

Autism Spectrum Disorder

March 2009

It is a year since the launch of the NZ Autism Spectrum Disorder (ASD) Guideline. Significant progress has been made to meet Richard Belton's (CEO of Autism New Zealand) challenge to 'make a difference' to all those who attended the launch of the Guideline. Richard proposed we meet to review progress within a year.

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, and their updates or links to updates are included in this newsletter.

These groups include:

- 1) Ministry of Health
- 2) Ministry of Education
- 3) New Zealand Guidelines Group and the Implementation Advisory Group
- 4) Altogether Autism
- 5) Autism New Zealand

1) News from the Ministry of Health

- Cabinet approved the ASD implementation plan and the Ministries of Health and Education have been working with the New Zealand Guidelines Group (NZGG) to purchase services to meet the requirements of the implementation plan within the broad priorities set by the Implementation Advisory Group (IAG).
- We are pleased to announce that the Ministry of Health has made progress against the implementation plan in the key areas for development. The key four areas include;
 - 1) Assessment and Diagnosis
 - 2) Support to strengthen families
 - 3) Interventions (including early intervention and behaviour support to strengthen families, and transitions)
 - 4) Respite

Improving co-ordination and developing the workforce flows through all of the above priorities.

The Technical Implementation Group, led by the New Zealand Guidelines Group have been contracted to support the implementation process in three key areas. These are:

- i. Working with the Implementation Advisory Group
- ii. The Living Guideline
- iii. Contributing to the management of the Implementation Plan

Working with the implementation advisory group

The Ministries of Health and Education continue to appreciate the work of the Implementation Advisory Group. Leadership from across the ASD sector was visible at the launch of the NZ (ASD) Guideline and the strength of this commitment has continued throughout.

The Living Guideline

- Living Guideline

The Ministry of Health and Ministry of Education have appointed the New Zealand Guidelines Group (NZGG) to help implement the recommendations in the guideline. Part of NZGG's work

includes putting in place a process for updating areas of the guideline which are no longer current. This process is called a "Living Guideline Process".

NZGG will get support by establishing a Living Guideline Working Group who will give advice on which areas of the guideline are no longer current. Any changes will be based on changes in evidence, as published in research literature.

Implementation Plan

This newsletter will highlight activities to date under the heading of the first phase of service development planned to implement this funding. This phase is called 'Scaling up existing, proven programmes and services'.

Planning is in progress to implement the second and third phases of the implementation plan in the following areas. These include;

- Bringing on stream new initiatives and embarking on 'investment' activities
- Delivering on the 'investment' activities, consolidating initiatives and incorporating measures to provide for sustainability

Scaling up existing, proven programmes and services

1) Assessment and Diagnosis

- Development of ASD Recognition, Referral and Diagnosis Handbook

The New Zealand Guidelines Group is developing a resource that focuses on recognition, referral and diagnosis of ASD. This resource will target a wide range of both specialist and generalist professionals and address all age groups. The delivery of the content of these resources is the 30 June 2009.

- Autism Spectrum Disorder Training package for Specialists

A complementary resource is being developed by the Werry Centre for Child and Adolescent Mental Health ("the Werry Centre") which will target specialists in both health and education sectors, will focus on 0-18 age group, and will include training on ongoing support and management of people with ASD (ie beyond initial diagnosis). They are well underway to completing a training package that includes assessment and diagnosis of ASD, treatment of ASD and clinical team leadership.

The training tool-kit is intended to inform specialists working in ASD, particularly child and adolescent psychiatrists, paediatricians, and clinical psychologists and educational psychologists about latest evidence as per the NZ ASD Guideline. The final draft is due to the Ministry of Health by 31 March 2009.

- Autism New Zealand contract for resources for Home and Community Support Providers

The Ministry of Health, through Disability Support Services (DSS) has contracted Autism New Zealand to scope, plan, and develop the Autism Spectrum Disorder (ASD) specific resources for ASD Home and Community Support Providers. Home and Community Support Providers contracted by the Ministry of Health, Disability Services, provide home based care and support to people with disabilities including those with ASD under the age of 65.

- Needs Assessment Service Co-ordination (NASC) ASD Service Enhancement Programme

The Association of Needs Assessment and Service Coordination Agencies New Zealand (NASCA NZ) has started managing 4 discrete projects within the ASD NASC Work programme.

The four specific projects aim to support and improve the efficiency, effectiveness and quality delivery of NASC organisations and, ultimately, improved support outcomes for people with ASD and their families, whanau, aiga and carers, as well as the community whom NASCs serve.

NASCA NZ is contracted to four individual projects to complete the following activities:
The four specific projects are;

- i. Review/revision of core NASC Standards, Protocols, Guidelines and Practice Resources
- ii. Development of a guideline specifically for Ministry contracted NASC to guide all aspects of their contracted and professional work with people with ASD and their families, whanau, aiga and carers
- iii. New resources and tools required to deliver NASC services based on the Development of ASD Specific Guideline for NASC and revised NASC Standards/Guidelines
- iv. Explore, propose for implementation, and evaluate innovative options to establish a NASC ASD coordination function to service Ministry of Health NASC throughout New Zealand.

For any further information please contact Adri Isbister at 0800 008 011

The diagram below visually depicts the range of work presently contracted to increase skills in recognition diagnosis and assessment of Autism Spectrum Disorder.

2008 / 2009

ASD Projects related to resource development and co-ordination roles within Implementation Plan	
Werry Centre	Resources assessment and diagnosis for specialists (0 – 19 years)
NZ Guidelines Group	Resource for allied health primary care on assessment & diagnosis
	Resources assessment and diagnosis for specialists (Adults)
Autism New Zealand	Scope, plan, and develop the Autism Spectrum Disorder (ASD) specific resources for ASD Service and Home and Community Support Providers.
NASCA	Review core NASC Standards and Protocols
	Develop ASD specific Guideline for NASC
	Develop NASC resources
	Development of a NASC ASD Coordination function

2) Support to strengthen families

- SPELL evaluation

One part of the implementation plan is to evaluate the SPELL training programme that is provided by Autism NZ. SPELL training gives families and carers the opportunity to further develop their understanding of ASD. Kiwikiwi Research and Evaluation Services have nearly completed this evaluation that is to be presented to the Ministry of Health and the final draft will be delivered in April 2009.

- Bright Sparks

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.

Further enhancements to the programme include a training programme for the induction and ongoing development of staff, quality and programme documentation and increasing the access of the programme to Maori and Pacific children and young people and their whanau and aiga. The work will be completed by 30 June 2009.

- 'tips for autism'

The Ministry of Health wishes to expand and enhance an existing, proven, professional learning and development programme already supported and funded by the Ministry of Education - 'tips for autism'.

'tips for autism' is a course where a team of people dedicates four days to developing interventions and plans to support their particular child with ASD. This programme is evidence-based, not prescriptive, and is based on facilitated learning rather than lecturing. There is plenty of opportunity for discussion and practical application of what is learned. Resource material is available at different levels and individualised to meet the needs of different children's strengths and interests.

- ASD-specific parent education: jointly purchased by the Ministries of Health and Education
Evidence cited in the NZ ASD Guideline shows that parents highly value parent education services. For nearly a decade, the Ministries of Health and Education have jointly contracted Autism NZ to provide ASD-specific parent education, using the EarlyBird programme developed in Britain. The ministries also funded an independent evaluation of EarlyBird. With the information from the NZ ASD Guideline, the evaluation and the requirements on government agencies to use open purchasing processes, the two ministries have sought proposals for the next stage in providing ASD-specific parent education that is a good fit with New Zealand's unique culture and geography. The new purchasing processes are underway and the ministries plan for the service(s) to be in place from 1 July 2009.

3) Interventions (including early intervention and behaviour support to strengthen families, and transitions)

- Feasibility Study for ASD specific Behaviour Support Services

Bennett and Bijoux are contracted to determine the feasibility of providing ASD-specific behaviour support services as they would apply in a New Zealand context. Bennett and Bijoux are working with a Specialist Advisory Group to support them to complete this contract by the end of June 2009.

- Auckland based Family and Whanau community outreach services

The Ministry of Health has tendered to provide this service on an ongoing basis. The service will be provided for individuals (0-21 years) with ASD and their families and whanau. The purpose of the service is to work alongside families to link with and access services and supports. The service also aims to improve access by Māori, Pacific and other cultural groups to ASD related services.

The Service provided will be in addition to needs assessment and service co-ordination (NASC) and the disability information and advisory services (DIAS). The key difference will be the emphasis on getting involved as early as possible and a higher intensity of service provided e.g. home visiting.

The Service will promote and actively encourage and facilitate cross sector and multi-disciplinary collaboration with children and young people referred to the service and their families.

- Auckland based ASD specific communication and behaviour services

One of the proven services is communication and behaviour support services for people with ASD. This service was piloted in the Auckland Region in 2005 and 2006 and evaluated by the Donald Beasley Institute with positive outcomes. The Ministry has tendered to purchase the service on an ongoing basis and contract negotiations are underway.

4) Respite

An investment of \$1 million per annum over the next three years is allocated from ASD implementation funding to contribute to the Ministry of Health requested proposals for new "out of family" respite services. The Ministry has now signed contracts for the five following services:

- i. Waikato service for people 17 years of age and over with an intellectual disability and/or ASD - Spectrum Care Trust
- ii. 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
- iii. 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
- iv. Hawke's Bay service for people under 17 years of age with an intellectual disability and/or ASD - The Open Home Foundation
- v. 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.

- Develop other respite models

The New Zealand Guidelines Group is working with the Implementation Advisory Group to deliver a report on the principles that should underpin ASD-specific respite models. This will be followed up with a service specification and request for proposal for services that would meet those principles.

2) Ministry of Education

As part of the Ministry of Education contribution to implementing the NZ ASD Guideline, a draft education ASD Action Plan is being developed. The Plan responds to recommendation 6.24 in the NZ ASD Guideline: "The development of a coordinated national plan for professional learning and development should be undertaken. This should include standards for professional learning and development and competencies for professional roles." It also addresses Guideline recommendations 6.6 - 6.7, 6.9 – 6.14, 6.16 - 6.23 and 6.27, as well as embarking on developing the information and resources which need to accompany professional learning and development.

The draft ASD Action Plan stresses the need for activities to be connected and coherent. It 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. Over the next few months, feedback on the draft Plan will be sought from people with ASD, parents, whānau and other educators, including the Implementation Advisory Group. In the meantime, existing commitments such as 'tips for autism' and the Early Intervention ASD Project continue to be expanded to reach more young people, their families, whānau and wider support teams.

3) New Zealand Guidelines Group and the Implementation Advisory Group

As written above, the New Zealand Guidelines Group (NZGG) and its consortium partners (Matthew Frost and Acqumen Ltd) are reasonably involved in administering aspects of guideline implementation. We:

- have administered a range of tender processes;
- are working on the assessment and diagnosis handbook (with an external reference group and Tanya Breen and Richard Belton)
- are starting up the living guideline process (sponsored by the Ministry of Education)

- working with the Implementation Advisory Group to consider the principles to underpin ASD-specific respite services and the feasibility of ASD-specific behaviour support services (building off the work to be completed by Bennett and Bijoux Ltd).

For more information, please follow this link to a letter from the Chair of the Implementation Advisory Group, Matt Frost.

<http://www.nzgg.org.nz/download/files/ASDTechnicalInformationService-2.pdf>

4) Altogether Autism

Altogether Autism is busy ensuring a comprehensive specialist information service is being delivered nation wide. The first year of service delivery has brought its challenges. Numbers accessing the service in many cases more than doubled. The point of difference in this specialist information service is the access to a professional expert group led by Tanya Breen. This ensures quality information and specialist contribution to regional meetings and information on the web site.

LIFE Unlimited and Parent to Parent, the organisations partnered to provide the information service Altogether Autism, have been strategically planning regarding regional positions for Altogether Autism. It is the intention to look at re modelling the regional service; an innovative approach to re modelling is being announced at the end of March.

Actual statistics reveal

	1 July –31 Dec 07	1 July – 31 Dec 08	Difference
Number of pamphlets distributed	7500	8881	1381
Number of requests for information (face to face)	3	369	366
Number of requests for information (email, fax, telephone)	56	1120	1064
Number of seminars held	20	97	77