



We are an information and advisory service for people with Autism Spectrum Disorders, their families, whanau and the wider New Zealand community

Summer 2011

Journal

Introduction

Welcome to the first edition of the Altogether Autism Journal – our plan is to publish editions of the journal several times a year. Altogether Autism's role is to provide reliable evidence based information to people of New Zealand regarding Autism Spectrum Disorders (ASD). Over the last 10 years there has been increased awareness of the incidence of ASD in our community and attention and interest in understanding ASD from many different groups of people – families of children diagnosed with ASD, teachers, professionals and support workers, adults with ASD, and from interested members of the public.

This journal is a collection of articles on some of the topics and issues we hear being asked and talked about most frequently. Our approach is to be carefully evidence based in all of the material we present. There is a huge amount of information regarding autism and ASD available, and the challenge is to find information which is reliable and relevant to your own situation and interests. If you have particular questions please do not hesitate to contact us – we have teams of people able to access and research information regarding the area of your interest – for contact details and to find out about other services provided by Altogether Autism please see pages 9 and 10. Please also let us know regarding other topics or matters you would like to see covered in future editions.

We hope you find the first edition of our journal helpful and thought provoking in understanding ASD.

Mark Brown and Anne Wilkinson

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Cyber Bullying

It is well known that children with special needs are more likely to be bullied in the traditional sense. There is little research on the incidence of cyber bullying, which is the 'new wave' of bullying. A recent study looked at the prevalence of both traditional and cyber bullying in children with Asperger Syndrome and ADHD, the effects of bullying, and their parents' understanding of it.

Traditional Bullying versus Cyber Bullying

Traditional bullying can be defined as trying to harm the other person, and is repeated over time. There is

typically a power balance between individuals. Cyber bullying differs from traditional bullying in that it is not face to face, many victims do not know who the bully is, and it can occur at any time of the day or night. It occurs through the internet or by cell phone. In the case of traditional bullying, victims often do not want to report the bullying because they are scared they will be further victimised. However, victims of cyber bullying do not want to report the bullying

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From page 1... because they are scared the technology will be taken from them. Victims of bullying can experience effects such as anxiety, depression, low self esteem, and physical health symptoms such as headaches and stomach upsets.

The Study

The children and adolescents in the study were 24 males and 18 females from the US, diagnosed with ADHD and/or Asperger Syndrome. They were asked many questions about how much they used the internet and how safe they felt using it; whether their parents had established internet rules and discussed how to be safe on the internet; their experiences of traditional and cyber bullying; and, about the physical and psychological effects of bullying. The parents of the children in the study were given the opportunity to complete a questionnaire about their own internet use, their child's internet use, and questions about bullying.

Sources of Cyber Bullying

Cyber bullying was most likely to happen when the children were using instant messaging (e.g., MSN Messenger) or social network sites (e.g., Facebook). Twenty percent of cyber bullying occurred through using cell phones.

Affects of Bullying

Traditional and cyber bullying had similar affects on psychological and physical health. Victims and those who had bullied others showed higher levels of anxiety and depression, and lower levels of self esteem than those were not involved in bullying.

Incidence of Bullying

The study found that 57% of the children had been victims of traditional bullying in the previous two months, and for 19% of these children this had occurred several times per week. Thirty eight percent admitted to themselves being bullies in a traditional sense in the same time frame. Twenty one percent of the children reported having been cyber bullied in the previous two months, and 5.8% admitted to cyber bullying others.

While the incidence of cyber bullying was lower than the incidence of traditional bullying, over one in five children reported that they had experienced cyber bullying.

This incidence may have been underestimated by the children in the study, who, due to poor social skills, may not recognize some online behaviour as cyber bullying. Cyber bullying has been

found to have the same negative effects on physical and psychological health as traditional bullying. In addition, children with special needs may spend too much time online due to difficulties they experience with face to face interaction. This means that cyber bullying is a serious problem that needs addressing.



Parents' Role in Preventing Cyber Bullying

Almost half of the children said that their parents never or rarely talked to them concerning internet safety issues. Some of the parents had never set any rules regarding the internet and most of the parents felt that their children were moderately safe using the internet. Overall, parents were uninformed of their children's experiences of bullying, especially with cyber bullying.

This suggests that parents need to educate themselves about cyber bullying and internet safety and should be more aware of what their children are doing online. Parents should learn about the dangers of the internet, ways to prevent cyber bullying, and relay this information to their children, along with rules about how to safely use the internet.

Summary

Cyber bullying is a recently developed form of bullying and an area that is lacking in research. It occurs through the internet or cell phone, can happen at any time of the day or night, and has the same negative effects on physical and psychological health as traditional bullying. Although this study found rates of cyber bullying to be lower than that of traditional bullying in children with ADHD and/or Asperger syndrome, more than one in five children had experienced cyber bullying. The parents of the children in the study were lacking in knowledge of internet safety, cyber bullying and the experience of cyber bullying among their children. Parents should communicate with their children about internet safety and cyber bullying, and create rules to ensure the online safety of their children.

Reference

Kowalski, R. M. & Fedina, C. (2011). Cyber bullying in ADHD and Asperger Syndrome populations. *Research in Autism Spectrum Disorders*, 5 (3), 1201-1208.

How Our Lives Changed Forever...

We are a family of four, Sharon, Mike, Regan (12) and Luke (10). On November 30th 2002 our lives changed forever; Luke was diagnosed with Autism Spectrum Disorder. He was 2 years and 2 months old.

After the initial shock, we started receiving help from the Vera Hayward Centre, which is the Child Development Service at Dunedin Public Hospital. Through the Centre we received weekly speech language therapy and occupational therapy, for one hour each a week. We also attended a music therapy class run at the Centre. Luke was non-verbal. We had access to an Educational Support Worker, through Group Specialist Education (GSE) for 8 hours per week, to help him at kindergarten.

Through speech language therapy we were trying very hard to teach Luke how to use PECS – which is picture exchange communication. Luke struggled with the pictures used in this communication method but soon picked up what to do when we showed pictures of the actual item, such as a picture of Luke's drink bottle as opposed to a drawing of a bottle. To encourage Luke to use this system we rewarded him with chocolate chips (only one or two), as we needed a strong motivator for him to want to do this. Our home was decorated with pictures to help Luke with requesting; we had things stuck to our fridge and on the back of doors. Luke also had a communication folder which he could use to get a picture to bring to me so I knew what he wanted.

We had to be a bit clever and put all his favourite things out of sight or up high so Luke would be motivated to get a picture card, before he got the item he requested. He also had to attempt to make a sound to get what he wanted.

Luke turned 5. He was off to school. What a terrifying experience this turned out to be. Along with any parent's worries about their child starting school, we had a lot more going on in our heads. How will Luke communicate? He is still in nappies; who will change him? Will he be safe? How will he learn? We had already completed an ORR's (Ongoing Renewable Resourcing Scheme) application which came back at High Needs. He had teacher aide funding, so at least he was safe. Luke only attended school in the mornings, as he did not have funding for a teacher aide all day.

Six weeks after he started school we re-submitted an ORRS application, which came back as Very High



Needs. Yay! He is finally getting the help he needs, which included speech language therapy. As a parent new to this system, now that Luke was at school, I thought he would be getting speech language therapy, as he had in Early Intervention. How wrong I was. I could count on my hands how often Luke was seen by the speech language therapist.

Remember Luke was still non-verbal. This was breaking our hearts; this little boy, who could not talk, was not getting the right support. I know that speech language therapists have big caseloads but every parent wants the best for their child and a speech language therapist was what my son needed. We employed a private therapist for 1 hour per week; this costs us \$80 every time.

As a result of our needs assessment we were referred for an Assistive Technology assessment, which costs lots of money to have people flying around the country to see Luke in various settings at school and at home. Unfortunately for us, I felt this was a waste of time and money, as all they come up with was PECS (Picture Exchange Communication System) which we were using and a GO Talk, which you could programme the names of the objects into. Luke just used this as a toy, not as a communication device.

Luke has come a long way in the last five years, with a lot of people helping him on his way – for which we are truly grateful. There have been some boulders in the path we are travelling. Sometimes it feels like systems are just too hard and it seems like we are in a pot hole but we just carry on and take little steps over the boulders. We get there in the end.

Luke is now talking. He is a fantastic “Wiggles” singer and if one of them wants to retire Luke could take over; he knows every word to each of their songs. After 6 years I finally heard those words “love you Mum” which were worth all that we paid out for private SLT.

By Sharon Bain

The following advice is written for use by Needs Assessment and Service Coordination agencies working with people with Autism Spectrum Disorder.

Unfortunately need for behaviour support services (BSS) often outweighs capacity, and waiting lists can be long. Asking for behaviour support is often a 'last resort', occurring when the person with ASD, their parents or family, or support service feel under extreme stress, and near 'breaking point'. Being referred, but put on a lengthy waiting list, can be devastating.

However there are things that people can do while they are on the waiting list which give relief, address stress, and speed up interventions when the person finally comes to the head of the queue. In a few situations, 'waiting list strategies' take away the need for behaviour support at all.

Re-empowering People, and Attend to Basic Needs

Often people with ASD, and their parents, families/whanau and support services have been managing on a day to day basis. Sometimes, for years. Being referred for behaviour support does not take away the ability to manage. NASC staff need to support people to continue implementing positive strategies that have been working for them already. Also helpful is encouraging people to consider their needs and support holistically, rather than as behavioural issues. Look for ways to relieve pressure, even if not directly

related to the referral issue. Consider natural supports, like wider family and the local community (i.e. are there relatives who can take on some of the day to day responsibilities? Could the person go to after school activities, have a buddy, or join a club?). Identify practical and tangible help (e.g. nappy services, home help, or section maintenance) which could free people up so that they have more energy/ability to manage with problem behaviours.

Sometimes people benefit from problem-solving, ways to eat healthily, exercise, get sufficient sleep, have opportunities to relax, and have time for themselves. Find creative and previously unrecognised support which could assist (e.g. whilst a parent may have to support their child with ASD, a friend or relative could take other children to sports practice).

Support Services: Generic, Disability and ASD-Specific

Talking through problems helps. Many generic services offer practical advice and a sympathetic ear. Consider referring people to Citizens Advice, Plunket, Presbyterian Support Services, etc.

Meeting people with shared experiences is invaluable. Encourage contact with disability and ASD-specific organisations, like: Parent to Parent, CCS, Autism New Zealand, Altogether Autism, Cloud 9 Children's Foundation, and networks of adults with Asperger Syndrome (contact Altogether Autism for further information).

Important note: the information above does not apply to seriously challenging behaviour that threatens safety and well-being. In these extreme cases, professionals (doctors, psychiatrists, psychologists) should be consulted *with urgency*.

By contacting Altogether Autism people can request information on ASD-related topics, such as behavioural and emotional problems commonly experienced by people with ASD. Altogether Autism will discuss the problem with the caller, and put together an information pack which addresses their specific needs and is at a level of sophistication that is appropriate to them. NASCs can also use this service.



the individual concerned. Using the 'triad of impairments' in ASD (problems in communication, social/emotional understanding, and fixed interests/routines) is a good guide. More information on ASD signs and symptoms can be found on www.asdguideline.com.

It can be helpful to write a 'manual' or 'users guide' on the person with ASD, and (if the person with ASD is old enough) on the non-ASD people that they interact with. This helps people:

1. Recognise when behaviour is specifically ASD-related, which can take blame and anger out of situations. (There is a big difference between deliberate naughtiness and an ASD-related anxious reaction).

Learning About ASD and Applying Knowledge to the Person Concerned

One of the key ways to help people with ASD and their families and wider supporters is to assist them to understand ASD as it affects

2. Prevent or avoid situations likely to trigger unwanted behaviour.
3. Plan ahead, to minimise the impact of unavoidable triggers.
4. Identify helpful strategies in advance, so that people know what to do, and how to react, and their response is consistent every time.

Prepare for Behaviour Support

Sometimes 'problem behaviour' is an expression of other issues, like pain. This is particularly so when communication skills are poorly developed. Before



attempting behaviour support, exclude medical reasons. Arrange for the person concerned to be seen by their GP, Paediatrician, other medical specialist, and dentist. Check for hearing loss, seizures, pain, discomfort, and constipation.

The frequent 1st step of BSS is to collect information on the problem behaviour. Having information easily available will save time when the referral comes to the top of the list. This should speed up intervention. Relevant information includes:

1. Developmental milestones (e.g. birth details, information on when the person crawled, walked, said 1st words, said sentences, any diagnoses)
2. Key events in the person's life across time (e.g. illnesses, residential moves, starting or moving schools, bereavements or losses).
3. Describe problem behaviour clearly, noting strategies (helpful and unhelpful).
4. Video problem behaviour.
5. Record how often the problem behaviours occur (e.g. mark occurrences on the calendar).

6. Names and contact details of key staff and professionals involved (or recently involved).
7. Historical reports and letters from the pre-school, school, GP, other doctors, Psychologists, and other allied health or educational staff.

Parent Implemented Behaviour Management

Parents (and support workers) can implement basic behavioural strategies, as outlined below.

1. Make written descriptions of the problem behaviours that you want help with, in enough detail that anyone reading the description would be able to picture it happening.
2. Carefully consider possible reasons for the behaviour (consider changes in routine, new people, access to desired items or opportunities, avoidance). It may help to talk this through with other involved people.
3. Record occurrences of the problem behaviour, noting down the setting it occurred in, potential triggers, action taken, and responses of the person and others.
4. If patterns are found, make changes to the setting, triggers, action and responses. Consider using:
 - a. Exercise (e.g. walking, running, trampoline), to let off energy.
 - b. Visuals and clear instruction to ensure that communication is understood.
 - c. Social stories to explain situations and suggest more appropriate behaviour.
 - d. Simple relaxation strategies (e.g. listening to music, having a relaxing bath, going for a walk, relaxing breathing).
 - e. Simple rewards for desired behaviours.
5. Avoid using punishments, which rarely makes things better and often makes things worse.
6. Whatever you do, be consistent, and try out the strategy for a reasonable time.

For more detailed information on:

parent-implemented behaviour management
Contact Altogether Autism for an information pack, and (if possible) specify what the problem behaviour is.

The following 'tips' for getting the most from behaviour support services (BSS) are written for use by Needs Assessment and Service Coordination agencies working with people with autism spectrum disorder.

1. **Take steps to identify and/or eliminate physical or medical causes of problem behaviour**, by arranging for assessment by medical, dental and other relevant health professionals.
2. **Achieve support** for the BSS referral from the person with ASD, their family/whanau and key support person, before initiating a referral. This includes explaining that intervention strategies often involve making changes in routines, environments, and the behaviour of families and support people.
3. **Be descriptive and detailed** in the referral, so that the BSS has a clear idea of what the issues are at the point of referral. This is important because it allows the BSS to identify which team members might be most appropriate to take on the referral.
4. **Provide names and contact details** of all key people, including family, school, and health and educational professionals.
5. **Be realistic** in your expectations. Even the best BSS is unlikely to be successful in situations where people are wrongly placed, being abused, or when families and support people are unwilling or unable to make changes themselves.
6. **Prepare for behaviour support** by encouraging people to:
 - a. Record developmental milestones (e.g. birth details, information on when the person crawled, walked, said 1st words, said sentences, any diagnoses)
 - b. Record key events in the person's life across time (e.g. illnesses, residential moves, starting or moving schools, bereavements or losses, etc.)
 - c. Write descriptions of the problem behaviours that they want help with, in enough detail that anyone reading the description would be able to picture it happening, and/or video the problem behaviour when it occurs.
7. **Encourage and accept feedback** on suitability of residential or vocational placements, support needed, training, and other relevant system factors.
8. **Expect thorough assessment**, involving interviews with the client and key significant others, data collection, behavioural observation, and review of relevant historical information.
9. **Request copies** of assessment reports, interventions, and progress reports.
10. **Question the rationale and supporting data** for interventions, and be particularly inquisitive if interventions do not appear to be making positive progress.



Bullying is different from good natured teasing. The victim will be distressed. A bully intends to harm their victim and directs negative actions toward the victim again and again. Typically, there is a power imbalance between the bully and the victim, for example, large versus small, alone versus with others.

Types of Bullying

- There are several different types of bullying:
- Physical bullying (e.g., hitting, tripping, grabbing belongings, etc.)
- Verbal bullying (e.g., teasing, threatening name calling, gestures, etc.)
- Social bullying (e.g., exclusion, rumours, embarrass in front of others, etc.)
- Educational bullying (e.g., sarcasm, being over critical, favouring or humiliating students etc.)

Possible Effects of Bullying for the Victim

Bullying can have devastating effects for the victim. These include embarrassment, low self-esteem, anxiety and depression, headaches and stomach pain, social isolation and loneliness. Victims of bullying may be avoided by others as they do not want to be seen as a victim and also bullied. School work may suffer as a result of worrying about the bullying and missing school. Victims of bullying may seek revenge on bully using violence. In the very worst cases, some victims of bullying may turn to suicide.

An Epidemic

According to the DVD “Being Bullied: Strategies and Solutions for People with Asperger’s Syndrome”, there is currently an epidemic of bullying in schools. Up to three quarters of children experience bullying at some stage in their schooling. 85% of this bullying takes place in front of others. Because of such bullying, thousands of children miss school each day.

Bullying and ASD

Almost all children on the Autism Spectrum will experience bullying, and they are more likely to be targeted than neuro-typical children. The same victims tend to be targeted again and again. According to the DVD “Being Bullied: Strategies and Solutions for People with Asperger’s Syndrome”, in some cases, teachers can contribute to the problem by blaming the victim and by being apathetic.

Children with ASD are Easy Victims

This is because children with ASD have minute differences such as motor issues, sensory difficulties, special interests, social impairments and the use of odd language.



Solutions to Bullying as Suggested by “Being Bullied” DVD:

- Encourage victims to enlist bystander support
- Reassure victims that as they get older, people get nicer
- Reassure the victim it is not their fault
- Encourage the victim to empower themselves and increase their self-esteem by pursuing interests and hobbies (e.g., martial arts)
- Help victims to prepare witty comebacks to common putdowns
- Educate school about ASD and how children with ASD react to bullying
- Encourage school to create a bullying policy
- Anonymous student questionnaires for information on bullies and victims
- Ask the teacher to identify several popular children to mentor children with ASD
- School bully register to keep track of incidents
- Anti-bullying assemblies
- Teach bystanders that bullying is wrong
- Help bullies to use their power to help others rather than to harm

Reference

Dublin, N. (Producer/Director) & Dubin, L. (Producer/Director) (2006). Being Bullied: Strategies and Solutions for People with Asperger’s Syndrome [DVD]. London and Philadelphia: Jessica Kingsley Publishers.

Heinrichs, R. (2003). Perfect Targets: Asperger Syndrome and Bullying. USA: Autism Asperger Publishing Co.



The way John Greally sees it, all “Aspies” are fascinated by something, be it railway engines or bus timetables. His particular interest is Asperger’s Syndrome itself.

He knew he was different from others at an early age and by 19 was calling himself “semi autistic” as a way to rationalise his place in the world. It still stuns him that he didn’t recognise similar signs in his son, now 11.

“It was pointed out by a kindergarten assistant. I kicked myself that I didn’t recognise it,” he says.

Now at 48, John Greally, is a passionate advocate for people with higher functioning autism and Asperger Syndrome. In 2007 the Upper Hutt man launched Asperger’s Syndrome New Zealand, a not-for-profit organisation specifically by and for autistic people.

While New Zealand had parent support groups, government groups and social groups, John believed there was a need for an information and advocacy organisation by, of and for “Aspies”.

“Some of us don’t just want to hang out socially. We want to fix some of the poor attitudes and a lot of the ignorance about autism that is out there. Much of the information comes from parent and professional sources – not from those who actually experience autism themselves.

“I wanted an organisation that was just for people with Asperger’s. Information from

Autism New Zealand is largely parent-based and Altogether Autism is evidence based. We are the one that was largely missing.

“When people with autism are looking for information, we are more likely to be trusted. We can talk about something we have that nobody else can understand. It’s like looking at a monkey through the bars. In the end, it pays to be the monkey.”

John’s days are filled with emails, phone calls, advocacy work and meetings, occasionally to the point where his neighbour has cooked dinner because there hasn’t been a break in the day for him to prepare it.

At Government level, he has served on the ASD advisory group preparing guidelines for service to people with disabilities. He was recently appointed to a new advisory group that will carry on from the guidelines group.

John is driven by his belief that Aspies have a human right to their own place in society without limitation. He says the government has spent \$18 million on the needs of children and adolescents with autism. Now the focus should go onto adults, especially those aged 22-26 who would have been among the first officially diagnosed in New Zealand since 1996.

“Those people are now through school and university. Some have no jobs. Some are living rough. To my mind, these are the people who are supposed to be driving the knowledge-based economy. If you squeeze out the people who are different, you squeeze out the edge that New Zealand has traditionally had in innovation.”

For all the time John puts into his work, he wouldn’t have it any other way.

“I swear I get more out of what I do than the people I assist get out of me. They are an incredible array of people with so much important in common but also so much difference. We are people you warm to slowly – an acquired taste, like all the best types of wine.”

Asperger’s Syndrome New Zealand

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Website: www.asnz.exofire.net

Address: Unit 1, 4 Moeraki Road,
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The Information and Matching Team

Our information and matching team is made up of Kym Watkins, Karina Johnson and Rhonda Warlow and is managed by Paula Gardner. Working alongside each other they ensure that the information compiled is consistent, relevant to your specific request and delivered in a timely manner.

One of Altogether Autism's points of difference is its individualised information packs. These packs contain a wide range of relevant material, specifically researched, and individually compiled by a member of the team to meet your specific request.

The types of requests for information we receive cover a wide range of Autism Spectrum Disorder (ASD) related topics, for example information relating to the diagnostic process, coming to terms with a new diagnosis, communication and behaviour management strategies, toileting issues, transitions and puberty, plus many more. We can also supply information to teachers or other professionals working with adults or children with ASD.

The team works closely with our regional coordinators throughout New Zealand who provide a wealth of local knowledge and information regarding supports and service providers. The coordinators also run regional Network Meetings throughout the year. These meetings are open to anyone with an interest, personal or professional, in ASD and are a chance to hear about the Altogether Autism service, meet some of the staff and network with others.

Altogether Autism's information service provides evidence based information and advice through a Clinical Psychologist and a panel of professional experts (PEG). The PEG are there to answer or guide us around some of the more complex requests we receive. As well as consulting with the PEG, we also

have available to us a consumer reference group, made up of people with, people working with, and parents of people on the autistic spectrum.

Through Parent to Parent we can provide one to one support from a trained volunteer Support Parent who has a child with ASD. This can be of particular value to parents and is an opportunity to have contact for support and understanding as well as speaking about any particular issues.

You can make an information request through to the team in a number of ways, either through your regional coordinator (their contact details are on the back page), or through our...

Freephone number: 0800 ASD INFO (0800 273 463)

Email: info@altogetherautism.org.nz

Website: www.altogetherautism.org.nz

We look forward to hearing from you.

Paula, Kym, Karina & Rhonda



Consumer Reference Group

Altogether Autism is pleased to announce a recently formed Consumer Reference Group. The aim of this group is to provide expertise and input in an advisory capacity to the work of Altogether Autism to ensure that the service remains useful and relevant to people with Autism Spectrum Disorder (ASD). The focus is on the responsibilities under the existing ASD service, as well as on developing new opportunities.

The role of the group is to provide expertise and

advice for the development and refining of services to best meet the needs of the ASD community. They will look to provide feedback and advice on options and discuss how these might work in practice, provide advice and comment from personal experience and expertise as a person with ASD, as well as raise with Altogether Autism issues or concerns for the ASD community regarding how services are being implemented and managed.

It's always a little strange introducing oneself on paper to an invisible audience, especially if one is an Aspie. My name is Paula Jessop and I was recently invited to coordinate the exciting new initiative of a Consumer Reference Group to Altogether Autism. I have 'lived experience' of Autism Spectrum (AS). Like many other adults on the spectrum I grew up not knowing why I was different and was thankfully formally diagnosed in my mid-twenties. From here I travelled a journey of self discovery at a time when little was known about the experiences of adults with AS. In my life I have had first hand experience of finding a way to live a productive, functional life as a person with differing ability in the world.

My professional background contained many years at university, with my formal qualifications being in social science research and study focused on the experiences of people with disability, mental ill health and difference in society. More recently I have moved into working directly with AS people as a 'peer support person or mentor'. I run support groups, assist people in gaining an AS diagnosis and support people through their post diagnosis journey.

I am honoured to be asked to coordinate the Consumer Reference Group and am sure I speak for all of us on the group when I suggest our aim will be to provide practical consumer feedback to the

organisation to assist in maximising their services to AS people and those who live or work with AS individuals. Working with me in the group will be a range of individuals who have either 'lived experience' of Autism or 'experience living with and/or assisting Autistics'. The group is still being formed and we hope to have a cohesive mix of individuals with a range of knowledge early in 2012. At this point we will introduce the other members more fully and begin the important and exciting job of working together as a team to combine our diverse knowledge and experience into a positive contribution to Altogether Autism in their future organisational directions.

By Paula Jessop



Professional Expert Group

The Professional Experts Group is a group of qualified and experienced professionals who each individually have expertise in autism spectrum disorder. Drawn from the general and mental health sectors, disability sector, and from education, the professions represented on Professional Experts Group include paediatrics, psychiatry, clinical psychology, forensic psychology, applied behaviour analysis, teaching (at secondary and tertiary level), occupational therapy, and communication/speech and language therapy.

The Professional Experts Group is coordinated by Tanya Breen, our Clinical Consultant. When a complex information request is received by the Information Service, it is forwarded to Tanya, who circulates it to the Professional Experts Group, and develops a written opinion, based on the responses from the group. This

response is sent on to the person requesting the information. Information provided by the Professional Experts Group is based on the professional and academic training of each member, the research evidence-base, and practical experience. From time to time members of the Professional Experts Group have contact with an information requester via telephone or e-mail.

Some topics recently addressed by the Professional Experts Group include: early intensive behavioural intervention, self-soothing, support for adults with ASD, differentiating between high functioning autism and Asperger syndrome, dual diagnosis, and writing problems.

Members of the Professional Experts Group also make presentations at conferences and Altogether Autism events, and write articles for our website.

Meet the Altogether Autism Team



Paula Gardner
National Manager

Paula is our National Manager. Paula's primary responsibility as National Manager is to manage and lead Altogether Autism, with a particular emphasis on ensuring a seamless and coordinated service between LIFE Unlimited, Parent to Parent, clinicians, our 15 regional coordinators throughout the country and other relevant agencies. She is also Service Leader at Parent to Parent where along with Kym and Karina she researches and compiles our individualised information packs. She has been involved with the Altogether Autism service since its inception four years ago.



Tanya Breen
Clinical Consultant

Tanya is our Clinical Consultant. She works on complex information requests, and involves the Professional Experts Group when needed. Tanya presents seminars, writes/organises articles for our website, and represents Altogether Autism in national forums. Tanya was one of the writers of the NZ Autism Spectrum Disorder Guideline, and has been involved in follow-up projects implementing the guideline. When not working for us, Tanya is a Consultant Clinical Psychologist specialising in autism spectrum disorder and disability issues.



Sue Davies
ASD Coordinator

Sue is our ASD Coordinator and is responsible for the maintenance of the Altogether Autism website ensuring that the content is dynamic and cutting edge. She also collates and manages the constantly changing information for the Events Calendar, Newsletters and The ASD Register of Service Providers. Some of Sue's many talents include liaising and coordinating network meetings, seminars and a vast array of demanding admin duties to achieve set deadlines.



Anne Wilkinson
CEO for Parent to Parent

Anne is the Chief Executive Officer of Parent to Parent New Zealand. Anne lives in Hamilton and is the parent of four adult children, one of whom was diagnosed with autism and an intellectual disability as a young child. Anne has had an extensive personal and professional involvement in the disability sector for more than 26 years, as a parent, in a voluntary capacity with disability organisations and through her roles with Parent to Parent New Zealand. Anne was integral in the set-up of Altogether Autism, which is provided through a partnership between Parent to Parent and LIFE Unlimited and she continues to be a member of the management and governance group for the service.



Mark Brown
CEO for LIFE Unlimited

Mark is the Chief Executive of LIFE Unlimited and is based in Hamilton. Mark has been involved in the health and disability sector for more than 20 years having held senior roles with the Ministry of Health as funder of services, as well as with several provider organisations in social services and in supporting people with disabilities. He is a member of the management and governance group of Altogether Autism.



We are an information and advisory service for people with Autism Spectrum Disorders, their families, whanau and the wider New Zealand community



Regional Coordinators Contact Details

Northland

Tel: 09 437 3337 or 0800 273 463

Email: northland@altogetherautism.org.nz

Auckland

Tel: 09 625 5021 or 0800 273 463

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Waikato

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Bay of Plenty

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Lakes

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Manawatu

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Otago

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Southland

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Regions covered by Head Office

Gisborne

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Taranaki

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Hawkes Bay, Wairarapa

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West Coast

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Upcoming Regional Network Meetings for 2012

Altogether Autism Regional Network Meetings are open to all people with an interest in ASD

The meetings will cover the following:

- Find out about the Altogether Autism service, its development to date and meet some of the team
- Feedback issues and gaps in services
- Raise awareness about Autism Spectrum Disorders
- Network with others and make connections

Cost: No charge

Please RSVP to your local Regional Coordinator

To receive announcements for Altogether Autism meetings/seminars please subscribe by visiting:
www.altogetherautism.org.nz

Date	Region
14 February	Southland (Gore)
February (TBC)	Wellington (Upper Hutt)
March (TBC)	Northland (Kaitaia)
21 March	Nelson
27 March	Gisborne
May (TBC)	Wellington (Central)
4 May	Westport
8 May	Manawatu (Palmerston North)
10 May	Auckland (Central)
23 May	Otago (Dunedin)
16 June	Bay of Plenty (Tauranga)

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