



From Hamilton...

It certainly has been a busy and productive 2008 year for Altogether Autism as the organisation looks towards 2009 and providing information services within New Zealand. Our focus of providing quality information to people with Autism, their families, whanau, support people and the wider community continues. With this constantly in mind plus limitations on financial resources we continue to investigate and strategize ways to add value for the people we serve.

As you will be aware Altogether Autism is a result of a joint partnership between LIFE Unlimited and Parent to Parent. In 2008 Altogether Autism signed a memorandum of understanding with Autism NZ which has bought together all relevant parties. Discussions continue on how best to make use of precious resources and utilise each others skills and expertise without duplication.

Altogether Autism has invested in internal quality. We are privileged to have Tanya Breen, Clinical Consultant on board ensuring overall guidance to the most efficient and effective ways to facilitate our service. We also welcome Sue Davies to the position of Altogether Autism Coordinator. Sue is responsible for ensuring this newsletter is disseminated, the website is current and the network meetings are coordinated and on the events calendar.

For those seeking information the Matching and Information team at Parent to Parent continue to provide the best quality information.

This service has tripled in the amount of requests received and we imagine that numbers will only increase in 2009.

The Altogether Autism Advisors working out in their communities have in 2008 created good networks and provided the personal touch sought by the people we serve.

On a personal note. I was privileged to attend the Needs Assessment Service Coordination Association (NASCA) conference in Christchurch in December. The presentation of the "In my Shoes" DVD was one of my highlights. Very well presented by Carolyn McPeak and gave an informative insight into those that experience Autism.

Enjoy the newsletter everyone. We look forward to progressing Altogether Autism in 2009.

Warm Regards

Adri Isbister

January 2009

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Regional Network Meetings to be held in February 2009

Region	Date	Time	Venue
Wanaka	Wed 11 th Feb	9.30 - 12noon	Lake Wanaka Centre 89 Admore Street Wanaka
Balclutha	Thurs 12 th Feb	9.30 - 12noon	South Otago Town and Country 1 Yarmouth Street Balclutha
Danniverke	Fri 20 th Feb	1.30 - 3.00pm	To be confirmed

DVD Launch - 'In My Shoes'

Step into the shoes of a person with Autism Spectrum Disorder

About the DVD

- 'In my shoes' is a DVD that gives the viewer a glimpse of what it's like to live in the shoes of someone with Autism Spectrum Disorder (ASD).
- The DVD has been designed and developed by a group of families of young people with ASD. Together they have formed a trust - Promotion of Acceptance and Inclusion of Autism Spectrum Disorder (PAI 4 ASD) - Te Hapaitanga o te Whakaatanga Trust.
- Over and over again, the families found themselves explaining how the world appears to their children and why they respond in what may seem different ways.
- Then Bernie Wastney, the founder of the Trust, said, "Wouldn't it be great if there were a DVD to educate New Zealanders about ASD?"

- There are four sections to the DVD, each 11 -16 minutes long. The sections cover: Being Māori; Going to Primary School; Experiences at Secondary School, and in the Community.

Creating the DVD

- From the start, members of the PAI 4 ASD Trust have been open and inclusive. Guided by Dr Jill Bevan-Brown, renowned researcher, they created a website and invited people to fill in an online questionnaire about what they thought should be included in the DVD.
- The results of the research were turned into draft 'storyboards' for the DVD, and then sent out for comment to advisory groups and ASD organisations. The network of advisors was extensive and included: parents, students with ASD, siblings and peers, teachers, teacher aides and principals in primary and

secondary schools, Māori advisors, Autism New Zealand Advisors, Ministry of Education advisors, health professionals, Altogether Autism, the Open Home Foundation, and Idea Services. The suggestions kept coming in, ideas were tested, and the scripts were revised and revised again until there were four final scripts.

- Meanwhile, PeopleMedia Production Company was contracted and worked with the members of the Trust in planning and coordinating every aspect of the production.
- Te Wananga o Aotearoa Papaeoia campus volunteered seven of their tutors to speak on behalf of parents in the Māori DVD. Although none of them have any personal association with ASD, they were more than happy to translate parent comments and present them.

IN MY SHOES WAS LAUNCHED IN PALMERSTON NORTH ON 15 OCTOBER 2008

As an Altogether Autism Advisor and parent (Carolyn McPeak) I am so pleased with the end result. The turnout of people at the launch (over 300 approx) was awesome.

To describe the value of the DVD I include here an excerpt from a parent who attended as this says it so well:-

"I have not long been home from going to the launch of the DVD. I would like to express how great the evening went. The DVD is marvelous. It explained a lot of things for me.

During one of the segments it explained about how some children cannot deal with going to the dental nurse. I almost cried, as that is exactly how my daughter is. She

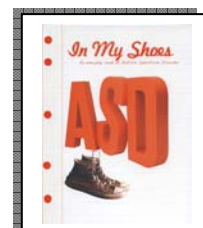
panics at the mere noise of the drill. We have always thought that it was just a ploy for her not to be there, but obviously it is not. The more I read about Asperger's the more things my daughter does make sense. I have been reading the Tony Attwood book and upon reading it I now realise that when Lisa laughs at us or smiles when we are telling her off is not her being silly or thinking it is a joke, it is a part of Asperger's as well.

I am becoming more aware that she does not mean to do a lot of the things she does that makes us angry, and now we can find some steps to deal with it.

Please could you pass on my thanks

to all the lovely ladies involved in making the DVD possible? They have done an excellent job. I hope that people, who are unaware of what these children go through, can now understand a little better that they are not naughty children as they have always thought, but children who just need a little more understanding than the average child. Regards - (Parent name supplied)

You can order your own DVD by visiting the website www.inmyshoes.co.nz and provide your name and physical address for delivery.





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ASD Guidelines Implementation Group Update

The following press release is directly from the Ministry of Health website:

Implementation of the recommendation from the ASD Guideline

We are pleased to announce the Ministry of Health has been given approval to allocate funding for improving services in line with the recommendations of the New Zealand Autism Spectrum Disorder Guideline.

An implementation plan has been developed, a key component of which was deciding on the most appropriate way to allocate funding. This process received input from:

- the Ministries of Health and Education
- the cross-sector Intersectoral Advisory Group
- the Senior Officials Interagency Advisory Group
- the Implementation Advisory Group established from the sector

The New Zealand Guidelines Group is contracted to support the implementation process. They have worked closely with the Implementation Advisory Group to determine the priorities for the allocation of funding. These priorities were:

- Assessment and diagnosis
- Support for families
- Interventions (including early intervention and behaviour support to strengthen families, and transitions)
- Respite
- Improving co-ordination and developing the workforce flows through all of the above priorities

Three phases of service development are planned to implement this funding. These include:

- scaling up existing, proven programmes and services
- bringing on stream new initiatives and embarking on 'investment' activities
- delivering on the 'investment' activities, consolidating initiatives and incorporating measures to provide for sustainability

We are pleased to announce the implementation and purchase plans were approved by Cabinet on November 4, 2008. Funding is allocated in line with the agreed priorities.

The Ministries of Health and Education are working closely with the New Zealand Guidelines Group to progress November 4, 2008. Funding is allocated in line with the agreed priorities.

Allocation of approximate funding over the next three years against these priorities is listed on the right.

The implementation process will take a number of years to complete. The current funding provides the government with an opportunity to

Implementation Programme Management	
Priority	Approximate funding allocated 2008 - 2011
Improved assessment and diagnosis including research and development	\$1.6m+
Support for strengthening families (e.g. Further parent education)	\$4m+
Effective interventions (e.g. early support and behavioural support)	\$2.5m
Effective respite	\$3.5m
Improved coordination (NASC and DHB)	\$2m+

improve services and allows for future development the implementation plan. It is anticipated that scaling up of existing services and the development of new initiatives will happen quickly to increase the capacity of the sector to support people with ASD. These services will be increased.

Pilot programmes that were positively evaluated will be further developed, and the Ministry of Health will offer this work formally through requests for proposals. They will be advertised on the Government Electronic System (GETS) at www.gets.govt.nz.

Message from Felicity Jordan (ASD Advisor from Nelson and Greymouth)

We have had a busy couple of months here in Nelson. Not only with a well attended and very well received regional network meeting, Paul Taylor (Paediatrician) was the guest speaker, but a fundraising and awareness evening at our regional masked parade.

We raised \$185 to purchase a CD rom called ME which will be kept in Autism NZ local branch as a resource for members.

I have been interviewed on the local radio for a disability weekly programme, Fresh FM.

We are also receiving a steady increase in requests from the community, especially service providers who are looking to up skill their workforce to the needs of people with ASD.

News for people on the coast.

There is a new parent support group being run by Autism NZ. This group will be for parents/whanau of younger children. Please contact Claire Lovelock for more information on this at the West Coast branch.

Paul Taylor will be acting as a locum for

the West Coast DHB. Paul has a breadth and depth of knowledge in ASD and PDD-NOS. He is happy to see families who want clarification over diagnosis.

For further information please contact: Felicity Jordan

Phone: 03 546 8973

Email: nelson@altogetherautism.org.nz

SibSupportN.Z.®



Parent to Parent New Zealand delivers a programme, which supports the specific needs of siblings who have brothers and sisters with special needs. The aim of SibShop Parent to Parent's SibSupportN.Z. programme is to provide children with an experience that will assist them to cope with the challenges and stresses of living with a brother or sister who has a disability. Siblings develop their own support network, through sharing and making friends with others who understand.

Parent to Parent's SibSupportN.Z. programme is designed for children aged from eight to eighteen years, who do not have special needs themselves, and who have a brother or sister with a disability or special need.

Weekend Programme

It begins with theatre sports, drama games or other trust activities, continuing onto SibShops and recreational activities. Siblings are divided, according to age, into groups for formal SibShop sessions. SibShop facilitators are siblings themselves and are able to offer empathy, individual support and an emotionally safe environment for the young people. A variety of recreational activities are also part of the weekend. The recreational experience is fun and rewarding and promotes informal sharing, with friendships continuing long after the weekend camp.

Sibling Day

This is a busy interactive day for siblings. Issues are discussed and feelings shared in a SibShop interspersed with team building games, theatre sports and lots of fun. The young people are supported by

facilitators and leaders who also have brothers and sisters with special needs.

SibSupportN.Z. programmes are provided throughout New Zealand by Parent to Parent National Office.



If you would like to know more please contact:

Parent to Parent New Zealand
PO Box 234
Waikato Mail Centre, 3240

Phone: 0508 236 236

Email: sibsupport@parent2parent.org.nz

Or visit our website:

www.parent2parent.org.nz



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Simoana's Surfcoaching

Presents: A Free Special Needs Surfing Experience

A fun recreational experience for the family (with an autistic child) to enjoy together. A safe surfing experience on a tandem board with life jackets.

I am certified by International Surfing Assn. (ISA) & Surfing NZ. I also have my Surf Life Saving certificate and current first aid certificate.

Parents/care givers will be fully responsible for their children and be

expected to be involved and assist in the water with the surfing experience. Please advise beforehand if you require a wetsuit.

Additional helpers on the day to get children into wetsuits/life jackets are appreciated.

Contact: Simon Parking by calling: 04 383 6670 or **Mobile:** 027 240 2059

Please Note people are likely to be taking photos. Please advise if you do not wish your child's photo to be used for publicity purposes.

Dates/times will be subject to the conditions being suitable on the day

25 Jan 09	2.00pm
15 Feb 09	10.00am
22 Feb 09	10.00am
15 Mar 09	1.00pm
29 Mar 09	10.00am

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A koha or donation appreciated



Autism New Zealand Inc.
Including Asperger Syndrome and Related Disorders

Presents: Socially Speaking Seminars by Alison Schroeder and Justine Aldous

Stress and Anxiety

This practical workshop is designed to support parents/carers/teaching staff in understanding their child's stress and help provide simple strategies to implement at home/school. Each participant will design a personal stress management plan for their child.

Topics covered:

- The Stress Response
- Stress Triggers
- Physical Strategies

- Cognitive Strategies
- Communication Strategies
- Environmental Adaptations

Relationship and Friendship

This informative workshop will develop an understanding of the challenges children on the Autistic Spectrum face everyday in the social world. Once again it provides practical strategies for both school/home to implement in order to support their child.

Topics covered:

- The Social World

Strategies at School - working together as a team - a) developing awareness of the peers and teaching staff, b) setting up peer supports c) structured playtimes and d) develop social skills

Strategies at Home - play dates, working within the community, teaching social skills at home

LOCATIONS			COSTS	
Christchurch	27 March 09	Chateau on the Park	Professional Fees	\$160.00
Wellington	3 April 09	West Plaza Hotel	Family Fees	\$130.00
Auckland	1 May 09	Spencer on Byron Hotel	DURATION	9.00am - 4.00 pm
<p>Please contact Autism New Zealand Inc. to complete a registration form by calling: Phone: 03 339 2627 or 0800 AUTISM (288 476) or visit the website: www.autismnz.org.nz</p>				



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Skills for Provision

Speech-Language Therapists and other communication support professionals may be interested to know about a position statement recently released by Speech Pathology Australia (SPA), titled "The role and responsibility of speech pathologists in assessing, diagnosing, and treating clients with Autism Spectrum Disorders" (<http://www.speechpathologyaustralia.org.au/library/Autism%20Position%20Statement.pdf>)

One of its most useful contributions is a section highlighting the skills and abilities required of speech-language therapists who are supporting people with ASD. SPA recognises that in many cases speech-language therapists/speech pathologists may be among the first professionals consulted by families and people on the spectrum and have a key role to play in many aspects of screening, diagnosis, intervention and support. For this reason it is vital that therapists have a thorough understanding of ASD and an ability to provide the support required by people on the spectrum and their

support networks.

In broad terms the requisite knowledge and skills may include:

- A sound knowledge and understanding of the core characteristics of ASD including the communication and behaviour of a child with ASD;
- A knowledge of available screening, assessment and observation tools and ability to interpret results and evaluate the language and pragmatic skills of a child with ASD;
- Ability to analyse the underlying pragmatic language disorder and its impact on the communication development of a child with ASD;
- Knowledge of a range of intervention approaches and programs appropriate to an individual with ASD;
- Ability to plan and implement communication intervention;
- Skills to develop functional visual strategies to assist with the child's communication and

behaviour;

- Knowledge of behavioural techniques and programs and ability to manage the child's behaviour and optimise outcomes during therapy;
- Ability to work with families and utilise family-centred approaches, as appropriate; and
- Application of a multidisciplinary consultative approach through contact with other specialists, educators and support workers involved in the management of an individual with ASD.

Speech Pathology Australia have indicated that this work is being developed further at present and that a document titled **Guidelines for speech pathologists assessing, diagnosing and treating clients with Autism Spectrum Disorder** will be available in the near future. In the meantime, the information provided in the Position Statement is a good starting point for therapists wishing to develop their practice and learn more about supporting people with ASD.

New Arts Centred Youth Group for Young People with Disabilities

CALLING YOUNG PEOPLE IN WEST AUCKLAND

If you are in the west, 16-25ish years have a disability, days not full, want to meet other young people, try new things... no super talent or experience needed...

WANT TO TRY NEW THINGS & MAKE NEW FRIENDS

Hi - I am starting up a group for young people, before finalizing arrangements I would like to hear from young people who may be interested... so please contact me to talk about times, our cool venue, what you might want to do and what as a group we can do together.

For more information please contact

Julie 09 837 0581 (evenings)
or email youthtogether@live.com

PLEASE NOTE

This youth group is being held in Auckland, if you would like to find out if there are any youth groups in your area please contact Autism NZ (National Office) 0800 288 476 or 03 339 2627

or Email: info@autismnz.org.nz

Rett's Syndrome

By

Dr Muhammad Arshad, Child and Adolescent Psychiatrist, Hawkes Bay Hospital, New Zealand
 Professor Michael FitzGerald, Henry Marsh, Professor of Trinity College, Dublin, Ireland and
 Professor Shamim Salahuddin, Punjab University, Lahore, Pakistan

"Trust the parents who make most of the diagnoses, not the physicians." (Hajra 1943--2003)

Rett syndrome (RTT) is a complex postnatal neurodevelopment disorder that is classified as a pervasive development disorder which is the second most common cause of profound learning disability in girls.

Incidence

RTT is noted 1:10,000-20,000 females aged 12-15

History

Dr Andrea Rett (1954) and Dr. Hagberg (1960) described young females with repetitive hand washing/wringing movements. Ruthie Amir (1999) discovered MECP2 (methyl-CpG binding protein 2) gene near the end of the long arm of the X chromosome at the Xq28 site, when mutated causes RTT which is found in majority patients.

Characteristics

A child goes through **five** stages of illness.

Normal stage

Classically, children with RTT seemingly achieve normal milestones from 6-18 months.

Stagnant stage

Gross motor developmental delay, loss of eye contact, head deceleration growth, microcephaly, hypotonia, weight loss, weak posture, short hands and feet

Regression Stage

Typically age 1-4 years

- Autistic behaviour: expressionless face, hypersensitivity to sound, with loss of verbal a non verbal communication, unresponsive

to social clues and social withdrawal

- Abnormalities of midline hand movements: hand-wringing, clapping, flapping, hand washing and mouthing of the hands
- Breath holding, aerophagia, forced expulsion of air and saliva, apnoea
- Epilepsy, insomnia, self abusive behaviour
- Mental retardation, ataxia

Stationary stage

Typically aged 2-10 years

- Stereotyped hand movements
- Generalised rigidity, bruxism (grinding the teeth) and involuntary movements of the tongue
- Dystonia, feeding difficulties and poor weight
- Scoliosis, osteopenia

Post regression stage

Typically occurs after age 10

- Dystonia, hypertonia and [Parkinsonism](#)
- [Growth retardation](#), walking difficulty
- Quadriplegia, muscle wasting
- Scoliosis/[kyphoscoliosis](#)
- Seizures
- Breathing abnormalities
- Behavioural: teeth grinding, night laughing, screaming fits, low mood, anxiety episodes

- Hypotrophic cold blue feet, severe constipation, oropharyngeal dysfunction,
- Tachycardia, Long QT interval, sinus bradycardia
- Parkinsonian features

Differential diagnosis

[Cerebral Palsy](#) [Angelman Syndrome](#), [Downs Syndrome](#), [Fragile X Syndrome](#), [Prader-Willi Syndrome](#), Autism, Psychoses, [Prion Disease](#), [Phenylketonuria](#), Spastic [Ataxia](#),

Management

Currently there is no cure for Rett Syndrome, although there have been some promising results with gene therapy in mice. It is a multidisciplinary approach in which pediatrician, psychiatrist, cardiologist, surgeon, neurologist, social worker, psychotherapist, occupational therapist and geneticist play an important roles

Prognosis

Prognosis is variable depending upon developmental difficulties such as maintaining useful hand and communication skills females can live up to 40 years or more but deaths are due to spontaneous brainstem dysfunction, [cardiac arrest](#), [seizures](#), abnormally prolonged QT interval and gastric perforation.