

Tariana Turia

4 OCTOBER, 2010

Disability Support Services Consumer Consortium

When I looked at the list of those attending today's consumer consortium meeting, I was greatly pleased at the range of organisations represented -

- Autism New Zealand;
- Pacific Information Advocacy Support;
- Ngati Kapo;
- CCS Disability Action;
- People First;
- Mana Turi;
- Brain Injury Association;
- IHC Advocacy;
- Association of Blind Citizens;
- Carers New Zealand;
- Cerebral Palsy Society;
- Rescare;
- NZ Down Syndrome Association;
- Deaf Blind New Zealand;
- Hearing Association;
- Royal NZ Foundation of the Blind;
- Deaf Aotearoa;
- Parent to Parent;
- Muscular Dystrophy Association;
- And in attendance - DPA - the national Assembly of People with Disabilities.

I wanted to start off by simply acknowledging all of you; your amazing commitment; your resilience; and the investment you each make in the wellbeing of the people whom you care for.

And I think the list is important to remind us all, just how complex and diverse the work is, that we are all involved in, one way or another.

I have to admit that when I first looked at the list, all I saw were the people - people whom I respect, people whom I have met with over the years either in my capacity as Minister for Disability Issues, or Member of Parliament; people whom care.

Today then is a wonderful opportunity to bring together those people and the organisations they represent; their support persons, interpreters; advisors from the Ministry of Health and other guests.

The key focus for the Consortium is driven by people with a disability and their families. This is exactly how it should be.

Your brief, as a member of the Consortium, is to bring together the strength of your experience to focus on the information and advice most pertinent to the people who access disability funded services.

I have always had some difficulty with labels such as client; consumer; end user - categories which appear to place the focus on the goods or services being acquired, rather than the actual people who benefit from them.

To me, what has always been uppermost in my mind is hearing the voice of disabled people and their families.

It is because of this, that I have introduced as a regular part of our meetings as the Ministerial Committee on Disability Issues, to listen to the sector. To take a pertinent example, earlier this year we met with the group working to make Auckland accessible for the 2011 Rugby World Cup. The Committee was heartened by their enthusiastic efforts to ensure accessibility is a more visible goal for all.

And just this morning, I attended the inaugural Access Tourism conference in Auckland, where we heard that there is so much more that must be done to build an environment which is accessible to all. I have asked the group from the Accessible Rugby World Cup to come back to the Ministerial Committee later this month, to really see how we can lift our game to ensure accessibility is a target in everyone's planning.

The priority I place on the people's voice is very much supported by the focus on what will make the difference.

Tomorrow, Jenny Moor and John Wilkinson from the Ministry, will spend some time talking about the **new model we have been developing to support disabled people**.

You will be aware that the request for proposals for an independent support organisation to assist in implementing the demonstration project closed on 19 August.

John Greally from Autism New Zealand and Bronwyn Hayward on behalf of Disabled Persons Assembly have provided a very strong contribution to the programme of work, and I am very keen for you all to continue to be heard, in terms of the model in general, and the lessons we can take from setting up the first demonstration site.

Alongside the new model, I am really delighted to announce that as of 30 August 2010, there were 453 people using **Individualised Funding** - a massive increase from 260 a year ago.

Karen Smith will be talking more about this tomorrow morning, but I want to acknowledge the important leadership that home and community support services are providing, in becoming contracted hosts for individualised funding.

At this point, providers who have completed the process include Dunedin Home Support, Whaioranga Trust in Tauranga; Vision West from West Auckland; Florence Nightingale in Blenheim and a national provider, Manawanui in Charge.

I'm interested in your thoughts about how Individualised funding is working, and how we can improve the coordination and access to information for disabled people and their families.

I know that some of you have thought the NASC providers are not always informing you of the different options. To try to address this, we have a consumer information booklet going to print next month; we're trying to ensure the website and magazines such as *Family Care* have regular updates; and we're doing all we can to spread the word to providers and Needs Assessment Service Coordinators. But I'm always open to hearing what we could do better.

Other sessions on your agenda include an update on the first **National Pasifika Disability Action Plan**; Faiva Ora; and the establishment of the first National Pasifika Disability leadership group. It is fantastic to also witness the progress that has occurred with the Lu'i Ola Strategic Framework - meaning simply, Together I am Able.

And isn't that the truth! Together we are able to make the difference - and together, we must continue to keep our eyes firmly fixed on that goal.

Another area that I will be looking forward to your thoughts is the creation of the **Maori Disability Strategy and Action Plan**. I am really keen to hear from this Consortium about who they believe the Ministry should be talking to, to ensure the voices of tangata whenua are fully engaged throughout this work.

Finally, I want to remind us of the significance of the **United Nations Convention on the Rights of Persons with Disabilities**, and in particular, Article 33 which requires countries to set up structures to monitor the implementation of the Convention.

The Office of Disability Issues is working full steam ahead, on preparing our first report, due in March 2011. As part of the work supporting Article 33, we have been working with a coalition of six disabled people's organisations - DPA, Association of Blind Citizens, People First, Deaf Aotearoa, Ngati Kapo and Nga Hau e Wha who are bringing the experiences of people with mental illness to the discussion.

This work - and the new roles for the Human Rights Commission and the Ombudsman as independent agencies in promoting, protecting and monitoring the Convention - are fundamental to our future pathway forward.

Our Ministerial Committee on Disability Issues has asked the Chief Executives Group to develop a disability action plan to focus on making progress - and the emphasis I am asking them to take is very much on hearing the voice of disabled people and their families. I want to ensure that anything we do has the mandate of the people - rather than simply activity for activity's sake.

So for instance, when we look at respite care for parents of children with autism - what we have been told from parents is that they want a menu for families to mix and match with what suits them best - such as individualised funding options alongside in-home or shared care.

I've been really inspired by the ideas I picked up from the Community Living Project in Adelaide, and have been excited to see how well concepts such as the Circle of Friends resonates with many of our disabled people and their families here at home.

I have asked the Ministry of Health to look more into this concept as I think it offers another way forward, in building on the natural support network that families and friends already provide.

There's so much more to talk about that I would never be able to do justice to. But what I do want to say is that my over-riding passion is to ensure all families and whanau can be supported to the best that they can be; to be self-managing; to do for themselves.

My focus is on investing in hope - the hope and the knowledge that we will honour our roles and responsibilities to each other; and that we will do all that we can to make the difference in disabled persons lives that they are determined to achieve.

I wish you well at this very important hui. Tena tatou katoa.