



Good Connections for Valued Lives

Ko te herenga-pai ki te wāriu o te ora





Introduction

“No safeguards can protect people with disabilities in a world where their lives are not valued.”¹

Good Connections for Valued Lives is IHC’s second report monitoring progress on rights and citizenship being real in the lives of people with intellectual disabilities.²

For all of us, our wellbeing is linked to our connections and interdependence in relationships and communities. Just as individuals, families, whānau and communities are connected and interdependent, so are human rights, policies, practices and laws. These are linked with citizenship and the nature of our social contract, and are reflected in the trust and confidence we have that systems are fair.

From the end of 2017, and throughout 2018, the new Coalition Government introduced a change in direction that applies a broader social investment approach and a wellbeing and sustainability lens. 2019 will see a ‘wellness’ budget that goes beyond monetary measures of GDP. A transformational programme of work has begun that aims to create a fairer

society in which all cultures and human rights are valued, and inequality and poverty is reduced. Inquiries have been launched, and major reviews of New Zealand’s education, social welfare, health, criminal justice and tax systems are underway. Accessible and affordable housing is high on the agenda, along with proposals for new healthy homes standards and changes in the Residential Tenancies Act.

In order to achieve equitable access and outcomes, people with intellectual disabilities and their families and whānau need to be included in the universal initiatives that are underway. They should not be left behind in benefitting from improvements and changes that result from this work. For sustainable positive change it is also critical that the transformation of disability support systems connect with wider transformations in ways that go beyond the ‘trial, learn and adjust’ approach of the MidCentral region prototype Mana Whaikaha.

There is much to be learned from the three-year evaluation report on the Australian National Disability Insurance Scheme (NDIS)³ - released in 2018. Of major significance is the finding

that people with intellectual disabilities fared less well than other participants with disabilities in relation almost all key outcome areas. The report highlighted unfavourable and inequitable impacts that can affect people who have difficulty accessing, understanding and navigating information and processes, and who are less able to advocate for themselves.⁴

Getting the right evidence base

“People’s lives happen across time, not within a data point.”⁵

It’s vital for us to have good data – for people to count and be counted.

There are positive steps underway, such as Indicator Aotearoa New Zealand (IANZ), which is seeking to develop indicators and a wellbeing dashboard to answer the question “how is New Zealand doing?”⁶ This will also be linked to the Standard of Living framework. However, the results of this work are still sometime away, as is the final outcomes framework for monitoring the New Zealand Disability Strategy.

There are problems and questions surrounding the 2018 New Zealand Census. At this stage, the extent of the difficulties in its collection and comprehensiveness, and the full implications for policy and resourcing across universal and disability sectors, are unknown.

What we are doing in this report

Much of the work referred to in the introduction is still in development, or yet to be reported back, actions implemented or evaluated. As a result, there is little new information available against which to track progress on achieving equitable access and outcomes for people with intellectual disabilities.

Given this context, the focus of this report is that of people with intellectual disabilities and their families and whānau being connected with, and counted in, these initiatives, along with what needs to happen for good connections to link across universal and disability sectors and, where information is available, what progress has been made.

We look at these questions across the domains of home, family and community life; fair systems; education; health; work; money; and justice. Information is drawn from Government announcements, terms of references for inquiries, reviews, strategies and progress updates, transforming disability support systems work, New Zealand research and the 2018 evaluation of the Australian National Disability Insurance

Scheme (NDIS).⁷

Key themes

There are some key themes that emerge across all domains in this report:

- There has been some progress with greater visibility and inclusion of people with disabilities as a specific population group in terms of references and consultations.
- Many initiatives underway across government are promising, and may contribute to, improvements in quality of life for people with intellectual disabilities and their families and whānau. It is simply too early to tell what impact they will have.
- In the meantime, people with intellectual disabilities are still being left behind. How long do they and their families and whānau have to wait to address what have been longstanding and serious issues?

What needs to happen?

- People with intellectual disabilities and their families and whānau must be counted and heard so that changes underway in the health, education, welfare, justice and children’s systems are inclusive.
- Systematic effort needs to be made to promote and protect the rights and citizenship entitlements of all people with intellectual disabilities and their families and whānau as an essential part of enhancing their wellbeing.
- Across party and across government, there must be agreement and consultation with disabled people, families and whānau, their representative organisations and non-government agencies to connect, build on and sustain transformative changes and gains.
- We need to draw on the lessons learned in the introduction of the Australian NDIS.
- Disability supports must be properly resourced, health outcomes improved, education made inclusive and wait times for early intervention reduced.
- There needs to be legislative change and reviews for consistency with the UNCRPD, and specifically the PPP&R Act and the IDCC&R Act.

1. Tim Stainton, 2013, quoted in (Council of Canadians with Disabilities (CCD) and Canadian Association for Community Living (CACL), 2013)
2. We use ‘people with intellectual disability’ 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.
3. (Mavromaras, Moskos, Mahuteau, & Isherwood, 2018)

4. Jackson, 2018
5. (Morgan, 2018)
6. (Stats NZ, 2018)
7. (Mavromaras, Moskos, Mahuteau, & Isherwood, 2018)



What's been happening?

Nov 2017 - Dec 2018

18 July

Report led by Rosemary Marks into Ruby Knox death released

12 July

Advisory group, Hāpaitia Te Oranga Tangata, established to improve community safety and the way justice works

5 July

Children's sector, including IHC, release joint submission to New Zealand's 3rd Universal Periodical Review (UPR)

2 July

National Care Standards a Regulations promulgated for children and young people in state care

30 November

NZ Independent Monitoring Mechanism makes submission to help UNCRPD develop The List of Issues for the country

17 December

Waitangi Tribunal Health Services and Outcomes Inquiry confirmed

28 May

Formation of an expert advisory group to support the overhaul of the welfare system announced

24 May

Child Wellbeing Strategy announced

20 December

Tax Working Group created to consider the future of tax

23 January

Inquiry into Mental Health and Addiction announced

31 January

Child Poverty Reduction Bill introduced

1 February

Royal Commission of Inquiry into historical abuse in state care announced

7 February

Mother of disabled child, Diane Moody, wins battle with Ministry of Health over carer pay

23 March

UN Committee on the Rights of Persons with Disabilities releases The List of Issues for NZ

21 March

Employment Support Practice Guidelines launched at Parliament

6 March

2018 New Zealand Census of Population and Dwellings

21 February

Three-year plan to overhaul education system announced

16 February

IHC makes submission to Committee on Economic, Social and Cultural Rights on the lack of systems, procedures and supports by which people with intellectual disabilities can realise and enforce their rights

27 August

Consultation begins on reform of Residential Tenancies Act

4 September

Consultation begins on healthy homes standards to make rental homes warmer and drier

11 September

Amendments to Family and Whānau Violence Bill announced

21 September

Draft Disability and Learning Support Action Plan released

27 September

Changes to the Funded Family Care policy announced

1 October

New disability support system prototype, Mana Whaikaha, launched in the MidCentral DHB region

16 October

Draft government report released responding to The List of Issues for NZ by the UNCRPD

4 November

New workforce of Learning Support Coordinators announced

12 November

Inquiry into the historic abuse of children in state care expanded to include abuse in the Church

20 November

Disability Action Plan 2019-22 consultation begins

7 December

Tomorrow's Schools Report released

Home, family and community life

“Where, after all, do universal human rights begin? In small places, close to home ... [in] the world of the individual person; the neighbourhood [they] live in; the school or tertiary learning institute they attend; and/or in the places where they work. Such are the places where everyone seeks equal justice, equal opportunity, equal dignity without discrimination. Unless these rights have meaning there, they have little meaning anywhere.”⁸

Connections for a good start

“New Zealand is the best place in the world for children” is the proposed vision for New Zealand’s initial Child and Youth Wellbeing Strategy.

“A place where every child has a warm dry home, where their local school is the best school possible, where there is food and a health system that is there when they need it. And perhaps most importantly, a place where they are loved, valued and heard.”⁹

For children¹⁰ with disabilities to get a good start, they need to be viewed and valued as part of the community of all children, with equitable access to and outcomes from universal services, as well as the supports they and their families and whānau need. A number of current initiatives relate to getting a good start.

New Zealand’s first Child and Youth Wellbeing Strategy is under development. The strategy’s principles acknowledge the intrinsic value and dignity of all children, children’s rights under New Zealand law and view children in the context of their families, whānau, hapū and iwi, and other culturally recognised family groups and communities. The initial draft strategy includes disabled children as one of 16 focus areas for improving opportunities and outcomes. There is potential for good connections to be created as the strategy is implemented, with the interests and needs of disabled children, as well as children of disabled parents, being considered within each of the other focus areas under the strategy. For example, access to social housing and education.

Coherent links between the systemic changes underway for children, across government, and the transformation of the Disability Support System will also be critical to improved wellbeing of children and young people with disabilities. One of the challenges in assessing progress on the implementation of the Child and Youth Wellbeing Strategy is the lack of robust baseline data.



Early access to support

On current drafting the Child and Youth Wellbeing Strategy has an initial focus on all children thriving socially, emotionally and developmentally in the early years (around 2 to 6), a similar focus to GSIL.¹¹ The stated aim of the 2014-2018 Disability Action Plan (DAP) - Good Start in Life (GSIL) was to develop policy options to improve government funded supports for parents, family and whānau of disabled children aged zero to eight.

It has been disappointing that no substantive progress was made in 2018 on the DAP- GSIL. There are opportunities with the proposed initial progression of GSIL in Mana Whaikaha, alongside the review of Child Development Services and the roll out of the new Disability and Learning Support Action Plan.¹² It is critical that these are linked with the Child and Youth Wellbeing Strategy as well as other areas of system reform.

Getting early support remains problematic with long waiting lists for early intervention and specialist services again being highlighted in 2018.¹³ Despite extra resourcing, children and their families and whānau still face lengthy waits for early intervention services. Caps on learning support staffing have contributed to the long waiting lists for early intervention and other specialist areas such as communication and behaviour support.



In response to a parliamentary question, Associate Minister of Education, Tracey Martin stated “...the average waiting time for Early Intervention Service support has increased from 97.52 days as at 30 June 2018, to 98.24 days as at 30 September 2018.”

New Zealand faces similar workforce issues in accessing early support and specialist services as to those as those identified in the 2018 Australian NDIS evaluation. These included particular shortages for allied health services and early intervention supports.¹⁴

As a consequence, many people and their carers experienced continued difficulties in accessing disability supports for which they had NDIS funding. Having funding is not enough.

Respecting and responding to the rights of children with disability

The rights of children with disabilities under both the United Nations Convention on the Rights of the Child (UNCROC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) have been included in both Oranga Tamariki legislation and the Child Poverty Reduction Bill.

Among other things, this means the rights of children and young people with disabilities to have their views taken into account now have legislative protection. Along with the recognition of rights in the Child Wellbeing Strategy, this is significant progress.

IHC will track progress on:

- levels of support families receive and the quality of early childhoods for those with disabilities, including:
 - waiting lists for early intervention services
 - workforce/staffing levels for early intervention services
 - impacts on children and young people of Mana Whaikaha, in relation to the GSIL priority areas
 - the policy options that eventuate from GSIL and how they are put into operation
- the impact of current child poverty reduction, child wellbeing and education initiatives on children and young people with disabilities, and the realisation of their rights on an equal basis with other children

8. Adapted from speech Eleanor Roosevelt made in 1958 at the 10th anniversary Universal Declaration of Human Rights, cited in Smith, 2018, p.viii

9. (Ardern, The importance of family-friendly policies around the world, 2018)

10. Note the definition of children used by IHC is all those aged under 18, as defined by the United Nations Convention on the Rights of the Child

11. (Department of the Prime Minister and Cabinet, 2018)

12. (Office for Disability Issues, 2018)

13. (Gerritsen, 2018) and (Redmond, 2018)

14. (Mavromaras, Moskos, Mahuteau, & Isherwood, 2018)



Choice, control and wellbeing

“It (living independently) means for me self-esteem... it means you can live your life on your own terms.”¹⁵

“Choice and control are on a continuum, and a continuum in different dimensions in life. In this sense choice and control are always going to be issues to be negotiated to some degree.”¹⁶

Being able to make and act on self-determined choices contributes significantly to our wellbeing and people feeling good about their lives. This relationship is reported in both general population studies and those drawing from self-reported experiences of people with intellectual disabilities.¹⁷

Enhanced wellbeing and increased choice and decision-making authority for individuals and families and whānau underpin transformations in universal and disability support systems.¹⁸ We are interdependent and are influenced by others in our decisions.

The evolving capacity of children and young people is recognised in UNCROC and is a key principle of the UNCRPD. There is, across government, increasing attention being given to the views and participation of children and young people in decisions that affect them, including children with disabilities. An example is engagement with children and young people

in the development of the initial Child and Youth Wellbeing Strategy, which was conducted by the Office of the Children’s Commissioner.

New provisions under the Oranga Tamariki Act 1989 (to come into force on 1 July 2019) mean a child or young person must be given reasonable assistance to understand the reasons for the proceedings or process they are involved in, the options available to the decision-maker, and how these options could affect them. Also, from 1 July 2019, children and young people with disabilities will have the same processes and protections for entering care as non-disabled children and young people, including supports to ensure they are able to express their views and contribute to their care experience.¹⁹

Many decisions are made in the context of relationships. Recent research²⁰ has reinforced what we know about the pivotal place of families and whānau as the primary and most continuous relationship for people with intellectual disabilities. Family for study participants included their birth family, foster family or the family that they had made through setting up home with their partner. Work across universal and disability support sectors needs to respect and respond to cultural preferences and changing family roles and structures in ways that are more than that of just a ‘carer’ role.

The 2018 Australian NDIS evaluation provides useful insights for policy and practice in its analysis of the extent to which increased choice and control and improved wellbeing had been achieved for participants:

- Compared with other participants, people with mental/psychosocial disabilities, and those unable to articulate their support needs or navigate the NDIS website, experienced lower levels of choice and control.
- Those who cared for children with disabilities, or a person with mental/psychosocial disabilities, reported lower satisfaction for choice and control. While levels of wellbeing generally improved for many NDIS participants, these remained considerably poorer than that of the general population, and enhanced wellbeing was not evenly distributed across participants. Poorer levels of wellbeing were recorded for people with developmental²¹ and mental/psychosocial disabilities, and in rural areas and/or with unmet demand for supports.
- Improved wellbeing was found to be associated with increased levels of support and independence, opportunities for greater social participation and improved skills.

- The NDIS did not have an impact on the wellbeing of children and the evaluation found no evidence of improved wellbeing for families or carers. In fact, a negative impact of the NDIS was reported by those caring for children with disabilities. The wellbeing of families and carers was strongly related to the amount of perceived control over how they spent their time.
- While there were benefits for many in having more flexibility, anxiety about the long-term sustainability of the new system and administrative burden also contributed a negative impact on carer wellbeing.

Connecting with the right indicators

Changes that happen over a lifetime are often ignored... People change throughout their lives, change ideas, get in and out of relationships, shift home, change job, get older and retire. All of these are natural transitions.”²²

The above quote highlights the importance of having indicators for wellbeing, choice and control that capture the different ages and stages of a person’s life. IANZ is working towards building an evidence base for tracking progress on the wellbeing of New Zealanders. This should be linked with the indicators in the New Zealand Disability Strategy (NZDS) outcomes framework when this is complete.

Research tells us about the importance of relationships in wellbeing. *“People with strong and developed social relationships may have a 50% less risk of mortality compared with people with less developed social relationships” and that the “magnitude of the effect of loneliness is comparable to smoking, and the impact is greater than that of many well-known risk factors, such as obesity and physical inactivity.”²³*

We know that people with intellectual disabilities are more likely to have smaller social networks than the general population and are less likely to live with a partner or have children. However, information is needed beyond just counting the number of people and social connections in order to get a deeper understanding of the meaning of relationships for an individual. This is illustrated in a New Zealand study

investigating experiences and outcomes for adults with intellectual disabilities living independently.²⁴ For participants, the strength of relationships was more important than the number – often with a focus on a few close friendships and contact with family rather than having lots of friends.

IHC will track progress on:

- the assistance provided to children and young people with disabilities in Oranga Tamariki to ensure they understand the proceedings or processes, the options available and how these could affect them
- increased choice and decision-making authority and improved wellbeing for people with intellectual disabilities
- across universal and disability support sectors, recognition and respect for families and whānau as the primary relationship for people with intellectual disabilities

The government has been asked to report progress on:

- making and recognising the shift from substitute to supported decision-making in our laws and policies
- providing responsive and tailored supports for the exercise of legal capacity, responsive flexible approach to the admission of evidence
- establishing accessible oversight, complaint and redress mechanisms to ensure and strengthen freedom from exploitation, harm, violence and abuse

15. (Conder & Mirfin-Vietch, 2018), p.18

16. (Kendrick, Ward, & Chenoweth, 2017) p.1342

17. (Rickard & Donkin, 2018)

18. See Fair systems connections that need to be made with national and international law, policy and quality standards.

19. (Oranga Tamariki (National care standards and related matters) regulations, 2018), Part 4

20. (Conder & Mirfin-Vietch, 2018)

21. Developmental disabilities are those acquired in the period up to 18

22. (Jarrett, 2018)

23. (Rickard & Donkin, 2018), p.7

24. (Conder & Mirfin-Vietch, 2018)



Fair and connected systems

To be fully included in society, people with disability should be able to access mainstream systems such as education, health, and be supported to participate economically.²⁵

Getting fairer, more transparent and better connected systems are central themes across much of the Government's transformation programme for education, health, social welfare, justice, housing and the disability support system. Critical to the success and sustainability of these transformations is having the right legal frameworks, policies and standards to support and safeguard human rights. Additionally, quality fair resource allocation and review processes, access to justice and independent advocacy.

People with intellectual disabilities and their families and whānau have been particularly disadvantaged and discriminated against by both universal and disability support systems that are fragmented, complex and unfair. As described in a recent Court judgement, the complexity of the statutory instruments governing funding eligibility for disability support services verges on being the impenetrable.²⁶ Similar comments can be applied to universal supports and services with individuals, families and whānau experiencing barriers to accessing their rights and entitlements as citizens to quality support and services.

The Australian evaluation after three years of the NDIS reported that while clearer boundaries had emerged over time, unresolved issues remained regarding the interface between the NDIS and the mainstream sectors. These included responsibilities for funding shortfalls, increased demand, service gaps, duplication and delays and challenges with new and untested referral pathways between mainstream and disability sectors, IT and staff training. Overall, the continuing complexity of the NDIS was found to be impacting negatively on its capacity to work well with related mainstream agencies and provider organisations. Further, at the end of the initial three-year period the demand for disability services and supports exceeded supply in the sector.

Hearing directly from individuals, families and whānau, communities and representative organisations to 'have their say' has been a key information gathering strategy for government. While there is good intent, the sheer volume of consultations that have occurred during 2018, often at short notice, have stretched the capacity of civil society to take part.

System safeguards

Choice, control and increased decision-making authority

To enable and make real our human rights obligations to support and safeguard equal access to the law and justice²⁷ there needs to be consistency across, and also changes to, current laws and policies. These include both positive safeguards, such as supported decision-making, and access to advocacy and timely responses to abuse and neglect.

Having fair and just systems for people with intellectual disabilities was a key focus in the United Nation's questioning in preparation for New Zealand's report in 2019. Significant progress is needed in these areas in order to achieve the aims of current transformational reform and policy initiatives and to support and safe guard rights.

Without these, people with intellectual disabilities will continue to face instances where their decisions are not recognised as valid and court orders are demanded when they should not be.

Given importance of this area, the delays reported in the latest Disability Action Plan to ensure that disabled people can exercise their legal capacity are extremely concerning. Over recent years there has been a lot of activity linked to this action so it disappointing to see this summed up as "MSD will develop an engagement plan by December 2018 on a proposed consultation with the community on the shared understanding, which is intended to be run in early 2019." Delays in progressing this work will negatively impact on the opportunities for engagement with the transformation²⁸ and many other areas of people's lives.

A recent stocktake undertaken on the consistency of New Zealand legislation with the UNCRPD yielded 59 pieces of legislation, 31 of which were identified as likely contravening the Convention.

Laws and policies in need of immediate attention and review are:

- Laws and policies relating to how capacity is assessed, including in-court proceedings and under the Mental Health Act
- The Protection of Personal Rights and Properties Act
- Intellectual Disability Compulsory Care and Rehabilitation Act (IDCC&R)²⁹

25. (Mavromaras, Moskos, Mahuteau, & Isherwood, 2018)

26. (Chamberlain V Minister of Health NZCA 8, [2018])

27. UNCRPD Articles 12 & 13

28. (Office for Disability Issues, 2018)

29. Funding and services that are under the IDCC&R Act have not been included in the initial stages of the MidCentral region prototype. These will need to be integrated into the final model that is put to government in 2020 so that people who have orders under the Act have equal access to the benefits and protections of the new system design.

Government’s commitment to working towards a comprehensive Accessibility Act with enforceable and mandatory accessibility standards in response to the Accessibility Alliance’s campaign is a major step forward. This will build on current accessibility initiatives and help clarify and embed reasonable accommodations in law across a number of areas.

A positive step has been the incorporation of supported decision-making and supported consent in the Draft National Ethical Standards for Health and Disability Research. This both aligns with New Zealand’s obligations under the UNCRPD and gives practical ways to support and safeguard people’s rights, consent and participation in research.

The absence of publically funded advocacy in New Zealand has been a longstanding problem and a need that is not currently met by available government-funded providers. The importance and availability of advocacy (either formal or informal and, where needed, as a funded support) was identified as an area to address in order to improve fairness and equity within the NDIS.

The lack of clear pathways available to adults with intellectual disabilities, or those supporting them, to raise concerns about abuse and other breaches of rights was again highlighted in the review by Dr Rosemary Marks³⁰ of care given by the Nelson-Marlborough District Health Board, after the death of Ruby Knox. The report called for better systems for protection and taking action for vulnerable adults in New Zealand. This problem could be addressed by the establishment of a public advocate role or office with the mandate to act similarly to the Victorian Office of the Public Advocate.

Getting a fair deal

“I am committed to ensuring that people have access to every assistance available, and no one misses out.”³¹

“Families shouldn’t have to use Courts and Tribunals to get a fair deal.”³²

Fair systems require transparent, easy to use and equitable resource allocation and independent review processes of decisions.³³ Again, these are among the aims of the universal and disability support transformations underway.

In the meantime, longstanding problems continue with unfair

resourcing that cannot wait for the recommendations of reviews, inquiries and the trial-learn-adapt and final evaluation of the MidCentral prototype to be addressed. The inadequacy of disability support funding is one such area, with an estimated shortfall of \$150 million. This has serious implications, not only for service providers but for the adequacy of purchasing power in individual budgets. A report by Deloitte, commissioned by the New Zealand Disability Support Network (NZDSN),³⁴ shows the costs of providing support - including housing, electricity and the wages of the disability workforce - have far outstripped funding increases over the past decade. There are major concerns that if this underfunding is not addressed soon, quality and safety will become further compromised.

Further evidence of unfair systems was reported in a review and analysis of the flexible funding policy to support disabled people and their families. The current policy and practices are wasteful – they remove choice and control, lack transparency, and impose unnecessary additional costs and work.³⁵ Concerns were also raised about the discrimination that occurs in the policy and its application. The report made recommendations for immediate actions to address these problems and flagged other opportunities and issues to be addressed to accelerate system transformation for those who want to self-manage personal budgets.

The Ministry of Health’s Funded Family Care (FFC) policy has been fraught with problems since its introduction in 2013. The policy has been described as a nightmare by families and subject to protracted and expensive litigation on the basis of unfair and discriminatory practices. A report commissioned by the Carers Alliance³⁶ found navigating FFC to be complex, with hard to understand eligibility criteria, and onerous and expensive processes as an employer that require juggling several funding streams. Assessment and reporting processes were reported as unfair with the transaction minutes per task was seen as ‘demeaning and nonsense’.

After a long battle, progress was made in 2018 when the government announced it would undertake a review addressing the key problems within FFC, such as eligibility, pay rates for carers, the employment relationship and the type of care.³⁷ The government also intends to repeal Part 4A of the Act that denied families rights to complain about breaches of their human rights relating to FFC.



IHC will continue to track progress on:

- The Government’s response to:
 - the underfunding disability supports identified by the NZDSN report
 - calls to make FFC fairer
- The development of the supports and safeguards required for people with intellectual disability to have equal recognition before the law
- Legal reform in order to meet New Zealand’s human rights obligations
- The development of publicly funded advocacy and clear pathways for raising concerns about abuse and other breaches of rights as called for in the Marks report
- Government response to the recommendations of the United Nations Committee on the Rights of Persons with Disabilities

30. (Nelson Marlborough Health, 2018), (Eder & Bohny, 2018), (Neal, 2018)
31. (Sepuloni, Addressing poverty for New Zealanders with disabilities is vital, 2017)
32. (Esplin, Moore, & Rook, 2018), p.11
33. See Education for an example
34. (Kirk, 2018)
35. (Synergia, 2018)
36. (Esplin, Moore, & Rook, 2018)
37. (Clark & Shaw, Making Funded Family Care fairer, 2018)

Education

The government announced in February last year a major reform of the education system with the goal to establish a 30-year vision for education. “We need a system from the cradle to the grave. . . that is inclusive ... that can adapt to the needs of the modern world. It needs to engage every learner . . . in a much more personalised learning experience.”³⁸

As illustrated in the diagram, all aspects of the education system reform programme will impact on students with disabilities, however a key initiative intended to create positive change for disabled students is the Disability and Learning Support Action Plan. The reform of Tomorrow’s Schools has the potential to address the systemic and structural barriers that result in the discrimination experienced by disabled students identified in IHC’s Human Rights Act complaint.

“Multiple reviews and reports over several years have shown the education system is not working for disabled students. Significant outstanding issues for the system include under-resourcing, a lack of good accountability mechanisms, lack of data and options and a lack of training and support for teachers. We’ve known this for a long while; New Zealand just has not addressed these issues meaningfully and comprehensively.”³⁹

Disabled people, families and whānau and the disability and human rights sectors have expressed concerns in the initial stages of the reform about the lack of connection between the Disability and Learning Support Action Plan and all other aspects of the education system reform. Visible connections are also missing with other government system priorities impacting on disabled children and young people specifically the Child and Youth Wellbeing Strategy, the transformation of disability supports and the Disability Action Plan “Good Start in Life” work programme.

Systems and structures to enable inclusive education

“Inclusive education is not about students fitting into existing systems, rather, it involves modifying schools and teaching methods to accommodate the learning styles and needs of all students. Such an approach leads to excellence in education for all.”⁴⁰

The report from the Tomorrow’s Schools Independence Taskforce, released in November 2018⁴¹, says the education system is not working well enough for New Zealand’s most disadvantaged children and young people and that this situation is not fair or just.

Disabled students are identified as a group that the education system does not serve well. The taskforce found that there are few mechanisms to enable system wide improvement to be initiated, supported and sustained.

The Taskforce has called for a cultural and structural transformation to build a system that supports every learner and is “a coherent, connected and interdependent system based on collaboration, support and improvement” (p.11)

The range of recommendations to bring about this change will be consulted on early 2019 before being put to Cabinet.

Many of the Independent Task Force’s recommendations respond well to the barriers identified and remedies sought within IHC’s legal action, including:

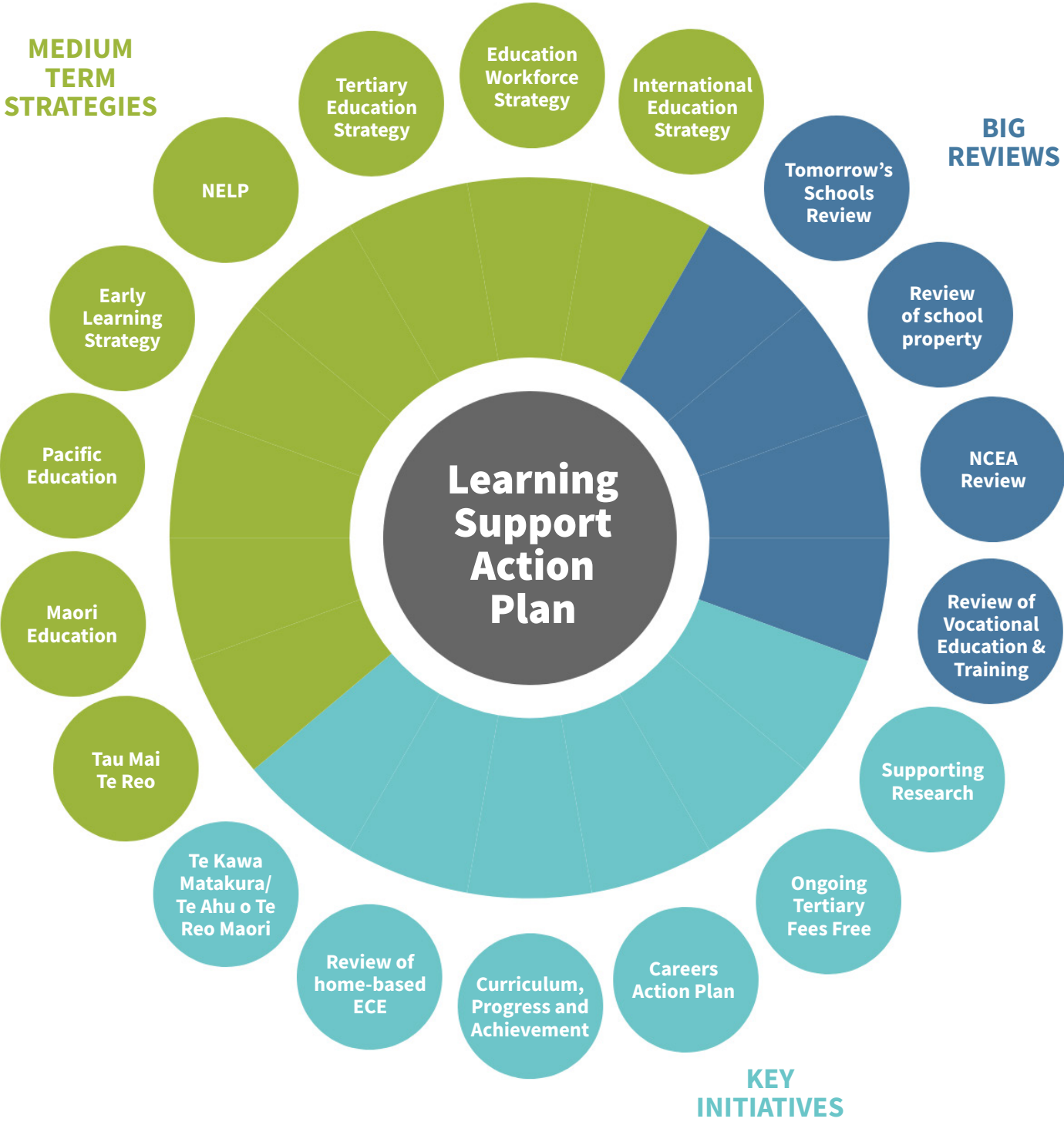
- the need for improvements to initial teacher education and school leadership
- increased system resourcing and improved data
- the establishment of an independent mechanism to review school decisions in relation to student behaviour
- removal of the barriers to enrolment and participation through shifting decision-making from schools to education hubs
- improvements to school reporting requiring increased visibility of priority learners
- provision of an advocacy service

Getting better supports and resourcing

The May 2018 Budget brought a number of announcements including increased funding to increase pay rates for teacher aides, the Ongoing Resourcing Scheme (ORS), and the Intensive Wraparound Service (IWS). Funding for the first tranche⁴² of newly created Learning Support Coordinator and kura signalled in the Budget was announced in November.

Unlike school and early childhood education funding, which is automatically adjusted for population growth, current policy and regulatory settings for learning support funding is not. The increased resourcing announced so far does not meet either current or anticipated levels of need, nor do they indicate any government intent to change what is known to be a flawed resourcing model characterised by a range of strict criteria based eligibility requirements with many children missing out on the supports they need for equitable access to the education.

While the Budget announcements and additions, such as the Learning Support Coordinator role, have been enthusiastically welcomed as a step forward, the lack of certainty about future budget provision and government decision-making in respect to the wider reform process is problematic.



38. (Hipkins, 2018)
39. (Tesoriero, 2018)
40. (Richler, 2018)
41. (Tomorrow’s Schools Independent Taskforce, 2018)
42. (Ardern, Prime Minister’s speech to 2018 Labour Party Conference, 2018)

Getting better data

An area of potential progress lies in the proposed development of a central data system that aims to ensure personalised responses across education settings and inform funding policy and resource allocations. In the meantime, the visibility of disabled children in school and Ministry reporting remains a problem with insufficient data being collected and analysed about the presence, participation and achievement of different groups within the disabled population.

It is unknown how many children and young people in New Zealand schools and early childhood education settings require additional supports to learn, where they attend school and what would be the cost of providing that support.

Progress on the right to education

The United Nations Committee on the Rights of the Child recommendations to the New Zealand government include the development of comprehensive measures for inclusive education and ensure that this is given priority over the placement of children in separated institutions and classes, and that families of children with disabilities are aware of the services to which they are entitled.

The UNCRPD has also asked about progress on their 2014 recommendations that more be done to increase the provision of reasonable accommodation, implement anti-bullying programmes and establish an enforceable right to inclusive education.

IHC to continue to track progress on:

- Tomorrow's Schools Independent Taskforce recommendations
- connecting the Learning Support Action Plan with wider education reform
- establishment of an inclusive education system, including:
- entitlement to reasonable accommodations in legislation
- resourcing levels based on the number of students requiring support to be at school and learn
- inclusive pedagogy and practice
- independent accountability mechanisms
- reporting on the presence, participation and achievement of disabled students

Health

“This (Health and Disability System review) is a once in a generation opportunity to improve equity and outcomes for New Zealanders. It will chart a course for a fairer, more sustainable health and disability support system.”⁴³

“Every New Zealander should be able to have affordable access to quality healthcare.”⁴⁴

Both the Health and Disability System Review: Hauora Manaakiki Aotearoa Whanui⁴⁵ and the Mental Health and Addictions Inquiry: Oranga Tangata, Oranga Whānau⁴⁶ aim to improve supports, services and structures in order to achieve better equity of outcomes, especially for those population groups with the poorest outcomes.⁴⁷ The recommendations from that work will need to be connected with that in social welfare, housing, justice, corrections, accident compensation, employment and children's and older person's sectors and the Waitangi Tribunal Health Services and Outcomes Inquiry.⁴⁸

“Much of the action to improve the social determinants of health for those with learning disabilities (intellectual disabilities) will also improve health for others at higher risk of ill health because of social disadvantage, could also help to reduce inequalities in health across the population.”⁴⁹

It is well established that people with intellectual disabilities experience among the greatest inequities and poorest health and wellbeing outcomes of any population group in New Zealand. For improved access, quality of service and outcomes, children and adults with intellectual disabilities need to be included alongside individual and impairment specific support that may be needed. Disadvantage is compounded and discrimination experienced when health and mental health problems are missed and the cause attributed to intellectual disability⁵⁰, or services are denied because of funding and contracting silos. Difficulties in the health and disability interface were identified in the NDIS evaluation. These included responsibilities for funding shortfalls, the support of people with complex or chronic health conditions and those requiring rehabilitation services.

Improving health outcomes for people with intellectual disabilities is an action in the 2014-2018 Disability Action Plan and in the 2016 New Zealand Health Strategy. In IHC's 2017 tracking progress report we expressed serious concerns that the recommendations of the Disability Action Plan reference group had not been turned into a plan with timeframes for specified actions.



In 2018, not only has there been no progress but a potential risk of going backwards with this project “being re-scoped in line with the government's policy priorities, and work associated with the DSS System Transformation project.”⁵¹ Improving health outcomes for people with intellectual disabilities does not need to be re-scoped or re-prioritised, nor should it wait until the outcomes of the Mental Health and Addictions Inquiry, the Health Review or the DSS transformation. We know enough already from national and international evidence to identify people with intellectual disabilities as a priority population group and to be taking action.

New Zealand is far from being able to respond positively to UNCRPD Committee⁵² questions and issues to ensure all persons with psychosocial and/or intellectual disabilities are identified, supported and accommodated, particularly in the context of health. We are far from having taken the needed measures to ensure access to full healthcare access for all persons with disabilities, including persons with disabilities whose disabilities are a result of health conditions that require specialist services. Nor has there been any substantive progress on taking progress to enact legislation to prohibit and prevent the practice of non-consensual treatments including forced sterilisation, with particular attention being paid to children.

Being visible and counted

Most of the current work refers to disabled people rather than impairment specific population groups. This is illustrated in the Waitangi Tribunal Health Services and Outcomes Inquiry Wai 2575 stage two priority areas that include Māori with disabilities. The Mental Health and Addictions Inquiry terms of reference identified people with disabilities among those groups with the poorest mental health outcomes. Another example is that of the Health and Disability System Review priorities where getting improvements in health outcomes of Māori and other population groups who experience the greatest inequities. Clearly, people with intellectual disabilities are one such population group.

2018 saw the first stage consultation on proposed changes to the National Health Index system which included adding disability status. While this has the potential to be a valuable step in getting better data, there are problems with the suggested use of the Washington Group Short Set (WGSS). Without modifications, the survey questions do not reliably identify children with disabilities and adults with intellectual disabilities and will not get reliable and valid impairment specific data.

IHC will continue to track progress on:

- people with intellectual disabilities being identified as a priority population group by the Ministry of Health
- Ministry of Health's implementation of the recommendations of the improving health outcomes for people with intellectual disabilities reference group
- people with intellectual disabilities and their families and whānau being visible in interim and final reporting from the Waitangi Tribunal Wai2575 Inquiry, the Mental Health and Addictions Inquiry and the Health and Disability Support System Review
- getting better health impairment specific data, recording and reporting for people with intellectual disabilities including accurate reporting of cause of death and the establishment of mortality review processes for people with intellectual disability

43. (Clark, Details of major health review finalised, 2018)

44. (Clark, Speech to the Association of Salaried Medical Specialists' Annual Conference: 23 November 2017, 2017)

45. (New Zealand Health and Disability System Review, 2018)

46. (Mental Health and Addiction Inquiry, 2018)

47. (Ardern, Inquiry to improve mental health services, 2018)

48. (Waitangi Tribunal, 2018)

49. Professor Sir Michael Marmot, Foreword in (Rickard & Donkin, 2018), p. 3

50. This is often referred to as diagnostic overshadowing where problems are missed and causes attributed to intellectual disability.

51. (Office for Disability Issues, 2018)

52. (Committee on the Rights of Persons with Disabilities, 2018)

Money

*“It was clear that the amount of money they (adults with intellectual disabilities living independently) had and how they chose to prioritise their spending was a major contributor to how people lived. A number of people were just managing with basic necessities.”*⁵³

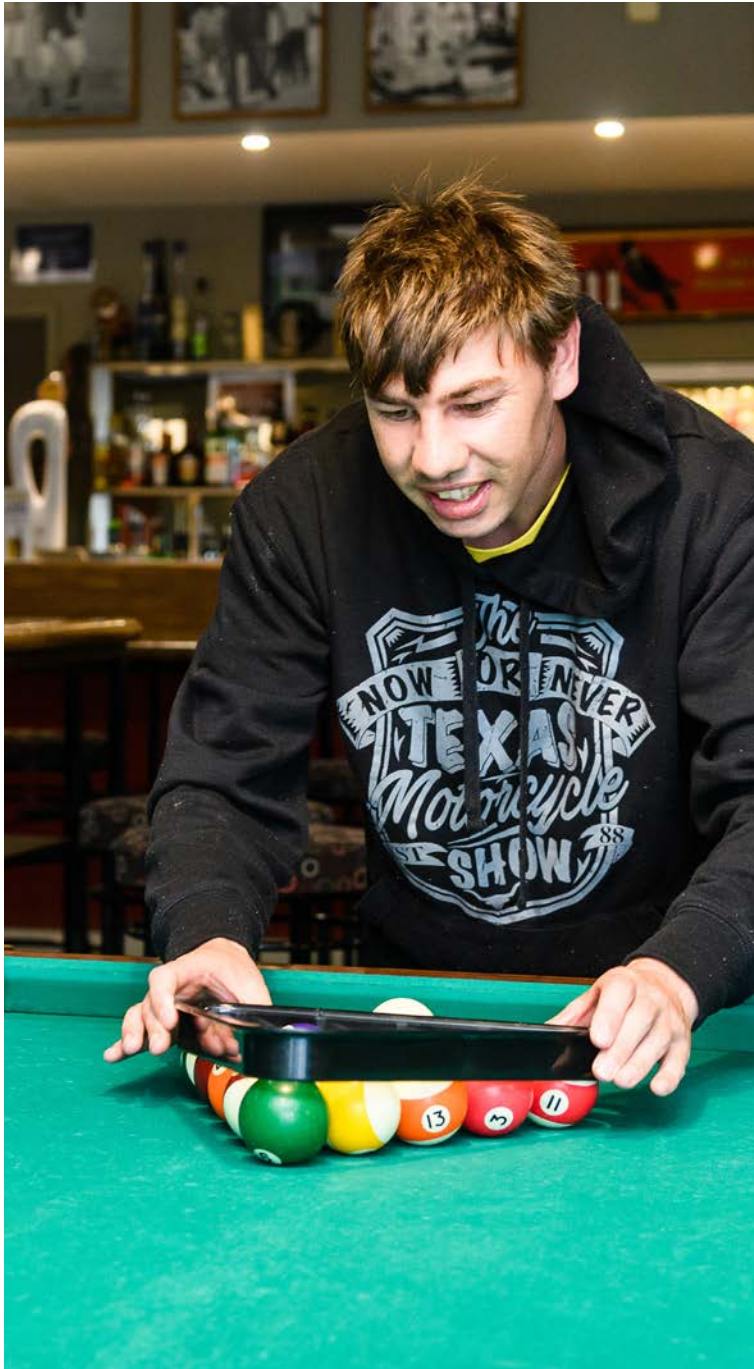
Reducing child poverty and ensuring everyone has an adequate income and standard of living, can live in dignity and participate meaningfully in their communities are priority areas for the government. There are a number of reviews and initiatives underway that have the potential for better outcomes, but there are also many challenges. It is too early to see whether the work that is underway will lead to the linked-up systems, policies and practices that are needed across all ages and stages of life for people with intellectual disabilities and their families and whānau.

Having enough money for a good life and adequate standard of living

People with intellectual disabilities are more likely to have among the lowest rate of employment and poorest economic outcomes when compared to the general population. There is a well-documented link between children with disability and family and whānau income poverty. Disabled children are more likely to live in a one-parent household than non-disabled children. Also, the primary carers of disabled children have a higher unemployment rate than one parent households in general. As a result, households with disabled children are significantly more likely to experience income poverty.⁵⁴

The Child Poverty Reduction Bill has set a child poverty reduction target and proposed changes that include tracking progress on reducing child poverty in the Budget. Reporting will be required on measures of poverty for identified groups, such as disabled children and children with a disabled parent, guardian or caregiver. Making disabled children and disabled parents and caregivers visible and counted in this way is a positive step. However, the Bill includes a caveat that reporting does not have to include an analysis of identified populations if available data is not reasonably adequate. To be meaningful beyond just recognition in the Act substantial progress needs to be made to ensure robust disability and impairment specific data is available.

Included in the terms of reference for the Welfare Expert Advisory Group to consider are: ensuring that people know about and are able to receive the assistance they are entitled to; and improving outcomes for people disproportionately



impacted by negative social outcomes such as Maori, Pacific peoples, youth, disabled people and people with health conditions. The review provides opportunities to increase income, such as increasing the amount that people on benefits can earn before abatement rates start; an increase in earnings other than benefit payments not affecting the accommodation supplement; indexing benefit payments in line with inflation and abolishing benefit sanctions that affect families with children. By comparison, in the United Kingdom, which has higher disability related allowances, households with children with disabilities tend not to be at greater risk of income poverty.⁵⁵

What is counted as income?

The July Cabinet paper⁵⁶ identified problems in directly paying disability support funding payments into people’s bank accounts. This may lead to payments being counted as income and/or assets for some income tax and financial assistance purposes. Also, there are implications for GST costs incurred when individuals purchase support. So far the policy and regulatory solutions have not been found in order operationalise the proposed changes for more flexible and integrated funding. Without a resolution the ability to implement and test an integrated model that that gives greater flexibility and funding directly to individuals and families and whānau will be severely compromised.

Having enough money for a good life in retirement

Issues with New Zealand’s ageing population and workforce and being able to afford retirement have been to the forefront of policy and planning discussions for some years. Additional difficulties for people with intellectual disabilities and their families were highlighted in two examples in 2018.

The first was when Tim Fairhall, a 39-year-old-man with Down syndrome, took his fight to access his KiwiSaver funds before the age of 65 to Parliament.⁵⁷ Tim wants to enjoy the money he has saved and travel overseas to see his brother while he is in good health and not be disadvantaged by ageing faster and not being able to work as long as most people. It was acknowledged by the Minister of Commerce and Consumer Affairs Kris Faafoi that the present rules created an unfair situation and that KiwiSaver is not working for all New

Zealanders. Significant progress in has been made with the appointment of two independent advisors, including IHC’s Donna Mitchell, to advise the Minister on finding the best way for people with life shortening conditions to withdraw their KiwiSaver money when they need to retire.⁵⁸

The second is that of the double disadvantage that occurs for many parents and others in caregiving roles in planning and saving for retirement.⁵⁹ When caring long term for a loved one, (there are) significant long term impacts.”⁶⁰ Along with losing a wage, those in such roles are not able to receive other benefits such as KiwiSaver.

Financial literacy and managing

*“You’ve just got to prioritise your money.”*⁶¹

Recent research⁶² has reinforced how choices about how and where to live are influenced by people’s limited discretionary income and ability to manage a budget. Choices included whether they went on holiday, how they socialised, how they accessed transport and how they sought medical or dental treatments. Those who were employed had more money but their income left little extra for saving. Participants in the research thought learning about money management was important. Many used community budget services, which are a good way to provide help that is independent from services, however, there are already capacity issues for budgeting agencies let alone if there is an increase in numbers with more people living independently.

An area of achievement in recognising and responding to the financial needs and rights of people with disabilities is the 2018 Code of Banking Practice.⁶³ The Voluntary Guidelines to Assist Banks to Meet the Needs of Older and Disabled Customers are no longer voluntary. The “What to expect from us (Banks)” section in the 2018 Code requires that Banks follow the guidelines for older and disabled customers. The Bankers Association, working with representatives from disabled and older people’s organisations and banks, have started a revision of the 2009 Voluntary Guidelines to Assist Banks to Meet the Needs of Older and Disabled Customers that will be completed in 2019.

53. (Conder & Mirfin-Vietch, 2018)
54. (Murray, 2018)

55. (Murray, 2018)
56. (Cabinet Social Wellbeing Committee, [2018])
57. (Man with Down syndrome appeals for early access to KiwiSaver, 2018)
58. (Faafoi, 2018)
59. (Carers NZ, 2018)
60. (Esplin, Moore, & Rook, 2018)
61. (Conder & Mirfin-Vietch, 2018), p.24
62. Ibid
63. (New Zealand Bankers Association, 2018)

IHC to track progress on:

- inclusion of children and young people with disabilities and their families in child poverty reduction and welfare reform
- the effect of welfare reform on people with intellectual disabilities and their families, including:
 - the recommendations of the Welfare Expert Advisory Group and Government's response
 - getting clarity about what counts as income for income tax and financial assistance purposes
- changes to KiwiSaver and other initiatives to ensure people with life shortening conditions have enough money for a good life in retirement
- people with intellectual disabilities being able to access support for financial literacy and managing money when they need it

Work

*Getting and keeping paid employment was very difficult. For the few who had employment, their jobs were important to them, paid work added extra income, contributed to sense of belonging and widened their community connectedness.*⁶⁴

The relationship between good quality work and wellbeing is well documented.⁶⁵ Along with increased skills and income, work brings benefits to health, wellbeing and making contributions as a valued citizen. Being able to have good working conditions and a fair wage is a matter of social justice.

As with other domains, there are a number of initiatives and reviews either underway or in development that aim to ensure decent, well paid work for all and improved employment outcomes for groups who experience the greatest disadvantages. For people with intellectual disabilities who have among the poorest outcomes this should part of an employment strategy, not a welfare strategy – although there are obvious links with the review of the welfare system. Connecting with the education review is another area of overlap.

Post school experiences and pathways

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.⁶⁶ Raising aspirations and starting early are key aspects of getting better transition pathways and outcomes for further education, training and employment. Making improvements in career and transition planning and experiences are priorities in the Education Review and the Draft Learning Support and Disability Action Plan (DAP), as well as the Child and Youth Wellbeing Strategy.

As an action (1c) on the 2014-2018 DAP, improving transitions has not made much progress. The Transitions Working Group has identified options to increase the number of disabled youth transitioning into employment plans to undertake some engagement with disabled youth and families to test these options, with the timing dependent on the availability of youth-oriented disability groups to host the engagement.

Getting better employment outcomes

*"There aren't many jobs out there."*⁶⁷

Improving employment outcomes for people with intellectual disabilities has been the focus of much discussion and identified as a priority in strategies and action plans. There has been no shift in people with intellectual disabilities getting more jobs, or more hours at their current job. While there may be opportunities to trial some initiatives as part of Mana Whaikaha, there is nothing definitive planned in this area further than intended engagement with focus groups around transition. It is of note that NDIS did not change economic outcomes for participants but it did raise expectations.

Positive progress has been the release of the NZDSN Employment Support Practice Guidelines: How to support disabled people to get the job they want. Employment services have an important role in improving the participation rate in workforce and by working alongside disabled people and employers to tailor work opportunities. The guide is based on principles and practices that are evidenced based. They also provide a set of quality indicators against which to judge quality, performance and outcomes.

Fair wages/living wage

People with intellectual disabilities want to be paid a fair wage for the work they do. Identifying alternatives so that the minimum wage exemption process can be removed has been on the agenda for a long time. The DAP Action on this is reported as being behind the original timeframe but progressing with advice being prepared to enable the government to address the discriminatory nature of minimum wage exemption permits.



IHC to track progress on:

- people with intellectual disabilities being included in the government's employment strategy
- reducing the disproportionate numbers of young people with intellectual disabilities not in education, employment or training
- employment outcomes for people with intellectual disabilities
- people with intellectually disability being paid fairly for the work they do
- removal of disincentives for people with intellectual disabilities working, such as adjustment of abatement rates
- the Government's response to the recommendations of the United Nations Committee on the Rights of Persons with Disabilities in relation to work

Justice

"We (Australasian Society for Intellectual Disability) – New Zealand region) are concerned that a person with an intellectual disability has been subjected to repeated Court assessments, and lengthy periods of prison and hospital based detention."^{68, 69}

The quote above highlights that we are far from having the supports and accommodations needed to ensure equal access to justice. This situation is illustrative of many that occur for people with intellectual disabilities in their interactions with the justice system and raises questions as to why legislative protections and service coordination processes have not worked.

Hāpaitia Te Oranga Tangata is a wide-ranging review being undertaken to get safer and more effective justice in a system that has been described as broken.⁷⁰ Consideration is also being given to how aspects of the Family Court system are working. There are overlaps in these initiatives with what is

64. (Conder & Mirfin-Vietch, 2018), p. 40

65. (Rickard & Donkin, 2018)

66. (StatsNZ, 2017)

67. (Conder & Mirfin-Vietch, 2018), p.26

68. (Australasian Society for Intellectual Disability, 2018)

69. (Christian, 2018)

70. (Te Uepū Hāpai i te Ora - the Safe and Effective Justice Advisory Group, 2018)



happening in the mental health, education, children and young people, social welfare and wellbeing area along with the equal right to justice and exercise legal capacity (UNCRC Article 12).

Improvements to interviewing people with intellectual disabilities of all ages, as well as generally supporting communication and true participation in the justice system, are also areas that require attention. IHC has been working with Police to promote the use of communication tools/aids and their use with interview-style questions.

Impact of new legislation

New Family and Whānau Violence Legislation has come into force, and its application in practice provides a strong basis for improving people's right to justice and to be free from violence and abuse. The new legislation should help agencies and organisations deliver an integrated approach to family and whānau violence and safeguarding adults. The definition of family relationship has been amended to make it clear that a close personal relationship may exist between a carer and the person being cared for. In addition, the definition of psychological abuse recognises the power imbalance in relation to a person who is unable, including due to disability, to withdraw from the care or charge of another person.

The new legislation has added provisions for situations when a carer hinders or removes access to any aid or device, medication, or other support that affects, or is likely to affect, the person's quality of life. There are also provisions for where a person is eligible to apply for a Protection Order but lacks capacity, or where an adult is prevented by physical incapacity, fear of harm, or another sufficient cause from making the application personally. Reasonable steps must be taken to get the views of the person on whose behalf the order is sought.

As at 1 July 2019, the youth justice age will go up to 18. This means young people under 18 years of age who offend will be included in the youth justice system. However, there are issues about the capacity of the youth justice system to respond and therefore a potential risk that the numbers of under 18-year olds held under the Intellectual Disability Compulsory Care and Rehabilitation Act (IDCC&R) may increase.

Another area that requires attention is that of improved supports and access to justice for parents with intellectual disabilities. There has been an increase in the numbers of children being taken into state care⁷¹ and anecdotal reports indicate parents with intellectual disabilities continue to face discrimination in decision-making around parenting and uplifts of children.

Addressing past abuse and injustice

The Royal Commission of Inquiry into Historic Abuse in State



Care was one of the government's earliest announcements in February 2018 and was extended to include abuse in faith-based care in November 2018. At the same time, former Disability Commissioner Paul Gibson was appointed as a commissioner on the Inquiry. The aims of the Inquiry are to: understand, acknowledge, and respond to the harm caused to individuals, families, whānau, hapū, iwi, and communities; and ensure lessons are learned for the future. The Inquiry has a wide scope and covers physical, sexual and emotional abuse and neglect. Children, young people and adults with disabilities are over-represented in institutional abuse that occurred historically.

IHC to track progress on:

- Numbers of young people aged under 18 held under the IDCC&R Act
- Supports and accommodation made so people with intellectual disabilities and their families, whānau, iwi and communities heard and responded to
- The number of protection orders sought on behalf of people with intellectual disabilities
- Operational policy changes around Police interviewing
- Opportunities and support for people with intellectual disabilities to take part in the Royal Commission of Inquiry into Historic Abuse in State Care and in the Care of Faith-based Institutions

71. (Children's Rights Coalition, [2018])

Bibliography

Ardern, J. (2018, January 23). Inquiry to improve mental health services. [Press Release]. Retrieved from https://www.beehive.govt.nz/release/inquiry-improve-mental-health-services

Ardern, J. (2018, November 4). Prime Minister’s speech to 2018 Labour Party Conference. Retrieved from https://www.beehive.govt.nz/speech/prime-minister%E2%80%99s-speech-2018-labour-party-conference

Ardern, J. (2018, September 24). The importance of family-friendly policies around the world. Speech to 9th Annual Social Good Summit. New York City. Retrieved from https://www.beehive.govt.nz/speech/importance-family-friendly-policies-around-world

Australasian Society for Intellectual Disability. (2018, November 15). Press Release.

Cabinet Social Wellbeing Committee. ([2018], [September]). Cabinet Paper: Disability support system transformation - Paper 2: policy and regulatory issues. Retrieved from http://www.enablinggoodlives.co.nz/dmsdocument/272-disability-support-system-transformation-paper-2-policy-and-regulatory-issues-pdf

Carers NZ. (2018, September 20). Flexible Funding To Support Disabled People and their Families report. [Press Release]. Retrieved November 2018, from http://carers.net.nz/flexible-funding-support-disabled-people-families-report/

Chamberlain V Minister of Health NZCA 8, CA460/2017 (NZCA February 7, [2018]). Retrieved November 2018, from https://forms.justice.govt.nz/search/Documents/pdf/jdo/22/alfresco/service/api/node/content/workspace/SpacesStore/6e9c5846-6fe2-4759-b099-6e430b8e1e3a/6e9c5846-6fe2-4759-b099-6e430b8e1e3a.pdf

Children’s Rights Coalition. ([2018]). Children’s Rights Report - UPR 3 Aotearoa New Zealand. Retrieved from https://ihc.org.nz/sites/default/files/UPR%203%20Aotearoa%20New%20Zealand%20Children%27s%20Rights%20Coalition%20final%20submission.pdf

Christian, H. (2018, November 15). Not fit for prison: The journey of a mentally disabled woman through the criminal justice system. www.stuff.co.nz. Retrieved from https://www.stuff.co.nz/national/crime/108565933/not-fit-for-prison-the-journey-of-a-mentally-disabled-woman-through-the-criminal-justice-system

Clark, D. (2017, November 23). Speech to the Association of Salaried Medical Specialists’ Annual Conference: 23 November 2017. Retrieved from https://www.beehive.govt.nz/speech/speech-association-salaried-medical-specialists-annual-conference

Clark, D. (2018, August 8). Details of major health review finalised. [Press Release]. Retrieved from https://www.beehive.govt.nz/release/details-major-health-review-finalised

Clark, D., & Shaw, J. (2018, September 27). Making Funded Family Care fairer. [Press Release]. Retrieved November 10, 2018, from https://www.beehive.govt.nz/release/making-funded-family-care-fairer

Committee on the Rights of Persons with Disabilities. (2018, March 6). List of issues prior to submission of the combined second and third periodic of New Zealand. CRPD/C/NZL/QPR/2-3. Retrieved from https://tbinternet.ohchr.org/Treaties/CRPD/Shared Documents/NZL/CRPD_C_NZL_QPR_2-3_29635_E.docx

Conder, J., & Mirfin-Vietch, B. (2018). From presence to belonging: Experiences and outcomes of living independently. Dunedin, New Zealand: Donald Beasley Institute. Retrieved November 2018, from http://www.donaldbeasley.org.nz/assets/Uploads/publications/From-Presence-to-Belonging.pdf

Council of Canadians with Disabilities (CCD) and Canadian Association for Community Living (CACL). (2013, October 9). Media Advisory: Comment on appeal of Carter v. Canada (assisted suicide). [Press Release]. Retrieved from http://www.ccdonline.ca/node/1251

Department of the Prime Minister and Cabinet. (2018, October 19). Child Wellbeing Unit. Retrieved November 2018, from dpmc.govt.nz: https://dpmc.govt.nz/our-business-units/child-wellbeing-unit

Eder, J., & Bohny, S. (2018, July 18). Review prompted by Ruby Knox murder blasts NZ’s disability care. www.stuff.co.nz. Retrieved from https://www.stuff.co.nz/national/health/105553241/review-prompted-by-ruby-knox-murder-blasts-nzs-disability-care

Esplin, J., Moore, D., & Rook, H. (2018). Discussion Paper for Carers New Zealand and the NZ Carers Alliance Paid Family Care Discussion: Funded Family Care and other schemes in New Zealand. [Auckland]: Sapere Research Group. Retrieved November 2018, from http://carers.net.nz/wp-content/uploads/2018/05/Paid-Family-Care-Discussion-Paper-FINAL-24-April-2018.pdf

Faaoi, K. (2018, December 11). Minister progresses KiwiSaver withdrawals for people with life-shortening conditions. [Press Release]. Retrieved from https://www.beehive.govt.nz/release/minister-progresses-kiwisaver-withdrawals-people-life-shortening-conditions

Gerritsen, J. (2018, September 3). Pre-schoolers with disabilities face long waits for specialist help. Retrieved November 2018, from radionz.co.nz: https://www.radionz.co.nz/news/national/365505/pre-schoolers-with-disabilities-face-long-waits-for-specialist-help

Hipkins, C. (2018, February 21). Ambitious three-year work programme for education. [Press Release]. Retrieved November 2018, from www.beehive.govt.nz/release: https://www.beehive.govt.nz/release/ambitious-three-year-work-programme-education

IHC New Zealand. (2018, January/February). IHC Hot Issues – Census may lead to a lower reporting of disability . Retrieved from www.ihc.org.nz: https://ihc.org.nz/ihc-hot-issues-januaryfebruary-2018

Jarrett, S. (2018). Transition to adulthood: why is it still such a problem? Community Living, 32(1), 3.

Kendrick, M., Ward, M., & Chenoweth, L. (2017). Australia’s national disability insurance scheme: looking back to shape the future. Disability & Society, 32(7), 1333-1350. Retrieved from https://www.tandfonline.com/doi/abs/10.1080/09687599.2017.1322493

Kirk, S. (2018, December 9). Disability and support sector at funding breaking point ‘waiting on a tragedy’. www.stuff.co.nz. https://www.stuff.co.nz/national/politics/109133519/disability-and-support-sector-at-funding-breaking-point-waiting-on-a-tragedy.

Man with Down syndrome appeals for early access to KiwiSaver. (2018, September 12). Retrieved November 2018, from https://www.stuff.co.nz/business/money/107037685/man-with-down-syndrome-appeals-for-early-access-to-kiwisaver

Mavromaras, K., Moskos, M., Mahuteau, S., & Isherwood, L. (2018). Evaluation of the NDIS: Final Report. Adelaide, Australia: National Institute of Labour Studies, Flinders University. Retrieved November 15, 2018, from https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf

Mental Health and Addiction Inquiry. (2018). Government Inquiry into Mental Health and Addiction. Retrieved November 2018, from https://www.mentalhealth.inquiry.govt.nz/

Ministry of Health. (2018, October 24). I Choose. Retrieved from https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respice/i-choose

Morgan, G. (2018). Māui Street. Wellington, New Zealand: Brigit Williams Books.

Murray, S. (2018). Breaking the link between disability and child and whānua poverty. Policy Quarterly, 14(4), 68-77. Retrieved November 2018, from https://www.victoria.ac.nz/igps/policy-quarterly

Neal, T. (2018, July 18). Report findings after Ruby Knox’s death released. www.radionz.co.nz/news. Retrieved from https://www.radionz.co.nz/news/national/362093/report-findings-after-ruby-knox-s-death-released

Nelson Marlborough Health. (2018, July 17). Nelson Marlborough Health statement and information relating to the Serious event review into the care and treatment of RK (Rosemary Marks). [Press Release].

New Zealand Bankers Association. (2018, June). The Code of Banking Practice: What you can expect from your bank. [Wellington], New Zealand: New Zealand Bankers Association. Retrieved November 2018, from https://www.nzba.org.nz/consumer-information/code-banking-practice/code-of-banking-practice/

New Zealand Health and Disability System Review. (2018). Retrieved November 2018, from https://systemreview.health.govt.nz/

Office for Disability Issues. (2018). Disability Action Plan 2014 - 2018 Progress report: September 2018. Retrieved November 2018, from https://www.odi.govt.nz/assets/Uploads/DAP-Progress-Report-September-2018.docx

Oranga Tamariki (National care standards and related matters) regulations. (2018).

Redmond, A. (2018, October 14). Wait times for Early Intervention Services appointments grow longer, despite \$21.5m investment. www.stuff.co.nz. Retrieved from https://www.stuff.co.nz/national/107789033/wait-times-for-early-intervention-services-appointments-grow-longer-despite-215m-investment

Rickard, W., & Donkin, A. (2018). A Fair, Supportive Society: Summary Report. [London]: Institute of Health Equity. Retrieved from http://www.instituteofhealthequity.org/resources-reports/a-fair-supportive-society-summary-report/a-fair-supportive-society-summary-report.pdf

Sepuloni, C. (2017, November 16). Addressing poverty for New Zealanders with disabilities is vital. [Press Release]. Retrieved from https://www.beehive.govt.nz/release/addressing-poverty-new-zealanders-disabilities-vital

Stats NZ. (2018, October 23). Indicators Aotearoa New Zealand – Ngā Tūtohu Aotearoa: Consultation. Retrieved November 2018, from https://www.stats.govt.nz/consultations/indicators-aotearoa-new-zealand-nga-tutohu-aotearoa-consultation

StatsNZ. (2017, August 2). New Zealand Household Labour Force Survey 2017 – June quarter. New Zealand: StatsNZ. Retrieved from https://www.stats.govt.nz/information-releases/labour-market-statistics-june-2017-quarter

Synergia. (2018). Flexible Funding to Support Disabled People and Their Families: A Review and Analysis of the New Zealand Market [Summary]. [Auckland]: Synergia. Retrieved November 2018, from http://carers.net.nz/wp-content/uploads/2018/09/Carers-Alliance-Synergia-Overview-June-2018-002.pdf

Te Uepū Hāpai i te Ora - the Safe and Effective Justice Advisory Group. (2018). Safe and Effective Justice - Hāpaitia Te Oranga Tangata - Criminal Justice Sector Review. Retrieved November 2018, from https://www.safeandeffectivejustice.govt.nz/

Tesoriero, P. (2018, November 20). Inclusive education produces better outcomes for all. New Zealand Herald. Retrieved from https://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=12162766

Waitangi Tribunal. (2018, December 12). Health Services and Outcomes Inquiry. Retrieved from https://www.waitangitribunal.govt.nz/inquiries/kaupapa-inquiries/health-services-and-outcomes-inquiry/



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