



## **IHC Submission**

# **Implementing the United Nations Convention on the Rights of Persons with Disabilities: Draft Government Report and Focus Areas**

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## 1. About IHC

**Mission Statement:**

***IHC will advocate for the rights, inclusion and welfare of all people with an intellectual disability and support them to lead satisfying lives in the community.***

IHC New Zealand Incorporated (IHC) is a community-based organisation providing support and advocacy for people with an intellectual disability and their families. Through our service arm, IDEA Services, IHC works with approximately 3000 families with children who have an intellectual disability, provides support and training for 4000 adults in work places and helps more than 4000 with disabilities to live in IHC houses and flats. IHC also advocates for the rights of more than 50,000 people with an intellectual disability.

IHC has a long history of political and systemic advocacy and is committed to non-government funded programmes of work related to individual and systemic advocacy, empowerment of individuals and families and inclusion of people with intellectual disability in society. IHC has a particular interest and expertise in human rights and social justice issues affecting people with intellectual and other disabilities.

A member of IHC represented Inclusion International on the United Nations' committee that drafted the UN Convention on the Rights of Persons with Disabilities (UNCRPD), now ratified by New Zealand. IHC endorses the New Zealand Disability Strategy and the UNCRPD as strong frameworks for guiding Government policy, practices and decision-making.

## **2. Introduction**

IHC appreciates the opportunity to comment on the Government's draft report on implementing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). We congratulate the team involved on their efforts to undertake a genuine consultation process and to make the report a "living document" through the links with what is required in the disability action plan and specifically in relation to the three focus areas for discussion.

IHC notes that in addition to the three identified focus areas – supports for living, mobility and access and jobs - being ones that the government considers the UN will focus on in their consideration of New Zealand's report, they are also areas that the Government is concentrating on as it develops a disability action plan.

This submission draws from information gathered from a number of sources. These include: 27 community forums for people with an intellectual disability run by the IHC National Self Advocacy Team around New Zealand in 2010 that have been attended by 1,060 people; IHC Advocacy Team's Start Strong work programme to improve early support services for disabled children and their families that has involved three seminars attended by over 250 people; and discussions with more than 100 service users and 80 families about support needs for older people with an intellectual disability. Specific consultations about the draft government report were also undertaken within IHC and its Association membership.

### 3. Overall Response

New Zealand's ratification of the UNCRPD in 2008 presents the opportunity to consider the status of disabled people in relation to their rights through a wider lens. The first government report on implementing the Convention along with other reporting activities such as from the Convention Coalition and the Human Rights Commission (HRC) will provide a baseline against which subsequent reports can be measured. In addition as part of the consultation process on the draft government report three focus areas have been highlighted for discussion with particular reference to the development of the disability action plan.

IHC notes that there are a number of inter-related initiatives underway, many of which are referred to in the draft government report. These include the development of the disability action plan, the Ministry of Health's (MoH) new model, the Welfare Working Group (WWG) and the work of the Human Rights Commission (HRC) and their recently released updated status report and identified priority areas for action. It is vital that these initiatives are all in step. An integrated whole of government approach is required to work with disabled people and their families and the disability sector to address the systemic problems that have resulted from disjointed service delivery and the division of people's lives into funding silos.

What is most important is that whatever tools are used, they must be ones that actually bring about meaningful change and make a difference to the everyday lives of people with intellectual disabilities and their families. There is no doubt that there has been progress in respecting and responding to the rights of disabled people but there have also been many promising beginnings that have not been built on or sustained or have not achieved their intended outcomes and there remain many areas in which New Zealand needs to do better.

IHC agrees with the identification of a number of areas that require further action. These include the need to do better with regard to education for disabled students, to improve health outcomes for people with an intellectual disability and the need for improved data collection. IHC considers, however that there are a number of areas of omission from the draft government report. These include the need for improved early supports for disabled children and a commitment to inclusive education. In places the tone of the report would benefit from a greater recognition of the interdependency of individuals and the overlap of support systems both funded and natural. This would also add to a better reflection of issues for Maori as well as for Pacific people and those from other ethnic groups.

Our comments on the draft government report follow in section four and our feedback on the identified focus areas is in section five of the submission.

#### **4. Implementing the UNCRPD - draft government report, 12 October 2010**

IHC recognises the constraints that the writing team is working under in terms of the UN requirements for the format and page limit for the report. Within this context our comments on the draft government report highlight issues of particular concern for people with an intellectual disability and their families/whanau and addresses areas where we consider there are inaccuracies or clarification is needed or could be omitted from the final report. Where feedback is specific to the text the paragraph number in the draft government report is noted. Some areas are discussed more fully in section five in our feedback on the three focus areas.

##### **4.1 Overview**

3 - We agree that the New Zealand Disability Strategy is underpinned by a paradigm shift in which inclusion is a core component. The strategy also values diversity and recognises the full citizenship rights of disabled people. Inherent in the paradigm shift is the recognition of the interaction between a person's impairment and the environment. The removal of barriers to participation and the provision of supports, resources and environmental adaptations to enable participation in all facets of life are central to achieving an inclusive society. Within this context impairment specific needs should be recognised and appropriately responded to. An alternative phrasing to that currently at the end of the section where reference is made to "dedicated services for disabled people where this is not possible" (inclusion and mainstreaming as the default option) is required to better convey what inclusion entails.

6 &7 – These points could be combined into one that emphasises partnership between disabled people and their families/whanau, the disability sector and government.

14 – In relation to the statement that the "underlying philosophy and the government's commitment are consistent", the draft government report accurately refers to the fact that "practice can and sometimes does, fall short" and while "the list of potential support services is impressive, there is a comparable list of instances where service ideals are not realised." The experiences of many people with intellectual disabilities and their families/whanau can also be that they cannot readily access support services in a timely manner and when they do they have to fit with what is available rather than their supports being individually tailored to meet their needs. Accessing information and navigating the system can be an immensely difficult task.

15 – Under the heading "The future" would be a good place to introduce the proposed disability action plan as a vehicle to progress changes as part of plans that "exist to help redress weaknesses in services as part of a progressive realisation".

#### **4.2 Articles 1-4 Purpose, definitions, general principles, general obligations**

29 – This section would benefit from further explanation as to why the “differences in services provided by ACC are different from those in health and disability support systems and this difference has been the subject of litigation” i.e. the anomalies that exist where people eligible for ACC often have access to a wider range of entitlements and funding for services at higher rates.

#### **4.3 Article 5 Equality and non-discrimination**

44 & 45 – This section would benefit from an introductory positive statement as to what reasonable accommodation is in relation to New Zealand legislation and the UNCRPD rather than the current “reasonable accommodation means the rights of a disabled person should not be met if doing so would be unreasonable”. The uncertainty described relates to the application of reasonable accommodation in practice.

51 – It would be useful to give an indication of the outcomes of complaints to the HRC on the grounds of disability to illustrate “we have mechanisms to resolve complaints about discrimination.”

#### **4.4 Article 7 – Children with disabilities**

IHC’s Start Strong campaign to improve early supports for disabled children and their families has clearly identified some serious human rights issues for this group of children which require government recognition and response. These have been longstanding issues in New Zealand and in some areas families consider that available services have actually gone backwards. Concerns include barriers to being included in the community of all children, inadequate responses from well child and early childhood education and childcare providers, a lack of an integrated and timely response to child and family/whanau needs, and a lack of outcomes monitoring or the collection of baseline information to inform future planning. These concerns are exacerbated when the diversity of families is not recognised or where families are from already marginalised groups.

These concerns are captured in the recent Public Health Advisory Committee (PHAC) Report (2010) *‘The Best Start in Life: Achieving effective action on child health and wellbeing’* which highlighted New Zealand’s low investment in the early years in comparison to international standards. The report also identified significant systemic issues in poorly coordinated policies and service delivery that negatively impacted on all children and their families. They, however, considered that families of children with high and complex needs or disabilities were among those most affected by such incoherent policies and services having to face navigating their way through inconsistent information and disjointed service delivery.

IHC is deeply concerned about the number of children with intellectual disabilities living in poverty within families or with sole parents who are dependent on beneficiary income. In its submission on the Social Assistance (Future Focus) Bill, IHC opposed the requirement of solo parents of disabled children over the age of six to return to work when there are inadequate supports in place for that child, either in schools or in after-school care. Supporting sole parents of disabled children into paid work requires well connected, across-agency policy settings, systemic flexibility, appropriate resourcing and responsiveness. Threatening to enforce obligations and work expectations is not the answer and some of the options proposed by the WWG would place unrealistic burdens and constraints on families that will exacerbate the situation rather than provide constructive solutions.

67 & 68 – These paragraphs could be excluded as they do not add anything meaningful to this section. Male and female differences in the rates of disability are well established and so greater numbers of male having high support needs and receiving support to access early education are hardly surprising. As referenced at the bottom of the page “Rett syndrome is a neurodevelopmental disorder that affects girls almost exclusively” so mentioning in the text that “more girls than boys have Rett syndrome” seems rather redundant.

71 – IHC would question as to whether the Children’s Rights Line qualifies as an example to illustrate the assertion “we have a voice for disabled children.” This is not a medium that would either be known by or accessible to most children with an intellectual disability.

79 – In addition to the statement in the draft government report that “in practice not all disabled children have access to the supports they need” it should be added that there are also issues with disjointed and uncoordinated services which result in inefficient use of resources.

80 - This section needs rewording in order to better convey the sentiment that we assume is trying to be expressed. The text currently begins with the sentence “In cultures with traditionally strong hierarchical structures (e.g. Pacific Island peoples) parents often make many decisions on behalf of their children.” Surely it is the case in most cultures that parents often make decisions on behalf of their children and indeed there are many instances that legally require parents to do so. It would be more appropriate to talk about respecting families’ cultures in order to work with families in the best interests of the child.

#### **4.5 Article 9 - Accessibility**

Fuller comments in relation to accessibility are made in section 5.2 in relation to the focus area – mobility and accessibility.

87 – We agree with the statement that the “reality is that significant barriers still exist in buildings, transport, employment and access to information” and would add others such as health, education and community participation to the list.

91 – “Training workshops to assist key people who support those who have communication difficulties are undertaken across the country each year” are referred to in the text. What are these and who are these “key people”?

94, 95, 96 & 97 – These sections on accessible buildings could be condensed

99 – IHC fully endorses the view that “successful towns and cities should be inclusive communities that respect and celebrate diversity and care for the disadvantaged” and the implementation of the framework provided by the Urban Design Protocol.

#### **4.6 Article 10 – Right to Life**

The UNCRPD applies to people from birth so technically antenatal screening does not fall within the areas to be commented on. However, *the Antenatal Screening for Down Syndrome and Other Conditions - Quality Improvements* programme introduced this year raises serious issues of concern regarding the value that society places on the lives of disabled people and in particular what the programme implies about the lives of people with Down syndrome. Despite the Ministry of Health saying that the extended screening provisions were not about reducing the number of babies born with Down syndrome, cabinet papers obtained under the Official Information Act state that the outcome of the programme will be a reduction in the number of births of babies with Down syndrome, with some 90% of unborn children diagnosed with the condition being aborted.

#### **4.7 Article 12 – Equal recognition before the law**

People with an intellectual disability require access to support in order to assist them in exercising their legal capacity. Provision of procedural accommodations are central to people with intellectual disabilities being able to exercise their full legal rights and capacity on an equal basis to others, to have their rights respected and facilitate their effective role in participating in all legal proceedings.

IHC recommends that the issue of supported decision making warrants a new and specific focus in New Zealand policy and practice. We note that the HRC has identified

this in their recently released status report on Human Rights in New Zealand and have included supported decision-making as an action area.

126 – When the Protection of Personal and Property Rights (PPPR) Act was introduced in New Zealand in 1988 it was state of the art in setting out a presumption of competence. As started in the draft government report “Practice, however, is still problematic” and the Act has not been consistently applied as intended. It is timely to consider the PPPR Act which involves substitute decision making in light of the UNCRPD obligations for supported decision making. The last sentence in the paragraph which refers to not adequately addressing “support for decision-making” seems to confuse enduring powers of attorney and guardianship i.e. is it referring to someone for whom power of attorney has been set up or someone who has a welfare guardian appointed or both?

#### **4.8 Article 13 – Access to Justice**

The comments made with regard to the need for people with an intellectual disability to access support to assist them to exercise their legal capacity in 4.7 apply equally in relation to their access to justice.

128 – This section outlines the services the government provides to ensure that “disabled people have effective access to justice on an equal basis and can participate in legal proceedings.” The adoption of a total communication approach (total communication is discussed in section 5.2 of the submission), including access to social interpreters, would further enhance the ability of people with an intellectual disability to access justice.

132 – There are a number of systemic and human rights issues in the implementation of the 2003 Intellectual Disability Compulsory Care and Rehabilitation (IDCC&R) Act that require review. Ensuring that international human rights standards are adequately reflected is one area that needs particular attention

#### **4.9 Article 14 – Liberty and security of the person**

141 – To counter the issue of “the limited choice that people in community homes have in choosing their fellow residents, the house they live in and their daily lives” more is required than “the implementation of the independent living model”. What is needed is greater flexibility in funding to allow a greater range of options that enable innovation, personalisation and working differently rather than people having to fit into what is available.

142 – This section needs to be clarified. The discussion appears to relate to guardianship but is under the heading “People in compulsory care are encouraged to

be involved in decision-making”. Guardianship under a PPPR order is not the same as a compulsory care order under the Mental Health Act or the IDCC&R Act.

#### **4.10 Article 16 – Freedom from exploitation, violence and abuse**

Being bullied by members of the community was the most frequent concern expressed by people with intellectual disability attending the 2009 Self Advocacy Community Forums. In response to this issue IHC’s National Self Advocacy Team included sessions in the 2010 forums to support people with an intellectual disability to develop solutions to dealing with bullying.

People feel that this is not an issue which would appear in complaint statistics with regard to discrimination, but is one of the biggest barriers to being, and feeling part of a community. For some people, this directly impacts on their ability to do their jobs, to feel safe in their community and to participate in social activities. This means for some people that they would not be comfortable in their own communities without support, although they feel capable in every other way of participating in work, or community based activities.

#### **4.11 Article 19 – Living independently and being included in the community**

A more detailed discussion on living independently and being included in the community is undertaken in section 5.1. IHC considers that it is necessary to take a whole of life approach. Within this framework there are issues with regard to older disabled people and the supports required to enable people to continue living in their homes and communities.

183 – The proposed new model has the potential to enhance independent living and being included in the community, however, this will not be achieved if a comprehensive, integrated whole of government approach is not taken. There is limited detail available as to how the new model will actually work in practice. From what is known, however, there are concerns that it could make the system more complex for people with an intellectual disability and their families to negotiate rather than simplify it with the addition of local area coordination and individualised funding agencies to Needs Assessment Service Coordination (NASC) agencies. As the new model currently has been described its only applies to disability supports funded through the Ministry of Health. Without integrating the system across health, education, work and income, housing and other areas the problems of a disjointed and siloed system will remain.

190 – Does the statement “However, many community residential services are still institutional in nature” refer to the preceding “Today, 90 percent of mental health consumers receive community based care’ or is it meant in relation to all disabled

people? It would be useful to state what it means not to be “institutional in nature” i.e. there is more work to be done in providing choice, flexibility, personalised options and enabling greater community inclusion.

192 – This section needs clarifying. The statement is made that “limited residential housing availability means that some disabled people are placed in residential facilities for older people”. Then the report goes on to say “ACC currently has 136 clients under the age of 40 living in residential facilities, only three of which are not in age-appropriate facilities”. Three out of 136 clients who are inappropriately placed, while three too many, is not strong supporting evidence to illustrate and also minimises what is an issue of considerable concern. The unsuitable placement of people with an intellectual disability in rest homes because of health problems or extra support not being available so that they can either stay in their own home or move to a home of their choice that is age appropriate is an unacceptable situation.

#### **4.12 Article 20 – Personal mobility**

200 – There seems to be the assumption in this section that public transport is available everywhere in New Zealand. Many small towns have no public transport within the town and no or a very limited taxi service. This creates barriers not only for travel to work or community participation but also being able to travel the great distances often required for doctor or hospital appointments and education or training courses.

#### **4.13 Article 21 – Freedom of expression and opinion and access to information**

Access to information in understandable forms and a variety of formats is an important issue for people with an intellectual disability to enable them to make informed choices and decisions. We discuss this further in section 5.2.

#### **4.14 Article 23 -Respect for home and the family**

Article 23:4 states “States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, State Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families”. As has been discussed earlier in section 4.4 the provision of early supports to disabled children and their families is an area in NZ that needs improving. That 20% of all children in out of home care (5,000) have disabilities (Department of Child, Youth and Family, National Disability Advisor) is

cause for considerable concern and falls well short of meeting the obligations inherent in this article.

#### **4.15 Article 24 – Education**

IHC is pleased to see that the government has acknowledged that the area of education is one in which New Zealand needs to do better and this is reinforced by the high number (17%, being the fourth highest) of complaints have been received by the HRC from disabled people about education issues. We note also that other organisations such as the office of the Children’s Commissioner and non government organisations such as IHC also receive and respond to special education complaints about access and participation for disabled children at their local school.

A fundamental in the draft government report, however, is any reference to New Zealand’s obligations under the Convention to provide an inclusive education system. Although the report presents considerable information about the levels of funding and support it cannot be inferred that this results in inclusive education. Article 24 of the Convention states unequivocally that “States Parties shall ensure an inclusive education system at all levels”. The report fails to show any commitment to complying with this requirement, despite highlighting the consequences of having *not* provided an inclusive education system.

225 - IHC notes the recognition that despite the right to enrol, some schools are not complying with legal obligations to accept disabled students.

235 - We are pleased to see acknowledged that there is an absence of data currently available on educational outcomes for disabled children and young people. IHC suggests that among the data that needs to be collected and analysed is that which compares educational outcomes for disabled children in regular schools with disabled children in segregated education settings.

242 -246 - IHC acknowledges the manner in which the report presents the reality of education for disabled students as being far from ideal. IHC affirms the comments in the report relating to the need for high quality leadership in schools to bring about quality inclusive education experiences for disabled students. We suggest that the other factors required for inclusive education are investment in initial and ongoing teacher education, accountability mechanisms easily accessible for caregivers, a Code of Practice which sets out legislative, policy and human rights imperatives and strong leadership from central government to ensure that self managing schools are supported to respond to the rights and interests of disabled children at school.

247 - Since the publication of this draft report, the government has released the outcome of its Review of Special Education. IHC believes the Review of Special Education has not gone far enough to ensure that all disabled children’s rights to an

inclusive education will be recognized and responded to. At the most basic level, there is still no clear policy statement that New Zealand will have an inclusive education system. The Review maintains a dual system with continued segregation for some students. It also says that special school staff will provide advice to regular schools on how to teach for diversity. There is no support for schools or Colleges of Education/Universities to move towards professional development of teachers for inclusive teaching practices. No funding has been allocated to supporting schools to become fully inclusive. In fact, the government has instead committed many millions of dollars into improving and resourcing segregated learning settings. The Review sets an aspirational goal of 80% of schools being inclusive by 2014. This raises serious concerns about what disabled students will experience in the remaining 20% of schools which, by default, will be allowed to fail to be inclusive.

IHC would not wish to see any claim by the government in its final report that the outcome of the Special Education review will lead to an inclusive education system. Such a claim would be misleading and not reflect the reality of the challenges ahead for all in the education sector.

#### **4.16 Article 25 – Health**

IHC has lobbied for many years for changes to improve the health outcomes of people with intellectual disabilities and welcomes the identification in the report of “the need to improve the health of people with intellectual disabilities”. The poor health status of people with intellectual disabilities continues to be overlooked in New Zealand despite the specific review and recommendations in the National Health Committee’s 2003 report *To Have an Ordinary Life*. The Committee identified an urgent need to address the systemic neglect of the health of adults with an intellectual disability and improving poor health and prescribing practices as a priority area for action.

Many issues around health care arose in the discussions at the Self Advocacy Community Forums. People expressed concerns about the high cost of health care for some people with intellectual disability. People feel that they do not have the same access to health care in that they may need longer to create good relationships with their health care provider. They may need longer appointments which will enable them to build trust, explain their health concerns and for health professionals to take the time to explain health issues and procedures properly. There is a very strong feeling that health professionals are not educated about, or respectful to, people with intellectual disability. Many reported experiences where the health professional spoke to the support person rather than asking them directly.

251 - In addition to the evidence given in this section people with an intellectual disability experience inequalities in health care access, including to mental health services, and outcomes. They experience lower life expectancy and greater prevalence of health problems compared to the general population. However, often

these health conditions, including mental health concerns, are either under recognised or inadequately managed. People with intellectual disability do not have access to the same levels of preventative health care and health promotion programmes as others in the community.

#### **4.17 Article 27 Work and employment**

There is further discussion of issues related to work and employment in section 5.3

267 - The government in establishing the WWG has stated that people on benefits, including disabled people, should have the expectation and the opportunity to receive the financial and social advantages of participating in the workforce. IHC concurs with this position and many people with intellectual disabilities have attained this goal for themselves. However, the barriers to achieving employment are significantly greater than for other disabled people. Intellectually disabled people are least likely to secure employment in tight economic circumstances, or times of high unemployment, and are often the most likely to be the first to lose their job when employees need to be laid off.

In our submission on the Social Assistance (Future Focus) Bill IHC explained that under the proposed provisions it will become more difficult to qualify for an Invalid's Benefit. This will impact particularly on young school leavers with intellectual disabilities who are unable to find suitable employment. This may mean that more intellectually disabled people who are possibly unable to work will be put on a Sickness Benefit, where they will be unrealistically expected to work, or be subjected to regular reviews of their entitlements. Having to go through such an exercise regularly is expensive and stressful. The expectations and requirements laid down by the Bill are incongruous with the realities of life for this most vulnerable group of people in our society.

People with intellectual disabilities who successfully secure meaningful employment find it challenging at times to stay in their job due to lack of appropriate work-place support. In such circumstances, they will still need the "safety net" of the Invalid's Benefit as they transition in and out of employment. Tightening the criteria for re-applying for the Invalid's Benefit would discriminate against intellectually disabled people, pushing them deeper into poverty.

285 – It would be useful to have a breakdown of who minimum wage exemptions were for and on what grounds they were granted. IHC recommends that the Department of Labour reviews the use of the Minimum Wage Exemption Permits and other labour market support mechanisms to ensure that they are consistent with the work and employment requirements of the CRPD.

#### **4.18 Article 30 – Participation in cultural life, recreation, leisure and sport**

Reference is made in this section to the government's "No Exceptions" strategy to support disabled people. Many people with an intellectual disability experience barriers

in being welcomed in and there is a need for funded positions to help community organisations be more responsive. This type of support, however, appears to have dried up with the “No Exceptions” policy not being resourced. Participation in “special” recreation should be an active choice and not occur because it is the only option available.

#### **4.19 Article 31 Statistics and data collection**

307 - IHC strongly agrees with the identified need to improve data collection and that this is “essential to enable better monitoring of the situation for disabled people in New Zealand”. Robust comparative data is needed to enable better analysis of the position of disabled people on key social, health, education and economic outcomes. The availability of more comprehensive information will also contribute positively to informing policy and planning processes.

## 5. Focus areas

The discussion document put out by the Office of Disability Issues on New Zealand's report on the UNCRPD notes the three focus areas selected from draft report are those that the government thinks the UN will focus on. These are also the areas that the government is concentrating on improving as it develops a disability action plan.

It is important to recognise that for meaningful change to occur a number of areas must be addressed in an integrated way. The three focus areas of supports for living, mobility and access, and jobs all overlap with each other and to other areas such as access to healthcare, education, legal rights, and income support. All citizens, not just people with a disability, are interdependent and social policy needs to acknowledge the interdependency of any individual.

A whole of life approach that overcomes the barriers imposed by funding silos needs to underpin a whole of government framework that is developed in partnership with disabled people and their families/whanau and the disability sector. As has been discussed there is the promise of this in some of the current work under way but we have not yet seen anything substantive come to fruition in terms of improving outcomes for disabled people. IHC notes that 2008 *Inquiry into the Quality of Care and Service Provision for Disabled People* called for an immediate action plan and yet two years later at the end of 2010 such a plan is still only in its development stage.

People with an intellectual disability and their families have endured a succession of initiatives that have held out promise but failed to deliver. The 1994 New Framework for Disability Support Services is one such example. Speaking in a very similar way to what is being talked about now for the new model in 2010, the government of the day in 1994 heralded the new framework as signalling a change in disability support services that aimed to put disabled people in charge.

The learning needs of people with an intellectual disability need to be recognised within the context of an integrated framework and supports made available to help them do everyday things in everyday ways that are consistent with the principles of the UNCRPD, the NZ Disability Strategy and the Treaty of Waitangi. As described by David Corner, an IHC Self Advocacy Coordinator, in his presentation to self advocates at the 2010 Inclusion International Conference good support means:

- that we can have a greater understanding of our world;
- that we can have greater access to the community we live in; and
- that we have more opportunities to have our say and be heard.

## **5.1 Supports for living**

The easy read version gives the background to this section as “government pays for different types of supports to help disabled people have a good life at home and get out and about in the community” which gives a broader focus to the question areas than that conveyed in the discussion paper. What is hoped to be achieved by improvements in this area is to “make it easier for disabled people, and their families, to have more choice and control over the supports provided to them”.

Recognition of what “home” means – be it living at home with family, in your own home, flatting with others, in a shared residential services home, in supported independent living or boarding arrangement - is critical in considering supports for living. The Convention Coalition identified social participation as the biggest single issue in their recently completed monitoring project. This included friendships and other social networks and access to social, cultural and recreational worlds as important aspects of community participation.

People with an intellectual disability and their families need access to supports to enable them to live in the home of their choice and participate as valued and equal citizens in their communities. All too often people have to fit in with living arrangements or programmes that are not their choice because it is all that is available or have to shift because of changing support needs. This is particularly an issue as people with an intellectual disability age and experience health problems that may require higher levels of care. Inflexibility in funding options or service provision results in a lack of control and choice rather than people being able to access supports to enable them to live in their preferred housing arrangement or adaptations made so they can stay living in their home and local community.

Individualised funding has been promoted as the key mechanism that will provide the solution to the issues of choice and control. While there may be benefits for some it will not address all the issues involved. Not everyone may want to manage their own funding either themselves or with the assistance of their family yet they should still have the same choices in services and supports. It is not real choice if the power and control remains with purchasers and service providers. People with an intellectual disability and their families should be represented in governance structures, policy and service development and when evaluations are undertaken. Achieving meaningful change also requires addressing quality and capacity issues. Choice and control of an individual budget is of limited value if there are no suitable services available or the choice is between poor quality options that are not responsive to individual needs.

What we know from New Zealand and overseas experiences about what works well includes the following:

- Flexibility in funding/contracting to enable more personalised responses that are tailored to individual and family needs, supports an integrated approach that enables interagency collaboration, facilitates trust partnerships and focuses on outcomes rather than just service compliance and reporting.
- A whole of life approach that is proactive and allows for times when more intensive support may be required such as during transitions and other times when less support or resources are needed without forcing people to continually have to jump through hoops or prove need in order to access services.
- Easy access to up to date information in suitable formats so that people with an intellectual disability and their families can make informed choices.
- Access to timely, quality, integrated services and supports that are delivered flexibly in response to identified and agreed needs and in a manner that respects individual and family diversity.
- Availability of a range of living options including that of owning a home.
- Adaptations and increased support (maybe personal or technological) so disabled people can remain in their own home and familiar community as they age.
- Community development to increase the capacity and capability of communities to provide inclusive and natural supports
- Investment in the disability support workforce

## **5.2      *Mobility and accessibility***

The easy read document describes this focus area as being about “getting about and having information that is right for you, finding out about things, get to and around places so you can participate, getting a job”. The area of mobility and accessibility – getting about and being able to participate – has links to many of the areas related to community inclusion discussed in earlier sections of our submission such as access to health, recreation, jobs, and legal rights. Addressing the barriers to accessibility and participation are crucial and include making “mainstream” services and organisations more welcoming and responsive.

As has been highlighted in the draft government report accessible information in a variety of formats is important in helping people get started, make informed choices and have more control in their lives. Further work is required developing easy to read information for people with an intellectual disability and in making other necessary adaptations and accommodations to support them to exercise their rights and make informed decisions.

What works well for support?

- *Total communication approach*

Accessible information is a crucial component of a wider total communication approach that should be implemented. Total Communication is internationally recognised as the best way to support the communication needs of people with an intellectual disability. Total Communication is about creating supportive communication environments and responsive communication partners using whatever it takes to help people understand and be understood so that all people with an intellectual disability will: be able to understand their world; have someone to communicate with; have a reason to communicate and something to communicate about; and have a way of communicating. The adoption of a total communication approach will not only enhance the access to information and legal rights but will also support the participation of people with an intellectual disability in their communities.

- *Transport*

Transport is major issue that was identified at the Self Advocacy Community Forums for people with an intellectual disability but in relation to the costs both for individuals and for support people for those who need assistance to transport. These occur in the context of wider difficulties of participating in the community if you cannot afford to pay for transport or for the cost of the activity when you get there. People living at home or in supported living have to pay for their own transport costs and may also have to find money to pay the transport costs for a support person if needed. This can severely limit their ability to get out and about in the community. People living in smaller towns or country areas that are not serviced by public transport face additional hurdles. As well as the restrictions that they face in being able to get out and about the costs of getting to work if they have a job can be very high.

There are many people who need support, and this support need can be increased by the amount of discrimination that occurs. “It is really hard to focus on learning to catch the bus, like the money and the timetables, when you are worried about who is going to be mean to you on the bus”.

### **5.3      *Jobs***

Being in meaningful work is associated with benefits both to the individual and to society. People with an intellectual disability are entitled to the same aspirations and life opportunities as others including opportunities to work. This has quite rightly been identified as a focus area for action to extend the options available in ways that are

satisfying and valued, provide for ongoing growth and development and meet the goals of social inclusion.

As with supports for living this is an area that requires creative and diverse alternatives and no one size will “fit” all people with an intellectual disability. Development of supported employment in the 1980s has shown what can be achieved by people with an intellectual disability including those labelled with moderate or severe intellectual impairment. Despite positive examples, the promise of supported employment has not been realised to the extent hoped for.

A conundrum for people with intellectual disabilities is that jobs offering the average wage are often inaccessible to people supported by benefits, who are part of a pool of low skill workers competing for a range of minimum wage, low paid, casual, seasonal, part-time, shift-work or otherwise poor jobs. This situation has historically existed both in times of economic prosperity as well as recession.

The complexity of the rules around benefit abatement can result in people not taking up part-time work for fear of losing their benefit. IHC is aware that there are misunderstandings about the processes and rules in this area and changes that may result from the WWG’s proposed options may further compound this situation. The benefit system, abatement rules and requirements for work need to recognise that part time work is the best option for many people with an intellectual disability.

Amongst the WWG’s options is an emphasis on the employer’s responsibility to promoting wellness which is easily achieved by productivity and profitability imperatives. Missing is a recognition of reasonable accommodation (as described by the UNCRPD) and what is required of employers in order to provide an accessible, inclusive work place for disabled people.

Getting a job is one of the concerns that have been most frequently raised at the Self Advocacy Community Forums in 2009 and 2010. Feedback has been that: people want to make a contribution to the community they live in; people want meaningful activities to participate in; and people want paid employment. People reported that they felt discriminated against in regard to being able to work because of the level of support they need to find, and keep employment. They feel that there are employers out there willing to give them employment, and feel capable of keeping this work, if they have the right support. An additional issue for people who live in small townships is that there is not much work around.

People are very angry about the discrimination against those in employment receiving less than the minimum wage. Their anger was less about the money than the “being treated differently to their workmates”.

People with an intellectual disability consider that tertiary education is a way for them to develop further skills to enable them to gain and keep employment but courses

often are inaccessible to them. Appropriate adaptations and accommodations should be made in order that people with disabilities can take part in such courses. The cost of courses can also be a barrier to the participation of people with an intellectual disability.

People with an intellectual disability spoken with stated strongly that they felt people need to be in the community not in day services where they get bored. People also expressed that they “don’t want to be with the same people 24/7” as often happens when people go to the same daybase as the people who they live with.

For some volunteering can be a step on the way to paid employment while for others it can be an end in itself providing meaningful work that they enjoy and that makes a contribution. What is important is that having a volunteer position does not stop efforts to find paid work for those who seek that option.

What needs to happen and what we know works well?

- Changing expectations about work for people with an intellectual disability and growing the presumption of employability from an early age
- Implementation of a consistent transition planning process that is available to all disabled students from the age of 14
- Effective access to vocational guidance, training and placement programmes and tertiary education
- Accessible and affordable vocational and continued training options
- Increased understanding of and support for employers to enable them to put into practice reasonable accommodation provisions to provide accessible and inclusive workplaces
- Support that recognises the learning needs of people with an intellectual disability and might include – a job coach to help them be able to carry out the tasks required in the job, assisting employers to understand how a person learns and help to develop natural supports in workplace and solve any problems that may arise
- Once intellectually disabled people are in long-term, meaningful employment, on-going work place support is required to ensure their success and there needs to be increased government investment in strategies and incentives for employers to provide on-site support
- Leadership from employers in both the public and private sectors



- Ongoing investment in workforce development for the disability employment/vocational providers to ensure a skilled and responsive workforce.

## **6. Conclusion**

IHC values the opportunity to provide feedback on the draft government report and comment on the three focus areas identified for discussion.

IHC as a rights based advocacy organisation is pleased to note the improvements achieved over recent years in the recognition and realisation of the human rights of people with intellectual disability.

We believe, however, that there is some distance to go in responding to the human rights of one of the most vulnerable population groups in New Zealand society, those with intellectual disability and for New Zealand to fully meet its obligations as a signatory to the UNCRPD. It is clear from our consultation and experiences with people with intellectual disability and their families that there are persistent and enduring barriers to people with intellectual disability being able to exercise and enjoy their human rights in most spheres of their everyday life.

IHC notes that there are a number of inter-related initiatives in the disability area that are either underway or planned and reiterate our call for these to be aligned under a whole of government approach.

We look forward to ongoing dialogue with government to ensure that the points raised within the IHC submission are considered and taken account of.

## **7. Recommendations**

- 7.1** That the additions, clarifications and changes referred to in IHC's submission are addressed in the government's final report to the UN
- 7.2** That there is alignment between the implementation of the UNCRPD, the HRC action plan and the government's disability action plan
- 7.3** That there is continued consultation and partnership with disabled people and their families/whanau and the disability sector in developing and implementing the disability action plan.
- 7.4** That indicators are established against which to measure progress in improving outcomes for disabled people.

We are happy to provide any further information or clarification about these matters.

Trish Grant  
**Director of Advocacy**