

Autism Spectrum Disorder

June 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 March 2009 newsletter.

The last newsletter was structured by organisation. This newsletter is structured by the areas where progress is being made, and references the key parts of the New Zealand Autism Spectrum Disorder Guideline (NZ ASD Guideline) that are being worked on.

This newsletter focuses on activities that are coordinated nationally. But the NZ ASD Guideline belongs to everyone in the ASD community, and its implementation cannot rely on what is done nationally. Indeed, any implementation is in the end done by people in their local communities and families. 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 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 handbook for assessment and diagnosis for education and health specialists involved in performing assessments and making diagnoses**
 - *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 assessment and diagnosis
 - b. To provide options for the dissemination of the handbook

- c. To provide analysis of options available for tools that will assist the standardisation of assessments.
- *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:* The handbook has been drafted.
- *When can you expect to see something from the work?* The content should be completed by the end of June 2009. It will be accompanied by a paper that provides options for the distribution of the Handbook, which should occur prior to Christmas 2009.

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.
- *Goals:* 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 is in its final stages and currently being reviewed by the Ministries of Health and Education. Once the training package is finalised, further work will be required to scope how it will be implemented (delivered).
- *When can you expect to see something from the work?* The final draft of Specialist training package is expected by the end of June 2009. An implementation plan will then 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:* Project well underway. A review of the key NASC documents is underway. Workshops with NASC managers occurred in May and a stakeholder workshop is planned for June. The workshops aim to test out findings from the document review and gather feedback on issues. Further workshops will occur in late June to provide input to the development of the final report and implementation plan.
- *When can you expect to see something from the work:* A final draft of the revised NASC Standards and Guidelines is due in early July 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 Part 7 and 8.
- *Status:* The project has started. Peer review workshops with NASC managers occurred 21/22 May and a stakeholder workshop (with consumers and front line NASC staff) occurred on 29 May, with the aim of getting input into the design and development of the ASD-specific Guideline for NASCs.
- *When can you expect to see something from the work:* Finalised ASD-specific Guideline for NASCs will be completed by the end of June 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 Part 7 and 8.
- *Status:* Project well underway. This project is working in parallel with the development of the ASD-specific Guideline for NASCs, as the resources will need to support the ASD NASC Guideline. Peer review workshops with NASC managers occurred on 21/22 May. Valuable information on existing resources was gained as well as the need for robust tools and resources to assist in ensuring that the ASD NASC Guideline is implemented. A workshop with stakeholders (consumers and front line NASC staff) occurred on the 29 May with the aim of getting input to the design and development of the ASD Resources.
- *When can you expect to see something from the work:* Resources will be developed by mid July 2009. Training for NASC staff in the new NASC ASD Resources will commence in July 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.
- *Goals:* 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:

- i. Website development
- ii. Targeted media follow-up
- iii. Developing promotional packs for stakeholders
- iv. Identifying conferences for communicating the NZ ASD Guideline
- v. Distributing conference materials
- vi. Library development
- vii. One off training for professionals
- viii. Evaluating the reach and effectiveness of the NZ ASD Guideline distribution.

Additionally:

- i. 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.
- ii. Altogether Autism has developed a reference library accessible to the public.
- iii. Training for professionals using a tool called ADI-R is planned for August and September in Hamilton and Christchurch. Registrations have already been received.
- iv. In May a questionnaire has been sent to a sample population of the people who were sent the guideline for feedback on the guideline. The feedback will assist future communications and planning. Feedback from the survey will be analysed by the end of June. This will inform the Ministries of Health and Education about areas to target further distribution of the NZ ASD Guideline.

2. Parent Education

- *Leading organisations:* Ministry of Health, Ministry of Education.
- *Goals:* 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?* The process is expected to conclude with contract(s) with one or more providers by July 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. In 2009 (up until the end of May), 'tips for autism' has been delivered in 7 locations (in Manukau (Auckland), Porirua (Wellington), Invercargill, Gisborne, South Canterbury, Hawkes Bay and North Shore (Auckland)) with a further 11 courses planned (Auckland Central, Christchurch, Stratford (Taranaki), Hamilton, Nelson, Whangarei, Bulls (Manawatu), Central Otago, Taumaurunui, Rotorua and one location to be confirmed).
- *When can you expect to see something from the work?* It is happening right now. Further information and applications for the course are available at www.tipsforautism.org.nz.

4. SPELL evaluation

- *Leading organisation/s:* Kiwikiwi Research and Evaluation Services Ltd, 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. It will be finalised in June 2009. Decisions will be made following consultation with the Implementation Advisory Group and the cross sectoral Senior Officials Group. Autism NZ continues to provide this education programme.

5. Bright Sparks: Programme Enhancements

- *Leading organisation/s:* Autism New Zealand (Auckland Branch), Ministry of Health.
- *Goals:* To build on the positive evaluation of Bright Sparks 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; an Auckland community-based recreational based programme for children with ASD, the Ministry has contributed to one-off funding to respond to recommendations contained within the report.

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.

- *When can you expect to see something from the work?* The work remains on schedule for completion on 30 June 2009.

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 services will be available by August 2009.

2. ASD-specific communication and behaviour support services

- *Leading organisation:* Ministry of Health.
- *Goals:* 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 is negotiating this contract at present.
- *When can you expect to see something from the work?* The new services should be available prior to Christmas 2009.

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

- *Leading organisations:* Bennett & Bijoux Ltd, Ministry of Health.
- *Goals:* 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:* Bennett and Bijoux have this contract. They have established a Specialist Advisory Group to advise them with this work.
- *When can you expect to see something from the work?* The report will be presented to the Ministry in August/September 2009. Whatever steps are taken after that will depend on the findings of the report.

Respite

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

1. Extending disability respite services

- *Leading organisation:* Ministry of Health.

- *Goals:* 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:
 - Waikato service for people 17 years of age and over with an intellectual disability and/or ASD - Spectrum Care Trust
 - 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
 - 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
 - Hawke's Bay service for people under 17 years of age with an intellectual disability and/or ASD - The Open Home Foundation
 - 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. The purchase proposal process is not complete and contracts for the provision of other services may be signed in other areas in the future. Respite continues to be an important area of priority.

2. Describing ASD-specific respite services

- *Leading organisations:* New Zealand Guidelines Group, Acqumen Ltd supported by the Implementation Advisory Group.
- *Goals:* 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 any changes to respite services. 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?* As it is under consideration, it is difficult to forecast what will happen next. The Ministry should make decisions prior to Christmas 2009.

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.
- *Goals:* To develop new resources and tools to support the revised NASC Standards/ Guidelines and ASD-specific Guideline for NASC.
- *Links to NZ ASD Guideline Recommendations:* 1.2.9, 2.4.1- 2.4.4, 7.3.
- *Status:* The Ministry has conducted preliminary consultation with child development centres and with the ASD Implementation Advisory Group. As a result of this work, the

Ministry decided to complete a formal business case with options for how best to achieve the outcomes desired by the guideline. Work has commenced on this business case.

- *When can you expect to see something from the work?* The business case will be available to the Ministry by September 2009.

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 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 Part 7 and 8.
- *Status:* Project started. Initial concepts and approaches have been worked through with NASC managers at peer review workshops in late May. A stakeholder workshop (with consumers and front line NASC staff) occurred on 29 of May aimed at getting input to the design and development of the ASD Coordination Function.
- *When can you expect to see something from the work?* The ASD Coordination Function will be trialled from the end of June 2009 with the view of full implementation being completed by June 2010.

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? 30 June 2009. 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:* New Zealand Guidelines Group, 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 the evidence since 2004 has changed enough to warrant changing a NZ ASD Guideline recommendation.
- *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 put through the living guideline process to determine if the evidence identified in the reviews requires changes in the current recommendations about ABA.
- *When can you expect to see something from the work?* The work plan will be with the Ministry of Health at the end of June 2009. The next newsletter should contain more information about timeframes.

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?* Initial scoping of the associated and detailed work plan will be completed by 30 June 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?* 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.