

Altogether Autism

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Outline

- Development
 - Public Meetings
 - Primary tasks
- Structure
- Relationship with Autism New Zealand
- Services provided
 - How, where & what
 - Some data
- Information requests
 - standard
 - complex
 - professional expert group
- Customer satisfaction
- Other involvement
- Work in progress
- Question time

Development

- Need for Disability Information Advisory Service (DIAS) identified in 2006
- Joint proposal made by Parent to Parent and LIFE Unlimited in late 2006 & early 2007
- Contract signed July 2007
- Public meetings in 17 locations July - August 2007, over 800 participants
- Established 1 October 2007

Public Meetings

- Purpose of meetings:
 - to inform people about the new DIAS
 - to connect with community
 - identify information & advice needs of community
- General concerns
 - service duplication
 - lack of services
 - lack of funding
 - needs of Maori & other ethnic groups

Primary Tasks

- To provide information & advice to people with ASD, their families/whanau, & the wider community
- Project work as contracted with Ministry

Relationship with Autism NZ

- Regular meeting at CEO & President level
- Memorandum of Understanding 22/2/08
- Work collaboratively & in good faith
- Refer to each other
- Priority: strategic goals NZ Disability Strategy



Structure

- Management & Administration Teams - Hamilton
- National Administrator - Hamilton
- Clinical Consultant - Hamilton
- Professional Expert Group - all through NZ
- Matching & Information Team - Hamilton
- ASD Advisors - all through NZ

Where are the services?

- At the end of your telephone
- On your computer (e-mail, internet)
- Offices throughout New Zealand
- In your regional centres (network meetings)
- In homes, schools or workplaces (as required)
- At national level

At the end of your telephone

- 0800 or local calls
- Advisors respond to information requests (process outlined next slide)
 - local services
 - general information
 - support parents
 - complex issues



On your computer

- Service providers (with guidance)
- Useful resources (e.g. general ASD information, NZ ASD Guideline, FAQ)
- Links & calendar of events
- Currently being updated



Offices throughout NZ

- Northland, Auckland, Waikato, Bay of Plenty, Lakeland, Gisborne, Hawkes Bay, Manawatu, Wellington
- Nelson, West Coast, Canterbury, Otago, Southland



In your regional centres

- Regional network group meetings twice yearly
- Update on activities
- Guest speakers
- Share information on local services & issues
- Feedback to MoH



Within your roopu

- Hui in Auckland, Bay of Plenty, Nelson & Waikato
- More planned
- Facilitated by Barry Kiwara (Maori Services Manager, LIFE Unlimited)



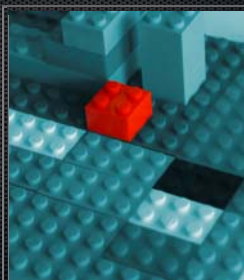
Home, school, workplace

- More resources needed to provide this
- Advisors work part-time
- Not routine, but as negotiated



At national level

- Dissemination of guideline & resources
- NZ ASD Guideline Implementation Advisory Group
- Conference presentations on Altogether Autism & the NZ ASD Guideline



Some data

	2nd half 2007	1st half 2008
Pamphlets sent	7,500	10,337
Information requests	59	675
Seminars held	20	90
Newsletters sent	650	1569

Information requests

- Taken by advisors
- Logged into "Matching & Information" database
- Local information managed locally
- National, general & complex information sent managed by M&I team
- Information collected (database & internet search)
- Complex requests sent to Clinical Consultant & Professional Expert Group
- Information collated and pack sent out

Standard requests

- Local services
- Network opportunities
- What is ASD?
- Sources of diagnostic assessment for children
- Recommended reading



Sample of complex requests

- Information required on: programmes claiming to have a significant impact on or cure ASD, catatonia, cost effectiveness of ABA, various medications, dyslexia, stem cell research, casein-gluten free diet
- Clinical advice to other professionals on: diagnosis in adulthood, pica, medicine compliance, mental health
- Agencies wanting advice on staff training resources
- Responses must be evidence-based

Professional expert group

- Tanya Breen** Clinical Consultant
- Nic McKenzie** Speech language therapy
- Neville Blampied** Head of Dept of Psychology, University of Canterbury
- Associates
 - Muhammad Arshad, Consultant Psychiatrist
 - Paul Taylor, Paediatrician
 - Ian de Terte, Forensic Psychologist & Former Police Officer
- Ian Evans** Professor of Psychology, Massey University
- Philippa Clark** Developmental Paediatrician, Starship Children's Health
- Maria Booleris** Occupational Therapist
- Jenny Gibbs** Clinical Psychologist, Child Development Centre, Waikato DHB
- Peter W. Dowrick, ASD Lecturer & Researcher
- Oliver Mudford, Lecturer in Psychology & Applied Behaviour Analysis

Qualitative customer satisfaction survey

- Dec 2007 & June 2008
- Independent researcher
- 10% of customers contacted by telephone
- Randomly selected
- Ascertain perceptions & feelings about the service
- Results both times have been extremely positive
- But:
 - Response speed to information requests must improve
 - Website and provider database underused

Feedback from stakeholder groups

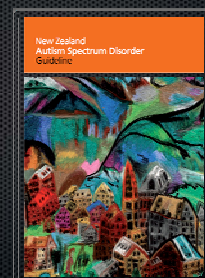
- June 2008
- Independent researcher
- One geographical area
- Questionnaires (31) disability organisations, family/whanau, health professionals, agencies
- 45% response rate
- 99% satisfied with staff contact
- 100% satisfied with information provision
- 92% satisfied with the organisation

Feedback from stakeholder groups

- What stakeholders want:
 - "one stop shop" for all ASD support needs (information, personal contact, respite care, training, community awareness)
 - strategic network plan for each region
 - register of respite carers
 - establish family support groups
 - provide targeted training

Other involvement

- Work with Ministry of Health
 - information packs
 - local presentations
 - national & international conferences
 - national media



Other involvement

- Two presentations to support Autism New Zealand in Autism Awareness Week
- Suggestibility
- Diagnosis in young people & adults
- Video-conference facilities



Work in progress

- Establishment of specialist ASD reference library
- FAQ & complex information on website
- Podcasts of presentations on website
- Links with international ASD organisations (e.g. virtual conferences)

Work in progress

- Training Autism Diagnostic Interview (ADI-R in September 2009)
- Training in Autism Diagnostic Observation Schedule (ADOS) to follow
- 0800ASD INFO



Conclusion

- On 1 October 2008 celebrated our 1st birthday
- It's been a challenging & rewarding year
- Our enthusiasm is strong
- We're looking forward to the next year, and more
- We invite you all to be involved!

Thank you for your
attention

Question time

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0800 ASD INFO (0800 273463)