Feedback on the refresh of the New Zealand Disability Strategy

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About IHC

IHC advocates for the rights, inclusion, and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community.

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health, and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare, and inclusion of all people with an intellectual disability throughout their lives.

We believe that people with an intellectual disability have the right to be to be part of a family, to be treated with respect and dignity, to have a say in their own lives, to live, learn, work and enjoy life as part of the community, and to have support that meets their goals and aspirations.

IHC is New Zealand's largest provider of services to people with intellectual disabilities and their families. IHC supports 1500 families with children who have an intellectual disability, provides support and training for 4000 adults in workplaces and helps more than 3500 people with disabilities to live in IHC houses and flats. We also provide specialist services such as behaviour support and training.

IHC advocates for the rights of all people in New Zealand with an intellectual disability an estimated population of 49,000.

Introduction

1.1 Comments on the background of the strategy

IHC is focused on the outcomes of people with intellectual disability who face unique and distinct challenges, as their population profile is significantly different from the majority of the disabled population. For example, while the disabled population overall in Aotearoa New Zealand tends to be older (Stats NZ, 2025), people with intellectual disability have a much lower life expectancy of around 65 years (Beltran-Castillon & McLeod, 2023). Any strategy that aims to improve outcomes for disabled people must therefore include targeted interventions for this distinct group.

1.2 Note on the improvements made by disabled people generally

Education

There have been some small improvements in educational qualifications across the disabled population overall. Disabled people were less likely to have no qualification in 2023 (34%, down from 42% in 2018) and more likely to have a bachelor's degree or above (13%, up from 10%).

Whilst admirable, these improvements do not meaningfully close the gap for people with intellectual disability. When adjusting for age, 59.1% of adults with intellectual disability still have no qualifications, compared with only 11.4% of adults without intellectual disability – more than five times the rate (Beltran-Castillon & McLeod, Forthcoming). Although there has been a slight improvement since 2018, the relative gap has not narrowed. Similarly, just 1.52% of people with intellectual disability hold a bachelor's degree or higher – only a negligible increase since 2018 (1.34%) (Beltran-Castillon & McLeod, Forthcoming).

For Māori with intellectual disability, the picture is particularly stark. In 2023, 60% had no qualification (compared to 61% in 2018) and only 0.22% more had achieved a bachelor's degree or higher since 2018 (Beltran-Castillon & McLeod, Forthcoming). The comparisons presented in the strategy for Māori disabled people as a whole therefore do little to describe the realities faced by Māori with intellectual disability.

School attendance has also worsened significantly. Chronic absence among students with intellectual disability has increased from 14% in 2018 to 21% in 2023 (Beltran-Castillon & McLeod, Forthcoming), a collapse in attendance that urgently needs to be addressed.

Employment

While employment rates for disabled people overall have improved - from 46% in 2018 to 52% in 2023 - these gains have not been matched for people with intellectual disability. Employment rates for this group have risen only marginally, from 19.1% in 2018 to 20.8% in 2023 (Beltran-Castillon & McLeod, Forthcoming). The disparity is even greater for Māori and Pacific people with intellectual disability, whose rates remain well below the national average (17.3% and 16.3% respectively) (Beltran-Castillon & McLeod, Forthcoming).

Housing

The 2023 Census reported modest improvements in housing quality for disabled people overall, with fewer reporting damp (27%, down from 29%) or mouldy homes (22%, down from 24%). For people with intellectual disability, housing quality has also improved, but the level of poor housing remains unacceptably high - in 2023, 30% were still living in damp or mouldy housing, down from 35% in 2018 (Beltran-Castillon & McLeod, Forthcoming).

Accessibility

People with intellectual disability remain disproportionately excluded from the digital world. Only 80% reported having internet access in 2023 compared with 94% of the total population (Beltran-Castillon & McLeod, Forthcoming). This has significant implications for education, employment, and access to government services. We strongly agree that more government information should be provided in accessible formats, particularly letters from Work and Income NZ. Accessibility is fundamental, but strategies must specifically address and articulate the accessibility needs of people with intellectual disability, who are often left out of generic "accessibility" initiatives.

Data

Since 2023, IHC has been extracting and using data from the Integrated Data Infrastructure to analyse outcomes for people with intellectual disability. We developed and funded a method to disaggregate this data ourselves, given the historic lack of government attention to this population. The data clearly shows the extremely poor outcomes people with intellectual disability face in New Zealand. Improvements in data are important - consistent with the government's overall approach, ideally, IHC would want to see specific targets for people with intellectual disability in key outcome areas with defined actions supporting those outcomes.

That said, there are still critical data gaps:

- Service use by key equity groups (our data shows that Māori with intellectual disability underutilise services and funding)
- Unmet need across service types
- Waiting times - including time to diagnosis, time to NASC assessment, time to receive services, and length of waiting lists nationwide.
- The inclusion of disabled people who in live in residential care in Stats NZ surveys such as the Household Economic Survey.

Filling these data gaps is essential for measuring whether the system is working for people with intellectual disability and ensuring equitable access to supports.

Poverty

The strategy does not adequately address the extreme poverty experienced by people with disability, despite clear evidence that this is a critical determinant of health, education, and social outcomes.

In particular, people with intellectual disability are twice as likely to live in hardship up to age 39 and almost three times as likely between ages 40 and 64 compared to the

rest of the population, with severe hardship peaking in young and middle adulthood (Beltran-Castillon et al., 2025).

Across all deprivation indicators, households including people with intellectual disability report higher levels of financial strain, including difficulty paying unavoidable bills, affording sufficient food, keeping warm, taking holidays, or accessing transport (Beltran-Castillon et al., 2025).

Children with intellectual disability are disproportionately affected: they are almost twice as likely to lack basic clothing, access to fresh food, or internet and computer access for homework, and over 6.5 times more likely to miss out on school events due to cost (Beltran-Castillon et al., 2025).

These disparities demonstrate that poverty is not simply a background issue but a pervasive barrier to participation, wellbeing, and inclusion. Without explicit actions targeting financial hardship, the strategy risks leaving one of the most fundamental determinants of inequity for people with intellectual disability unaddressed.

Enabling Good Lives

The draft strategy does not acknowledge or integrate the Enabling Good Lives (EGL) approach, despite its widespread support among disabled people and families in Aotearoa New Zealand. EGL embodies principles of self-determination, choice, inclusion, and community participation that align closely with Te Tiriti o Waitangi and the UNCRPD, and it represents the vision many in the disability community are seeking. Its omission is significant: if EGL principles are not explicitly included, the strategy should make an overt statement referencing these principles as a foundation for cross-government action. EGL provides a well-established, community-driven framework for improving outcomes and should underpin both the development and implementation of disability policy across all sectors.

1.3 Education

Compared with their peers, children and young people with intellectual disabilities are nearly twice as likely to be referred to attendance services for non-enrolment (Beltran-Castillon & McLeod, Forthcoming). Although the relative gap between intellectually disabled and non-intellectually disabled students has narrowed slightly, this is not a positive trend: referral rates have risen for both groups since 2018, and the absolute difference between them has widened. In 2023, referral rates were highest for Māori students with intellectual disabilities (13.2%), followed by Pacific students (11.3%) (Beltran-Castillon & McLeod, Forthcoming).

Chronic absence is also a growing issue, with 21% of students with intellectual disabilities missing enough school to be classified as chronically absent - nearly double the rate of their non-intellectually disabled peers (Beltran-Castillon & McLeod,

Forthcoming). These students are also almost twice as likely to be stood down, nearly three times as likely to be suspended, 1.3 times more likely to move schools, and more than five times more likely to leave school without any qualifications (Beltran-Castillon & McLeod, Forthcoming).

Barriers outside the classroom compound these challenges. Students with intellectual disabilities are almost twice as likely to lack access to a computer and the internet for homework and more than 6.5 times more likely to miss school trips due to financial hardship (Beltran-Castillon et al., 2025). This entrenched poverty remains unaddressed in the current strategy.

While the education goal and description of success are broadly appropriate, they are too high-level to respond to the specific and well-documented problems faced by students with intellectual disabilities - most notably, that they are not at school every day school is open, for the entire school day. The plan also fails to address the high levels of restraint used on disabled students or explain how this will be monitored.

Many of the proposed education actions simply restate Budget 2025 investment decisions rather than offering new, future-focused commitments. Action 2 should move beyond “exploring” options and commit to commissioning and implementing them. The plan should also explain how learning support funding processes will be simplified and include clear actions to improve attendance and reduce the use of restraint on disabled students.

1.4 Employment

Employment rates for people with intellectual disability remain very low. In 2023, just 20.8% of people with intellectual disability had paid employment, up slightly from 19.1% in 2018 (Beltran-Castillon & McLeod, Forthcoming). Employment outcomes are even poorer for Māori and Pacific people with intellectual disability, with rates of only 17.3% and 16.3% respectively. These small gains are not enough to meaningfully close the employment gap (Beltran-Castillon & McLeod, Forthcoming).

The goal for employment should explicitly commit to *equal pay for equal work*. No non-disabled person in New Zealand can legally be paid below the minimum wage, yet people with intellectual disability continue to be paid less under the Minimum Wage Exemption scheme - a practice that must end.

Parents of people with intellectual disability

Issues with employment start early for families with a member with intellectual disability. For children with intellectual disabilities, 67% have at least one parent not in full-time employment, compared with 56% of other children (Beltran-Castillon & McLeod, Forthcoming). Between 2018 and 2023, the proportion of children under 15 with at least one parent not in full-time paid work decreased for both groups, but the

decline was greater for children without intellectual disability (Beltran-Castillon & McLeod, Forthcoming). As a result, the gap between the two groups widened, with the rate ratio increasing from 1.15 in 2018 to 1.21 in 2023. These facts highlight the additional challenges these families face in maintaining dual incomes while raising a child with intellectual disability, which directly affects their financial security.

Most of the proposed employment actions are unlikely to be highly effective for people with intellectual disability, with the exception of the targeted awareness campaign. This campaign would be most effective if it commits to highlighting the robust research about the reliability and value of employees with intellectual disability.

More explicit commitments are needed to address structural barriers. These should include:

- Ending the use of minimum wage exemptions so that people with intellectual disability are paid fairly.
- Improved school-to-work transition planning, beginning in early secondary school and linking students to supported employment or vocational pathways.
- Expanded tertiary study options that go beyond “life skills” courses and provide meaningful qualifications.
- A public sector employment target, with government committing to hire more people with intellectual disability and model inclusive practices.
- A review of benefit abatement rates so that working does not leave disabled people financially worse off.

Without stronger action, employment outcomes for people with intellectual disability will remain unacceptably low and families will continue to experience financial hardship at far higher rates than other families.

1.5 Health

People with intellectual disability experience significantly poorer health outcomes than the general population. They are:

- 1.82 times more likely to be treated for substance use
- 1.53 times more likely to have chronic obstructive pulmonary disease
- 1.61 times more likely to have diabetes
- 1.17 times more likely to have cancer
- 3.04 times more likely to have a mood disorder
- 13.54 times more likely to be treated for a psychotic disorder
- 3.74 times more likely to have dementia
- 2.47 times more likely to have any mental health condition
- 1.12 times more likely to visit the GP
- 2.66 times more likely to visit the emergency department

- 2.41 times more likely to be admitted to hospital for an injury
- 3.67 times more likely to be hospitalised for potentially avoidable conditions (Beltran-Castillon & McLeod, Forthcoming)

Life expectancy for people with intellectual disability remains significantly lower than for the general population. In 2023, males with intellectual disability had a life expectancy of 64 years compared to 81 for non-disabled males, and females with intellectual disability had a life expectancy of 64 compared to 84. Although life expectancy for people with intellectual disability has improved slightly since 2008, the gap has not narrowed. For Māori with intellectual disability, life expectancy is even lower - 62 years for males and 61 for females - highlighting a double disadvantage (Beltran-Castillon & McLeod, Forthcoming).

This highlights persistent and systemic health inequities, with people with intellectual disability facing higher rates of illness, injury, and preventable hospitalisations, as well as poorer health behaviours and outcomes. IHC recommends that robust research be undertaken to understand why these outcomes persist in New Zealand. This research should be informed by international evidence on the systemic barriers and poor-quality healthcare often experienced by people with intellectual disability.

The goal for health in the draft strategy is excellent, and the success statements are similarly strong. IHC welcomes the acknowledgment of the health inequities experienced by people with intellectual disability in New Zealand. However, as the data show, we are a long way from achieving this standard espoused in the goal.

Regarding specific actions:

- Health workforce capability & training (action 2): IHC supports this action, provided programmes specifically address the health inequities experienced by people with intellectual disability, as well as developing communication skills, and promoting equitable care.
- Data collection & monitoring (actions 4 & 5): Identifying people with intellectual disability in datasets is critical, but data must be disaggregated, analysed and action upon.
- Improving communication & accessibility (actions 1 & 5): IHC supports efforts to make policies and practices more accessible and to ensure people with intellectual disability can participate fully in health decisions.
- Self-determination & involvement (action 3): Creating opportunities for people with intellectual disability to participate in service design, consultation, and governance is strongly supported.

Gaps Requiring Targeted Action

To truly address the extreme health inequities faced by people with intellectual disability, additional targeted interventions are required:

- Comprehensive annual health checks and preventive screening
- Specialist services and a twin-track model, including accredited specialist intellectual disability healthcare positions in healthcare
- Improved transitions between paediatric, adult, and geriatric services
- Programmes targeted at reducing over-medication of people with intellectual disability (e.g. the STOMP model from the UK)
- Carer involvement in hospital care and the introduction of disability liaison officers
- Public health policies specifically targeting intellectual disability health outcomes, including a mortality review team and a quantitative wellbeing framework.

1.6 Housing

People with intellectual disability face significant housing inequities:

- People with intellectual disability are 1.96 times more likely to live in the most deprived areas; children with intellectual disability are 1.53 times more likely
- People with intellectual disability are 1.19 times more likely to live in a mouldy house; 40% of Māori with intellectual disability live in mouldy housing
- People with intellectual disability are 1.38 times more likely to live in overcrowded housing
- Children with intellectual disability are 2.48 times more likely to live in social housing; 32% of Pacific children with intellectual disability live in social housing
- Adults with intellectual disability are 3.41 times more likely to live in social housing
- Children with intellectual disability are 1.91 times more likely, and adults with intellectual disability 3.63 times more likely, to be on the social housing waiting list (Beltran-Castillon & McLeod, Forthcoming)

While the strategy rightly focuses on accessibility, this alone does not address the broader housing issues for people with intellectual disability, which include the ability to live where and with whom they want and living in housing that is safe, dry, and uncrowded.

1.7 Justice

People with intellectual disability experience significant overrepresentation in justice and child protection systems:

- Children with intellectual disability are 2.14 times more likely to be victims of crime; adults with intellectual disability 1.65 times
- Children with intellectual disability are 1.46 times more likely to be exposed to family violence
- Children with intellectual disability are 6.7 times more likely to be placed in state care; parents with intellectual disability are 16.34 times more likely, and women with intellectual disability 20.32 times more likely, to lose care of their child
- People with intellectual disability are 1.68 times more likely to be convicted of a crime; 3.38 times more likely to be imprisoned (Beltran-Castillon & McLeod, Forthcoming)

The strategy acknowledges general justice concerns but fails to specifically address the rights and overrepresentation of parents with intellectual disability, who experience extreme inequities in child removal.

1.8 Measuring Progress

The selected indicators should have been included in the consultation, as they are essential for tracking real change. Without clear indicators, it is impossible to assess whether outcomes for people with intellectual disability are improving.

1.9 Inclusion of People with intellectual disability

In developing this strategy, Whaikaha and the Government face a challenge in addressing the issues experienced by all disabled people in New Zealand and reflecting the diverse experience of groups in that population, such as people with intellectual disabilities. IHC is concerned and have evidenced in this response that people with intellectual disability experience outcomes significantly worse than the 1 million plus New Zealanders covered by this strategy. No strategy can be successful for people with intellectual disability if it is not honest about this gap and the implications.

Given the perilous state of outcomes for people with intellectual disability and threats to their rights, relative of other disabled people, we recommend Whaikaha consider how those specific issues can be highlighted. Options include a specific profile of issues for people with intellectual disability within the strategy and direct actions to address those issues, or a commitment to develop a strategy and action plan following that is specific to people with intellectual disability.

We also note the barriers that people with intellectual disability face every day in society have also prevented them from fully participating in this process. It is important that their voice is heard and reflected in all aspects of the strategy, and we encourage you continue talking to people with intellectual disability to ensure that is the case.

2. References

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