New Zealand Disability Support Network submission on the Pae Ora (Healthy Futures) Bill

Thank you for the opportunity to make a submission on the Pae Ora (Healthy Futures) Bill. The New Zealand Disability Support Network supports the objectives of the Government's reforms in the health and disability sectors, particularly the creation of a new Ministry for Disabled People and the recognition that disability needs to be addressed holistically, not just as a subset of the health system. We have some specific recommendations on how the Pae Ora (Healthy Futures) Bill can be improved to work better for disabled people and the disability sector.

NZDSN would like to make an oral submission on this Bill.

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About NZDSN

NZDSN is a national network of over 160 organisations that provide support services to disabled people, mainly through contracts with government. We are governed by an elected Board from the wider membership and employ a full time Chief Executive with a small staff team mostly based in Wellington.

Our focus is leading and influencing change that supports inclusive lives for disabled people. We provide a strong voice and policy advice to government on behalf of our members and facilitate innovation and quality with providers.

General comments

NZDSN and other disability sector groups have long called for a separation of health and disability within government and recognition that disability should not be thought of as primarily a health issue. While many disabled people have ongoing health needs, the impact of these health issues cannot be seen in isolation from their lived experience of disability and issues such as income support, family and professional care, home support, education, and socialisation are just as important.

We welcome, therefore, the Government's decision to create a new Ministry for Disabled People to incorporate functions from across government agencies and de-emphasising disability as a health issue.

While this Bill necessarily concentrates on the health aspects of disability, such as by mandating the creation of a health disability strategy, we would like to see more explanation of how the systems set up under this Bill will interact with the new Ministry for Disabled People.

In general, we want to see a greater level of co-ordination and partnership across relevant government and non-government agencies reflected in this legislation.

An example of the risk for lack of coordination is the disconnect in having the Minister of Health and the Ministry of Health writing a Disability Health Strategy without being required to work with the Minister for Disability Issues and the Ministry for Disabled People, who will be responsible for updating and amending the New Zealand Disability Strategy, which is due to expire in 2026.

We agree with the establishment of the proposed health authorities, but we think the Bill fails to make an integral component of their respective responsibilities to understand and publish research, data and information about the characteristics of at-risk populations of interest in order to better inform policy development and service delivery in both the public and private environments. While we limit our suggested amendments to disabled people, the same logic can be extended to other at-risk populations, such as Māori, Pasifika, and the LGBTQI+ communities, children and older New Zealanders. Disabled individuals may also identify as eg Pasifika + LGBTQI, they are not a homogeneous group.

Comments on specific clauses

Clause 12

Clause 12 of the Bill defines the Board of Health New Zealand. In this clause there is no reference to disability or disabled New Zealanders. Given the number of New Zealanders with a disability, and their outsized use of the health system compared to non-disabled New Zealanders, we think it is appropriate that the board should have to have members that includes personal experience of disability issues.

There must be representation on the respective Boards of Health NZ and the Māori Health Authority from the disability community/sector. While recognition of the

disparities/inequities and obligations within UN Convention on the Rights of Disabled Persons is acknowledged, we expect to have it clearly defined how disabled people/the sector will have authority to be heard regarding how the health needs will be identified/planned for/services and systems developed/monitored/evaluated etc. These disparities are particularly critical for Tāngata Whaikaha Māori and people with intellectual impairment/learning disability.

The disability sector/communities need to be at the decision-making tables. Such a connection is consistent with the intent behind the establishment of clear relationships between these authorities and the Ministry for Disabled People. The establishment of the new Ministry specifically calls for (amongst other things):

"the health system should engage with Māori, other population groups, and other people to develop and deliver services and programmes that reflect their needs and aspirations, for example, by engaging with Māori to develop, deliver, and monitor services and programmes designed to raise hauora Māori outcomes"

<u>NZDSN recommends that clause 12 be amended to:</u>

- require that the Board of Health New Zealand has personal experience of disability issues.

12 Board of Health New Zealand

(1) The board of Health New Zealand consists of not fewer than five, and not more than eight, members.

(2) The Minister must appoint the members of the board (other than the member referred to in subsection (4)) and the chairperson.

(3) When appointing members, the Minister must be satisfied that the board, collectively has knowledge of, and experience and expertise in relation to, —

(a) te Tiriti o Waitangi (the Treaty of Waitangi) and tikanga Māori; and

(b) the public funding and provision of services; and

(c) public sector governance and government processes;

(d) financial management; and

(e) disability issues through personal experience

(4) The chairperson of the Māori Health Authority (or the nominated co-chairperson referred to in section 22(3))—

(a) is, by virtue of holding that office, a member of the board of Health New Zealand with voting rights; and

(b) may delegate that membership to a deputy chairperson of the Māori Health Authority.

Clause 14

Clause 14 defines the functions of Health New Zealand, including working with and engaging with a range of organisations. However, there is no mention of working with disability organisations, or even the Ministry for Disabled People.

Clause 19 of the Bill sets out the following requirement of the Māori Health Authority:

"(l) monitor, in co-operation with the Ministry and Te Puni Kōkiri, the performance of the health system in relation to hauora Māori"

We argue that the same requirement is needed for Health NZ with the Ministry for Disabled People.

NZDSN recommends that clause 14 be amended to:

- include working with Ministry for Disabled People among Health New Zealand's functions

14 Functions of Health New Zealand

(1) The functions of Health New Zealand are to—

(a) jointly develop and implement a New Zealand Health Plan with the Māori Health Authority; and

(b) own and operate services; and

(c) provide or arrange for the provision of services at a national, regional, and local level; and

(d) develop and implement commissioning frameworks and models for the purpose of paragraph (c); and

(e) set requirements and specifications for publicly funded services; and

(f) develop and implement locality plans; and

(g) undertake and promote public health initiatives, including commissioning services to deliver public health programmes specified by the Public Health Agency; and

(h) improve service delivery and outcomes at all levels within the health system; and

(i) collaborate with other providers of social services to improve health and wellbeing outcomes; and

(j) work with the Māori Health Authority when performing any function in paragraphs (c) to (i); and

(k) contribute to key health documents in subpart 5; and

(l) engage with iwi-Māori partnership boards; and

(la) engage with the Ministry for Disabled People to monitor the performance of the health system in relation to disabled people; and

(m) evaluate the delivery and performance of services provided or funded by Health New Zealand; and

(n) provide accessible and understandable information to the public on health system performance; and

(o) provide, or arrange for the provision of, services on behalf of the Crown or any Crown entity within the meaning of the Crown Entities Act 2004; and

(p) perform or exercise the functions, duties, and powers conferred or imposed on it by this Act or any other enactment; and

(q) perform any other functions relevant to its objectives that the responsible Minister directs in accordance with section 112 of the Crown Entities Act 2004.

(2) Health New Zealand must give effect to the GPS and the New Zealand Health Plan when performing its functions.

(3) In performing any of its functions in relation to the supply of pharmaceuticals, Health New Zealand must not act inconsistently with the pharmaceutical schedule.

Clause 40

Clause 40 requires a Disability Health Strategy to be developed. NZDSN supports the development of such a strategy as a complement to the New Zealand Disability Strategy.

There are significant inequities of health status non-disabled people compared to disabled people, including people with intellectual impairments/learning disabilities. This inequity extends to the significantly lower average age at death of disabled people, compared to those without disabilities. The health system also needs to address current systemic barriers for disabled people accessing mental health services (again, especially people with intellectual impairments).

A Disability Health Strategy could be a useful tool for identifying these problems and how to fix them.

However, it must avoid being developed in isolation from the wider New Zealand Disability Strategy and conceiving of disability as primarily a health issue.

The Government needs to ensure that this is not just another strategy that sits on the shelf, as previous reports have done. There needs to be funding attached and a commitment from the Government to implementing the Strategy.

We are concerned that the requirements of the Disability Health Strategy listed in the Bill do not include any requirement to assign funding to the implementation of the strategy. While we acknowledge that the Bill's requirements are not limiting and the Government could choose to include funding commitments in the Strategy, it is just as possible to comply with the law by producing a Strategy that is just a piece of paper, with no funding commitment behind it.

As mentioned above, the clause as drafted includes no requirement to align the Disability Health Strategy with the New Zealand Disability Strategy or to consult with

the responsible Minister. Indeed, there is no requirement for consultation at all in clause 40.

While we expect that the Minister would do this, it should be explicitly stated in the legislation, just as consultation requirements are laid out in other legislation (eg the Climate Change Response Act requires the Climate Change Commission to consult in the preparation of its advice to the Government).

NZDSN recommends that clause 40 be amended to:

- require that the Disability Health Strategy is developed to be compatible with the New Zealand Disability Strategy.
- include a requirement that the Strategy include funding for implementation of the plan.
- include a requirement that the Minister consult with the Minister for Disability Issues, organisations representing disabled people, their families, carers, and service providers, as well as the general public in the development of the Disability Health Strategy. It may be appropriate to list other groups that should be consulted with, such as Māori, Pasifika, and the LGBTQI+ communities.

Draft Amendments to clause 40

40 Disability Health Strategy

(1) The Minister must prepare and determine a Disability Health Strategy, which must be compatible with the New Zealand Disability Strategy.

(2) The purpose of the Disability Health Strategy is to provide a framework to guide the health system in improving health outcomes for disabled people.

(3) The Disability Health Strategy must—

(a) contain an assessment of the current state of health outcomes for disabled people and the performance of the health system in relation to disabled people, including the younger average mortality of age of disabled people compared to those without disabilities; and

(b) contain an assessment of the medium and long-term trends that will affect the health of disabled people and health system performance; and

(c) set out priorities for services and health system improvements relating to the health of disabled people, including workforce development; and

(d) include an estimate of funding required to implement the services and health system improvements relating to the health of disabled people set out in accordance with **paragraph (c)**, to be appropriated through normal Budget processes

(4a) In the development of the Disability Health Strategy, the Minister must consult with relevant stakeholders including, but not limited to –

- the Minister of the Crown responsible for disability issues

- disabled people, their families and carers, organisations representing disabled people, and disability service providers

- the general public

(4) **Subsection (3)** does not limit what may be included in the Disability Health Strategy.

Clause 53

Clause 53 of the Bill requires the Health Quality and Safety Commission to develop a Code of Consumer Participation. NZDSN supports this and the requirement that the "code must contain principles for the purpose of supporting consumer participation and enabling the consumer voice to be heard."

However, we would like to see explicit mention of disabled people in the principles of the Code.

We also recommend that the Code reference the "Enabling Good Lives" strategy for disabled people as implementation of this is a core expectation for the new Ministry for Disabled People. We believe the emphasis must be on the ability of disabled people to access universal health services that are responsive to disabled people's needs, and having specialist health services where appropriate.

We also recommend that there is a requirement for consultation with disabled people and disability groups in the formation of the Code. As with clause 40, there is no requirement for consultation at all in clause 53. While we expect that the Minister would do this, it should be explicitly stated in the legislation, just as consultation requirements are laid out in other legislation (eg the Climate Change Response Act requires the Climate Change Commission to consult in the preparation of its advice to the Government).

NZDSN recommends that clause 53 be amended to:

- require that the Code of Consumer Participation explicitly acknowledges the needs of disabled people as consumers in the health system
- require HQSC consult with stakeholders including the Minister for Disability Issues, organisations representing disabled people, their families, carers, and service providers, as well as the general public in the development of the Code of Consumer Participation. It may be appropriate to list other separate-but-interested groups that should be consulted with, such as Māori, Pasifika, and the LGBTQI+ communities.

Draft Amendments to clause 53

53 Code of Consumer Participation

(1) The HQSC must develop a Code of Consumer Participation.

(a) In developing the code, the HQSC must consult with relevant stakeholders, including, but not limited to –

- Minister of the Crown responsible for disability issues,
- the Ministry for Disability Issues
- disabled people, their families and carers, organisations representing disabled people, and disability service providers
- the general public

(2) The code must contain principles for the purpose of supporting consumer participation and enabling the consumer voice to be heard.

(a) this must include recognition of the specific needs of disabled people and principles to enable their participation

(3) The code is made when the Minister approves it.

(4) The code must, as soon as practicable after it is made, —

(a) be presented to the House of Representatives; and

(b) be made publicly available.

Clause 73

Clause 73 lays out functions for the Health Quality and Safety Commission, which NZDSN supports. However, as with the prior clauses highlighted, there is a lack of explicit reference to disabled people and stakeholders that are relevant to disabled people, including government agencies.

NZDSN recommends that clause 73 be amended to:

- require that the functions of the HQSC specifically reference advising on the health outcomes for disabled people health system and how they can be improved.
- require HQSC work collaboratively with stakeholders including the Minister for Disability Issues, organisations representing disabled people, their families, carers, and service providers. It may be appropriate to list other groups that the HQSC should work collaboratively with, such as Māori, Pasifika, and the LGBTQI+ communities.

73 Functions of HQSC

(1) The functions of HQSC are—

(a) to advise the Minister on how quality and safety in services may be improved; and

(b) to advise the Minister on any matter relating to—

(i) health epidemiology and quality assurance; or

(ii) mortality; and

(ba) to advise the Minister and Minister of the Crown responsible for disability issues on any matter relating to disabled people's -

(i) access to health services; or

(ii) access to mental health services; or

(iii) health outcomes; and

(c) to determine quality and safety indicators (such as serious and sentinel events) for use in measuring the quality and safety of services; and

(d) to provide public reports on the quality and safety of services as measured against—

(i) the quality and safety indicators; and

(ii) any other information that HQSC considers relevant for the purpose of the report; and

(e) to promote and support better quality and safety in services; and

(f) to disseminate information about the quality and safety of services; and

(g) to support the health system to engage with consumers and whānau for the purpose of ensuring that their perspectives are reflected in the design, delivery, and evaluation of services; and

(h) to prepare a Code of Consumer Participation for approval by the Minister; and

(i) to perform any other function that—

(i) relates to the quality and safety of services; and

(ii) HQSC is for the time being authorised to perform by the Minister by written notice to HQSC after consultation with it.

(2) In performing its functions, HQSC must, to the extent it considers appropriate, work collaboratively with—

(a) the Ministry of Health; and

(b) the Health and Disability Commissioner; and

(c) the Māori Health Authority; and

(d) providers; and

(e) any groups representing the interests of consumers of services; and

(f) any other organisations, groups, or individuals that HQSC considers have an interest in, or will be affected by, its work.

(g) the Minister of the Crown responsible for disability issues,

(h) the Ministry for Disabled People

(i) disabled people, their families and carers, organisations representing disabled people, and disability service providers

(3) The Minister must, as soon as practicable after giving a notice to HQSC under subsection (1)(i)(ii), publish in the Gazette, and present to the House of Representatives, a copy of the notice.

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