



Submission to the Productivity Commission about an inquiry into A Fair Chance for All: breaking the disadvantage cycle

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Trish Grant
Director of Advocacy
IHC New Zealand Inc
PO Box 4155
Wellington**

Tel: 04 495 2773

1. Key points and recommendations

IHC recommends that the government focus on

- 1.1. Monitoring the well-being of intellectually disabled people in all facets of life in a similar way to how government monitors gender and ethnicity groups. The Livings Standard Framework and the Child and Youth Wellbeing Strategy both are light on disability. This monitoring also needs to separate the outcomes of intellectually disabled people from the general disability group as the life course and outcomes for intellectually disabled people are very different.
- 1.2. Providing 'joined up' services where people are funded to be supported in the way they are entitled. System delivery across health, education and welfare are fragmented, confusing, and inefficient. Disabled people and their families have lobbied for an across government, joined up response to their circumstances. Disabled people stay in bad situations, with poor providers or at ableist schools, because switching is complicated and can mean losing funding or applying for new funding. Government funding should also reflect and be linked to reality, the 'situation on the ground'. The government needs to use greater effort to determine what disabled people need to ensure equitable access to government systems, how many disabled people there are, how they can best be supported, and what effective and person centred support would look like. For example, current funding available for disabled students at school is not linked to data about the prevalence of disability and does not provide what disabled students need to attend a full school week or access the curriculum. The funding that intellectually disabled people receive in residential care is also out of touch with reality. The personal allowance that intellectually disabled people in residential care receive is \$67 a week. No one should be expected to buy all their toiletries, clothes, and activity costs etc on \$67 a week.
- 1.3. Listening to disabled people and their families and adopting genuine co-design approaches to policy development. The government must make a greater effort to reach out to groups they would not usually

consult. They need to talk to disabled people who are non-verbal and their families, disabled people with high and complex needs, and disabled people in rural and remote areas.

- 1.4. Creating and implementing systems for disabled people and their families to have government decisions reviewed, and complaints finalised that are free, quick, and just. To help with this, the government needs to make free advocacy services available in all regions in New Zealand.

2. About IHC

IHC advocates for the rights, inclusion and welfare of all intellectually disabled people 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 intellectually disabled children. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare, and inclusion of all intellectually disabled people throughout their lives.

We believe that intellectually disabled people have the right 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 intellectually disabled people and their families. IHC supports 1500 families with intellectually disabled children, provides support and training for 4000 adults in workplaces and helps more than 3500 intellectually disabled people 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.

3. What aspects of disadvantage should this inquiry focus on?

Thank you for the opportunity to have input into the Terms of Reference for the Fair Chance for All inquiry into the drivers of persistent disadvantage.

IHC strongly recommend that you devote a significant part of your inquiry to discussing the wellbeing and lives of intellectually disabled New Zealanders. If you want to increase the life quality of all New Zealanders, we think you should look at the people that our society devalues and discriminates against the most. We think it is this group of New Zealand citizens.

Intellectually disabled people get the least of a “fair go” in New Zealand. If we can get the settings and support right for intellectually disabled people, then we will have them right for all groups.

4. Points of interest in the consultation document

Your consultation document discusses the four aspects of mana that people need to thrive. Firstly, that people have power, authority, or agency.

Intellectually disabled people have the least power, authority, or agency of any group of people in New Zealand. When people talk about having agency, they are most likely talking about having agency to pursue major things in their lives, careers, house purchase, having a family.

Intellectually disabled New Zealanders, when they talk about agency, are often talking about being able to choose what they want for dinner, when they go to bed, what television programme to watch. They frequently have very little agency in their lives and there has been little effort from previous governments to work to change this such as changing laws that put in place substitute decision-makers in people’s lives.

When you talk about having a strong sense of identity and belonging, we urge you to think about whether intellectually disabled people feel like they belong in New Zealand given that they are not visible (minimal disaggregated data available) in existing data sets.

Intellectually disabled New Zealanders are constantly segregated, in special schools, and group homes. They are routinely suspended, stood down, expelled from school due to behaviours that are a part of their disability. It is not unusual for disabled students to spend years out of the schooling system and it is common for them to leave school having been taught very little with experiences of having been discriminated against, secluded, and restrained. They are certainly not prepared to enter the workforce and very few do. They experience a high level of bullying, and isolation.

Intellectually disabled people in New Zealand are constantly thwarted and prevented from deciding on their aspirations and achieving them. In some cases, they are legally prevented, such as when placed under a welfare guardian as prescribed by the Protection of Personal and Property Rights Act, and in everyday life, by the reluctance of government and society to implement processes that enable supported decision making.

And finally, intellectually disabled people are not able to grow their prosperity, as they are usually not able to access an inclusive education and then are not supported to take up employment, additional training or education once they leave school and have no appropriate, accessible transition to career pathways available for them.

It is safe to say that in New Zealand, intellectually disabled people are, overall, not thriving.

In your scoping document you mention a few areas that I think are of particular interest to intellectually disabled people:

4.1 Quality housing – Lifemark has estimated that about 2 percent of the existing housing stock is accessible for disabled people.¹

4.2 Transport –intellectually disabled people who live in residential care lose about \$43 a week from their benefit as their residential service provider is contracted to provide them transport so they can participate in their community and follow their interests and strengths. There is very little oversight from government as to whether providers are supplying the transport they are funded to provide.

Intellectually disabled people in residential care are restricted to a personal allowance of \$67 a week. This \$67 is meant for all toiletries and whatever they need. If they need a new warm jersey, they will have to save up for a while. They have not received two recent increases to their core benefit that their peers in other settings have received. IHC believes this situation is unfair and discriminatory

4.3 Healthcare - Males with intellectual disability have an average life expectancy of 59.7 years, which is 18 years less than the life expectancy for all New Zealand males (78.4 years). Females with intellectual disability have an average life expectancy of 59.5 years, which is about 23 years less than the life expectancy for all New Zealand females (82.4 years).² This group has the shortest life expectancy of any group.

A high number of intellectually disabled people die from potentially treatable and preventable conditions. There has been no research in New Zealand, but recent Australian research has shown that intellectually disabled people are twice as likely to suffer a potentially avoidable death compared to the general population. The same study

¹ <https://www.stuff.co.nz/life-style/homed/real-estate/125303303/lack-of-accessible-housing-left-woman-showering-at-work-for-months>

² <https://www.health.govt.nz/publication/health-indicators-new-zealanders-intellectual-disability>

found that one in three deaths in intellectually disabled people was from a potentially avoidable cause.³

4.4 Education/Employment – IHC has been deeply worried about the education that disabled students receive for decades despite their legal right to be enrolled and attend on the same basis as other children and young people. Disabled students are not being provided the reasonable accommodations they need at school, they are being stood down and expelled at high numbers, they are forced out of the education system altogether and parents are giving up work to home school them. There was little government interest in fixing the system for disabled learners so IHC started legal action against the government in 2008. This case is ongoing, and our education system is still not accessible for disabled learners.

Research from the Ministry of Education in 2020 states that disabled students are between 1.5 and 3 times more likely than their non-disabled peers to be stood-down, suspended and frequently move school. Disabled students are half as likely to attain NCEA Level 3 as non-disabled students, and more than twice as likely to attain no qualification at school.⁴

The poor experiences and outcomes for disabled learners then reduce their ability to participate in the workforce. There are also very few effective transition services available for disabled students from school to the workforce.

This means that we end up with 48% of disabled youth not in employment, education, or training.⁵ This has devastating effects on disabled people as they grow up. They are more likely to live in poverty, and experience loneliness, live in damp houses. For further information about the lifelong consequences of this devaluing of disabled lives see the Disability Gap.⁶

This is just an outline of the isolation, dehumanisation, under investment, and discrimination that intellectually disabled people experience in New Zealand.

³ <https://www.abc.net.au/news/2017-02-08/study-finds-intellectually-disabled-two-times-preventable-death/8248772>

⁴ <https://www.educationcounts.govt.nz/publications/schooling/he-whakaaro-the-educational-experiences-of-disabled-learners>

⁵ <https://www.stats.govt.nz/information-releases/labour-market-statistics-disability-june-2020-quarter>

⁶ <https://www.stats.govt.nz/infographics/the-disability-gap-2018>

IHC hopes that you will focus on improving outcomes for this group in the inquiry. Good luck with your important work, we would love to be further involved.