

# ASD Technical Information Service

## Newsletter One

*December 2008*

Kia ora tautou,

For those who do not know me, please let me introduce myself. I'm Matt Frost, a 28 year old Policy Researcher from Wellington. I am also really lucky on two accounts. Firstly, I have Asperger's Syndrome. My special fields of interest- the New Zealand Parliament, politics and history, come in very handy in my day job at CCS Disability Action National Office. I am also honoured to chair the New Zealand ASD Guideline Implementation Advisory Group. This is a group of 20 passionate and skilled people with a wide variety of life experience who are advising the Ministries of Health, Education and the New Zealand Guidelines Group on the implementation of the Guideline.

I am very aware that one of my responsibilities is to make sure that you understand what it is that these groups are doing, how they are trying to help you, and how you can help them. I hope this newsletter (and those that come), will go some way to meet that responsibility.

So first, the New Zealand Guidelines Group. Who are they and why are they involved?

The New Zealand Guidelines Group (often known as NZGG), are an organisation that researches and writes clinical guidelines for health and disability services. They did not publish our guideline, but they contributed to it. They have written many guidelines over the last 10 years. They have also written versions of guidelines that are much easier to digest than the guidelines themselves. They also get involved in the implementation of guidelines, which is why they are supporting the implementation of our Guideline.

One of the first things that NZGG did was to put in place an Implementation Advisory Group. You may have been aware of this, as there was a large level of interest in being a member. The people on the group are enthusiastic about contributing to the implementation of the Guideline. While some of them do represent the organisations they work for, or their professional groups (e.g. special needs educators), others are there representing themselves as people with lived experience of ASD and/or as parents.

The role of the Implementation Advisory Group is to advise the New Zealand Guidelines Group on how best to implement the Guideline's key recommendations. It has met three times and advised on the Guideline priorities we feel are the most important to address. This has been a very challenging exercise and I was personally thrilled that we came to a general consensus on this so quickly.

The priorities are:

- Assessment and Diagnosis (How do we know people have ASD?)
- Support for Strengthening Families (How do we make sure that people with ASD and their families have support to have a great life?)
- Early Intervention/Support. (How do we make sure that whenever you are diagnosed, people with ASD get support to get important life skills)
- Respite Services (How do we make sure that families and people with ASD get a break if they need it?)
- Coordination (How do we ensure that people with ASD and families/whanau get support which is consistent and means you don't have to tell your story again and again to different people?)

We understand that our input has had a significant bearing on the final decisions that the Ministry of Health is making on how it can use the additional government funding to benefit our lives. Their preference is to firstly support current services and pilot services that have worked, and then put money into new initiatives.

The Implementation Advisory Group is now advising on what is important about ASD specific respite provision. Are there ways in which we could do things in a way which would allow families and people with ASD to 'take a break' without having to leave home? This will hopefully lead to the development of new services in 2009/2010.

In the new year, we will advise on what is important about behavioural support services for people with lived experience of ASD and their families, whanau and carers. We hope that this will also lead to new services in 2009/10.

Back to the New Zealand Guidelines Group. They are also working at putting in place a process for keeping our Guideline up-to-date. And they have started thinking (which includes talking to other information providers), about the types of summary documents that should be written to make it easier for people to work with the Guideline. They will do this in line with the above priorities. This means that they are looking at tools to assist with assessment and diagnosis, as well as information summaries that the general public can use. We will make sure that nothing gets duplicated when NZGG does this, and as NZGG starts to work on these projects, so they will look to involve a lot more people than just those on the Implementation Advisory Group.

As I said in a recent presentation to the Autism NZ Conference, this is YOUR Guideline- it's really crucial that YOU are involved. I know that all the members of the IAG would be happy to share information such as in this newsletter. And we'd really welcome your feedback too.

With best wishes,

Matt Frost

Chair, NZ Autism Spectrum Disorder Guideline Implementation Advisory Group.