

Making citizenship and rights  
real in the lives of people with  
intellectual disabilities





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## Introduction

**A nation of valued individuals leads to stronger communities and a better society for all.**

Without a doubt there have been significant advances for people with intellectual disabilities<sup>1</sup> in New Zealand but progress has not been good enough. People with intellectual disabilities continue to experience persistent disadvantage and be defined by the labels others give them. Too often people are positioned as ‘other’ and seen as a ‘burden’. There are too many gaps and there is a way to go before we can say people with intellectual disabilities are living valued and good lives as citizens where no voice is unheard and no rights ignored.

This report outlines what has happened and what needs to happen to make rights, citizenship and valued lives real for people with intellectual disabilities and identifies some indicators and possible measures for tracking progress.

The landmark 2003 National Health Committee (NHC) report *To Have An ‘Ordinary’ Life, Kia Whai Oranga ‘Noa’*: Community

membership for adults with an intellectual disability (THAOL) provides a reference point to reflect on the current situation. THAOL was concerned with the lives of adults. In this report we take a whole of life approach that includes children.

New Zealand’s ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2008 has given us a new lens through which to consider the lives and citizenship of people with intellectual disabilities. The CRPD provides standards against which laws, policies and practices can be monitored and measured. It has also given the impetus for new conversations, collaborations and ways of monitoring.

A revision of the New Zealand Disability Strategy (NZDS) is being undertaken in 2016. The new strategy for 2016 aims to show how the CRPD should be implemented in the New Zealand context. Integral to this work is the development of a monitoring framework.

We conclude with IHC’s plans to track progress on the realisation of citizenship and rights in the everyday lives of people with intellectual disabilities.

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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.

## Background

The *'To Have an 'Ordinary' Life'* project arose from NHC concerns about the service provision environment for adults with intellectual disabilities that was emerging in the wake of deinstitutionalisation. The word 'ordinary' was used to "reflect the aspirations of adults with intellectual disabilities to access the everyday things that others take for granted" (p.5).

THAOL spoke to the things people said mattered most – belonging, relationships, friendships, family/whānau, culture, home, learning, health, deciding where and how to live, money, work, having fun and getting around. The report was grounded in human rights and citizenship.

The NHC asked the question: To what degree were adults with intellectual disability able to live 'ordinary' lives and accorded, and able to access, the same rights and responsibilities as other New Zealanders? They found that many had lives that were far from 'ordinary' and that there was a long way to go for them to achieve the same day-to-day rights of citizenship as the rest of the population or the vision of the 2001 NZDS.

The NHC reported "that although services in New Zealand have, with good intent, sought to move away from institutional-based services, much of this has focused on removing bricks and mortar rather than on ensuring support is provided in a way that is not institutional. Service purchase and provision have failed to keep up with international best practice." (p.8) Adults with intellectual disability were seldom "integrated into community life on their own terms, individual choices in the most fundamental of life decisions are not available to them, and their aspirations and goals are not supported" (p.6).

The Committee considered a cross-government response was needed to achieve community membership for people with intellectual disabilities as envisaged by the NZDS. 58 specific recommendations across 23 recommendation areas were made.

THAOL has become a landmark document for people with intellectual disabilities and their families and allies about what needed to change and key areas to be addressed. Many disability support providers have used the idea of an 'ordinary life' and recommendations of the report to help guide their policies and practices. The framework used in the project has also been adapted for use with children.

THAOL was, however, a report to government. What was their response to the recommendations made? Have effective actions been taken that have resulted in better outcomes in people's lives? More than 12 years later the answer is similar to that of the 2003 THAOL report. There's been good intent and steps in the right direction but progress has not

been good enough. It has been slow, piecemeal and reached too few. Considerable knowledge has built up about what people with intellectual disabilities and their families want and what works. We should be further ahead than we are in achieving meaningful and sustainable change so that rights and citizenship are real in the lives of people with intellectual disability.

See Appendix 1 for a summary of progress on the 23 THAOL recommendation areas.

## Policy and practices since 2003

In the years since the release of the THAOL report there have been numerous advisory groups and reviews and reports to, for and from government (see Appendix 2). There have been legal and human rights challenges to government in areas of disability policy and discrimination. A Ministerial Committee on Disability Issues responsible for co-ordinating disability support and related policies across government has been established and new disability sector networks have been set up.

A range of pilots, trials and demonstration projects, many with the aim of increasing choice and control for people with disabilities, have been embarked upon. New terms and acronyms have entered our language such as 'New Model', individualised funding (IF), enhanced individualised funding (EIF), local area coordination (LAC), Choice in Community Living (CiCL) and Enabling Good Lives (EGL).

These events have occurred within a wider context of government policy and actions that have included the adoption of an investment approach, the introduction of welfare reforms, a focus on vulnerable children and the 2015 Productivity Commission recommendations on more effective social services. Growing inequalities and poverty have been highlighted. As with many other countries New Zealand is experiencing increasing cultural diversity and an ageing population. Digital advances and social media have brought changes in the way people communicate and connect.

Despite all this activity since 2003 many people with intellectual disabilities are still not able to live valued and good lives and do not have equal access to opportunities and citizenship. There are silences with people with intellectual disability and their families not being included or visible in policy or reporting for all New Zealanders. There is a lack of an overarching framework that gives cohesive and coherent design. Co-production and co-design have become new buzzwords but this is seldom matched by authentic practices. More often than not people with intellectual disabilities and their families and whānau are not involved from the start and what happens is at best is consultation about pre-determined options.

Responding with urgency to “the systemic neglect of the health of adults with intellectual disability” (THAOL, p.26) was a priority action identified by the NHC. At IHC’s 2012 ‘Making Rights Real’ symposium David Rutherford, Chief Human Rights Commissioner decried the lack of progress by government in implementing this and other THAOL recommendations. It took until 2015 for a government-led response with the establishment of the improving health outcomes for people with intellectual disabilities reference group as part of the 2014-2018 Disability Action Plan.

Children and adults with intellectual disability and their families and whānau struggle to get the right support at the right time. They are forced to negotiate a complex maze to access services and support, endure endless assessments and long waiting lists and often have to be in crisis before they can get help if they get help at all. It can be particularly difficult for people with severe and profound impairments and those with high and complex needs to access quality supports and services.

Too often children are denied their rights to education and as adults are confronted by numerous barriers to post school education, training and paid work. Disadvantage can be compounded for some groups within the disabled population. 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>2</sup>.

Custodial models of service delivery are still very much in evidence. Not being able to choose where and with who to live remains the norm for most people. Community participation can often be more like an ‘outsider’ visit as part of programmed activity rather than as an ‘insider’ who belongs and is able to act spontaneously or change their mind. Too many people live isolated and impoverished lives on the margins. People with intellectual disabilities continue to be subjected to discrimination, abuses, incarceration, sterilization, overmedication, and punishment regimes that would not be tolerated in most other population groups.

There is no clearer illustration that we are not getting the basics right in terms of quality and safety than the abusive situations and poor quality services that led to Social Service Select Committee ‘Inquiry into the quality of care and service provision’ that began in 2006 and was reported on in 2008. The cases that led to the 2013 review, *Putting People First: A review of Disability Support Services performance and quality management processes for purchased provider services* and other instances of abuse that hit the media around the same time demonstrate that we continue not to get the basics right.



Trials and demonstrations under the ‘New Model’ umbrella such as LAC, EIF and CiCL were among the government’s responses to the Social Service Select Committee’s recommendations. These have occurred alongside and been linked to the EGL demonstrations in Christchurch and Waikato that also aim at getting more flexible and individualised support and use of funding in ways that increase choice and control for people with disabilities. Evaluations of these projects and trials have reported benefits for many participants in having greater flexibility, being able to get supports in ways that work for them and achieving sought outcomes.

The benefits offered by these different ways of working have only been available to a small proportion of the population of people with intellectual disabilities and their families and whānau. There are unanswered questions about the implications and ability to scale up if these new approaches are adopted nationally. Within the trials not all participants have benefitted equally. An evaluation<sup>3</sup> found while many participants achieved sought outcomes from the CiCL those requiring 24 hour care who were not able to share paid support with others were excluded, there were problems when staff had a “residential” (custodial/institutional) mentality and not having enough money for transport costs restricted some people’s ability to participate in community life.

2. New Zealand Disability Survey, 2013 He hauā Māori

3. M.Roorda et al, Demonstrating changes to disability support: Evaluation Report, 7 April, 2015



## What needs to happen to make citizenship and rights real?

To be real rights must be accompanied by opportunities in people's day-to-day living and be matched by real duties and obligations to respect, fulfil and safeguard. Actions that enhance wellbeing and enable human rights and citizenship benefit not only people with intellectual disabilities and their families and whānau - they benefit all and build stronger communities.

All New Zealanders share the responsibility to promote and protect citizenship and rights. Government in its stewardship role, however, plays a critical part in creating enabling environments for individual, family and whānau and community wellbeing and where rights can be real in people's lives.

In this section we identify what we would expect to see if rights were real in people's lives. These are drawn from what people with intellectual disabilities and their families say<sup>4</sup> matter most in being able to live 'valued', 'good' and 'ordinary' lives. We use a developmental lens to apply a whole of life approach across the lifespan and different areas of life. Just as people are interdependent so are human rights. Actions need to work together in ways that are consistent, coherent and connected.

### Belonging and being included

*"We (parents) are still asking permission for our children with disability to join a sports club or a dance class. We don't ask for our other kids who do not have a disability, they are just enrolled"*

*"It's really important to feel like I am part of my community. When I walk into town, I always bump into people I know. It's great to feel like I belong where I live and to say hello to the locals in town"*

*"Sometimes we are left out, people see us with a label, and they think we can't do anything"*

*"We're not asking for anything special. We want people to look beyond the disability and 'find' the person. We want to be included in the community and we just want to be treated equally and have the freedom to make our own choices like anyone else, to be independent, have a normal life and decent career, and to spend time doing things with family and friends"*

People with intellectual disabilities are family, whānau and community members, friends, partners, students, workers, athletes, artists, colleagues, neighbours, customers, and so much more.

Being seen as people first and being connected in their communities and culture is the essence of what has been long called for by people with intellectual disabilities and their families and whānau. Inclusive communities are ones where we all belong and know we belong, where people can live together with fairness and justice, where everybody's contribution is valued and where we can be equal but different<sup>5</sup>.

Families and whānau are the foundation of communities. Families come in a range of sizes and family life and dynamics change as children grow, people age and family circumstances alter. But family love and commitment is almost always a constant.

The words we use, how we behave and how others talk to and behave with us have powerful effects on our sense of identity, agency and authority and on how others see us. There have been positive changes in how people with intellectual disabilities are viewed but many old ways of thinking and behaving that devalue and stigmatise persist. Still too often people with intellectual disabilities are positioned as 'other' and are missing from mainstream agendas or are included as an 'add on' rather than being there from the start.

4. Note – unless otherwise stated quotes are from people with intellectual disabilities and family members gathered by IHC

5. Simon Duffy (2003) Keys to citizenship



### What would we expect to see:

- People with intellectual disabilities participating and contributing to family and community life in the same ways and at the same rates as their non-disabled peers.
- Adjustments and accommodations are made without a fuss – it is just the way things are done.
- People are spoken to, referred to and represented in respectful ways in everything from day to day interactions to formal written material.
- Children and adults with intellectual disability are included and visible in all government policy and reporting.

### Being and feeling safe

*“It’s really hard to focus on learning to catch the bus, like money and timetables, when you are worried about who is going to be mean to you.”*

*“Half of the female participants revealed that they had been sexually abused and one-third of the men, but only a very small number had been complainants in sexual abuse cases.”*

Brigit Mirfin-Veitch, Kate Diesfeld, Sue Gates and Mark Henaghan (2014)<sup>6</sup>

Effective safeguards respect rights, support decision-making and are tailored to individual circumstances. Having people in

your life who love, care, look out and advocate for you are the best protections. This does not always happen. People with disabilities are more likely to be targeted and be victims of abuse and neglect than the general population and typically this is under-recognised, under-reported and inadequately addressed.

Being bullied is one the most frequently expressed concerns made by people with intellectual disabilities and can act as barrier to being and feeling part of the community. Disabled children are three times more likely than non-disabled children to be abused or neglected and these rates are even higher for children with communication impairments, behaviour difficulties, intellectual disability and sensory disabilities.<sup>7</sup> Women with disabilities are more likely to experience violence than both men with disabilities and women in the general population.

### What would we expect to see:

- Policies and processes where people know their rights, are supported and able to speak up, where concerns about and reports of abuse are listened to and where immediate response action is taken.
- Increased capacity and capability in community organisations such as victim support, women’s refugee and children’s action teams in working with people with intellectual disabilities.
- All publically funded anti-bullying and anti-violence campaigns and initiatives to include people with intellectual disabilities.
- Government to collect information on intellectual disability in all care and protection, family violence and victim of crime reporting.

### Communicating and making decisions

*“Our family uses a phone app. My son can’t talk but he can tap on the phone and use a combination of Makaton and NZ sign language”*

*“It’s my right to make decisions, just like everyone else does”*

*“Having the freedom to choose to do things just like other people without disability”*

*“He’s (son) not verbal so you need to look at his body language to ascertain what he wants”*

*“It’s important to have lots of people who care for you. It’s better if you have got lots of friends and people who care; they look out for you and help you to make decisions”*

6. Brigit Mirfin-Veitch, Kate Diesfeld, Sue Gates and Mark Henaghan (2014) *Developing a more responsive legal system for people with intellectual disability in New Zealand.*

7. Sally Robinson (2012), Sally Robinson and Julia Truscott (2014)

Being able to make things happen in ways that work for us is a fundamental part of our lives that contributes significantly to our wellbeing<sup>8</sup>. The realisation of the right to equal recognition before the law (UNCRPD Article 12) is central to being able to choose where and with who to live, have a bank account, agree to an employment contract, sign a tenancy agreement, make health decisions and consent to medical procedures, and many more aspects of life.

Research has demonstrated that young people who rate more highly on measures of self-determination go on to have better outcomes in their adult lives than those who do not.<sup>9</sup> Being able to make decisions and being seen making decisions and having control in our lives helps others view us with respect and makes us safer. It does not mean that we have to do everything for ourselves or that as individuals we have unlimited choice and control. We are interdependent and help and are helped by others.

All people with intellectual disabilities, including those with the most significant impairments, can exercise their self-determination in being supported in their right to decide<sup>10</sup>. Increased choice and control have been highlighted as aims in recent plans and initiatives and in efforts by disability service providers to improve the ways they work. Yet people with intellectual disabilities continue to be denied the opportunity to make decisions and do not get the necessary support or communication assistance to exercise their legal capacity. Accessing independent advocacy is often difficult and sometimes impossible to find.

Decisions made by individuals, including those made with their families and whānau and others in their support network, are often not recognised and more formal legal processes such as welfare guardianship are wrongly demanded. Good intent can be thwarted by confusion and misunderstanding about the practical ways to shift from substitute to supported decision-making.

### What would we expect to see:

- Everyone has communication assistance and support for understanding and expressing choices in ways that work best for them so everyone's voice is heard and preferences known.
- Children and young people are learning about and making choices and decisions like their brothers and sisters and peers.

- Information is easy to find, understand and use so people can make informed decisions.
- Families, others in support roles, health and legal professionals are well informed about rights in supported decision-making and safeguarding.
- People are given the chance to try as much as possible, to learn from their experiences and try again.
- Decisions made by people with intellectual disabilities, including agreements made with or represented by an individual's support network, are recognised and responded to as valid decisions.
- Legal orders are not demanded by banks, doctors and others when they are not required for consent.
- Government to strengthen and broaden the scope of publicly funded independent advocacy services.
- Where restrictions are imposed for reasons of personal safety or safety to others these be for a short a time as possible and the person and their advocates be involved in decision-making and regular review.
- New Zealand legislation, policy and practices are guided by and compliant with the Committee on the Rights of Persons with Disabilities comments on Article 12<sup>11</sup> and recommendations to New Zealand on shifting from substitute to supported decision-making.<sup>12</sup>

### Speaking up for self and others

A powerful way of becoming confident as a self-advocate and to contribute, is to meet with people who share similar experiences, work together to support each other and represent the interests of the group in local and national forums. Peers can help others with planning, learning skills and developing capacities that can be shared. People First New Zealand provides opportunities and a representative voice for people on a number of advisory and governance groups.

Sometimes when a representative voice is sought people do not have the right support to participate and the ways of working are determined by others rather than being the ways that work best for the individual. Current arrangements for representative voice are adult focused and typically the voice of children and young people with disabilities is missing or not visible.

8. Michael Marriot (2015) The health gap: The challenge of an unequal world

9. Michael Wehmeyer et al (2013) Establishing a causal relationship between interventions to promote self-determination and enhanced student self-determination. *Journal of Special Education*, 46(4), 195 – 210

10. Inclusion International (2014) *Global Report 2014 Independent but not alone*, p.26

11. Committee on the Rights of Persons with Disabilities, 31 March-11 April 2014, General comment No. 1 (2014)

12. Committee on the Rights of Persons with Disabilities, 3 October, 2014, (Advanced unedited version) *Concluding observations on the initial report of New Zealand*

## What would we expect to see:

- Strengthened representative voice for children and young people through an umbrella association or forum for bringing together representative groups.
- Support is given and accommodations made so people with intellectual disabilities are able to participate in meetings and advisory and governance groups on an equal basis.
- Sustainable funding for self advocacy groups so that people can build up knowledge and skills and peer mentor new members.

## Health

*“A lack of communication between departments at the hospital meant that my daughter did not receive a hearing check despite being recognised as having a high risk of hearing loss or impairment”*

*“The doctor treated our daughter’s needs as if she was a second-class citizen”*

*“Our doctor is amazing as he speaks to us in a way we understand”*

Being healthy plays a big part in our well-being. It’s well established that people with intellectual disabilities have significantly poorer health outcomes than the general population. That’s despite long standing concerns about inequities in access to and the quality of healthcare and high rates of polypharmacy, difficulties in accessing health promotion activities and the development of assessment tools, health passports and some better ways of working.

People with profound and multiple impairments (high and complex needs) are particularly vulnerable. Breathing and airways problems, eating problems, epilepsy and pressure care are among the some of the concerns that are often not well recognized or responded to for this group<sup>13</sup>. Some people with multiple impairments or high and complex health needs find it hard to get the specialist care needed when they move from paediatric to adult services. Difficulties are often experienced in accessing mental health and aged care services.

As already noted increasing access to health services and improving health outcomes for disabled people with a specific focus on people with intellectual disabilities is a priority action in the current Disability Action Plan.



13. Eric Emerson and Chris Hatton (2014), Brigit Mirfin-Veitch and Anna Paris (2013)

## What would we expect to see:

- In 2016 the government making a commitment to implementing with urgency the recommendations that result from the work of the Disability Action Plan priority ‘Improving health outcomes for people with intellectual disabilities’.
- People with intellectual disabilities identified as a priority population group and included in the New Zealand Health Strategy and other Ministry of Health policy, initiatives and reporting.
- Reduction in disparities in access to healthcare and in health outcomes.
- Government funding of annual health checks for adults with intellectual disability and longer GP appointment times where needed.
- All publically funded health and mental health campaigns contain plans for including and reaching people with intellectual disabilities.
- All health practitioners have initial education and ongoing professional development in working with people with intellectual disabilities.
- Improving health outcomes for people with intellectual disabilities is a priority area for Health Research Council funding and partnerships.

## Health and bioethical decisions

There have been longstanding bioethical issues that have not been adequately addressed and continue to breach people’s rights. These are compounded by persistent beliefs that view people with intellectual disabilities as ‘less worthy’ or ‘eternal children’. The denial of medical treatment and sterilisation of girls and women<sup>14</sup> for non-therapeutic reasons are two examples. New challenges are being faced with developments in genetics and medical technologies. These have been highlighted recently with the introduction of the National Screening Programme for Down Syndrome and the use of treatments to stunt growth.

## What would we expect to see:

- Robust processes for bioethical decision-making that are consistent with the United Nations’ Convention on the Rights of the Child (UNCROC) and the UNCRPD.
- Government takes urgent action to address the concerns raised by the Committee on the Rights of Persons with Disabilities about the sterilisation of children and adults with disability.

## Early support and education

*“There are lots of positive things that come from children with disabilities attending their local school...there is a generation of children who have had classmates with disabilities...children with intellectual disability participating in regular class from programmes learn decision-making and other skills from other children as well as the teacher”*

*“When my son was younger there was a petition at the school to get rid of him so we had to change school”*

## Early years

The profound impact of children’s early experiences on their health, well-being and learning and their engagement in school, work, family, and community life is well recognised. Being included in the community of all children and being able to get timely and flexible support contributes to getting a strong start. This should begin an integrated, whole of life approach that continues throughout the school years, into adulthood and to the end of life. For many families, however, it is still a hit and miss affair as to whether they get needed information and access to early support and services.

Good early engagement and supports has positive impacts for children with developmental delay and their families and family<sup>15</sup>. Lack of timely and quality support and services increases stress for families and for some can led to an out of home placement for the child being sought.

## What would we expect to see:

- Easy to find information and support.
- Greater investment in early and proactive support for children and their families that is available from when concerns are first raised and is not dependent on having a diagnosis.

14. The concluding observations from the Committee on the Rights of Persons with Disabilities, 3 October, 2014, identified the need for New Zealand to address concerns about the sterilization of disabled children and adults

15. Jenny Wyber (2012), *What are the risk factors in the abuse and maltreatment of children with disabilities?*



- All children with developmental delay having equal access to universal services alongside needed additional support and specialist services.
- Family-centered approaches and planning that respect family knowledge, culture and preferences.
- Children with developmental delay participating in same rates as their non-disabled peers in quality early childhood education.
- All ECE teachers and early intervention practitioners are trained in inclusive and collaborative ways of working.
- Children experiencing a seamless transition to school.
- Families are no longer asked to pay for extra teacher aide hours or to keep their children home from school when the teach aide is unavailable.
- All teacher education and ongoing professional development includes programmes in inclusive education and practice.
- All schools, teachers, teacher aides and other school staff have the right support and resourcing to create and sustain inclusive practice.
- All students with intellectual disability are included in school careers and work experience programmes and government funded youth initiatives.

## School years

Inclusive schools that value and welcome disabled children are a critical building block for inclusive communities where adults with intellectual disability can live as active citizens. Research has demonstrated the benefits of inclusive education to students with disabilities and for all students<sup>16</sup>.

Despite the promises in law and special education policy, New Zealand's obligations under international human rights conventions many children and young people with intellectual disabilities still struggle to get a fair deal at their local school. They are treated differently from their non-disabled peers from enrolment to accessing the curriculum and participating in school life. In the later stages of school life students with disabilities are often not included with their non-disabled peers in work experience or career planning.

Schools say that they do not have the right resourcing or support from government to do their best by disabled children and some resort to using disciplinary processes such as stand-downs and suspensions to respond to disability related behaviour. There is a lack of monitoring and accountability around achievement, inclusive practices and other experiences of disabled children at their local school. These problems have existed for far too long.

## What would we expect to see:

- Students with disabilities being seen as learners first.
- All students have access to the curriculum and achieving quality learning outcomes.
- Reasonable accommodations are understood and applied.
- Stand-downs, suspensions, expulsion and exclusion for disability related issues are unlawful.

- Young people are leaving school at the same age as their non-disabled peers.
- The establishment of an Independent Education Review Office with the Statutory Authority to ensure that disabled children and young people are participating and learning in school.
- Government agencies (including Boards of Trustees, Ministry of Education, Education Review Office) routinely collect, analyse and make publically available data on the participation, experiences, and achievement of disabled students that is reported by impairment.

## Work and post school education and training

*"Going to work makes life good for me"*

*"We want real jobs for real pay"*

*"Getting up and going to work, it doesn't matter if it is voluntary or paid. It's about being out there and doing something"*

*"I would like to do new things but the courses need to be accessible....some of them are too expensive and hard to get on"*

Belonging to and contributing in our communities is central to our citizenship and gives us a sense of purpose, helps us develop our interests, skills and confidence, and extends our social networks. Paid work gives us more money for independence and to do the things we want.

Many people with intellectual disabilities want to work but have one of the lowest participation rates in employment in our communities. It is hard to get their foot in the door and they do not have the same opportunities for tertiary courses,

16. Jude MacArthur (2009), Kathy Cologan (2013), Sally Robinson and Julia Truscott (2014)

work experience or internships. Too often people have to endure endless getting 'ready' programmes that do not lead to jobs or take them on pathways with dead ends or where they are not paid a 'fair' wage.

In the post school years people with intellectual disabilities do not have the same opportunities to tertiary education and on-going learning courses as their non-disabled peers. Cost is often a barrier.

### What would we expect to see:

- People with intellectual disabilities having the expectation of working.
- A range of options are available that enable people to contribute and participate in their communities.
- Information about and support for employment is easy to find and use.
- People being able to access affordable tertiary courses and ongoing training and education.
- Parents (usually mothers) do not have to give up their jobs or be unable to take up work or training or seek a residential service because there are not suitable post school options for their sons and daughters.
- Employment and community inclusion and participation services are fully funded.
- People receive a fair and living wage.
- People are not penalised by financial disincentives to work or loss of needed supports and allowances.
- Employers have confidence in employing people with intellectual disabilities and have access to help where needed to understand and apply reasonable accommodations.
- Government leads the way by employing people within public services in same proportion to that of intellectual disability in the population.
- Government collects and reports on the participation of people with intellectual disabilities in the NZ Labour Force Survey.

### Home

*"One of the staff comes in and wakes me up at 6am and tells me to get out of the house because she has lots of work to do. I am happy with getting up at that time but I would like to stay at home on Fridays but I am not allowed"*



*"I have a girlfriend – no kissing because staff would come out and tell me off. I can cuddle her nicely though"*

*"She (daughter) should be able to decide when to get up and when to go to bed. I don't think that always happens where she lives"*

Having a real home gives us place and a base in our community. Despite the closure of the last long stay residential institution and the development of a wider range of living options many institutional practices (what THAOL termed a 'custodial ownership' model) remain. Many people with intellectual disabilities continue to have home lives that are far from 'ordinary' and where as adults they do not choose where and with who they live, what they have for meals, what time they go to bed or who they can have stay over.

People who are most vulnerable to institutional practices are those who live in situations: where they share a home, but are not friends or in a relationship with the person they share with; where they have the label 'challenging' behaviour; where they have staff in their homes on a fulltime basis and; where the person has significant impairment and is not able to make big life decisions.<sup>17</sup>

Too many regulations, standards and rules are being imposed on and added to disability services that were that were designed for hospitals, rest homes and industry. These limit peoples' ability to have 'ordinary' lives and 'homes', learn from experiences, inhibit support staff's capacity to provide good support and add huge compliance costs.

17. Sam Sly (2008) *KeyCheck: a path to citizenship for all*

## What would we expect to see:

- People living with those they like living with, close to family, friends and facilities.
- People having a key to their home, being able to control who they let in and having their right to privacy respected.
- Where adults are sharing homes with others as a group they decide the house rules.
- Individuals and groups who live together and families and whānau are involved in staff recruitment processes.
- People have the right to say 'no' to particular support workers.
- Support workers are consistent and unknown people do not appear in a person's life or home unless it has been agreed.
- Everyone is living in 'healthy homes' that are warm and well insulated and ventilated.
- People have the same tenancies rights as all New Zealanders and all rental properties have a warrant of fitness.
- People are not at risk of losing their home at the convenience of a service provider or if their support needs change.
- People are supported to age 'in place' in their own homes.
- Services that are policy and rule light and where particular ways of working are needed to support an individual they have a specific plan rather than imposing policies and rules for the whole service or household.
- Commissioning and funding practices that include the right of adults with intellectual disability to have the opportunity to choose their place of residence and with whom they live.<sup>18</sup>

## Income, having money to pay for things, having fun and getting around

*"You can go out and do things, be involved in what you want, be included in what you want and what is on offer"*

*"I'd love to start dancing again. I had to give up dancing because they said I was too old for the classes, but I miss it"*

*"Money (not having enough) stops me from doing all the things I would like to do"*

*"I can choose what I spend my money on. But then I suppose I can't really if everyone is checking up on me with my receipts. I don't really understand it"*

As with all New Zealanders people with intellectual disabilities have the right to an adequate standard of living. People need enough money in order to pursue their goals and direct their own life and support, and contribute to and participate in community life, have fun and get around.

Disabled people are over represented in those living in poverty and on low incomes<sup>19</sup>. A lack of affordable and accessible transport often restricts people's participation and ability to stay connected with friends and is one of the most commonly mentioned barriers reported by people with intellectual disabilities. A recent report<sup>20</sup> found the exclusion of transport costs from funded support in CiCL meant that some people were unable to participate in community life in the way they would like.

Additional challenges are faced when people are not able to take up opportunities because it is not in the plan, sought activities don't meet inflexible funding criteria, people do not have control of their own money or are restricted by protocols and rules.

## What would we expect to see:

- People are supported to understand the cost of things, about saving and to make decisions about how they spend their money.
- People have improved social and economic outcomes.
- Benefits are good enough to live on and are regularly adjusted to meet real cost of living increases.
- Abatement rates are increased so people can earn more and build up savings.
- More people with intellectual disabilities own their own homes.
- Transport and other costs are not a barrier to work, participating in community life, spending time with friends and family or getting around.
- Affordable transport and support options are available – such as a Kiwi Able card and/or Gold card equivalents and companion cards.
- Children and adults with disability are included in all initiatives to reduce poverty.
- People with intellectual disabilities are included in all government reporting on incomes, poverty, and social and economic outcomes.

18. Where there are exceptions if a person is under legal orders or restrictions for safety reasons these should be applied in the least restrictive way possible

19. Disability Survey, 2013

20. M. Roorda et al, Demonstrating changes to disability support: Evaluation Report, 7 April, 2015



## Keeping up with technology

The rapid rise in the development and use of technology has given us new ways of connecting and opened up opportunities for greater independence and control. There are also dangers that people with intellectual disabilities will be left behind and not be able to take full advantage of the benefits on offer. Sometimes designs are too complex, aren't in an accessible format or are too expensive for those on a limited income.

### What would we expect to see:

- People with intellectual disabilities, their families and whānau and other supporters working with government agencies and technology developers to design accessible formats.
- Government and community partnerships for affordable technology and funding assistance for assistive technology that is prioritised on the basis of the value for independence and self-management, rather than on cost reduction.

## Access to Justice

*“Some people had an OK experience – and a lot of people didn’t. They didn’t feel they were treated respectfully and didn’t understand what was happening to them. The work we did highlights the long way we have got*

*to go to ensure that everyone has their legal needs met  
Brigit Mirfin-Veitch, Kate Diesfeld, Sue Gates and Mark  
Henaghan (2014).<sup>21</sup>*

There are times when people may interact with the more formal aspects of the justice system whether as victims of, or witnesses to, crimes, as part of proceedings under the Children, Young Persons and their Families Act 1989 (CYF), Protection of Personal and Property Rights Act (1989) (PPPR), the Intellectual Disability Compulsory Care and Rehabilitation Act (2003) (IDCCR) or the Mental Health (Compulsory Assessment and Treatment) Act 1992, being interviewed by police, or having been charged with an offence and appearing in court or involved in family court proceedings concerning out of home placements for children.

Rights to exercise legal capacity and to justice are absolutes, yet people with intellectual disabilities are typically disadvantaged and don't get the support needed to enable equal access. Recent New Zealand research<sup>22</sup> shows that there is much to be done in developing a more responsive legal system and to address gaps in education and training for the legal profession, police and others involved implementing court mandated orders.

### What would we expect to see:

- Children with intellectual disability have the same legal representation as all children in family court proceedings.

21. Brigit Mirfin-Veitch, Kate Diesfeld, Sue Gates and Mark Henaghan (2014) *Developing a more responsive legal system for people with intellectual disability in New Zealand.*

22. Ibid

- People with intellectual disabilities are identified at the start of any police or legal proceedings and have the support needed and accommodations made to participate on an equal basis.
- All judges, lawyers and other court officials, police and prison and forensic mental health staff have initial and on-going training in working with people with intellectual disabilities.
- The recommendations of the research project *Developing a more responsive legal system for people with intellectual disabilities in New Zealand (2014)*<sup>23</sup> are implemented
- People receive the rehabilitation services they are entitled to under the IDCCR Act, achieve the outcome goals sought and orders are not extended for undue lengths of time.
- A review of the 2003 IDCCR Act and reporting of outcomes, including long term outcomes, for people who are or have been subject to the Act.
- People are not subjected to abusive restraint and seclusion practices.
- Concerns about the deprivation of liberty and use of seclusion are urgently addressed.

### Good support for families and whānau

*“I want her to blossom as a person, that’s my role as a parent”*

– Super Power Baby Project, Rachel Callander, 2015, p.62.

*“Down syndrome is what he had, not who he was. His whānau and his whakapapa connect him to us”*

– National Health Committee (2003)<sup>24</sup>

*“(Government agency) said I couldn’t fill in a form on behalf of my son even when I explained he was non-verbal and couldn’t read or write. They wouldn’t speak to me (his mother), so I took my son into the office and when it was his turn said to them you wanted to speak with him, I’ll be waiting outside the office. What does it take for common sense to prevail?”*

Families and whānau can only thrive if they are connected to, are valued by and have a sense of belonging in their own communities<sup>25</sup>. Many families with a disabled member find it hard to get the life others take for granted. These struggles often begin in the early years and continue through to

adulthood and the later stages of life. Transition to school, out of school and shifting from the family home can be particularly stressful and difficult to negotiate. Parents with intellectual disability experience additional disadvantages in getting supports to care for their children and/or being able to stay involved with their children if legal processes have removed them from parental care.

### What would we expect to see:

- The knowledge, culture, expertise and advocacy of families and whānau is respected and responded to.
- Child or person-centred is not seen as excluding families.
- Families are knowledgeable about support services and how to access them.
- Families do not have to be in crisis before they can get help.
- Families have flexible support that is a ‘good fit’ for their family and is responsive to changing situations and developmental stages.
- Parents with intellectual disability being supported to bring up their children and keep their family together.
- Families are able to access a fair and respectful way of being paid for their care of an adult family member if that is the option chosen.
- Families know about and are able to connect with other families and family based organisations.

### A voice in policy and services

Families and whānau have valuable contributions to make to policy and service development. When there is a silence about the important role of families and whānau in sharing knowledge and in systemic advocacy this implicitly reinforces a denial of these powerful functions and diminishes the richness of policy and practice.

### What would we expect to see:

- Strong sustainable family-based support networks whose voice is heard and valued.
- Families are represented on advisory, reference, governance and monitoring groups.

23. Ibid

24. National Health Committee (2003) *To Have An Ordinary Life*, p.41

25. Pippa Murray (2011) *Developing family leadership*, p.2

## Good support for the workforce

*“If we are asking support staff to work with people with intellectual disabilities in person-centred, skillful and committed ways then staff need to be treated in the same way” – William Gaventa, 2008<sup>26</sup>.*

The disability support workforce is an integral part of communities, schools and early childhood education in working with people with intellectual disabilities and their families and whānau. Continued and increased efforts are needed to demonstrate valuing of disability support workers, to improve training, career pathways and pay and to underpin the changing demands and ways of working that are occurring in the health and disability sectors.

There have been long standing issues in the recruitment and retention of good support staff. This is exacerbated by an ageing workforce with what is predominantly female. In 2010 DHBNZ reported that 94% of the disability workforce were female workers between 40-50 years of age. Alongside this there have been a number employment related cases and decisions that have implications for pay and conditions – paid sleepovers<sup>27</sup>, carer support workers are home workers<sup>28</sup> and women care workers’ low pay as discriminatory<sup>29</sup>.

### What would we expect to see:

- A support workforce with the right values and skills.
- Service providers and individuals and families who directly employ staff are able to recruit and retain good support workers.
- Support workers are able to access funded initial and ongoing training regardless of whether support staff are employed by service providers or directly by individuals and/or families.
- Organisations provide good support for support staff by creating a climate in which staff feel able to contribute, be skilful and reflective in their practice.
- Support workers are paid a fair and living wage.
- Adequate protections are in place for support workers employed under IF arrangements.

## Embedding citizenship and rights in fair systems and better ways of working

*“I get really cross that I can’t get support for the things I need, yet I get too much help for things I don’t want”*

*“You have to accommodate their world. Yes it costs money, but that is money spent wisely. For my sons it was the best way to meet their needs and has saved money in the long run”*

*“Uncertainty about funding puts you (person and family) on tenterhooks”*

*“The rules around how carer support can be used make it difficult to get help to look after my son in the holidays when I have to work”*

*“A system that does not know how to enhance commitment relies instead on compliance”*  
– William Gaventa (2008).

People and their families and whānau have the greatest incentive to get things right and make sure resources are used in the best possible way. While there are initiatives underway to give people greater choice and flexibility in how they use their funding these have reached only a few and are often difficult to make work. Accessing support services is still dominated by transactional approaches rather than being based in trusted relationships.

There are still too many people who don’t know what support they can get or how decisions are made so often are not able to act with confidence. Confused, unclear and disjointed policies and systems and ill-informed practices have led to wasteful and sometimes discriminatory ways of working. Rights are often ignored or watered down and standards for what is fair are compromised to fit budgets.

Too much time and money is spent on looking for ways to exclude rather than working together to find ways to include and share decisions. Too many resources are devoted to establishing and re-establishing eligibility, repeating assessments and reviewing assessments, plans and funding and too few lead to meaningful outcomes in people’s lives. There is uncertainty for service providers as to how more individualised funding arrangements will work. The balance is out of kilter.

The THAOL report called for a change to policy and practice to better recognise and respond to the citizenship of people with intellectual disabilities. More recently the Productivity Commission report ‘More effective social services’ made a number of recommendations for better government stewardship, changes in commissioning and funding practices and more collaboration to enable individuals and families and whānau to have greater choice and control in the services and supports they use.

26. William Gaventa (2008). Rekindling commitment: reflections from a pastoral educator enmeshed in direct support professional workforce development and person-centred supports. *Journal of Intellectual Disability Research*, 52, 7, p.602

27. IDEA Services vs Phillip Dickson CA45 2010

28. Service Food Workers Union/Lowe v. Ministry of Health and Capital Coast District Health Board 2015

29. Service and Food Workers Union/Bartlett v. Terranova Homes and Care (2013)



## What would we expect to see:

- A support system that is easy to find and use and that recognises the life-long nature of intellectual disability.
- Supports and systems that are based in relationships and where people's rights are respected and responded to.
- People and their families and whānau are aware of their rights and entitlements.
- People and their families and whānau are positioned as active decision makers who direct their own lives and supports – regardless of whether they self manage or use a service provider.
- Funding models that are triggered by opportunities for learning, independence, participation and contribution and are not based on deficit and having to appear 'tragic' and in desperate need.
- A reduction in the number of times individuals and families have to tell their story and go through eligibility assessment and gate-keeping hurdles.
- Access to a key worker who can walk alongside individuals and families (regardless if called LAC, facilitator, navigator, connector).
- Timely access to quality universal, disability support and specialist services.
- Transparent and fair processes for resource allocation and review of decisions.
- Greater certainty for individuals and families and whānau by having up front indicative budgets with integrated funding and flexible review periods depending on different individual and family and whānau situations.
- Individuals and families and whānau are supported to manage their own funding if they choose to do so.
- Greater investment in community development and funding in contracts to enable devolved decision-making and collaborative working between individuals, families and whānau, communities and service providers.

## Tracking progress

*“The thing that disturbs me deeply is the lack of good data about people with intellectual disabilities. There*

*is nothing that draws attention to the disparities, and therefore there is no ability to drive change or to track progress in addressing them” – service provider*

The THAOL report highlighted the lack of decent data and made recommendations for more research and improved gathering and reporting of demographic information. This is still a problem and recommendations continue to be made to get better quality information to inform decisions, track progress, evaluate outcomes and analyse the impact of policies and practices.

People with intellectual disabilities continue to be invisible in much data collection or are included as an after-thought rather than from the start. The lack of robust, long-term and publically available data severely limits our ability to monitor and report on progress on the realisation of rights in people's everyday lives.

Indicators signpost how successful policy, strategies, plans and actions have been. The areas identified in 'what we expect to see' in the previous sections provide the basis for indicators that address questions such as what progress has been made, what still needs to be done, and have actions have been timely and resulted in intended and quality outcomes that have made a difference to the lives of people with intellectual disabilities and their families and whānau. On a population level indicators for all New Zealanders provide benchmarks against which to measure outcomes for people with intellectual disabilities.

We have identified some indicators (Table 5.1) that are signposts as to whether we are making progress in achieving the outcomes people have told us they are seeking and that contribute to wellbeing and the realisation of rights and citizenship.

Table 5.1 gives some possible measures of the indicator areas. At this stage many of the measures referred to are possible in name only as they do not currently include or report on disability or give impairment specific information.

In June 2015 a 'Disability Data and Evidence' working group was established that is jointly facilitated by Statistics NZ and the Office for Disability Issues. The focus of the group is to find ways to get the data and evidence required to ensure sound policy development to improve the everyday lives of disabled people and to understand life outcomes over time. If the work of the working group and other cross government initiatives to get better information are successful there will be new robust measures that can be used to establish baselines and track progress.

Table 5.1 Indicators and measures

Indicators	Possible measures
<p><b>Belonging and being connected: Community and family life</b></p> <p>Individuals and families and whānau feel welcomed and connected in their communities</p> <p>Children have the same rates of participation as non-disabled children in activities such as spending time with friends, being invited to birthday parties, joining clubs, taking part in school life, being a member of sports teams, going on family holidays</p> <p>Adults have the same rates of participation as their non-disabled peers in social, recreational, leisure, cultural and sporting activities, in study and work, as members of community groups and in volunteering</p> <p>Families receive needed supports so children stay living with family and whānau.</p> <p>Reduction in out of home placements for children and young people with developmental delay/intellectual disability and where such placements are needed these are with extended family or foster family in or close to community of origin</p> <p>Children and adults with intellectual disability are included in all government policy and reporting</p>	<p>Direct experiences of people with individual disability and their families and whānau</p> <p>IHC 'Buzz' survey attitude sections</p> <p>Growing up in New Zealand study</p> <p>NZ Disability Survey</p> <p>Independent quality, standards and monitoring evaluations</p> <p>Evaluations of 'New model' and 'Enabling Good Lives' trials and demonstration projects</p> <p>UNCROC and CRPD and other human rights monitoring and reporting</p> <p>MoH and CYFS data and reporting</p> <p>Content analysis of government policy and reporting</p> <p>Independent quality, standards and monitoring evaluations</p> <p>New Zealand Social Survey</p>
<p><b>Communicating and self-determination: Supports and safeguards</b></p> <p>Everyone's voice is heard and preferences known</p> <p>People have needed supports for decision-making in ways that work best for them</p> <p>There is a shift from substitute to supported decision-making with a reduction in the involvement of the Family Court in people's lives</p> <p>New Zealand is compliant with CRPD Article 12 obligations</p>	<p>Direct experiences of people with individual disability and their families and whānau</p> <p>Evaluations of 'New model' and 'Enabling Good Lives' trials and demonstration projects</p> <p>Independent quality, standards and monitoring evaluations</p> <p>Ministry of Justice data on PPP&amp;R Act and orders issued</p> <p>CRPD independent monitoring</p>

## Preschool and school years

Children with developmental delay/intellectual disability participate at same rates as their non-disabled peers in early childhood education

All students with intellectual disability have access to the curriculum and are achieving quality learning outcomes

All students have needed additional supports and accommodations

Stand downs, suspensions and exclusion for disability related issues disappear

Schools and teachers are adequately resourced and supported

Direct experiences of children and young people and their families and whānau

Well Child/Tamariki Ora ECE indicators

Data collected by NZ Council on Early Childhood Education and NZ Childcare Association

IHC survey on education

Ministry of Education, Education Review Office and Board of Trustee reporting

Data collected by NZEI, PPTA, NZ Principals Association

## Work and having enough money to pay for things and get around

People have an adequate income to allow quality of life

Everyone gets help to find work regardless of how many hours of work they are seeking

Increase in numbers of people in paid employment

Abatement rates increased so people are not penalised by financial disincentives to work or loss of needed supports and allowances

Transport costs are factored in to disability support funding

Number of people with intellectual disabilities in paid employment in government agencies is proportional their numbers in the general population

Direct experiences of people and their families and whānau

Service provider reporting by NZDSN, Workbridge and Inclusive NZ data

Work and Income data and reporting

Ministry of Business, Innovation and Employment (MIBE) data

Government reporting on public service employment of people with disabilities

Government reporting on CRPD, UNCROC and the Covenant of Social and Economic Rights

## Health

People with intellectual disabilities are identified as a priority population group and this is reflected in the New Zealand Health Strategy and MoH policy, initiatives and reporting

Reduction in disparities in access to healthcare and health outcomes

Decreases in deaths from preventable causes

Increases in life expectancies

Direct experiences of people and their families and whānau

New Zealand Health strategy reporting

Content analysis of MOH policy and reporting

MoH and DHB data

Well Child/Tamariki Ora indicators

Independent quality, standards and monitoring evaluations

## Embedding rights and fair systems

Individuals and families are able to self direct and organise supports and services in ways that work best for them

Funding models invest early and are triggered by opportunities for learning, independence and participation

Transparent resource allocation processes with upfront indicative budgets

Rights are not ignored or watered down

Standards for what is fair are not compromised to fit budgets

Direct experiences of people and their families and whānau

MoH and MSD data and reporting – including numbers of individuals and families and whānau using individualised funding

Independent quality, standards and monitoring evaluations

Evaluations of ‘New model’ and ‘Enabling Good Lives’ trials and demonstration projects

UNCROC and UNCRPD and other human rights monitoring and reporting

Government reporting on UNCRPD, UNCROC and the Covenant of Social and Economic Rights

## What IHC plans to do

Starting in 2017 IHC will work with others to report annually on progress, achievements and shortfalls in making citizenship and rights real for people with intellectual disabilities and their families and whānau.

We will report against the Minister of Disability Issues annual report on the implementation of the New Zealand Disability

Strategy and the monitoring framework that will be developed by the Office for Disability Issues to support the revision of the 2016 – 2026 strategy.

See Appendix 3 for Office for Disability Issues information on where the NZDS fits and the proposed monitoring framework.

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## Appendix 1 – Summary of progress on 2003 THAOL recommendations

Recommendations	Progress
<p><b>Rights of citizenship</b></p> <p>1: People with intellectual disabilities are supported to exercise the same rights and opportunities and responsibilities as the rest of the New Zealand population by the Minister of Health and the Minister for Disability Issues adopting the recommendations in this report as a focus for monitoring the implementation of the New Zealand Disability Strategy (NZDS) for adults with intellectual disability.</p>	<p><b>No progress</b> as no action was taken on using the THAOL report recommendations as the focus for monitoring and reporting on the NZDS for adults with intellectual disability</p>
<p><b>Accommodation* THAOL priority area for urgent action</b></p> <p>2: To facilitate a move away from the current ‘residential care’ model to supported living arrangements, the Minister of Health and the Minister of Disability Issues initiate the separation of accommodation costs from the funding of disability support</p>	<p><b>No substantive progress and a failure to address this priority recommendation urgently</b> - there has not been the fundamental change sought. While there have been increases in numbers in supported living and using individualised funding ‘residential’ and ‘custodial’ care models still dominate. People do not have the same tenancy protections as all New Zealanders. The CiCL demonstration trial that began in 2011 includes separating costs.</p>
<p><b>Health* THAOL priority area for urgent action</b></p> <p>3: the systemic neglect of the health of adults with intellectual disability be urgently addressed by the Minister of Health and Disability Issues</p>	<p><b>Some progress</b> recently from government with DAP ‘improving health outcomes for people with intellectual disabilities’ begun in 2015 but a failure to address this priority recommendation area urgently. There have been service and community efforts such as IHC’s funded annual health checks, Special Olympics health screening for athletes and the Health and Disability Commission health passports.</p>
<p><b>Communicating</b></p> <p>4: Adults with intellectual disability have a personal voice around the control of their own lives and a representative voice to promote the best interest of the group.</p>	<p><b>Some progress</b> with an increased emphasis in policy and practice on people having choice and control. Many still are unable, however, to access needed communication support.</p> <p><b>Substantive progress</b> with People First established as an independent organisation for representative voice in 2003.</p>
<p><b>Paying for things</b></p> <p>5: Adults with intellectual disability have access to full income support, employment assistance and training to which they are eligible.</p>	<p><b>No substantive progress</b> and there is not the evidence base in place as recommended by the NHC for monitoring. There has been recent acknowledgement by MSD of the need for easy to use procedures, plain language information and upskilling of staff but there is way to go to achieve this.</p>

### Work (paid and unpaid)

6: Adults with intellectual disability are able to pursue personally meaningful lives, in which vocational services and non-vocational community participation are available as part of the range of supported living.

**No substantive progress** – as part of government’s the programme of welfare reforms there has been an increased emphasis on work and some initiatives for more flexible ways to get more meaningful work and community participation options. Many difficulties remain in getting flexible and integrated support and funding. Vocational services are still not fully funded as recommended by THAOL.

### Being part of the community

7: Adults with intellectual disability hold valued roles and are well supported from school into retirement.

**Some progress** with greater recognition transition from school and ageing but still a long way off getting good support across the lifespan. Policy and funding silos that artificially divide up people’s lives remain as significant barriers to transition across different life stages.

### Learning new things

8: Potential for adults with intellectual disability to grow and develop throughout their lives be recognised by the relevant Ministers determining how best to purchase services designed to promote and measure lifelong learning and access to ongoing educational and cultural opportunities.

**No substantive progress** with access to tertiary education and ongoing learning still a problem and one that is frequently raised by people with intellectual disabilities. There have been some community based initiatives such as People First’s ‘Learn with Us’ and IHC’s skills based volunteering programme.

### Relationships

9: Recognition be given to importance of adult relationships in lives of adults with intellectual disability with active support to make and maintain adult relationships an essential component of all needs assessment, service specifications and purchasing arrangements

**No substantive progress** - relationships may be included in needs assessment and service specifications but there isn’t the data to evidence whether this is more than a tick box exercise. Reports from people with intellectual disabilities of their experiences suggest that for many there has not been any meaningful change. Community organisations and many service providers have recognised and provided support for making and maintaining friendships and relationships such as friendship link programmes and IHC volunteering.

### Having fun

10: Recreational, sporting and leisure opportunities for adults with intellectual disability are promoted.

**Some progress** with some more inclusive practices and initiatives such as local area coordination, EGL, friendship and volunteering programmes and continued and expanding opportunities. Attitudinal and other barriers such as money and transport remain as issues.

### Moving around

11: Adults enabled to access the ordinary places of life and community as easily as possible.

**No substantive progress** with access to affordable transport and being able to get around still among the most frequently raised concerns from people with intellectual disabilities.

## Māori adults

12: Facilitate community membership and 'ordinary lives' by ensuring Māori adults with intellectual disability can access the same initiatives and opportunities as the rest of the Māori population

13: Needs assessment, service coordination and service provision relevant to lives of Māori

14: Māori adults with intellectual disability have the option of referral to adequately resourced Māori service providers

**Some progress** with the 2012-2017 Whāia Te Ao Mārama: Māori Disability Action Plan and an external advisors group to support the implementation of the plan and to provide advice to the Ministry of Health. In some areas people have access to Māori service providers. The 2013 New Zealand Disability Survey found 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.

## Pacific adults

15: Increase the understanding with Pacific communities about intellectual disabilities

16: Needs assessment, service coordination and service provision relevant to the lives of Pacific adults with intellectual disability

17: Pacific adults with intellectual disability have the option of referral to adequately resourced Pacific service providers

**Some progress** and increased awareness with the 2014–2016 Pasifika Faiva Ora – National Pasifika Disability Plan aimed at improving services for Pasifika people and their family members and carers and enhance the capability of the workforce. A Faiva Ora leadership group has been established.

## Government capacity and service development: Creating an aware and responsive public service

18: Collection and coordination of demographic information about people with intellectual disabilities to be improved

19: High quality research about lives of adults with intellectual disability undertaken, ensuring adequate funding is available

20: Facilitate sharing of information about best practice, new directions and innovative approaches among self-advocates, whānau, families and service providers

**Some progress** - the availability of robust demographic information and data on the lives of people with intellectual disabilities remains as a significant issue. There has been growing recognition of this problem in recent years and the beginning of efforts to find solutions such as the setting up of the 'Disability Data and Evidence Working Group' in 2015. There has been an increase in forums to share information and research such as those offered by NZ ASID and NZDSN. Funding for intellectual disability research as a small population group is hard to come by especially from major funders such as the Health Research Council.

Improving needs assessment and service coordination (NASC) \* THAOL priority area for urgent action

21: Shift focus of needs assessment and service coordination from allocating pre-purchased services to ensuring each adult with intellectual disability has support to meet their needs.

**No substantive progress and a failure to address this priority recommendation urgently** - there have been a number of projects aimed at getting more flexible and individualised support and funding in ways that increase choice and control. Evaluations of these various projects and trials have reported benefits for participants in having greater flexibility, being able to get supports in ways that work for them and achieving sought outcomes. These demonstrations have involved small numbers, reached only a few and there are unanswered questions about the implications for NASCs if these new approaches are adopted nationally. A review of NASC and DIAS services is being undertaken in 2016.

Supporting family and whānau

22: Ensure families and whānau are adequately supported.

**No substantive progress** with getting good support a hit and miss affair for and family and whānau representative voice missing from many policy initiatives. There has been an increase in the use of individualised funding and in some areas the in the range of options available. There is recognition in the 2008-2013 Carers Strategy and 201-2014 New Zealand Carer's Strategy Action Plan'. In 2015 the Ministry of Health funded a 'National Carer Learning and Wellbeing Resource 'Care Matters' and 'National Carer Matching Service'. In 2015 – work started on 2014-2018 Disability action Plan – 'a good start in life'.

Promoting workforce development

23: Strengthen workforce by making an urgent investment in leadership and development across the disability support workforce

**Some progress** but the disability support workforce is undervalued and poorly paid with continuing issues in recruitment and retention of a skilled workforce. There is recognition in the Disability Workforce Action Plan 2013-2016 and the development of resources such as Te Pou's resource "Let's get real: A framework to help the disability workforce meet the needs of disabled people, whānau and communities'



## Appendix 2 – Timeline

- In 1985 the government announced the beginning of a process deinstitutionalisation that concluded with the closure of the last long stay institution for people with intellectual disabilities in 2006
  - The 1989 Education Act gave the right to education to all children by removing the barrier to school attendance for students who had been excluded on the grounds of significant intellectual impairment
  - In 1994 a New Framework for Disability Support Services was introduced that promised to put people with disabilities ‘in control’ and provide a ‘one stop shop’ in the newly established needs assessment and service coordination services
  - Special Education 2000 with the aim to deliver a world class inclusive education system
  - The 2001 Pathways to Inclusion signalled a new direction for vocational services aimed at achieving greater participation for people with disabilities in employment and in our communities
- 2003 – National Health Committee, To Have an Ordinary Life: Kia Whai Oranga ‘Noa’: Community membership for adults with intellectual disability. Report released.*
- 2003 – People First People First New Zealand, Nga Tāngata Tuatahi became an independent organisation (People First started in the 1980s, set up within IHC)
  - 2006 – The Social Service Select Committee ‘Inquiry into the quality of care and service provision’ begins and is reported on in 2008 with the government response presented in 2009
  - 2006 – United Nations Convention on the Rights of persons with Disabilities (CRPD) ratified by New Zealand in 2008
  - 2006 – Closure of Kimberley Centre - the last long stay institution for people with intellectual disabilities

The 2001 New Zealand Disability Strategy that gave a framework to guide policies and services to achieve a vision of a society that highly values the lives and continually enhances the full participation of disabled people

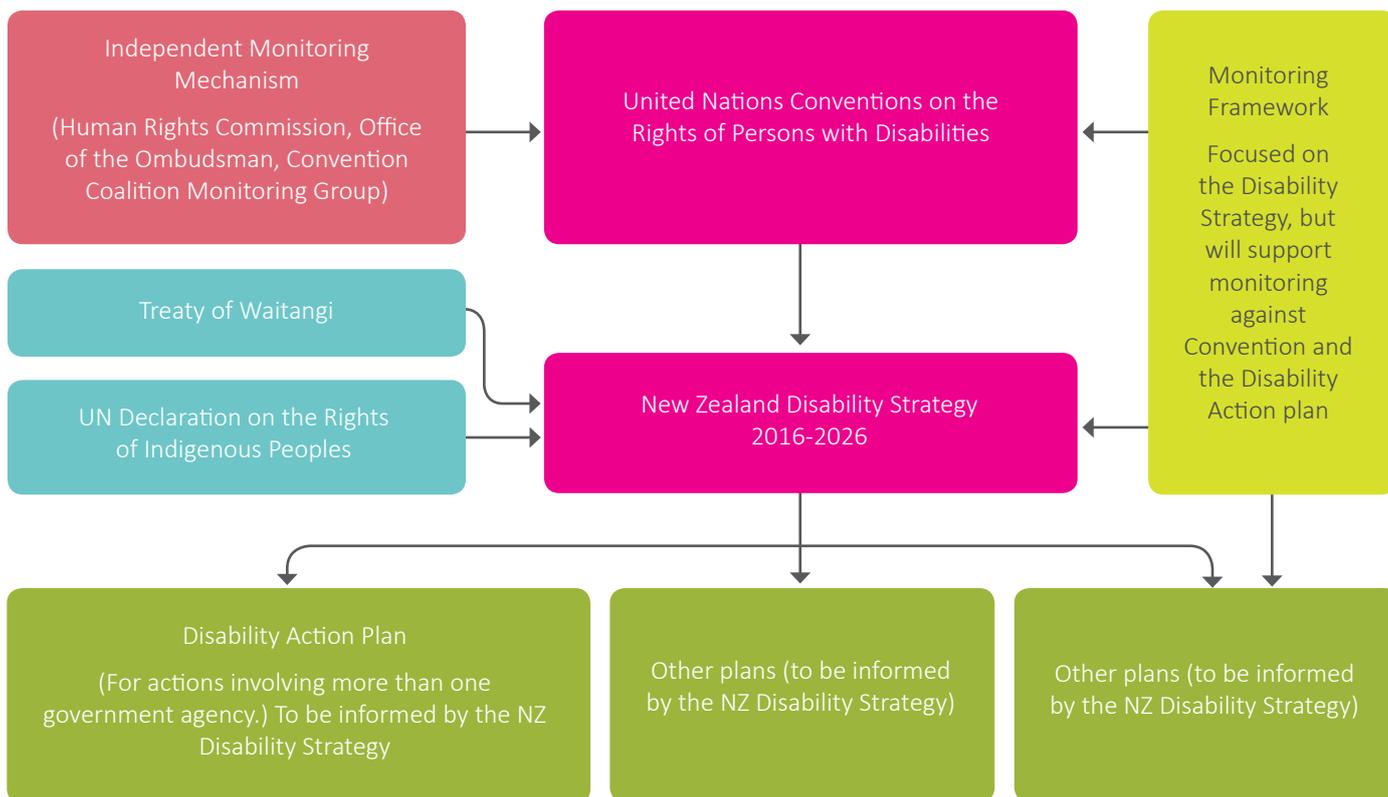
- 2008 – IHC lodges an Education complaint (under Part 1A of the Human Rights Act)
- 2008 – 2013 - Carers' Strategy, 2014 to 2018 - The New Zealand Carers' Strategy Action Plan
- 2009 – Ministerial Committee on Disability Issues established to get better across government working and accountability for implementing NZ Disability Strategy and CRPD
- 2009 and 2011 – Appointments of Disability Commissioners to the Health and Disability and Human Rights Commission
- 2010 – Establishment of the Independent Monitoring Mechanism comprising DPOs -including People First - in a Convention Coalition, the Human Rights Commission and the Office of the Ombudsman to independently monitor progress on the implementation of the CRPD
- 2010 – Success for All: Every School, Every Child report and actions
- 2010 - Launch of 'Thinking Differently' campaign and fund
- 2010 – 2014: DPO, family and disability sector collaborations in education (Education for All) and employment (Disability Employment Forum)
- Government Disability Action Plans - 2010, 2011 to 2012 (focus on Christchurch) 2012 to 2014 (focus on results), 2014 to 2018 (updated 2015)
- 2012 – 2017 - Whāia Te Ao Mārama: Māori Disability Action Plan
- 2014 – 2016 Pasifika Faiva Ora – National Pasifika Disability Plan
- 2010 – New Model work introduced including initial local area coordination demonstration project, enhanced individualised funding initiatives, and trials of different ways of working such as Choice in Community Living
- 2011 – Enabling Good Lives paper and subsequent Enabling Good Lives demonstrations in Christchurch and Waikato
- 2011 – Ministry of Health 'Health indicators for New Zealanders with intellectual disability' report
- 2011 – Green paper on vulnerable children
- 2012 – Government's response in a White paper and Children's Action Plan
- 2012 – Introduction and ongoing implementation of welfare reforms. Included change to benefit system and renaming of the Invalid's Benefit to Supported Living Payment

### 2012 (September) IHC Human Rights Symposium: Making rights real

- 2013 – Introduction of Ministry of Health Funded Family Carers policy following the Court of Appeal decision in Atkinson and others v Ministry of Health (2012)
- 2013 – Putting people first: A review of Disability Support Services performances and quality management processes for purchased provider services
- 2015 – Improving health outcomes for people with intellectual disabilities – reference group established and work begun (Disability Action Plan 2014-2015, priority 11c)
- 2015 – NZ Productivity Commission report 'More effective social services'
- 2015 – Ministry of Education Special Education update
- 2015/2016 – Disability Information Service (DIAS)/ Needs Assessment Service Coordination (NASC) review
- 2016 – Revision of NZ Disability Strategy

## Appendix 3 – Where the Disability Strategy fits in

This page describes the relationship of the Disability Strategy with other strategic documents and frameworks on disability issues.



The diagram above shows the relationships that the New Zealand Disability Strategy has with other key strategic documents and frameworks on disability issues. The Disability Strategy is at the centre of the picture.

At the top is the United Nations Convention on the Rights of Persons with Disabilities.

An arrow from the Convention points downwards to the New Zealand Disability Strategy 2016-2026, showing that the Convention informs the Strategy.

Separately, the Strategy is informed by the Treaty of Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples.

Below the Disability Strategy sit action plans, which have a shorter timeframe for implementation. The first of these is the Disability Action Plan, which sets out actions involving more than one government agency. Other action plans will be developed according to information set out in the Disability Strategy.

The diagram also shows monitoring activity. The Convention is monitored by the Independent Monitoring Mechanism, which is made up of the Human Rights Commission, Office of the Ombudsman and the Convention Coalition Monitoring Group.

The Disability Strategy will be supported by a Monitoring Framework, which will focus on the Disability Strategy but will also monitor against the Convention, Disability Action Plan and other plans developed from the Strategy. The Office for Disability Issues will develop the Monitoring Framework alongside the Disability Strategy.

<http://jointheconversation.nz/wp-content/uploads/2016/04/Where-the-new-strategy-fits-in.pdf>

