



## **IHC feedback: New Zealand Disability Strategy Revision – First phase public consultation**

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## 1. Key points and recommendations

IHC welcomes the opportunity to contribute to the consultation on the revision of the New Zealand Disability Strategy and makes the following summary points and recommendations.

- As stated in the purpose of the review it is timely to update the NZ Disability Strategy in the context of current times, shifts in policy and practice and to align with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).
- The underpinnings of the 2001 Disability Strategy remain the same – that disabled people are able to live valued lives in inclusive communities that recognise and respond to our interdependence and diversity.
- To be meaningful and sustainable the revised Strategy needs to recognise that success is dependent on government working in partnership with people with disability, families and whānau, communities and service providers.
- The 2001 Strategy lacked a monitoring framework to track progress on implementation. We are fully supportive of the inclusion of the development of a monitoring framework in the revision process.

IHC recommends

- That the new Disability Strategy 2016-2026 is linked to government policies, strategies, planning and reporting for all New Zealanders.
- That the new Strategy reflects the critical place of the CRPD Article 12 and addresses the gaps in the 2001 Strategy by aligning the 2016-2026 Disability Strategy with the CRPD.
- That monitoring of the 2010-2016 Strategy is undertaken in a partnership with civil society - people with disabilities, families and whānau, communities and non government organisations.

IHC looks forward to contributing to the next phase of the NZDS revision process.

## 2. About IHC

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education and health systems for their children with intellectual disability. The IHC of today is still striving for these same rights and is committed to advocating for the rights, welfare and inclusion of all people with an intellectual disability. We support people with intellectual disability to lead satisfying lives and have a genuine place in the community.

We have around 5,500 staff working to support 7,000 people in IDEA services (IHC's service arm) that include residential care, supported living, home support, employment and community participation and inclusion, support for families, specialist services, autism spectrum disorder (ASD) services, and through Accessible Properties (a

subsidiary company of IHC) are New Zealand's largest non-government social housing provider.

Through our charitable arm IHC raises awareness and advocates for the rights of over 50,000 people with intellectual disability at both a national and an international level. This includes an extensive advocacy programme, a one to one volunteer programme and the country's largest specialist intellectual disability library.

### 3. IHC's overall response

The stated purpose of the revision of the 2001 NZDS is to *"provide a clear direction for government over the next 10 years helping to make informed decisions on issues that impact on disabled people."* In the 15 years since the introduction of the strategy there have been changes in thinking and ways of working in the disability and wider community sector and in government and its agencies.

New Zealand's ratification in 2008 of the United Nations Convention on the Rights of People with Disabilities (CRPD) has given us a new lens through which to consider the lives and citizenship of people with intellectual disability. 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.

The new Strategy aims to *"enable New Zealand to better support disabled people to achieve their potential, and improve the lives of disabled New Zealanders and their families"*. The revision *"will show how to implement the CRPD in a New Zealand context, taking into account the Treaty of Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples"*.

A review is long overdue and IHC welcomes the signalled intent to ensure a good fit for the Disability Strategy with other government strategic documents, frameworks, action plans and monitoring. As with the original Strategy the 2016 revision includes extensive public consultation that encourages people to *'Join the conversation'*. This engagement and working with people with disabilities and their families and whānau and communities needs to extend to more than just giving the government a clear sense of direction to help make informed decisions on disability issues. To be effective and sustainable the Disability Strategy has to embed an inclusive way of working across all of government and a different way of working with people with disabilities, families and whānau and communities.

All New Zealanders share the responsibility to promote and protect citizenship and rights and to make the aims and objectives of the Disability Strategy real in people's lives. This is reflected in Inclusion International's (2012) statement

*"A shift is required from seeing disability as a programme or issue area in which people with disabilities are the recipients or subjects of policy to a transformative process which helps build stronger communities. It means not only looking at the person with a disability but also at their families and support circles and the communities that they live in and understanding how to strengthen the social fabric of our societies". (p.9)*

Inclusive societies are ones in which people can live together with fairness and justice; where we all belong and know we belong; where everybody's contribution is valued; and where we can be equal but different<sup>1</sup>. The foundation lies in a strong base in equal access to opportunities and universal services in which we are all entitled to enough good support to achieve citizenship and participate in communities. This includes having timely access to needed accommodations, additional supports and specialist services.

Government in its stewardship role plays a critical part in creating enabling environments for individual, family and whānau and community wellbeing. An essential part of this as stated in the vision of the 2001 Disability is to ensure that *“human rights are protected as a fundamental cornerstone of government policy and practice”*.

### 3.1 Being included with all New Zealanders

*“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”.*

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 disability and their families and whānau. This means being included in strategies, policy, planning and reporting for all New Zealanders. Still too often people with intellectual disability are positioned as ‘other’ and are missing from mainstream agendas or are included as an ‘add on’ rather than being there from the start.

The 2001 Strategy has the vision of a fully inclusive society that recognises and values our interdependence. Along with the revision taking into account the CRPD the Strategy would be strengthened by including reference to relevant legislation, strategies and planning for all. As examples

- Education is prominent in the Strategy with *Objective 3: Provide the best education for disabled people*. The 1989 Education Act gave the right to education to all children and removed the barrier to all children who had been excluded on the grounds of significant intellectual impairment. Despite this promise being enshrined in legislation many children and young people with intellectual disability experience discrimination, struggle to get a fair deal at their local school or are excluded from attending. The new Strategy should start by seeing children with disabilities as learners first and set the direction for an inclusive education system where all students have access to the curriculum and are able to achieve quality learning outcomes. All schools and teachers should have the right support and resourcing to create and sustain inclusive practices. The Strategy and its implementation should ensure that alongside government enabling schools to be inclusive that the right to an education is enforced and monitoring for accountability takes place.

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<sup>1</sup> Simon Duffy and Wendy Perez. (2014). *Citizenship for All: An accessible guide*.

- Objective 4 of the Strategy aims to ‘*Provide opportunities in employment and economic development for disabled people*’. In 2016 disabled people are over represented in those living in poverty or on low and inadequate incomes, people with intellectual disability have one of the lowest participation rates in employment in our communities and do not have the same opportunities for tertiary courses, work experience or internships as their non disabled peers. The new Strategy should set the direction to build on actions in the 2014 – 2018 Disability Action Plan and other initiatives to include students with disabilities with their non disabled peers in career and work experience programmes, ensure people know about and are able to access support for employment and their entitlements and employers have confidence in employing people with intellectual disability and can get help where needed to apply reasonable accommodations. The government should collect and report on the participation of disabled people in the New Zealand Labour Force Survey.

### 3.2 Critical place of CRPD Article 12

*“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”.*

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>2</sup>. The realisation of the right to equal recognition before the law (CRPD Article 12) is central to being able to choose where and with who to live, managing money, having a tenancy agreement, making decisions about health and work and many more aspects of life. Recognition and response to this human right for people with intellectual disability is critically linked to the realisation of other human rights. At its core it recognises personhood and personal agency and has a parallel in Article 12 of the United Nations Convention on the Rights of the Child (UNCROC) for children as emerging citizens.

Increasing attention has been paid to what needs to happen to make this right real in people’s lives and has been a significant focus of IHC’s advocacy work in recent years. We have consulted with 114 people with intellectual disability and 48 family members to inform IHC’s contribution to Inclusion International’s global report *Independent but not Alone*, delivered 56 workshops across New Zealand to 1,200 people to individuals and supporters and developed a *Supporting Decision Making: A guide for supporters of people with intellectual disability* resource.

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. Policies and processes need to be in place so 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. There needs to be increased capacity and capability in community organisations to recognise and respond to people with disabilities.

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<sup>2</sup> Michael Marriot (2015) The health gap: The challenge of an unequal world

The new Strategy should reflect the critical place of CRPD Article 12 and provide clear direction for the multi layered and practical steps needed to realise this right. These include ensuring: that everyone has needed communication assistance and support for understanding and expressing preferences and choices in ways that work best for them; that decisions made by people with intellectual disability and their support networks are recognised and responded to as valid decisions; families, others in support roles, health and legal professionals are well informed about supported decision making and safeguarding; and there is access to independent advocacy services.

### 3.3 Enabling policies and practices

*“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”.*

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

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. There have been and currently are initiatives underway to give people greater choice and flexibility in how they organise supports and use funding. These have reached only a few and accessing support services is still dominated by transactional approaches rather than being based in trusted relationships. Confused, unclear and disjointed policies and systems and ill-informed practices have led to wasteful and sometimes discriminatory ways of working. We are a long way from achieving the holistic and rights based approaches that were sought in the 2001 Disability Strategy.

In setting the right direction the revised strategy needs to embed fair and transparent processes for resource allocation and sharing authority so that rights are not ignored or watered down or standards for good support compromised to fit budgets or unethical practices. This includes: having easy to find and use information, supports and services; early and timely proactive investment; positioning people with disabilities and their families as active decision makers rather than passive recipients; and enabling flexible and integrated services and funding that are responsive to developmental stages and changing circumstances.

### 3.4 Tracking progress

*“The thing that disturbs me deeply (service provider) is the lack of good data about people with intellectual disability. 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”.*

The lack of robust, long-term and publically available data from which we monitor and report on progress on the realisation of rights in people’s everyday lives has been a long identified problem. *Being able to collect and use relevant information about disabled people* is Objective 10 in 2001 Strategy. In 2016 people with intellectual disability 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 has severely limited our ability to monitor and report on progress on strategies, plans and the implementation of the 2001 Disability Strategy and the CRPD.

IHC is heartened to see that the Office of Disability Issues is developing a monitoring framework to support the new 2016-2026 Disability Strategy. The monitoring framework will focus on the Disability Strategy along with monitoring against the CRPD, Disability Action Plan and other plans developed from the revised Strategy. If the work underway in the Disability Data and Evidence working group and other initiatives to get better information are successful then there will be more robust measures that can be used to track progress on achieving the objectives of the Strategy. This should occur along people with disabilities being included and visible in all government reporting on policies, strategies and plans for all New Zealanders.

## 4. Responses to consultation questions

The first phase consultation asks *“What are the most important things for disabled people and their whānau to live a good life, to feel valued, supported and to be able to participate in their communities?”* We have drawn our responses from what people with intellectual disability and their families and allies have told us about living valued and good lives, being included in their communities, having the right supports at the right times and their hopes for the future.

### 4.1 Valued and good lives

*“Sometimes we are left out, people see us with a label, and they think we can’t do anything”.*

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

When we see the person first and not the label and recognise others of equal value to ourselves we enter into relationships of respect. Enablers for valued and good lives have starting points that value each person for their unique gifts and contributions and knowing and understanding the person, their families and whānau, culture and communities.

Barriers to valued and good lives are starting points with attitudes and behaviours that see and place the person as ‘other’ and a ‘burden’ and where the person is known and responded to in silos separate from their family and whānau, culture and communities. Being bullied is one of the most frequently expressed concerns made by people with intellectual disability 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>3</sup>

People with intellectual disability spoke about importance to them of *“being treated with respect”* and being seen as able *“to make their own decisions”*. It felt bad when others didn’t treat them with respect such as when they were *“picked on and bullied”* or when decisions were made about or for them without them having a say or sometimes even knowing what was happening.

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<sup>3</sup> Sally Robinson (2012), Sally Robinson and Julia Truscott (2014)



Families stated that positive approaches where their family member with an intellectual disability *“was seen as a valued community member made it easier for families to comfortably engage with people providing support or education”*. Others identified *“looking at disability through a deficit lens”* or defining their family member by a label – *“We’ve had one of **those** children here before”* - as barriers.

Respondents who worked in services talked of the importance of supporting people in ways that were respectful of preferences and treated people with dignity. Organisations and staff should support people to have *“valued roles”* and to participate and contribute in school, employment, as members of community groups and as self-advocacy representatives on governance, advisory and working groups.

## 4.2 Belonging, participating and contributing

*“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”.*

*“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”.*

Feeling we belong and being welcomed is at the heart of inclusive communities. Families and whānau are the foundation of communities and can only thrive if they are connected to, are valued by and have a sense of belonging in their own communities<sup>4</sup>. Having a home gives us a place and base in our community. 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.

People with intellectual disability said that wanted to *“spend time with family and friends”*, to be able to choose where they live and who they live with, *“to have long term relationships and get married”*, *“to go out independently and buy their own food”* and *“to get a job”*. People wanted to have more friends, to be in more social situations with bigger groups and *“to have more help”* to be able to participate in the community and get jobs. Many people struggled to find work and in one group of 15 who took part in a discussion only two people had a job.

Feeling safe and access to transport were two issues that were frequently raised. People reported feeling annoyed and vulnerable when they were *“hassled”* on the street by beggars *“asking them for money and food when they were by themselves”*. Not feeling safe reduced their ability to be independent. People wanted more accessible, frequent and affordable public transport with *“discounts for people with disabilities”* and *“more electronic bus and train timetables that are bigger and easier to*

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<sup>4</sup> Pippa Murray (2011) *Developing family leadership*, p.2

*read*". Road crossings need to be safer and "*made better so everyone is able to use them*". Some people wanted information about being safe if there was an earthquake.

Families want their family member with an intellectual disability to be able to live a typical life and reach their full potential, like their siblings and non disabled peers. Parents want their children "*to be happy, healthy and safe*". They want their children to go to school, take part in community activities and be involved in decisions that affect them. A generational change was noted by some with a belief expressed that that the younger generation had become more accepting and in turn, this has made it easier for children with intellectual disability to participate in activities considered part of ordinary life and belong in their communities and schools.

For disability service providers it was important that communities included people in communities, in school, in recreational activities, in clubs, in jobs, and as friends, neighbours and customers. Organisations and support staff have critical roles in working in partnership with individuals and their families in ways that work best for good support and effective use of funding.

### **4.3 In 10 years time**

Across all groups spoken with – people with intellectual disability, families and whānau and allies, including service providers – all wanted to see an inclusive education system where children and young people had equal opportunity to learning in preschool, school and post school years. What participants in discussions hoped to see in 10 years are all early childhood education centres and schools being "*welcoming*" and accommodations "*being made without a fuss – it is just the way things are done*". This should be continued across the lifespan so that in the adult years people with intellectual disability had equal access to tertiary education and ongoing learning.

People said they "*wanted a job*", "*to live in the city with friends and family*", "*to be independent and have support for decision making*", "*to have more opportunities for actives and leisure (sport, singing, drama)*", "*to have a job at a rest home and a school and be paid for it*". Some people want to move away from home and go flatting and other people want to stay at home with their parents.

Looking to the future families want their family member to "*go flatting, get employment, have networks outside of the family and be as independent as their capabilities allow*". One parent noted that their expectations for their child with intellectual disability had increased over the years as they "*realised that the sky is the limit*". Families' hopes were for services and supports that were responsive to both the changing life stages of their family member with intellectual disability and the family and whānau, parents and siblings. A particular concern was for the time when parents were no longer able to provide support and advocacy for their sons and daughters.

Service providers wanted to see the benefits of greater flexibility and increased control for people with disabilities and their families that are currently being trialled in projects in some regions be available to everyone in New Zealand "*no matter where they live and who they are supported by*". They hoped for a wider range of individualised services where people were "*truly able to shape their own supports*" and where there was "*easy access and no waiting lists*". Respondents also identified building on and extending collaborative partnerships between government, communities, disabled people and their families and whānau and service provides as important to achieving

better outcomes. Reducing bureaucracy and compliance costs would also be beneficial.

#### **4.4 Influence of the 2001 Disability Strategy and strengthening the impact of the new Strategy**

Different words may have been used but since its inception in 1949 IHC has always sought an inclusive society. IHC was active in consultations to develop the 2001 New Zealand Disability Strategy and with the Ministry of Health produced an Easy Read version of Strategy.

Having the Strategy made it easier for New Zealand to engage in the development of the CRPD. The Strategy has, however, been somewhat overshadowed by the CRPD and efforts to implement and monitor the Convention both at the wider community level and within IHC. In addition for us a focus on the Disability Strategy has been overtaken by other government strategies that have received more attention such as the Carers Strategy and Ageing Strategy.

In the first few years following the launch in 2001 the Disability Strategy was useful as a reference point to engage self-advocates and guide advocacy and service provision principles. The National Health Committee's 2003 *To Have an Ordinary Life* (THAOL) report with its specific recommendations and actions had a greater impact. THAOL has become a landmark document for people with intellectual disability and their families and allies about what needed to change and key areas to be addressed. IHC funded annual health checks for people living in IDEA services and advocated for and participated in research to improve health outcomes as responses to THAOL recommendations.

To strengthen the usefulness and sustainability of the new Strategy recognition needs to be made that success is dependent on government working in partnership with people with disabilities, their families and whānau, communities and non government organisations. Much of the innovation that has occurred has come from people with disabilities and their families and whānau working with communities and service providers. This continues to be the case as is evidenced by IHC's one to one and skills based volunteering programmes help people with intellectual disability participate, have fun and contribute in their communities and partnership through IHC's service arm IDEA with Hell's Pizza to provide paid internships.

Along with our suggestions in section 3 to link the revised strategy to government policies, strategies and planning for all New Zealanders and to reflect the critical place of CRPD Article 12 there are some gaps and areas in the 2001 Strategy that need to be addressed or more strongly emphasised. These include: access to justice; bioethical decision making; the right to bodily integrity; freedom from inhuman or degrading treatment or punishment and from exploitation, violence and abuse. Alignment with the CRPD provides the way for these to be included in the revision.

We reiterate our endorsement for the development of the monitoring framework. The adoption of an integrated framework to track progress is a vital element of the review process.

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