

# Valuing All:

Leave no one behind





## Introduction

IHC's 2017 Valuing All: Leave no one behind report tracks progress on making rights real in the lives of people with intellectual disabilities<sup>1</sup>. Is New Zealand making progress in the right direction? Are rights being protected? Across the lifespan are people with intellectual disabilities and their families/whānau achieving equitable access to and outcomes from universal and disability policy, services and new initiatives? Ensuring everybody is valued means ensuring everybody is counted. This report provides a baseline to identify indicators and track progress, achievements and shortfalls in the areas of: being included; home, family and community life; education, health, work, money; being heard and making decisions; and fair systems.

The title of this report “Valuing all: Leave no one behind” describes IHC’s ongoing commitment to monitor the rights, interests and wellbeing of people with intellectual disabilities and their families/whānau over the next five years while significant changes to education, social and disability policy are being implemented. This report evidences that people with intellectual disabilities have not experienced equitable

access to and outcomes from advances in government policy over the last decade. The United Nations Sustainable Development Goals (SDG’s), which New Zealand has signed up to, asks nations to ensure that marginalised groups are ‘not left behind’ in the progressive realisation of human rights. Clearly for people with intellectual disabilities in New Zealand the SDG’s have particular importance and resonance.

The previous government implemented a social investment approach that began with its welfare reforms. This introduced major changes to the commissioning and funding of social disability services. The new coalition government has signalled a review of the social investment approach.

The Disability Support System high level design<sup>2</sup> aims to implement the Enabling Good Lives (EGL) principles and integrate these with a social investment focus on individual and service outcomes and cost effectiveness. People with intellectual disabilities and their families/whānau should not be left behind in equitable access to and benefits from new initiatives and more responsive and coordinated ways of working.

1. We use ‘people with intellectual disabilities’ as the officially recognized term in New Zealand. We acknowledge ‘people with learning disability’ as the term used by People First New Zealand, Nga Tāngata Tuatahi.

2. Associate Minister of Health, Minister of Disability Issues, Cabinet paper - Disability Support System transformation: Proposed high level design and next steps, June 2017.

Nor should they be penalized by misguided notions of what quality support entails or inadequate resourcing that compromises the ability to live a good life in which rights are promoted, protected. Similarly this applies to the changes being implemented in the learning support system and its delivery.

Real and sustainable transformation requires genuine community engagement and sharing of information and decision-making otherwise we will get renamed versions of old ways of thinking and working that replicate past and current problems. While there is general agreement on the benefits of investing early, having better information and tracking outcomes, a more nuanced and broader understanding of what is meant by social investment is needed. There are some fundamental questions and tensions that have not been adequately addressed - who is in, who is out, who decides who is worthy of investing in, on what basis and who is counted?

In getting better evidence we need to consider are the right questions being asked of the right people, what does success look like and what are the signposts that indicate we are heading in the right direction to evaluate outcomes and the impact of policies across the short, medium and longer term. Responsiveness to diversity, cultural appropriateness and concerns about equity and human rights are all critical elements that need to be included to inform decision-making, monitor progress and evaluate the impact of policies and practices. Both quantitative and qualitative information is required in order to meaningfully understand the experiences of, and evaluate outcomes for, people with intellectual disabilities and their families/whānau.

The lack of data about people with disabilities has been a long-standing problem. The situation in having impairment specific information is even worse. More often than not people with intellectual disabilities are not counted or they are subsumed within the disabled population. Often evidence put forward does not get beyond anecdotal. Differing definitions and missing robust baseline data add to the difficulties in benchmarking against the general population and tracking progress for people with intellectual disabilities across different life stages and in key areas of life.

There has been a government commitment to getting more comprehensive and frequently available data sets for people in order to monitor change across a range of socioeconomic measures. The work of the Disability Data and Evidence Working Group to improve the quality of disability data has led to the inclusion of disability questions<sup>3</sup> in the New Zealand General Social Survey, the New Zealand Household Labour Force Survey and the 2018 Census.

There is, however, a long way to go in getting robust publicly available data that answers the enduring questions identified by the working group in ways that are able to provide impairment specific information. The next Disability Survey is not scheduled until after the 2023 census. Getting better evidence to inform policy and track progress for people with intellectual disabilities requires the collection and analysis of indicators such as is undertaken with the United States National Core Indicators for developmental disabilities.

For this report we had hoped to use the outcomes framework that was to be developed for monitoring the 2016-2026 New Zealand Disability Strategy as the basis for identifying and tracking progress on key indicators. However, it has yet to be finished so as a starter our first annual tracking report is a baseline of some of the areas that were identified in IHC's 2016 Making citizenship and rights real in the lives of people with intellectual disabilities report.

IHC asked the question "How is New Zealand doing for people with intellectual disabilities"<sup>4</sup> in an online survey and group discussions with people with intellectual disabilities to get a snapshot of how people rated progress in eight areas. More than 700 people participated in the online survey or focus groups<sup>5</sup> - 77 people with intellectual disabilities, more than 400 families/whānau and around a quarter of respondents who work in disability support services.

In this report we add our survey findings to information from official statistics, reports, surveys and research in the domains of being included; home, family and community life; education; health; work; money; being heard and decision making; and fair systems. In some areas where New Zealand information specific to people with intellectual disabilities is not available we have drawn from data on disabled people as a population group or referred to overseas research.

### Key Themes

- Across all areas of their lives people with intellectual disabilities tend not to be visible, counted or equally valued.
- People with intellectual disabilities continue to face unacceptable barriers and discrimination undermining both their quality of life and citizenship.
- The quality of people's lives depends on where they live, individual circumstances like wealth and connections and, too often, luck.
- Families/whānau feel worn down by the difficulties accessing support for their children and are worried a future where access to supports is even harder, when their child is an adult.

3. The Washington Group Short Set (WGSS) is recommended for use in censuses and general surveys.

4. IHC (2017) How is New Zealand Doing for People with Intellectual Disabilities? [www.ihc.org.nz/survey](http://www.ihc.org.nz/survey).

5. Note unless otherwise stated the quotes used in this report come from IHC's online survey and discussion groups.

- People with intellectual disabilities and their families/whānau often experience compounding disadvantage so that opportunities for a good life are limited in a multitude of ways.
- Government systems are not responsive enough to individual circumstances and do not deliver fairly. Although there are some promising signs, it is too early to assess whether all people with intellectual disabilities will benefit from the changes that are underway with the systems transformation.
- More and better impairment specific information is needed in order to inform planning and funding decisions and track progress in making rights real in the lives of people with intellectual disabilities and their families/whānau.



### Who is the population group of people with intellectual disabilities?

- There are 96,800 people with intellectual disabilities (2% of the population) in New Zealand. Children with intellectual disabilities 0-14 make up 5% of the children's population and adults with intellectual disabilities aged 15 – 44 making up 3% and those over 45 1% of the adult population<sup>6</sup>.
- There are more males living with intellectual disabilities. The pattern is the same for both children and adults.
- Māori and Pacific people have higher than average disability rates after adjusting for differences in ethnic population groups.
- Research<sup>7</sup> indicates that 20-30% of people with intellectual disabilities also have autism.
- People with intellectual disabilities are the largest group using Ministry of Health (MoH) Disability Support Service's<sup>8</sup> with around half identifying an intellectual disability as their primary disability. Many of this group also have a physical disability.

### Being included

**More respondents to IHC's 2017 online survey thought New Zealand is heading in the right direction for inclusion, being connected and participating in communities for children (43%) than for adults (38%). 38% think we are stuck and not getting this right for children and 42% for adults.**

"I think younger children are more included in communities. Adults become more isolated."

"There are very few groups that would officially say my disabled child is not welcome but also there are very few that actually cater for him, so he is still largely unable to participate in any meaningful way."

6. Statistics NZ 2013 New Zealand Disability Survey.

7. Eric Emerson and Susannah Baines, 2010 Improving health and lives: Learning disabilities observatory.

8. Ministry of Health, Demographic report on clients allocated Ministry of Health's Disability Support Services as at September 2016 – released July 2017.



“This is hard to answer as it will change community to community as well as family to family. For us we’re somewhere between still not getting it right and heading in the right direction.”

“True inclusion only occurs with a change of attitude in general society. Although people with intellectual disabilities are considerably more ‘accepted’ in their local communities than in the past there is still a long way to go.”

In the discussion groups people talked about enjoying spending time with family and friends. Participants took part in a range of community activities, many of which were organized for people with intellectual disabilities. Access to, and cost of, transport was an issue for some.

“It makes me feel good to be part of my community”

“I don’t feel a part of my community. I don’t do enough activities throughout the day as I’ve moved out of town so all the activities are too far away. I would like to be able to do some more sport and meet friends for coffee.”

### What’s happening?

Respect and responsiveness to diversity within inclusive and welcoming communities underpins many initiatives to create and sustain more accessible communities and are central

to the implementation and monitoring of the New Zealand Disability Strategy (NZDS), the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the EGL principles and new disability system design. For people with intellectual disabilities to be valued and counted with all they must also be included in general population surveys. The inclusion of disability in the New Zealand General Social Survey is a step in the right direction.

### What do we know about inclusion, connections and participating in communities for people with intellectual disabilities?

Where available most New Zealand information about disabled people is not disaggregated by impairment. A global review on raising awareness and combatting stigma that included New Zealand contributions described the overall view of intellectual disability in Oceania as one of “progression and inclusion”<sup>9</sup>. However, the review’s overall conclusion that intellectual disability mostly appears to be subsumed within disability, or is overlooked entirely applies to many situations in our country. From international research there is evidence<sup>10</sup> to suggest that contact with people with intellectual disabilities has an important role in changing attitudes and prejudice. Increased community participation appears to lead to more positive attitudes. Inclusive education is closely linked to the right to live and participate in communities.<sup>11</sup>

9. Katrina Scior et al (2015). Intellectual disabilities: Raising awareness and combating stigma.

10. Katrina Scior and Shirli Werner 2015 ‘Changing attitudes to learning disability: A review of the evidence.

11. United Nations Committee on the Rights of Persons with Disabilities General comment No.4 (2016) on the right to inclusive education 25 November 2016, CRPD/C/GC/4. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>



The majority of respondents in IHC's 2013 intellectual disabilities survey with a representative sample of 510 people aged over 18 found;

- Most felt a person with an intellectual disability would want to engage in conversations, sustain friendships, be friends with people without disabilities, have a loving relationship, and get married. Respondents suggested a diverse range of other things they thought those with intellectual disabilities might want to do with nearly half mentioning they would just like to 'do what everyone else does'.
- About a third felt it was unlikely people with intellectual disabilities would want to get married or vote and just under half thought they were unlikely to want to raise children.
- Greater acceptance, more services and support and better public education about the capabilities of people with intellectual disabilities are the main things people felt would improve the life of a person with an intellectual disability.
- The key reasons identified for people with intellectual disabilities to be discriminated against are society's tendency to pre-judge others or treat them with difference, a lack of understanding and education among the general population and not having the same opportunities available to them as others.

The 2013 Disability Survey and Statistics New Zealand estimated that disabled children were less likely, in the previous four weeks, than non-disabled children to have music, art, or similar lessons; played a team sport; done other physical activity such as swimming or gymnastics; visited friends; or been away on holiday in the last 12 months.

The 2016 NZ General Social Survey reported a similar sense of belonging as a New Zealander for both the disabled and non-disabled groups. For both groups face-to-face contact with families/whānau was similar, but the disabled group was less likely to have face-to-face contact with friends at least once a week and more likely to have felt lonely in the last four weeks some or most of time than nondisabled respondents. Disabled people were more likely to report being discriminated against.

An Australian survey<sup>12</sup> reported that young disabled adults aged between 15 and 29 years were more likely to experience social exclusion than their non-disabled peers. The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (TILDA)<sup>13</sup> shows how differences in smaller social networks and community involvement become more pronounced for older people with intellectual disabilities. As people with intellectual disabilities age they are generally single, without children or grandchildren, more reliant on siblings and family and had a decreased rate of engagement in social activities. This was even more so for people with severe and profound impairment and high support needs.

### IHC to track progress on government data and reporting

The New Zealand Disability Strategy Outcomes Framework and evaluation framework for the new disability support system report on wellbeing, social connectedness and inclusion for people with intellectual disabilities should cover:

- The same questions on belonging, social contact, connectedness and discrimination used in the New Zealand General Social Survey; and
- The enduring questions identified by the Disability Data and Evidence working group on attitudes, awareness, discrimination, accessibility and reasonable accommodations.

12. Emerson E., Honey A. & Llewellyn G. (2013) Left Behind: Monitoring the Social Inclusion of Young Australians with Self-Reported Long-Term Health Conditions, Impairments or Disabilities. Technical Report 1, 2013. Centre for Disability Research and Policy, University of Sydney.

13. Eilish Burke, Philip McCallion & Mary McCarron (September 2014), Advancing Years, Different Challenges: Wave 2 IDS-TILDA.

## Home, family and community life

***IHC's 2017 on-line survey asked whether people with intellectual disabilities and their families/whānau are able to live in ways that work for them, respect their culture and preferences and enable choice and control. Most respondents felt this wasn't the case. One respondent stated "the right to quality service is lacking". There was a difference between how respondents rated this area for children and adults. 42% thought that mostly New Zealand was heading in the right direction for children with intellectual disabilities and their families/whānau compared with 32% who gave this rating for adults.***

"Now that my daughter is an adult, it seems a lot of the support has dried up."

A number of survey comments highlighted the importance of good family/whānau connections and resources. Similar comments occurred in other areas including health, money and income. A number of respondents commented on the benefits of initiatives such as EGL and individualised funding and the promise of benefits reaching more people when a transformed system is rolled out nationally.

"If you are from a wealthy family and/or a family with high cultural capital things may go well but it is a matter of chance whether this happens and many are left behind."

"We seem to get bounced from specialist to specialist with nobody actually able to help us and give strategies to deal with challenges we face with daily life and the impact intellectual disability has on siblings and our family unit."

"There is too much responsibility and pressure put on families/whānau to work it all out. The government seems to be systematically withdrawing from taking responsibility for problems in the system."

"Yes, I think IF (individualised funding) really supports this."

"Still have the disconnect of it being my home but someone else's workspace. My home does not need exit signs, work rosters etc on the wall but a workspace does."

Most of those who took part in the discussion groups lived at home with parents. This is in part reflective of the largest numbers of participants being in the 20-29 age range. Almost all said they were happy with where they were living.

When asked if they were looking to move from their family home some people said yes.

"I'd like to move out one day in the future, somewhere close to friends and where it is easy to walk to the train station."

"My mum is looking at that for me. I said I want to take it nice and slowly."

### Where do people live and what DSS funded supports do they use<sup>14</sup>?

- Almost half of MOH DSS clients live in their own home or their family home.
- People with intellectual disabilities account for around 83% of people in community residential services. Most of those with very high needs live in residential care. People in residential services are predominately European/Other (77%) and Māori (15%) with people of Pacific and Asian ethnicities being under-represented.
- People with intellectual disabilities make up 68% of those using supported living services. The representation of people by ethnicity is similar to that for community residential services.
- Almost three-quarters of people accessing Choices in Community Living have an intellectual disability.
- People with intellectual disabilities make up 45% of those whose carers receive carer support payments.
- Half of those accessing Funded Family Care (FFC) have a family member with an intellectual disability.
- Nearly 40% of IF users have an intellectual disability and 17% identify autism as their primary disability.
- Of those accessing Enhanced Individualised Funding (EIF) in Bay of Plenty, 46% identified as having an intellectual disability.
- Over half of behaviour support services clients have intellectual disabilities while 40% have autism.
- Trends identified include a greater proportion of people with higher and more complex needs requiring higher levels of support and young people transitioning to residential services due to a lack of alternative support options.

14. Ministry of Health, Demographic report on clients allocated Ministry of Health's Disability Support Services 2014 - released 2016 and, 2016 - released 2017.

## What's happening?

Having greater choice, control and flexibility have long been called for and are core features of new approaches trialled in new model and EGL demonstrations and underpinning the transforming systems work. The Disability Action Plan 'Good Start in Life' work is developing policy options to improve government supports for family and whānau of disabled children aged 0-8 years.

## What do we know about home and family life for people with intellectual disabilities and their families/whānau?

The 'Good Start in Life' project has identified known issues including parents, family and whānau not being valued or having choice and control over supports and services for their child; variable access to timely services and supports depending on where families/whānau live, eligibility criteria and capacity issues; and a lack of consistency, coherence and integration in the support system. Ratings and comments on IHC's survey highlighted similar concerns.

Many of the same concerns identified in IHC's survey were raised in Disability Connect's 2017 survey and meeting with families<sup>15</sup>. Many families/whānau spoke about feeling exhausted and worn down. While there was the promise of better with EGL this wasn't available in Auckland. An overriding concern was that of what will happen to their disabled children when their parents are no longer around or able to care or advocate them. Poorly funded support results a greater reliance of disabled people on other family members<sup>16</sup>.

Family Funded Care was won through the actions of a group of parents winning a Human Rights Act complaint. There has, however, been a lower uptake of funded family care than anticipated. Auckland Disability Law (ADL) estimates that of the \$23 million per annum allocated by Treasury only a third has been used. The requirement that the employment responsibility be a neutral third party has created problems for families/whānau.

Evaluations<sup>17</sup> of new model components and EGL Christchurch and Waikato demonstrations have reported benefits for many participants from the increased choice, control and flexibility that have been offered.

While the synthesis of new model findings allows some analysis by impairment group (for example use of enhanced individualised funding) the EGL reports do not. In the EGL reports people are described by funding labels such as ORS and Very High Needs.



15. Colleen Brown 'Who will speak for her when I can't'. Radio New Zealand interview 29 June <http://www.radionz.co.nz/national/programmes/ninetoon/201849280/who-will-speak-for-her-when-i-can-t>; Disability Connect <http://disabilityconnect.org.nz/>.

16. Sam Murray, Age will weary funding models Otago Daily Times, 19 July 2017.

17. Mathea Roorda et al, Demonstrating changes to disability support: Evaluation Report, 7 April, 2015; Dianne Anderson et al, EGL Christchurch Demonstration: Phase two Evaluation report 2016; Louise Ware, Enabling Good Lives Waikato: Phase two evaluation summary report February 2017.

There are some indications in the evaluations of new model components and EGL demonstrations that not all participants benefit equally.

- Choices were more limited for those with high support needs as identified in an evaluation of Choices in Community Living where those requiring 24 hour care who were not able to share paid support with others were excluded.
- Those with limited resources as identified in the Christchurch EGL where some people from families/whānau who fell into this groups were identified as not gaining as much as those with more resources to draw on.
- Management of individualised funding was difficult for a number of disabled people and their families/whānau. Agents were not always easy to find and for some this meant they were unable to take up funding.

### IHC to track progress on government data and reporting

1. The New Zealand Disability Strategy Outcomes Framework, evaluation framework for the new disability support system and Ministry of Health data and reporting should include indicators for people with intellectual disabilities and their families/whānau that:
  - Demonstrate respect and responsiveness to preferences and culture and flexibility, choice and control in how supports are used.
  - Identify by living situation – community residential service, supported living, living with family and by funding used and by type and amount of funding used.
  - Include family and whānau wellbeing.
2. Disability is included in SuperU's Family Whānau Status report and that the subgroup of children with disabilities/developmental delay are identified and tracked in the Growing Up in New Zealand study.
3. Oranga Tamariki reports on numbers and outcomes for children and young people in state care/out of home placements.

## Education

**While 37% of respondents to IHC's online survey thought New Zealand is heading in the right direction in education for children with intellectual disabilities, 44% thought we are stuck and still not getting this right.**

New Zealand's education legislative and policy framework provides for education at the local school and in special education settings for children with disabilities. The vast majority of disabled children attend the local 'regular' school while a small number (3,266)<sup>18</sup> attend special schools, units or residential special schools. An inclusive education system requires the provision of support and reasonable accommodation and early intervention so that all learners, including learners with disabilities are able to fulfil their potential<sup>19</sup>. Families/whānau of children with intellectual disabilities continue to articulate problems with enrolment, accessing the curriculum, inadequate resourcing and specialist support and teachers lacking capacity in inclusive education. IHC's complaint of systemic, unjustified discrimination against students with disabilities requiring accommodations to learn lodged in 2008 is still to have a full hearing in the Human Rights Review Tribunal.

### What's happening?

New Zealand's education system is undergoing significant change with legislative and policy underpinnings intended to lift participation, progress and achievement, change the way schools work together, report and are funded. In 2015 the Ministry of Education reported that the system is complex to navigate, slow in providing support for children with additional learning needs, and has too many layers of process and bureaucracy. Gaps in information were identified including no nationally aggregated information about the progress and achievement of students with additional learning needs<sup>20</sup>. In order to assess the extent to which the right to inclusive education is being realised across the school sector, accurate and coordinated data gathering, reporting and monitoring is required<sup>21</sup>.

18. Based on student numbers as at 1 July 2016 from Education Counts Website: <https://www.educationcounts.govt.nz/statistics>.

19. United Nations Committee on the Rights of Persons with Disabilities General comment No.4 (2016) on the right to inclusive education 25 November 2016, CRPD/C/GC/4.

20. Ministry of Education. Learning Support update information.

21. Independent Monitoring Mechanism "Article 24 The Right to Inclusive Education" (June 2016).



## Do children with intellectual disabilities and their families/whānau have timely access to quality early childhood education, early intervention and child development services?

Of the 200,000 children in early childhood education, 22,000 are estimated to have a disability<sup>22</sup>. In 2015/16 15,000 children received an early intervention service provided by the Ministry of Education<sup>23</sup>.

“Many children who need extra support to engage in learning do not receive it due to the limited criteria. The implications are that some children who need the most educational support are missing out.<sup>24</sup>”

Despite increased early childhood education (ECE) attendance being a Ministry of Education targeted initiative and the 98% Public Service goal, participation rates for children with developmental delay/intellectual disability are not reported. The recently released Growing Up in NZ study ‘Now we are four’ report includes data on ECE participation rates and there is potential for further analysis of participation rates for the subsample of children with disabilities.

Recent reports and surveys<sup>25</sup> have identified a lack of timely access, unmet needs, increased complexity and demands, and inadequate support and resourcing.

## Are children with intellectual disabilities and their families/whānau welcomed into school communities?

“The only good thing about school was seeing my friends”

“Unless you are lucky enough to find a supportive school, education in New Zealand is discriminatory to children with intellectual disabilities”

Many disabled children and their families/whānau experience barriers to being included at school. IHC’s 2014 online education survey found that significant numbers of children with disabilities were denied enrolment, excluded from classroom and extra-curricular activities or and/or only attended for part of the day. Youthlaw reported similar experiences and barriers in their 2016 report<sup>26</sup>. The establishment of a disputes resolution service has the potential to reduce barriers of access and increase accountability although the resourcing of services is currently problematic.

Bullying is an issue for children with disabilities. Thirteen out of 14 young people in one of the group discussions associated with IHC’s 2017 online survey reported being bullied at school and the negative impact this had on them.

While MOE does not currently report on exclusions and suspensions by disability there is evidence that students with disabilities face discrimination and are over-represented<sup>27</sup>. In 2016 Youthlaw reported that they have seen a substantial increase in the number of cases dealing with students with special needs<sup>28</sup>.

## Do children and young people with intellectual disabilities have needed support, accommodations and services?

As at 25 August 2016 9,093 students (1.1%) were receiving individually targeted support from the Ongoing Resourcing Scheme (ORS)<sup>29</sup>. Just over half of these students are likely to have intellectual disabilities and a quarter autism<sup>30</sup>.

“If things were too hard I could get help to learn different things.”

“I found it hard at school, I had no support.”

A 2016 survey of Special Education Needs Coordinators (SENCOs) reported that the numbers of students requiring additional support has grown and far exceeds the one percent eligible for ORS funding. The survey found that on average 16% of students are listed on schools’ special needs registers and 89% of respondents considered that government support was inadequate.

## Do schools and teachers have needed resources, supports and training?

The 2016 New Zealand Principals’ Federation survey found that 57% of principals said they would benefit from additional resourcing, less than half considered they had the capacity to include all students with moderate to severe learning needs and only 16% agreed that ‘their school has the capacity to include all students with moderate to severe behaviour needs’<sup>31</sup>.

22. Statistics NZ 2013 New Zealand Disability Survey.

23. Ministry of Education. Learning Support update information.

24. New Zealand Kindergarten Special Education Working Group (SEWG) Success for every learner: report on special education survey May 2015.

25. Widdowson, D., Dixon, R., & Kushner, S. (2013 - 2015). Stocktake and Needs Analysis of Child Development Services in New Zealand- unpublished report; New Zealand Kindergartens Inc Special Education Working Group (SEWG) Success for every learner: report on special education survey May 2015 2015; NZEI Te Riu Roa Supporting diverse learners: Survey of special education needs co-ordinators (SENCO) 2016 .

26. Youth Law 2016, Challenging the barriers: Ensuring access to education for children with special education needs.

27. Independent Monitoring Mechanism on the Rights of Persons with Disabilities (2016) Article 24: The Right to an Inclusive Education June 2016;

28. Youthlaw (2016) Barriers to Education in New Zealand: The Rise of Informal Removals of Students in New Zealand.

29. Ministry of Education. Learning Support update information.

30. Based on information from the Ministry of Education in Response to request for Official Information by Youthlaw (2015).

31. New Zealand Principals’ Federation Ngā Tumuaki o Aotearoa Special Education Survey November 2016.

## Are students with intellectual disabilities counted and is progress on inclusive education adequately monitored?

Although government currently spends in excess of \$650 million on Learning Support per annum the Ministry of Education still does not know how many children and young people with disabilities are enrolled in our schools, where they go to school, or the type, extent and true cost of the supports they need to learn and participate in school life.

Students with disabilities continue to be invisible on key education sector indicators collected by MOE. The progress and achievement of children with intellectual disabilities is not currently monitored and reported on to Boards of Trustees and parents<sup>32</sup>. The Independent Monitoring Mechanism (IMM) of the Convention on the Rights of Persons with Disabilities noted in its 2014 report “without student’s learning being assessed educational outcomes for students with disabilities cannot be improved<sup>33</sup>.” In its June 2016 report the IMM noted the current lack of outcomes data and encouraged the development of a data strategy specifically designed to assess and monitor inclusive education practices and outcomes<sup>34</sup>.

**The majority (74%) of respondents to IHC’s 2017 online survey considered that New Zealand has not got it right for people with intellectual disabilities to participate in tertiary education, training and life-long learning. 53% of respondents thought that we are stuck and 21% that it is getting worse. Only 24% thought we are mostly heading in the right direction or getting this right.**

“The disparity of educational support when you are younger versus older is huge. It is like once young people reach 17 or so, supports drastically reduce.”

Students on community vocational and work skills courses spoken to as part of the IHC’s 2017 online survey talked positively about what they learnt on their courses and the support they got from their tutors but had variable experiences participating in mainstream courses.

“I left the (mainstream) course as it wasn’t a supportive learning course. People were really hard on me. I didn’t know what I was supposed to do.”

There is a lack of information about the participation of students with intellectual disabilities at the tertiary level. Changes in reporting required by the Tertiary Education Commission (TEC) for equity funding may result in more disability information being available.



## IHC to track progress on government data and reporting

1. Children and young people with intellectual disabilities are counted and visible in all reporting by schools, Ministry of Education, Education Review Office and New Zealand Qualifications Authority at, school and tertiary levels. Specifically data on:
  - student engagement (attendance and stand downs; suspensions and exclusions);
  - national standards; and
  - National Certificate of Educational Achievement (NCEA).
2. Participation rates of children with intellectual disabilities in early childhood education is collected and reported on.
3. Participation rates of young people with intellectual disabilities in tertiary education collected and reported.
4. Learning support delivery model effectiveness reported on measures of
  - increased family/whānau satisfaction with access to and quality of services provided,
  - increased teacher engagement with learning support services;

32. Ministry of Education. Learning Support update information.

33. Independent Monitoring Mechanism on the Convention on the Rights of Persons with Disabilities, Making Disability Rights Real (June 2014).

34. Independent Monitoring Mechanism on the Rights of Persons with Disabilities (2016) Article 24: The Right to an Inclusive Education June 2016.

- increased collaboration within the Communities of Learning (CoL) to demonstrate progress towards addressing learning support achievement challenges and comparison with schools who are not part of a CoL;
- increased rates of attendance and engagement amongst students accessing services or supports; and
- reduced waiting times to access learning support services.

## Health

***IHC's survey asked how New Zealand is doing for people with intellectual disabilities in being able to live well, stay well and get well. A higher percentage of respondents to IHC's 2017 online survey thought that New Zealand is mostly getting this right for children (46%) than for adults (36%). 37% of respondents considered that we are stuck and 20% that the situation is worse for adults in this area.***

Comments made in the on-line survey and in discussion groups reflected both positive and negative experiences, problems with transition from children's to adult services and for those with complex health needs and highlighted the importance of an educated health workforce able to work with people with intellectual disabilities.

"My doctor is good at explaining things."

"The doctor asks mum [about me], mum does all the talking."

"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."

"For those with high and complex needs in particular there is no clear service pathway and families struggle for support."

"The transition from paediatric to adult care is difficult."

"Support post 18 years of age is non-existent. Our adults need free dental and medical care and access to psychiatric services when needed."

"Often it is very dependent on family or caregivers as to whether the person gets proper healthcare or not."

"I've never had any problem obtaining health treatment for my daughter and I find the professionals are pretty good at dealing with her and listening to me on how best to communicate."

"There is a lack of education of healthcare professionals about how to care for individuals with intellectual disabilities."

## What do we know about the health of people with intellectual disabilities?

- It is well established that there are disparities in health outcomes for people with intellectual disabilities compared to the general population. On all indicators examined in the 2011 MOH report<sup>35</sup> people with intellectual disabilities were more disadvantaged, in terms of their health and life expectancy, compared to people without intellectual disabilities. Males with intellectual disabilities had an average life expectancy of more than 18 years below the life expectancy for all New Zealand males and females with intellectual disabilities had an average life expectancy almost 23 years below the life expectancy for all New Zealand females.
- One example of disparity recently highlighted is that of potentially preventable deaths. An Australian study<sup>36</sup> found higher rates of these deaths such as those from respiratory disease occurred for people with intellectual disabilities at over twice the rate of the general population. Similar rates are found in IDEA services with 17% of deaths caused by respiratory disease compared with 9.3% in the general population.
- In addition the Australian study found that many deaths were wrongly attributed to intellectual disability, masking the actual cause of death or the underlying health condition. For example, a cause of death being incorrectly recorded as Down syndrome when the cause was pneumonia. IHC confirms similar findings in the New Zealand context with death reports lacking accuracy.
- People with intellectual disabilities are more vulnerable to mental health conditions than the general population<sup>37</sup>. Around 30% of people with intellectual disabilities will have a mental health condition if behaviour disorders are included and 20% if behaviour disorders are excluded.

35. Ministry of Health 2011. Health Indicators for New Zealanders with Intellectual Disability.

36. Julian Trelor et al., 2017, Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open* 2017; 7 <http://bmjopen.bmj.com/content/7/2/e013489>.

37. Sally-Ann Cooper et al., 2007, Mental ill-health in adults with intellectual disabilities: Prevalence and associated factors. *British Journal of Psychiatry*, 190, no.1.



- It is recognized that ageing and age related health problems occur both earlier and more severely in people with intellectual disabilities. Some genetic conditions are associated with higher rates of significant health conditions with one of the most well-known being the high incidence of dementia in people with Down syndrome.

### What's happening?

Government recognition of the need for systemic change to improve the health of people with intellectual disabilities is evidenced in the current Disability Action Plan and the 2016 NZ Health Strategy. Alongside older people with intellectual disabilities being included in all areas of the updated Older Persons Health Strategy there are pertinent aspects in the focus areas of living well with long term conditions and supporting people with high and complex needs. There have been and continue to be health initiatives undertaken by community organisations including Special Olympics NZ's healthy athletes programme.

### What progress is being made on improving health outcomes for people with intellectual disabilities?

It is of serious concern that the Ministry of Health is yet to turn the recommendations of the Disability Action Plan reference group into a plan with timeframes in which the specified actions will occur. The continued systemic inaction severely compromises people's right to the highest obtainable standard of health without discrimination on the basis of disability.

Despite a high incidence of mental health conditions people with intellectual disabilities face difficulties in accessing needed mental health services. Added to and compounding the struggles faced is the high association of mental health problems with deprivation (as rated on deprivation indices). Getting better access to mental health services needs urgent attention. People with intellectual disabilities are among the most disadvantaged in a system that is neglected, under strain and under resourced<sup>38</sup>.

38. Marianne Elliot 2017, People's Mental Health report; Bill Rosenberg 2017, Working Paper on Health, 18 - Did the budget provide enough for health?

A positive achievement is that of Spectrum Care's project<sup>39</sup> reviewing how medicines are prescribed and managed for people in their residential services. While medicines are often an essential part of treatment plans, there are a myriad of risks associated with polypharmacy such as increased falls, adverse reactions and health costs. Spectrum Care worked with Auckland DHB pharmacists and other partners to review medications and develop transferrable guidelines for people in residential care that are consistent with pharmacy/use of medicines best practice.

### IHC to track progress on government data and reporting

1. Progress by the Ministry of Health on the Disability Action Plan and New Zealand Health Strategy actions to improve health outcomes for people with intellectual disabilities.
2. People with intellectual disabilities are counted and visible in all work and reporting by the Ministry of Health and District Health Boards with specific data on:
  - Progress and outcomes on the New Zealand Health Strategy and Health of Older People Strategy.
  - Participation in and outcomes from screening and public health programmes.
  - Numbers, waiting times and quality indicators for general and specialist health services.
  - Numbers of referrals, waiting times, services received and outcomes for mental health and behaviour support services.
  - Implementing Medicines New Zealand 2015 -2020 indicators for improved access to medicines and ensuring medicines use is safe, effective and of high quality achieving optimal outcomes.
3. Accurate health information is gathered and recorded for people with intellectual disabilities on demographic data sets and on individual records.

## Work

**50% of respondents to IHC's 2017 online survey thought we are stuck and not getting this right in having the right support so people with intellectual disabilities can contribute to their communities through paid and unpaid work. The next largest proportion thought the situation is getting worse – 26% for young people and 30% for adults. Less than 25% thought we were mostly getting this right or that we had got this right for young people and only 20% for adults with intellectual disabilities.**

“Finding a job for my son is difficult.”

“There needs to be a lot more invested in helping people find jobs.”

“I've filled in the forms (for help to find a job) but am still waiting to hear back.”

“There is very little on offer, it worries me greatly to think of my daughter getting to this stage of life.”

“We feel helpless and hopeless as far as work options are concerned.”

“There is little real work on offer for people and so they are stuck on low incomes and all that it means in terms of housing and living options.”

“There are certainly opportunities out there but there is limited resource. I think this could be a major area for development.”

Most focus group participants contributed to their communities through work in a number of ways including that of voluntary work. A few people had paid work with the most paid hours being 15 hours a week. Of those not in paid jobs many said that they would like paid work. A number had undertaken unpaid work experience but for most this had not resulted in a paid job.

“Work is better than being at home doing nothing.”

“I would like to work but is difficult to find.”

“I have worked there for 6 years but still haven't been offered a paid position. Mum and dad have tried but they (employer) came up with silly excuses. I'd like to get paid for my job.”

39. Judy Garroick and Adele Print, 2016, Polypharmacy Report prepared for Spectrum Care.

## What do we know about employment for people with intellectual disabilities?

- The 2013 New Zealand Disability Survey identified 45% of disabled people of working age are employed compared with 72% of the general population. New Zealand Household Labour Force data for the June 2017 quarter reports a labour force participation rate of 25.2 % for disabled people and 72.6% for the non-disabled group. The lower rate in the 2017 Labour Force survey is a result of the difference between the two surveys and the questions used to identify disability.
- In the 2017 New Zealand Labour Force Survey disabled young people aged 15-24 are four times more likely to not be in employment, education or training than non-disabled young people in the same age group.
- Evidence from countries where employment rates are reported by impairment shows that people with intellectual disabilities have among the lowest participation rates within the disabled population. From national labour force data, Inclusion Australia<sup>40</sup> reported that 32% of people with intellectual disabilities were in some form of paid work with 11% in open employment.
- United States data collected over 10 years<sup>41</sup> showed that employment rates for people with intellectual disabilities in paid jobs in open employment had not increased and remained at low levels. While we don't have equivalent data we expect the situation in New Zealand is much the same.
- 10% of MOH DSS clients in the working age range are in employment
- Most people with intellectual disabilities who have paid work are in part-time employment. Nearly three quarters of people in paid work who use IDEA Services are working less than 15 hours per week.
- An Altogether Autism project found that of the people surveyed 50% were unemployed. Of those who did have work, less than 10 percent were in fulltime employment and 10 percent had part-time work.

## What is happening?

There are a number of initiatives underway to increase employment rates for disabled people. Major changes are being introduced by the Ministry of Social Development in outcomes focused contracting and payments for employment services. NZDSN, Inclusive NZ and Platform are undertaking work to further develop indicators for service level intensity (SLI) and nationally consistent processes. A jointly led Disability Employment Forum and Business NZ project is working with other partners to build disability confident employers. A partnership between DPA, People First, NZDSN, Inclusive NZ and Platform Trust is putting together Employment Practice Guidelines that identify the best approaches for better employment outcomes. Inclusive NZ is undertaking an action research project to build the evidence base around the value and impact of employment, participation and inclusive services.

## What progress is being made?

Despite the increased attention for young people on education, training and work, young people with disabilities still face transition, further education and work pathways that are very different than those of their non-disabled peers. The continued lack of adequate transition planning and post school options are illustrated in a study undertaken for the charitable trust, Life Unlimited<sup>42</sup>. Parents reported the need for better planning for disabled young people, for this to start early and for it to be evaluated in Education Review Office (ERO) reviews. Parents said that they would like their sons and daughters to leave school at the same time as their non-disabled peers but many face limited or no post-school options for work, training or tertiary education, particularly those with higher support needs. These are the same experiences found in IHC's survey.

People with intellectual disabilities continue to say they want jobs but for many nothing happens to make this a reality. We don't have the same specific information for New Zealand but from what we know the situation would be similar to that reported in the latest United States NCI 2015/2016 employment information. 47% of those who did not have a paid community job in open employment wanted one yet only 30% of this group had finding paid job as goal in their service plan.

40. Inclusion Melbourne (2014). Choosing Employment: Part 1-Survey of people with intellectual disability and family.

41. National Core Indicators (NCI) <https://www.nationalcoreindicators.org/>.

42. Mark Shanks (2017) "Disabled students' post school transition lacking" <http://www.radionz.co.nz/news/national/325442/disabled-students'-post-school-transition-lacking-advocate>.

Two studies<sup>43</sup> have provided evidence that investing in support for employment for disabled people is an investment worth making. A cost benefit paper by Workbridge with Allen and Clarke found that if disabled people had the same rate of employment as the general population the return on investment would be more than eight times the placement costs. This would yield over \$1.1 billion a year in welfare savings, tax revenue, and increased economic activity. An NZIER report found that if jobs were available and no-one was displaced from work equalizing the unemployment rate for disabled people would add \$1.45 billion to real gross domestic product and make fiscal savings from social support payments of \$270 million per annum.

### IHC to track progress on government data and reporting

1. Young people with intellectual disabilities are visible and counted in data collected by the Ministry of Education and Ministry of Social Development on transition and post school outcomes in education, training and employment.
2. Progress on and outcomes from the Disability Action Plan to improve transition experiences for young people with disabilities with specific reporting for young people with intellectual disabilities.
3. Participation rates, type and hours of work and pay for people with intellectual disabilities are collected and reported on in Ministry of Social Development/Work and Income and Ministry of Business, Innovation and Employment data using the same questions and categories as the New Zealand Household Labour Force Survey.

## Money

**People with intellectual disabilities and their families/whānau need to have enough money for a good life and the right to an adequate standard of living realised and protected. The majority of respondents did not think this was happening. 41% of respondents to IHC's 2017 online survey thought the situation is getting worse for children and their families and 44% for adults.**

“People with intellectual disabilities need good advocates and a family who will financially provide for them throughout their lives. The benefit system doesn't provide sufficient income for a healthy lifestyle and good housing.”

“We have to continually top up \$ for medical expenses due to her condition, she has no spending money because it is all going to residential care.”

“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.”

“The families I work with aren't focused on fun; they are worried about grocery bills and getting through the next week.”

“Financial hardship adds an extra burden to families already struggling to do their best for their disabled loved ones, limiting their choice and control over a long period of time.”

“We are lucky to have access to EIF (Enhanced Individualised Funding) in our region which is a huge help.”

A number of respondents commented on difficulties they experienced in dealing with Work and Income in getting information and accessing their rights to social protections. “With regards to WINZ it is so hit and miss, unless you know exactly what you are asking for, you will never find someone who says you aren't getting everything you are entitled to.”

Almost all participants in the focus group discussions received the Supported Living Payment (SLP). One participant knew he was not eligible for the benefit as he and his family had recently shifted to New Zealand. For some there was uncertainty about whether they could earn money from a job if they were on a benefit.

“Mum looks after my account, when I want money I ask her.”

“I can't afford to go flatting.”

43. Eric Krassi Peach (2006) A Billion Dollar Opportunity: The potential benefits of equal employment for disabled people in New Zealand. Paper prepared for Workbridge by Allen and Clarke; Micheal Bealing, Todd Kriebel & Daniel Pambudi (2017), Valuing Access to work. An NZIER report commissioned by the Blind foundation for the Access Alliance.

“I help my family – I pay board.”

“It can be difficult to come up with the money or save when things come up out of the blue, or when I have bills coming up.”

### What do we know about income for people with intellectual disabilities and their families/whānau?

- Most people with intellectual disabilities are life-long beneficiaries
- The 2016 Child Poverty Action Group report<sup>44</sup> outlines financial hardships faced by many families/whānau with a disabled child.
- People with disabilities are over represented in those living in poverty or on low incomes compared to the general population<sup>45</sup>.
- Findings from the 2013 New Zealand Disability Survey showed that while many disabled Māori enjoy good levels of material well-being and quality of life, overall they tend to fare worse than non-disabled Māori<sup>46</sup>.
- 50% of people accessing MoH disability support services live in deciles 4 and 5 of the NZ deprivation index, the two most deprived decile ratings.
- A cycle of low income and extra costs compounds disadvantage and makes it very hard, across the lifespan, for people with intellectual disabilities to have a good life.
- The low level at which abatement rates kick in and the loss of some allowances if an individual comes off the Supported Living Payment add barriers to taking up more hours of paid work for some people.
- As identified in previous sections there are indications from new model and EGL demonstration evaluations that the amount of funding disabled people received may be insufficient to achieve the vision of a good life. Those who wanted to move out of home and live independently were particularly affected and those from families/whānau with limited resources were also disadvantaged. Not having enough money for transport restricted some people's ability to participate in community life.

### IHC to track progress on government data and reporting

1. People with intellectual disabilities and their families/whānau are visible and counted in government reporting on
  - Poverty, income and patterns of multiple disadvantage
  - Outcomes and impact of welfare reforms, benefit changes and social investment
  - Minimum wage exemptions
2. Ministry of Social Development reporting on numbers of and trends for people with intellectual disability and their families/whānau receiving benefits and allowances – Supported Living Payment, Supported Living Payment for Carers, Superannuation, Child Disability Allowance, Disability Allowance and Accommodation Supplement.
3. Ministry of Health reporting on numbers and trends for people with intellectual disability and their families/whānau – by living situation, support level and type of funding such as Individualised Funding and Funded Family Care, decile area/deprivation index

### Being heard and decision making

**The survey asked whether people with intellectual disabilities were heard and involved in decisions, able to access advocacy, raise concerns and make complaints. Around a third thought New Zealand was mostly getting this right but 60% thought we are stuck or it's getting worse for both children and adults. Just over 40% feel the country is stuck on these measures.**

“My daughter has been actively taught at school how to voice her concern about things.”

“It would be good if New Zealand had a more robust means of protecting rights.”

“It now feels as if we are ‘stuck’ in terms of getting to the next steps of true empowerment.”

“In reality choices are getting more restricted as service providers are on such tight budgets.”

“The Enabling Good Lives principles have helped with this.”

44. Child Poverty Action Group 2015 It shouldn't be this hard: children, poverty and disability.

45. Statistics NZ, New Zealand Disability Survey 2013.

46. Statistics New Zealand Disability Survey, 2013 He hauā Māori.

“Always room for improvement but I feel that this is an area where progress is being made.”

Lack of access to and availability of publicly funded advocacy was highlighted as an area of concern.

“Where are the independent advocates, planning services and facilitators? There is still an inherent power structure in services that prevent complaints, concerns from being honestly addressed. If a person has no family then they can be trapped in a system”.

“It is likely that some people miss out in being properly involved and ethically supported in decision making and life choices. What about government’s responsibility to uphold and protect people’s rights and make services accountable and inclusive?”

“Advocacy is what we need more of. People [with intellectual disabilities] need to feel secure before they can trust people enough to share their concerns.”

“It is crazy that you can only access advocacy when there is trouble afoot, or concerns. What about having another voice to ensure things are done right first up?”

Most participants in the discussion groups said they were in charge of themselves. A smaller number identified staff or their parents as being in charge. Family, staff and friends were identified as people they would go to for help to make decisions or if they were not happy about something. Some of the things that made making decisions harder were if they felt sick, tired, sad or overwhelmed.

“Mum and dad help give me ideas and then I can think what’s a good one to do.”

“When people put words in my head, give me questions, lots of questions can be confusing, and confuses me about what is the right call.”

### What is happening?

IHC Advocacy is contributing along with other groups to the work facilitated by the Office of Disability Issues on UNCRPD Article 12: Equal recognition before the law. IHC’s Community Advocacy team is active in work to provide information and practical ways to support decision making.

The Donald Beasley Institute is building on their previous research and education work to develop evidence based guidelines in their Benchmark project. This will be a valuable resource for lawyers, judges and other legal professionals on best practice

### What progress is New Zealand making in shifting from substitute to supported decision making and people with intellectual disabilities having equal recognition before the law (Article 12 UNCRPD)?

There is still a way to go to ensure that the preferences of people with intellectual disabilities are respected and that they are supported to make their own decisions. Misunderstandings about supported decision making and misapplications of legal orders remain problematic. IHC and other organisations continue to hear of situations where welfare guardianship and property management orders are wrongly insisted on and where rights to be heard have not been promoted or protected.

The care and protection and youth justice sectors are areas where children and young people with disabilities particularly need adequate supports and safeguards. Data is very limited but indications are that a disproportionate number of those in the care and protection and youth justice systems are likely to have disabilities. Ministry of Health DSS recipients are more likely to have had a CYF finding of abuse or neglect. Recent law changes under the Oranga Tamariki Act 1989, specifically recognise the right of children and young people with a disability to have their voices heard and to be provided with assistance to express their views and to be understood.

New principles under the Act expressly require decisions about a child or young person with a disability to support their full and effective participation in society. These changes are welcome.

The move to Oranga Tamariki, and associated legislative change, has seen the removal of sections 141 and 142 of the Children, Young People and Their Families Act 1989 which provided separate processes for children with disabilities in the care system with fewer safeguards. As children and young people with intellectual disabilities are brought within the new Oranga Tamariki care processes, and standards of care are developed, it will be essential their rights are met, they are well looked after and protected from harm on an equal basis with other children.

Longstanding issues that have yet to be adequately addressed are those of having clear and safe pathways where people can take concerns, challenge decisions and access publicly funded advocacy. People with intellectual disabilities who do not have family support are a particularly vulnerable group. IHC continues to call for a role with functions and mandate similar to that of the Australian Office of the Public Advocate in order to strengthen safeguards.

The human rights case taken by Tony Ellis on behalf of three men with intellectual disabilities is indicative that New Zealand is not meeting its obligations in this area. Too often and for too many people rights are breached with the use of seclusion causing serious concerns. A 2017 report revealed high levels of use of seclusion and restraint in New Zealand within both Ministry of Health and Department of Corrections facilities<sup>47</sup>. Several of the recommendations made were aimed at reducing the use of seclusion “because it is damaging, inappropriate, not conducive to the therapeutic relationship between patients and their care-givers, and because it has no therapeutic value.”

A scan over a ten year period of the Intellectual Disability Compulsory Care and Rehabilitation (IDCC&R Act 2003) Framework<sup>48</sup> found the average length of consecutive stay was four years and that there had been changes with an increased complexity, a younger age for individuals and higher rates for Māori for individuals under the Act. There is no publicly available information on short or longer term rehabilitative and wellbeing outcomes and there has been no review of how the Act is working. Recently senior clinicians have spoken out about under-funding, insufficient beds and lack of access to needed care for people detained under the Act in secure units<sup>49</sup>.

These concerns were backed by Chief Human Rights Commissioner and Children’s Commissioner and calls made to better respond to the rights of Intellectual Disability Compulsory Care and Rehabilitation Act (IDCC&R Act) care recipients.

### IHC to track progress on government data and reporting

1. That New Zealand legislation, policy and practice is consistent with and meets the State’s obligations under UNCRPD, enables access to reasonable accommodations and advocacy and the shift from substitute to supported decision making and recognition of the agency and preferences of people with intellectual disabilities.

2. Ministry of Justice to identify and report the Protection of Personal and Property Rights (PPP&R) Act on
  - numbers of people with intellectual disabilities who have orders, reasons for orders and trends over time; and
  - the alignment of the intent and application of the Act with the UNCRPD.
3. Ministry of Vulnerable Children Oranga Tamariki reporting on progress, complaint and advocacy mechanisms and National Core standards for children and young people with intellectual disabilities.
4. Ministry of Health and Ministry of Justice report on compliance with human rights obligations and short and longer term rehabilitation and wellbeing outcomes for people who are and have been subject to the IDCC&R Act and the Mental Health Act.

## Fair systems

*The majority of respondents to the on-line survey thought that New Zealand was either stuck or things were getting worse in terms of support, services and systems being easy to find with fair ways to make and review funding decisions. This was both for children (43% and 25%) and for adults (42% and 25%). 29% thought we were heading in the right direction for children and families and 25% for adults.*

“There are lots of great ideas such as person-centred planning, enabling good lives, social enterprise, micro-businesses, individualised funding, but all of these are not properly funded or resourced.”

“Too many agencies. Too many paper shufflers. Too much bureaucracy. Took me 3 meetings and 3 people from occupational therapy to get a \$75 buckle guard.”

“The process is complex enough, but the lack of funding to create a meaningful weekly schedule is the major barrier for creating a better future for them. When they fall through the cracks, the families crumble too.”

47. Sharon Shalev, 2017, Thinking outside the box? A review of seclusion and restraint practices in New Zealand.

48. Rachel Daysh 2015, Ten years of the IDCC&R framework – presentation to NASCA conference 2015.

49. ‘Doctors reveal secure care in crisis’, 6 July, 2017 <http://www.radionz.co.nz/news/national/334546/doctors-reveal-secure-units-for-intellectually-disabled-in-crisis>.

“Supports are only as good as the people involved. We need a well-trained and supported workforce and it is wrong to assume that all a family needs to get good support is adequate funding.”

“There are so many departments, agencies, support groups and committees all with similar names and acronyms, that it is a minefield of confusion and gobbledegook.”

“It’s very confusing. Help that is available seems to unfairly vary between regions. And often you have to ‘hear about’ something your child qualifies for. Lots of things are NOT easily found or hear about (in our experience). And services that are available are usually very over-subscribed with long, long waiting lists.”

“There is a culture of having to prove ‘how bad you are’ to get services.”

“We still expect people with disabilities and their families to navigate a maze of services, which are often incoherent and unfair.”

“Enabling Good Lives has made an improvement for some but the funding varies hugely from case to case.”

### What’s happening?

Building individual, family/whānau, community and system capacity have been identified as important features of getting different and better ways of working. These are included in the proposed high level design for transforming systems. Some fundamental changes are needed to government commissioning and funding practices. These include a shift to higher trust and less prescriptive rules for how people can use funding and workable and sustainable processes for service providers. The system transformation sits within the wider context of government’s obligations under the UNCRPD. It will therefore be important that the transformation embeds the rights of people with intellectual disabilities, under the UNCRPD, within the disability support system and within other government systems, particularly the health, welfare, justice and education systems.

### What progress is being made to get fair and safe systems?

While further development work is being undertaken before the first roll out of the new transformed system in the Mid Central region in July 2018 too many people with intellectual disabilities and their families/whānau are not having their rights adequately responded to and are unable to access timely and quality supports and services. A national roll out of a better connected and more enabling system is still sometime away. Meanwhile people with intellectual disabilities and their families/whānau continue to be subjected to prescriptive, inflexible and inconsistent practices of funders and NASCs and have to endure multiple assessments.

### How long do people with intellectual disabilities and their families/whānau have to wait?

We lack sufficient data and terminology and definitions differ across studies making comparisons difficult in assessing the benefits of more individualized and flexible approaches. However, research from Scotland suggests that individualized service design increases the chances of better outcomes, directing your own support does not necessarily cost more than services commissioned by a third party and overall individual support does not necessarily cost more than that in group settings where individuals have not chosen the people they share support with<sup>50</sup>. There are warnings in this work about rights being compromised in the name of cost efficiencies with some moves to high volume models of supported accommodation rather than individualized support.

The use of individualized funding (IF) in New Zealand has increased over the years however the use of IF by people with intellectual disabilities is proportionally less than their representation as DSS funded support users<sup>51</sup>. In a 2015 analysis of the use of Enhanced Individualised Funding (EIF)<sup>52</sup> people with intellectual disabilities used EIF in lower numbers than their representation in the trial and use of disability support funding than did people with sensory and physical disabilities. A higher proportion was reported in 2016 Ministry of Health report on the Bay of Plenty on use of EIF, where 46% were people with intellectual disabilities.

50. Alice Squire and Pete Richmond, 2017, No place like home: The economics of independent living

51. Ministry of Health, Demographic report on clients allocated Ministry of Health’s Disability Support Services as at September 2016 – released July 2017.

52. Mathea Roorda et al, Demonstrating changes to disability support: Evaluation Report, 7 April, 2015 Evalue.

An analysis of cost patterns of IF funding undertaken for Manawanui-in-Charge<sup>53</sup> found evidence to indicate that cases of higher costs for IF users over time fall below that of non IF users and IF users with high and complex needs were less likely than non IF users to move to residential care. There is a danger of arguing on the basis of cost alone. Human rights and choice should be considered and the right balance struck between accountability and risk and choice and control.

### How are well are human rights complaints and monitoring mechanisms working?

Delays in the Human Rights Review Tribunal responding to IHC's Human Rights Act education discrimination complaint have resulted in justice being denied to the many children whose families/whānau gave evidence to IHC in 2008.

Clearly the accessibility and timeliness of New Zealand's human rights mechanisms require review.

A review<sup>54</sup> of New Zealand's Independent Monitoring Mechanism (IMM) found strong support for the mechanism as coordinated and by Disabled Peoples Organisations (DPOs), the Human Rights Commission and the Office of the Ombudsman. The review identified a need to broaden the groups involved in the process to give a wider representation of disability groups and of civil society.

In October 2016 New Zealand signed the optional protocol of the UN CRPD and it came into force in November 2016. This gives people with intellectual disabilities the option of taking complaints to the UNCRPD if their rights are breached and certain criteria are met.

In 2016 New Zealand reported to UN Committee on the Rights of the Child (UNCRC). Non-government agencies submitted a report<sup>55</sup> calling for a coherent, rights based approach to government services for children with disabilities. The UNCRC recommended, amongst other things, that New Zealand adopt a comprehensive, child rights and participatory approach to the fulfillment of the rights of children with disabilities and ensure that the Disability Action Plan takes children into account.

### IHC to track progress on government data and reporting

1. Reporting on government initiatives and system changes and improvements for vulnerable children, education, work and income and disability support services demonstrate evidence for people with intellectual disabilities and their families/whānau of
  - Easy to use, responsive and connected systems.
  - Less time and money spent in having to prove eligibility and more time and money getting to individuals and families/whānau and communities.
  - Sufficient purchasing power for individuals and families/whānau and resourcing for service providers.
  - Improved and sustained positive outcomes and reductions in disadvantage and disparities.
  - Rights embedded in systems and being promoted, protected and fulfilled.
2. That people with intellectual disabilities and their families/whānau are included in governance groups at national and regional levels at all steps of co-design, monitoring and making ongoing improvements.
3. Progress on getting more accessible and timely Human Rights monitoring and implementation mechanism and broadening the representation in New Zealand's Independent Monitoring processes including that of children and young people.

53. Adrian Field, Michael McGeachie & Julian King, MIC Individualised Funding Analysis. Report prepared by Dovetail for Manawanui InCharge 27 October 2015.

54. Malatest International 2017, Review of disabled people led monitoring of the UNCRPD.

55. Action for Children and Youth Aotearoa 2016, Counting what matters – Valuing and making visible the lives of children with disabilities: Supplementary information for the United Nations Committee on the Rights of the Child.

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# Appendix

## IHC to track progress on government data and reporting

### Being Included

1. That New Zealand Disability Strategy Outcomes Framework and evaluation framework for the new disability support system report on wellbeing, social connectedness and inclusion for people with intellectual disability covering:
  - The same questions on belonging, social contact, connectedness and discrimination used in the New Zealand General Social Survey; and
  - The enduring questions identified by the Disability Data and Evidence working group on attitudes, awareness, discrimination, accessibility and reasonable accommodations.

### Home, family and community life

1. The New Zealand Disability Strategy Outcomes Framework, evaluation framework for the new disability support system and Ministry of Health data and reporting should include indicators for people with intellectual disability and their families that:
  - Demonstrate respect and responsiveness to preferences and culture and flexibility, choice and control in how supports are used.
  - Identify by living situation – community residential service, supported living, living with family and by funding used and by type and amount of funding used.
  - Include family and whanau wellbeing.
2. Disability is included in SuperU's Family Whanau Status report and that the subgroup of children with disabilities/developmental delay are identified and tracked in the Growing Up in New Zealand study.
3. Oranga Tamariki reports on numbers and outcomes for children and young people in state care/out of home placements

## Education

- 1.** Children and young people with intellectual disability are counted and visible in all reporting by schools, Ministry of Education, Education Review Office and New Zealand Qualifications Authority at, school and tertiary levels specifically data on:
  - student engagement (attendance and stand downs; suspensions and exclusions);
  - national standards; and
  - National Certificate of Educational Achievement (NCEA)
- 2.** Participation rates of children with intellectual disabilities in early childhood education is collected and reported on.
- 3.** Participation rates of young people with intellectual disabilities in tertiary education collected and reported.
- 4.** Learning support delivery model effectiveness reported on measures of:
  - increased family/whanau satisfaction re access and quality of services provided,
  - increased teacher engagement with learning support services
  - increased collaboration within the Communities of Learning (CoL) to demonstrate progress towards addressing learning support achievement challenges and comparison with schools who are not part of a CoL.
  - increased rates of attendance and engagement amongst students accessing services or supports and
  - reduced waiting times to access learning support services.

## Health

1. Progress by the Ministry of Health on the Disability Action Plan and New Zealand Health Strategy actions to improve health outcomes for people with intellectual disabilities.
2. People with intellectual disabilities are counted and visible in all work and reporting by the Ministry of Health and District Health Boards with specific data on:
  - Progress and outcomes on the New Zealand Health Strategy and Health of Older People Strategy.
  - Participation in and outcomes from screening and public health programmes.
  - Numbers, waiting times and quality indicators for general and specialist health services.
  - Numbers of referrals, waiting times, services received and outcomes for mental health and behaviour support services.
  - Implementing Medicines New Zealand 2015 -2020 indicators for improved access to medicines and ensuring medicines use is safe, effective and of high quality achieving optimal outcomes.
3. Accurate health information is gathered and recorded for people with intellectual disabilities on demographic data sets and on individual records.

## Work

1. Young people with intellectual disability are visible and counted in data collected by the Ministry of Education and Ministry of Social Development on transition and post school outcomes in education, training and employment.
2. Progress on and outcomes from the Disability Action Plan to improve transition experiences for young people with disabilities with specific reporting for young people with intellectual disabilities.
3. Participation rates, type and hours of work and pay for people with intellectual disability are collected and reported on in Ministry of Social Development/ Work and Income and Ministry of Business, Innovation and Employment data and using the same questions and categories as the New Zealand Household Labourforce Survey.

## Money

1. People with intellectual disabilities and their families are visible and counted in government reporting on:
  - Poverty, income and patterns of multiple disadvantage
  - Outcomes and impact of welfare reforms, benefit changes and social investment approaches.
  - Minimum wage exemptions
2. Ministry of Social Development/Work and Income reporting on numbers of and trends for people with intellectual disabilities and their families receiving benefits and allowances.
3. Ministry of Health reporting on numbers and trends for people with intellectual disabilities and their families – by living situation, support level and type of funding.
4. Progress on integrating funding streams across government and evidence for more flexible and effective use of resources.

## Being heard and decision making

1. That New Zealand legislation, policy and practice is consistent with and meets the State's obligations under UNCRPD, enables access to reasonable accommodations and advocacy and the shift from substitute to supported decision making and recognition of the agency and preferences of people with intellectual disabilities.
2. Ministry of Justice to identify and report the Protection of Personal and Property Rights (PPP&R) Act on
  - numbers of people with intellectual disabilities who have orders, reasons for orders and trends over time; and
  - the alignment of the intent and application of the Act with the UNCRPD.
3. Ministry of Vulnerable Children Oranga Tamariki reporting on progress, complaint and advocacy mechanisms and National Core standards for children and young people with intellectual disabilities.
4. Ministry of Health and Ministry of Justice report on compliance with human rights obligations and short and longer term rehabilitation and wellbeing outcomes for people who are and have been subject to Intellectual Disability Compulsory Care and Rehabilitation Act and the Mental Health Act.

## Fair systems

1. Reporting on government initiatives and system changes and improvements for vulnerable children, education, work and income and disability support services demonstrate evidence for people with intellectual disabilities and their families of
  - Easy to use, responsive and connected systems.
  - Less time and money spent in having to prove eligibility and more time and money getting to individuals and families and communities.
  - Sufficient purchasing power for individuals and families and resourcing for service providers.
  - Improved and sustained positive outcomes and reductions in disadvantage and disparities
  - Rights embedded in systems and being promoted, protected and fulfilled.
2. That people with intellectual disabilities and their families are included in governance groups at national and regional levels at all steps of co-design, monitoring and making ongoing improvements.
3. Progress on getting more accessible and timely Human Rights monitoring and implementation mechanism and broadening the representation in New Zealand's Independent Monitoring processes including that of children and young people.

**IHC National Office:**

Level 15, 57 Willis Street, Wellington

PO Box 4155, Wellington 6140

Phone: 04 472 2247 or 0800 442 442

Fax: 04 472 0429

Email: [national.office@ihc.org.nz](mailto:national.office@ihc.org.nz)

