Early Intervention for Children with Autism Spectrum Disorders:

Guidelines for Best Practice

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utism is a severe neurodevelopmental disorder beginning at birth or shortly after. The characteristic symptoms have been described as a triad of impairments involving delay and deviance in social and communication development, along with restricted interests and repetitive behaviours. The term Autism Spectrum Disorders (ASD) covers diagnostic labels which include Autistic Disorder, High Functioning Autism, Asperger Syndrome, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). Children with these labels all share the social and communicative symptoms which are the core of autism, but they vary in severity of symptoms and in level of functioning. No specific cause has yet been identified although there is evidence that autism may be inherited to a degree in some cases. To help children with autism it is essential to focus on the earliest years of development, since this is a critically important time for early learning which powerfully affects the child's future life course.

A review of early intervention (EI) services for children with autism was undertaken by the authors during 2006 for the Commonwealth Department of Health and Aging, to evaluate the evidence of the value of the available intervention programs. The review can be found on the DoHA website.

Roberts, J. M. A., & Prior, M. (2006).

A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Health and Ageing, Australia.

This booklet provides: a summary comment on research findings relating to early intervention for autism; an outline of the kinds of programs available in Australia; research and evidence based guidelines for best practice in early intervention; and a list of contacts for programs across Australia.

Evidence based treatment guidelines are particularly important in the field of autism where there has been so much debate, and where there are many heavily promoted approaches for which there is no scientific evidence, and which can even be harmful.

Intensive educational and behavioural interventions have produced positive outcomes for children with autism. There is little supporting evidence for other kinds of programs, or for medical or drug treatment. Some drugs may help in treating particular symptoms such as agitation and aggression in some children, but none can 'cure' autism. Many families are choosing to try a variety of alternative therapies, but there is no scientific evidence that any of these can make a significant difference. Information about biologically based interventions can be found in the review (Roberts and Prior, 2006). A summary of various kinds of educational and behavioural interventions is provided in the adjacent table.

Educational Interventions (see full table in the review document)

Type of program

Behavioural Interventions

Focus on application of learning theory and skill development. Use of Applied behaviour Analysis (ABA)

Developmental Interventions

Focus on building relationships and development of social emotional capacities. Example; Relationship Development Intervention (RDI)

Therapy based Interventions

Focus on communication and social development or sensory motor development. Usually designed for use with other interventions. Example; Picture Exchange Communication System (PECS), Auditory Integration Training (AIT).

Combined Interventions

Incorporate behavioural and developmental strategies. Often include sensory issues. Focus on working with and managing the characteristics of autism. Example; TEACCH (Treatment and Education of Autistic and related Communication handicapped CHildren)

Other Interventions

Example; Music Intervention Therapy

Family Based Interventions

Focus on working with families to develop skills in working with their children. Example; The Hanen Program

The most systematic evidence available has come from evaluations of intensive behaviour intervention programs, such as The Lovaas program which uses Applied Behaviour Analysis (ABA) including Discrete Trial Training (DTT). These evaluations have shown improved learning and behavioural development in a significant proportion of children. However these methods do not suit all children and families, and strict conditions of timing, intensity, and quality of therapist training influence the success of these methods. Other programs have so far not provided sufficient evidence of short or long term improvement to qualify for unreserved support.

Reviews of programs available internationally for children with autism are cautious in their conclusions about longer term outcomes for the children, in social, adaptive or vocational areas, or greater independence in adulthood. There are too few well controlled studies to allow for confident claims about what types of intervention are best for improving long term learning and adaptive functioning into adulthood.

We can define the key common elements which are necessary for effective intervention provides:

- An autism specific curriculum content focusing on attention, compliance, imitation, language, and social skills.
- Highly supportive teaching environments which deal with the need for predictability and routine, and with challenging behaviour, obsessions, and ritual behaviours.

- Support for children in their transition from the preschool classroom.
- Support for family members including partnership with professionals involved in treatments.

Number of hours of treatment per week

To be successful EI needs to be extensive and intensive. A minimum of 20 hours a week over two or more years is essential for young children to make major gains.

Individual Variation

It is important to account for the whole spectrum of autism disorders and to recognise that no one child with autism will have the same pattern of strengths and needs as another. In addition, families differ in their goals, strengths, and needs.

Hence, no one program will suit all children with autism and their families. There are benefits from early, intensive, family-based treatment programs, so long as these are adapted to the child's pattern of strengths and weaknesses and take account of family circumstances

BEST PRACTICE GUIDELINES

Reference to the guidelines presented here will help parents, carers and professionals to judge the value of programs for children with autism.

It is not our role to recommend any specific program. We provide a set of guidelines to interventions of value, which can help in decision making about the suitability of any program on offer for children with autism.

Recommendations for best practice in Early Intervention

i) Preparation

All children on entering intervention programs should have had a comprehensive, multidisciplinary diagnostic assessment from an interdisciplinary team of experienced clinicians and based on national and internationally agreed criteria. Diagnostic evaluations should include;

- interviews with parents/care givers to review the child's developmental history, family history, previous assessments and interventions;
- collection of information from all professionals involved in the care of the child;
- paediatric, psychological, and speech pathology examinations to assess communication, relevant health conditions including motor skills, vision, and hearing, and any associated problems such as intellectual disability and anxiety.

Direct observation of the child is important in the assessment of cognitive, social, communicative (verbal & nonverbal), fine and gross motor, and adaptive functioning using both standardised tests and informal procedures. The assessment should detail the child and family strengths and areas of need, to guide the development of intervention and management plans. With very young children, re-assessment and review within a year is desirable, since behaviour may change and the effects of intervention need to be monitored.

Recommendations from the assessment, and implications for intervention support should be combined in a comprehensive written report presented to the family. Contact and consultation with potential intervention program providers needs to be part of this process. Entry to an intervention program should follow as soon as possible following the assessment and diagnostic evaluation.

ii) Timing

Intervention should begin as early as possible in the child's life, (optimally between 2 and 4 years).

iii) Process

All children should have an Individual Plan (IP), for their education, designed to best fit their needs and strengths, developed in consultation with parents, and reviewed and revised regularly in light of the child's progress and ongoing needs

iv) Intensity

A program needs to be of at least 20 hours per week over an extended period of at least two years, with continuing support into, and through the school age years.

v) Content and focus

Autism specific content including:

Teaching joint attention skills, play, and imitation skills.

Building functional communication skills through language and Alternative and Augmentative Communication (AAC) such as picture systems, gestures and signs.

Teaching social interaction skills in a supported environment.

Daily Living skills, e.g. toileting, washing hands, eating.

Management of sensory issues.

Generalization of learning strategies to new situations and with new people

Management of undesirable or challenging behaviours.

vi) Settings

Programs can be delivered in various settings, individually, and with peers. Both centre-based and individual/home-based interventions are valuable. Including typically developing peers for at least a part of the program is highly desirable but peer interaction needs to be supported.

vii) Program design and methods

A high degree of structure in the program is essential, i.e. well organized, regular and predictable, focused on specific objectives, and consistently managed.

A supportive teaching environment with modelling, prompting, praise, shaping, and generalization strategies will maximise learning.

Centre based programs require a low child/ staff ratio with a maximum of 2-4 children per adult.

viii) Problem behaviours

A functional approach to problem behaviours including positive behaviour support (PBS) which includes teaching alternative appropriate skills, and communication skills to replace the problem behaviours.

ix) Staffing

Teachers, therapists, and child-care personnel should be specifically trained in working with children with autism, and have knowledge and skills required for their special needs.

x) Family collaboration

Parents need information about autism and services, especially at key times like first diagnosis and school entry. Programs should include parent involvement, such as provision of support, counselling, and parent education to help the child with play, social, and communication skills development, and with management of challenging and repetitive behaviours.

Families are often in need of respite care, hence reliable provision for this service is essential to decrease family burden and stress.

xi) Associated therapies

Multidisciplinary collaborative teams including specialist support such as speech therapy, occupational therapy and counselling should be available as needed.

xii) Research and evaluation of program

Evaluation of treatment outcomes should be built into El programs using systematic assessment of the child's social, cognitive, and adaptive functioning before, during, and at the end of the program.

xiii) Transition

There should be systematic connection and integration between the early intervention program and the next stage for the child, whether it is transition to school or to another therapeutic or special educational setting. Parents, teachers and therapists need to collaborate in preparing the child for transition.

Interventions for Infants

Recognising and diagnosing autism before pre-school age has been uncommon until the last few years. But increasingly autism is being identified very early in development. It has been shown that diagnosis can be valid and reliable at 2 years of age, and signs can be recognisable and predictive of autism even from early in the second year of life. In future it is likely that autism will be diagnosed for

most children in the toddler age period (18 - 30 months). Very early therapeutic intervention is likely to improve developmental and adaptive outcomes so it will be necessary to develop, implement and evaluate interventions for this age group in Australia. Trials of interventions in the USA and UK are focusing on training parents to work with their very young children in the key areas of social responsiveness, attention skills, early communication skills, and interactive play.

Information families need. Families should ask for more than personal stories of treatment success when deciding which intervention programs would be safe and beneficial for their child. When considering a program for your child use the information provided in this booklet to determine the extent to which the program meets recommended guidelines.

INTERVENTION SERVICES FOR CHILDREN WITH AUTISM AND THEIR FAMILIES IN AUSTRALIA

Please note that while every effort was made to ensure this information is as accurate, up to date and comprehensive as possible, there may be services which are not included. See review for information about program costs, type, waiting times, staff training and more.

| Lead Agency | Program | Contact |
|--|--|--|
| ACT Department of Education and Training | Autism Intervention Units | (02) 6205 9198 |
| | Communication & Social Awareness Playgroups | |
| | Learning Support Units (Autism) | |
| | ASD consultancy and | |
| ASD Consultancy and Support Service | Support Service | (02) 6291 0425 |
| | The Social and | |
| | Friendship Skills Program | |
| Gay Von Ess, Autism Consultant & Special Educator | Consultancy services | 0413 776 922 |
| Therapy ACT | Autism Assessment and Family Support Team | (02) 6205 1274 |
| | ACT Department of Education and Training ASD Consultancy and Support Service Gay Von Ess, Autism Consultant & Special Educator | ACT Department of Education and Training AUTISM Intervention Units Communication & Social Awareness Playgroups Learning Support Units (Autism) ASD Consultancy and Support Service The Social and Friendship Skills Program Consultancy services Therapy ACT Autism Intervention Units Communication & Social Awareness Playgroups Learning Support Units (Autism) ASD consultancy and Support Service The Social and Friendship Skills Program Consultancy services Autism Intervention Units |

Continued on page 7

| State | Lead Agency | Program | Contact |
|-------|---|---|----------------|
| | | ASPECT Schools for Children with Autism | |
| | Autism Spectrum Australia (ASPECT) | Building Blocks Early Intervention Services | |
| | | Behaviour Intervention Service | |
| | | Central Coast School Early Intervention Service | (02) 8977 8300 |
| | | Jigsaw Program | |
| | \ | "Recipe for Success" Parent/Carer Training Program | |
| | | School Outreach Service (SOS) | |
| | Autism Behavioural Intervention NSW | Behaviour Support Program | 0438 074 604 |
| NSW | Connect Therapy | Connect Therapy | 0402 119 319 |
| | Centre for Autism and Related Disorders (CARD) | Centre for Autism and Related Disorders (CARD) | (02) 9763 5466 |
| | First Chance: The University of Newcastle | Early Childhood Intervention | (02) 4921 5000 |
| | Ciant Stone | Early Learning | (02) 0070 4074 |
| | Giant Steps | Play Steps | (02) 9879 4971 |
| | Hunter Prelude | Hunter Prelude Early Intervention | (02) 4937 4549 |
| | Koorana Child and Family Centre | Supported Playgroups | |
| | | Home Based Early Intervention | (02) 9750 4100 |
| | | Inclusion Support Program | |
| | | Preschool Preparation Group | |

| State | Lead Agency | Program | Contact |
|-------|--|--|------------------|
| | Learning Links | Let's Play | (02) 9534 1710 |
| | | Early Starter's Program | |
| | | Learning Links Preschool | . (02) 9534 1710 |
| | | Linking with Pre-School Program | |
| | | Parents experiencing children with autism | |
| | | The Hanen Program: More Than Words | |
| | Lifestart Cooperative Ltd | Various Programs throughout Sydney | (02) 9807 9700 |
| NSW | Lizard Children's Centre | Lizard Children's Centre | (02) 9428 2467 |
| | Mission Australia | Macarthur Early Childhoold Intervention Service | (02) 9641 5000 |
| | Pathway Early Childhood Intervention Service | Pathway Early Childhood Intervention Services | (02) 9572 8840 |
| | Relationship Development Intervention (RDI) | Relationship Development Intervention (RDI) Program | (02) 9405 5833 |
| | Sound Therapy International | Sound Therapy for Children | 1300 55 77 96 |
| | Together Hand in Hand | Together Hand in Hand | |
| | Wisconsin Early Autism Project | Early Autism Project Pty Ltd | (02) 9310 7322 |
| | Woodbury School | Woodbury School | (02) 9639 6152 |
| ÓſĐ | Autism Behavioural Intervention Queensland | Autism Behavioural Intervention Queensland | (07) 3264 2582 |
| | Autism Early Intervention Outcomes Unit (AEIOU) | Autism Early Intervention Outcomes Unit (AEIOU) | (07) 3849 6099 |
| | Autism Intervention and Management Strategies | Applied Behavioural Analysis | 0402 854 390 |

| State | Lead Agency | Program | Contact |
|-------|---|--|-------------------------------|
| | Autism Queensland | ProAQtive Early Intervention Group Placement | (07) 3273 0000 |
| | | Early AQtion Programs + Advisory Visits | |
| QLD | Little Souls Taking Big Steps | Little Souls taking Big Steps | (07) 55 631 490 |
| | Minds and Hearts Clinic | Minds and Hearts Clinic | (07) 3844 9466 |
| | Symmetry Psychological Services | Intensive Home-Based Applied Behaviour and Verbal Behaviour Intervention Program | symetry.psych @bigpond.com |
| | | Diagnostic Services | |
| | Autism SA | The Early Development Program | (08) 8379 6976 |
| | | Family Support Program | |
| | Department of Education and Children's Services | The Briars Special Early Learning Centre | (08) 8365 9808 |
| SA | Pyramid Educational Consultants of Australia P/L | Pyramid Educational Consultants of Australia P/L | (08) 8240 3811 |
| | SASRAPID Inc | Aquatic Therapy for Children with Autism | (08) 8410 6999 |
| | School of Psychology, Flinders University | Early Intervention EI Reserach Program | (08) 8201 5104 |
| TAS | Autism Behavioural Intervention Tasmania | Autism Behavioural Intervention Tasmania | (03) 6223 2317 |
| | Behavioural Intervention Services | Behavioural Intervention Services | 0409 557 958 |
| | Giant Steps | Giant Steps | (03) 6362 2522 |
| VIC | Autism Behavioural Intervention Association (ABIA) | Autism Behavioural Intervention Association (ABIA) | (03) 9830 0677 |
| | Integrated Education and Communication | Integrated Education and Communication | (03) 9893 5547 |
| | Irabina Childhood Autism Services | Irabina Childhood Autism Services | (03) 9720 1118 |

| State | Lead Agency | Program | Contact |
|-------|---|---|----------------|
| | Catawaya Sunnant Samilar | Barwon ECIS flexible packages program | (03) 5221 2984 |
| | Gateways Support Services | Gateways early childhood Intervention program | |
| / | Knox City Council | Illoura Early Childhood Intervention Services | (03) 9758 7991 |
| | Mansfield Autistic Centre & Travelling Teacher Service | Mansfield Autistic Centre & Travelling Teacher Service | (03) 5775 2876 |
| | Noah's Ark West | Noah's Ark West Autism Program | (03) 9304 7402 |
| VIC | Pam Langford Psychological Services | ABA or Intensive Behavioural Intervention Programs | (03) 9553 8808 |
| | Kalparrin ECI Program/Specialist Children's Services | Northern Autism Outreach Service | (03) 9435 8311 |
| | Southern Autistic School | Southern Autistic School | (03) 9563 8139 |
| \ | The Learning For Life Autism Centre Inc. | The Learning For Life Autism Centre Inc. | (03) 9836 0422 |
| | Victorian ABA Providers Pty Ltd | Victorian ABA Providers Pty Ltd | (03) 5485 2036 |
| | WestArc – Autism Program | WestArc – Autism Program | (03) 9284 7267 |
| | Western Autistic School | Western Autistic School | (03) 9337 9175 |
| | Yooralla Society of Victoria + Broad Insight Group | Early Childhood Autism Services — Northern | (03) 9359 9366 |
| | Autism Association of Western Australia | Early Intervention Program | (08) 9489 8900 |
| | David J Leach | The Whole Behaviour Program | (08) 9456 2423 |
| WA | Department of Education and Training | Autism Units | (08) 9264 4111 |
| | Disability Services Commission | Mildred Creak Autism Team | (08) 9472 1608 |
| | Disability Services Commission | Individual and Family Support, Home Based Autism Service | (08) 9426 9200 |
| | ISADD | DSC funded program | (08) 9397 5970 |
| | | Private funded program | |

| State | Lead Agency | Program | Contact |
|-------|----------------------|--|----------------|
| | Kim Beazley School | Kim Beazley School ABA Program | (08) 9335 7933 |
| WA | Leaps and Bounds Inc | Leaps and Bounds Inc | (08) 9401 8119 |
| | Therapy Focus | Therapy Focus in Early Intervention | (08) 9478 9500 |

CONTACT INFORMATION FOR AUTISM ASSOCIATIONS IN AUSTRALIA

Autism Council of Australia

Head: Mr Mick Clark (President)
Phone: (02) 8977 8300 (Secretary)
Web: http://www.aspect.org.au/aca/

Autism Victoria

Head: Mrs Amanda Golding (CEO)

Phone: (03) 9885 0533

Email: admin@autismvictoria.org.au Web: http://www.autismvictoria.org.au

Autism Association of South Australia

Head: Jon Martin (Executive Director)

Phone: (08) 8379 6976

Email: admin@autismsa.org.au

Web: http://www.autismsa.org.au/html/contact.html

Autism Spectrum Australia (ASPECT)

Head: Adrian Ford (CEO)
Phone: (02) 8977 8300

Email: contact@aspect.org.au

Web: http://www.aspect.org.au/contact/centraloffice.asp

Autism Association of Western Australia

Head: Mrs Joan McKenna Kerr (Executive Director)

Phone: (08) 9489 8900

Email: autismwa@autism.org.au Web: http://www.autism.org.au/

Autism Tasmania

Head: Penny Cromarty (President)

Rose Clark (Family Support Coordinator)

Phone: (03) 6423 2288

Email: autism@autismtas.org.au

Web: http://www.autismtas.org.au/oldsite/index.htm

Autism Northern Territory

Head: Alison Bird (Director)
Phone: (08) 8948 4424 (9-1pm)
Email: autismnt@bigpond.net.au

Autism Queensland

Head: Mrs Penny Beetson (CEO)

Phone: (07) 3273 0000

Email: tonic@autismqld.com.au Web: http://www.autismqld.asn.au/

Autism Asperger ACT

Head: Mrs Gaye Von Ess (President)
Phone: (02) 6290 1984 (c\-SHOUT)

Email: autismact@homemail.com.au or

 $asperger syndrome_act@assn.org.au$

Web: http://autism.anu.edu.au/ and

http://www.assn.org.au/

The full text of

A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders

by Jacqueline Roberts and Margot Prior

available on the website of the Australian Government Department of Health and Ageing

www.health.gov.au

(review includes this booklet both in abreviated and more comprehensive versions)