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What is advocacy?

We're often asked what it means to be an advocate. The main goal of advocacy is to ensure that a person's voice is heard. An advocate encourages and supports people to speak up for themselves or, when that is not possible, an advocate can speak up for the rights of another as if those rights were his or her own. Advocacy is about establishing and maintaining human rights.

The two main types of advocacy are individual and systemic:

- Individual advocacy is representing another person on issues that relate directly to that individual.
- Systemic advocacy is working to change attitudes, policies, systems or laws that impact negatively on people's lives.

There are six advocates in the IHC Advocacy team along with Director of Advocacy Trish Grant. We bring a wide variety of skills and experience to our advocacy work – in advocacy, social work, counselling, benefits, complaints handling, teaching, law, management, policy, government, parliamentary, voluntary and community sector, as well as two of us being parents of young people with an intellectual disability.

Recent examples of advice and advocacy support on individual issues include: housing, education, immigration, support in the justice system, welfare guardianship, DNA sample gathering, consent for medical procedures, ACC payment and impact on invalids benefit, funding for psychometric and adaptive function testing, and Work and Income carer back-payments.

In our systemic work the IHC Advocacy team provides information, education and training, writes submissions, lobbies and works with government for change, partners with other NGO groups, and utilises complaints and legal mechanisms on behalf of all people with intellectual and other disabilities.

For more information about what we do, including our advocacy updates, go to www.ihc.org.nz/advocacy/tabid/1118/default.aspx. Read our submissions at www.ihc.org.nz/getinformation/submissions/tabid/1462/default.aspx.

Disability review queue

In March, Minister Dyson heralded the results of the inter-agency review of long-term disability supports begun in 2004 as a significant milestone for Objective 7 of the New Zealand Disability Strategy – “Create long-term support systems centred on the individual”. Such support includes equipment for moving round or communicating, modifications to the home or work place, help finding a job, assistance for moving around the community, and help at home and with personal care.

So what will the promised “coherent cross-agency work programme” to create a “fairer and simpler system” mean on the ground? The Disability Strategy is to be used as the basis for a framework which concentrates on outcomes. Details are yet to be unveiled but what is proposed must surely be an improvement on what the review identifies as an overly complex and inconsistent system that is difficult to find and access and the patchy ticks-in-boxes approach by government agencies to the Disability Strategy so far.

While the first five-year review of the Disability Strategy has not yet been completed, Cabinet has directed the Office for Disability Issues to develop targets for longer term planning and reporting against the Disability Strategy.

Covering much of the same ground is the stalled Social Services Select Committee report on its inquiry into the quality of disability services and how they might be improved – a subcommittee of members has been formed and charged with the task of ensuring that the final report accurately reflects the evidence considered by the committee.

One year after New Zealand signed the UN Convention on the Rights of Persons with Disabilities, the process of assessing consistency with our laws and government policies and practices continues, with the expectation the Convention will be ratified this year.

Encouraging equity of funding and service provision

Objective 7.5 of our Disability Strategy is “Encourage equity of funding and service provision for people with similar needs, regardless of the cause of their impairment”. This must be part of the long-term disability supports and other reviews. However, the Government continues to seek to strike out a Bill of Rights Act and Human Rights Act claim in the High Court on the basis that discrimination based on the cause of an impairment or disability is permitted.

It is five years since Melanie Trevethick first complained to the Human Rights Commission. As a person with multiple sclerosis, Melanie would have been eligible for funding of little more than \$11,000 from the Ministry of Health for assistance for moving around the community in a modified vehicle that also enables her to use her wheelchair. ACC would have provided the full \$92,000 cost. It is difficult to understand how the huge disparity in funding and disability support systems can be justified.

The Ministry of Health, under whose legislation the Disability Strategy is required, argues that a person whose physical disability is caused by illness can't be compared with someone with a similar disability caused by injury and hence under the ACC scheme. How does discriminating based on the cause of a disability fit with our commitment to the UN Convention on the Rights of Persons with Disabilities, which focuses on addressing needs and looks to outcomes of full and effective participation and inclusion in society? This includes in Article 20 taking effective measures to ensure personal mobility with the greatest possible independence for people with disabilities.

IHC education complaint to the Human Rights Commission

IHC is preparing its own complaint to the Human Rights Commission against the Government, about practices that prevent disabled students participating fully at their local school. The complaint is based on such practices breaching the right to freedom from discrimination in the Bill of Rights Act and the Human Rights Act, on the ground of disability.

The Education Act gives parents of students with disabilities the general right to choose to enrol their child at their local school. Inclusive education is also acknowledged within the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities as central to ensuring inclusive communities. However, parents who attempt to choose an inclusive education for their child regularly report instances where their children are not given the opportunity to participate on the same basis as other students.

For anybody interested in being involved with the complaint, including young people, parents, teachers and other educational practitioners, please contact Tony McGurk on 0800 442 442, tony.mcgurk@ihc.org.nz.

Increased funding for disabled young people

One of the measures resulting from the long-term disability supports review is funding to enable disabled young people with very high needs to leave school before they are 21. As mentioned in a previous *Hot Issues*, students with very high needs were not eligible for funding for support by adult vocational services until they were 21, effectively forcing them to stay at high school. While IHC has lobbied hard for and welcomes this change, it does not cover the full cost of support. If the service provider can't cover the shortfall the young person ends up spending more time at home than they did when attending school.

IHC along with many other disability sector organisations has been lobbying the Government for full-funding of vocational support services for some time, but an adequate response has not been forthcoming. As vocational services do not fall within the definition of essential social services they are not covered by the recently announced sustainable funding model for NGOs.

Hidden abuse of people with disabilities

People with disabilities are one of the groups most at risk of violence and abuse – now in the community and not just a legacy of the institutions. Yet people with disabilities barely rated a mention in the Ministry of Justice discussion paper on the Domestic Violence Act review. The hidden problem of abuse of people with disabilities is under-reported, under-resourced and under-researched.

As IHC said in its recent submission, adults and children with an intellectual disability may experience or witness domestic violence in their own families, in residential settings or at the hands of caregivers. 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.

In response to the Families Commission questionnaire on family violence research priorities in March, IHC said that abuse of people with disabilities must be a priority area along with child abuse and elder abuse. We also asked for a Disability Reference Group to be set up to inform ongoing research.

Abuse and violence towards people with disabilities, including reference to IHC's Domestic Violence Act submission, featured on "One in Five" on 23 March 2008 www.radionz.co.nz/nr/programmes/oneinfive.

Speaking up

In that "One in Five" programme, Deputy Health and Disability Commissioner Tania Thomas encouraged people with disabilities who wish to complain about any aspect of disability services to phone 0800 11 22 33 and ask for her. Tania will also visit people where they are.

Independent health and disability advocates are also embarking on a programme of visiting all services for people with intellectual disabilities to talk to them about their rights. IHC advocates will act as a liaison between these independent advocates and management, staff and self advocates to facilitate visits to IDEA homes.

IHC advocates are also available to help sort out individual issues for any person with an intellectual disability in New Zealand by phoning 0800 442 442.

Overlooked health of people with disabilities

In yet another major oversight, the Public Health Bill refers only once to people with disabilities, despite one of the Bill's aims being to reduce health inequalities. IHC broadly supports the Bill which recognises the wide determinants of health status, provides new strategies to promote good health such as screening and providing guidance on key health issues, improves emergency management and provides for public health powers to be exercised within a human rights framework which balances the rights of the individual with the public interest.

IHC's submission urging that the health of people with disabilities and other specific population groups feature at the highest level in the Bill met with a positive response from the Health Select Committee, along with others who made similar points. IHC told the committee that the health status of people with an intellectual disability is a national disgrace, despite the National Health Committee's recommendation in *To Have an Ordinary Life* in 2003 that these be urgently addressed.

We have not yet heard whether government will progress one of the National Health Committee's key recommendations which IHC is currently calling for, that of funding an annual comprehensive health check for all adults with an intellectual disability in New Zealand, as the Australian government does.

Behaviour supports review

The Ministry of Health is taking a long overdue look at the way it purchases Behaviour Support Services across the country. It has begun a series of consultations with current contracted providers of Behaviour Support Services, and will also be seeking ideas from disability services and families. IHC welcomes the review and sees it as a great opportunity to encourage the government to take into account the changing needs of people with disabilities whose behaviour challenges our systems. For details of the review and how to be involved contact Debbie Hughes at Debbie_Hughes@moh.govt.nz.

Disability information

Two newsletters that update generally about disabilities are:

- *Participate* from Ruth Dyson
www.beehive.govt.nz/portfolio/disability+issues/newsletter_issue
- *Email Update* from the Office for Disability Issues
www.odi.govt.nz/publications/e-mail-update.html.

The revamped government website newzealand.govt.nz has accessible information from all government agencies, including 335,000 pages about disability at last count. We have suggested that they add a specific disability heading on the home page as they do for other groups such as Kids and Youth, 60s plus and Maori.

We also welcome that the Government is looking into having a website for government information on disability supports via a single entry point, as one result of the disability supports review.

The recently launched Families Commission information website for parents has links to disability support information provided by other organisations, including IHC
www.nzfamilies.org.nz/parenting/disability-support-services.php.

Update

- IHC has joined the Lifetime Design Foundation
www.lifetimedesign.org.nz
- The Inclusive Education Action Group has now finalised its constitution and applied for incorporation. To become a member go to www.ieag.org.nz/IEAG/
- The Autism Guidelines were launched at Parliament on 2 April
www.moh.govt.nz
- The Carers' Strategy will be launched at the end of April, date yet to be advised.

Last words

The high-level principles and statements regarding people with disabilities have been well established through the New Zealand Disability Strategy and the UN Convention on the Rights of Person with Disabilities. Yet as seen in this *Hot Issues* there are major government departments which do not incorporate these principles in their work or which act inconsistently with them. While the disability sector may feel 'reviewed out', we look forward to continuing to work with government so that these objectives achieve real change in the everyday lives of people with disabilities.

Welcome to our new readers – past *Hot Issues* are here www.ihc.org.nz/newsevents/hotissues/tabid/1523/default.aspx. We welcome feedback and ideas for items and news on issues.

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