

Health and Disability System Review:

Submission of the Human Rights Commission

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Introduction

1. The Human Rights Commission ('the Commission') welcomes the opportunity to provide this submission to the Health and Disability System Review Panel ('the Review').
2. The Commission supports the goal of the Review as set out in the Terms of Reference, that being *achieving equity of outcomes, and contributing to wellness for all, particularly Māori and Pacific peoples*. The particular focus on Māori and Pacific people is important given the social and economic disadvantages these groups face and the resulting impact this has on health outcomes.
3. To achieve the stated goal, it is essential to have a health and disability system that is underpinned by a human rights framework and the Treaty of Waitangi and which is consistent with core human rights principles.

Summary of Recommendations

4. The Commission recommends that:
 - a) ***The human right to health is explicitly recognised, and is placed at the forefront, in any legislation, regulation and policy that underpins New Zealand's future health and disability system.***
 - b) ***The legal, policy, governance and funding frameworks supporting health and disability services are created and implemented consistently with domestic and international human rights obligations, including the Treaty of Waitangi.***
 - c) ***The system is co-designed and provided in a manner consistent with core human rights principles such as participation and inclusion; equality and non-discrimination; interdependence and indivisibility of rights; and accountability. It must also be based on concepts of autonomy and respect for human dignity.***
 - d) ***Meaningful and active participation of affected people, at all stages of service design and delivery, must be embedded in the design of the system. This includes involvement in strategy, development, delivery, monitoring, governance and implementation. This is important for all groups, but particularly so for Māori as tangata whenua, who disproportionately bear the burden of health inequality in our country.***
 - e) ***The system must be equitable and inclusive and approaches and responses should fully reflect, involve, value and support all people regardless of age, sex, sexual orientation, gender identity and expression, disability, religion, race, colour and ethnicity.***

f) The underpinning framework should recognise and support the relationship between the right to health and the right to other core economic, social and cultural rights protected under the International Covenant on Economic Social and Cultural Rights (ICESCR). These include the right to housing, water, sanitation, food, and safe working conditions.¹

g) It should also incorporate and reflect the rights embodied in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child (CRC), the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Convention on the Elimination of All Forms of Racial Discrimination (CERD).

h) The system should be developed and delivered in alignment with the health and wellbeing related goals set out in the United Nations Sustainable Development Goals (SDGs).

5. These recommendations are discussed in more detail below. The Commission notes that although some of these matters may initially appear complex, the basic principles are simple and can be easily and sensibly incorporated into reports, legislation and practice, to the benefit of all those who live in Aotearoa New Zealand.
6. The Commission is also available to meet and discuss any of these matters further if that would be of assistance to the Review Panel.

Domestic and International Human Rights Obligations

The Human Right to Health

7. Neither the New Zealand Public Health and Disability Act 2000 nor the current New Zealand Health Strategy refer to the human right to health. These are significant omissions for a country that prides itself on the general quality of its health services and its human rights record.
8. The right to health² is a fundamental human right that has been recognised in international treaties and conventions that New Zealand has ratified. The right encompasses access to timely, acceptable and affordable healthcare of an appropriate standard and requires the State to generate conditions in which everyone can be as healthy as possible.

¹ As acknowledged in the drafting history and express wording of article 12.2 of the International Covenant on Economic Social and Cultural Rights

² The right to health specifically refers to “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” as set out in article 12.1 of the International Covenant on Economic, Social and Cultural Rights.

9. The State is required to take progressive steps, to the limit of its available resources, to ensure the highest possible standard of physical and mental health for its population.³ It must do so in a non-discriminatory and transparent manner.
10. The right to health extends to underlying determinants of health such as access to food and water, healthy housing, sanitation, education, the right to be free from violence and abuse, and the right to an adequate standard of living.⁴ It is not possible to consider the right to health in isolation from broader social rights. These factors are all complex and interlinked, as are the responses and potential solutions. Having a safe, healthy home, sufficient food and clothing, a job and enough money to live on are all baseline requirements for being physically and mentally healthy.⁵ Social connections, physical activity, meaningful engagement and relationships with others are also crucial to good health. Inability to access all or any of these basics of living will have a detrimental impact on wellbeing.
11. The Commission also notes that oral health is a key indicator of overall health, wellbeing and quality of life and that “*public health solutions for oral diseases are most effective when they are integrated with those for other NCDs [noncommunicable diseases] and with national public health programmes*”.⁶ The Commission encourages the Review to carefully consider arrangements for funding and delivery of dental services for both adults and children.
12. It is essential for the human right to health to be explicitly recognised within our Health and Disability System. It is not an optional extra or an “add on”. A human rights-based approach, grounded in concepts of individual dignity and autonomy, should be a cornerstone of any review being undertaken for the purpose of improving the Health and Disability System.
13. **The Commission urges the Review Panel to explicitly recognise and adopt the human right to health as a guiding principle for its report and any related recommendations.**

Freedom from Discrimination

14. The Health and Disability System must be equitable and should provide approaches and responses that are equal and inclusive and which reflect, value and support all people regardless of their age, sex, sexual orientation, gender identity and expression, disability, religion, race, colour and ethnicity.⁷

³ World Health Organisation Fact Sheet, <https://www.ohchr.org/Documents/Publications/Factsheet31.pdf>

⁴ As set out in the International Covenant on Economic, Social and Cultural Rights articles 11 and 12.

⁵ Article 25.1 of the Universal Declaration of Human Rights affirms: “Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services”

⁶ <https://www.who.int/news-room/fact-sheets/detail/oral-health>

⁷ Universal Declaration of Human Rights, Article 2

15. Several human rights treaties apply across the whole health system and give guidance to assist the realisation of the right to health on a non-discriminatory basis for populations who may experience barriers and differential outcomes. These include:
- a. Convention on the Rights of Persons with Disabilities
 - b. Convention on the Rights of the Child
 - c. United Nations Declaration on the Rights of Indigenous Peoples
 - d. Convention on the Elimination of All Forms of Racial Discrimination
 - e. Convention on the Elimination of All Forms of Discrimination Against Women
 - f. International Covenant on Economic, Social and Cultural Rights
 - g. International Covenant on Civil and Political Rights
16. The Commission notes the proceedings in *Atkinson v Ministry of Health* which culminated in 2012 with the Court of Appeal decision that the Ministry of Health's policy of not paying family carers for care provided to dependent adult disabled family members constituted unlawful discrimination on the grounds of family status.⁸
17. The Commission further refers to the related case of *Spencer v Attorney General* that resulted in the High Court awarding a family caregiver damages for pecuniary loss incurred as a result of the discriminatory policy and ordering the Ministry of Health to undertake human rights training.⁹
18. In a 2018 judgment, the Court of Appeal noted its unease at the complexity of the statutory instruments governing funding eligibility for disability support services, describing them as "impenetrable". The Court further commented that they hoped that, in the future, the Ministry would streamline its funding processes to make them accessible for disabled people and their families, and to enable disputes over funding eligibility to be settled without litigation.¹⁰ Since this time, the Government has announced that it will change the law and policy in this area.
- 19. The Commission urges the Review to take these important judgments into account and ensure that the Health and Disability System operates in a non-discriminatory manner and that all relevant legislation, policies and practices are fair and lawful, including those that underpin the delivery of support for disabled people.**

⁸ *Ministry of Health v Atkinson* [2012] NZCA 184

⁹ *Spencer v Attorney General* [2013] NZHC 2580 constituted the first time such orders had been issued under the Human Rights Act in respect of a Government policy. In light of the *Spencer* decision, further claims have been filed in the Human Rights Review Tribunal by family carers seeking compensation for loss incurred as a result of the pre-FFC non-payment policy.

¹⁰ *Chamberlain v Minister of Health* [2018] NZCA 8, para 90

Convention on the Rights of Persons with Disabilities

20. The Convention on the Rights of Persons with Disabilities (CRPD) is highly relevant to the review of the Health and Disability System. The CRPD takes a social rather than medical approach to disability. The Convention emphasises the importance of non-discrimination and active participation and imposes specific obligations in relation to awareness raising activities, combatting of stereotypes, and ensuring equality before the law.
21. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. The principles outlined in the CRPD support good people-centred practice.
22. The CRPD rejects the medical model of disability. Rather, it recognises that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. A traditional medical model can see disabilities as health problems to be diagnosed and treated by means of medical intervention. A medical model can foster social and cultural assumptions about the incapacity of persons with psychosocial disabilities to make decisions concerning their personal livelihoods and medical treatment. In contrast, 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.
23. Article 4 of the CRPD provides that states parties undertake to consult and actively involve persons with disabilities in all matters that affect them, including the development and implementation of legislation and policies. This is particularly relevant to the design of the future Health and Disability System.
24. Article 4 of CRPD also includes an obligation to promote the training of professionals and staff working with persons with disabilities in the rights recognised in the CRPD. This was reiterated in the family care court case, *Spencer v Attorney-General*.¹¹ The Health and Disability System should ensure it meets this obligation.
25. Under Article 9 of the CRPD, all information, communication and environments need to be accessible. This applies across all levels of health care. Information and communication processes (including policy consultation) need to be accessible. General information, including websites and specific individual information such as appointment details, need to be provided in multiple and accessible formats, such as Easy Read, plain Language, large print, captioned video and NZ Sign Language. Accessible

¹¹ *Spencer v Attorney General* [2013] NZHC 2580

environments also need to take account of diverse requirements including sensory and neurodiverse impairments (not only physical accessibility).

26. Article 12 of the CRPD provides that state parties recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. The article acknowledges that some people will require support to exercise this legal capacity and an emphasis is placed on the importance of supported, rather than substitute, decision-making. Some people will require extra supports in order to express their will and preferences and it is essential that processes and resources are in place so that this can happen effectively. Substitution of another individual's view or making decisions in the "best interests" of someone else are not permissible under the CRPD.
27. Article 25 of the CRPD recognises that all persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. They have the right to the same range, quality and standard of free and affordable health care as everyone else, including sexual health and fertility services.
28. Adequate resourcing to support persons with disabilities to access health and disability services and participate in the Health and Disability System is crucial to ensuring the realisation of the above rights. To ensure the full participation of disabled people, the health system needs to take responsibility for resourcing supports that people need to make the decisions that affect them and to be able to provide informed consent. At present this is especially lacking for Deaf and NZSL first language speakers, people with learning impairment and people who use augmentative /assistive communication.
29. Early investment in assistive technologies and equipment, and reducing waiting times for these would enhance personal autonomy, as would better investing in habilitation and rehabilitation services, such as orientation and mobility, as outlined in Article 26
30. Article 31 of the CRPD obliges states to ensure high quality data infrastructure. In order to attain an equitable health system, there is a need for a human rights and privacy compliant data infrastructure disaggregated for gender, ethnicity, age and disability, that allows both understanding of health status and effective monitoring of intervention effectiveness and outcomes. This obligation is consistent with that under the Sustainable Development Agenda, discussed further below.

Convention on the Rights of the Child

31. The Convention on the Rights of the Child (CRC) is relevant to the Review. The CRC sets out the rights of children, aged zero to 18 years. It emphasises the following general principles that apply across a range of contexts, including health:
 - that all children have the right to protection from discrimination on any grounds (Article 2),

- that the best interests of the child should be a primary consideration in all matters affecting them (Article 3),
- that all children have the right to life, survival and development (Article 6), and
- that children are enabled to have their voices heard and be active participants in decision making (Article 12).

32. Article 24 expressly recognises the right of the child to enjoy the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. In pursuit of this right, states should ensure provision of primary health care and ensure all segments of society, in particular parents and children, are informed and supported in the use of basic knowledge of child health and nutrition.

33. Article 23 of the CRC recognises the special needs of children with mental or physical disabilities and obliges states to ensure disabled children have effective access to, and receive, health care services in a manner conducive to the child achieving the fullest possible social integration and individual development.

34. Also relevant to the Health and Disability System review is the obligation under Article 39 to take all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of any form of neglect, exploitation or abuse in an environment which fosters health, self-respect and dignity of the child.

35. The Commission recommends that the Review ensure the recognition and realisation of these rights in the Health and Disability System.

United Nations Declaration on the Rights of Indigenous Peoples and the Treaty of Waitangi

36. Indigenous concepts of health encompass individual and collective wellbeing, and are interconnected with the realisation of a range of rights, including self-determination, development, culture, language, land and the natural environment. The right to health for indigenous peoples is affirmed in articles 21, 23, 24 and 29 of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Article 22 emphasises the need for specific focus on children and young people, as well as women, older people and disabled people in the implementation of the Declaration.¹²

37. The right to health is reflected and affirmed in the Treaty of Waitangi (the Treaty). The human rights obligations contained in the Treaty include partnership, good faith cooperation and shared decision making; protection of rangatiratanga (self-determination) and taonga (treasured possessions, tangible and intangible, including such things as: culture, language, land and health) and participation in society on an equal basis to others.

¹² Further information on these rights in the Declaration can be found in the 2016 Study by the UN Expert Mechanism on the Rights of Indigenous Peoples, *Right to health and indigenous peoples with a focus on children and youth*, A/HRC/33/57, accessible at: <https://www.undocs.org/a/hrc/33/57>.

38. Alongside the human rights instruments which protect the universal right to health, the Treaty and UNDRIP affirm the rights of Māori, as New Zealand's indigenous people, to health equity, participation in the development of health services and programmes, and to their own traditional health practices, medicines and resources.
39. 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. Further, the Commission also supports the urgent introduction of measures to ensure equitable access of Māori to health and disability services in a manner according with the rights guaranteed under the Treaty and UNDRIP. The Commission also notes the 2018 report of the Aotearoa Independent Monitoring Mechanism for the UNDRIP¹³, recommending that a Whānau Ora approach be applied to the disability sector reforms. That report identifies Whānau Ora as a model and approach that would align with Treaty and UNDRIP obligations and which could facilitate improved outcomes if applied (and adequately resourced) across the health and disability sector.

Convention Against Torture

40. The Convention Against Torture (CAT) has Optional Protocols that New Zealand has ratified and which are of relevance. The Optional Protocol to CAT (OPCAT) underpins New Zealand's National Preventative Mechanism (NPM) regime under the Crimes of Torture Act 1989, which provides for the monitoring of, and reporting on, places of detention. At present the Ombudsman's responsibilities include oversight of prisons (including prison health services), inpatient mental health units and other health and disability places of detention. Since March 2019 the Ombudsman has also been responsible for monitoring privately run aged care facilities.¹⁴ The Commission urges the Review to be mindful of obligations under the Convention Against Torture and OPCAT in the Review of the Health and Disability System.

Sustainable Development Agenda

41. New Zealand has endorsed the United Nations 2030 Sustainable Development Agenda. The agenda envisages a better world where physical, mental and social wellbeing are assured. The agenda is supported by 17 globally agreed goals, each supported by detailed targets and indicators. Goal 3 is to "ensure healthy lives and promote wellbeing for all at all ages". Targets such as 3.4 (prevention, treatment and promotion of mental health and wellbeing), 3.5 (strengthening the prevention and treatment of substance abuse, including narcotic drug use and harmful use of alcohol), 3.7 (ensuring integration of reproductive health into national strategy), and 3.8 (ensuring universal health coverage,

¹³ Aotearoa Independent Monitoring Mechanism for the UNDRIP, (2018), *Report of the Independent Monitoring Mechanism regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018*, A/HRC/EMRIP/2018/CRP.2, at pp6-7. Accessible at:

https://www.ohchr.org/Documents/Issues/IPeoples/EMRIP/Session11/EMRIP_CRP.2.docx

¹⁴ NZ Gazette, Notice Number 2018, GO2603, 6 June 2018, <https://gazette.govt.nz/notice/id/2018-go2603>

access to quality essential and affordable health-care services, medicines and vaccines) are particularly relevant to the Review.¹⁵ Goal 10 of reducing inequalities is also relevant.

42. The Sustainable Development Agenda prioritises the collection of high-quality data, disaggregated by vulnerable groups, to ensure that progress towards implementation is accurately tracked and monitored. The Commission supports this objective but also notes the need to ensure that individual privacy and personal information is appropriately protected during data collection and analysis. This is necessary to ensure that people are not deterred from seeking assistance or support because of concerns about unnecessary access to their personal health details at an individually identifiable level.
43. The Commission urges the Review to align the Health and Disability System with the health-related Sustainable Development Agenda goals and targets. The Commission further recommends developing a human rights compliant data infrastructure as part of the Health and Disability System that generates high quality disaggregated data, including data disaggregated by gender, race, ethnicity, disability, migratory and income status.

Disparities in the Health and Disability System which need to be addressed

44. There are currently a range of population groups who experience disparate access to health services and/or health outcomes.¹⁶ There are wide disparities, not only for Māori and Pacific peoples, but for other socio-economically disadvantaged or vulnerable population groups including people living in the most socially deprived deciles, people parenting children alone, and disabled people.¹⁷
45. Māori have a significantly lower life expectancy,¹⁸ higher rates of health conditions and chronic diseases, including cancer, diabetes, cardiovascular disease and asthma,¹⁹ high rates of disability²⁰ and are more likely to have unmet health needs as a result of socio-economic barriers arising through cost and access to transport and childcare.²¹
46. Furthermore, Māori children and young people are over-represented in negative health outcomes.²² This correlates with a higher rate of unmet health needs, which are also

¹⁵ United Nations, Resolution adopted by the General Assembly on 25 September 2015 [A/RES/70/1] https://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E

¹⁶ Submission of the Human Rights Commission for the Fourth Periodic Review of New Zealand under the International Covenant on Economic, Social and Cultural Rights, 15 February 2018, https://d3n8a8pro7vnmx.cloudfront.net/nzhrc/pages/3147/attachments/original/1519072968/Final_ICESCR_Report_15.02.2018x.pdf?1519072968

¹⁷ Ibid

¹⁸ The most recent Statistics from Stats NZ cover the period 2012-2014, http://www.stats.govt.nz/browse_for_stats/health/life_expectancy/period-life-tables.aspx.

¹⁹ Ministry of Health, Tatau Kahukura: Māori Health Chart Book 2015 (3rd ed, 2015, Wellington, Ministry of Health) <http://www.health.govt.nz/publication/tatau-kahukura-Māori-health-chart-book-2015-3rd-edition>

²⁰ Ibid

²¹ Ibid

²² For example, around one in five Māori children has asthma – a rate 1.4 times that of non-Māori children. Māori children are almost twice as likely to be either obese or morbidly obese compared with

indicative of the socio-economic barriers many Māori whānau face. Māori children are 1.4 times more likely not to have received primary health care when they needed it than non-Māori children.²³ Māori children are also more likely to be exposed to the risk factors linked to poor health, social, educational and developmental outcomes.²⁴

47. Pacific communities experience similarly inequitable health outcomes. Life expectancy is over four years less than for the total population²⁵ and Pacific peoples also experience higher rates of infectious diseases than other New Zealanders.²⁶ Furthermore, like Māori, Pacific peoples experience higher levels of unmet primary health care need and associated negative health outcomes. This is particularly the case for Pacific families with children.²⁷ Pacific children are more likely to face an unmet primary healthcare need than other non-Pacific children.²⁸
48. Persons with disabilities also experience inequitable health outcomes. The life expectancy for those with intellectual disabilities is significantly lower than for those without. A 2011 report by the Ministry of Health found that males with intellectual disability have an average life expectancy of 59.7 years which is more than 18 years below the life expectancy for all New Zealand males.²⁹ Females with intellectual disability had an average life expectancy of 59.5 years which is almost 23 years below the life expectancy for all New Zealand females. People who access mental health services experience higher risks of premature death.³⁰ Cost, time pressures, and accessibility of primary care create barriers for persons with disabilities.³¹
49. Reports indicate that cost is an issue for access to primary care for persons with disabilities, that short appointment periods do not support good communication, and cost

non-Māori children. See Ministry of Health, Annual Update of Key Results 2014/15: New Zealand Health Survey, 2015, <http://www.health.govt.nz/publication/annual-update-key-results-2014-15-new-zealand-health-survey> pp 17, 51

²³ Ibid. p viii

²⁴ Ministry of Health, Health and Independence Report 2015, 2015, <http://www.health.govt.nz/system/files/documents/publications/health-and-independence-report-2015-oct15.pdf> pp 32-33

²⁵ Ibid

²⁶ Close-contact infectious diseases: An increasing concern for Pacific peoples, 32 BJP, 10 http://www.bpac.org.nz/BPJ/2010/November/docs/BPJ_32_infectious_pages_10-14.pdf

²⁷ Social Policy Evaluation and Research Unit, 2016 Family and Whanau Status Report, http://www.superu.govt.nz/sites/default/files/F%26W%20Status%20Report%202016_0.pdf pp 39, 41, 46,

²⁸ Jensen Sorensen et al, Pacific People in New Zealand: How are we doing?, Pasifika Futures Ltd, 2015, <http://pasifikafutures.co.nz/wp-content/uploads/2015/06/PAF0018-Pasifika-People-in-NZ.pdf>

²⁹ Ministry of Health, Health indicators for New Zealanders with Intellectual Disability, 2011, <https://www.health.govt.nz/system/files/documents/publications/health-indicators-nzders-intellectual-disability.pdf>

³⁰ Ruth Cunningham et al, Premature mortality in adults using New Zealand psychiatric services (2014) 127 The New Zealand Medical Journal 1394.

³¹ The National Centre of Mental Health Research, Information and Workforce Development, Primary health and disability: a review of the literature, September 2013, <https://www.tepou.co.nz/uploads/files/resource-assets/primary-health-and-disability-a-review-of-the-literature.pdf>

is a barrier to booking double appointments. Premises and equipment are not universally accessible, which creates a further barrier.

50. People with diverse sexual orientations, gender identities and expression, and sex characteristics (SOGIESC) also face barriers accessing mental and physical health services. Evidence indicates poorer rates of mental health and higher risk of distress, addiction, and suicide for sex, gender, and sexuality diverse people.
51. Mainstream health services can lack cultural competence around SOGIESC communities, creating a level of distrust that may deter people from seeking necessary care. Addressing health disparities requires sustainable and funded community leadership, high-quality and disaggregated data, and equal access to services across the country.
52. The Commission recommends that the Health and Disability System Review ensures an equitable system that guarantees for all people, particularly vulnerable groups, equal access to health services and outcomes. To address this disparity, the Commission recommends that the Review should increase the provision and accessibility of primary health care and Whānau Ora providers to vulnerable communities and socioeconomically deprived communities.
53. Further, the Commission recommends that the Review promote effective, full and meaningful civic participation in the design and implementation of the system, in particular for socio-economically disadvantaged or vulnerable population groups. For Māori, Pacific and culturally and linguistically diverse people, developing and supporting a health and disability workforce that is reflective of their communities will also help build trust and enhance the system's ability to provide effective and responsive services.

General Comments

54. The Universal Declaration of Human Rights recognises the inherent dignity, and the equal and inalienable rights, of every member of the human family. Personal dignity is central to any discussion about the health and disability system.
55. The health and disability services system must be fully inclusive and should reflect, value and support all people regardless of age, sex, sexual orientation, gender identity and expression, disability, religion, race, colour or ethnicity. This requires an inclusive approach that values diversity of thought and behaviour and demonstrates compassion and understanding towards others.
56. It is essential to harness the lived experiences of service users to develop a truly inclusive and responsive system. The approaches most likely to be acceptable for rights-holders and most successful in improving outcomes and general wellbeing are those that are developed with, and alongside, those who are most deeply affected.
57. A human rights approach emphasises participation and empowerment of individuals and supports active involvement in design and implementation of processes and actions that

affect them. It requires action to be taken in a non-discriminatory and transparent manner and includes accountability processes to help ensure that those who have duties to discharge fulfil their responsibilities to an acceptable standard. Participation is particularly important for those who are most vulnerable and disenfranchised – including marginalised groups and those who face socio-economic and cultural barriers that might hinder their active involvement in matters that affect them.

58. The Review can explicitly adopt and model a human rights approach in its own proceedings, and can promote the development of a health and disability system aligned with human rights principles and approaches. Transparency of the underlying rights-based frameworks will also assist in enhancing community and sector understanding of the scope, and limitations, of these rights and corresponding State obligations.
59. The Review provides an important opportunity for a system to be created in a way that serves the people of Aotearoa, and which eliminates some of the silos, barriers and unnecessary bureaucracy that hinder current health and disability service delivery.
60. Artificial distinctions and categories created by funders and service providers alienate service users and their families and can lead to people “falling between the gaps”. This can occur when there are insufficient linkages between social support agencies *vis a vis* “clinical” support services and also within services. To be effective, services must be flexible and meet the needs of rights-holders, not the other way around.