage, circumstance, and belief. Currently we do not have that happening in New Zealand and we need to implement this with a sense of urgency. It is easier to be proactive, rather than reactive.* (Organisation submission)

Submitters noted that loneliness is a particular societal challenge for older people that can have negative impacts on health. Some pointed to factors such as inaccessible transport options and ageist wider societal attitudes as facilitating loneliness in this group. Some submitters proposed a need to *"encourage societal attitude change so that older people are respected and valued"* (Organisation submission). Others suggested that communities should proactively introduce age-appropriate social groups to meet the social-connectivity needs of older people.

> *Loneliness is a common experience among older people that is associated with health risks and negative well-being. Many of our elderly are isolated in this society and keeping them 'at bay' remotely is not a humanly-acceptable approach.* (Individual submission)

Submitters wanted health and disability services that enable older people to live life as well and as independently as possible. This was particularly important for those with dementia.

Some submitters spoke positively of aged residential care as an essential part of the health and disability system in New Zealand. It was feared that without aged-residential care, hospitals would then face a significant burden of caring for this population group.

These submitters also noted, however, some current issues within aged residential care including facilities being run as a business model; a lack of collaboration between DHBs, GPs, specialist services and aged care providers; and unsafe staffing levels which negatively impact patient care and aged care workers.

The need for improvements to end of life care for older people was also raised. Submitters wanted end of life care to be integrated, holistic, wrap-around care provided in a community setting. It was noted that aged residential care facilities are becoming "*de-facto hospices but without the funding*" (Organisation submission), and suggested that aged residential care facilities could be viewed as an alternative to end of life care in a hospital, and appropriately funded to do so.

> *[…] aged residential care facilities are improving the ways in which end of life care is managed, to avoid moving people to hospital care.* (Organisation submission)

In particular, submissions suggested utilising Advance Care Plans (ACP) to support improved end of life care for older people. Submitters considered ACPs to be important as they give older people and their families greater autonomy over future care plans, instead of needing to make decisions amidst the emotional turmoil of declining health. Submitters want to be able to access ACP and end of life care discussions with qualified health professionals in the community, such as with their GP or local Nurse Practitioner.

> *Promote advanced care plans for older adults. At our hospital this winter we have literally dozens of patients in their late 80's and in their 90's being admitted with pneumonia, falls with fractures, "general decline" […] and they and their families are too traumatized by their decline to contemplate [advanced care plans] and thinking about the future. We desperately need to encourage people to document their wishes after talking about it with their GP or nurse practitioner. What do they really want.* (Individual submission)

3.4.3. **Rural people**

While less than a quarter of individual submitters live in rural areas, there were some strong and consistent themes about access to health and disability services for rural populations from individuals and rurally focused organisations. Submitters want more health services in outlying communities to improve equity of access. Specifically, submitters want either hospitals or smaller clinical centres with the ability to provide specialised treatments. They emphasised that geographic location should not be a barrier to access, or impact the standard of care, compared to urban areas.

> *There are still many people living in these areas, they may not have vehicles, or whānau to get them to hospital, or currently not enough health services to cater for those outlying communities without long distance travelling.* (Individual submission)

Submitters discussed several enablers to improve access, including:

- Increased use of telehealth for consultations. Submitters also stated that nurses would be able to provide most of the care in rural areas (either in the home or primary care setting), with remote support from specialists;
- Improvement of 4G and broadband in rural areas to enable the delivery of technology in these settings;
- Increased use of mobile health closer to service users' homes, including mobile dentistry, optometry, specialist clinics, scanning, screening, and minor surgery;
- Increased use of personal monitoring devices that provide data to their health professionals, including holter monitors, blood pressure meters, and glucose meters;
- Support for rural families and whānau to travel to the main centres for health services or provide health shuttles;
- Establish a Rural Health Commissioner position to provide accountability for the health of rural populations;
- Use data and research to monitor and inform the allocation of resources and targeted responses to improve equity;
- National planning to determine the most appropriate location of facilities to decrease the impact of distance on access to treatment; and
- Funding models to support primary healthcare facilities in rural communities to ensure practices can be sustainable and attract good practitioners.

In order to have greater investment in rural communities, some submitters commented on the need to have a clear and consistent definition of 'rural'. Submitters want to see more investment in infrastructure for rural areas, with a focus on community health and disability hubs in rural areas that provide a comprehensive range of services and integrated funding. In addition, there needs to be investment in the rural health workforce to ensure retention and maintained competency. They suggested recruiting rural people and providing training in the communities to build a sustainable workforce. Bond schemes could also be used to incentivise practitioners to work in rural areas.

> *Access to services is inextricably linked to medical, nursing, midwifery and allied health professional workforce issues – both to shortages, workforce sustainability and salaries. There are constant big pressures on health professionals working in rural areas. Pressures are across the workforce and the role of other health workers in sustaining our health services is undervalued and under-recognised.* (Organisation submission)

3.4.4. **Maternity and early childhood**

Submissions from both organisations and individuals highlighted pregnancy and early childhood as critical life-stages for influencing health outcomes throughout life. Submitters called for increased investment into, and focus on, the first 1000 days of a child's life (that is, conception through early childhood). This included investment into increased provision of effective, culturally appropriate antenatal and postnatal services, maternal mental health services, and building the capacity of the midwifery and Well child/Tamariki Ora nursing workforce.

> *Invest heavily in the early years - so we have the best chance of healthy infants - that means better supporting pregnant women.* (Individual submission)

> *A focus on the first 1000 days is an opportunity to put a coordinated focus on a period of life that is critical to better outcomes and future health.* (Organisation submission)

These submitters argued that a lack of investment into services provided during the first 1000 days can lead to poorer health and social outcomes, and more costly health interventions/services required later in life. Submitters indicated that pregnancy and early childhood are cost-effective areas to target investment compared to adulthood.

> *There is also strong evidence that maternal and childhood health and wellbeing is critical to future health and wellbeing […] Poor health in childhood can lead to poorer health, education, employment, welfare and justice outcomes for individuals and populations. However, strong health and education foundations provide protection against challenges faced later in life and are worth the investment.* (Individual submission)

Submitters argued that a focus on the first 1000 days goes beyond simply viewing health in isolation. Numerous factors such as poverty, housing, parenting skills, domestic violence, and education all contribute to health outcomes of pregnant women and children, and should be addressed.

> *Pregnancy is a key opportunity to change trajectories for the better. Protection of the unborn child from the negative impact of smoking, alcohol, drugs, domestic violence etc. through effective support of the mother and whānau antenatally should be a major focus of the health system.* (Organisation submission)

> *The stress of unsafe and unhealthy living environments and the highly likely deterioration in physical, spiritual, and psychological health places an unacceptable burden on pregnant women, women with newborn infants and young children and their families.* (Organisation submission)

Some submitters pointed to the particular importance of the role that parents play. The health, wellbeing, and support available to parents and pregnant women was seen by submitters as critical to the health and wellbeing of children. It was noted that parents facing socioeconomic disadvantages may require additional, focussed, culturally appropriate support.

> *substantial support for parents, particularly those disadvantaged currently, is required to support their irreplaceable role in good child development. Families facing multiple adversity should receive culturally and socially appropriate supports for quality parenting and education, including a focus on literacy.* (Organisation submission)

4. Māori

4.1. Te Tiriti o Waitangi / The Treaty of Waitangi

What submitters said about te Tiriti/ the Treaty

Māori and non-Māori submitters identified similar issues in relation to te Tiriti/the Treaty and its position within the health and disability system. Submitters supported the concept that the right to health is affirmed within the Treaty. The following issues appeared consistently in submissions discussing te Tiriti/the Treaty:

- There is a need for the Crown to better meet its obligations to Māori under the Treaty
- The right to health is reflected and affirmed as a human rights obligation in the Treaty of Waitangi. Therefore the status and rights of Māori to achieve equitable health outcomes need to be acknowledged and upheld
- Honouring te Tiriti/the Treaty throughout the health and disability system is essential to improving Māori health and achieving equitable health outcomes
- The Crown's non-performance in relation to Māori rights (including the right to equitable health outcomes) under te Tiriti/the Treaty is a Treaty breach
- The obligations and responsibilities contained in te Tiriti/the Treaty are not just requirements of the Crown but also useful guidelines for improving the health and disability system and facilitating effective partnerships with Māori
- te Tiriti/the Treaty needs to underpin the core values of any future health and disability system
- Current attempts to incorporate te Tiriti/the Treaty within the health and disability system fall short of what is required of the Crown
- The principles of partnership, protection and participation need to be expanded/developed/strengthened further to better articulate the Crown's obligations to Māori.

Crown obligations under te Tiriti/the Treaty

> *Recognising and honouring obligations under te Tiriti o Waitangi, as the founding document of Aotearoa New Zealand, is vital to ensuring Māori are treated equitably through the health and disability system.* (Organisation submission)

Submitters commenting on te Tiriti/the Treaty consistently indicated the need for the Crown to more adequately fulfil its obligations to Māori as outlined in the Treaty. In the health context, submitters suggested this would mean a more demonstrable and sustained effort throughout the health and disability system to achieving equity for Māori at all levels – governance, decision-making, policy development and implementation and service provision.

Submitters provided a range of definitions for what the Crown's obligations and responsibilities are under te Tiriti/the Treaty, often referring to the three key principles of partnership, protection and participation. However, some submitters have pointed out that the principles alone give a limited view of how the Crown's Treaty obligations should be interpreted.

Some submitters highlighted that the health and disability system should recognise the four articles of te Tiriti/the Treaty (Kāwanatanga, Tino Rangatiratanga, Oritetanga, Te Ritenga/Wairuatanga) as a more definitive guideline of what is required of the Crown to support improvements to Māori health and the achievement of health equity.

Health service values

Submitters consistently commented on the importance of using te Tiriti/the Treaty and its articles/principles to inform the health and disability system's core values. Some submissions noted that the current system is focussed on what works best for health professionals and business owners, rather than upholding values that place service users, their whānau and families and the wider community at the centre of service provision. Te Tiriti/the Treaty and the values inherent within it were frequently highlighted as providing an appropriate model to underpin any future health and disability system.

Application of Treaty of Waitangi across the health and disability system

Submitters said the current application of te Tiriti/the Treaty within the health and disability system is variable and often confined to brief acknowledgement or mention in strategic or annual planning documents belonging to the Ministry of Health (the Ministry) or district health boards (DHBs). It was argued that the acknowledgement of te Tiriti/the Treaty was often used as an overarching concept (a 'guiding principle' in itself) with few tangible activities or examples of how the values and principles inherent within te Tiriti/the Treaty will be effectively operationalised.

> *New Zealand is founded on te Tiriti o Waitangi and the health and disability sector has applied versions of the principles of te Tiriti in its business, with a focus on the principles of partnership, participation, and protection since 1999. However, these principles barely scratch the surface of what is truly required in a responsive health and disability sector.* (Organisation submission)

As mentioned previously, submitters have highlighted that honouring te Tiriti/the Treaty is central to achieving health equity for Māori. It has been submitted by various individuals and organisations that this can only be achieved by embedding te Tiriti/the Treaty and its values throughout the health and disability system.

Submitters have said a health and disability system that more adequately acknowledges and meets its obligations to Māori under te Tiriti/the Treaty would:

- Respect the beliefs, values and aspirations of Māori service users, the Māori health and disability workforce and Māori communities;
- Enable Māori to pursue and achieve their goals and aspirations in relation to health;
- Recognise the right to health and Māori health equity reflected in the Treaty;
- Provide adequate and sustained levels of funding and support to provide for kaupapa Māori health care services, ensuring that all health services are provided in a culturally appropriate way; and
- Allow for Māori to participate in decision-making, governance and leadership at all levels, especially in relation to the provision of Māori health services.

Governance and Leadership

For the most part submissions on application of te Tiriti/the Treaty at the governance and leadership level focused on the ‘relational interdependencies entailed in te Tiriti/the Treaty’ and the need for Māori to have an equal position with the Crown as Treaty partners. Submitters have emphasised their belief that genuine commitment to te Tiriti/the Treaty and its values and principles would include recognition of Māori health leaders, researchers and practitioners as experts in Māori health. These experts, and Māori more generally, would be given a more active role in leading the design, implementation and administration of the health system. In doing so, Māori would be empowered to operate as active partners within the system rather than one of many different groups of stakeholders, granting them the status provided under te Tiriti.

> *The Review should encourage the development, in partnership with Māori, of appropriate governance, funding and service delivery systems that give full effect to Tino Rangatiratanga.* (Organisation submission)

Funding

Submitters suggested that a separate Māori funder of health and disability services could improve equity for Māori. They proposed that a Māori funder would ensure greater alignment with the principles and requirements of te Tiriti/The Treaty and enable the design and delivery of more appropriate services for Māori. Submitters also wanted greater funding allocated towards Māori health and disability services.

Policy design, development and implementation

> *We believe embedding te Tiriti o Waitangi into health policy and more broadly, across all government policy and strategy, is the single most effective measure to ensure equity of health outcomes for all populations in New Zealand, not only Māori.* (Organisation submission)

Submitters noted that there is a need to strengthen alignment of health policy design, development and implementation to more adequately enable Māori to pursue and enact their own aspirations in relation to Māori health advancement and development. This would require adhering to te Tiriti/the Treaty within all policy, strategy and health administration. Meaningful and substantive relationships and genuine engagement between government agencies (the Ministry, DHBs and other related Crown entities) and Māori iwi, hapū an whānau were also noted as important components to the development and design of all health policy.

Other submitters argued for stronger accountability and transparency mechanisms within current policy settings to ensure the Crown is more accountable for its responses to poor Māori health outcomes, is more comprehensively meeting its health obligations to Māori and is consistently working to improve its performance. Taking this approach to monitoring and evaluation would, as one submitter suggested, “*enable Māori to enact their right to monitor the Crown’s progress*” (Organisation submission) in relation to improving Māori health outcomes.

Workforce knowledge of the Treaty of Waitangi

Some submitters commented on the training of the workforce and suggested that te Tiriti/the Treaty knowledge in the health sector needs to be strengthened and made a part of ongoing professional development for all health practitioners. It was suggested that this would strengthen its status as well as maintain its currency within the health and disability system.

4.2. Institutional Racism

What submitters said about Institutional Racism

> *It is critical for the Review to understand and recognise how institutional racism and bias affect the entire trajectory of a person's health care journey. Structures established by the dominant or mainstream culture can be, by design, ignorant of the needs of others.* (Organisation submission)

Submitters who commented on institutional racism noted that experiences of institutional racism within the New Zealand health and disability system are well documented. The work of researchers such as Dr Heather Came, Donna Cormack and Ricci Harris were consistently referenced to highlight the impact of institutional racism, the different ways it can manifest as well as the opportunities available to address the current issues relevant to it.

Submitters raised a range of issues relating to institutional racism, including:

- A lack of 'explicit acknowledgement' by the health and disability system and the Crown that institutional racism exists;
- A lack of political will amongst successive governments to address racism (including institutional racism) and health inequities, particularly health inequities for Māori;
- The gap between legislative and policy requirements and how these are operationalised within the health and disability system;
- Differential access to health services and differential treatment between population groups despite experiencing the same conditions;
- Low priority and low visibility given to Māori health equity within core policy documents;
- Decision-making practices that marginalise the views of Māori and other minority population groups; and
- Systems, policies and practises that perpetuate power and resource distribution imbalances and health inequities for Māori.

Addressing Institutional racism across the health and disability sector

> *We need a health and disability system that fully commits to correcting the health inequities faced by many populations as a result of institutional discrimination.* (Organisation submission)

Submitters pointed to a number of different ways in which the health and disability system could address institutional racism.

Some suggested that as a first step the system needed to openly acknowledge that institutional racism exists. Others pointed to a need for the system to take more responsibility for ensuring that all legislation, policies, decision-making processes and operational practices are underpinned by a focus on equity. Other suggestions from submitters included:

- A commitment throughout the health and disability system to address institutional racism where it occurs;
- Preventing the further use of decisions and approaches within the system that serve to perpetuate power imbalances and inequity;
- Developing a diverse health workforce that is representative of different population groups (discussed further below);
- Using health equity research that is self-produced or co-designed with Māori and other minority populations served to inform all health policy development;
- Meeting New Zealand's international obligations to uphold the rights of Māori under Articles 23 and 24 of the UN Declaration on the Rights of Indigenous People;
- Developing a national action plan to eliminate racism (as recommended by the Committee for the Elimination of all forms of Racial Discrimination in 2017), as well as measures to develop a culturally competent workforce that is knowledgeable in mātauranga Māori;
- Increasing Māori participation and decision-making powers in consultation processes for service re-design through increased support and capacity building to enable Māori to fulfil leadership and governance roles;
- Developing robust evaluation and quality improvement processes to monitor and evaluate the performance of the system in eliminating institutional racism;
- Recognising and responding appropriately to Māori health need and ensuring Māori worldviews are embedded throughout the health and disability system (this aspect is discussed in more detail in the Māori Health Frameworks section); and
- Using a systems-change approach to address institutional racism, described as being suited to complex and persistent problems and involving establishing change management teams, developing and improving socio-political factors, and using a series of action research rounds to "*identify and disrupt sites of racism in cycles of incremental change and continuous learning*". (Organisation submission)

Workforce development and cultural competency

Submitters identified workforce development and cultural competency training as an area where institutional racism could be addressed effectively. Often, submitters thought the health and disability workforce should adequately reflect all sections of the population served (particularly in relation to the active recruitment and retention of the Māori health workforce). In addition, they requested a supportive care environment for Māori and other minority population groups with a system-wide focus on achieving equity.

Submitters also noted that the elimination of racism needs to be established as a key responsibility for all those working in the health and disability system. It was suggested by submitters that the responsibility to identify, prevent, and remove institutional racism become individual and team key performance indicators within relevant employment contracts. This would include all those in health governance and leadership positions.

It was suggested that cultural competency training should incorporate education to understand the history of New Zealand, what institutional racism is and how to recognise and address it.

4.3. Better models of care for Māori

Submitters argued that there was a need for the current health and disability system to take a more holistic approach to health service provision and health treatment. They described a system that is currently under-delivering not only to Māori but across a range of demographics (e.g. age, gender, ethnicity), a system that is too "narrow" in its approach to treating illness and one that lacks the appropriate frameworks to treat both the individual and their wider whānau and families using a health and wellbeing lens.

Māori submitters emphasised the need for the health and disability system to take a more holistic approach to health and wellbeing. It was suggested that this would be achieved by acknowledging the interconnectedness between the physical, mental, spiritual and environmental aspects of the individual alongside their connection to their wider whānau and their community.

> *The best health and disability system for New Zealand in 2030 is one that has been designed with Iwi and Māori, and as such, will have seen a drastic reduction in health disparity. The holistic approach and world views of Māori will be at the heart of investment, planning, design and delivery. We say this with the conviction that what works for Māori will work for all New Zealanders.* (Organisation submission)

Definitions of holistic health differed slightly across submissions but shared similarities in that they described an approach to health care that placed the service user at the centre of care. Some phrases used in submissions to characterise holistic health included:

- Wellbeing-centric;
- Whānau-centred or whānau-centric (focussed on collective health concepts of whanaungatanga and whānau and community health);
- Whole-health focussed; and
- Wairua-centric (an approach to health described as addressing human wellbeing as inextricably linked to the natural and spiritual environment).

The focus of most of these submissions was on reconfiguring the health and disability system to reflect and promote Māori models of health and wellbeing and their alignment with universal values of compassion, respect and understanding for service users in the treatment of illness.

Submitters argued that adopting Māori frameworks and approaches to health and wellbeing:

- Promotes and uses a broader definition of health that acknowledges the interconnectedness of the mind, body, spirit and whānau/family alongside environmental influences;
- Draws on kaupapa Māori philosophies, Māori health frameworks, concepts and values;
- Incorporates continuous quality improvement using Kaupapa Māori quality improvement paradigms together with western approaches to monitoring and evaluating the performance of the health and disability system;

- Supports individuals and their whānau to play a greater role in managing their health and wellbeing;
- Places people, whānau and communities at the centre of health service provision;
- Commits to adequately funding Māori models of health and health service delivery; and
- Prioritises and expands on Māori knowledge, understandings and approaches to health and wellbeing, embedding them throughout the health and disability system.

Submitters commented on the importance of Māori health providers who operate using a range of holistic Māori health frameworks in the provision of care to the communities they serve. These providers, submitters suggested, should be viewed as integral to pathways of care when addressing the health and disability needs of Māori.

Māori Frameworks

Submitters referenced a range of Māori health frameworks as examples of health and wellbeing approaches that should be incorporated more widely throughout the health and disability system, particularly in relation to addressing Māori health needs and achieving Māori health equity. These include frameworks that acknowledge the interconnectedness between mental, physical, spiritual, family and community health in contributing to overall wellbeing. The most commonly cited frameworks and concepts derived from Māori knowledge and approaches to health and wellbeing that submitters discussed included:

- Te Whare Tapa Whā;
- Te Pae Mahutonga;
- Te Hau Mārire;
- Atua Matua;
- Kawa Oranga/Pae Ora;
- Mana whānau, whānau ora;
- Whanaungatanga and kaitiakitanga; and
- Mahi-ā-Atua narratives-based programmes.

Whānau ora initiative

> *The Māori patient cannot be treated in relation to their most pressing symptom, the care they receive must be based on a holistic approach to their ongoing health and wellbeing, taking into account a range of factors that impact on their spiritual and physical health. This is, in effect, the essence of Whānau Ora care – and this must become the norm.* (Organisation submission)

Submitters indicated their support for Whānau Ora models of care and the need for the approach to be better funded, more effectively implemented and utilised throughout the health and disability system. These submitters pointed to the success of Whānau Ora in providing whānau-centred services that are tailored to the needs of service users, as well as its multidimensional approach to treating illness. Some submitters highlighted the potential of the Whānau Ora approach to cater to the needs of a range of different demographics, including rural communities.

There was support from submitters for the Whānau Ora approach to also be used to deliver healthcare to people with disabilities. They suggested this approach to supporting disabled people would ensure the disabled person and their whānau and family were supported to meet their health aspirations collectively. The benefit in this approach, it was suggested, would be the inclusion of the disabled individual as an integral part of a family system that enabled and supported all members to achieve optimal health and wellbeing.

Submitters called for greater acceptance of Māori approaches, expansion of these services, and more resources. Many non-Māori submitters echoed these sentiments, supporting a shift of the whole health system to reflect Māori models of care.

> *Whānau ora providers work in partnership with families and offer holistic health and social care. Their model of care is culturally anchored, whānau-centred and strengths-based (focussing of the family's strengths, resources, and abilities). The whānau ora providers work in the community and are trusted by many people who may not prefer to use mainstream providers.* (Individual submission)

Submitters noted that one of the key challenges since the establishment of the Whānau Ora initiative was the "skewing" of the underlying philosophies through health procurement and commissioning processes. It was suggested that funding processes altered Whānau Ora from a model of care grounded in Te Āo Māori to one more strongly influenced by western approaches to healthcare provision.

5. Settings

5.1. Governance and leadership

Submitters overall supported stronger, more unified national leadership and stewardship, with longer time horizons and a more collaborative, less competitive approach. They expressed many and varied ideas on who should lead, which entities should be responsible for which functions, how decision-making should be shared across the system, and whether and how restructuring should occur.

5.1.1. Stronger more unified national leadership and stewardship

Submitters expressed a view that the system has become too fragmented with unclear direction. They said it is too complicated and difficult for both people and practitioners to navigate. Many said that New Zealand is too small a country to split responsibilities across so many different organisations. Submitters were also concerned that opportunities have been lost to influence wider government policy and services that would improve people's health and wellbeing.

Submitters called for stronger and more effective leadership across different parts of the system, and especially at a national level. Many commented on the need for a longer-term view in making decisions, which they regarded as largely absent at present.

> *The role of the MoH in providing the health system stewardship over the next five-ten years is critical to driving the change we require in health outcomes. The DHB model is well placed to respond to local needs. However, it currently occurs in a vacuum of poor strategic vision from the centre about how services should be organised nationally, regionally and, most importantly, sub regionally. Clarity of vision of the role of DHBs, the role of good governance and how and where services should be configured for maximum sustainability is critical.* (Individual submission)

Submitters identified transparency as an important element of the system. They wanted public reporting on the health and wellbeing of different population groups, and on the availability, effectiveness and expenditure on health and wellbeing services across different parts of New Zealand. Submitters said this would allow greater public scrutiny and more informed debate on priorities and investments. They also said it would facilitate greater consideration of long-term outcomes. For Māori, it would allow the system to be more readily held to account for obligations under te Tiriti o Waitangi/the Treaty of Waitangi.

Submitters also wanted strong national leadership, that would set the direction for the system, but would be collaborative and allow for regional and local decision-making. Some submitters wanted stronger central control and leadership. Others emphasised collaboration rather than competition.

> *National agencies must work together to effectively guide the health system. By working together, agencies combine their expertise, mandates, tools and resources creating broader ability to support change in the most useful and appropriate ways.* (Organisation submission)

5.1.2. **Who should lead?**

While the Ministry was viewed by most submitters as the natural lead for the system, most did not feel it had delivered on this mandate. Some thought it had too many conflicting roles to provide effective leadership; others thought that closeness to the Government and serving the Minister interfered with its ability to lead.

Some submitters commented on the effects of a short-term political cycle on decision-making about health. They thought this contributed to decisions that were not in the long-term interests of the country as a whole. Submitters called for the appointment of an independent public authority to report on health matters, increasing public transparency and accountability of Government and the health and disability system.

Suggestions included:

- A parliamentary commissioner role for health, similar to that of the Parliamentary Commissioner for the Environment
- An independent "think tank" to provide authoritative advice on health matters.

> *Health is NZ's biggest industry yet there is very little informed public comment about its efficiency and effectiveness, in contrast to extensive daily commentary about agricultural production, milk prices, business performance, regulatory impacts, etc, etc. […] This lack of public watchdog oversight leads to a lack of understanding of the health system by the public and a lack of confidence in the system.* (Organisation submission)

> *We live in an Information Age where there is a great deal of misinformation and opinion masquerading as fact. Attitudes and practices are subject to influences that may lack experience and expertise. Therefore having a central New Zealand voice would ensure that there is one source for 'truth and authority' on health matters.* (Organisation submission)

Submitters agreed that leadership and decision-making were needed at all levels in the system. They wanted a clear framework for which decisions would be made nationally, which regionally, which locally and which by individuals (clinicians or people and whānau). There were wide ranging views on the makeup of such a framework, but strong support for a more unified, joined up approach that recognised the shared nature of leadership and that allowed for community input at local level.

As well as a strong national approach, submitters supported regional clusters (the suggested number of regions varied) and most wanted some local and district leadership to address the issues specific to each community.

There were widely varying views on who should be involved in governance and on boards, from those supporting appointed professional directors only, through to many seeking greater representation by people who would benefit most from health improvement.

> *Disabled person's organisations and other people with lived experience of disability need to be active contributors in all levels of the Health and Disability system* (Organisation submission)

> *Include patient groups, and representatives in governance and decision-making in the health and disability service.* (Organisation submission)

> *"Consumers" (non clinicians) need to have a place at the table. The system exists to serve us, not the other way around.* (Individual submission)

Across submitters, there was support for increased Māori leadership and for the system as a whole to embrace Te Ao Māori, incorporate tikanga Māori and become more holistic and people and whānau centred. Submitters expressed the view that what works for Māori would work for all.

Māori argued that services that embrace Te Ao Māori should be available to all Māori, and that input from hapū and iwi is necessary at many levels. Submitters wanted:

> *A system where Māori feel a sense of belonging and where te reo Māori, Māori culture and values flourish. A system where the mana of te tangata is recognised and tikanga reflected in all health practices. {A system where} all staff and governance have the opportunity to use and improve their understanding of te reo and tikanga Māori.* (Organisation submission)

Submitters said the current system had served Māori poorly, and major change was needed. Some submitters wanted a separate system for Māori, led and governed by Māori.

> *Māori have continuously attempted to fix a broken health system that has not served Māori. What we need is a Māori Commissioning body controlled and managed by Māori. The Māori providers have the experience, workforce and knowledge to enable and realise Hapu aspirations for Whānau health. The iwi role in this is higher strategic alignment with other government agencies.* (Organisation submission)

> *Māori providers and PHO's need to stand outside of the government to provide by Māori for Māori services for themselves. Māori should have 15% of vote health funding to provide care for our own.* (Organisation submission)

Submitters called for changes to the leadership, governance and operating style of mainstream agencies, services and governance structures. Specific changes suggested included more Māori members of boards and councils, reporting and accountability to iwi and hapū, greater attention to Māori workforce and provider development, and new executive Māori leadership positions.

Submitters recognised that there was a need to grow leadership and advocated for investment in developing leaders across the system. Particular effort for some communities was sought by submitters.

> *Empowered and bold Pacific leadership, who are supported and not isolated from the system. Pacific need opportunities to develop this cohort of leaders; the system needs to make these opportunities available and attainable.* (Organisation submission)

5.1.3. **Which entities should be responsible for which functions?**

Submitters were concerned about the number of DHBs and PHOs in New Zealand, and the associated administrative overheads, duplication and inconsistencies. They thought that a coherent national approach would result in effective, efficient and consistent service availability, especially for hospital and other highly specialised services.

> *We see that current structures are driving inequities and inefficiencies across the system. There are blurred roles and responsibilities that exist between relatively complicated DHB and PHO structures. There is also considerable variation in capability and capacity for service commissioning decisions across 20 DHBs, as well as what we would see should be avoidable cost inefficiencies by having 20 DHBs and 32 PHOs in a country of New Zealand's size.* (Organisation submission)

> *I have had experience of one fairly rare condition where a national system to deal with it was implemented. This has had marked effects in creating an equitable system for all, no matter what ethnic group or region they live in. While some regional input is probably helpful, in a nation of under 5 million people, I fail to see why we cannot have a national health system.* (Individual submission)

Submitters thought a national approach would provide a backbone to improve many local services. National decision-making, set-up and implementation was suggested for many functions that support service delivery. These functions included information systems, clinical pathways, public-facing health information, library and learning resources, workforce and leadership development and research and innovation.

> *Provision of accessible services with clear, pathways nationwide for assessment, review and treatment. Excellence available to all.* (Organisation submission)

> *the infrastructure of the health and disability sector be improved to reduce complexity for service users and providers.* (Organisation submission)

Submitters had a range of suggestions about the sorts of entities that should be responsible for running national or regional services and functions. Some of these submitters suggested a national specialist health service that would run all hospitals and provide backbone functions. Some thought this could be a government department reporting directly to a Minister. More thought it should be a separate authority at arm's length from government. Some thought a regional model could work to run hospital and specialist services for that region, with each region contributing some centres of excellence that would provide the national backbone on specific functions.

Some submitters thought that having 20 DHBs around New Zealand was a good thing, but that their roles should be different from the current DHB board roles. Rather than running hospitals, boards should be responsible for community-based services and for making representations on the priorities for their communities to a national, specialist secondary and tertiary service system (or one of only a few, e.g., three to six, regional systems). The specialist secondary and tertiary service system would be run to achieve consistency and excellence of care throughout New Zealand.

Submitters thought that such a national or regional system to run hospital and other specialist or highly expensive infrastructure would free up by resource by reducing administrative and governance overheads and achieving economies of scale. They variously thought this resource could be invested in increased quality of specialist care, improved access for people in geographically isolated areas, or health promotion and community care activities.

Submitters wanted greater community involvement in and local governance of services that were close to the community. They particularly wanted a greater community voice in developments focused on wellbeing, promoting health and getting early help when needed. They wanted iwi and rūnanga to have much more say.

> *We urge decentralisation of the funding for health promotion across New Zealand, with communities given greater capability and funding to develop, implement and evaluate their own campaigns in fully engaged ways with their target populations.* (Organisation submission)

> *More Iwi controlled delivery of health and disability services for Māori.* (Organisation submission)

Submitters expressed views on the difficulties for DHBs in taking an overall population health approach when the Ministry retained the purchasing function for a number of services. DHBs had limited ability to prioritise funds, change service models or promote integration across services when they had to fit in with a national contract for a significant part of the service. Examples included maternity, Well Child, public health and disability support services, and – mentioned most frequently – primary health care.

> *Devolving primary maternity services and Plunket would make it much easier for DHBs to plan and coordinate the provision of these services with DHB-funded maternal and child health providers.* (Individual submission)

Other submitters raised the difficulties Ministry purchasing caused not for DHBs but for the Ministry itself. Submitters said the Ministry's involvement in service provision and purchasing limited its ability to hold DHBs to account for population health goals, and to provide independent advice to ministers. Some submitters were of the view that the Ministry should not directly provide, run or purchase services.

Disability support services is one area where submitters wanted a more cohesive approach, not just across the health and disability system but across all of Government support for disabled people.

> *We strongly support the development of an alternative to the current, fragmented disability support system, with a view to seeing whether a single, integrated disability support system could be established in Aotearoa New Zealand.* (Organisation submission)

5.1.4. **Whether and how restructuring should occur**

Submitters were concerned about the adverse effects of changing structures in the system. They said that the loss of focus and progress that would accompany major changes in structures far outweighed any gains that might eventually result.

> *A top down approach and decision to reduce and consolidate DHBs is likely to create more waste. It will not significantly reduce costs and may give the impression that something is being fixed. Restructuring is itself a costly process. Such costs include paying for redundancies, loss of institutional knowledge, loss of leadership and staff time to focus on health issues (as time and resources are diverted into the restructuring process), slower progress against health priorities, the cost of back-filling staff and contracting with consultants, and the costs associated with any re-branding and IT systems. The disruption and costs associated a top-down approach to restructuring the system would be high.* (Individual submission)

They supported small and incremental change in structures, and larger change in culture, relationships, inclusivity and accountability.

> *A primary emphasis on structural change in health system reform is a red herring and a mistake. There are institutions and policies already in place which, on paper, are fit for purpose – the barrier has been in giving expression to this policy intent – the issues of implementation.* (Individual submission)

Others said that structures should not be tinkered with, that if there is to be restructuring it should be full and complete.

> *It is our view that anything shy of significant structural reform to create equity focused accountability and appropriate monitoring with consequences is likely to repeat mistakes of the past.* (Organisation submission)

Submitters suggested where priority should be placed in any structural change. Many placed greater equity of outcomes across the population as the most important reason for change. They wanted more efficient and consistent management and distribution of the most technical and expensive services, with less room for parochial decision-makers.

On the other hand, submitters wanted more effective local decision-making about community services, with greater involvement of service user representatives, Māori and younger people who in their view had had little direct input in recent years.

> *The new design should embrace complexity, and celebrate diversity both within the providers, the structures and the communities served.* (Individual submission)

They asked for

> *Clarity on what's best done locally, regionally, nationally. This is a delicate balance with efficiency/avoiding duplication vs being close enough to community to understand their needs.* (Organisation submission)

5.2. Funding and Finance

> *Funding often determines opportunity, choice and approach. Thus for any sustained change in New Zealand's current health and disability system, funding mechanisms must adapt to enable the desired system change. […] The most powerful mechanism is funding. Minimal or superficial change will result from the current Review unless the current funding model(s) are addressed.* (Organisation submission)

Submitters identified the important role that funding has on the health and disability system and how influential it is to drive and enable change. Submitters comments on the issues and better uses of funding cover a range of topics, which are discussed in more detail below:

- Delineation between funders and service provider;
- Who should purchase what and where;
- Issues with budgets, priorities, and level of funding;
- Current and future contracting and commissioning approaches;
- How funding should be allocated across the system;
- Considerations for private organisations, public organisations, NGOs, and insurers; and
- Investment in other health infrastructure and activities.

5.2.1. **Funder or service provider**

Submitters suggested having greater delineation between purchaser and provider roles. While there were different views as to the best purchasing entity(ies), most submitters implied that blurring these roles creates layers of political and market complexity. Submitters have concerns that DHBs under financial pressure shift strategic and long-term investment and funding away from future-focused and proactive services to contain budget deficits and meet immediate demand. Submitters said that if an organisation remains both a purchaser and provider, then some funding should be ring-fenced for specific services or populations, with more accountability placed on the funder.

5.2.2. **Purchasing entities**

Submitters suggested extending the range of services purchased by a national funder throughout the health and disability system. The concept is intended to improve the quality, consistency, oversight, planning, equity and efficiency of services delivered across New Zealand. There were mixed views from submitters (including ambivalence) on whether the national funder should be the Ministry or another entity (such as the previous Health Funding Authority), but most suggested that the separation of roles was important.

> *Move most primary and community care funding to a national funder (either the MOH or a new national funder). […] The national funding agency should have regional commissioning agents to facilitate the development of regional alliances and regional plans between primary and secondary players.* (Organisation submission)

Submitters discussed how services are purchased for Māori, and whether a national funder would purchase services for Māori and non-Māori, or whether a separate Māori funder would purchase services for Māori. Regardless of structure, submitters request that purchasing approaches are founded on the principles and requirements of te Tiriti/The Treaty. Some submitters cite other indigenous health systems that may offer learning opportunities from both a governance and funding perspective, for example:

> *Indigenous lead health systems - handing funding and decision making over to indigenous people (NUKA health systems of care, Alaskan model). Led to improved health outcomes, actively engaged families, wellness models of care.* (Organisation submission)

Submitters acknowledge that while some services could be purchased nationally under a single entity, there are other scenarios where this is less appropriate. Submitters also emphasised that funding should be flexible to local needs.

5.2.3. Current issues with budgets and strategic planning

Submitters recognised how budgets and financial drivers heavily influence the shape of services and their interface with the community. They indicated that funding also determines investment and focus of other critical elements of a functional health and disability system, such as information technology, infrastructure, integration and collaboration, and workforce.

Submitters said that planning and funding needs to occur at both a national and regional level, but they also identified several current issues that inhibit its effectiveness:

- The annual DHB budget cycle inhibits long-term strategic planning;
- There are too many strategic priorities at both national and regional levels, with short-lived initiatives; and
- There is inadequate funding to meet current service demands, in addition to investing in upstream issues.

The annual DHB budget cycle inhibits long-term strategic planning

Discussion points raised by submitters in regard to DHB budget cycles included concerns that:

- DHBs are focused on delivering services to meet the growing demand within their short-term budget;
- Limited planning and investment in strategic or longer-term approaches;
- Difficulty to commit to contractual terms for longer than one-year, placing more uncertainty and risk on organisations contracting to the DHB;
- Ongoing service continuity is at greater risk of interruption;
- Stifled innovation and collaboration, and difficulties in developing partnerships; and
- Service delivery organisations can become hesitant to invest in their workforce (i.e. attracting, developing, and retaining the right talent).

Submitters also noted particular issues with capital spending. With tight budgetary constraints and pressures, investment in much needed IT and facilities is also delayed or deprioritised.

> *New Zealand needs to move away from the current annual planning and budgeting cycle that requires DHBs to meet zero or low deficits every year. This approach can mean that DHBs defer infrastructure and IT upgrades and building and clinical equipment maintenance. It also limits the ability of DHBs to make significant up-front investments in order to increase efficiencies, mitigate rising demands on hospital services, and reduce costs over the long term.* (Individual submission)

> *It is worth noting that if every DHB must break even every year then the funding formula-based allocation would have to be perfect, and perfectly predict the range of influences upon demand and expenditure. The annual fiscal focus with no longer term planning and pathway has severely curtailed the health system's ability to focus on strategic change and service improvement.* (Individual submission)

Too many strategic priorities and short-lived initiatives

Some submitters reported that funders (i.e. the Ministry, DHBs, PHOs) are subject to many different strategic priorities, initiatives, and targets across different stakeholders, which affects their ability to cohesively and comprehensively focus and deliver-upon these effectively. Submitters said that some of these initiatives are also short-lived, with funding ceasing after the initial period is over. When introduced, these services have often fill an identified service need gap, but if ongoing funding is not secured, the service gap could be wider than before.

Inadequate funding to meet current service demands, in addition to investing in upstream issues

> *Bolstering the health service to such an extent that the service could be based on needs of the consumer not rationing services based on resources available. Health is the most important thing in life and the govt budget should reflect this.* (Individual submission)

Submitters commented on inadequate funding across most aspects of the health and disability system over many years. Some suggested that the funding has not increased at the same rate as the costs to deliver services. They cited many contributing factors to increasing costs such as increasing demand pressures (i.e. ageing population, multi-morbidities), and increasing costs-to-service (i.e. higher service user expectations, information and technology, and workforce). Submitters suggested that these cost pressures make it difficult for DHBs to directly control expenditure, and DHBs are required to invest in demand management to indirectly influence costs. Submitters stated that constant cost pressures have resulted in:

- Public health system: increased wait times, higher entry thresholds for access to care, and inadequate care provided to support recovery (i.e. early and incomplete discharge due to cost and capacity pressures); and
- Private health system: lower margins and less appetite for innovation and cherry-picking the most profitable service users at the expense of the most in need.

However, some submitters acknowledged that simply increasing the amount of funding without making necessary changes to the system and how funding is used will not address these issues in the long-term.

> *DHBs also generally lack the capacity to be strategic, constantly faced with funding deficits, which does not allow for long-term planning or innovation.* (Organisation submission)

5.2.4. **The contracting and commissioning process**

Submitters described current issues and future direction in two main areas of contracting and commissioning: 1) the funding models; and 2) the commissioning (and contracting) approaches.

Funding models

Submitters suggested adopting different funding models to achieve more equitable health outcomes. Some described a need to shift from fee-for-service and input-based approaches towards other models. The most frequently discussed models included:

- Outcome/value-based models;
- Service bundle models;
- Enhanced capitation models; and
- Individualised funding approaches.

Submitters indicated that whichever model is adopted, the future model should be based around a few fundamental concepts, such as:

- It should enable and promote more diverse, integrated, holistic, culturally appropriate, and comprehensive services, with enough scope and funding to address current unmet needs;
- It should be co-designed by health professionals and service users, and adequately funded to appropriately support those with greater barriers and needs, not just the mainstream population;
- It should be flexible enough to promote access to the right services, rather than defined one-size-fits-all approaches;
- It should include a focus on wellbeing, including population health and earlier intervention; and
- There should be greater sophistication and focus on measuring outcomes, with clear accountabilities.

> *the best (and fastest) way to achieve outcomes will be to invest in a commissioning model that measures health outcomes, invests in frontline activity on the ground, and provides wraparound services for whānau.* (Organisation submission)

> *There must be a shift from a fee-for-service model to a value-based model.* (Organisation submission)

Submitters indicated that funding should follow the person rather than be based on the service provider.

Commissioning approaches

Submitters identified issues with the current standard commissioning and contracting approaches for providers of health and disability services. A frequent comment was that the length of the contract cycle was too short (often annual) and that three-year contracts have the potential to provide more certainty and strategic planning within the sector.

> *That health service commissioning should operate on a planning cycle of three years with a greater focus on medium to long term investments, aligned with the longer-term outcomes focus of System Level Measures.* (Individual submission)

Submitters also suggested that the current commissioning process has led to stifled innovation, reduced creativity (through uniform responses), and unnecessary constraints that limit integration, flexibility and collaboration. Some submitters indicated that there should be greater emphasis on commissioning more diverse and multi-disciplinary services, which could include collaboration with iwi and other community organisations.

> *One cultural change required is the understanding of the strengths and limitations of contracting approaches. Micro management of contracts extinguishes creative and responsive practice at the provider level, and decreases the potential advantages of a multi dimensional provider community (public, private, third sector). Under current practice they all begin to look like and behave the same. NGO providers loose […] their original social purpose as the contracting system enforces uniformity of response.* (Individual submission)

Some submitters also noted that commissioning approaches could better target inequities, rather than contracting services that work just for the majority. They suggested that the funding associated with contracts should cater for more complex populations, and the values be consistently updated to reflect the true demands (including increased service delivery requirements) and costs of delivering the services.

5.2.5. **Funding allocation**

Submitters commented on how funding is - and could be – allocated, including increasing overall health funding and improving the way in which it is allocated. Suggestions included:

- reducing the level and proportion of funding allocated for Tier 2 services over time, in favour of Tier 1 and population health services.
- channelling more funding towards specific health and disability services;
- increasing funding for specific population groups;
- adequate funding for integration activities;
- increasing funding for Māori providers and workforce; and
- decreasing salary and overhead costs by reducing the number of DHBs and PHOs.

Funding of population health

Key themes raised in relation to population health funding included:

- Concerns about a lack of clear direction, accountability, and responsibility for population health at all levels, with many different agencies and organisations involved with funding and providing different and overlapping aspects of population health services;
- Challenges of meeting current demand and providing existing services while simultaneously increasing efforts towards preventive and earlier intervention approaches;
- Greater emphasis and priority on appropriately funding population health (i.e. health promotion, wellness, and prevention);
- Ensuring that all providers (public and private) have a shared responsibility for addressing equity; and
- Ring-fencing funding for the core population health functions.

> *It is critical that the health and disability system considers public health spending as a high-value investment rather than a cost.* (Organisation submission)

Funding for specific population groups

To improve equity, some submitters identified specific population groups that face significant cost barriers and that additional funding would be beneficial to improve access to health and disability services for these groups. While the range of groups identified was large, the most commonly cited were:

- Low-income;
- Māori;
- Children;
- Young adults;
- Pregnant women;
- Older people;
- Disabled;
- Pacific people; and
- Rural.

Submitters suggested reducing or removing copayments for these population groups, while some suggested the addition of other services to gain partially or fully funded status. Submitters also mentioned that additional funding was not necessarily required across all services that a profession offers and funding should focus on 'core' services that have demonstrable impact on health outcomes.

Submitters provided examples of the importance and/or the benefits of reducing healthcare costs to specific population groups, including:

> *Removal of the prescription copayment should in the first instance, be offered to all users of the Community Services Card and to all superannuitants. Both of these groups tend to have higher needs and have the least resources to cover the cost of funded medicines. The additional cost to the government would be offset by the savings in primary and secondary care costs.* (Organisation submission)

> *Funding of children less than 13 years of age has been beneficial as low income women are more likely to seek medical assistance themselves, but extending free*

> *visits to those less than 18 years of age would improve healthcare for low income families and prevent more serious health issues developing at a greater cost to all.* (Organisation submission)
>
> *Ensure that funding is adequate to meet people's needs for the basic everyday human functions such as showering, dressing, eating well and living in a clean, healthy environment. Partial funding is not an option for people who may be already disadvantaged by lack of mobility, unemployment, low incomes etc.* (Organisation submission)
>
> *The funding system must be carefully designed to support sustainable health care for isolated and rural communities, taking account of real provider costs.* (Organisation submission)
>
> *One of the biggest areas of need is for health services provided to 18-24 year olds. They have low incomes on minimum wage with zero or low hours, or on student loans and yet are expected to pay the full amount for primary care.* (Individual submission)

Submitters described the current funding for people with disabilities as being fragmented and siloed. Other issues for disabled people that submitters described included:

- a reduction in funding for frontline services;
- inability to share budgets across funding streams;
- not working in partnership with providers (resulting in ineffective or inappropriate service procurement);
- constrained funder rules that at times contradict each other;
- limited access to subsidised physiotherapy for some conditions;
- a lack of funding to support parents with disabled children; and
- inadequate funding for treatment of rare disorders.

Some submitters suggested that resources and support for disabled people should be funded through Ministry of Social Development (or another agency that is separate to the health system). Submitters regarded this as an important change to shift the disability paradigm from a medical model to a social model.

Submitters suggested improvements to the funding of the disability system, including:

- Integrated and transparent funding models that are person-centred and facilitate the involvement of the multiple services that people need;
- Nationally consistent funding (to ensure equity of outcomes across DHBs) with local flexibility that is determined by needs;
- More comprehensive and consistent funding for home-based care to keep pace with demographically foreseeable increases in the aged population plus the worsening of disabilities with age;
- More longitudinal funding support for NGOs for disabled people who rely on services provided by NGOs; and
- Funding for the unique supports that people might need to enable effective participation in decisions about their health and disability care, such as interpreters and digital tools.

Submitters noted that young adults (18 to 25) are usually in a life-stage of relatively low income and that cost becomes a barrier to proactive and early engagement with health services. Submitters discussed inconsistencies in the ages that young New Zealanders can access fully funded health services and suggested that for priority health services, the eligibility age for fully funded support should be increased.

Youth mental health services is cited as another area of increasing demand, and while there are technically funded services, some submitters were concerned that a lack of funding and resources leaves significant unmet need that may escalate at a later stage.

> *although [Child and Adolescent Mental Health] services are enabled to go up to 25 years of age for 'youth mental health', it cannot in reality due to lack of funding, leaving many highly vulnerable young adults unable to access services.* (Organisation submission)

Tier 1 and 2 funding

> *Insufficient funding passed on to Primary Care. After 15 years of Government Policy directing greater funding to, and development of, Primary Care little has been achieved. Instead, the DHBs have been allowed to keep too much of the funds earmarked for Primary Care for their own businesses. As a result, Primary Care remains underfunded and ineffective in both managing and preventing the many illnesses that they were expected to do. Years of under-funding has created competition between clinical service providers rather than the planned collaboration.* (Individual submission)

Submitter comments were centred around two key aspects:

1. Reduce costs to service users (including subsidies); and
2. Increase funding to service providers.

Reduce service user costs

Submitters identified cost as a significant barrier to access services for many people, but particularly those who are already exposed to greater service inequities. Some submitters said that some costs should be reduced or removed for any and all who use a particular service (e.g. oral care, ambulance services, contraception), while others suggested (discussed previously) that costs are reduced for specific population groups.

Some submitters noted that current attempts at reducing inequities within Tier 1 services (such as Very Low Cost Access (VLCA) primary care funding) are not totally successful, and do not always direct the additional funding to the people who need it the most.

> *The current VLCA system is not the best way to fund GP services in order to improve access and quality of care. A better system would be to have the funding correspond to the health needs of the patient. Having worked in VLCA, many patients who are not high needs take advantage of the lower funding when they don't really need it.* (Individual submission)

Some submitters noted that the service costs do not reflect the full and actual costs of engaging in services. Travel, parking, childcare, and the loss of earnings to attend appointments were frequently cited as significant additional expenditures. Submitters commented that for some, these costs will create additional access barriers, particularly for those currently experiencing poor health outcomes. People living further from services are more likely to experience these challenges, as well as Māori and Pacific people due to their overall lower socioeconomic status.

> *[…] an example of invisible costs faced by parts of their population. These patients drive unregistered, unwarranted vehicles. When they access healthcare, i.e. driving to the GP or pharmacy, leaving their vehicles visible to parking enforcement officers, the resulting fine adds to the cost of treatment. Given gang turf boundaries in [town], healthcare is not locally available, travel by car is essential and there is no readily accessible public transport for these patients.* (Organisation submission)

Some submitters suggested that sector processes to seek funding and support for those who have difficulty paying (i.e. via WINZ) should be simplified and streamlined as many find these barriers too difficult to overcome, meaning that people do not receive the right support when they need it. They also called for increases in the amount funded for some services, as the costs of some services have risen faster than inflationary increases.

> *Financial assistance for emergency oral health care may be available, if eligible, through a single $300 per annum special needs grant from Work and Income New Zealand. A special needs grant is available only once per annum and the amount of each grant has not increased since the late 1990s. The average cost of a mid-sized filling in private dental practice in New Zealand was $246 in the 2018 recent New Zealand Dental Association fee survey, a considerable increase from $52 in 1993 (inflation-adjusted against the consumer price index, this would equate to $87 in 2018 currency). This cost does not include a consultation, or the tests needed to diagnose the problem, such as dental radiographs. Consequently, the current level of financial assistance precludes many from accessing even emergency dental care through the special needs grant from Work and Income New Zealand.* (Organisation submission)

Increase service provider funding

Some submitters identified funding issues related to existing services. These issues relate to:

- Viability and financial incentives to address those with more complex conditions;
- Erosion of sustainable profit margins over time, where funding has not kept pace with the costs of delivering healthcare;
- Service funding breadth is too narrow, and depth is too shallow. It does not promote broader and more integrated services (i.e. inclusion of mental health services in a primary care setting);
- Perceived funding inequities between Tier 1 and Tier 2 services, where community/home-based services are not adequately funded; and
- Perceived funding inequities between different Tier 1 services where some services receive little or no central funding.

> *Currently the funding system for primary care in New Zealand does not support general practice to provide comprehensive mental and physical health care to people who have high needs (including mental health and/or substance abuse problems).* (Organisation submission)

Submitters suggested possible system solutions for these issues were to increase community-based funding to enable more sustainable and comprehensive services and support. Submitters requested expansion of funding for services such as mental health, disability, rehabilitation, dental, vision, and social services. In addition, there were suggestions to increase the funding to allow for longer consultations for those with more complex, cultural and/or holistic needs. Submitters stated that this would allow more time to comprehensively identify and address needs.

> *Payment for services needs to allow for lengthy and complex consultations. There is huge variation in the complexity of consultations, in the same way there is variation of the person / family seeking the services. Capitation and fee-capping assumes a 10-15min length visit, but this is often exceeded – doubled, tripled, even quadrupled especially in the case of complex situations.* (Individual submission)

Funding integration

Submitters indicated that the current services delivered outside of the hospital are typically funded based on discreet, non-complex, single-discipline care. They stated that these funding models and contracts are regularly based on narrowly scoped inputs rather than outcomes, while providing minimal incentives or accommodations for collaborative and integrative activities. Submitters suggested that in the future, funding and contracts could be broadened to allow for more flexible and team-based service delivery using a more diverse workforce.

> *Funding models must be changed to encourage and support primary care practices to utilise a more diverse staff including allied health professionals.* (Organisation submission)

> *The current top-down health targets and funding frameworks prevent providers, across both primary and secondary care, working as one-team with patients at the centre of everything they do. It is time to remove the barriers inherent in the silo funding of providers for their specific service functions and give them a collective incentive to 'do the right thing' for their patients and the local community. The system needs to encourage relevant providers in communities to work together in a collective organisation, with patients' outcomes and longer-term wellbeing as the focus of their attention. This will ensure collective benefit through the right care being provided, regardless of who provides that care or service. (Organisation submission)*

Māori providers and workforce

Most of what submitters said about the workforce is summarised in Section 7.1; however, some funding related inequities are highlighted below. Specifically, submitters commented that Māori health providers who deliver services consistent with Māori frameworks are not adequately or fairly funded in comparison to those providing similar services in other parts of the health and disability system.

> *Contracts awarded to Māori providers do not allow for pay equity nor recognition of the dual competencies of Māori practitioners and the complexities of working with complicated intergenerational health and social dynamics.* (Organisation submission)

Proposed ways of addressing this varied, with some suggesting increasing Māori funding to recognise the higher levels of input required to address the current inequities. Others thought that a broader, more centralised approach may help to reduce inequities – suggesting that the Tier 1 and 2 workforce could be employed and salaried nationally.

5.2.6. **Other investment**

Infrastructure

Submitters reported that there has been under-investment on physical and technological infrastructure in the public sector. In particular, they said that appropriate maintenance of DHB properties (i.e. Hospitals) is being curtailed because of budgetary pressures, and additionally, there has been consistent under-investment in digital and technological infrastructure.

> *Capital expenditure is a significant issue and will be an ongoing for most of our DHBs. Treasury reported in 2007 of DHBs "sweating their assets and under-funding repairs and maintenance to help balance their books" (Treasury, NZ, 2017). The neglect of capital expenditure over the last ten years means that the need for additional Crown support will continue.* (Organisation submission)

Health research

At the system level, some submitters commented on the need for greater investment in New Zealand-based health and research to promote relevant and innovative practice. They also suggested that there should be more research that is focused on people with less common conditions, and relevant to New Zealand ethnicities.

> *every one of the last ten years government health research investment has been less than 1% of government health care expenditure. […] We believe therefore that 2.4% is a reasonable, albeit somewhat conservative, advocacy position, and we submit that New Zealand should have a target of achieving this by 2027.* (Organisation submission)

> *the main thrust of our submission is that health and medical research should be fully recognised as a key essential component of the New Zealand Health and Disability System, we have sought to set out the reasons why it is essential for New Zealand to continue to invest in in its own research programmes.* (Organisation submission)

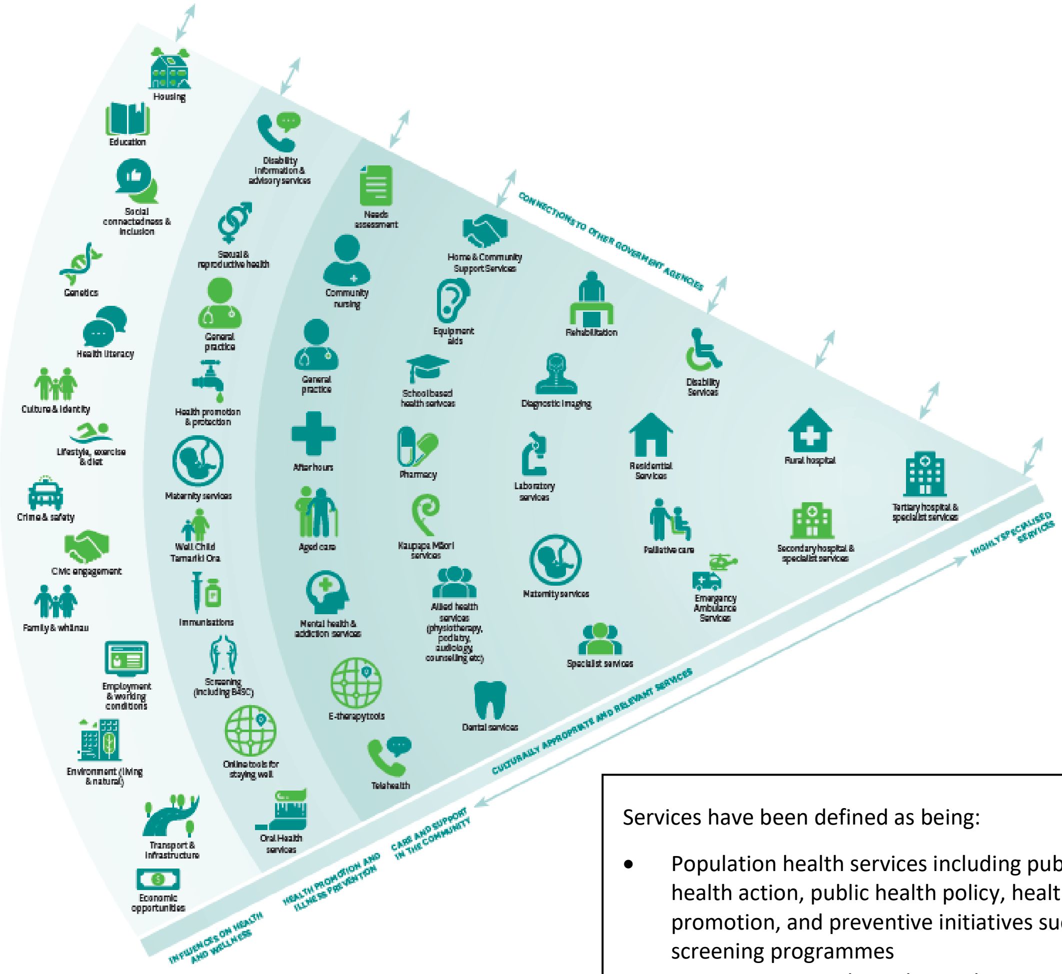
Submitters identified gaps in the capture, research and learning in relation to some specific populations such as disabled, rare or even some common conditions. They state that there is an opportunity to better understand and target services more appropriately for these groups.

> *Currently some groups of disabled people (e.g. neurological conditions such as Alzheimer's or Down Syndrome) can be excluded from taking part in research as Aotearoa New Zealand legislation does not enable their participation without informed consent. Review of this legislation could result in more research and consequent increased evidenced-based care available to people with disabilities.* (Organisation submission)

Submitters also indicated that clinical research should be a high priority throughout hospitals in New Zealand to advance healthcare. Some submitters suggested mandating medical research as a core requirement for providers, or integrating research requirements with the funding and KPIs for DHBs.

6. Services

The current health and disability system, and its influencers, is shown below:



Services have been defined as being:

- Population health services including public health action, public health policy, health promotion, and preventive initiatives such as screening programmes
- Tier 1: Services taking place in homes and local communities including; Self-care, diagnostic and treatment services such as general practice, school health services and pharmacy
- Tier 2: Public and private hospital and specialist treatment and diagnostic services.
- Disability: Services provided to people with disabilities that support them to live well with disability.

6.1. Service-level concepts

Submitters described concepts that applied broadly to the wider system and its services that were not specific to either population health, Tier 1, Tier 2, or disability services. These broader issues and ideas are discussed in this section.

6.1.1. **Models of care**

Submitters commented on the wider health and disability system, and its general approach to hauora and wellbeing. They said that the traditional model of care in New Zealand has been dominated by a biomedical approach, and indicate that this is not the only option for our future system. Submitters indicated that the philosophy underpinning each model of care influences what services are delivered, how they are configured, and where/when they are accessed.

Issues that submitters identified with the current model of care are discussed below, followed by their descriptions of the characteristics of a more suitable model.

Current Issues

Submitters stated that the current model was not ‘broken’ and may work adequately for many. However, submitters were concerned about how the system has not been working well for people who are at greater risk of poorer health outcomes, or for those who experience more barriers to access. Māori, Pacific peoples, disabled, deprived, older people, rural, children and youth are just some of the groups who face additional challenges. Submitters identified the following issues with the current biomedical model of care:

- Social determinants and causal factors are not identified or addressed;
- There is a lack of holistic and comprehensive services – models tend to compartmentalise and treat people based on illness or impairment rather than looking at a person’s entire context or causal factors that lead to poorer health;
- The health and disability system lacks focus on prevention and wellbeing;
- Services are fragmented and poorly integrated;
- The biomedical model does not adequately support Māori and other cultural health approaches; and
- The current paradigm of care is centred on a deficits-based approach.

> *it is absolutely bizarre, in principle, to treat persons as if their minds, emotions, relationships, families, traumas, experiences, stories, cultures, spiritualities, and more, may be reasonably disregarded in our considerations of the emergence and treatment of illness. And yet we constantly, habitually, implicitly and systemically practice as if that is so.* (Organisation submission)

Future approaches

When describing more equitable, effective and sustainable models of care, the approaches described by submitters usually fell within at least one of three broad categories:

- Needs and/or rights-based approaches;
- Person and whānau centred, holistic, integrated, and Māori approaches; and
- Wellbeing, preventive, and life course approaches.

Needs and rights-based approaches

Submitters suggested taking more of a needs based approach would help to reduce inequity. Approaches included:

- Basing service provision on health needs rather than convenience or efficiency.
- Eliminating the biases present in the current system and the model of care to systematically target and address barriers to access for those in the most need.
- Developing a better understanding of a person's needs, and enabling the workforce to meet these needs.
- Aligning needs with an individual's fundamental rights with clear accountability and responsibility to ensure that these rights are upheld.

Person and whānau-centred, holistic, and integrated approaches

In addition to Māori models of care (discussed in Section 4.3), submitters commented on approaches that have similar concepts to Whānau Ora. They described these approaches as:

- Placing the service user and their whānau at the centre of health and disability services;
- Emphasising and prioritising experience;
- Incorporating the service user's context into how services are delivered; and
- Taking a holistic view of the person when providing health services.

Submitters emphasised the need for better integration across organisations, services and sectors within the community if adopting a more holistic approach to health, with the subsequent involvement of a wider range of support people.

> *A tweaking of the current biomedical approach will not suffice; a radical transformation is required that considers the wellbeing of the whole person, within their whole environment. This is called 'Whole Health'. This transformation necessitates a shifting at the foundational level from reductionism towards holism, from fragmented industrialised medicine towards compassionate whole person-centred care, and from disease management towards prevention and wellbeing promotion.* (Individual submission)

Wellbeing, preventive and life course approaches

Submitters stated that current system is mostly focused on getting unwell people better rather than preventing people from getting sick or helping them stay well. There was strong support for a shift towards wellbeing focused models of care. These included approaches that enable and empower communities to maintain health and prevent or delay deterioration of wellbeing wherever possible. Population health approaches are described in Section 6.2.4, but submitters wanted that the current workforce (particularly Tier 1) to play a bigger role in preventive approaches. Submitters reasoned that shifting resources and focus to earlier and preventive services will reduce the demand on more costly and specialised services.

Submitters suggested that wellbeing and preventive models would work well in conjunction with life course approaches. They indicated that life course approaches emphasised a deeper understanding of the circumstances, risks and factors that influence health over the course of life, which enabled more proactive and optimal use of resources, such as the timing, location and the type of support based.

> *The role of the healthcare provider/system is to empower people and communities to reconnect with their own ability to take control of the factors influencing their health both at the internal (mind-body-spirit) level and external (social determinants) level.* (Individual submission)

6.1.2. **An inclusive and collaborative planning and design process**

The process of planning and designing services featured strongly in submissions. Submitters suggested that service users should be more involved at all stages of the service design process. This was particularly important for the populations with greater levels of inequity such as Māori, Pacific peoples, and disabled people. For local service delivery, many submitters suggest that local government, iwi, and the wider community be involved. They also want services to meet the requirements of te Tiriti o Waitangi.

> *Services are planned and delivered in partnership with Māori, local government, and the wider health, social, and education sectors.* (Individual submission)

In order to support appropriate co-design and engagement, submitters said that development and investment in the right capabilities is required. Skills including project management, change management and facilitation of co-design is important to improve the quality of the outcome without over-burdening busy frontline staff.

> *Co-design and co-production with consumers and whānau, meeting the requirements of te Tiriti o Waitangi, must be a core skill and way of working.* (Organisation submission)

6.1.3. **Quality and clinical governance**

Submitters noted the importance of high-quality services with robust clinical governance to ensure care is both effective and safe. Submitters were concerned about the current absence of a consistent approach to measuring and monitoring quality, clinical appropriateness, and best practice. They indicated this has led to inappropriate variation in healthcare delivery and workforce capability. Submitters thought a future system should strike a good balance of standardisation and flexibility while adhering to high quality standards, but acknowledged the challenge to get the balance right.

> *It is noted that whilst this trend towards personalisation will increase people's access to a wider range of services, it will also create challenges for the health system - including issues to do with monitoring the quality of care and maintaining professional standards, which will need to be considered as part of any change process.* (Organisation submission)

Submitters also suggested that mid/meso-level organisations could broaden their scope of clinical oversight and strategic direction setting to promote higher quality, more diverse and holistic pathways, while addressing the current lack of consistency across different professions and organisations. They described the potential for greater sophistication in how service provision is evaluated and health outcomes data are used to inform better clinical practice.

6.1.4. **Improvement and innovation**

Submitters identified the importance of learning, service improvement, and innovation to improve long-term health outcomes and efficiency. Submitters indicated that the current system suppresses innovation and is not oriented towards collaboration. Some wanted more consistent and nationwide approaches to capturing and sharing information, learnings and research. A few suggested centralised and dedicated teams to support dissemination activities. Submitters also stated that it is not often known if innovative approaches are successful or not as many health and disability providers do not currently have the resources or the capacity to develop and evaluate innovative practices.

Submitters wanted the system to build evaluation and improvement approaches into standard practice, and invest in enablers such as harnessing the right capability, capacity, and technology. They suggested improving these feedback loops will lead to incremental change.

> *Investment in innovative provision, which can be effectively evaluated, is needed to meet the needs of all communities, particularly Māori, Pacific people and disabled people.* (Organisation submission)

Submitters’ comments regarding investment in New Zealand based research is covered in the funding and finance (Section 5.2.6)

6.2. Population Health

6.2.1. What is population health?

The terms 'public health' and 'population health' are often used interchangeably. While some submitters have used 'public health', for this report, to avoid confusion with the term 'the public health system' and the 'publicly funded health system', we use the term 'population health'. This term incorporates the broad definition and meaning of 'public health'.

6.2.2. Population Health in New Zealand

The current issues affecting the health of the population as cited by submitters covered a range of issues including:

- Increasing prevalence of non-communicable diseases, particularly conditions that are preventable and driven by risk factors such as: smoking, alcohol, physical inactivity, unhealthy food, and air pollution. Multiple morbidity of chronic health conditions was also considered to be a complex population health issue;
- Poorer health outcomes among vulnerable populations, including Māori, Pacific peoples, high deprivation whānau and families, and disabled people; and
- Loneliness and social isolation, and its impacts on mental health and wellbeing.

In addition to current population health issues, submitters were concerned about the sustainability of the health and disability system in the face of future population health challenges. Submitters suggested that the future system could be designed and equipped to respond to and manage challenges, including:

- **Environmental changes,** including climate change and the depletion of natural resources. Submitters indicated that climate change will have a greater impact on vulnerable populations (including Māori, Pacific people, children, older people, and high deprivation communities) through rising food prices, storm damage to low-quality housing, heat stress, unsafe drinking water, and changing patterns of disease.
- **Threats associated with antimicrobial resistance**, particularly among Pacific and Māori populations who are at higher risk. Submitters noted that New Zealand has been slow to develop and implement a comprehensive response to antimicrobial resistance, partly due to overlapping roles from multiple national agencies and a lack of central leadership.
- **Emerging and re-emerging infectious diseases**, including the threat of global pandemics.
- **Demographic changes**, including population growth (migrant population and environmental refugees), changes to age and ethnicity distribution (noting that health conditions increase in complexity with age), and increasing urban density.
- **Increasing burden of non-communicable diseases** as the population ages and people are more exposed to lifestyle risk factors.

The future of population health

As discussed in models of care (Section 6.1.1), submitters said that the system should be reoriented towards upstream disease prevention to focus on the health and wellbeing of people, whānau and communities.

> *Changing the current system requires a disruption to the status quo and shift from a reactive, individually-focused, diagnostic, illness and treatment-based model to a proactive preventative model […] it requires us to look beyond the health system to address the social, economic, cultural and environmental determinants of health, not just a person's individual characteristics and behaviours.* (Organisation submission)

Submitters suggested:

- A greater focus on 'lifestyle' diseases and specific areas or health conditions where more preventive efforts are required;
- A wider acknowledgement, that preventive measures take time to yield tangible results and that a focus on short term gains will not achieve the required results to reduce preventable diseases; and
- Investing in population health as a mechanism to improve health equity and health outcomes.

6.2.3. **Population Health system enablers**

Current issues

Submitters described a number of issues in the structure and function of organisations that drive, deliver, or influence population health activities, including:

- A lack of national coordination, effective intersectoral collaboration, and consistency in service provision and strategic policy direction;

> *There is duplication; there are inefficiencies; and there are systemic failures. With [the range of organisations involved in delivering population health], successful public health and health promotion requires more than better coordination. It requires national leadership and investment.* (Organisation submission)

- A lack of leadership in population health at all levels - ministerial, professionally, departmental and cross- governmentally;
- A lack of funding and investment in population health, in part due to the benefits of these investments occurring far in the future;
- Limited ability and mandate for population health organisations (e.g. HPA and Public Health Units) and statutory officers to provide independent advice to Government and other Government agencies; and
- No agency acts as te Tiriti/the Treaty partner of the Ministry of Health in relation to population health, resulting in few institutional mechanisms to fulfil the Crown's obligations under the Treaty.

New Zealand and global commitments

Submitters pointed to the Government's commitment to the Sustainable Development Goals (SDGs) and were concerned about New Zealand's limited progress towards these goals, indicating a lack of cross government and cross sector collaboration as hindering progress. Submitters also referred to the current Government's wellbeing focus and goals and stated the health system should align with these goals. Submitters also noted that the Living Standards Framework aligns with a paradigm shift to wellbeing and prevention.

Submitters noted that New Zealand could better align with global population health priorities through the following suggestions:

- Alignment with the 2015 Paris Climate Change agreement; and
- Meeting the legal framework of obligations under the International Health Regulations 2005 that requires New Zealand to "*develop, maintain the capacities to detect and assess, respond to and report acute public health threats*" (Organisation submission).

New Zealand's population health system

Submitters stated that population health services are currently delivered by many organisations including the Ministry, Health Promotion Agency (HPA), DHBs, Public Health Units (PHUs), PHOs, and non-governmental organisations. They also cited other (non-health) organisations which contribute to population health including Ministry for Primary Industries, Institute of Environmental Science and Research, and local and regional councils.

In order to address these system issues, some submitters suggested institutional redesign and legislative change to improve New Zealand's population health infrastructure and the delivery of services. Other submitters noted that the system could be integrated and "*configured to enable strong and well-coordinated regional service planning and delivery, and accountability across the system, to achieve overall population health outcomes*" (Organisation submission) without needing major reconfiguration.

Leading population health

Submitters commented on the need for stronger leadership and coordination of population health services, from national to regional and local levels. Suggestions include:

- appointing an Associate Minister for Public Health to provide leadership and responsibility for population health outcomes across the system;
- giving the Director of Public Health (within the Ministry of Health) position statutory powers; and
- applying population health performance measures across all relevant agencies (national, regional and local), which balance short term views of productivity and long-term population outcomes.

> *Increased accountability for population health outcomes across the health and social sectors, including the introduction of accountability measures to plan, fund, implement, measure and report on outcomes. This should include an accountability framework for District Health Boards (DHBs) and Public Health Units (PHUs) to address and report annually on the state of population health. Clear, collective accountability for cohesive delivery of public health services throughout the entire health system. This would be supported by accountability frameworks for all health service providers, not just public health service providers, to address the population health priorities.* (Organisation submission)

National population health infrastructure

Submitters commented on the need to strengthen the capacity and mandate of national organisations to provide population health functions across Government. Submitters described services that could be provided at a national level, including:

- Legislative oversight and a range of technical support;
- Surveillance and analysis of national/international communicable and non-communicable disease trends;
- Co-ordination of inter-district emergency responses;
- National programmes, registers, or information systems
- Population health workforce planning and development;
- National population health and intersectoral policy analysis and development; and
- Developing and maintaining for the full spectrum of population health services a clear strategic direction, consistent service specifications, and a transparent funding model which takes into account the particular population health needs of New Zealand's very varied local communities.

Submitters also suggested a range of issues and options that should be considered when assessing the future structure and functions of national agencies. These suggestions included:

- Establishing a Ministry of Public Health, with funding independent of the Ministry;
- Establishing a new agency separate from the Ministry with broad population health functions including those relevant to health protection and health promotion, and assessment and monitoring of key population health attributes of the health care system (i.e. effectiveness, cost-effectiveness, equity and quality);
- Strengthening the Population Health and Prevention Directorate in the Ministry to have an explicit focus on population health goals and targets;
- Reforming the HPA to:
    - become the Health Sponsorship Council, eliminating, with Crown funds, any perceived need of the community to seek sponsorship from tobacco, alcohol, sugar sweetened beverages and fast food companies;
    - expand its legislative mandate and give it greater responsibility for population health functions, such as monitoring, making policy recommendations, and Government advice; and
- Devolving the resources and responsibilities of the HPA to local areas, rather than a central Crown agency. Submitters suggested that decentralised funding for health promotion would give communities greater ability to deliver targeted activities for their population.

Submitters also provided examples of other jurisdictions that have built their population health infrastructure by establishing separate entities with high levels of autonomy in policy, advocacy and/or monitoring, for example, Public Health Scotland and Public Health Canada.

Regional and local population health infrastructure

> *Currently, public health is unnecessarily fragmented and complex given New Zealand's small size. In particular, PHUs are diverse in size, specialisation, service*

> *scope, levels of service provision, and ability to deliver across the five core public health functions.* (Organisation submission)

Submitters sought improved coordination of population health activities across organisations at a regional and local level. They cited inconsistent approaches across the many providers who undertake population health activities, including DHBs, PHUs, Healthy Families, NGOs, and PHOs. Some submitters suggested moving much of the funding for and delivery of population health activities from PHUs to DHBs, with PHUs focused more on their health regulatory function. Other submitters argued for PHUs to have a broader scope of work to ensure sufficient critical mass to attract and retain staff.

Submitters suggested the functions provided at a regional level should include:

- Advanced surveillance and analysis;
- Population health policy analysis;
- Programme design and evaluation;
- Environmental health technical expertise;
- Support for outbreak investigation and control;
- Health impact assessment;
- Development of consistent operational protocols to suit local needs; and
- Population health workforce training.

Submitters suggested the functions provided at a local level should include:

- Identification of locally emerging population health issues;
- Communicable disease and outbreak control;
- Public health emergency response;
- Regulatory controls on alcohol, tobacco and the physical environment, and associated health promotion;
- Immunisation co-ordination;
- Liaison with and support for local authorities, DHBs and PHOs;
- Support and co-ordination for health promotion in settings (e.g. workplaces, education, primary care); and
- Planning and funding of health care and population health programmes to meet local needs.

6.2.4. **Population health approaches**

This report has applied five core functions of population health, as informed by submitters, to summarise submitters' comments relating to population health:

- Health assessment and surveillance;
- Population health capacity building;
- Health promotion;
- Health protection; and
- Preventive interventions.

Health assessment and surveillance

Submitters emphasised the importance of consistent and reliable population health data collection. Surveillance and health research was considered important for ensuring the health system is responsive to new and emerging threats, allocating resources to areas with poor health outcomes (ensuring an equity lens), and focusing on illness prevention (including communicable and non-communicable diseases). Submitters pointed to a number of activities and enablers for improved assessment and surveillance, such as:

- Greater investment in research;
- Implementation of a national surveillance strategy;
- Development of an integrated national information system for disease management (linked to local service delivery);
- Collaboration between researchers, clinicians, iwi, and government (including the Ministry, DHBs, and PHUs); and
- Disaggregated reporting of official statistics so that similarities and differences among Pacific and Asian sub-groups are evident.

Some submitters described specific areas or conditions where more monitoring and research is required, including:

- Health and disease data routinely/regularly collected to more accurately assess population disease prevalence and causal factors (for eye health, breast cancer, dementia, occupational, mental health etc);
- Wider evidence to determine the extent to which ethnicity and/or socioeconomic or lifestyle factors influence health outcomes, including Māori and Pacific people;
- More frequent data collection on true unmet need (i.e. specialist services and dental); and
- Data collection on lifestyle and behaviours such as diet, nutrition, physical activity, alcohol and drug use as some of these surveys were carried out over 10 years ago.

Submitters suggested that monitoring and evaluation could be embedded into population health activities. Evaluation capacity was considered important for measuring the impacts and outcomes of all new policies and to ensure evidence is used to inform future investments. Routine monitoring of equity of health services and outcomes was also an important aspect.

Submitters indicated that good examples of health assessment and surveillance include the Canterbury Wellbeing Index, the Canterbury Wellbeing Survey, and the Health Quality & Safety Commission Atlas of Healthcare Variation. These tools "*will be incredibly useful for seeing patterns and starting to ask questions about why, after you've accounted for the different populations living there, different places seem to do things differently*" (Organisation submission)

Population health capacity building

Submitters reported that the health system currently has limited ability to prevent and manage environmental health and infectious disease threats and that there is increasing need to invest in population health capacity, including expertise and infrastructure, to manage these threats.

Submitters suggested:

- Developing a national digital technology platform to inform population health interventions and support health improvement and equity;

- Introducing a centralised information system for communicable disease management; and
- Improving the capacity of PHUs to deliver and support the population health core functions.

Population health workforce

Submitters provided a range of comments about the population health workforce, particularly in areas where there are shortages and training gaps. Submitters described a shortage of public health medicine specialists (including future recruitment and retention challenges), health protection officers, drinking water assessors, and health promoters.

Submitters emphasised that the population health workforce development needs to be a multi-year priority for the Ministry. Other areas of expertise in the population health workforce that submitters sought investment included public health intelligence, law and policy formation and implementation, professional development for health promoters, senior level expertise and leadership capability, and professionalisation of non-medical roles.

> *Health promotion has been 'professionalised' away from whānau and communities but it can be seen as 'everyone's business' and all frontline practitioners can have the skills, tools and resources to be health promoters, to have a positive influence on health and wellbeing.* (Organisation submission)

Planning, partnerships, and engagement

Submitters emphasised the importance of local partnerships to deliver population health programmes effectively, suggesting that local communities had a deeper understanding of their needs. Other submitters proposed partnering with local territorial authorities to plan for, and engage, their communities in health initiatives.

Submitters also noted the importance of consistent and appropriate engagement with Māori and Pacific peoples on any health policy decisions.

> *The [Group] promotes the thinking of a collaborative approach to planning and funding public health unit contracts with all partners, and asks that the public health voice is given prominence during decision-making as we will be impacted the most by the outcomes.* (Organisation submission)

Investment and resource allocation

Submitters discussed the importance of applying cost-effectiveness assessments to population health investments. Submitters stated that greater investment in population health activities would be beneficial on the basis that it is cheaper to prevent rather than treat illness and it is an effective way to manage the demand on services. Submitters cited research showing population health interventions (at both local and national levels) can generate substantial cost savings and have a good return on investment.

However, submitters also noted that the health system's ability to invest in population health interventions is constrained by financial and workforce resources. As a result, submitters said that DHBs are in a vicious circle where they want to increase their focus in these areas but are limited in their ability to make this shift within current resources which are stretched responding to the growth in acute needs.

Submitters also highlighted the importance of prioritising spending and proposed drawing on a range of tools/approaches such as:

- Pharmac's prioritisation principles;
- Prioritising using Rawlsian value judgements (to increase equality of outcomes by targeting the most disadvantaged groups proportionately more); and
- Using models such as BODE3 (Burden of Disease, Epidemiology, Equity and Cost-Effectiveness) to provide information, and compare interventions on health gain, cost and cost-effectiveness.

Submitters proposed using cost-effectiveness analyses that adequately assess longer term benefits against upfront costs.

> *Striking a new balance in proactive versus reactive activity will require investment. Investment in prevention, early intervention, and integration initiatives need to be accelerated. If we don't do this, the health system will not be able to cope with the tidal wave of demand that is coming its way. Demand is rising due to an ageing population and deep rooted inequities. We either put some funding in now to fix the system, or we risk the system becoming so unaffordable that it cannot be sustained. This would lead to service and significant gaps in care will emerge.* (Individual submission)

Health promotion

Healthy policies

Submitters requested a Health in All Policies approach across central and local government departments. Submitters wanted other sectors (e.g. housing, education, and transport) to consider the health impacts of all decisions and avoid harmful health impacts in order to improve population health and health equity. Submitters stated that cross-sector collaboration should occur in the development of policies and programmes.

Provide quality health information to the public

Submitters discussed health literacy as a foundation for building healthy lifestyles. They suggested increasing awareness of the linkages between lifestyle risk factors and disease prevention. While some submitters discussed providing health information through national campaigns, others suggested that information should be targeted to 'at risk' individuals or specific population groups, including children, Māori, Pacific people, and other ethnic groups.

Submitters commented that the information should be evidence-based, culturally appropriate, easy to understand, and accessible in multiple formats and languages. Submitters suggested that if people have better information, they would be empowered to take responsibility for keeping themselves as healthy as possible. Some areas they suggested would be beneficial included gaining knowledge about nutrition, growing and cooking healthy food, and providing information on how to navigate the health system so that people know where to find the services they need. Additionally, submitters suggested that health education could be more widely incorporated into school curriculums.

Build and support community capacity and healthy environments

Submitters proposed incorporating health promotion into environments and settings that are not traditionally seen as 'health' services. For example, workplaces, marae, churches and schools. Submitters considered this important for empowering communities and individuals, and ensuring a more inclusive environment that prevents social isolation.

> *Linking public health initiatives into communities and Tier One services and providing these in ways that really engage the populations most needing to benefit from these is required.* (Organisation submission)

Submitters noted that this would require stronger integration between health promotion and clinical interventions and that a specific role could be created to facilitate this engagement in the community.

> *An integrated role allows counsellors to be in the community delivering health promotion messages and engaging and participating in community groups and projects. This interaction allows the building of rapport and trust with the community which in turn leads to the opening of doors for a conversation to happen (a clinical intervention). We know that clinical interventions don't need to only happen in an office or a counselling room, allowing counsellors to be immersed in communities, educating and raising awareness increases access to service and decreases stigma.* (Organisation submission)

Health protection

Fragmentation of the health protection function is a key theme described by submitters.

> *The health protection function in NZ is highly fragmented, with response capacity and resources spread across multiple agencies. This problem is exemplified by the area of outbreak response where roles are spread across the Ministry of Health, Ministry of Primary Industries, and the Institute of Environmental Science and Research Ltd (in addition to the multiple local/regional agencies involved).* (Organisation submission)

Submitters described the need for strong political leadership to improve the approach to health protection (regulation, taxes, fortification, fluoridation).

Regulation and legislation

Submitters suggested that regulatory and legislative measures could be implemented to improve population health outcomes. Submitters focused on regulating unhealthy industries such as tobacco, alcohol and sugar to provide healthier environments. They referred to the Smoke-Free Environments Act as an example that has resulted in significant reductions in ill health through taxation, regulation, education and other interventions.

The following mechanisms were described by submitters as mechanisms to improve population health:

- Tax certain products that have proven detriments to health outcomes (i.e. tobacco, high sugar content beverages, alcohol);
- Remove taxes on fresh fruit and vegetables;
- Improve nutrition labelling on food and beverages;
- Implement a mandatory limit on salt in basic food items;
- Reduce the number of takeaway and liquor outlets in low socioeconomic areas;
- Regulate advertising and availability of unhealthy food choices;
- Remove of alcohol and major beverage sponsorship;
- License of tobacco retailers;
- Regulate to ensure quality living standards, such as for air, housing, water, wages, income support;
- Ban direct consumer advertising of pharmaceuticals;
- Regulate folate fortification; and
- Mandate community water fluoridation to improve oral health.

Preventive interventions

Submitters commented on preventive interventions as an essential and important function. Immunisation, particularly for children, was mentioned by submitters as an area for further investment to increase coverage.

Submitters also emphasised the importance of existing population-based screening programmes and provided suggestions to improve health outcomes through screening, including:

- Self-administered cervical smear testing to improve uptake from rural areas and cultural groups;
- Development and extension of national screening programmes for targeted conditions and at-risk population groups (such as Keratoconus, an eye disease, common among Māori and Pacific People, or bowel screening for everyone over 50 years of age). These programmes could consider tailoring the timing and modalities to the needs of individuals and population groups based on their risk profiles for better health outcomes;
- Tailored (through timing and modality) breast screening for high-risk population groups; and
- Greater community and whānau involvement to ensure ongoing engagement in screening.

Physical activity programmes were supported by submitters who described the potential benefits of Green Prescription programmes; however, some noted this was limited in practice due to lack of time during GP consultations.

Submitters also commented on the need for suicide prevention initiatives, particularly for males.

6.2.5. Population health in relation to Māori

Submitters saw the opportunity to reduce inequities in Māori health outcomes by targeting population health approaches to Māori communities. They indicated that this requires taking a broad view of health, including recognising culture and wairua as critical components of health. Areas described by submitters that are particularly important included:

- Increasing the size and capacity of the Māori public health workforce, and, upskilling the mainstream workforce so it has the capability to address Māori health needs to more effectively meet commitments to the te Tiriti/the Treaty;
- Improving Māori health literacy so whānau have more confidence in accessing health care; and
- More resources directed towards enabling people to live healthier lives, targeted at issues of particular relevance to Māori such as healthy eating, healthy homes and healthy environments.

> *The development and adoption of a Wairua centred approach would ground our way of working in cultural strengths and beliefs. This would benefit all New Zealanders and indeed the planet as a Wairua centred approach addresses all things in relationship to each other and human wellbeing as inextricably linked to the natural and spiritual environment. Indigenous systems thinking hold the solutions for the grave threats of sustainability and climate change.* (Organisation submission)

6.3. Tier 1

6.3.1. Current issues in Tier 1

Tier 1 health services comprise all health services and activities undertaken in community and home settings (including aged residential care), excluding care delivered in hospitals.

Issues identified with Tier 1 services were largely consistent with issues identified in a number of previous health inquiries, reports, strategies, and surveys. With regards to Tier 1 system-level issues that submitters cited, the following were the most common:

- Fragmented services delivered across numerous community organisations with different business models and drivers;
- The funding mechanisms are numerous, inconsistent, and are not well suited to reducing inequities (and in some cases exacerbate it);
- Cost and travel are significant barriers for some service users to access Tier 1 services;
- Many current services do not align with te Tiriti o Waitangi / the Treaty of Waitangi, Māori world views or hauora approaches, which contributes to poorer health outcomes;
- A strained community workforce that is struggling to meet current demand;
- Inadequate planning and collaboration to cohesively tackle equity issues;
- A model of care that is largely medical and deficit-based which is not optimised for the achievement and maintenance of wellbeing; and
- A lack of comprehensive involvement of service users (particularly from those facing inequity) throughout the planning, service design and decision-making process.
- Service users and whānau are not consistently empowered to control and decide on the right pathway for them.

6.3.2. What role should Tier 1 play in the system?

Submitters' description of the role for future Tier 1 services centred on the provision of support to help people live well when facing additional health and disability needs. This included a focus on early intervention, restoration of wellbeing, and the monitoring/management of long-term and life-long health and disability challenges.

Submitters described many different needs that Tier 1 services should address. Some examples (not an exhaustive list) are:

- Psychological support
- Physical and functional support
- Cultural support
- Behavioural support
- Social and vocational support
- Domestic support
- Maternity support
- Emergency support and transportation
- Pain management
- Palliative support
- Oral care
- Nutritional support

When describing which specific types of services are required to meet the service user needs of the future, submitters typically requested enhancement or expansion of existing services, rather than the introduction of entirely new services. There was broad census across submitters in terms of what service users wanted from the future Tier 1 services:

- Focus more on early intervention;
- Be holistic and comprehensive;
- Be timely and responsive;
- Have low / no barriers to access;
- Be culturally appropriate;
- Be of high quality; and
- Be inclusive and delivered compassionately.

6.3.3. Māori hauora in the community setting

Both Māori and non-Māori submitters noted that disparities exist, with Māori more likely to have complex conditions and multi-morbidities, while also facing greater barriers to access. They also stated the importance of delivering service in the community and home settings to improve Māori health and disability outcomes. There was support from submitters to align Tier 1 service configuration and delivery with te Tiriti/the Treaty. This included Māori involvement in all aspects of governance, decision-making, service design and delivery.

> *Te Ritenga (right to beliefs and values) provides Māori with the right to practice their own spiritual beliefs, rites and tikanga. The health system has a Te Tiriti obligation to honour the beliefs, values and aspirations of Māori patients, staff and communities across all activities.* (Organisation submission)

Submitters also identified that Māori more often face specific challenges at the community service-level:

- Lack of consistent access to traditional and contemporary Māori services, delivered by Māori;
- There are few services provided in Te Reo Māori;
- Whānau have minimal input or control over their treatment options; and
- Health and disability services are not consistently well connected with other sectors to address wider social determinants.

Some submitters indicated the importance and relevance of Māori frameworks being embedded across Tier 1 in the future. Māori frameworks were described in Section 4.3. Submitters described better community-based services for Māori as services that:

- are based on Māori approaches and concepts of hauora;
- provide adequate navigation support for Māori;
- provide adequate time to address all needs of Māori not just the most urgent;
- are more affordable or free for Māori;
- are located locally and are easily accessible, comfortable and appropriate for Māori (e.g. marae, homes, community centres);
- are person and whānau centric, and include whānau in decisions; and
- are holistic and integrated, and can trigger easy access to wider supports including social, housing, and financial services.

> *The crucial role that rural and/or iwi community organisations play in the wellbeing of whanau is woven into every level of the health and disability sector from locally based health promotion and education to service navigation, specialist care, high level strategic planning and sustainable funding models. All rural health and social service providers have easy access to training and locally based iwi support so they can reach the highest standards of cultural competency*. (Organisation submission)

Submitters also suggested that Māori health and disability approaches should increasingly be based upon traditional Māori perspectives.

> *we should apply a traditional Maori perspective when approaching contemporary health and disability, that we should be informed by our traditional Maori knowledge and cultural context. The challenge is how do we translate that to fit a modern context. We should avoid "transliterising" or "maorifying" the western health and disability system that effectively retains the western perspective at its core.* (Individual submission)

Other possible service-level solutions proposed to improve equity specifically for Māori, included:

- Establishing whānau-centred health services in kōhanga reo, Māori ECE, and kura kaupapa, with sustained government funding;
- Providing greater access to whānau-centred services and programmes for Māori tamariki in emergency departments;
- Facilitating the transition of care for Māori tamariki to primary care and Māori health community providers;
- Ensuring the Health and Disability System meets the needs of disabled Māori, including disabled Māori children and their whānau; and
- Eliminating pharmacy charges to encourage service users to use prescriptions, particularly among Māori and Pasifika.

6.3.4. **Service delivery model and configuration**

This section summarises submitters’ comments on what Tier 1 services should be delivered, where, when, how they could be structured, and integrated.

> *Practices will co-operat[e] in “clusters” covering populations of 30-40,000 patients. These clusters, with extra scale, will be able to engage a wider range of services and integration, including enhanced therapies, physical, rehabilitation and other allied therapies, mental health and mentoring capacity. There will be increased use of imaginative therapeutic and health-supporting activities such as music, dance, sport, art and gardening. Aged residential care will be a major primary care activity. Most practices will be involved. Some practices and practitioners will develop further expertise and capacity. Virtual technology will greatly assist here also. Practice ownership and governance will continue to be varied with a mix of GP and/or nurse ownership, Iwi owned and operated, community trust owned and PHO owned. There will still be a need for special resourcing of some remote or challenging locations.* (Individual submission)

Submitters described current variance in the configuration of services across different communities as a whole, with both positive and negative impacts on health outcomes. They described additional challenges when there was limited access or availability of ‘core’ Tier 1 services locally. However, submitters also indicated that the types of services available within each community should differ based on the unique needs and challenges of each community.

Submitters identified variance in the capacity and expertise of service providers within different localities and suggested that some of this variation was due to:

- Different service funding arrangements;
- Different leadership and extent of collaboration across:
    - regional/local health and disability organisations; and
    - local government and iwi;
- Different proximity to larger urban centres and whether or not areas or classified as ‘rural’.

Regardless of the type of Tier 1 service, submitters acknowledged the growing challenges of meeting the ever-increasing demand in an industry that is continuously exposed to change and increasing service user expectations. Some submitters believed that New Zealand needs to make more radical changes to the model and configuration of community-based services to make better use of available resources and expertise and to slow the demand pressure on more costly services.

6.3.5. Service integration and coordination

Submitters supported the idea of having a core range of services available in each region (at a minimum), and that these services are structured and funded in a more integrated manner. These services would be the primary point of contact with the health and disability system. Submitters cited the prominent role that General Practice currently plays in the delivery of ‘core’ Tier 1 services within communities. However, some submitters described variation in the service scope of each practice. They suggested that the typical practice scope was too narrow to meet the holistic health and wellbeing needs of the community alone. For instance, whānau ora, pharmacy, radiology, mental health, social work, maternity, and physiotherapy services (among many others) were regularly indicated as required to fulfil ‘core’ community service needs. Submitters regularly cited the absence of these wider services within community General Practices.

> *Offer more intense services based on need. This would include increased access to mental health services, drug and alcohol dependency services, talking therapy, social work and financial advice, mentoring and support, Whānau Ora and Navigator services for those who need them.* (Organisation submission)

Submitters described a number of challenges to effectively integrate different Tier 1 services, including:

- **Different contractual and funding arrangements** across Tier 1 services. Submitters stated that a single service provider may have many different streams of income, such as ACC, Ministry of Health, private insurers, service user payments, DHBs, PHOs, and donations which created additional complexity (i.e. each may have their own requirements, drivers, and expectations) that must be overcome to integrate more effectively.

- **Limited funding and resources:**
  - creates a competitive service provision environment rather than a collaborative one.
  - minimises the time to understand broader service user context, collaborate, and jointly problem-solve.
  - makes the logistical challenges of integration even greater; and
- **Commissioning processes can limit creativity and restrict the scope of services delivered**, including who may deliver them. Submitters suggest that this places limits on the extent of innovation and integration that can occur;
- **Fragmented practice management systems** make information sharing across providers difficult, time-consuming and incomplete;
- **Workforce may have limited understanding of different service providers**, which prevents more effective coordination.

Submitters recognised the challenges of effective coordination and collaboration, particularly when multiple service types are involved. Yet it remained that submitters wanted better integration across more services.

> *Community-based Mobility Action Programmes are a good example of integrated health services. These programmes are serviced by the Allied Health workforce (such as physios, dieticians, and nurses) with the support of specialist expertise. They are achieving positive results with some participants having surgery delayed, and some having surgery avoided altogether.* (Individual submission)

> *A study by Auckland City Mission interviewed 100 families who frequently used food banks. They found that a typical family of four on a benefit with complex health and social needs was required to visit 45 agencies over a two-week period […]. They had to tell their story over and over again - each time to different agencies and to different people within the agencies.* (Individual submission)

Submitters identified possible solutions to reduce fragmentation and support greater levels of integration within community and home-based services. These included:

- **Sharing and extending traditional professional scopes.** Submitters suggested this would allow (where suitable) professionals with lower levels of training and expertise to perform activities in the lower-range of scope and drive service delivery models to work more as a team, rather than being single clinician based;
- **Unifying different single service organisations** to enable more coordinated delivery of multiple services with more diverse and multi-disciplinary teams. They indicated that this may involve structural and business model changes to better reflect service user needs.
- **Better approaches and technology to collaborate** across different organisations that share service users. This would require allowing appropriate time for wider discussion, shared planning, and collaboration across multiple health practitioners, as well as using technology that supports integration across multiple providers and organisations; and
- **Multiple service user entry points** and improved referral pathways to allow service users to choose the health practitioner that best suits their needs.

> *Primary health care teams should be supported to cluster together in local wellness networks to work with the local community and iwi and to provide services that otherwise do not have critical mass (eg podiatry, phlebotomy, occupational therapy, speech language therapy, psychiatry, geriatrics, endocrinology, radiology, retinal screening, nurse specialists).* (Organisation submission)
>
> *As well as time pressures on consultations with patients, the increasing dependence on multidisciplinary teamwork and growing complexity of illness with an aging population also requires additional clinical time for collaboration between health professionals.* (Organisation submission)

Submitters had different views about providers' roles to coordinate and integrate care. In particular, there were contrasting views as to whether or not general practice should remain at the core of local service provision, or whether a different, (often multidisciplinary team-based) configuration of providers would be better to fulfil this type of role.

> *General Practice already takes a holistic approach and recognises the psychosocial (and spiritual) influences in people's health. It is important to recognise the importance of GPs as generalists and to nurture the value of the GP-patient interaction which, in itself, has therapeutic value. We believe that GPs should be at the centre of the health care system, helping people maintain healthy lives, preventing disease, treating acute illnesses, and caring for people with chronic diseases.* (Organisation submission)

Some submitters indicated that a single primary point of contact may be less relevant for the future. Submitters described trends including:

- Service-users and the workforce are more mobile and live in different regions;
- The workforce has evolved (e.g. increased GP use of locums and short-term international staff, nurses and Nurse Practitioners are delivering more aspects of care);
- There is wider uptake and acceptance of other health professionals managing core elements of the service user's pathway (i.e. Physiotherapy for musculoskeletal conditions);
- Health information is becoming digitised and more easily transferable, including apps, and wearable monitoring devices; and
- A wider range of health professionals can refer for different services.

> *The rise of the patient-centred health care home in New Zealand is a step in the right direction toward the delivery of better community based health and social services, but this development is still bound within the current model of primary care in New Zealand - with general practitioners at the centre of it.* (Organisation submission)

6.3.6. **Prevention, early intervention and wellbeing**

Submitters believed that Tier 1 services should be reconfigured to enable more emphasis on the delivery of prevention, screening, and the maintenance of wellbeing activities. This includes greater expectation on Tier 1 service providers to discuss prevention and wellbeing with service users and whānau.

> *Health promotion activities and lifestyle advice given by GPs and [Practice Nurses] can contribute to a decrease in alcohol use, smoking cessation, increased physical activity and weight reduction.* (Organisation submission)

Some submitters suggested that more comprehensive public health services should be provided to individuals in the primary care setting via 'wellness' checks. Tailored preventive and risk reduction information can increase people's knowledge and encourage more effective self-care.

> *Introduce a layer of funded 'pre-primary care' (for both treatment and prevention) which is community-based and peer-led. This Involves a whole person approach with a focus on addressing mind-body and lifestyle factors.* (Individual submission)

There were a range of suggestions on who should be responsible for delivering these services, including:

- General Practitioners, but noting time is a constraint to provide more comprehensive care.
- A centrally coordinated programme delivered locally.
- A wider, more available and less costly workforce to support wellbeing and preventive activities.

> *Using different strategies to deliver healthcare support for Pacific communities. For example, health coaching and self-management programs.* (Organisation submission)

Submitters proposed an increased focus on earlier intervention to more quickly identify and address risk factors, prevent deterioration and speed up the return to wellbeing and participation.

> *People with poorly managed arthritis are more likely to be depressed than those with well controlled arthritis. The link between mental health and arthritis is more evidence of the need for early intervention on arthritis to avoid deteriorating health in other areas.* (Organisation submission)

Submitters identified a number of Tier 1 services that already carry out elements of early intervention (e.g. cardiovascular risk assessment), but they felt that approaches were not always systematic or specifically targeted using more sophisticated risk profiling.

Submitters also suggested that more collaborative and integrated Tier 1 services would enable better and earlier identification, access, and transition into appropriate services.

> *Each and every health professional should be trusted to act in the patient's best interests. If a community midwife identifies the symptoms of depression during a routine visit with a prospective or new mother, they should be empowered to enable the patient to directly access the community mental health service working within the same 'one team' - rather than having to direct the patient back to their own GP to be referred for that support. All health care contracts, covering both primary and secondary care, should include an obligation on the provider, and their practitioners, to support patients in an integrated system and recognise where other health*

> *providers, professionals and practitioners may be better placed to offer the required care or support the patient's needs – all within 'one-team'.* (Organisation submission)

To meet previously unmet need, submitters suggested that holistic, wraparound services should be readily available within environments that people can easily access (e.g. locating services for children in schools).

Submitters suggested that the traditional GP gatekeeper role which triages access to other services could be redesigned to place more trust in, and expectation on, the wider workforce, allowing them to take early and appropriate action when needed. They believe that service users with multiple or more complex needs would be better served with such an approach, but indicated that this should be supported with adequate funding and time allowances.

> *At each GP consult, in addition to dealing with the presenting feature with a quick flick of the wrist and a grin, there needs to be systematic study of the patient risk profile. At first this is a massive task, but once taken in hand the task becomes trivial. Neglecting it has led to the current flood of costly late-stage presentations.* (Individual submission)

6.3.7. Management of acute and chronic conditions

Submitters supported the ongoing role of Tier 1 services in managing established, long-term and life-long conditions. While prevention and early intervention services may reduce the demand on these services in the long-term, this function will still be required for the foreseeable future.

> *For example any acute medical issues are treated biomedically (medication/surgery) as necessary, and once stabilised other wider determinants of health are also addressed i.e. internal determinants of health (mind-body factors such as thoughts, beliefs, emotions, spirituality) and external determinants of health (social determinants of health such as trauma, behaviours, lifestyle factors, socio-economic situation, physical environment.* (Individual submission)

Many submitters supported the concept of more flexible services rather than a uniform approach, and that these flexible services should be based on the service user's context. For example, submitters described how service users with more complex conditions might require support from a wider range of services. Some submitters also suggested that there should be wider adoption of community 'navigator' roles, where there is a person who can support the individual and whānau to identify their needs, and facilitate access to appropriate services that meet their needs, particularly for more complex situations.

> *Health and disability affects all areas of life and funding needs to include support for returning to work, starting work, and remaining in work.* (Individual submission)

Some submitters provided international examples of different Tier 1 configurations, or their own ideas about possible approaches that might work in New Zealand's context. Such models included estimates of the types of professions and the FTE required based on population need, with high need populations requiring greater resource. Some accounted for currently unmet needs and introduced more diversity in the workforce, including factoring in possible changes to roles and capabilities.

> *The vision presented here aims to strike a balance between, on the one hand, setting out a significant change to the core model of general practice as it has traditionally been delivered, and on the other describing a model that is realistically achievable across a majority of services.* (Organisation submission)

Other submitters highlighted that a single approach to organising diverse services will not work for every situation, but suggested that commonalties in the configuration of integrated/collective facilities could exist across different geographies and population groups. Some suggested features of a collective organisation included:

- Providing services spanning general practice, pharmaceuticals, allied health, community midwifery, aged care and relevant non-government organisations (including Māori, Whānau Ora and Pasifika providers where relevant);
- Be owned, governed and financially structured in a way that prioritises patient outcomes and collective interests over business interests; and
- Incentivise integrated practice in delivering local solutions to local problems.

Some submitters wanted greater inclusion of secondary care in the community setting to reduce travel and waiting times in hospital clinics, particularly in rural areas.

> *The business model for primary care needs to change to empower doctors, nurses and allied healthcare professionals to do more primary care with less effort. Primary care needs a lot more resources and a lot more creative ways of leveraging expertise from specialists. Specialists shouldn't assume that their work involves hospital and private hospital work - they should assume that they will provide primary care specialist services routinely.* (Individual submission)

6.3.8. Improving accessibility for service users

Colocation of services

Submitters stated that locating Tier 1 services within communities could improve access (e.g. existing clinics, rooms and offices, local marae, community centres and mobile health vehicles).

> *Māori uptake of screening services is low due to the nature and location of these services (such as breast and cervical screening). If these services were provided in a mobile format in the communities in which Māori live, the barriers to acceptance could be reduced.* (Organisation submission)

Submitters described the advantages of “one-stop shops” or “clusters”, where multiple services are colocated. Submitters suggest that colocated services would reduce travel time, effort, and cost when there is a need to access multiple services. Submitters noted this may support better planning and integration. Submitters indicate that this may work particularly well for services that are commonly accessed concurrently or sequentially – such as general practice, pharmacy, laboratory and radiology.

Submitters described many other configurations or clustering of services such as counselling, psychology, and social services. Some submitters recommended that specialists and other agencies also deliver services from these community premises.

> *Developing complex health and comprehensive community service models will replace the simple, narrowly funded models of service delivery that prevail at the moment. For example, there are opportunities to create more one-stop community facilities for people who have complex health and social needs that include housing, benefits, health care and other social services. There is also scope to deliver health services in more accessible and convenient settings such schools, pharmacies, maraes, community hubs and supermarkets.* (Organisation submission)

Extending business hours

Submitters stated that getting support at the right time is a common challenge across Tier 1 services. Waiting lists and delays could limit the effectiveness of early and proactive care. From a service user and whānau perspective, there was also greater expectation for services to be available outside normal office hours.

> *There would be vastly improved access to healthcare outside 'routine office hours' - with primary care being offered 16 hours a day - so there would be more alternatives to hospital emergency departments available after hours.* (Organisation submission)

Delivering health services remotely

Submitters identified the potential of technology (including telephone, video/virtual, SMS and email and online) to help overcome distance barriers, provided the digital infrastructure is readily available and low-cost. Submitters noted that these digital services would supplement, not necessarily replace, locally-based services.

Access to services in rural areas

Submitters raised a number of concerns about access to services in rural areas.

Submitters identified that some of the biggest challenges for service providers serving remote regions are staffing and ownership. Submitters said rural/remote clinics, which are often small owner-operator models, are not only hard-to-staff and more vulnerable to unanticipated events, but also find it difficult to attract others willing to take over ownership when owners retire or move. A rurally based GP said "*Our margins are so low and the health need of the poverty stricken and the huge populace of elderly [Region] means I can't work less or my business would fold and patients would not get good care. The drive for GPs to have open access and low prices is ignorant and poorly planned or financially supported*". (Individual submission)

Submitters noted that different ownership models would need to be explored, including approaches such as trade unions health clinic models to tackle these types of issues.

> *Community ownership of practices will be increasingly necessary because practitioners and their partners are now less willing to make long-term commitments to an isolated/rural practice; including ownership. Rural practices are struggling in a primary healthcare system that was never designed to take account of their particular challenges:*
>
> - *The current system doesn't adequately provide (funding and support) for a "practitioners as employees" model in small communities;*
> - *Low capitation/revenue bases mean that they can't easily accumulate reserves needed for crises and events such as staff grievances, patient complaints, practitioner illness/departure, accidents, locums etc.* (Organisation submission)

6.3.9. **Local leadership, networks and planning**

Some submitters identified issues with the leadership of Tier 1 services at a national and regional level. Many submitters supported the intent of public organisations such as DHBs and PHOs, but there is mixed view of how effective they have been. Some submitters identify that both DHBs and PHOs do not fulfil a public health leadership, planning or funding role for all Tier 1 providers – leading to service gaps and inconsistencies. Much of the criticism is focused in two areas:

- DHBs efforts are overly focused on hospital services at the expense of the community services; and
- PHOs are Medical Practitioner dominant and overly focused on General Practices and medical models of care. Submitters want mid/meso-level organisations to provide a much broader range of services.

> *In some cases, PHOs have extended their organising reach beyond the traditional general practice focus, but there is scope for more organised networks, at scale, that encompass a wider range of professions and providers. Pharmacy, physiotherapy, midwifery are good examples of where local organising networks have great potential.* (Individual submission)

Despite the criticism, some submitters outlined the positive impacts these public organisations were having on the direction of some Tier 1 services. The positive impacts highlighted included:

- The coordination and integration of care horizontally and vertically;
- The development of initiatives to target inequalities;
- Establishing professional development opportunities;
- Clinical governance; and
- Frameworks to drive efficient and effective primary care via mechanisms like Health Care Homes.

Further discussion regarding funding and finance is in Section 5.2.

6.3.10. **Service-level changes to improve equity**

Cost, time and travel improvements

To overcome the cost barriers within Tier 1 services, submitters proposed:

- Removal of copayments for low-income families/individuals;
- Introducing income-based copayments where costs are relative to income;
- Extending the ages people can access fully-funded public services (e.g. 18-year-olds can access the GP for free);
- Extend the limits to the number of fully funded services available (e.g. increase from 3 to 12 free counselling sessions);
- Simplify payments and processes for low income families who need financial assistance;
- Extending the range of fully funded or subsidised services (e.g. contraception, pharmaceuticals);
- Subsidising (or making free) transport options to services for those in need;
- Longer appointment times at no cost; and
- Timely appointments that allow people access services when they need to.

> *[…] patients with long-term medication costs and modest or little income should be able to collect their medications without costs being a barrier, and without having to fill in forms and visit other agencies.* (Individual submission)

Navigation

Submitters stated that the current system requires service users to have a high-level of health literacy and understanding of what services were available and which entitlements they could access.

Submitters proposed a number of system level improvements including:

- Simplify the service user pathway through the system and where needed use a 'Navigator' workforce to support service users and whānau. This was particularly important for disabled and Māori.
- Developing a deeper understanding of the individual and their needs, and involvement of the service user and whānau in decisions, had the potential to improve services.

> *Individuals and whānau are owners of their care, and are involved in decision-making about their care.* (Individual submission)

6.4. Disability system

Some topics relevant to disability services and disabled people are included under other sections of the report, including funding and finance (Section 5.2), service-level concepts (Section 6.1), and workforce (Section 7.1).

6.4.1. Issues

Submitters (including individuals who self-identified as disabled) described issues with physical accessibility of buildings, including homes, public transport, health services, public facilities, and the wider urban environment. Submitters also described delays and barriers to access support services that provide assistance for accessibility improvements.

A lack of funding and resourcing pressures on the disability sector was acknowledged by submitters. Submitters considered that this has created an environment where there is competition between the interests of disabled people, workers and providers and it negatively impacts on cooperation, collaboration and genuine co-design processes.

6.4.2. What do disabled people need from society?

Submitters commented on the desire for a society that focuses on inclusion, equity and justice for disabled people:

> *Equity can only be achieved when each individual is empowered and abled to meet their own needs, desires, [and] dreams for a life they want to live.* (Individual submission)

Some of the key themes that submitters described about disabled people's needs from society included:

- **Upholding the rights of disabled people.** Submitters wanted:
    - Policies of the health and disability system to align with the rights stated in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCROC);
    - The rights of disabled people to be upheld in society, including the right to enjoy a full and decent life, right to legal capacity on an equal basis with others (including supported, rather than substitute, decision-making), and the right to an adequate standard of living;
    - The New Zealand Disability Strategy to be promoted and embedded in society and disabled people and their caregivers to be aware of their legislative rights within the Strategy;
    - A broader understanding of human rights law within the health and disability workforce, so that equal opportunities for life advancement exist naturally; and
    - Disabled people to have the right to control their lives without others (including family) taking control of what the disabled person wants.
- **Wellbeing of disabled people.** Submitters wanted:

  - More resources towards enabling disabled people to live healthy and well lives to address inequities and ensure disabled people have access to housing that is physically accessible, affordable, safe and healthy;
  - Access to transport that is no-cost/low-cost and disability friendly to reduce barriers that create emotional and financial distress for disabled people; and
  - More support for young disabled people during education and to transition from school to the workplace or tertiary education.
- **Employment for disabled people**. Submitters wanted:
  - Better employment opportunities and assistance to access meaningful work to enable disabled people to contribute to the household income, have more independence, be a part of the community and have a sense of purpose and self-achievement;
  - Incentives or support (e.g. telephone equipment for a hearing-impaired person) to encourage employers to hire disabled people and provide accessible workplaces;
  - Protected jobs for disabled people (i.e. disabled people should not have to compete with able-bodied people for jobs;
  - Financial support for disabled people to remain in or return to work on a part-time basis; and
  - Disabled people to be able to earn at least the full-time minimum wage without affecting benefit entitlement.

See disabled people as real people with skills, education, aspirations as other people in the community. (Individual submission)

- **An inclusive society for disabled people.** Submitters wanted:
  - Disabled people to be able to participate at all levels of society (including at a governance and advisory level);
  - 'Champions' to advocate for disabled people in the community and raise awareness of disabilities that cannot be seen (e.g. ADHD and autism). Submitters suggested this could raise the value of how disabled people are seen in society;
  - All buildings, including schools, homes, Kiwibuild houses, and workplaces to be accessible to all people; and
  - Technology and equipment to enable disabled people to fully participate in society.

The term 'disability' implies residual function in some area of intellectual, physical or mental capacity. A significant barrier faced by people with disabilities is discrimination due to deficit thinking - defining disabled people and classifying their functioning in terms of what has been reduced or lost. (Organisation submission)

We would create a societal change where inclusivity is the norm, and our people with disabilities are valued, and contributing members of society, where their voices are heard. Encompassed in this would be accessibility everywhere, right from within their own housing through to the community they live in. (Organisation submission)

6.4.3. **Health and disability system enablers**

System values

In addition to the health system values suggested by submitters in Section 3.1, some submitters commented on health and disability system values that are more specific to meeting the needs of disabled people. These include:

- A flexible system that can adapt to a variety of disabilities and circumstances;
- Adequate support for disabled people to stay in their own homes;
- A system that recognises diversity and unique aspirations and needs;
- A system that supports and empowers individuals' choices and autonomy;
- Equitable and timely access to health and social support services (including financial support) for disabled people, recognising that disabled people are the highest users of the system;
- Treating disabled people with dignity and respect;
- A system that supports early intervention for disabled people;
- Empower and partner with disabled people to contribute to service design and development;
- Ensuring the needs of disabled people and their whānau are at the centre;
- Culturally safe system for Māori and Pacific people.

System responsiveness

Submitters stated that the system is fragmented with health and disability services and agencies currently operating in silos. They commented on long wait times for assessment, allocation of support and equipment, and modifications to houses. Submitters also noted that services should be organised more around client needs and preferences than provider preferences.

In order to be more responsive, submitters called for improved transparency of prioritisation processes, better consistency and coordination of care and integration of services. They also proposed redefining the concept of "disability" and applying the definition uniformly across providers and funders to ensure that disabled people (including those with chronic illnesses) have equal access to health and disability services.

Governance and leadership

Submitters wanted improved coordination in planning, policies and decision-making across government (including national, regional and local). Suggestions from submitters about governance and leadership included:

- Putting disability at the core of all government decision-making (i.e. a Health in All Policies approach), which has the potential to lessen the risk of disabled people 'falling through the gaps' or stigmatising disabled people;
- Considering and incorporating the diverse spectrum of disabilities into government policies and strategies;
- Improving integration and partnerships between funders and service providers (including government agencies, DHBs, NGOs, private companies), which could be enabled by:

    - Improved leadership and communication across the system
    - Developing and implementing strategies/plans at a national and DHB level;
- Improving representation of disabled people in all disability sector planning, policy making, service delivery and evaluation, particularly Tāngata Whaikaha (Māori disabled people), which could be achieved by organisations providing more opportunities to disabled people; and
- Strengthening legislation and enforcement to protect against discrimination of disabled people in the health system as well as other areas of society.

Engagement with disabled people

Submitters wanted more engagement with disabled people at all levels of the health and disability system. They suggested prioritising the voices of disabled people through consultation and active partnerships in co-design processes. Submitters also wanted people with 'less visible' disabilities to be a priority in stakeholder consultation and treating disabled people as experts in their own reality.

> *The Health and Disability system needs to prioritise the voices of disabled people as citizens, and take as a foundational basis that we are the experts in our own reality. This stands in contrast to the experience many of us have had in the current system, whereby health and disability professionals do not have a thorough understanding of our disabilities, yet simultaneously act as if they are the experts and know what is best for us.* (Organisation submission)

Submitters also suggested providing more information to disabled people on how to engage with the system to speak up and make complaints.

Data collection and research

Submitters wanted more focused data collection and research about disabled people and certain types of disabilities. Suggestions from submitters included:

- Increase investment in disability research, particularly research which is not based on a medicalised understanding of disability;
- More research about Māori experiences of disability and the disability system to ensure that systems are designed to be responsive and appropriate to Māori;
- More integrated data and evaluation systems to improve and provide a more responsive system for people with disability. It was suggested that Health Quality Registries for cerebral palsy have led to identifying disparities and improvements in care for children in international settings, these include a surveillance program in Sweden and Norway, Surveillance of Cerebral Palsy in Europe network, and Australian Cerebral Palsy Register;
- Establish a research ethics committee for disability-related research consisting of people with lived experience of disability;
- Improve disability data collection to inform policy and planning (including sharing information across government agencies), which could be enabled by:
    - Having a government agency responsible for collecting data that is more comprehensive than the Census and other Statistics NZ

    - A comprehensive disability survey every five years (with adequate representation of vulnerable groups) and collection of data on specific conditions
- Establish indicators and measures to track the needs and health outcomes of disabled people;
- Collect data from a service delivery level and aggregate into a national database. Data could be disaggregated for gender, ethnicity, age and disability, to enable understanding of health status and monitoring effectiveness of services and outcomes;
- Enable participation in research for disabled people with neurological conditions, which would require a legislation change; and
- Provide access to more clinical research and trials in New Zealand or facilitate patients going to other countries.

Disability workforce

Submitters commented on the capacity and skills of the health and disability workforce. Submitters wanted to see more disability support workers employed to address the increasing workload pressure on current staff. They thought this would better enable support workers to deliver person-centred care and help people to live well with long-term conditions. Submitters also suggested increasing staff or volunteers in hospitals to assist families/carers with patients who have an intellectual disability or autism, and establishing a navigator or coordinator role to provide support for disabled people.

Submitters also described skills that they consider to be important for the health and disability workforce, including:

- All health care professionals to have an understanding of disability rights (e.g. supported decision-making concepts, needs-based support, reasonable accommodation);
- Regular training for health professionals to work with disabled people, provided by people with disabilities or experience with disability services;
- Better training and understanding of complex conditions and disabilities, including rare diseases, behavioural issues, dementia, Foetal Alcohol Syndrome, and chronic conditions (e.g. ME/CFS); and
- Provide all disability support workers with first aid training.

6.4.4. **What do disabled people need from health services?**

Health service responsiveness to the needs of disabled people

While submitters identified that disabled people experience barriers to accessing health services that are similar to those described in Tier 1 (Section 6.3) and Tier 2 (Section 6.5), they also experience difficulties in the physical accessibility of healthcare facilities and equipment.

Key themes described by submitters included:

- Consistent and uniform healthcare for disabled people across regions and ethnic groups;
- Disabled people have access to the same resources and pathways of care, including the same access to quality and affordable healthcare as non-disabled people;

- Accessibility for disability health services in rural areas. Submitters suggested adapting service models to utilise the resources that are available in rural areas as well as improving access for required health needs; and
- Difficulties for disabled people to interact with health services and the interfaces between multiple providers and services. Submitters suggested having more transparent and understandable pathways, and 'health navigators' to link people with health, disability and social services to improve integration and continuity of care for disabled people.

> *Individuals with complex health needs require an easier way to navigate multiple healthcare professionals and appointments. There needs to be an easier way for high frequency healthcare users to communicate their needs and opinions.* (Organisation submission)

Submitters highlighted the importance of ensuring health information is accessible for a range of disabilities. This would ensure that disabled people have the information they need to manage their own health needs. Submitters recommended investments to ensure information is accessible in multiple formats, such as Easy Read, plain language, large print, captioned videos and NZ Sign Language. Disabled people may also require extra time and/or support at medical appointments to communicate with medical practitioners and make informed decisions.

Other suggestions included:

- Health services could be more responsive to disabled people by assessing an individual's access needs and recording this in their medical records; and
- Removing the physical barrier of a front desk at primary care practices as it is more welcoming for people in a wheelchair and some ethnic groups, including Māori and Middle Eastern.

6.4.5. **What do disabled people need from disability services?**

Current issues

Submitters described issues that disabled people currently face with support services, including:

- Clients feeling demeaned when applying for assistance for disability needs;
- Increasing fragmentation across the disability system leading to equity issues across New Zealand;
- Community and home-based services for disabled people are underfunded, often unavailable and variable in quality. Some providers do not provide all of the supports that people require; and
- Carers cannot be paid to care for disabled people in hospital, however the hospital staff often do not have time to attend to their needs. Submitters said this creates difficulties for whānau and families and can be life threatening for the patients.

Disability financial support

Submitters commented on a lack of financial support from the Ministry for disabled people and their whānau and family.

Submitters wanted to see less means testing for financial support as household incomes that fall outside of the eligibility are often not sufficient to cover the costs of living with a disability. Other specific financial issues described by submitters included addressing disparities between the Supported Living Payment abatement between blind people and people living with other disabilities, and transport subsidies not providing cover for access to all essential services.

Disability service design and models

Submitters called for a change in the model of care for disabled people. Submitters were supportive of a more holistic and person-centred approach to disability services across the life course and suggested using a social model of disability:

> *A "social model" of disability can present disability not as an intrinsic medical problem but as an extrinsic inequity caused by structural barriers that prevent some people from equal participation in society. A social model does not wholly abandon medicine; instead, its focus emphasises the importance of persons with disabilities being granted equal access to society and having autonomy and control.* (Organisation submission)

> *The new system would be based on a social model where people did not have to fight for everything that they need. Hauora would be at the focus of the system, meaning that all aspects of the person's life is incorporated to what their life looks like. This means ensuring that those around them are supported as well, and not having to fight for everything or not receiving anything.* (Organisation submission)

Submitters called for greater collaboration between disability service providers, as well as inter-sectoral collaboration for effective and streamlined care. They indicated that service providers and practitioners could work in multidisciplinary teams (MDT), similar to a Whānau Ora approach. Submitters also want to see MDT teams providing more mobile care in a range of settings as acute care environments can be challenging for some disabled people and their caregivers.

Submitters acknowledged that a change in the model of care may also require changing the funding that underpins the services. Some submitters suggested having self-directed packages of care that are flexible to disabled people's needs. Further comments on funding are in Section 5.2.

Specific types of support and services

Submitters want to be offered services in a timely way, rather than negotiating and pushing for support and services that they are eligible for.

Submitters identified a number of services that they believed would be beneficial, but they could not access. These include:

- Housework assistance for people who cannot safely do it themselves, especially those with vulnerable conditions such as lowered immunity from medication or advanced age, poor balance and osteoporosis;
- Services that understand the needs of disabled adults with Polio and can provide assistance and information;

- More services for mental health care for coping with disabilities;
- Access to services such as physiotherapy and hydrotherapy;
- Post-diagnosis dementia support, including tools, connections, resources and plans to allow them to live as well as possible with dementia;
- Support groups for adolescents living with disabilities;
- Case management or health navigator support for disabled people;
- Workshops that provide opportunities for disabled people to learn strategies and to enable them to live the life they want.

Needs assessment

> *Stop making a hard situation harder - remove narrow requirements for service access- widen requirements for community and household support.* (Individual submission)

Submitters stated that service providers are frequently acting in competition with needs assessment coordinators and other service providers, rather than working collaboratively. They said that this lack of coordination across organisations can result in delays for disabled people and their families.

Submitters called for more flexible and broader Needs Assessment and Service Coordination (NASC) criteria and greater support provided through needs assessment. Submitters indicated that there are competing incentives created by the current commissioning framework:

> *There are competing incentives to creating a flexible system, right from the Ministry which has an annual budget and doesn't forecast lifetime costs through to individual providers who have a disincentive to foster increased independence of people where therefore they may lose income.* (Organisation submission)

Suggestions provided by submitters included:

- Recognition that disabled people are a very diverse population (including intellectual, physical, mental and sensory impairment) and therefore need ways to describe different disabilities that translate into appropriate services to meet people's specific needs;
- Aligning incentives between funders, providers and NASCs to remove silos;
- Investing in new procurement and infrastructure models to streamline contracts and make them more flexible and outcomes focused;
- Alternative and flexible housing and living arrangements, funded through needs assessment, for disabled people that do not fit the traditional model and have nowhere to live safely with the supports they require;
- Enabling the person with the disability (and their family) to drive the needs assessment process, rather than someone else determining what they are eligible for; and
- Assessing people's abilities through the needs assessment process.

Choice and control, individualised funding

The ability for disabled people and their whānau and families to have choice and control over the supports they receive was a key theme. There were however differing views on how this was best achieved.

Organisations and individuals indicated their support for the Enabling Good Lives (EGL) approach. A key component of the approach that submitters spoke of favourably centred around the flexible, personal budgets that enable disabled people to have more autonomy around the support that they want, in the way that they want it. Training for carers and providers in supported decision making was also suggested as part of the approach.

Other submitters were less positive about the EGL approach and individualised funding. These submitters indicated that managing the funds and the additional responsibilities of engaging and employing staff adds stress to the family. They also said that the mechanisms and rules around some of the payment options are complex and not well understood by some individuals and families.

Submitters said that disabled people should have access to all types of payment mechanisms to ensure equal opportunities for all.

> *It is of concern that Parents/family/whānau will end up have the burden of managing services, finances, equipment, and decision making on top of caring for a child with already high needs. It is essential to have an individualised and family centred approach to health and disability but this can be achieved without individualised funding. It would be preferable to have both options retained.* (Organisation submission)

Aside from the EGL approach, submitters also provided general comments about choice and control. Submitters envisioned that disabled people would oversee their health and disability needs and have flexibility and choice about what options will work for them and their whānau and families. They said that having access to flexible choices could result in improved opportunities and a more inclusive society.

6.4.6. **Equity between groups of disabled people**

Submitters described disparities in services or support available between specific disabilities. Examples included:

- Neurological disorders such as Tourette's syndrome and autism, where disorders are diagnosed in the health system, but unless there is an additional disability diagnosis, children are not eligible for educational supports or additional training for their teachers;
- Foetal Alcohol Syndrome is not recognised as a disability by the Ministry and therefore these individuals are not eligible for all health and disability services that they need;
- People with physical disabilities receive less support than blind and deaf people and have to prove their disability each year;
- People living with stroke may receive free services in one area of the country, while other areas are charged (e.g. driving assessments);

- People with diabetes receive funded foot care that is not provided to people with scleroderma, despite people with scleroderma also having foot care needs and amputations; and
- More information, funding and services is required for people with rare disorders or complex, undiagnosed disorders. Similarly, submitters wanted to see more recognition and care for chronic conditions that cause disability, such as Chronic Fatigue Syndrome and Fibromyalgia.

> *The level of care and support for hidden and difficult-to-treat illnesses is actually a good measure of the system in its entirety.* (Individual submission)

Other submitters commented on specific population groups or areas that do not receive equitable access to services. These included:

- Different levels of service provision, compensation and rehabilitation available, based on whether the cause of a condition is accident-related or not. Submitters considered it to be discriminatory to provide differential access based on how a disability is acquired and suggested that those living with disabilities that are not acquired by an accident to have access to ACC-equivalent support and treatment;
- **Rural populations.** Specialist disability services or programmes are not available to many rural people, their families, and communities they live in due to low volumes. It was suggested that communities can self-deliver programmes have other resources available that can be used to provide services, such as community groups, schools, sports facilities, country pubs and community halls; and
- **Children.** Submitters provided comments about access to educational support for children living with disabilities, in addition to health care services:
    - Extra educational support, including funding for special needs teacher aids, to ensure that children are not disadvantaged in schools and those with extra learning needs are provided for;
    - More intensive treatments, including physiotherapy and speech therapy when young to minimise the need for services as they get older;
    - Greater access to children’s assessment for developmental, behavioural and mental health concerns;
    - Provide funding for Applied Behaviour Analysis, particularly for supporting children with neurological disorders; and
    - Provide more community support for young people with disability moving into adulthood.

6.4.7. Disability carers and respite (including support for family and whānau)

Submitters commented on the need for adequate financial and pastoral support for caregivers, as well as adequate access to respite care services. Submitters who have a caregiver responsibility described the mental, emotional, physical and economic burden that comes with caring for a disabled person. Evidence was cited that increased stress is correlated with increased likelihood of abuse of either or both of the parties. Submitters suggested there should be financial reimbursement for family members as carers, so they do not have to forgo employment opportunities or have a reduced income due to the level of care required for a disabled family member. Other support needs for family and whānau included better parenting tools for those with high needs children, and access to respite services.

There were suggestions that the volume and range of respite care options should be increased to better support families to choose a provider that is suited to the disabled individual's needs (particularly for younger disabled people, complex behavioural conditions and stroke survivors). Submitters also wanted respite services to be places where people are engaged in activities that will enable them to live well and have fun.

> *Our current system is giving a very limited amount of carer support days, which is at a low pay rate, which does not even cover a 24-hour period. With the correct supports and respite this means families who choose to stay together may be able to do so. Without the correct supports and respite families are getting torn apart.* (Organisation submission)

Submitters noted concerns around relying on volunteers for delivering some disability support programmes due to the declining nature of the volunteer sector. They thought that this reliance could create a risk for such programmes as an insufficient number of volunteers could lead to a worse service. Other submitters noted the importance of having a strong community and volunteers to help disabled people rather than relying on support from government.

6.4.8. Māori experiencing disability

> *The decades long, unacceptable state of deprivation experienced by Māori with disability demands significant and immediate action.* (Organisation submission)

Submitters wanted te Tiriti/the Treaty to be acknowledged and honoured by the health and disability system in order to achieve equitable health outcomes for Māori experiencing disability. They suggested identifying potential disparities in service delivery for Māori and non-Māori living with disabilities and chronic health conditions, particularly focusing on areas where there is limited data and strategies implemented to reduce disparities.

Submitters described barriers that Māori living with disability experience, including:

- Institutional racism;
- Lack of connection and engagement with service providers;
- Inaccessible transport and buildings;
- Treatment and prescription costs;
- Lack of cultural expertise among providers; and
- Lack of access to tri-lingual (Māori, English, sign) interpreters.

As a result of these barriers, submitters said that disabled Māori struggle to access Te Āo Māori and be an active member of their whānau, hapu and iwi.

Submitters want to see disabled Māori consistently represented in all disability sector planning, policy making, service delivery and evaluation.

> *To preserve the right of Tāngata Whaikaha to self-determination we counsel robust engagement with Māori at all levels of this roll-out to ensure Māori get equitable access to services. Anything less will exacerbate existing inequities.* (Organisation submission)

Māori induvial submitters who identified as disabled commented on the values of the health and disability system and wanted fairness in services and support for Māori disabled people. They said this requires eradicating prejudice and racism against disabled people and using a Māori lens to deliver services and engage with whānau. Submitters suggested basing the level of financial and material support on the requirements of the 'differently-abled', rather than the mainstream medical model. They wanted financial support to address disabled people's circumstances, irrespective of their partner's income.

> *No income testing all people with the same sickness or disability should be treated the SAME as they don't ask for the disability so why should they be penalised for having it ! It's hard enough feeling totally worthless because you can't financially contribute to your family anymore and then you add extra disappointment by not giving them the same financial assistance as others that have the same disability or disease.* (Individual submission)

6.5. Tier 2

This section summarises themes from submissions about hospital and specialist services in both the public and private sectors. Many of the issues overlap with points that have been discussed in early sections of the submissions analysis. The focus of this section is on issues which are more specific to Tier 2 services

6.5.1. Integration of services and transitions between care

Submitters presented a vision of a more integrated health and disability system.

> *Health and social and primary, secondary and tertiary services are integrated in both planning and delivery, with information shared and access facilitated through any provider or 'front door' and navigation support provided to those who need it.* (Individual submission)

Submitters wanted better horizontal and vertical integration to improve the transitions between Tier 2 services and all other services in the health and disability system. This was discussed from both an organisation/planning perspective as well as a service delivery perspective.

> *Integration can occur horizontally at different levels of the system, or vertically, and in real or virtual ways. Horizontal integration is when two or more organisations or services delivering care at a similar level come together. Vertical integration occurs where two or more organisations delivering care at different levels come together such as primary, community and hospital services.* (Organisation submission)

Submitters called for hospitals to have a clear plan for transferring patients between locations (e.g. inpatient to community care), and providing cohesive services where multiple specialities are involved.

Submitters also stated that IT systems are an important enabler to achieving integration with Tier 2 services. They considered that this is important so that all service providers have timely access to the same information.

> *More effective IT solutions are a key enabler of ensuring integrated patient-centred care, and of mitigating existing shortcomings in transitions of care. There is a pressing need for a nationally available, standardised, shared electronic health record that all healthcare providers can access and update.* (Organisation submission)

> *A well-functioning primary care service also depends on well-functioning, accessible hospitals. To reduce pressure on hospitals, a 'systems approach' is needed. This requires strong integration between hospital, primary care and social services to provide care that is truly patient-centred.* (Organisation submission)

6.5.2. **Service configuration**

Submitters commented on the location and configuration of Tier 2 facilities and services. Submitters stated that the location of Tier 2 services can be a barrier to accessing care. Submitters wanted more specialist services, including medical specialists, diagnostics, and treatments, to either be located in, or more accessible to, areas outside of the main cities.

> *There are still many people living in these areas, they may not have vehicles, or whānau to get them to hospital, or currently not enough health services to cater for those outlying communities without long distance travelling.* (Individual submission)

Submitters suggested a variety of enablers to improve access to health services for rural communities, including:

- Increased use of mobile technologies and facilities that can be shared across locations. Examples provided by submitters included diagnostic vans, mobile operating theatres and mobile endoscopy units;
- National planning to determine the most appropriate location of Tier 2 facilities to decrease the impact of distance on access to treatment;
- Support for rural families and whānau to travel to the main centres for specialist services or provide health shuttles;
- Increased use of telehealth for specialist consultations. Some submitters also stated that nurses would be able to provide most of the care in rural areas with remote support from specialists;

> *With technology, travel and access shouldn't be a barrier for people to have access to specialist visits more telehealth networking between the primary, secondary and tertiary interface has to occur. It is ludicrous that patient's travel 5 hours round trip to be seen for a 15 minute apt in a tertiary setting when this could happen with telehealth.* (Individual submission)

- Increased use of remote monitoring and wearable devices to provide data to health providers; and
- More 'local' hospitals outside of the main centres or providing specialist services within community settings. This could involve delivering more outpatient services in homes, communities, primary care facilities, and schools.

> *Have secondary care clinics in primary care facilities to enable patients to be seen in familiar surroundings and not have to travel and wait in hospital clinics. Important for rural and smaller urban centres. This has precedent in obstetrics and gynaecological clinics and specialists who visit outreach clinics.* (Organisation submission)

> *The system needs to unshackle itself from the constraint of bricks and mortar investment. Delivering care and support to the people, rather than asking people to come to where care and support have traditionally been delivered should underpin the new system.* (Organisation submission)

It was also acknowledged that while some care could be moved from the hospital to the community, there will be a growing demand for hospitals that can provide highly specialised care. However, it was also suggested that these services and facilities may need to be more centralised.

> *There is concern that the proliferation across DHBs of some highly specialised services may not be in the best interest of patients as many specialist areas require people to remain at the top of their scope. While there is always a balance in providing services as locally as possible people need to know when a highly specialist service would be better being congregated so that expertise is of the highest order.*
> (Organisation submission)

6.5.3. **Enhancing service delivery**

Submitters suggested improvements to specific services, including:

- Ensuring services are based on best-practice evidence and continuously informed by clinical research;
- Support from DHBs for aged residential facilities timely access to specialists;
- Increased availability of radiation therapy for cancer treatment;
- Well-resourced emergency care services to provide care for increasing numbers of acute presentations;
- More specialist services for mental health and addiction needs;
- Shorter wait times for scans and specialist appointments; and
- Ensuring services and treatments across DHBs are consistent and of the same standard.

6.5.4. **Culturally acceptable services**

Some submitters called for greater acknowledgement of different cultures and the need to provide culturally appropriate services in hospitals. For example recognising that Māori and Pacific people may need more time when engaging with health practitioners. Submitters also suggested making hospitals more inclusive. One example suggested by a submitter is to make hospitals and waiting areas more culturally welcoming to reflect all New Zealanders and cultures accessing these services.

Submitters also wanted whānau-centred services in hospitals, such as Māori Kaiarahi (navigators) available to assist patients and their whānau with the orientation of the hospital, as well as a place for whānau to rest when they are caring for a patient.

As with other areas of the health and disability system, submitters wanted greater use of Māori perspectives and involvement of Māori communities in the design and implementation of the system. This included Māori leadership at the governance level.

Submitters also called for more hospital services in areas with a high proportion of Māori and increased support for Māori to receive treatment away from home.

6.5.5. **Determining priorities**

Submitters provided varied comments on how hospital service spending should be prioritised. Some submitters suggested that everyone should have access to the care that they need, without being denied services due to inadequate resources or funding, and that there is enough specialist capacity to not require the delay of elective treatments due to emergency services.

> *Some members say that they are suffering from significant ill health, causing incapacity and distress […] because they have been refused adequate medical treatment/surgery even though their general practitioner believes they are in dire need. Elective surgery/treatment should be is [sic] based on genuine need not on the whims of various health personnel, the state of a DHB budget or personnel availability etc. at any particular time. [Organisation] recommends that if the health and disability system is to be fair and equal, the problems re elective surgery/treatment need to be over-come, even though that has proven difficult.* (Organisation submission)

Other submitters recognised the need to prioritise limited resources and maintain a financially sustainable health and disability system, but wanted more transparent "prioritisation" processes. Suggestions for prioritising services included:

- Developing national clinical prioritisation criteria to manage wait times for elective surgery consistently across DHBs;
- Prioritising resources for elective surgeries and treatment based on high-quality evidence and a "Choosing Wisely" approach to ensure those with the greatest risk/need and largest quality of life gain are targeted;
- Developing a dedicated elective surgery wait list that is not interrupted by acute cases, as well as a separation of staff and resources between acute and elective streams; and
- Ensuring there is a robust process for making decisions about the funding for expensive procedures that may only benefit a small number of people but may vastly improve their quality of life.

6.5.6. **Service planning and investment**

Submitters described factors that affect DHBs' level of investment and disinvestment, including:

- Growing demand for hospital services means that it is difficult to reduce hospital expenditure and redirect investment to primary and community care, and additional operational spending to 2021/22 will do little more than maintain current real funding levels per capita; and
- The mechanism for hospital capital planning can affect the ability to invest in new services and hospital priorities can crowd out investment in services for broader population outcomes.

Submitters suggested areas for further investment, including:

- Additional funding for hospital services to respond to demand pressures in the short to medium term, as it will take time for prevention and early intervention initiatives to have an impact;

- Ongoing investment in personnel, infrastructure and facilities to meet unmet elective surgery needs;
- Ongoing investment in cancer treatment therapies, equipment, and workforce; and
- Accurate demand forecasting that responds to population-based estimates.

Submitters also suggested improving long-term planning within organisations and at a national level across the health sector (including between organisations responsible for workforce, resources and infrastructure planning).

> *High level planning parameters, including budgets, should ideally be set out at least indicatively over a three to five-year period in order to enable a more strategic approach to services and to financial management. Such longer term indicative planning information has been used in the past, and a return to a longer-term approach at both national and local levels will be an important factor in achieving better stability both in services and in financial performance. This approach would allow the opportunity for DHBs to hump fund significant primary and community investments to drive key population health outcomes, if they could demonstrate a return to budget over a longer period of time.* (Organisation submission)

6.5.7. **Tier 2 workforce**

Submitters commented on increasing workforce shortages in some specialties and regions. They called for improved long-term workforce planning to address shortages and suggested different ways of working to reduce pressure on specialist services. Suggestions included:

- Utilise advanced/extended practitioner roles, such as Orthopaedic Physiotherapy Practitioner and Nurse Practitioners, in hospital teams;
- Achieve a better balance between generalism and subspecialisation of professions; and
- Greater investment in provincial area hospitals to make training opportunities more attractive to trainees.

This is discussed further in Workforce (Section 7.1).

6.5.8. **Innovation and technology**

In addition to the discussion about improvement and innovation in Section 6.1.4, submitters recognised that Artificial Intelligence will have a greater role in the delivery of specialist services in the future and the health system must be equipped for this. Submitters suggested that the future system should consider:

- Ensuring that technologies are underpinned by a strong ethical framework, and do not disadvantage vulnerable populations;
- Using data to monitor the use of technologies to ensure any problems are identified and addressed; and
- Ensuring the models of care and clinical practice are designed to best incorporate technologies.

This is discussed further in Digital and Data (Section 7.2).

7. Enablers

7.1. Workforce

This section focuses on submitters' comments around workforce relevant across the health and disability system. Please refer to other sections for more specific workforce comments relating to Population health (Section 6.2.4), Tier 1 (Section 6.3), Tier 2 (Section 6.5.7), and Disability (Section 6.4.3).

Submitters described the important role of the future health and disability workforce in enabling a better and more equitable system. Submitters identified a number of important factors when considering the work and the workforce of the future, including:

- The need for the health and disability workforce to work differently, in particular developing an integrated workforce of multidisciplinary teams that work collaboratively and make the best use of the skills of different providers, practitioners and health professionals;
- More choice for consumers about who is best able to meet their needs;
- The potential for technology to support the workforce and the need to develop the right skills to make use of it;
- How the workforce can empower people and communities and work with other sectors to live well and prevent and manage disease;
- Addressing workforce shortages and maintaining safe staffing levels;
- Workforce training, including building the cultural competency of the entire health and disability workforce;
- Growing the Māori and Pacific workforces so that the health and disability workforce better reflects the New Zealand population;
- Addressing workforce gaps in rural health care and making rural health roles attractive and supported through technology; and
- Valuing all health and disability staff and working towards pay equity across the sector.

7.1.1. **Working differently**

Many submissions presented a vision of the health and disability workforce working in quite different ways by 2030. These are discussed below.

Integrated care and improved access to services

Submitters wanted more integrated care and team-based approaches to providing health services, pointing to multi-disciplinary and interdisciplinary ways of working. However, some submitters indicated that current funding models can be a barrier to working in this way.

Submitters felt that there should be more flexibility as to who service users see when they have a primary health care need, and more choice as to how and where they can enter the system for treatment. Submitters proposed that a multi-disciplinary team approach could provide service users with more choice around their care.

> *A GP may not always be the best health professional for patients to see when they turn to the health system for support or assistance. If integrated, multi-disciplinary teams are available in primary and community settings, patients can make their own decision about when to see the dietitian, the podiatrist, the physiotherapist, the nurse or the counsellor, for instance.* (Organisation submission)

Submitters suggested re-examining specialist workforce scopes of practice and supporting all health professionals to work to their full scope of practice to make better use of the capacity and capability of the current workforce and foster more collaboration. Some submitters, such as pharmacists, provided specific examples of how expanding the scope of practice for their professions would enable them to provide more services to the community.

> *Pharmacists currently working in Community Pharmacy have shown that with funding and contracts they can step up to perform vaccinations. We would love to be able to manage Patient's health. For example, if a Patient was diagnosed with Gout, Diabetes, Asthma or COPD, we are more than capable of taking their blood tests when necessary, managing their medication, adjusting doses, assisting them with adherence issues, keeping the GP informed of progress, and referring them back to their GP if complications occur. Access to this level of service should be nationally consistent.* (Individual submission)

Making the best use of new technology

Submitters proposed some ways in which technology, such as telehealth and artificial intelligence, could be better used to support the health and disability workforce. Submissions discussed:

- How to select technology that is appropriate for use in New Zealand and is specifically designed for the needs of users;
- How to give staff access to technology and sufficient training on how to use it; and
- How to make sure that the technology reduces rather than adds to the workload of staff.

Submitters described how certain technologies could benefit service users and their families and whānau by, for example, making it easier for house-bound service users to access medical advice from home, or making it simpler to access online or app-based therapies for sleep, pain, and mental health concerns.

Submitters identified the need to prepare the health and disability workforce for a more digital future by assessing and analysing the future roles needed in the health workforce, the skills needed to be effective in those roles, and determining ways to develop those skills now.

> *A proper design-thinking approach to health technologies is needed, to ensure the solutions actually address a well-identified problem, taking into account the perspectives and needs of the user, that is, the patients and clinicians, and not the needs of the provider of the technology and their funding institutions. Failure to adopt such a design approach risks further burn-out amongst providers.* (Indivudual submission)

Supporting communities to look after their health and wellbeing and prevent disease

Some submitters noted the expanding role that the workforce can play in supporting service users, their families, and their communities to more proactively look after their health and wellbeing. Much of this discussion focussed on the integration of services (both across health services and with wider social services) and the need for health professionals to work more collaboratively with people in assessing and addressing their health needs.

The role of the workforce in prevention and wellbeing is further discussed in Tier 1 (Section 6.3.6) and population health (Section 6.2.4).

7.1.2. **Training and expanding the health and disability workforce**

Initial and ongoing training

Many submissions discussed workforce training – both how staff are initially trained and the types of ongoing training they should receive to keep skillsets current and prepare for the future. Submitters talked about how training can support new ways of working and new models of care.

Submitters proposed a range of workforce training topics such as:

- Leadership and people management skills;
- Quality improvement and effective change management processes;
- Cultural competency;
- Understanding of Māori and other non-Western medical models; and
- Providing care to people with intellectual, physical, and other disabilities.

Submitters also noted that processes are needed to incentivise staff to undergo the right sorts of training, and mechanisms to ensure that gaps in knowledge are identified and filled.

> *The outcomes of improved education are immense, as employees who have received job-specific training are typically more productive and confident. The need for ongoing education is also significant for a variety of health practitioners to stay current regarding constantly changing aspects of health practices. It is crucial that training not be limited to new employees, and that all practitioners be provided with access to ongoing training opportunities.* (Organisation submission)

Cultural competency and responsiveness

Many submissions raised the importance of cultural competency in the workforce. Submitters described about how the skills of the entire health and disability workforce could be improved to enable the workforce to engage more effectively with a diverse range of people, to value different world views, and recognise when cultural biases, stereotyping, and discrimination are influencing the level and quality of service provided to service users.

Submitters proposed that cultural competency could be included in initial training and ongoing professional development, with the potential for some form of monitoring to also be included.

Submitters suggested that compulsory cultural competency training would support a system-wide focus on health equity for Māori, Pacific peoples and minority population groups.

> *[…] nationally run Cultural Competency programmes for health providers can help all of us better understand the hundreds of thousands of New Zealanders who see the world differently than we do, leading to reduced health inequities.* (Individual submission)

> *We also reiterate our recommendation to adequately fund cultural competency across the workforce so that the workforce overcomes its cultural biases toward patients of certain ethnicity, religion, disability or sexual orientation.* (Organisation submission)

Submitters suggested changes to the training of the health workforce should start by building the entire workforce's understanding of te Tiriti o Waitangi/the Treaty of Waitangi, and the history and culture of local iwi/hapū in areas where health and disability services are being provided. Submitters suggested that te Tiriti/the Treaty education needed to be made a part of ongoing professional development for all health practitioners.

> *Tiriti education in the health sector needs to be repositioned from a one-off training to an ongoing professional development requirement so currency can be maintained and strengthened.* (Organisation submission)

Growing the Māori workforce

Many submitters identified the need to grow the Māori workforce so that the health and disability workforce is more representative. Submitters made suggestions on how best to achieve this, for example, by working in partnership with iwi, using a by Māori for Māori approach, or promoting health careers for Māori throughout the education pipeline, particularly in roles that need greater Māori representation.

> *Strengthen and support the Māori health workforce and Māori leadership. Māori health workforce capacity should be proportionate to Māori health need. To achieve this will require a significant capacity building focus at all levels of the educational system.* (Organisation submission)

Developing and supporting the Pacific workforce

Submitters also talked about growing a workforce that was reflective of New Zealand's Pacific population. The importance of involving Pacific groups in this process and supporting Pacific providers to recruit and retain Pacific health professionals was emphasised. Some submissions identified gaps in areas such as rural and public health and in being able to speak the different languages of consumers.

> *there must be equitable investment in Pacific health providers, the teaching of cultural competency of the whole health and disability workforce in each of the*

> *Pacific cultures, as well as active pursuit of diversity within all workforce recruitment.* (Organisation submission)

Staffing rural communities

Submissions discussed the challenges of staffing rural areas and providing services to meet the needs of rural communities. Submitters noted that more investment is required to retain rural staff and maintain their competency. Submitters suggested recruiting rural people and providing training in these communities to build a sustainable workforce. Bond schemes could also be used to incentivise practitioners to work in rural areas.

> *There are significant gaps in rural health care in New Zealand. Addressing challenges in the delivery of health care to rural communities is particularly important for Māori given the fact that a number of rural communities, such as Northland and Gisborne, have large Māori populations. There are numerous challenges to providing health care to rural communities including recruiting and retaining staff and ensuring confidentiality. It is important to investigate and invest in innovative ways of bringing health services to these communities – such as through telehealth, home visits, marae-based services and mobile clinics.* (Organisation submission)

Technological solutions such as telehealth and mobile services that provide services to people in rural communities and help train and maintain currency of the skills of local staff were seen by submitters as part of the solution.

7.1.3. **Pay equity within the workforce**

> *There must be pay equity for the health workforce regardless of where they work, e.g. nurses working outside the DHB sector, Māori providers. An underpaid workforce will not be able to contribute to the transformative changes the health and disability system requires making it fit for our current and future challenges.* (Organisation submission)

The difference in pay rates and conditions between different health professions or specialties was raised by submitters. Submitters noted that a lack of pay equity and poor pay in some areas of the workforce (e.g. nurses, cleaners, and disability and aged care workers) impacted on the ability of organisations to attract new staff, retain current staff, as well as having an impact on staff morale more generally.

Submitters also raised concerns about the differences in pay rates between employers, for example DHB pay rates being higher than NGOs, or Māori or Pacific provider rates being significantly lower due to funding levels. Submitters said that this is making it harder for these organisations to attract and retain staff and disadvantaging those providers who chose to target services to certain communities.

Submitters suggested addressing issues of pay equity for some roles through options such as providing a living wage, or earn-as-you-learn training options (e.g. paying student nurses as they earn their qualifications).

7.1.4. **Digital workforce**

Submitters expressed concern that the current workforce is generally lacking skilled and knowledgeable experts in digital technologies and data collection and analysis. Submitters noted that this lack of expertise has implications for healthcare delivery and outcomes for populations.

Submitters suggested that the health and disability workforce should develop skills in data integration and analysis, with a particular focus on implications for health services and clinical care.

> *Develop digital capability in the public health sector workforce. As the digital landscape is rapidly changing, and new technologies challenge and disrupt existing investment, service delivery, and clinical care models, System leaders must be aware of, and be able to make informed decisions about, the opportunities presented. [We see] an opportunity for all public health sector leaders to further develop their digital capability, as leadership of digital change is multi-disciplinary and the responsibility of all business teams.* (Organisation submission)

Submitters noted that developing the digital capability of the workforce will require ongoing funding.

> *Deliver a continuous programme of investment in technology and workforce capability that underpin patient centric pathways across and between local, regional and nationally provided services.* (Organisation submission)

7.2. Digital and Data

Submitters discussed a range of topics and issues regarding digital and data technology, including:

- Data, Access and Sharing (e.g. appropriate data governance, collection and ownership);
- Systems, Vendors and Interoperability;
- Information Equity;
- Digital Workforce and Capabilities;
- Digital ways of working; and
- Digital Investment and decision making.

7.2.1. **Data, Access and Sharing**

Discussion points raised by submitters about data, access, and sharing included concerns that there is:

- Inconsistent and inadequate data governance;
- Limited clarity of purpose regarding data collection, ownership and use, particularly surrounding national collections, consumer/commercial data ownership and commercial data use;
- A lack of clear approaches to manage service-user data and consent;
- Insufficient clarity surrounding the definition of data sharing/access and data privacy/security between healthcare consumers, providers, industry/sector and government;
- Limited definition and boundaries relating to New Zealand data sovereignty, in particular for Māori and Pacific peoples; and
- Inadequate focus on using appropriate, available data to inform proactive models of care and healthcare policy using modern technologies, transparent approaches and research methods.

Data governance

Submitters identified a current lack of consistency, transparency, ownership and responsibility regarding approaches to data governance, data sovereignty and data stewardship. Submitter views on these issues cited concerns about how data is used to inform population health interventions, health policy and support health improvement and equity.

> *New Zealand collects a rich and growing range of healthcare and health-related data, a valuable national asset. These data are often distributed, disconnected and inconsistently captured, utilised and governed – leading to inequities and missed opportunities. No organisation is empowered to ensure that the value of these data is maximised to the benefit of New Zealand and New Zealanders.* (Individual submission)

Submitters raised issues regarding Māori data stewardship and sovereignty, including:

- Data governance does not consistently adhere to Māori data governance frameworks and should be enabled by Māori governance and leadership;
- A lack of a national policy on access to Māori data;
- Unclear and inconsistent approaches to clarify ownership of data and the subsequently difficulties ensuring it is used appropriately.
- Researchers currently experience challenges when accessing publicly held data sets, particularly for Māori.

Submitters made suggestions for how approaches to these issues could be improved, including:

- Improved mechanisms to govern and control access to Māori data to better align with te Tiriti / the Treaty. Indigenous data governance should be an integral part of any approach to improve Māori health and increase Māori participation in the health and disability workforce;
- Governance that meaningfully ensures feedback from, and engagement with, Māori. This included suggestions for an independent national body to ensure data is accessed and used appropriately;
- Provide health and disability researchers and organisations greater clarity and simplified processes to access and use data for research purposes; and
- Introduce consistent approach for capturing, categorising, and analysing multiple ethnicities that recognises each ethnicity.

Submitters also identified a number of data governance issues for providers and organisations within the health and disability system. These included:

- Inconsistencies in health professional access to different healthcare information;
- Issues with intellectual property and ownership of interpretations and synthesised data or findings;
- Limited public awareness and guidance regarding modern data challenges, including cloud computing (the transfer of health data to a data storage platform) and the use of offshore servers; and
- Limited clarity regarding social license, and appropriate access to publicly owned data sets.

Submitters offered a range of possible improvements, which included:

- Greater central guidance on modern data challenges;
- Focus on using appropriate, available data to inform models of care and healthcare policy;
- Incorporate a shared system level governance across all agencies
- Establish a "*national Health Data Centre of Excellence*" or 'think tank' that provides skills and expertise to government, policy-makers, researchers and industry, with potential functions including:

- *Use data to apply the principles of precision-driven health to work towards the most precise, efficient, and safe health care for an individual patient or whanau;*
- *Identify variation in quality of care at the macro, meso, and micro (individual provider) level. This would allow the early identification of e.g. treatment failure (as per surgical mesh), over- or under- treatment and investigation, and performance monitoring;*
- *Understand and explore the implications (including health outcomes and cost) of policy options, and identify how best to construct health care teams, and care management plans;*
- *Drive research of national and international relevance;*
- *Become the leading provider of products for national, regional, and local organisations, including advanced data visualisations, analyses, and interpretations; and advise in the selection of appropriate tools for local data processing and analytics; and*
- *Inform and engage in data governance, ethics, social license, and sovereignty discussions at a national level.* (Individual submission)

7.2.2. **Systems, Vendors and Interoperability**

Discussion points raised by submitters in regard to software and hardware systems, vendors and system interoperability included concerns that:

- Inadequate adoption of and adherence to data and interoperability standards results in inefficiency and significant costs;

> *There is no standard method and structure for referrals to and from [organisation]. There is no clear method for end to end integration. There are multiple methods for accepting e-referrals resulting in significant additional cost to implement.* (Organisation submission)

- Frustrations voiced about inefficiencies and poor patient and provider experience that required considerable duplication and used of multiple systems to source data or complete workflow
- Procurement processes do not mandate the use of system-wide and cross-sector interoperability requirements;
- Significant challenges that health organisations face regarding the systems they need to interface with, decision making processes and the complexity that arise when individual organisations can choose or develop their own ICT solutions independently; and
- Ineffective leadership and governance structures relating to interoperability.

> *There are too many DHBs with too many disparate, expensive-to-maintain legacy systems that don't talk to each other. We need consolidation and centralisation of systems and of decision making.* (Individual submission)

Submitters who raised these issues suggested that data and interoperability standards should be a national priority for the future health and disability system. Some submitters also indicated their support toward the concept of a National Health Information Platform (NHIP). Their ideas included having a nationally hosted cloud-based platform and partnerships with a specific provider of cloud platforms. They suggested this approach could be a springboard for interoperability.

> *While the National Health Information Platform project is approaching this problem, a significant increase in consistency and availability of data across the System is necessary, including the use of (existing) data standards and interoperability between distributed information systems.* (Organisation submission)

Other submitters recommended the use of modern, open standards via APIs and web-based interfaces to enable improved interoperability between disparate systems, rather than the option of a single solution.

Submitters proposed a range of ways of achieving this. Some suggested that the Ministry or another central agency with appropriate expertise and resources, should take a lead in providing and developing interoperability standards for health IT services nationally. They suggested that the Ministry could set minimum levels of healthcare service standards with the aim of achieving a consistent level of health and disability services across New Zealand. Other submitters indicated that centrally governed interoperability standards could benefit the health sector and provide the opportunity to implement regulations to ensure that healthcare software providers meet the standards required for them to be licenced or approved to participate in the New Zealand health IT industry.

> *This does require agreed standards and should be supported by regulations that ensure that software vendors supplying health software in New Zealand provide open systems which are licensed to operate.* (Individual submission)

7.2.3. **Information Equity**

Submitters called for a greater focus on the use of data to improve access to health information and technology to improve equity of outcomes. Some were concerned about the risk of widening the equity gap.

Some submitters raised issues relating to some modern methods of collection and the use of available data that could result in potential inequitable, biased treatment and adverse healthcare outcomes in vulnerable populations:

> *[…] technological advances in data collection will pose some ethical challenges for the health and disability sector in the 21st century. Although the use of algorithms and predictive risk modelling may be seen to improve efficiency in services dealing with large amounts of data, we hold concerns that decision making based on trend and behaviour based algorithms may inadvertently reflect historical bias against*

> *vulnerable populations thereby promoting further bias, leading to inequality in health care.* (Organisation submission)

Submitters also discussed concerns about inequities that might arise through lack of access to technology:

> ’self-care’ as being central to the new model of healthcare. However […] this aspiration is difficult to achieve if access to technology and good information is inequitably distributed amongst the population. (Organisation submission)

Submitters suggested different solutions and approaches to improve issues relating to equity, including:

- Reviewing approaches to consent with an aim being to ensure that data for all populations is included in research;
- Ensuring that data is interoperable and accessible with the aim of improving its capability to be shared, so that the data is used to build algorithms that incorporate the complexity of vulnerable populations;
- Introducing online patient portals that support multiple languages on how, when and where to access various healthcare services.
- Incorporating measures of wellbeing as part of data collection and analysis to complement existing measures of mortality and morbidity rates;

> *[…] measuring health and wellbeing – an important complement to the mortality/morbidity and service volume measures which often dominate health sector comparisons.* (Individual submission)

- Broadening the focus of data that is collected regularly to include collecting data on mental health, alcohol and drug use, nutrition, physical activity, dental health, and unmet need, which may assist in organising more effective healthcare delivery; and
- Improved Māori data governance to increase participation rates from consumers through to workforce.

> *There is a clear need for Indigenous data governance to be an integral part of any strategy to increase Māori health and medical workforce participation. Data governance should adhere to Māori data governance frameworks and should be enabled by Māori governance and leadership.* (Organisation submission)

7.2.4. **Digital workforce and capabilities**

Submitters commented on the importance of having a digitally capable workforce across all areas of the health and disability system. This includes diverse organisations that support and interact with the wider system such as Shared Service Agencies, NGOs, educational institutions, and national bodies such as ACC, Health Quality and Safety Commission, Stats NZ, and relevant ministries.

Some submitters argued that the current health and disability workforce does not have enough skilled and knowledgeable experts in digital technologies and data collection and analysis. They said that this has implications for healthcare delivery and outcomes for populations.

> *health data is becoming increasingly complex, with the arrival and availability of new forms of data that present a challenge to integrate and to extract their value. Expertise in health data integration and analysis, and epidemiological/clinical interpretation is needed […] and New Zealand does not have sufficient numbers of people with this expertise to provide a robust service for all these entities - there is a risk that some organisations will miss out on this skills.* (Individual submission)

Submitters suggested that system leaders should invest in the development of the workforce's digital capability and capacity through collaborative and multi-disciplinary environments. They indicated that this environment could support teams to increase their skills in relevant digital areas. Submitters suggested that continuous resourcing and funding mechanisms to develop the digital health workforce capability is required at national, regional, and local levels.

> *Develop digital capability in the public health sector workforce. As the digital landscape is rapidly changing, and new technologies challenge and disrupt existing investment, service delivery, and clinical care models, System leaders must be aware of, and be able to make informed decisions about, the opportunities presented. [We see] an opportunity for all public health sector leaders to further develop their digital capability, as leadership of digital change is multi-disciplinary and the responsibility of all business teams.* (Organisation submission)

7.2.5. **Digital ways of working**

Submitters indicated that the current technology infrastructure, funding approaches, service delivery models, and organisations are not well setup to capitalise on, or optimise, modern ways of working. Submitters suggested that remote video-consultations, use of data from wearable technologies, mobile applications, and algorithm or AI based technology are under-utilised. Submitters also indicated that people cannot easily access their own health information, and have little control over who and what is shared.

Submitters suggested that service-users are ready for alternative digital approaches to receive healthcare, with many identifying that it will enable better equity of access to services and health outcomes. For instance, making use of modern technologies to better support rural and regional healthcare provision.

Submitters suggested that digital technology can also support workforce development with online training tools and peer teaching for healthcare providers. Another benefit of adopting digital ways of working was considered to be greater ability to share and scale local innovations and practice.

Some submitters highlighted the potential of working digitally to improve service-user experience, collaborate, and provide platforms to access information and services which cater to different languages.

7.2.6. **Digital investment and decision-making**

Submitters discussed their concerns about a lack of sustainable investment in healthcare technology and cross-sector integration at a system level. They said the current level of investment does not support future needs of the health and disability system or the ongoing population growth and diversity in New Zealand.

Submitters also indicated that there has been limited cooperation and open collaboration between health organisations (public and private), resulting in systems that do not exchange information or integrate effectively.

Submitters proposed a range of ideas to improve decision-making and investment in digital health and data, including:

- Conducting a comprehensive analysis to evaluate requirements, changes, and the best digital and data solutions;
- Ensuring there is national responsibility to maintain national datasets;
- Establishing a shared understanding of the digital health future state regarding system level roles and responsibilities between system agencies;
- Establishing an independent agency responsible for national digital investment programmes such as interoperability;
- Greater investment in capturing and measuring health outcomes data to enable value-based healthcare approaches; and
- Greater investment in healthcare data registries that underpin healthcare quality, safety and standards of care and outcomes.