

# **Submission to Finance and Expenditure Committee: Budget Policy Statement 2018**

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## IHC submission on Budget Policy Statement 2018

### Introduction

1. IHC welcomes the Government's commitment, outlined in the Budget Policy Statement 2018 (BPS), to lifting the wellbeing of all New Zealanders.
2. Several priorities identified in the BPS have particular implications for people with intellectual disabilities and their families.
3. This submission identifies those areas where lifting the wellbeing of people with intellectual disabilities and their families, on an equal basis with non-disabled New Zealanders, requires systematic attention and budgeting .

### Building quality public services for all New Zealanders and improving access to core services, such as health and education

4. There is clear evidence that people with intellectual disabilities are not currently able to access and benefit from public services, especially in health and education, on an equal basis with others.
5. People with intellectual disabilities experience some of the highest health needs, greatest disparities and poorest health outcomes of any population group in New Zealand.<sup>1</sup> Men and women with intellectual disability live, respectively, 18 and 23 years fewer than the general population, and people with intellectual disabilities have two times the rate of potentially preventable deaths.
6. There are similar issues of discrimination within the education system. Students with intellectual disabilities have the right to enrol and receive an education, yet they are excluded from New Zealand's education system, face barriers to equitable access to and outcomes from education and are over-represented in school disciplinary processes, particularly exclusions both formal and informal.
7. These disparities will need to be addressed if the Government is to truly make progress on its priorities and lift the wellbeing of *all* New Zealanders.

### Health

8. Examples of the sorts of health measures that should be budgeted for include the following.

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<sup>1</sup> Ministry of Health, 2011, *Health Indicators for New Zealanders with intellectual disability*; Mirfin-Veitch, B. & Paris, A. (2013). *Primary health and disability: A review of the literature*. Auckland: Te Pou o Te Whakaaro Nui.

- a) Increasing access to health services and improving health outcomes for disabled people with a specific focus on people with learning/intellectual disabilities (Action 9C under the Disability Action Plan), including the introduction of a free annual health check for people with intellectual disabilities.
- b) Inclusion of people with intellectual disabilities in all government health strategies and initiatives, such as:
  - free doctor's visits for children under 14
  - teen health checks for year 9 students
  - access to free counselling for under 25 year olds
  - free annual health checks for seniors and eye checks
  - ensuring every New Zealander has a warm, dry, secure home, whether they rent or own.
  - the Mental Health Inquiry, and re-established Mental Health Commission
  - work to reduce disparities and improving health outcomes.
- c) Addressing health issues specific to people with intellectual disability, such as:
  - the sterilisation of children and adults with disabilities
  - including the voices of people with intellectual disabilities in discussions on bioethical issues, especially ante natal screening, medically assisted dying, and the 2017 End of Life Choice Bill
  - gathering and recording accurate health information for people with intellectual disabilities on demographic data sets and on individual records
  - establishing a national cause of death register for people with intellectual disabilities to ensure accurate information is recorded on death certificates and used to improve health care and data on health outcomes for this population group.

## *Education*

- 9. Building an inclusive education system will require the following.
  - a) Proper resourcing of the learning support system and specialist support services (communication, behaviour and other specialists) so that students with disabilities and schools have access to the support they need, when they need it.
  - b) Collection of accurate prevalence data on students requiring additional supports to learn and use of that data and actual accommodation costs to inform education policies, resource frameworks, plans and programmes.
  - c) Investment in
    - initial teacher education programmes and professional learning and development that results in all teachers being confident in teaching all learners
    - systems for recognising, valuing, monitoring and reporting on the progress and learning achievement of all students, including those working long term within level one
    - making students with disabilities visible in all reporting, including system-wide indicators used to monitor and report on the performance of the education system, and appropriately disaggregating this information
    - enabling education system stewards (MOE, ERO and the Education Council) to work together to address concerns related to the enrolment, participation, learning and achievement of students with disabilities.

- d) The establishment of a quasi-judicial education tribunal or arbitration mechanism.
- e) Steps to ensure people with intellectual disability benefit equally from free tertiary education and that they are visible and counted in reporting on participation in tertiary education.

### Taking action on child poverty

- 10. Poverty is a barrier to children and young people with disabilities realising their right to “enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.” (Article 23, United Nations Convention on the Rights of the Child.)
  - 11. Children with disability are more likely to live in low income families. Data from the 2013 Disability Survey shows:
    - 34 % of disabled children living in families that earn under \$50,000 a year, compared to only 24 % of non-disabled children
    - 15.8% to 19.4% of carers of children with disability were unemployed
    - 30% of disabled children lived in one parent households, compared to 17% of non-disabled children.
  - 12. Estimates from 2013 Disability Survey also found that children with disability were less likely, in the previous four weeks, than non-disabled children to have had music, art, or other similar lessons; played a team sport; done other physical activity such as swimming or gymnastics; visited friends; or been away on holiday in the past 12 months.
  - 13. Like all children and young people, those with intellectual disability are impacted by wider systemic issues associated with poverty such as housing and household income levels. They must not be overlooked or left behind in policy responses to these broader societal issues.
  - 14. Child poverty reduction measures have the potential to counteract and disrupt the compounding disadvantage often faced by the families of children and young people with disability, improving the wellbeing and life chances of everyone within the family.
- “...the majority of parents would not both be able to work full time if they have a child with any sort of disability. People who are not in this situation do not understand the barriers that this places on the entire family unit.”<sup>2</sup>*
- 15. Together with their non-disabled peers, the wellbeing of children with intellectual disability needs to be at the heart of what the Government does, as part of its 100 day plan and beyond. This will require an explicit focus on alleviating poverty for children and young people with intellectual disabilities and their families, within the Government’s child poverty reduction work.

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<sup>2</sup> Comment from a response to IHC’s 2017 survey “How is New Zealand doing for people with intellectual disabilities?”. A snapshot of the survey results is available here: <https://ihc.org.nz/survey>

## Conclusion

IHC trusts that this information will assist the Government in setting and refining its budget priorities. We would be pleased to answer any questions or provide further information should that be required.

Information about IHC and people with intellectual disabilities is attached in Appendix 1 and 2 respectively.

A handwritten signature in black ink, consisting of several loops and a trailing line, positioned above the printed name and title.

Trish Grant  
Director of Advocacy

## Appendix 1.

### About IHC

IHC was founded in 1949 by a group of parents who wanted their children with intellectual disabilities to participate in and have equal access to services in their communities. The IHC of today strives for these same rights, advocating for the welfare and inclusion of an estimated 96,800 people with intellectual disabilities and their families/whanau in New Zealand.<sup>3</sup>

IHC's service arm IDEA is New Zealand's largest provider of residential, supported living and vocational services for people with intellectual disabilities providing support for around 4,500 people. In the 2017 financial year IHC held contracts for service provision totalling almost a quarter of a billion dollars. IHC's wholly owned subsidiary Accessible Properties is a registered community housing provider, is a charitable organisation and manages one of New Zealand's largest non-government social housing portfolios.

IHC's charitable arm includes an extensive advocacy programme, a one to one volunteer programme and the country's largest specialist intellectual disability library. Nationally we work with many disability, community and government organisations and contribute internationally through our membership of Inclusion International.<sup>4</sup>

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<sup>3</sup> Statistics New Zealand, *New Zealand Disability Survey 2013*

<sup>4</sup> Inclusion International is an international network of people with intellectual disabilities and their families.



## Appendix 2.

### Who are the population of people with intellectual disabilities?

People with intellectual disabilities are a diverse group with a wide range of skills and abilities. Having an intellectual impairment means it is harder to learn new things and understand complicated information; support may be needed with everyday activities and that the impairment is evident from birth or childhood and affects someone for their whole life.

There are an estimated 96,800 people with intellectual disabilities (2 per cent of the population) in New Zealand.<sup>5</sup>

- Children with intellectual disabilities make up 5 per cent of the children's 0-14 population.
- Adults with intellectual disabilities aged 15-44 make up three per cent, and those over 45 make up one per cent of the adult population.
- Maori and Pacific people have higher than average disability rates after adjusting for differences in ethnic population groups.
- There are more males living with intellectual disability, both as children and adults.
- Between 20 per cent and 30 per cent of people with intellectual disability also have autism.
- People with intellectual disability are the largest group using Ministry of Health (MoH) Disability Support Service's,<sup>6</sup> with around half identifying intellectual disability as their primary disability. Many of this group also have a physical disability.

In the future it is likely there will be increased numbers of people with intellectual disability due to:

- Increased in survival rates for pre-term babies and in numbers of people with high and complex needs.
- Increased in awareness and identification of autism spectrum disorder, foetal alcohol syndrome along with a growing number of syndrome specific conditions being identified.
- The ageing population which means, as with the general population, people with intellectual disability living longer.

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<sup>5</sup> Statistics New Zealand, *New Zealand Disability Survey 2013*

<sup>6</sup> Ministry of Health, *Demographic report on clients allocated Ministry of Health's Disability Support Services as at September 2016* – released July 2017.