



**Submission on the New Zealand Public Health  
and Disability Amendment Bill**

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## **1. Introduction**

IHC welcomes the opportunity to make a submission on the New Zealand Public Health and Disability Amendment Bill. In addition we wish to appear before the Parliamentary Health Select Committee to make an oral submission.

## **2. About IHC**

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education and health systems for their children with intellectual disability. The IHC of today is still striving for these same rights and is committed to advocating for the rights, welfare and inclusion of all people with an intellectual disability. We support people with intellectual disability to lead satisfying lives and have a genuine place in the community.

We have around 5,500 staff working to support 7,000 people in IDEA services (IHC's service arm) that includes residential care supported living home support, employment and community participation and inclusion: support for families, specialist services, and, through Accessible Properties (a subsidiary company of IHC), is New Zealand's largest non-government social housing provider.

Through our charitable arm IHC raises awareness and advocates for the rights of over 50,000 people with intellectual disability at both a national and an international level. This includes an extensive advocacy programme, a one to one volunteer programme and the country's largest specialist intellectual disability library.

IHC's membership includes families who choose to care for their disabled adult family member at home. As such IHC has a critical awareness of the negative impact on families due to the poorly considered legislative and policy framework that this Bill seeks to resolve.

## **3. IHC's overall response**

IHC strongly supports the repeal of Part 4A of the New Zealand Public Health and Disability Act 2000.

We unreservedly support the Bill's intent to ensure that family members who are currently excluded from being paid as care workers by Part 4A are eligible for payment. Those excluded previously include significant numbers of young carers and spouses and eligibility will result in improved standards of living and wellbeing to their households.

IHC further supports the intent to ensure consistency with human rights law and uphold New Zealand's commitments under the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

The Bill is well overdue given the ongoing national and international challenges through litigation, petitions, correspondence and media coverage.

IHC concurs with the information in the Regulatory Impact Statement that the Bill will minimise litigation risk, improve living standards for disabled people and family carers, minimise fiscal costs and risks to Government, improve public trust and confidence and aligns with the Government's strategic direction.

IHC acknowledges and recommends to Select Committee members research commissioned by Carers' New Zealand and the New Zealand Carers Alliance carried out by the Sapere Research Group

The research findings were unequivocal, carers believed that government approaches to payment of family carers and current payment systems were unfair, discriminatory, and needed remediation.

Research informants "were vehement and frequently used terms such as 'disgusting', 'discrimination', 'nonsense', and 'appalling'."

Families also report to IHC that along with discriminatory government policies they are adversely impacted by the complexity and lack of alignment between the different policy settings across government.

IHC supports government plans to simplify and improve the flexibility of the Funded Family Care scheme while also aligning the pay rate with that of non-family support workers.

The CCS Disability Action submission to this Bill appropriately cites the research finding that disabled people report one of the biggest barriers they face is a lack of time (Wilkinson-Meyersa, et al., 2014, p. 1547).

It is imperative that there is a government commitment to accessible, easy to understand and implement disability funding policies. IHC recalls court documents that described Ministry of Health disability policy as "impenetrable".

IHC supports an across government approach in responding to the care and support needs of disabled persons and their families. Currently families have to negotiate a complex maze of assessments and entitlements within government departments that don't "speak" to each other. IHC has long lobbied for the establishment of a Disability Commission to resolve these issues.

IHC acknowledges and supports the more balanced assessment of costs and benefits in the Impact Summary for this Bill and further suggests that sustained government investment in quality support will reduce the delayed and higher costs to government when living standards for disabled people are reduced.

In conclusion IHC strongly supports this Bill and we welcome the Government's ongoing efforts to develop a fairer and simpler Funded Family Care scheme, where the rights of disabled people and their whānau are upheld.

## **Bibliography**

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