

February 2018

## IHC Submission to the Committee on Economic, Social and Cultural Rights Fourth Periodic Report of New Zealand

### Introduction

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/whānau in New Zealand.<sup>1</sup>

Currently, in New Zealand, people with intellectual disabilities do not enjoy their economic, social and cultural rights on an equal basis with others. There are several reasons for the disparities in enjoyment of rights experienced by people with intellectual disabilities:

- There has been a lack of sustained political will and commitment to progressing the rights of people with disabilities, as evidenced by the serious lack of progress on Disability Action Plan<sup>2</sup> projects.
- Often people with intellectual disability are not included in public policy initiatives, monitoring and reporting. Policy issues affecting people with intellectual disabilities, and responses to those issues, tend to be regarded as “disability issues” rather than being considered as work, health or education issues for people with intellectual disabilities.
- Work is needed to change attitudes towards and continue to grow respect for people with intellectual disabilities as contributing and valued citizens within New Zealand society.

New Zealand’s obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>3</sup> and the Sustainable Development Goals (SDGs) are also relevant to people with intellectual disability not being left behind in New Zealand. We ask that the UNCRPD and SDGs are factored into consideration of this submission.

In this submission we firstly comment on the lack of systems, procedures and supports by which people with intellectual disabilities can realise and enforce their rights. We also comment on changes to the Disability Support System<sup>4</sup> that are currently underway in New Zealand and the implications of these changes for the economic, social and cultural rights of people with intellectual disabilities. Finally, we offer specific comments on the realisation of the following rights for people with intellectual disabilities:

- Articles 6 and 7 – rights to work and to just and favourable conditions of work.
- Article 10 – protection and assistance to the family
- Article 11 - adequate standard of living
- Article 12 – health
- Article 13 – education.

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<sup>1</sup> Statistics New Zealand, *New Zealand Disability Survey 2013*

<sup>2</sup> Information about the Disability Action Plan is available here: <https://www.odi.govt.nz/nz-disability-strategy/disability-action-plan/>

<sup>3</sup> United Nations Committee on the Rights of Persons with Disabilities (2014). *Concluding observations on the initial report of New Zealand*. CRPD/NZL/CO/1 31 October 2014.

<sup>4</sup> More information on the Disability Support System transformation is available here: <https://www.odi.govt.nz/nz-disability-strategy/other-initiatives/transforming-the-disability-support-system/>

## **Mechanisms for realising the rights of persons with intellectual disabilities**

There are a number of shortcomings in the infrastructure for realising human rights within New Zealand. Concerns and recommendations of international treaty bodies are not widely shared or understood, including within the public service. This, coupled with a lack of data (especially disaggregated, impairment specific data) means analysis of the human rights implications of legislative and policy development and reform is often far from robust<sup>5</sup>.

For people with intellectual disabilities these issues are compounded by a lack of publically funded independent advocacy or clear pathways for claiming their rights or seeking redress when their rights are breached. Several examples of these systemic shortcomings are below.

### **Delays in process - IHC education complaint<sup>6</sup>**

IHC lodged a complaint under the Human Rights Act in 2008 based on the continual systemic, unjustified discrimination against students with disabilities requiring accommodations to learn. This claim is still to have a full hearing in the Human Rights Review Tribunal. Children who started school when the complaint was lodged are now in year 10. The length of time this case has taken underscores the maxim justice delayed is justice denied.

### **The Atkinson litigation<sup>7</sup> – “impenetrable” policy governing eligibility of family members for support services funding.**

This litigation stemmed from the Ministry of Health’s policy to refuse to pay spouses or resident family members for the provision of disability support services. The Court of Appeal found in *Atkinson* that this policy discriminated unlawfully on the basis of family status. In response the Government agreed to allow some funding for family members caring for adults with disabilities. However in the recent case of *Chamberlain v. Minister of Health*<sup>8</sup> the Court of Appeal described the complexity of the statutory instruments governing funding eligibility for disability support services as verging on the impenetrable. The Court ordered the Ministry of Health to reassess the level of support payments provided to a mother caring for her adult son and articulated a hope that the Ministry is able to find an effective means of streamlining the funding regime, thereby rendering it accessible for the people who need it the most and those who care for them<sup>9</sup>.

### **Adoption legislation**

After two years of deliberation, in 2016 the Human Rights Review Tribunal found that New Zealand’s adoption laws, which date back to 1955, discriminate on a number of grounds including disability. Section 8(1)(b) of the Adoption Act 1955 states that the Family Court can dispense with the consent of a parent or guardian of a child to the adoption of his or her child, if satisfied that he or she is unfit to have the care of the child by reason of any physical or mental incapacity. The Government’s response to the decision by saying it was satisfied that, in practice, the provisions of the Adoption Act are interpreted in a rights consistent manner<sup>10</sup>. The response did not expressly address the issue of discrimination on the basis of disability. As well as demonstrating the shortcomings in the procedures available to people with intellectual disabilities when their rights are breached (time delay, enforceability of decision) this case also calls into question whether Government is meeting its obligations under articles 2 and 10 of the present Covenant.

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<sup>5</sup> Data collection and analysis must be done in accordance with individual’s civil and political rights, including those to privacy.

<sup>6</sup> More information about this complaint is available on the IHC website <https://ihc.org.nz/ihcs-education-complaint>

<sup>7</sup> *Atkinson v Ministry of Health* [2010] NZHRR 1, (2010) 8 HRNZ 902; aff’d (2010) 9 HRNZ 47 (HC) and [2012] NZCA 184, [2012] 3 NZLR 456.

<sup>8</sup> *Chamberlain v. Minister of Health* [2018] NZCA 8 [7 February 2018]

<sup>9</sup> *Ibid*, postscript.

<sup>10</sup> <http://www.justice.govt.nz/assets/Documents/Publications/govt-response-declarations-inconsistency-hrrt.pdf>

## **Article 2 – realising the economic, social and cultural rights of people with intellectual disabilities**

*“We still expect people with disabilities and their families to navigate a maze of services, which are often incoherent and unfair.”* 2017 IHC Survey respondent<sup>11</sup>

IHC submits that too often people with intellectual disabilities and their families are left behind in having equitable access to and benefits from government policies and initiatives.

### *Transformation of the disability support system*

Work underway to transform disability support systems holds the potential for a more effective and respectful way of working for better outcomes for people with intellectual disability. However, at this stage only the high level design has been completed and the operational detail is still not known. There are many unanswered questions about how to get the right balance of increased self-direction and flexibility for people with intellectual disabilities and their families, sustainability for service providers and fair conditions for the disability support workforce. An integrated, across government approach is needed to make the transformation work and ensure people with intellectual disabilities get the supports they need to realise their rights.

Community organisations providing disability supports have been struggling to meet increased demands for services in the face of chronic underfunding. Services have had to do more with less. In addition the gap in coverage of the pay equity settlement is causing significant funding difficulties for providers. The combined effect of these factors has led to an estimated 12-15% gap between actual costs for services and the funding provided in government contracts<sup>12</sup>.

In addition to the transformation of the disability support system it is important improvements are made to other government systems, particularly the education, health, welfare, care and protection and justice systems, so that they are inclusive and provide the reasonable accommodations necessary to meet the rights and needs of people with intellectual disability in accordance with the government’s obligations under the UNCRPD.

### *Equal recognition before the law*

While human rights are indivisible and interdependent, the realisation of UNCRPD Article 12, which provides for equal recognition before the law and personal agency, is critical to the realisation of all rights in the lives of people with intellectual disability. New Zealand still has a way to go to shift from substitute to supported decision making to ensure that the preferences of individuals with intellectual disabilities are heard and responded to. The legislative framework, particularly under the Protection of Personal and Property Rights Act 1988, needs review to ensure New Zealand is meeting UNCRPD standards around supported decision-making.

Another longstanding issue is the quality of support, compromised wellbeing, and breaches of rights for people with intellectual disability detained subject to the Intellectual Disability Compulsory Care and Rehabilitation Act 2003 and/or the Mental Health (Compulsory Assessment and Treatment) Act 1992. A small but overlooked group in State care are those young people held under the provisions of the Intellectual Disability Compulsory Care and Rehabilitation Act 2003 (IDCC&R). Their care is managed by disability providers under contract with the Ministry of Health. Unlike care under Oranga Tamariki – Ministry for Children (Oranga Tamariki) there are no obligations in those

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<sup>11</sup> In 2017 IHC conducted a survey on how New Zealand is doing for people with intellectual disabilities. More information is available here: <https://ihc.org.nz/survey>

<sup>12</sup> New Zealand Disability Support Network, *Briefing to Incoming Ministers: Achieving transformation, inclusion and citizenship*. November 2017.

contracts to ensure education and health rights are recognised or responded to or family connections maintained.

### *Violence*

People with intellectual disabilities in New Zealand are more likely to be abused and experience violence: disabled children are three times more likely than non-disabled children to be abused or neglected and these rates are even higher for children with communication impairments, behaviour difficulties, intellectual disability and sensory disabilities<sup>13</sup>; Women with disabilities are more likely to experience violence than both men with disabilities and women in the general population; Fifteen percent of those aged under 16, and 19 per cent of those aged under 28, receiving Disability Support Services have reported being abused or neglected<sup>14</sup>; Bullying is a frequently expressed concern and recognised issue.<sup>15</sup>

### **IHC recommends the New Zealand government:**

1. Consider the wellbeing and rights of people with intellectual disabilities and their families in the review of the social investment approach.
2. Count, make visible and include people with intellectual disabilities and their families in government strategies and new initiatives from the start, and monitor and report to ensure people with disabilities and their families have equal access to and are experiencing improved outcomes.
3. Ensure the transformation of the disability support system institutes commissioning and funding practices that safeguard human rights and wellbeing.
4. Adequately resource the new disability support system design, provide sufficient purchasing power in personal budgets and establish an independent process for reviewing funding decisions.
5. Provide information, support and funded advocacy so individuals and families can self-direct and manage personal budgets under the disability support system
6. Ensure people with intellectual disability have the supports needed for decision making and access to independent advocacy. This includes children and young people with intellectual disability under Oranga Tamariki having the supports they need to form and express their views at all levels of decision-making including when going into State care, while in care and when transitioning from care.
7. Fully fund the implementation of the pay equity legislation and develop a workforce strategy based on a sector wide consensus about how the tensions between flexibility and security of employment can be reconciled.
8. Clarify the interface between Oranga Tamariki and other government agencies, especially the education, health and disability systems, so it clear which agency is responsible for what aspect of State support to children and young people with intellectual disabilities and their families.
9. Put in place measures to identify people with intellectual disabilities at the start of any police or legal proceedings and to provide them with the support they need and to make any accommodations necessary to ensure equal access to justice.

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<sup>13</sup> Sally Robinson (2012). *Enabling and protecting: Proactive approaches to addressing abuse and neglect of children and young people with disability*. Issues paper, Children with Disability Australia; Sally Robinson, and Julia Truscott, Julia (2014). *Belonging and connection of school students with disability*. Issues paper, Children with Disability Australia.

<sup>14</sup> Ministry of Health, *Characteristics of Disability Support Service (DSS) recipients*. Minister of Disability Issues Forum, December 2016.

<sup>15</sup> <https://www.bullyingfree.nz/about-bullying/students-with-disabilities/#resources>

10. Ensure all judges, lawyers, and other court officials, police and prison and forensic mental health staff have initial and on-going training in working with people with intellectual disabilities.
11. Undertake a comprehensive review of the IDDC&R Act and associated practice to assess its fitness for purpose, particularly whether;
  - rehabilitation services are available and provided to people and are helping to achieve planned outcomes
  - orders under the Act are for appropriate lengths of time and not extended unduly
  - it is appropriate for those under 18 to be covered by the Act, or whether their rights would be better met by Oranga Tamariki.
12. Track and report on the application of the Protection of Personal and Property Rights (PPP&R) Act including.
  - The numbers of people with intellectual disability who have orders, reasons for orders and trends over time; and
  - The alignment of the intent and application of the Act with the UNCRPD.
13. Establish clear pathways and support for people with intellectual disabilities to realise their rights and seek redress for breaches of their rights by mandating roles and functions similar to those of the Australian State of Victoria’s Office of the Public Advocate<sup>16</sup>.
14. Make domestic and sexual violence protections and responses accessible and workable for people with intellectual disabilities
15. Put processes in place so that legislation, policy and practices are guided by and comply with the UNCRPD.
16. Address the United Nations Committee on the Rights of the Child 2016 recommendations on children with disabilities<sup>17</sup>.
17. Resource the Human Rights Review Tribunal to enable it to consider and make findings on potential discrimination in a timely manner.
18. Ensure the findings of the inquiry into the abuse of children in state care be used to inform ongoing practice improvements for children in care with intellectual disability.

### Articles 6 and 7 – Right to decent work

*“I’ve worked there for six years but still haven’t been offered a paid job. Mum and dad have tried but my employer came up with silly excuses. I’d like to get a paid job.”* 2017 IHC survey respondent<sup>18</sup>

People with intellectual disability want jobs and equal opportunities for the meaningful participation in society that work brings. However people with intellectual disabilities today in New Zealand have a significantly lower rate of participation in the workforce than both the general working age population, 69.3 per cent, and working age people who identify as disabled, 22.4 per cent. Young people with disabilities aged 15-24 are four times more likely than their non-disabled peers to not be in employment, education or training.<sup>19</sup>

Most adults with intellectual disabilities are life-long beneficiaries. People with intellectual disabilities have a significantly lower rate of participation in the workforce than both the general working age population (69.3%) and disabled working age population, 22.4 per cent<sup>20</sup>. Only 10 per cent of Ministry of Health Disability Support Services funded clients are in paid work.

<sup>16</sup> <http://www.publicadvocate.vic.gov.au/>

<sup>17</sup> UN Committee on the Rights of the Child (CRC) *UN Committee on the Rights of the Child: Concluding observations, New Zealand* 21 October 2016, CRC/C/NZL/CO/5 at para 30

<sup>18</sup> Above, n11

<sup>19</sup> New Zealand Household Labour Force Survey 2017 – June quarter

<sup>20</sup> Ibid

Community participation services are not fully funded by government. The New Disability Support Network (NZDSN) estimates these services only receive 50 per cent of the funding actually required to meet costs<sup>21</sup>. The result is services increasingly capping the numbers of people they can support and there are large parts of the country where services have wait lists and/or where no services are available. There are also concerns that the Ministry of Social Development's (MSD) payment for outcomes contracts for employment services may disadvantage those with more significant barriers to employment and those seeking part-time work.

#### **IHC recommends the New Zealand Government:**

19. Include students with intellectual disabilities with their non-disabled peers in the government's re-development of a comprehensive system of careers advice and guidance alongside early access to transition planning and work experience.
20. Include people with disabilities in the government's employment initiatives and have equal access to supports for employment.
21. Evaluate MSD's new employment services contracts with specific reference to access and outcomes for people with intellectual disabilities and sustainability for employment service providers.
22. Fully fund community participation services and ensure adequate support is available in individual budgets to enable people with intellectual disability to participate and contribute to their communities.
23. Continue the collaborative work begun by the Disability Employment Forum, Business NZ and government agencies to increase employment participation and employer confidence in employing people with disabilities.
24. Lead the way by employing people with intellectual disability in the public services.
25. Collect and report data on participation rates, type and hours of work and pay for people with intellectual disability

#### **Article 10 – Right to family protection and assistance**

*"If you are from a wealthy family – and/or a family with high cultural capital things may go well but that is a matter of happen-chance and many are left behind."* 2017 IHC Survey respondent<sup>22</sup>

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<sup>23</sup>
- 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.

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.

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

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<sup>21</sup> New Zealand Disability Support Network, *Briefing to Incoming Ministers: Achieving transformation, inclusion and citizenship*. November 2017.

<sup>22</sup> Above, n11

<sup>23</sup> Statistics New Zealand, *New Zealand Disability Survey 2013*

overlooked or left behind in policy responses to these broader societal issues. 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>24</sup>*

#### **IHC recommends the New Zealand government:**

26. Include 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.
27. In accordance with the Court of Appeal’s comments in the Chamberlain case<sup>25</sup> streamline the family carer’s funding regime so it is accessible to those caring for adult family members.

#### **Article 11 – right to an adequate standard of living**

*“We are pretty much living day to day on the ‘breadline’ no money for house maintenance so house in very poor condition, no money for outings, holidays, entertainment – a pretty meagre existence for both of us.”* 2017 IHC survey respondent<sup>26</sup>

People with intellectual disabilities today in New Zealand are more likely to live in poverty and have low incomes. The majority of people with intellectual disabilities are life-long beneficiaries and in 2013, disabled people, aged 15 to 64 were 1.8 times more likely to live in households that earn under \$30,000 a year.<sup>27</sup>

Many people with intellectual disabilities and their families/whānau struggle to have enough money for an adequate standard of living and a good life – for food, clothing, paying the bills, getting out and about and paying for additional disability costs.

In 2016, the United Nations Committee on the Rights of the Child recommended particular attention be paid to children with disabilities living in poverty to combat marginalisation and discrimination in their access to health, education, care and protection services.<sup>28</sup>

#### **IHC recommends the New Zealand government:**

28. Count and make people with intellectual disabilities visible in all government initiatives and reporting on increasing incomes, reducing poverty, and improving wellbeing.
29. Change the culture and practices in Work and Income so that all people with intellectual disabilities are treated with respect and receive all the assistance to which they are entitled
30. Ensure back to work requirements are fair for families with a child with intellectual disabilities and they are not subject to sanctions
31. Establish an independent panel to review Work and Income decisions.
32. Increase the Supported Living payment with regular adjustments to meet cost of living increases.

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<sup>24</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>

<sup>25</sup> Above, n8

<sup>26</sup> Above, n11

<sup>27</sup> Above, n20

<sup>28</sup> UN Committee on the Rights of the Child (CRC) *UN Committee on the Rights of the Child: Concluding observations, New Zealand* 21 October 2016, CRC/C/NZL/CO/5

33. Raise abatement rates on benefits so people can earn more while still having the security of the Supported Living payment.
34. Ensure people with intellectual disabilities benefit equally from the planned rise in minimum wages and taking steps to avoid any unintended consequences of raising Minimum Wage Exemptions.
35. Ensure individual budgets in the new MOH disability support system design have sufficient purchasing power to meet support needs.
36. Ensure people with intellectual disabilities and their families are able to access and benefit from innovative home ownership models and affordable and accessible social housing.
37. Introduce a Kiwi Able card and/or (Super) Gold card equivalent and companion cards to reduce transport costs for people with an intellectual disability

## **Article 12 – Right to Physical and Mental Health**

*“When I first got diagnosed with depression, my support worker and GP were arguing over whether I should be on anti-depressants. Nobody asked me what I wanted.”* 2017 IHC survey respondent<sup>29</sup>

In New Zealand 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>30</sup> Men and women with intellectual disability live, respectively, 18 and 23 years fewer than the general population. Compared to the general population people with intellectual disabilities have higher rates of: potential preventable deaths; mental health conditions; polypharmacy; and aging and age related problems occurring earlier. People with intellectual disability are less likely to be included in public health initiatives and routine screening such as women having mammograms and pap smears. Too often health issues, including mental health issues, are either under recognised or inadequately managed. People with high and complex health needs find it hard to get the specialist care needed when they move from paediatric to adult services. Disadvantage is compounded when discrimination is experienced and if people are members of already marginalised groups such as those living in poverty.

Despite these facts having been known for years and despite recommendations from the UNCRPD Committee<sup>31</sup>, and the previous recommendation of this Committee<sup>32</sup> that New Zealand ensure that its primary health system is adequately equipped to provide care to persons with intellectual disabilities, there has been little real action to address the decades of indifference and systemic neglect of the health of people with intellectual disabilities.

There are a number of bio-ethical issues affecting people with intellectual disability, including prenatal screening, sterilisation, growth attenuation therapy and assisted dying.<sup>33</sup>

### **IHC recommends the New Zealand government:**

38. By September 2018, set timeframes to implement Action 9C under the Disability Action Plan (increased access to health services and improve health outcomes for disabled people with a specific focus on people with learning/intellectual disabilities), including the introduction of a free annual health check for people with intellectual disabilities.

<sup>29</sup> Above, n11

<sup>30</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.

<sup>31</sup> Above, n2, at para 38.

<sup>32</sup> Committee on Economic, Social and Cultural Rights *Concluding observations on New Zealand*, 31 May 2012. E/C.12/NZL/CO/3 at para 13.

<sup>33</sup> The End of Life Choice Bill is being considered by Parliament, and has significant implications for people with intellectual disability <http://www.legislation.govt.nz/bill/member/2017/0269/latest/DLM7285905.html>



39. Explicitly include people with intellectual disabilities in all government health strategies and initiatives, such as: the Government’s signalled 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; and ensuring every New Zealander has a warm, dry, secure home, whether they rent or own.
40. Include a specific focus on access to and quality of mental services for people with intellectual disabilities in the Mental Health Inquiry, and re-established Mental Health Commission.
41. Respond to the UNCRPD concern about the sterilisation of children and adults with disabilities<sup>34</sup>.
42. Take the voices of, and issues for, people with intellectual disabilities into account in discussions on bioethical issues, especially ante natal screening, medically assisted dying, and the End of Life Choice Bill.
43. Gather and record accurate health information for people with intellectual disabilities on demographic data sets and on individual records.
44. Establish a national cause of death register for people with intellectual disabilities and ensure accurate information is recorded on death certificates and using the information to improve health care and data on health outcomes.

### **Article 13 – Right to Education**

*“Unless you are lucky enough to find a supportive school, education in NZ is discriminatory to children with intellectual disabilities.” 2017 IHC survey respondent<sup>35</sup>*

Students with intellectual disabilities have the legal right to enrol and receive an education and this is critical to their wellbeing and life outcomes, including their right to work. However, 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.

Children and young people with intellectual disabilities in New Zealand continue to experience significant barriers to inclusive education. These include barriers to enrolment, accessing the curriculum and required resourcing. Initial teacher education and ongoing professional development in inclusive practice remains a problem.

In addition there are long delays for students to access early intervention and specialist services including communication and behaviour support.

The current learning support resourcing framework is flawed and not informed by prevalence data creating problems for students and schools. Despite over thirty years of special education policy development and review it is unknown how many children and young people with disabilities are enrolled, where they go to school or the type, extent and true cost of the supports they need to learn.

Students with disabilities do not enjoy an enforceable right to education and have no access to an independent review of decisions made. New Zealand’s failure to provide inclusive education has lifelong impacts for people with intellectual disability, limiting their opportunities to be contributing citizens including through work. (Please see our comments and recommendations on Article 6 and 7 above)

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<sup>34</sup> Above, n27

<sup>35</sup> Above, n11

**IHC recommends the New Zealand government:**

45. Properly resource disabled students and schools under the learning support system
46. Collect accurate prevalence data on students requiring additional supports to learn and using that data and actual accommodation costs to inform education policies, resource frameworks, plans and programmes.
47. Review the Ongoing Resourcing Scheme, the verification process, criteria and benchmarks.
48. Ensure students with disabilities and schools have timely access to specialist support services (communication, behaviour and other specialists).
49. Ensure initial teacher education programmes and professional learning and development results in all teachers being confident in teaching all learners.
50. Take steps to ensure the progress and learning achievement of all students, including those working long term within NCEA level one, is recognised, valued, monitored and reported on.
51. Make 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.
52. Require 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.
53. Change the law so that school disciplinary policies and processes are not to be used to respond to student disability related behaviours.
54. Establish a quasi-judicial education tribunal or arbitration mechanism.
55. Make people with intellectual disability visible and counting them in reporting on participation in tertiary education.
56. Make sure that people with intellectual disability benefit equally from three years free tertiary.

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## **Appendix 1: Some facts about people with intellectual disabilities in New Zealand.**

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>36</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 Services,<sup>37</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>36</sup> Statistics New Zealand, *New Zealand Disability Survey 2013*

<sup>37</sup> Ministry of Health, *Demographic report on clients allocated Ministry of Health's Disability Support Services as at September 2016* – released July 2017.