

Autism Spectrum Disorder Newsletter

October 2009

This newsletter brings together information about the progress being made to improve autism services for people in New Zealand from some of the key groups who have been involved. It updates the information that was provided in the June 2009 newsletter.

This newsletter focuses on activities that are coordinated nationally. We have no doubt that there are many local or regional activities that are helping to implement the guideline and we would love to hear about them. If you have been involved in a project or activity that helps to implement the NZ ASD Guideline and you would like to share that experience, then please let us know. You can contact the New Zealand Guidelines Group (NZGG) through asd@nzgg.org.nz.

You can use the same email address to ask questions in relation to any of the projects outlined below.

Implementation Priorities

The Ministries of Health and Education agreed a set of priorities for the next three years of NZ ASD Guideline implementation. They made this decision after discussions with the ASD Implementation Advisory Group, the ASD Inter-sectoral Advisory Group, and a group of senior officials from a range of government departments.

The priority areas are (not in any particular order):

1. Assessment and diagnosis
2. Support to strengthen families
3. Interventions
4. Respite
5. Coordination.

The next parts of this newsletter provide updates on the projects that are underway in each of these areas.

Assessment and Diagnosis

There are five projects currently underway in this topic area. They are:

1. Development of a series of resources (including a handbook) for recognition and referral of suspected ASD, to be used by education and health and disability practitioners.

- *Leading organisation:* NZGG, supported by an expert reference group.
- *Goals:*
 - a. To provide education, health and disability practitioners with a cut-down version of the NZ ASD Guideline, targeted at them, and focused on recognition and referral of suspected ASD. This should assist with improved diagnosis and improved timeliness of diagnosis
 - b. To provide options for the dissemination of the resources

- c. To review the validity and availability of diagnostic tools that can improve the quality and comprehensiveness of diagnosis.
- *Links to NZ ASD Guideline Recommendations:* All recommendations from Part One of the NZ ASD Guideline. Also 2.3.02 – 2.3.15, and the sections of Part 6 that relate to specialists, and relevant recommendations from Parts 7 and 8 relating to the involvement of Maori and Pacific carers in the assessment process.
- *Status:* Content for the resources has been completed. The paper describing options for its promulgation has been completed. The paper that reviewed the validity and availability of diagnostic tools has been drafted.
- *When can you expect to see something from the work?* The Ministries of Health and Education are interested in making the resources readily available online, potentially with summaries provided in hardcopy. They are also interested in an ongoing and wide communication exercise. NZGG is in discussions with a programme in the Bay of Plenty to provide a hands-on test of the resources as well. All of these activities will occur over the next year. The launch of the resources on the website will occur in early 2010.

2. Development of training materials for specialists in the assessment, treatment and management of ASD.

- *Leading organisation:* Werry Centre, supported by an external reference group.
- *Goal:* to develop a training resource for specialists (paediatricians, psychiatrists, clinical psychologists & educational psychologists) in the assessment, treatment and clinical management of ASD for young people aged between 0 and 19.
- *Links to NZ ASD Guideline Recommendations:* All recommendations from Parts One and Four of the NZ ASD Guideline, the sections of Part 6 that relate to specialists, and relevant recommendations from Parts 7 and 8 relating to the involvement of Maori and Pacific carers in the assessment process.
- *Status:* The Specialist training package has been completed and submitted to the Ministries of Health and Education. NZGG and the Ministry of Health are in discussions with a programme taking place in the Bay of Plenty for them to test aspects of the training.
- *When can you expect to see something from the work?* The final draft of Specialist training package is completed. An implementation plan will be established so that the training can commence.

3. Review/ Revision of core Needs Assessment and Service Coordination (NASC) Standards, Protocols, Guidelines and Practice Resources

- *Leading organisation:* Needs Assessment Service Coordination Association Incorporated (NASCA).
- *Goal:* To enhance NASC practice through reviewing and updating its existing standards and guidelines and good practice resources.
- *Links to NZ ASD Guideline Recommendations:* Broadly takes into consideration all parts of the NZ ASD Guideline
- *Status:* The project is nearly completed. A review of the key NASC documents has been completed and an Implementation Report outlining recommendations has been drafted. The findings in the Review and Implementation Report were guided by input from NASC managers and two consumer workshops.

- *When can you expect to see something from the work:* A final draft of the revised NASC Standards and Guidelines and an Implementation Report will be completed for the Ministry of Health's consideration by the end of September 2009.

4. ASD Specific Guideline for NASCs

- *Leading organisation:* NASCA.
- *Goal:* To develop a new ASD-specific Guideline for NASCs.
- *Links to NZ ASD Guideline Recommendations:* Part 1 (overview recommendations 1 &2), Part 2 (overview recommendations 1,2,3,4,5,9,11,12), Part 3 (overview recommendations 1,2,6 &11), Part 4 (overview recommendations 1,3,&5), Part 5 (overview recommendations 1,2,3,4,5 7,9,10,11) and generally Parts 7 and 8.
- *Status:* The project has nearly completed. The NASC ASD Guideline was developed with input from consumer representatives and NASC managers. A draft version has been developed and is in the process of being finalised.
- *When can you expect to see something from the work:* An interim version of the NASC ASD Guideline will be completed by the end of October 2009.

5. Development of NASC Resources

- *Leading organisation:* NASCA.
- *Goal:* To develop new resources and tools to support the revised NASC Standards/ Guidelines and ASD-specific Guideline for NASCs.
- *Links to NZ ASD Guideline Recommendations:* Part 1 (overview recommendations 1 &2), Part 2 (overview recommendations 1,2,3,4,5,9,11,12), Part 3 (overview recommendations 1,2,6 &11), Part 4 (overview recommendations 1,3,&5), Part 5 (overview recommendations 1,2,3,4,5 7,9,10,11) and generally Parts 7 and 8.
- *Status:* Project well underway. This project is working in parallel with the development of the NASC ASD Guideline, as the resources will need to support the NASC ASD Guideline. The resources have been developed through workshops with consumers, NASC managers and NASC staff.
- *When can you expect to see something from the work:* Resources will be developed by November 2009. Training for NASC staff in the new NASC ASD Resources will commence in November 2009.

Support to Strengthen Families

There are five projects currently underway in this topic area. They are:

1. Improving information and advisory services

- *Leading organisation:* Altogether Autism.
- *Goal:* To ensure that that NZ ASD Guideline and its messages and recommendations are widely distributed amongst the ASD community.
- *Links to NZ ASD Guideline Recommendations:* 2.2.1, 2.2.3, and the recommendations from Parts 7 and 8 relating to the language-appropriate information provision.
- *Status:* Altogether Autism has been funded to support communication of the NZ ASD Guideline. Activities undertaken include:

- a. Website development, which includes a link to the ASD Guideline from the home page: www.altogetherautism.org.nz
- b. Targeted media follow-up
- c. Developing promotional packs for stakeholders – these are sent out as requests come in. Instructions for ordering are available at <http://www.altogetherautism.org.nz/page/66-NZ-ASD-Guideline+Downloads-and-Orders#Order%20a%20promotional%20pack>
- d. Identifying conferences for communicating the NZ ASD Guideline
- e. Library development – this is fully operational, accessed from 0800 273 463
- f. One off training for professionals - 38 participants recently completed training in the ADI-R diagnostic tool
- g. Evaluating the reach and effectiveness of the NZ ASD Guideline distribution – over 13,000 full guidelines and summaries distributed, and Altogether Autism have recently conducted a survey on the effectiveness of this distribution
- h. Pod casts are being developed for the website which will soon include audio and video files for download of lectures and talks undertaken for Altogether Autism. Pod casts will also include people's experiences of living with autism. These will be accessed from the Altogether Autism.

2. Parent Education

- *Leading organisations:* Ministry of Health, Ministry of Education.
- *Goal:* To provide quality-driven parent education programmes that will improve parents' knowledge of the impact of ASD. Focused on parents of young children (i.e. before the child starts school), the programmes are expected to enhance parents' ability and confidence to support their children to communicate, manage themselves and interact socially.
- *Links to NZ ASD Guideline Recommendations:* 2.2.1, 2.2.2 and 2.2.3, plus detailed information on pages 71 and 72.
- *Status:* Currently, the Ministries of Health and Education jointly purchase EarlyBird from Autism NZ. The Ministries have been running an open procurement process from November 2008 until the present.
- *When can you expect to see something from the work?* Contracts for parent education are being finalised and services will be established before the end of 2009.

3. 'tips for autism'

- *Leading organisation:* Ministry of Education and Ministry of Health.
- *Goal:* To extend the reach of the 'tips for autism' programme through funding additional programmes and additional facilitators.
- *Links to NZ ASD Guideline Recommendations:* Overview 2.1, 6.6, 6.8; Part 4, 4.3.3; Part 6: 6.17.
- *Status:* 'tips for autism' provides teams of parents, carers and school teachers with practical knowledge and skills to support children with ASD who are between the ages of 5 and 12. Each team completes a comprehensive long term plan and short term goals which they can action the day after the course ends. 'tips for autism' was written for the New Zealand context and is regularly updated to reflect new evidence and changing policies. From June –

September 2009, 11 'tips for autism' courses have been run: Hawkes Bay, central Auckland, Christchurch, Stratford (Taranaki), Hamilton, Nelson, Whangarei, Tauranga, Wanaka (Central Otago), Taumaurunui, and Rotorua.

- *When can you expect to see something from the work?* 'tips for autism' courses take place in the second half of Term One through to the end of Term Three. Expressions of Interest are currently being accepted for courses in 2010. Further information and Expression of Interest forms are available at www.tipsforautism.org.nz.

4. SPELL evaluation

- *Leading organisation/s:* Ministry of Health.
- *Goal:* To evaluate the success of the SPELL programme. This will inform the Ministry of Health as it determines whether or not to continue funding the programme.
- *Links to NZ ASD Guideline Recommendations:* 2.2.1.
- *Status:* The evaluation has been completed and is under consideration by the Ministry of Health.
- *When can you expect to see something from the work?* A draft of the report has been submitted to the Ministry. The Senior Officials Group has met to consider the SPELL evaluation recommendations. Autism NZ continues to provide this education programme while relevant consultation occurs.

5. Bright Sparks: Programme Enhancements

- *Leading organisation/s:* Autism New Zealand (Auckland Branch), Ministry of Health.
- *Goal:* To build on the positive evaluation of Bright Sparks, an Auckland community-based recreational based programme for children with ASD, by further developing and documenting the programme.
- *Links to NZ ASD Guideline Recommendations:* Part 5 of the Guideline, 5.2.1-5.2.8.
- *Status:* Following the evaluation of Bright Sparks, the Ministry has contributed one-off funding to respond to recommendations contained within the report.
 - a. Work is continuing on programme enhancements with the current focus on the access of the programme to Maori and Pacific children and young people and their whānau and aiga. Additionally, Autism NZ is documenting its model, so as to make it possible that it can be replicated in other parts of the country.
- *When can you expect to see something from the work?* Autism NZ has submitted a draft model description and is now finalising it following feedback.

Interventions

There are three projects currently underway in this topic area. They are:

1. Family/Whānau community outreach services

- *Leading organisation:* Ministry of Health.
- *Goal:* To provide ASD-specific family and whānau community outreach services to the ASD community in Auckland.

- *Links to NZ ASD Guideline Recommendations:* 1.1.1, 1.4.6, 1.4.7, 1.4.9.
- *Status:* The Ministry of Health has negotiated a contract with Autism New Zealand. Autism New Zealand will delegate responsibility to Ohomairangi Trust and the Auckland Branch of Autism New Zealand, to work as partners in the delivery of the new service.
- *When can you expect to see something from the work?* The new service is established and is now accepting referrals.

2. ASD-specific communication and behaviour support services

- *Leading organisation:* Ministry of Health.
- *Goal:* To provide ASD-specific communication and behaviour support services to the ASD community in Auckland.
- *Links to NZ ASD Guideline Recommendations:* 4.3.2, 4.3.4, 4.3.5.
- *Status:* The Ministry of Health has contracted IDEA Services for this contract.
- *When can you expect to see something from the work?* The contract commences from the 14th September and IDEA Services are in the establishment phase and are receiving referrals.

3. Assessment of the feasibility of having ASD-specific behaviour support services

- *Leading organisations:* Bennett & Bijoux Ltd, Ministry of Health.
- *Goal:* To assess the feasibility, in the New Zealand context, of having behaviour support services that are developed specifically for people with lived experience of ASD.
- *Links to NZ ASD Guideline Recommendations:* 4.3.7.
- *Status:* The report has been completed and is under consideration by the Ministry. It will be presented to the Implementation Advisory Group at its October meeting.
- *When can you expect to see something from the work?* Decisions on any new funding for new services will be made before December 2009.

Respite

There are two projects currently underway in this topic area. They are:

1. Extending disability respite services

- *Leading organisation:* Ministry of Health.
- *Goal:* To increase access to respite services.
- *Links to NZ ASD Guideline Recommendations:* 5.2.6.
- *Status:* In progress.
- *When can you expect to see something from the work?* The Ministry has now signed contracts for the five following services:
 - a. Waikato service for people 17 years of age and over with an intellectual disability and/or ASD - Spectrum Care Trust
 - b. Bay of Plenty/Lakes (to be located in Tauranga) service for people 17 years of age and over with an intellectual disability and/or ASD - Spectrum Care Trust

- c. Bay of Plenty/Lakes (to be located in Tauranga) service for people under 17 years of age with an intellectual disability and/or ASD - The Open Home Foundation
- d. Hawke's Bay service for people under 17 years of age with an intellectual disability and/or ASD - The Open Home Foundation
- e. Wellington service for people under 17 years of age with an intellectual disability and/or ASD - The Open Home Foundation

These services are currently in set-up phase. Purchasing of respite services is not complete and contracts for the provision of other services should be signed in other areas in the future. Respite, and the development of models that meet the needs of families, continues to be an important area of priority.

2. Describing ASD-specific respite services

- *Leading organisations:* NZGG, Acqumen Ltd supported by the Implementation Advisory Group.
- *Goal:* To describe ASD-specific respite services.
- *Links to NZ ASD Guideline Recommendations:* 5.2.1 – 5.2.8.
- *Status:* The paper has been completed and submitted to the Ministry of Health, along with a draft service specification that could be used in ongoing service developments for respite. The Ministry is now considering how to progress this, within the context of the overall increase in disability respite services.
- *When can you expect to see something from the work?* The Ministry is working with families to consider new models of service delivery that align with the paper submitted relating to ASD –specific respite services and meets the needs of families. At present a service trial is in place in the Auckland region, which includes respite as one component of wrap around service for high needs children. This is aimed at increasing the flexibility and choice for families.

Coordination

There are three projects currently underway in this topic area. They are:

1. Business case for DHB Developmental Coordination

- *Leading organisations:* New Zealand Guidelines Group, Ministry of Health.
- *Goal:* To develop a business case for allocating funding to DHBs that enable them to provide improved coordination across ASD-related services.
- *Links to NZ ASD Guideline Recommendations:* 1.2.9, 2.4.1- 2.4.4, 7.3.
- *Status:* The Ministry of Health is considering a regional approach and exploring the possibility of linking it with regional paediatric networks (the Paediatric Society and the Ministry of Health are exploring how these could be established). The funding will be focused on coordination for children and adolescents.
- *When can you expect to see something from the work?* Given the shift to exploring the possibility of linking with paediatric networks, the business case will be available to the Ministry later this year.

2. NASC ASD Coordination

- *Leading organisation/s:* NASCA.
- *Goals:*
 - a. To develop and establish a NASC ASD coordination function to support existing staff identify, plan and review packages of service/ supports required to meet the prioritised needs and goals
 - b. To improve knowledge skills, attitudes of NASC staff
 - c. To support NASC managers and team leaders
 - d. To improve linkages with and across existing disability support services.
- *Links to Guideline Recommendations:* Part 1 (1.1.01), Part 2 (2.3.14,) Part 3 (3.2.5.01, 3.1.08, 3.1.06, 3.4.05), Part 4 (4.1.01, 4.1.05), Part 5 (5.1.08, 5.1.14, 5.2.01, 5.2.06,) and generally Parts 7 and 8.
- *Status:* A NASC Coordination Function Report has been developed and a plan to implement the report's recommendations is being finalised. The report was developed with feedback from consumers and NASC staff.
- *When can you expect to see something from the work?* Implementation of the NASC ASD Coordination Function will commence in November 2009.

3. Review of interagency protocols (Equipment and Therapy) between Ministry of Education and Ministry of Health for school aged children

- *Leading organisation/s :* Ministries of Health and Education, Acqumen Ltd.
- *Goals:* To review the current Equipment and Therapy (physiotherapy and occupational therapy) protocols and make recommendations for revising the protocols within existing policy and resourcing. This includes:
 - a. achieving the best outcome for children and young people and their families/whanau
 - b. clarifying funding roles and service provision responsibilities
 - c. maximising cooperation between agencies
 - d. development of complementary roles and responsibilities
 - e. assisting families/whanau and fundholders in making appropriate referrals.
- *Links to NZ ASD Guideline Recommendations:*2.4.1- 2.4.4, 3.2.4.5, 4.1.1-4.1.5.
- *Status:* Following consultation with key stakeholders and families of students in four locations nationally and feedback from a questionnaire distributed to individuals and key organisations, the protocols are being updated into:
 - a. A Memorandum of Understanding
 - b. Therapy and Assistive technology/equipment Operational Guideline: Roles and Responsibilities.
- *When can you expect to see something from the work?* Once the revision is complete further work is required to scope how the above documents will be implemented.

Associated activity led by the Ministry of Education

In addition to the work that is led by the Ministry in the fields of parent education and teacher support (noted above), the Ministry is also leading the following projects in support of the NZ ASD Guideline:

1. Living Guideline

- *Leading organisation:* NZGG, Ministry of Education, supported by a Living Guideline Group.
- *Goal:* To ensure that the NZ ASD Guideline remains up-to-date and relevant as evidence changes. This process will not add new topics to the NZ ASD Guideline, but keep the current topics up to date. It will focus on areas where new evidence has emerged which warrants changing a NZ ASD Guideline recommendation. “New evidence” is research published since April 2004.
- *Links to NZ ASD Guideline Recommendations:* Not directly linked to any as this project is about ensuring that the recommendations remain derived from current evidence.
- *Status:* A Living Guideline Group has been convened and met in early June, chaired by Professor Ian Evans (with Matt Frost as the deputy-Chair). Its first job is to identify topics in the NZ ASD Guideline where the evidence has changed enough to possibly change a recommendation. Applied Behavioural Analysis (ABA) is one topic that is already confirmed. The Ministry of Education recently funded two literature reviews that can be considered in the living guideline process to determine if the evidence identified in the reviews requires changes in the current recommendations about ABA. NZGG are also critically appraising and synthesising evidence from relevant systematic reviews published since December 2007, when literature searches for the two literature reviews were completed, so that their evidence can also be considered the LGG.
- *When can you expect to see something from the work?* A meeting of the Living Guidelines Group to consider ABA will be held in November. The work plan beyond ABA will be determined once that process has been completed and evaluated.
- *Important points to note about what is happening:*
 - a. The living guideline process is a technical one. It is about considering whether evidence has changed enough to warrant a change in the guideline’s recommendations. Because it is a technical process, the Living Guideline Group is made up of people who have a good grasp of the evidence. The group is guided in its work by staff from the New Zealand Guidelines Group. These staff are experts in ensuring that technical experts are able to consider the evidence in a fair and transparent manner
 - b. If there is insufficient new evidence to warrant changing a current recommendation in the guideline, then it won’t be changed
 - c. The Living Guideline Group can suggest new recommendations if the evidence supports it
 - d. Any new recommendations will not automatically attract funding to implement them. This is the case for all of the recommendations in the guideline, and is why a prioritisation process has already occurred to fund the current implementation projects
 - e. As we receive questions on the living guideline process, so we will provide answers in this section of the newsletter
 - f. New Zealand Guidelines Group published an article on the living guideline process in its electronic bulletin. You can access it

http://www.nzgg.org.nz/index.cfm?fuseaction=fuseaction_17&windowmode_2009_change=open# (click on archived issues, 2009).

2. Education ASD Action Plan

- *Leading organisation:* Ministry of Education.
- *Goal:* To develop a coordinated national plan for professional learning and development, including establishing a network of 'Go To' people who will take a leading role in providing evidence-based support and current information.
- *Links to NZ ASD Guideline Recommendations:* 6.6, 6.7, 6.9-6.14, 6.16-6.25, 6.27.
- *Status:* The plan has been drafted and consultation is underway. The draft plan stresses the need for activities to be connected and coherent and affirms that everyone has a role to play in supporting children and young people with ASD to learn, achieve and contribute to society, and outlines support for these roles.
- *When can you expect to see something from the work?* Work on developing resources is underway, while consultation continues. It is hoped that regional roles will be agreed by November 2009.

3. Early Intervention ASD Project

- *Leading organisation:* Ministry of Education.
- *Goals:* Exploring the use of the Social Communication, Emotional Regulation and Transactional Support (SCERTS) framework in early intervention in NZ. Specifically, during Phase Two (2009-2010), the goals are:
 - a. Improved outcomes for more children, families and whānau
 - b. SCERTS effectively adapted and operating in the NZ context
 - c. More staff with a wider range of skills in providing effective interventions for children with ASD, their families, whānau and education teams
 - d. Further refining an effective model for providing professional learning and development and sustaining effective practices
- *Links to NZ ASD Guideline Recommendations:* 3.1.1 – 3.1.12, 3.2.1.10, 3.2.2.1 – 3.2.2.7, 3.2.3.1 – 3.2.3.3, 3.2.4.1 – 3.2.4.5, 3.2.5.1 – 3.2.5.3, 6.6 – 6.7, 6.9 – 6.12, 6.16 – 6.23, and 6.27.
- *Status:* Phase Two (2009 – 2010) underway, involving thirteen teams across the country, 77 early intervention practitioners and at least 144 children, their families and whānau.
- *When can you expect to see something from the work?* The teams are currently working with children, families and early childhood education services. There is a website for the project – www.inclusive.org.nz/asdev (part of the website is restricted to participants in the project). As resources are developed by the teams, they will be added to the website.