

Briefing to the Incoming Minister of Social Development and Employment Hon Paula Bennett



This briefing outlines priority issues for people with an intellectual disability and their families in the portfolio of Social Development and Employment. It discusses the challenges and opportunities for future work and partnership with IHC, people with intellectual disabilities and their families.

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. 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 these briefings.

We believe that New Zealand will be inclusive when people with impairments can say they live in:

'A society that highly values our lives and continually enhances our full participation.'

New Zealand Disability Strategy

The work of the Ministry of Social Development is integral to achieving this vision.

IHC is aware that the global financial crisis will impact on the spending priorities of the incoming Government. IHC believes however that the current economic climate shouldn't be the justification for stalling, or decreasing investment in support for people with intellectual disabilities and their families. Maintaining and building on current investment is the best way to ensure that people with intellectual disabilities and their families can contribute, in the same way as other citizens, to New Zealand's social and economic success.

Challenges in the current environment

Last year a Parliamentary Inquiry into the quality of care and service provision for people with disabilities found that "although people with disabilities make up a significant proportion of the population, their needs are frequently marginalised and neglected".

The inquiry confirmed the following issues:

1. There is a serious lack of leadership and collaboration between government agencies.
2. People with an intellectual disability and their families still experience unnecessary barriers in their day to day life.

The impact of this extends beyond people with an intellectual disability themselves.

“Because disabled people make up a significant proportion of the population that has poorer outcomes, New Zealand cannot make real social and economic progress until disabled people have the same opportunities to gain qualifications, to be employed and to earn a decent living that other people have.”¹

IHC strongly supports the Parliamentary inquiry recommendation that an appropriately resourced lead agency be appointed as a matter of priority to remove barriers experienced by people with an intellectual disability and their families and to resolve the serious funding and workforce issues in the disability sector.

Opportunities for partnership and future work

IHC welcomes New Zealand’s commitment to promote, protect and ensure the full and equal enjoyment of all human rights of people with an intellectual disability in:

- The New Zealand Disability Strategy
- The United Nations Convention on the Rights of Persons with Disabilities

IHC also welcomes the recommendations of the Parliamentary Inquiry as well as the other significant reviews released last year, the *Review of Long Term Disability Supports* and the *New Zealand Disability Strategy Implementation Review 2001-2007*. These documents present a compelling body of evidence from which to draw your priorities.

The Ministry of Social Development has a number of established projects that IHC wishes to see continue for the benefit of people with an intellectual disability and their families. These include:

- The Pathways to Partnership process – which we wish to see extended to include full funding of vocational services
- Implementation of the Pathways to Inclusion policy
- Implementation of the Carers’ Strategy and Five Year Action Plan
- Implementation of the Out of School Services Strategy and Action Plan
- Use of the Family Partnership model
- The Employer’s Disability Forum

Employment and vocational support

Many people with an intellectual disability can and want to work. Paid employment plays a significant role in social well being as well as economic opportunity. Successful transition from school to employment is crucial to ensure that young people become engaged in the labour force.

Successful employment and vocational support:

- is flexible, responsive, and tailored to individual needs and preferences
- facilitates inclusion in the community
- enables economic and social contribution

Implementation of the *Pathways to Inclusion* policy has led to momentum and increased expectations in this area. Young people with an intellectual disability are leaving school with more skills, a higher level of learning and an expectation that they will be able to participate and contribute after leaving school. Many however struggle with the disparity between supports provided in the education system and those available after leaving school.

Currently services that facilitate community participation and employment are funded by the Ministry of Social Development on a contributory basis only. Contributory funding means demand

¹ Office for Disability Issues, *Briefing to the Incoming Minister: Enabling participation by disabled New Zealanders*, Wellington, 2008.

for some services is unmet. It also limits service provider's ability to provide the support necessary to ensure people with intellectual disabilities are able to contribute economically and socially in the community.

We believe vocations services should be bought under the *Pathways to Partnership* programme and be fully and sustainably funded as part of this.

Supporting families

The briefings prepared for you by the Ministry of Social Development and the Social Sector Forum have highlighted the importance of early support for families and acknowledged that more work could be done in this area. IHC strongly supports these statements. We believe investment in early, flexible and sustained support for families is critical to ensure all family members have the chance to participate and contribute to the community.

Improvements can be made in:

- the responsiveness of existing universal and targeted family services, such as Well Child and Family Start
- availability of supports that are specific to families where a child or a parent(s) have an intellectual disability
- the appropriateness of the framework provided by the Children, Young Persons, and Their Families Act for the care and protection of children and young people with disabilities.

IHC supports the CCS Disability Action Early Support Framework as a proven and cost effective way of providing support that is disability specific but also that empowers families to connect with universal services and build their own natural supports in the community.

Income support

A large proportion of adults with an intellectual disability receive an invalid's benefit as their main source of income. It is fundamental that basic benefit rates and the accommodation supplement are increased to levels that meet the real cost of living, in order to assist people with an intellectual disability to live free from poverty and participate in the community.

IHC is concerned about the impact of extending work related obligations for those receiving an invalid's benefit (Social Security Amendment Act 2007). While it is true that people with intellectual disabilities want greater participation in the workforce, social welfare policies based on compulsion do not achieve this.

An effective benefit system must be able to respond adequately to individual need. For many people with an intellectual disability the need for state support will be life-long. An over-emphasis on full-time paid employment as an objective of social security risks losing sight of this, the consequences being everything that comes with an inadequate income: poor housing, poor health, inability to participate in community and social isolation.

IHC welcomes Government's rejection of the single core benefit proposal which if implemented would have had the effect of reducing the basic rate of the invalid's benefit. However, IHC is extremely concerned that imminent changes to the Social Security Act will leave the *concept* of a core benefit intact. The Government may have abandoned the single core benefit policy, but we remain wary that the concept, together with the reduction of main benefit rates and greater complexity, will remain onboard and travel through with the proposed changes.

Employment and vocational opportunities

Challenges	Opportunities
<ul style="list-style-type: none"> • The partial funding model for vocational services limits opportunities for choice, control and inclusion in the community for people who receive support from those services. • MSD funded <i>Support Funds</i>, administered by Workbridge are not enough to enable a person with an intellectual disability to undertake meaningful post secondary education. • There is a significant decrease in support that is available for education, training, employment and community participation after a disabled young person leaves secondary school. • Not all young people with an intellectual disability are eligible to receive specialist transition services and mainstream youth transition services do not respond well to disabled young people. There are no other coordination points for this part of life, despite the fact that it has been identified as crucial for future success. 	<ul style="list-style-type: none"> • IHC recommends MSD increase contract levels to provide full funding of vocational services that facilitate community participation and employment. We also believe these services should be recognised as essential social services under the Pathways to Partnership model. • IHC recommends that the level of <i>Support Funds</i> and availability of additional support for post-secondary education be reviewed to allow real opportunities for ongoing learning. • <i>Pathways to Inclusion</i> has created the momentum for significant change. IHC recommends the policy be updated to ensure developments and innovations continue. • IHC welcomes the increased availability of specialist transition services for disabled young people funded through ORRS and supports MSD's intent to improve the responsiveness of mainstream transition services to disabled young people. IHC is able to work with MSD on how services can best respond to young people with an intellectual disability. • IHC recommends that coordination of post-secondary vocational and education options be included in consideration of the role of Local Area Coordinators. • IHC supports initiatives that promote disabled people as employees such as the Employers Disability Network. We also support the employment of disability advisers to provide disability perspective and expertise within Work and Income.

Supporting Families

Challenges	Opportunities
<ul style="list-style-type: none"> • Currently the role of families in the lives of their disabled loved ones is under-recognised and under-supported. Families can have difficulties getting and coordinating the support they need. The complexity of the disability support system creates ongoing difficulties for families. • Families often must reach crisis point before significant investment in support is made. • Disabled children are still more likely to be removed from their homes by statutory authorities and not return. • Inadequate support for families where one or both parents have an intellectual disability. Ministry of Health Disability Support funding is not sufficient in these situations. Most children are removed from their parents and parents are unlikely to have ongoing contact with their children. • People with disabilities are one of the groups most at risk of violence and abuse. As well as experiencing forms of violence and abuse similar to those without disabilities, such as physical injury, sexual assault, emotional trauma and financial abuse, people with disabilities also face unique forms of abuse. This includes disabling or manipulating equipment, manipulating medications and refusal to provide essential personal assistance. 	<ul style="list-style-type: none"> • The Carers' Strategy sets out a cross government framework for action on priority issues for carers such as respite and payment for family carers. IHC supports ongoing investment and resourcing to ensure the Carers' Strategy Action Plan is implemented. • IHC supports MSD's intent to increase the responsiveness of mainstream universal and targeted services to families with disabled children. We believe that the implementation of the CCS Early Support Framework would give families the confidence and expertise required to access mainstream as well as disability specific services to their benefit. • IHC supports the recommendation from the 2008 Parliamentary Inquiry that implementation of the Local Area Coordination programme be considered as the best way of ensuring flexible, coordinated and sustainable support for families. • The Parents and Family Resource Centre in Auckland is piloting a cost effective initiative that assists families to establish and maintain natural supports for themselves and their family member. The pilot is based on a successful international programme developed by the PLAN network in Canada. IHC supports this initiative and investment in making it widely available across New Zealand. • The Out of School Services Action Plan includes proposals to improve the accessibility of out of school services and child care for families with children with an intellectual disability. IHC notes that any actions as part of this strategy are subject to funding. IHC supports ongoing investment and resourcing to ensure the Out of School Services Action Plan is implemented.

Supporting Families (continued)

Challenges	Opportunities
	<ul style="list-style-type: none"> • IHC recommends that work proceed with haste on the recommendations from the 2007 <i>Best of Care Review</i>. In particular the development of the policy and operational framework that will underpin work between CYF and MoH to improve the response to children with disabilities and their families. • CYF has indicated that they have a work programme to explore ways of supporting parents with intellectual disability. IHC support the appointment of disability advisers within CYF but have seen little other evidence of this work programme and wishes to be more closely involved with its implementation. • IHC supports the Ministry of Womens' Affairs research into effective support of survivors of sexual violence – noting that this has a particular focus on people with intellectual disability. We believe that abuse against disabled people should be regarded as a priority for policy and research. IHC would like to see a disability perspective within the MSD work programme on family violence and the opportunity for people with disabilities to give direct input into development of research and policy in this area.

Income support

Challenges	Opportunities
<ul style="list-style-type: none"> • Basic benefit rate does not cover the cost of living, many beneficiaries are living in poverty. • The Accommodation Supplement has not been adjusted since 2005 despite rents having increased by 17% between February 2005 and February 2008. • The Disability Allowance maximum has the effect of leaving disability, health and medical costs unmet, despite such costs having been identified as part of the Disability Allowance criteria as necessary and essential. • Poor recognition of those who may be life-long beneficiaries. • Existing provisions in the benefit system that allow people to move in and out of part-time work are not consistently and correctly applied. • Extremely negative impact of extending work obligations to people with an intellectual disability receiving the invalids benefit. • Increases in income support that occur when people in residential support services change from the invalids benefit to NZ Superannuation are currently kept by service providers not passed onto the individual. 	<ul style="list-style-type: none"> • IHC supports improvements to alleviate poverty such as: <ul style="list-style-type: none"> ○ Raising current benefit rates to meet the actual and real costs of living. ○ CPI indexing of benefits. ○ An immediate increase of the Accommodation Supplement to adequately support the real and actual cost of rental housing. ○ The Disability Allowance maximum removed to ensure it is paid to reflect actual costs. ○ Increasing the level of personal allowance that people in residential disability support services receive. • IHC believe that 100% of the income that people with an intellectual disability earn should be disregarded for benefit purposes, as is currently the case for people who are regarded as having as being totally vision impaired. We believe the 100% income exemption should be applied universally to people with an intellectual disability as general recognition of disadvantage in the labour market. • Removing work-related obligations and benefit sanctions from conditions around receipt of the sickness and invalid's benefits. • MSD to work with the Ministry of Health to prevent service providers keeping the increased income when a person transfers from the invalids benefit to New Zealand Superannuation.