

## Briefing to the Incoming Minister for Disability Issues Hon Paula Bennett

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This briefing outlines the challenges and opportunities IHC has identified for the Incoming Minister for Disability Issues. We enclose a copy of the complete set of briefings we have provided to the Ministers responsible for key areas affecting people with an intellectual disability.

IHC welcomes the opportunity to work with the incoming Government. IHC was formed as a membership based, advocacy organisation in 1949 by parents who wanted better lives in the community for their children. To this day IHC provides strong advocacy for the now 50,000 people in New Zealand with an intellectual disability and their families (2006 Disability Survey). We support the independent voice of people with an intellectual disability through the Self Advocacy movement and representation in our governance structure. IHC also works in partnership with disabled people's organisations such as People First.

IHC has a wholly owned subsidiary IDEA Services Ltd that provides \$195 million of government contracted disability support services to 6350 people with intellectual disabilities and their families. IHC has used feedback from our membership as well as the people who receive our services to inform this briefing.

### **What is intellectual disability?**

Having an intellectual disability means it is hard to learn new things or to think about problems; you need support in your life and it has been like this since childhood. People with an intellectual disability also have high incidence of other disabilities such as physical and sensory disabilities and mental illness. IHC therefore has strong connections across the disability sector.

### **Our Vision**

IHC's vision for people with an intellectual disability is to live satisfying lives in the community. This means participating in and contributing to their communities and realising their full rights and responsibilities as New Zealanders.

Essential to achieving this vision is:

- 1. Action**
- 2. Leadership and coordination**
- 3. Partnership.**

### **Challenges in the current environment**

In 2003 the National Health Committee found that adults with an intellectual disability were seldom integrated into community life on their own terms, individual choices in the most fundamental of life decisions were not available to them, and their aspirations and goals were not supported.

Five years later, the Social Services Select Committee stated that little had changed, commenting that "[A]lthough people with disabilities make up a significant proportion of the population, their needs are frequently marginalised and neglected."

There are serious issues impeding IHC from achieving our vision that are directly attributable to the lack of leadership and at times obstruction by the Ministry of Health and other government agencies. Separate funding streams across government are also creating considerable difficulty and complexity for families, individuals and service providers.

Highlights from, and IHC's views on, key disability reviews and the inquiry are appended.

## **Opportunities**

People with intellectual and other disabilities need disability support that:

- is flexible, responsive, and tailored to individual needs and preferences
- allows choice and control
- facilitates independence and autonomy
- enables contribution to the economy and community
- is measured by quality-of-life outcomes.

After almost a decade of good intentions and reviews, the new Government now has the opportunity to make a real difference in the everyday lives of people with intellectual and other disabilities. IHC supports National's Disability Policy.

We support the Minister's view that the time for action is now. We know what the problems and the solutions are. It is about building on the existing foundations to do better within the current resource constraints, not more talking.

IHC believes that current barriers to achieving the essential progress on disability support services, can be addressed by a focus on three core areas:

1. Implementation of a contracting and pricing model for disability support services that is sustainable, fair and supports quality service provision.
2. Development of a professional disability support workforce with pay rates and training and professional development that reflect the level of skill, knowledge and responsibility required to work in the sector.
3. Monitoring based on quality of life and opportunities for disabled people, rather than on compliance with minimum standards.

To achieve action on the desired outcomes, we need leadership and partnership with the disability sector.

## **Action**

The New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities provide the framework for action.

While the 9 February Government response to the Select Committee Disability Inquiry recommits to the essential principles of disabled people being able to exercise choice and control to live fulfilling lives in the community, it did not take the essential decisions on action.

IHC believes that investment in the following areas will provide good results:

- sustainable disability support services, including improvements in remuneration for the disability workforce
- early support for families
- inclusive education and effective transition to adulthood
- good income support, with opportunities for meaningful work and participation in the community
- improving the health of people with an intellectual disability
- improvements in housing and public transport to increase independence.

We have highlighted these as key priorities in our briefings for incoming Ministers.

## **Leadership and coordination**

This was the single most important issue identified by the Select Committee Disability Inquiry.

IHC welcomes the Minister for Disability Issues chairing the Ministerial Committee on Disability Issues and wishes to ensure that it has the mandate to drive and coordinate change. IHC is heartened by the Ministry of Social Development's leadership across the whole-of-social-sector in government in critical areas and would like to see this extended to disability issues. We believe the Ministry of Health, as the largest disability support funder, has abdicated any lead role.

Having a separate Minister and Office for Disability Issues (ODI) has not achieved what was expected in raising the profile and advocating for and monitoring disability progress. With only nine staff, ODI does not have the role, capacity or capability to exercise leadership in the government sector. This lack of resourcing has in fact served to further marginalise and segregate disability issues.

We await the new Disability Strategy implementation planning and reporting framework, and look forward to the opportunity for the disability sector to have input to this.

IHC also notes that on 19 January this year, the UK Government released *Valuing People Now: A New Three-Year Strategy for People with Learning Disabilities*. IHC commends to the new Government here the UK Government's strong commitment to cross-government action, with clear leadership, implementation and accountability measures set out for people with learning (intellectual) disabilities.

## **Partnership**

Leadership, planning, coordination, implementation and monitoring must include disabled people as well as be cross-sector and cross-government.

The Office for Disability Issues' proposal of a Disability Sector Forum is welcome as long as it includes disability sector CEOs and has a mandate for driving change. We also support the New Zealand Federation of Voluntary Welfare Organisations' call for a PM's Forum. IHC was disappointed not to be invited to attend the recent Jobs Summit, as the largest NGO employer in New Zealand as well as representing one of the most vulnerable groups in terms of employment. NGOs are the first to see the impact of hard times on vulnerable New Zealanders. We can mobilise the community and offer responsiveness, flexibility and value for money. IHC wishes to be part of ODI's disability advisory group.

## **Final words**

IHC acknowledges the impact of the global financial crisis on the priorities of the incoming Government. A recent OECD report highlights, however, that investment in support for disabled people is a true 'win-win' policy. Investment in disability services supports participation in the community and the workforce, leads to higher incomes and raises the prospect of higher economic output in the long term.

IHC believes that even in the current economic climate there is significant opportunity to improve opportunities for choice, control and independence by people with an intellectual disability and their families. We look forward to working with the incoming Government to make this happen.

## Appendix

### Key foundations for better lives for people with intellectual and other disabilities

#### To Have an Ordinary Life – community membership for people with intellectual disabilities

IHC calls on the new Government to commit to implementing the 23 recommendations made to the Ministers of Health and Disability Issues in *To Have an Ordinary Life*.

In 2003 the National Health Committee found that the lives of adults with an intellectual disability are very different from other New Zealanders and not consistent with the vision of the New Zealand Disability Strategy. It said adults with an intellectual disability are 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.

However, the *Ordinary Life* recommendations were never formally adopted by the previous government. At the urging of IHC, in late 2008, the former Minister of Health with support from the Minister for Disabilities Issues, directed the Ministry of Health to report by end March 2009 on the Health recommendation, one of the National Health Committee's top three priorities for action.

#### Review of long-term disability supports – accelerated pace of change needed

The Office for Disability Issues (ODI) March 2008 Cabinet paper on its review of long-term disability supports stated: "Ministers may consider there is a need to accelerate the pace of change by establishing a mechanism to ensure cross-sectoral leadership, accountability, and leverage, and consider additional options, including further funding injections."

IHC agrees all are needed.

However, ODI's recommendations then were primarily directional towards incremental change. It indicated that consideration of any greater mandate for change awaited the outcome of the Select Committee Disability Inquiry.

#### New Zealand Disability Strategy 2001 first review – progress too slow say disabled people

While IHC welcomes the review's 20 recommendations, including the additional focus on the most disadvantaged disabled people, we do not consider that these recommendations confront the problems identified.

The overarching challenges identified by the participants in the first Disability Strategy review commissioned by ODI and released in August 2008 are:

- the absence of a national implementation plan and linked funding
- the size and status of the Office for Disability Issues
- society's attitudes to disabled people
- barriers in government agencies to implementation.

We await the new Disability Strategy implementation planning and reporting framework, and look forward to the opportunity for the disability sector to have input to this.

#### Select Committee Inquiry – improving disability support across the board

Lack of direction and leadership in disability services provision, variable services and significant systemic problems were the overall problems found by the inquiry, instigated by National while in

Opposition. The report also said the 2001 New Zealand Disability Strategy had not been effectively implemented.

IHC supports the first inquiry recommendation that an appropriately funded lead agency with responsibility for disability issues, accountability and monitoring be appointed.

Other recommendations that IHC believes should be prioritised are:

- establish a new entry point in the community for people seeking disability information along the lines of local area coordination in Western Australia
- ensure funding is provided in a way that allows people with disabilities more choice about their day-to-day living arrangements, with better access to supported independent living and individualised funding
- strengthen and expand the scope of government-funded advocacy and complaints services for people with disabilities
- establish a strategy for improving training, pay rates and working conditions for the caring and support workforce.

While the Government response to the inquiry endorses the first two, IHC does not believe that enough has been proposed to address the latter two fundamental issues.

### **United Nations Convention on the Rights of Persons with Disabilities – implementation**

IHC appreciates the ongoing partnership approach by the Office for Disability Issues to promoting, protecting and monitoring implementation of the UN Convention. However, we are concerned about the limited time given for consultation on the implementation framework criteria and the negative criteria the draft framework leads with.

We note that New Zealand is required to have at least one independent mechanism to promote, protect and monitor implementation of the Convention.