Early Interventions in Autism Spectrum Disorders (ASD)

Dr Natalie Silove
Developmental Paediatrician
Widely accepted that early intervention in ASD is both necessary and beneficial.

- the earlier the better, the more the better.

- ASD needs to be identified as early as possible and

- referred on to an appropriate service.
Under two years of age it can be difficult to distinguish between children with autism and non-autistic, non-verbal children who have significant cognitive impairments. In these circumstances time and surveillance may be necessary before the correct diagnosis becomes clear. This, however, should not delay the introduction of early intervention which should commence as early as possible.
If confused re diagnosis

- TREAT
- OBSERVE
- REVIEW
Available Therapies

- Behavioural/Educational
- Communication therapies
- Combined approaches/
  Comprehensive/Integrative Educational Approach
- Sensory/motor therapies
- Biological interventions
- Psychodynamic interventions
- Miscellaneous
Intensive Behavioural and Educational Intervention Programs

- Behaviour intervention is based on the idea that most behaviour is learnt through the interaction between an individual and the environment.
Behavioural modification methods: three general approaches

- Operant conditioning,
- Respondent (Pavlovian) conditioning and
- Cognitive approaches.
The theory therefore assumes that children can learn new skills by:

- Changing the stimulus (antecedent)
- Providing a consequence (reinforcer or adversive)
- Teaching skill development and alternatives providing more adaptive behaviour. While all behavioural therapies have some basic similarities, specific behavioural techniques may vary in several ways.
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Naturalistic versus Directive Approaches

- Directive approach is where the therapist controls all aspects of the intervention for eg. Discrete Trial Learning (see later).
- A naturalistic approach attempts to match the therapeutic setting, antecedents and consequences to the child’s natural environment.
- Most interventions include aspects of both approaches.
Directive Approach

eg Applied Behavioural Analysis (ABA).

- Lovaas (1987) described the first major study applying an intensive behavioural intervention program for young children with autism. The program involved 40 hours a week of direct intensive instruction by the therapist for at least two years. The goals in the first year being to reduced self-stimulatory and aggressive behaviours, improve compliance, teach imitation and extend intervention into the family. The goals in the second year emphasise teaching expressive and abstract language, interactive play with peers and extension of intervention into the community. The goals in the third year were to teach appropriate expression of emotion, pre-academics and observational learning.
ABA would involve some use of Discrete Trial Training (DTT). This involves four steps:

1) presentation of a brief clear instruction/question (by the therapist)
2) prompt if needed (visual pictures/hand sign)
3) response (from the child)
4) consequence-reward, if correct for eg. clapping, ignore if incorrect.
This original research was criticised for a number of reasons including the claims of cure, improvement in IQ, high financial cost and level of needed expertise, the use of adversives (for eg. slap on the thigh) and the inability to replicate the degree of improvements initially claimed in subsequent studies.
ABA

- Research supports that behavioural interventions have produced positive outcomes for children with autism.

- Currently there are a number of different ABA service providers in Australia and each has a slightly different mode of delivery. Most of the ABA service providers have adapted the original Lovaas programme and addressed many of these initial criticisms – but some have not and therefore caution is needed when choosing a service provider.
Important to find out the details of specific available programs eg. cost, time, commitment, the inclusion of ‘naturalistic’ setting, communication strategies used and then consider suitability for a specific family.
Naturalistic Approach (normalised intervention)

- This follows a developmental approach which is relationship based. Examples include Greenspan’s developmental individual-differences, relationship-based-model (DIR) more commonly known as ‘floor time’. (Greenspan 1998) In NSW this approach is used by Theraplay. More recently has emerged Relationship Development Intervention (RDI) (Gutstein 2000).
This is a term commonly used by therapists and parents. It usually includes a ‘functional assessment’ of the maladaptive behaviour (for eg. head banging). This involves gathering of information as to what the causes, communicative intent and outcome of the behaviour may be. This leads to the formulation of a positive behavioural support program where the child is systematically encouraged and taught a more adaptive, socially meaningful and acceptable behaviour to replace the mal adaptive one. This almost always should include teaching functional communication.
Communication Therapies

- Communication deficits are a core element defining autism. There is little evidence supporting the role of traditional speech therapy on its own in ASD. Rather, speech therapy has an important role as part of developing a functional communication system in the young child with ASD.
Alternate Augmentative Communication Systems (AAC)

- picture boards,
- visual aids,
- computers,
- hand-signing or
- voice activation devices.
There is evidence to suggest that these forms of AAC’s assist with the development of verbal expressive language and do not retard it. A speech therapist treating children with ASD should have the appropriate experience and facilities to provide and tailor make these AAC’s to the individual child’s ability and needs.
**Picture Exchange Communication System (PECS)**

- PECS is a program that teaches children to interact with others by exchanging a picture or real object for the desired object for eg. giving the parent a picture of a bottle of milk and the parent takes the bottle, says ‘milk’ and gives the child an bottle of milk. It is important to emphasise to parents when starting to use the system, to ensure they don’t have a picture of a trampoline for eg. when it is raining outside and they do not wish the child to go outside.
Social Stories

Social stories are used to explain social situations, emotions and to teach appropriate responses. They are developed according to the child’s immediate needs and level of understanding and ability. For the younger child this usually includes the use of pictures of the real objects, and then symbolic representation and their skills improve.
Combined/ Comprehensive/ Integrative Educational Approach

- **Building Blocks Early Intervention Service NSW:**
- A number of different service models (centre, outreach and homebased) are provided depending on the individual age, ability and circumstances. Approach used combines all available best practice models most suitable to the individual, with focus on skill building, family education and support and transition into the community. Services are provided from preschool to adulthood, but places are limited due to funding and therefore the waiting lists are long.
This is the programme most similar to the approach used by the Autism Association NSW. The major feature of the TEACCH approach is structure (e.g. schedules, visual timetables) and the environment is organised to help the child or adult to understand and remember what to do. The programme provides continuity of services from preschool to Adult life and has been in existence since 1972.
Biological Interventions

There is no medication that targets the core symptoms of Autism Spectrum Disorders.
Medication has an important but discrete role.

- It is used to target four main areas in individuals with ASD when they are impacting significantly on the individual’s ability to learn, make progress and get through their day.
- severe hyperactivity,
- obsessive ritualistic behaviours,
- challenging behaviours for eg. aggression and
- sleep disorders.
Medication should always be part of an individualised education plan, targeted at a specific behaviour and monitored appropriately.
Other biological interventions

- Eg. hormonal treatment (growth hormone and secretin), immunological agents (immunoglobulin), anti fungal medication and gluten and casein free diets remain extremely controversial. They are not generally accepted by the scientific community either because they have been shown to be ineffective or because they have been insufficiently evaluated.
Sensory/motor therapy

- Sensory integration therapy, touch therapy, occupational therapy and music therapy do not have sufficient evidence to allow recommendations as a primary intervention method for children with autism. However, many children with autism have significant sensory and motor impairments and therefore aspects of these therapies may be incorporated to develop a specific treatment plan. In this capacity an occupational therapist is an invaluable member of the early intervention team.
Other therapies such as auditory integration training have not been able to demonstrate any effectiveness over placebo.

Facilitated communication has been largely discredited.
The Option approach (Son-Rise program) - known in NSW as “Connect Therapy” is based on the theory that a child with autism experiences the world as confusing and distressing and hence attempts to shut it out. This then starves the brain of the stimuli needed to develop social interaction skills, thereby further increasing confusion and reinforcing the desire for isolation. The essential principal underlying treatment is to make social interactions pleasurable for the child. The approach emphasises the importance of acceptance and recognising that the children’s behaviours are not deviant or inappropriate, but an understandable reaction to the difficulties in making sense of more controlling their world (Howlin 1997). Staff and parents are taught the differences between wanting change (which is acceptable) and needing change in order to improve of the child (which is not). Every action of the child is accepted (although some extreme actions may be redirected or ignored). There is some research evidence to support some of the principles underlying this approach but the outcomes had not been evaluated.
Giant Steps

This program originated in Canada and has two Centre’s in Australia in Sydney NSW and Tasmania. Giant Steps uses a holistic overview integration sensory-motor theory with a behavioural approach. This program claims a 95% success rate in teaching children to speak within 3 years though there is no research to substantiate these claims.
Psychodynamic Treatment Management

- There is no role for holding therapy or theraplay
Family Support and Education

- Empowering parents and providing constructive realistic optimism about what parents can do rather than what they can’t do is absolutely essential in maintaining the well-being of the parent, the state of the marriage and in turn, the care of the child. There is unfortunately little evidence to support best practiced models on how to assist families. Most of the services available in Australia do provide some form of parent education formally or informally. There are a number of structured programs which are currently being evaluated.
NAS Early Bird Program

- originated in the UK and there is a franchise operating in New Zealand. It is a parent focussed rather than family focussed model of early intervention and combines group sessions with one on one support of a professional during home visits. Parental education includes understanding the underlying deficits (social, communication and restricted interests), learning effective ways of communicating with their child and understanding the functional role of a child’s maladaptive behaviours. The parents are then taught basic skills to meet some of these needs.
The Hanen Program

- *More Than Words* is an intensive training program for parents of preschool children. It includes interactive classes and in home video taping and coaching sessions. It is aimed at teaching the parents how to Facilitate language development and use it for functional purposes in the natural environment. This program is available in Australia via a number of service providers.
Parent focussed model early intervention developed by the Centre of Developmental Psychiatry and Psychology at Monash University, Melbourne (Brereton 2002). Results indicate that there is a significant improvement in the mental health of parents participating in the intervention versus the control groups.
Respite

- Respite may come in many different forms. It includes in home, centre based, day time or over night respite. Respite services may be offered by the local Department of Ageing Disability and Home Care, local non-Government agencies or most commonly by family and friends. It can also be relevant for siblings to have respite!
Financial Supports

- There is no Government supported program that provides a minimum of 20 hours per week of educational/behavioural and combined communication based approach together with family support and education in Australia. There is a massive discrepancy between demand and supply of these services resulting in significant levels of frustration for families and professionals. The onus therefore falls heavily on the families to put together an acceptable intervention program for their child, frequently needing to combine a number of different services to achieve this. Many families are experiencing the added frustration of being told that they cannot be on two waiting lists at any one particular time and that receiving a service from one agency would automatically deny them services from another. This is a dismal state of affairs and the doctors have an important role to try keep up to date with the current information, effectively pass this on to families and to provide constructive support wherever possible.

- This includes expediting application for financial support such as:
- Carers Allowance,
- Enhanced Primary Care Program (a new Medicare plan to provide families with 5 visits in total to allied health professionals) [www.hic.gov.au/providers/incentives_allowances/medicare_initiatives/allied_health.htm](http://www.hic.gov.au/providers/incentives_allowances/medicare_initiatives/allied_health.htm)
- Letters in support of accessing superannuation funds and encouraging the families to talk to their accountants regarding tax rebates.
Families should be cautioned about the immediate and long term consequences of going into debt to meet the high costs of some service providers who claim they are able to cure autism. Although it may be under difficult circumstances, it is usually possible to put together a reasonable early intervention program without plunging the parents into depth of financial despair.
SUMMARY POINTS:

- Early intervention makes a difference
- The earlier the better, the more the better
- 15-25 hours per week appears reasonable
- Combined approaches best (behavioural/communication/visual)
- Skills taught must be generalised (naturalised)
SUMMARY POINTS:

- Transition to school essential
- Family involvement and education vital
- Respite for parents, child and siblings
- Financial considerations
- Parental expectations and social circumstances to be considered
SUMMARY POINTS:

- Beware any program that claims cures!
- Support parents – it’s a maze of confusing information out there, with no gold standard treatment, limited services, no realistic cure, and parents are entitled to feel frustrated and angry. Sometimes just listening and being supportive will make a difference.
COMPARATIVE ANALYSIS OF EARLY INTERVENTION PROGRAMS FOR YOUNG CHILDREN WITH AUTISM

INVESTIGATORS

Prof Trevor Parmenter
Centre for Developmental Disability Studies
02 88 78 05 00

A/Prof David Evans
School of Development & Learning, University of Sydney
02 9351 8463

Dr. Natalie Silove
Child Development Unit, The Children's Hospital Westmead
02 98452829

A/Prof Katrina Williams
Sydney Children's Hospital., University of NSW
02 9382 8183

Dr Mark Carter
Macquarie University Special Education Centre,
02 98507880
FUNDED

- ARC funding
- ASPECT Australia – main business partner
- “In Kind” CHW, Sydney/Macquarie University
The aims of the project are to:

- Assess the outcome of centre-based early intervention programs in terms of effectiveness and cost/benefit for children with autism and their families in comparison to a group of children receiving home-based program and to a group of children not receiving either program,

- Evaluate changes in parental skill and family functioning in families, and compare the difference between the three groups.
Background History

- Aspect (AANSW) offer BUILDING BLOCKS which consists of two EIP:
  - Starting Blocks – centre based
  - Early Play - home based
EIP programs – common components

- Parent education
- IEP – based on need
- Regular assess/review
- Assisting integration into mainstream preschool/natural settings
Interventions in common

- Combination of interventions
- 1:1 direct instruction
- Behav intervention
- Dev of functional communication systems
- Training in the use of visual supports
- Management of sensory issues
- Collaborative with families
STARTING BLOCKS

- Weekly centre based program – 2 ½ h
- Session for 6 children (special ed, speech OT volunteer), run simultaneously with
- parent training and information session (psychologist/social worker)
- Collaborative with CHW/CDU
EARLY PLAY PROGRAM

- Fortnightly home visit from a specialist team member
- 1:1 with the child
- Parent training /information on a needs basis
Who can participate in the study?

- Children aged 2.5 – 3.5 years, who are already on the waiting list for the Building Blocks Early Intervention Services from Aspect.
randomly assigned to either home-based or centre-based intervention programs for a twelve month period of intervention and parent training. 90 participants in each group.

Children on the Project will also be entitled to maintain any additional intervention services they are currently involved in or on the waiting list for.

Children on the waiting list for a Building Blocks program will act as the Control Group for the first year and then be allocated to an intervention (either centre-based or home-based) the following year.
ASSESSMENTS: centre based

- The *Griffith Mental Development Scales*

- *Autism Diagnostic Observation Schedule* (ADOS) – a measure to verify the diagnosis of Autistic Disorder/ASD/non - ASD

Home based


- *Pragmatics Profile of Everyday Communication Skills in Children* (Dewart & Summers, 1995) – an assessment of communication skills used by preschool and school aged students in everyday situations.
Parents to complete

- *Developmental Behaviour Checklist* (Einfeld & Tonge, 2002) – an assessment of behavioural and emotional outcomes, used often with young children diagnosed with autism

- The *Beach Center Family Quality of Life Scale* (Turnbull, Brown & Turnbull, 2004) - a questionnaire about life events and changes experienced by family members over the past year.

- The *Parenting Stress Index* (PSI short form) (Abidin, 1995) – a questionnaire about how families cope with managing and catering for a child with a disability.

- Parent Satisfaction Form – a questionnaire about your satisfaction with the services that you have received from ASPECT.
All assessors are:

- blinded to treatment groups
- previous diagnosis
- not involved with the early intervention program
Are there any benefits for my child participating in the study?

- There are a number of advantages to families participating in the study. Benefits include receiving a **range of comprehensive assessments to assess their child’s development over a twelve month period at no cost**. Assessments will be carried out by trained professionals including a psychologist and a speech pathologist to determine each child’s developmental skills both **pre and post intervention**. In addition, there will be **regular follow-up discussion** with parents to evaluate changes in parental perceptions of autism and how it impacts on their family life.
Subjects:

- Participation Group: 28 children:
  - home-based: 12
  - centre-based: 16

- Control Group: 12 children
Rate of Attrition:

- **Participation Group: 5 children**
  - T.A.: home-based: family issues and financial constraints - decided not to continue with BB
  - B.S.: home-based: has accepted a full-time school placement
  - T.P.: home-based: funding conflict and is ineligible for the program
  - D.K.: home-based: family decided they wanted centre-based BB - not eligible for research
  - C.E.: centre-based: timetable conflict - offered E.I. class at same time as group.

- **Control Group: 1 child**
  - L.L.: control group: offered place on the BB program
CHALLENGES

- Controlling for Variables in other intervention
- Control group not ideally randomised (ethical considerations)
- PLENTY OTHERS YET TO BE OVERCOME!!
THANKS TO:

- Dr Jacqueline Roberts – Speech Therapist, USyd, Research Coordinator
- Ms Sue Dodd – Masters in Special Education, Research Assistant
- Anthony Warren – Clinical Psychologist, Director of Outreach and Consultancy Services
- Emma Pierce – Manager, Building Blocks Early Intervention Service (Special Educator)
- Dr Trevor Clark – Director of Education and Research at ASPect
- Dr Paul Hutchins – Head, Child Development Unit, The Children’s Hospital at Westmead, for supporting the collaboration and research