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To the Health and Disability System Review Panel

Please find attached DPA’s submission on the Health and Disability System Review | Hauora Manaaki ki Aotearoa Whānui

Disabled Persons Assembly NZ

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**Introducing Disabled Persons Assembly NZ**

The Disabled Persons Assembly NZ (DPA) is a pan-disability disabled person’s organisation that works to realise an equitable society, where all disabled people (of all impairment types and including women, Māori, Pasifika, young people) are able to direct their own lives. DPA works to improve social indicators for disabled people and for disabled people be recognised as valued members of society. DPA and its members work with the wider disability community, other DPOs, government agencies, service providers, international disability organisations, and the public by:

* telling our stories and identifying systemic barriers
* developing and advocating for solutions
* celebrating innovation and good practice

**Equity and the Health and Disability System**

We at Disabled Person’s Assembly (DPA) welcome this review, focused on improving the performance of the Health and Disability System. We would like to start by acknowledging the progress which has been made in the Health and Disability system in the past few decades for disabled people. This is particularly in regard to increasing awareness of disability issues, changes in attitudes, and the exploration of new and innovative opportunities related to disability support. We are particularly pleased to see the Enabling Good Lives approach being embedded in disability system transformation. This approach is achieving significant and measurable positive outcomes for disabled people and whanau in the regions where it is being implemented. A further positive change is an emerging focus on cross Government collaborative practices which enable more effective delivery of Government services to disabled people.

In this submission, we discuss areas where we believe further progress can be made. The first section of this submission will summarise some of the key barriers to equity facing disabled people in Aotearoa New Zealand, while the second section will provide recommendations to address these issues.

We are pleased to note the strong focus on tackling issues related to equity for Māori and Pasifika people in the information available for this review, including your website and the New Zealand Health Strategy (2016). We would like to call your attention to the similar barriers to equity which disabled people face in the Health and Disability System, and in Aotearoa New Zealand more generally.

The New Zealand Health Strategy highlights some of the poor outcomes facing disabled people, including a shorter lifespan (learning / intellectually disabled people live on average 18-23 years less than the non-disabled population), and a significantly higher reporting rate of health being fair or poor (29% for disabled people, vs 4% for non-disabled people), as compared with the non-disabled population. The New Zealand Disability Strategy (2016) furthermore notes that “disabled people remain worse off than non-disabled people across all social and economic outcomes” (p. 9).

The barriers in the Health and Disability System will be discussed in detail in this submission, however we would like to note that barriers to full participation on society include:

* A severe shortage of accessible and affordable housing, with no discernible strategy to address this problem,
* High levels of poverty amongst the disability community, resulting in ongoing poor health outcomes such as people living in cold, damp housing, and not going to the doctor until a dire situation presents itself,
* Transport continues to remain a significant barrier to equity. Many disabled people struggle to access transport to access all parts of life which contribute to wellbeing. This includes getting out and about to join in community activities, spending time with friends and family, and accessing employment and medical facilities.

We would like to affirm a statement in the New Zealand Health Strategy, which recognises “the connections between health and other aspects of people’s lives” (p. 4). Having the ability to participate equitably in education, employment and wider community life has significant positive benefits for people’s health, and thus significant positive long-term financial impacts for the health sector.

**Barriers to Equity in the Health and Disability System**

We at DPA are concerned that the current approach to healthcare in Aotearoa New Zealand appears to be founded on the assumption of a “normal” body and mind. Under this assumption, people will present themselves to medical practitioners with a single health issue, will be able to communicate clearly with medical practitioners in a short time-frame, and also easily understand what those practitioners are saying. This approach does not take into account the intersectionality of people’s lives, whereby many people have multiple, complex health and disability-related concerns which all interact with each other, creating much greater complexity.

One particular concern related to the assumption of a “normal” body and mind is the short time-frame given to people in appointments with medical professionals. For instance, General Practitioner visits are scheduled for 15 minutes, and there is usually no flexibility to this time limit. When there is flexibility, patients are expected to pay a double fee, which many cannot afford. Many people with communication impairments require extra time to communicate with the medical practitioner, need information in accessible formats, or may need information explained more slowly. Added together, this creates a barrier to achieving quality healthcare in a 15 minute appointment.

Compounding this issue is the lack of disability training provided to medical professionals including doctors, nurses, mental health workers and Health and Disability Commission advocates. Many disabled people remark that they are required to spend significant time and energy teaching medical professionals about their support needs. Furthermore, when disabled people go to hospital their support staff stop being funded to provide support, as there is an assumption that the medical staff are able to support the person. Here is one example of such a situation from one of our members:

*My brother is non-verbal and has multiple and complex needs. When he went to hospital our family had to train the nurses and doctors on how to support him, and this had to be re-done when the shift changed and a new set of staff came on. My brother was hospitalised four or five times for pneumonia over a short period, and every time he was discharged, he had nappy rash because he was left in a soiled nappy for long periods and was unable to communicate this to the nurses. It is difficult for nurses to attend to supporting people with complex needs, on top of their already-high workloads.*

We believe this is an important issue having a significant detrimental impact on many in our community, and would like to see this issue addressed.

In the Disability Support System, there is an unacceptably long wait time for some people to receive basic supports related to their disability. For instance, Joshua Perry from Dunedin will shortly present a petition to parliament about the need to improve the processing for housing modifications under the Ministry of Health DSS funding. Joshua has been waiting nearly two years to get modifications done on his bathroom so that he can safely access it. Other members have reported to us that they have spent a similar amount of time urinating in jars and dragging themselves into the bathroom to shower, while they wait for modifications to enable them to access the bathroom in a wheelchair. We consider this an unacceptable wait, which has a detrimental impact on people’s health and wellbeing.

We are also concerned at the limited eligibility to access Ministry of Health supports, which relies on medical diagnostic criteria which view disability as a flaw inherent in individuals. In contrast to this approach, the New Zealand Disability Strategy uses the social model, which recognises the impact of a person’s impairment and ability to function in a disabling society. We would like to see access to disability supports using a social model approach.

Fragmentation of services also remains a key barrier to equity for disabled people in Aotearoa New Zealand. Many disabled people need to access a variety of services in order to have equal access to good lives in the community. These services include Work and Income, the DHB’s, disability support providers, general practitioners, other medical specialists related to impairment, and specialists in equipment and home modification, to name a few of the most common services. Each service has its own eligibility criteria, communication system and way of working, and must be navigated by the disabled person and their whānau in order to access support. This approach creates real barriers to quality lives as people become exhausted and confused navigating so many complex systems.

There is also a significant lack of data related to disability in Aotearoa New Zealand. For instance, there is no reliable data on how many learning disabled people there are in Aotearoa. Without this baseline data, is it nearly impossible to assess levels of employment and access to health services for this group, and it is similarly challenging to assess whether improvements are being made.

**DPA’s recommendations**

DPA is concerned to note that the Health and Disability Review Panel has no direct representation from people with a lived experience of disability. DPA recommends that this oversight be addressed in the second phase of the Review’s work. One option is to appoint a Disability Reference Group. This should be comprised of people with lived experience of disability and whānau members.

The values we would like to see underpinning our Health and Disability System:

* *Nothing about us, without us*. 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, including in leadership positions, acting as practitioners, providers of service, advisors, and on National Advisory Committees. The balance of power on such panels also needs to be addressed to ensure disabled representative voices are respected and heard. This would enable Aotearoa New Zealand to meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities, by ensuring that the voices of disabled people form an important component of the co-creation of health and disability services.
* *Citizens 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.
* *Diversity of experience, body and mind as the foundation of all Health and Disability systems*. This approach seeks to move away from the assumption of a “normal” body and mind, towards a system that is designed to cater for a wide variety of aspirations and needs.
* *Choice and control.* Everyone should have choice and control over the supports they receive. This value is in line with the United Nations Convention on the Rights of Persons with Disabilities, NZ Disability Strategy and the Enabling Good Lives (EGL) approach.
* *A proactive approach*. Such an approach will enable everyone to have access to quality disability support and healthcare when issues start to arise, rather than waiting until situations are dire before people are able to access support.

Disabled Persons Assembly further recommends:

1. 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.
2. We recommend investing for outcomes in the disability sector. The current funding and contracting system allocates funding to disability service providers to perpetuate models of support that often produce negative outcomes. This can be seen clearly in escalating costs of supporting some disabled people in residential care settings where they are deeply unhappy. They then behave in ways that are challenging and the solution is to apply higher and higher levels of funding for tighter staffing and environmental controls - all of which exacerbate the situation. Some work has been done already analysing the cost of supports and identifying the indicators and patterns that lead to costs increasing over time – DPA recommends more work is done in this area to address firstly, the rights of disabled people, and secondly the high costs associated with this model.
3. Disabled people need to be at the forefront of work assisting in the development of the Health and Disability System workforce, particularly so that practitioners come to understand us as a population group. We also need to be at the forefront of any work involved in (re)designing services that meet the needs and aspirations of our community. This will help the Ministry achieve one of the goals in the Health Strategy, which states: “*To improve outcomes for these groups, the health system will need to improve its understanding of different population groups, involve people in designing services and provide a range of services that are appropriate for the people who use them” (p. 13)*
4. An investment in adaptations to health services, so that disabled people can become “health smart” and have the information they need to manage their own health needs. This investment includes providing information in accessible formats, such as Easy Read and New Zealand Sign Language, having extra time and/or support at medical appointments to communicate with medical practitioners, and extra time and support to be able to make informed decisions. We would like to note that Easy Read information not only assists learning disabled people, but also helps many other communities including migrant communities, people with low vision and other reading-related challenges, and children.
5. A robust process for gathering reliable data on disability, including progress being made in addressing the barriers to equity facing disabled people.
6. A significant increase in investment in disability research, particularly research which is not based on a medicalised understanding of disability. Despite the importance placed on evidence in the Health Strategy, there continues to be a significant under-investment in non-medical disability research in Aotearoa New Zealand.
7. We would like to see a research ethics committee established for disability-related research, which is accessible to all researchers in the country. This panel would ideally consist largely of people with a lived experience of disability. Such a panel would help to ensure disability research is held accountable to the disability community.
8. DPA recommends a change to the rules regarding disability funding when a person enters hospital, so that disabled people can continue to retain their everyday support staff when this is required.
9. DPA recommends the Ministry address the unacceptably long wait times which some disabled people face in getting equipment and modifications to their houses.
10. The Disabled Person’s Assembly strongly recommends that an Enabling Good Lives approach to disability support services be implemented across the country. We believe that many of the current barriers to equity in the health and disability system will be reduced by adopting such an approach.

As an important voice of disabled people in Aotearoa New Zealand, DPA aims to provide robust policy advice to Government. We are available to talk with members of the Review Panel and its secretariat at any time, and welcome an opportunity to engage in the second phase of this important work. Our contact details are available at the bottom of this submission.

Thank you once again for undertaking this important work. We look forward to hearing from you.

Kind regards,

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