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Information backgrounder for Altogether Autism New Zealand Autism Spectrum Disorder Guideline and World Autism Awareness Day (2 April)

Purpose: Information for World Autism Awareness Day. To be distributed to sector networks

Helping make sense of a complex world.

About the guideline

- The guideline is a single, credible source of overseas and New Zealand evidence, experience and practice in recognising and treating Autism Spectrum Disorder (ASD), supporting children and adults with ASD, teaching children and young adults with ASD, employing people with ASD, and living well with ASD.
- We expect the information in the guideline will help improve the advice, support, services and care for people with ASD, and their families/whānau. We expect to see health professionals, educators, policy advisers and employers using the guideline to inform their decisions about care and interventions. We hope parents and individuals with ASD will also use the information in the guideline to seek the best advice, support and care available.
- The guideline was developed collaboratively with input from international and New Zealand researchers and experts, adults and teenagers with ASD, parents of children with ASD, and medical, educational and community providers.
- *One guideline; whole person; whole of life; everyone's responsibility.*
The guideline is one of the first of its kind in the world covering the whole person through their lifetime. Other countries are looking to us as a model.

About ASD

Autism Spectrum Disorder (ASD) is a life-long developmental disability that can affect the way a person communicates and interacts socially with other people. It is thought to affect more than 40,000 New Zealanders. People with ASD often use apparently rigid rules to make sense of the world. These rules are logical to the person with ASD, but may conflict with common social conventions and interactions.

ASD has been described as a 'hidden' disability that affects every aspect of a person's day-to-day life, including how well they are included socially. Each person with ASD has a unique range of abilities and needs. The form and severity and impact of ASD can vary, depending on the context and the person's emotional state. However, everyone who has ASD shares some difficulty in making sense of their world, including:

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- understanding and using verbal and non-verbal communication
- understanding social behaviour, which affects their ability to interact with other people
- thinking and behaving flexibly – their approaches may be interpreted as restricted, obsessive or repetitive.

Some people with ASD need significant support with everyday tasks, while others need limited support. Families/whānau may experience high levels of stress in caring for children with ASD who can have communication and behaviour challenges. Despite the challenges experienced by people with ASD and their families/whānau, they can, and do, make a valuable contribution to society.

Since its first description over 50 years ago, ASD has been the subject of intense research and a great deal more is now understood about the condition, although there is no known ‘cure’.

The human stories behind ASD

“Mum knew I was different from the day I was born. I never learnt to crawl and began walking at 22 months of age. Many sounds and most unfamiliar things terrified me.

I could only focus on one thing at once which meant I could not multi-task. My mental processing speeds tended to be slower. When a change occurred in my routines or in my environment, I could not cope. I hated touching sticky substances and still do. So I was the child at playcentre who wouldn’t touch the finger paints! However, I soon began showing above average ability in reading and writing.

Now most of these features, together with many others, were long lasting well into adulthood. However, at the time when I was born 52 years ago, there was nobody around who could put these clues together. I ended up in a psychiatric hospital, once for 8 months, but still without the correct assessment of my symptoms being made. In fact, some incorrect diagnoses were made, for example atypical schizophrenia. This scenario is still going on for some other adults in New Zealand who have undiagnosed Autism Spectrum Disorder.”

Jen Birch, Auckland

“After many years of not being able to have children, we followed the path of adoption and we were ever so lucky to adopt Elliot right from birth. He’s just such a joy, he’s just all that we longed for. We love him dearly. And even if he is autistic, it just doesn’t matter at all, he’s our boy, he’s fabulous.

Elliot’s 14. He’s pretty much non-verbal. He would be classed as severe autism, but his amazing skill of memory and retention of skills just surprises us all the time. He has learnt through therapy programmes how to read, his alphabet, colours, numbers, shapes but his verbal expression is pretty low. He can make his needs met. He can ask for a juice or sandwich, but he couldn’t tell me what he’s done today.”

Wendy Duff, Auckland

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“I’m one of the lucky parents in the autism community. I had a supportive family. No-one took my child off me and placed him in an institution and told me to forget about him. No-one told me he couldn’t attend their school. No-one asked me to pay for a teacher aide. And neither was he asked to leave school because they didn’t understand autism. No-one said his behaviour was ‘too difficult for respite care’. No-one said he was too disabled for a job, for independent living, to be treated as a human being with feelings, hopes and dreams. No-one said it was all my fault.”

Hilary Stace, Wellington

“A lot of us do notice a lot of detail. That is a typical feature of ASD, and sometimes those details of course are important to be noticed. That makes us very precise workers, for instance, in certain jobs when an eye for detail is required.”

Jen Birch, Auckland

“Ah, things I’m great at. I love – I mean I can write formally very well. So, for example, that’s extremely useful when you’re writing formal pieces of writing like submissions, where there’s a certain style. The other thing that I feel I’m good at is things like you know chairing meetings. You know, I’m chairing two or three groups now. And one of the things I’d say about that is that I think having ASD’s a real advantage in those situations because I think there are certain skills that a Chair needs in terms of keeping order, in terms of making sure that people have a chance to have a contribution, but do that in a very structured way.”

Matt Frost, Wellington

About the guideline

- One guideline; whole person; whole of life; everyone’s responsibility.
- The guideline helps make sense of a complex world.
- The guideline is a single, credible source of overseas and New Zealand evidence, experience and practice in diagnosing and treating ASD, supporting children and adults with ASD, teaching children and young adults with ASD, employing people with ASD, and living well with ASD.
- We expect that the information in the guideline will help improve the advice, support, services and care for people with ASD, and their families.
- The guideline was put together with input from international and New Zealand researchers and experts, individuals with ASD, parents of children with ASD, and medical, educational and community providers.
- Know what’s in it, use it, promote it, quote it, and expect to be asked by your clients how your advice matches with what’s in the guideline.

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What the Guideline tells us about effective interventions for children and young people with ASD

“No one model has been shown to meet the needs of all children and young people with ASD. All the models have something to offer in certain situations. The skill of the professional is knowing when to use which model to meet the needs of particular children, situations and skills.” (NZ ASD Guideline, page 90).

The characteristics of effective interventions have been identified as:

- making the earliest possible start to intervention
- individualising services for children and families and whānau
- providing systematic ‘planful’ teaching
- providing a curriculum to meet the need of the young child with ASD
- intensity of engagement of the child
- sustainable family involvement
- structured environments
- developmentally appropriate practices
- intervention in natural environments and with access to typically developing children

(NZ ASD Guideline, pages 91 – 93).

What happens next – promoting the guideline and implementing the recommendations

The Ministries of Health and Education are committed to implementing the NZ ASD Guideline – we know this will take time but we are in this for the long haul. Implementing the recommendations in the NZ ASD Guideline is everyone’s responsibility.

Following the launch of the NZ ASD Guideline, 11,000 copies of the NZ ASD Guideline publications have been distributed, and health, education and disability groups have met to consider the implications of the Guideline for their work.

The NZ Guidelines Group (NZGG) has been contracted to manage the technical implementation of the Guideline, using the implementation funding provided to the Ministry of Health. NZGG has established an Implementation Advisory Group, which includes leading representation by people with ASD, parents of people with ASD, and from across health, mental health, disability and education services. The group is chaired by Matt Frost, who identifies as being a person with ASD, and has provided invaluable advice on priorities for implementing the Guideline.

The leadership and commitment shown by people with ASD at the launch of the Guideline continues and is invaluable in guiding the work programmes of the Ministries of Health and Education.

In November 2008, Cabinet approved the joint Health-Education Guideline Implementation Plan. Since then, the focus has been on scaling up existing, proven programmes while also preparing for new services. Work is well advanced on: developing a handbook on assessment and diagnosis for health and education

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professionals; on designing ASD-specific parent education; designing ASD-specific respite services and exploring the feasibility of ASD-specific behaviour support services.

Regular updates on implementing the NZ ASD Guideline are provided at <http://www.moh.govt.nz/moh.nsf/indexmh/disability-keyprojects-asd-guideline-updates>

About World Autism Awareness Day

It is estimated that around 35 million people worldwide have ASD. In December 2007 the United Nations passed a resolution to make April 2 every year World Autism Awareness Day. The intention is to increase awareness of autism and the importance of early diagnosis and treatment.

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Organisations representing people with autism and their families

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