



HEARING THE UNHEARD VOICES OF PEOPLE LIVING WITH DISABILITIES

NZ Federation of Disability Information Centres including Independent Living Trust, Taranaki Disability Information Centre, Disability Information Service Centre Otago, NorthAble and Enable NZ partnering with Complex Care Group.

A GENTLE AND CONSIDERED CONSULTATION TO HEAR THE UNHEARD VOICES OF THOSE WITH PROFOUND DISABILITIES AND THEIR FAMILIES...

BACKGROUND

...to address issues of people with profound disabilities and their families being heard required change. The partners in this collaboration took the view 'Together we can change this.' It seemed that much disability support was designed for those with low levels of complex disabilities and accordingly they had more voice, energy and resources than those with higher level needs. This drove the Unheard Voices collaboration, a 2-stage process supported by the Working Together More Fund.

THE PROCESS

Using a mix of home based face-to-face conversations, a survey and small group meetings with those with severe disabilities and their families around the country, and using an experienced facilitator, the partners wanted to hear about currently available resources and concerns about these.

The partners had already developed a Collective Impact model of working so comfortably came together to co-design the process, including a desire to engage with non-engaged disabled people so they could be part of this collective group. This engagement was to ensure their wealth of experience and knowledge was shared and used to achieve better outcomes.

ACHIEVEMENTS

The initial stage identified how difficult it was for people to know 'who to ask for what', and the need for a high profile place to go to and access knowledge from other families facing the same concerns. It was these people 'who could give the best and most information' said Carol Wood, Executive Officer to the Federation.

The second stage advanced the process. It involved a survey of families with very high and complex needs, along with 10 geographically spread home-based interviews. As a result of the open format and parent-led process they gathered both statistical and narrative data. This ensured the beginnings of the unheard voices being heard.



WHAT WAS LEARNT?

The small groups worked well, as did going at a slower pace. Communication channels were opened and expectations were exceeded. Those often burnt-out and tired by not being listened to for so long found attending the meetings a 'mammoth task', so the decision was made to use face-to-face interviews in the next stage.

The shared understanding and determination of the partner organisations to provide a voice to the un-heard came with a shared and common vision for the outcome, and as Carol said 'embedded our approach in realism which was crucial to the success of this project. Understanding the needs of severely disabled people is synonymous with realism.' They operated from a 'non-territorial and non-partisan approach' and believe this 'cemented the success of this collaboration.'



The resultant report, Voices Project Report by Lisa Martin, provides a trusted 'go to' report which will increase awareness of families about the assistance they can access. The partners will use it to inform decision-makers and are now increasingly willing to engage more closely with these families and seek solutions to the many issues raised.

The Voices Project Report is available here: <http://www.nzfdic.org.nz/s/Voices-Report>

*For further information contact Carol Wood,
Executive Officer, NZ Federation of Disability
Information Centres.*

Email: executiveofficer@thefederation.nz

the
**WORKING
TOGETHER
MORE**
fund