

FROM HAMILTON ...

We hope that you have all survived the winter, particularly those of you recently affected by the storms. Isn't it nice that spring is here?

Altogether Autism turned one year old on 1 October, and we celebrated our birthday with a video-conference between regional offices, short talks from key people, and a morning tea. Altogether Autism now has a full contingency of staff of 12 advisors covering the 14 regions. Contact and further details for all our advisors can be found on the Altogether Autism website.



Altogether Autism has seen a steady increase in the number of requests for information since March 2008, with April recorded as the highest since the contract started. Much of the increase can be attributed to the networking and promotion carried out by advisors in their regions.

We have completed our second customer satisfaction survey and are very pleased with the results. Thank you to everyone who participated in this, your feedback is very valuable to our ongoing commitment to delivering a quality service to the community. Details of the survey are included later in this newsletter.

The Professional Expert Group and our clinical consultant have been kept very busy with responding to more complex information requests. Their contribution has been very valuable to the success of our service. So please take advantage of the opportunity to access their expertise through the service and keep those information requests coming.

Professional Expert Group

The Professional Expert Group met for the first time in Wellington on Friday 4 April 2008 to discuss their role and ongoing involvement with Altogether Autism. The meeting was lead by our Clinical Consultant, Tanya Breen, who is responsible for coordinating the group.

The role of the Expert Advisory Group is to provide evidence-based information on ASD issues, such as diagnosis, intervention and service provision. The group will provide a platform for provision of multi-disciplinary advice and commentary.

The Professional Expert Group comprises Members and Associates. All specialist information requests are sent out to members, who respond according to their expertise. Associates are typically only sent requests relevant to their expertise. Further details about group members can be found on Altogether Autism's website at www.altogetherautism.org.nz.

Website

Further development is underway on the Altogether Autism website, www.altogetherautism.org.nz. Articles written by the professional expert group will be included, as will short summaries of the New Zealand Autism Spectrum Disorder Guideline. A message bulletin board will be developed where users can post questions, which the Clinical Consultant, and/or members of the professional expert group will respond to. This information will remain on the bulletin for future reference. In addition we will be hosting pod casts of talks, addresses, presentations that users can access by downloading or streaming. The service provider database will be updated. We will keep you posted about this development but please take the opportunity to take a look at our website when you can.

ASD Reference Library

Altogether Autism has recently contracted a librarian to assist us develop a reference library for our service. The purpose of this library is to assist us with responding to information requests more effectively and with writing material for our website and other purposes.

Inside this issue:	
<i>From Hamilton continued...</i>	Page 2 & 3
<i>Sib Support Venture in Gisborne</i>	Page 3
<i>Autism NZ Gisborne Branch Office and Customer Satisfaction Survey</i>	Page 4
<i>GPS Tracking Devices and First Hand Experience of GPS System</i>	Page 5
<i>Standards Plus - Trusting Partnerships</i>	Page 6



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Regional Network Meetings

The second round of regional network meeting has commenced with the first taking place in Gisborne on 31 July. There was a great turn out to the meeting and our Clinical Advisor gave a very informative presentation on Autism Spectrum Disorder Assessment and Diagnosis of young people and adults.

A schedule of the finalised meetings has been included for your information. Closer to the meetings we will send out a notice about the venue and speakers for all those on our contact list. If you are not on our email contact list or you know someone who would like to be so that can receive future meeting notices, please contact Sue Davies on info@altogetherautism.org.nz with details.

NZ Autism Spectrum Disorder Guideline

The NZ ASD Guideline was launched at Parliament on the 2 April 2008, World Autism Day. The guideline includes information for people with ASD, health professionals, anyone involved in education, from early childhood to tertiary, community supporters, parents and grandparents, employers and policy advisors.

The ASD Guideline was written by three work streams, which included experienced Maori and Pacific researchers. The three work streams, each with a particular expertise, were set up to focus on different aspects of ASD and the different contexts in which people with ASD live, learn, work and play. Stakeholder reference groups were set up to provide input into each workstream.

The guideline will form the basis of a 'living guideline'. It will be updated regularly on the web with new research and evidence.

The guideline can be downloaded from the Ministry of Health website on www.moh.govt.nz/autismspectrumdisorder or you can order a hard copy by calling 0800 ASD 222 (273 222)

NZ ASD Guideline Communication Implementation Plan

Altogether Autism has recently been contracted by the Ministry of Health and Education to assist with implementation of the communication plan for the National ASD Guideline. As part of this work Altogether Autism will be responsible for putting together and distributing information packs for the NZASD Guideline. Altogether Autism will also include information and material on our website regarding the guideline. In addition we will be delivering presentations at our regional networks and other scheduled events about the ASD guideline as part of the communication plan work.

Contact Altogether Autism if you would like a promotional pack sent to you on 0800 273222 or email info@altogetherautism.org.nz

Autism NZ Collaborative Work

The memorandum of understanding (MoU) between Altogether Autism, and Autism NZ, was officially signed on the 22 March 2008. Both organisations have met on several occasions since, to discuss collaborative ways of working together to improve outcomes for people with ASD and their families and whanau. In most areas advisors for Altogether Autism and Autism NZ representatives are meeting monthly to discuss how they can work together by sharing information and discussing issues for people with ASD. Both organisations when appropriate regularly refer people to each other.

The respective management team for Altogether Autism and Autism NZ met recently with the Ministry of Health to discuss joint work development.

ASD NZ Guideline Implementation Advisory Group (IAG)

The New Zealand Guideline Group was awarded a contract to provide implementation services, including managing the expansion of services for people with ASD and development of national frameworks to improve the availability and quality of services for people with ASD. Eighteen individuals have been identified to serve on the IAG. All of them fulfilled multiple criteria from a criteria list, which included:



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- living with autism
- caring for people with autism
- working with people with autism as a professional
- working with people with autism as a researcher
- a track record of passion for improving the lives of people with autism
- a track record of good team work

The role of the IAG is defined in its Terms of Reference, which broadly are to advise the New Zealand Guidelines Group on how to implement the key recommendations in the Guideline and to advise the New Zealand Guidelines Group about how to improve the implementation process

The group met for the first time on 12 June 2008. On 14 August 2008 the NZASD Implementation Advisory Group met for the second time. The focus of that meeting was to provide advice to the Ministry of Health on which ASD initiatives the IAG thought should be prioritised, in advance of the Ministry making budget allocations for the 2008/2009. Tanya Breen, Clinical Consultant for our service is a member of this group.

Departure of Michelle Rivers, National Coordinator

Michelle Rivers, National Coordinator for the first 12 months of Altogether Autism, finished working for us on 25 September 2008. Michelle is taking up an exciting position with Hamilton City Council, as Manager of Cemeteries and Crematorium. Michelle was thrilled to receive a card from the ASD Advisors. She was given a beautiful picture from LIFE (a small version of the blue koru that is in the main office), flowers, expensive chardonnay (her favourite wine variety), and some exquisite wine glasses. Lots of people from LIFE, Parent to Parent, and the local disability sector attended. We wish Michelle all the best in her new venture.

Sib Support Venture in Gisborne

Idea Services family/whānau manager, Anne McNabb in Gisborne, along with managers from Hawkes Bay, Wanganui and Palmerston North could see a real need for the siblings of children with a disability amongst local families, to have an opportunity to have a weekend away with other children of similar ages, to have some special time for themselves and fun!

A group of seven children aged 7-14 years, from families who had siblings on the Autism Spectrum and intellectual disabilities were included, they travelled from Gisborne to Napier on a Saturday and spent the night at the National Aquarium of New Zealand.

The Aquarium calls this a "Piranhas in Pyjamas" experience! Food was pre ordered and brought in, individual boxes of chicken and chips we are told and interactive games and fun was had by all.

Idea Services family/whānau managers helped locally on arrival and the next morning to prepare freshly filled bread rolls and help organise other activities and games before returning to Gisborne in the afternoon.

As a follow up, Anne planned a get together for the group in the school holidays also to meet up, go to a movie and have lunch together.

We saw this as a great initiative from Idea services and Anne's colleagues hope the group will grow and offer great support to each other.

Funding for this venture came from the Lotteries Commission.



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Autism NZ Gisborne Branch Office

Calvin Gedye from Autism NZ Gisborne branch would like to advise that the local branch has reformed and have a new office based at 60 Peel Street, Gisborne. The phone has not been connected yet. But in the interim all enquiries can be made by phoning Grace on 06 868 1517.

The rooms at Peel Street will be open on Saturdays and will extend as more volunteers become available.

Please contact Grace if you would like to volunteer some time to help out in the office. The branch hopes to run a monthly meeting soon. Details of this will be posted on Autism NZ and Altogether Autism websites

Customer Satisfaction Survey



Qualitative Customer Satisfaction Survey was conducted at the end of June 2008 to gauge customer satisfaction of the service for this reporting period January to June 2008. A 10% sample of people who had contacted the service in the last 6 months was surveyed.

A person, independent of Altogether Autism was employed as a telephone evaluator to conduct the survey therefore ensuring honest and unbiased recording of the feedback. People were asked verbally to rate the service and were asked to make additional comments. Participants in this Altogether Autism Customer evaluation were given a range of questions, which they were asked to rate. The rating scale was from 1 being very unsatisfactory to 5 being excellent or outstanding.

Overall feedback about the extent to which the information provided assisted the person, was useful and specific to their requirements was rated as excellent or above satisfactory in 75% of people surveyed. High levels of satisfaction were reported with the friendly and respectful manner requestors will dealt with when contacting the service for information, with 70% surveyed as rating this as excellent. Overall survey participants reported satisfactory, above satisfactory and excellent in relation to the length of time it took for them to receive their information pack. However in a few instances people reported that it had taken too long to receive their information pack. This situation has since been rectified and a new information officer has been recruited to meet the increasing demand. Question 7 asked about the requesters contact with the ASD advisor in their area and how useful this had been, 85% of the people surveyed reported excellent or above satisfactory with this. The majority of participants reported that they had not accessed the Altogether Autism website or provider database. However where people had used the website, all reported this as excellent or above satisfactory. These results have identified the need to further promote the website and additional funding has been secured through the contract to develop and promote this further.



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GPS Tracking Devices and Other Safety Equipment for children with Autism

An article on GPS Tracking Devices recently appeared in the Autism NZ National Newsletter, December 2007. Sharon Bain, our Otago ASD Advisors has had experience of using this technology, which is outlined below:

Equipment for safety, such as wrist-tracking devices, may be considered for funding where they are considered as appropriate by the family and a needs assessment team. To access this funding, each child must undergo needs assessment with an occupational therapist registered as a specialized assessor, and other professionals skilled in behaviour management.

The role of a behavioural support team is to identify and provide strategies at home and school to minimize risky behaviour and make sure that all possible solutions have been considered. Use of equipment for safety such as tracking units needs to be considered in combination with other safety measures, for example, fencing. If the family and the assessment team consider a tracking device as essential for safety at home, the specialized assessor can submit an application for funding to the appropriate agency (Enable New Zealand for all areas south of the Bombay Hills and accessible for the northern regions).

If any parents wish to have their children assessed, I suggest they contact the occupational therapy department at their local district health board to arrange an assessment.

Contact details for local district health board can be found on the Ministry's website: www.moh.govt.nz/moh.nsf/indexmh/contact-us-dhb

Hon Pete Hodgson – Minister of Health

As published in the Autism NZ national newsletter December 2007

First Hand Experience of GPS system By Sharon Bain, ASD Advisor for Altogether Autism Otago Branch

Our son Luke has severe autism and a tendency to wander off and we worry for his safety. Luke can say a few words but is mostly non-verbal. We had been looking into the option of a GPS system for Luke when we came across a company in our local area called "TracPlus Global Ltd" and discovered that they supply GPS units. TracPlus work with the Rescue Helicopters, St John's, Air Rescue Coordination Centres (RCCNZ) and now Coastguard. The sample unit they showed me was waterproof, is a sealed unit about the size of a small slim cell phone. It also comes with a belt clip, if your child is like my son – he won't wear a belt, so I plan to put a false pocket in the polo shirt he wears to school. We have been practicing with an old cell phone in his pocket just to get him used to having it.

Several families with children attending the same school are able to share the software. They do this by sharing their access user codes with the caregivers at the school. Parents also share with each other, in a secure "Skype" style method where by they can make their own children visible for an hour one day, for ever to their friends or not. The children's tracking devices stay dormant when they are in school grounds unless one of the family or caregivers "Polls" the device to ask, "where are you?" If the child moves out of the school area, an automatic response is sent from TracPlus (including Latitude, Longitude heading and time of report) to each designated person's mobile / pager and of course the software, the i-tracker unit immediately starts reporting at predetermined intervals. The family or caregiver can then log in thru TracPlus; a Google maps page, or web capable mobile phone, and see exactly where the child is. And we as Parents will have Piece of Mind!

If you would like to know more about the I-tracker (GPS System) please phone Sharon Bain ASD Advisor phone 03 4701-086 or email Otago@altogetherautism.org.nz



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Standards  Plus
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TRUSTING PARTNERSHIPS

A conference to advance our understanding of the impact of establishing right relationships between families, disabled people, organisations, service providers and community.

To be Held: 30th October – 1st November 2008
Novotel Lakeside Rotorua
Lake End, Tutanekai Street
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Conference Themes: *Best Practice Principles*
Theoretical Perspectives
Outcome & Impact

International Speakers

Ann and Rud Turnbull; are professors in the Kansas Department of Special Education and Co-Directors of the Beach Center on Disability at the University of Kansas.

Michael Kendrick; is well known internationally for his work on the promotion and development of right relationship.

Includes New Zealand Plenary speakers and 19 workshops of topics as varied as

- Supported Living
- Partnerships with government
- Family governance

Taking personal authority

Registration:

Full registration includes: Powhiri, cocktails, lunches, morning & afternoon teas.

All fees are in New Zealand dollars and are GST inclusive.

Early Bird Registration	\$440 closes 21st September 2008
Full Registration	\$470 closes 17th October 2008
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Full conference details and registration available

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