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The University of Sydney

A Review of the Research to Identify the Most Effective Models of Best Practice in the Management of Children with Autism Spectrum Disorders

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With assistance from Greta Ridley

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Autism Treatment Review

Disclaimer

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Glossary of terms

AAC	Alternative and Augmentative Communication
AANSW	Autism Association of New South Wales
ABA	Applied Behavioural Analysis
ABC	Aberrant Behavior Checklist
AIT	Auditory Integration Training
ASD	Autistic Spectrum Disorder
BCOHTA	British Columbia Office of Health Technology Assessment
CABAS	Comparative Applied Behavioural Analysis to Schooling Program
CARD	Centre for Autism and Related Disorders based on the UCLA Young Autism Project Lovaas and operating from Los Angeles with branches internationally
CDDS	Centre for Developmental Disabilities Service
CEO	Catholic Education Office
DADHC	Department of Ageing, Disability and Home Care
DBC	Developmental Behaviour Checklist
DET	Department of Education and Training
DIR	Developmental Individual-Difference, Relationship
DLT	Daily Life Therapy
DSM	Diagnostic and Statistical Manual
DSP	Developmental Social-Pragmatic model
DTT	Discrete Trial Training
DT-TB	Discrete Trial Traditional Behavioural
EIBI	Early Intensive Behavioural Interventions
FAPC	Fisher's Auditory Problems Checklist
FC	Facilitated Communication
FCT	Functional Communication Training
HFA	High Functioning Autism
IBI	Intensive Behavioural Intervention
ICD	International Classification of Diseases
ILT	Incidental Language Teaching
IO	Support Class for students with moderate intellectual disability (NSW DET)
IQ	Intelligence quotient
ITTT	It Takes Two to Talk
JAFA	Joy and Fun Assessment
LCDC	Language and Cognitive Development Center
LEAP	Learning Experiences: an Alternative Program for Preschoolers and their Parents
MADSEC	Maine Administrators of Services for Children with Disabilities
MR	Mental Retardation
MRC	Medical Research Council
MTW	More Than Words
NAS	National Autistic Society
NLP	Natural Language Paradigm

NOS	Not Otherwise Specified
NSW	New South Wales
PBS	Positive Behaviour Support
PCDI	Princeton Child Development Institute Program
PDD	Pervasive Developmental Disorder
PECS	Picture Exchange Communication System
PET	Parent Education and Behaviour Management Training
PMA	Prorated Mental Age
PRT	Pivotal Response Training
PS	Parent Education and Support
RCTs	Randomised Control Trials
SCERTS	Social-Communication, Emotional Regulation, and Transactional Support
SI	Sensory Integration
SIB	Self-Injurious Behaviour
S-P/D	Social Pragmatic Development
SPELL	Structure Positive Empathetic Low arousal Links
TEACCH	Treatment and Education of Autistic and related Communications Handicapped Children
UCLA	University of California Los Angeles
UCSF	University of California San Francisco
UK	United Kingdom
USA	United States of America
VABS	Vineland Adaptive Behaviour Scales
WHO	World Health Organisation

EXECUTIVE SUMMARY

Introduction

The purpose of this review of research literature relating to the management and treatment of children with autism is to identify the most effective models of best practice. The review was commissioned by the Department of Ageing, Disability and Home Care (DADHC), NSW Government and completed by Jacqueline Roberts of The University of Sydney, Centre for Developmental Disability Studies (CDDS).

The review includes:

The definition of autism spectrum disorders

Autism is a life long neurological disability of unknown aetiology. The criteria for a diagnosis of autism are based on a triad of impairments in social interaction, communication and a lack of flexibility in thinking and behaviour. There is a spectrum of autistic disorders which includes: Autistic Disorder (Some people with Autistic Disorder with IQ in the typical range may also be described as having High Functioning Autism, HFA), Asperger Syndrome (there is some dispute about the validity of the distinction between Asperger's Syndrome and HFA), Retts Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS), also known as Atypical Autism. The diagnosis of autism spectrum disorders, referred to throughout this review as autism, is made on the basis of observed behaviour. As a result there is some variability across professionals in the assessment and diagnosis of autism. There are also differences in the reported incidence and prevalence of the disorder which range from less than 4 per 10,000 to more than 100 per 10,000. There are several factors which are likely to contribute to this variation including the definition of autism and variability in diagnosis amongst professionals, however anecdotally there appears to have been a steadily increasing demand for services reported by agencies in NSW which is disproportionate to the growth in population. . The association between autism and intellectual disability is about 70% of the cases.

Comparative evidence supporting a range of treatment and intervention models, across the range of individuals included within autism spectrum disorders.

There are several important considerations which inform examination of the evidence for the range of treatments and programs available for children with autism and their families:

- Cultural perceptions of the characteristics of autism and the validity of the autistic and non-autistic ways of perceiving the world
- The need for a multi-dimensional, multi-professional approach to the treatment and management of autism

- Individual differences in terms of the type of autism and individual characteristics of the child and their family
- Claims made by service providers in relation to potential outcomes of treatment and family expectations resulting from these
- Difficulty in measuring outcomes in an empirically valid and reliable way and
- Lack of reliable information about the range of options and potential options available to families.

Psychodynamic treatment/management
These therapies are based on the assumption that autism is the result of emotional damage to the child, usually because of failure to develop a close bond (attachment) to parents, especially the mother. Therapies include, Holding Therapy and Pheraplay. Psychodynamic treatments are seldom used today, with the possible exception of Cognitive Behavioural Therapy (CBT) for high functioning adolescents and adults with autism. The evidence that autism is a developmental rather than an emotional disorder is strong and there is little convincing empirical evidence demonstrating the effectiveness of psychodynamic interventions.

Biological Treatments
There is no specific or universal medical treatment or cure for the core symptoms of autism, however, a number of biomedical approaches have been tried in an effort to treat particular symptoms or co-morbid disorders, and/or to increase the likelihood that the individual will benefit from concurrent educational or behavioural interventions. The following medications have been demonstrated to be somewhat effective for individuals with autism, though careful monitoring is required to measure effects and side effects: Neuroleptics/Antipsychotics, Risperidone, Selective Serotonin Reuptake Inhibitors (SSRIs), Antidepressants, Stimulants, Anticonvulsants.

The following medications have been demonstrated to be ineffective and/or harmful for children and adolescents with ASDs: Naltrexone, Secretin, Adrenocorticotrophin Hormone (ACTH). Other biomedical treatments not recommended due to minimal evidence and potential risks include: Vitamin and dietary supplements, Exclusion diets (casein and gluten-free diet), Anti-yeast therapies, Chelation.

Educational/Behavioural Interventions

Behavioural approaches:
Behavioural approaches are based upon the principles of learning theory, that is, the idea that human behaviour is learned and that it is governed by its antecedents and its consequences. The theory assumes that children can learn new skills by modification of stimuli and the presentation of reinforcement. Behavioural strategies can be divided into three categories:
- Antecedent interventions that are implemented before a target behaviour is likely to occur
- Consequence interventions that are implemented following the occurrence of a target behaviour

- Skill development interventions designed to teach new skills and alternative, adaptive behaviours

It is essential to specify the nature of the behavioural intervention being discussed. Behavioural interventions may range from a social story to a discrete trial training program. Emerging trends in behavioural interventions include, positive behaviour support, functional assessment, and functional communication training.

Applied Behaviour Analysis (ABA)

Applied Behaviour Analysis (ABA) is the process of applying sometimes tentative principles of behaviour to the improvement of specific behaviours and simultaneously evaluating whether or not changes noted are indeed attributable to the process of application. The goal of ABA is to improve socially significant behaviours such as academics, social skills, communication, and adaptive living skills, to a meaningful degree. ABA is used to:

- Increase behaviours
- Teach new skills
- Maintain behaviours
- Generalize or to transfer behaviour from one situation or response to another
- Restrict or narrow conditions under which interfering behaviours occur:
- Reduce interfering or potentially harmful behaviours

Discrete Trial Training (DDT) is one of the instructional methodologies frequently used in ABA-based programs. In DTT each training trial, consists of four major components: Presentation of a brief, distinctive instruction or question (stimulus), the instruction is followed by a prompt, if the child needs one, to elicit the correct response, the child responds correctly or incorrectly (response), the teacher or therapist provides an appropriate "consequence." Correct responses receive a reward, which may be an edible treat, a toy, hugs or praise; incorrect responses are ignored and/or corrected, data are recorded.

(Early) Intensive Behavioural Interventions (EIBI/IBI)

Early, intensive behavioural intervention (IBI or EIBI) appears to be a generic term that refers to behavioural interventions that are intensive and comprehensive. Severe behaviour disorders may be treated with intensive behavioural intervention. Proponents point out that children with autism typically do not learn from their environment spontaneously, and therefore need to be taught virtually everything they are expected to learn. Intensive programs refer to the number of hours of treatment the child receives per week as well as the intensity of training, curriculum, evaluation, planning, and coordination. IBI/EIBI intervention programs recommend between 30-40 hours of child: therapist sessions per week.

Key Behavioural intervention programs include: Douglas Developmental Disabilities Centre Program, Autism Preschool Program, Princeton Child Development Institute Program (PCDI), May Institute, Lovaas Program, In the Sydney metropolitan area, ABA programs are offered by four private service providers (Learning to Learn website, www.learningtolearnsydney.com.au, accessed August 2003.

There is universal agreement that behavioural interventions have produced positive outcomes for children with autism that are well supported by research. However, there continues to be a great deal of controversy about particular behavioural interventions and programs, concerns about methodological issues and differences in the interpretation of research findings. IBI/EIBI programs exemplified by the Lovaas program which use ABA and DTT are among the most controversial intervention strategies for children with autism. This controversy revolves around outcome claims, exclusivity, extensive use, and personnel. There is controversy as to whether ABA and DTT can lead to recovery. Controversy related to exclusivity pertains to whether ABA and DTT should be used to the exclusion of all other methods. While 40 hours of weekly DTT has been used, controversy exists regarding the extensive use of DTT and the appropriateness for some children and families.

Naturalistic/Developmental approaches
Generally naturalistic interventions follow a developmental approach, which is relationship based and aims to help the child to learn to 'attend, relate, interact, experience a range of feelings, and, ultimately, think and relate in an organized and logical manner' (Atchison et al., 1997, p. 50). Naturalistic interventions are also known as normalised interventions.

Developmental Social-Pragmatic Model (DSP).
This approach emphasises the importance of initiation and spontaneity in communication, following the child's attentional focus and motivations, building on the child's current communicative repertoire even if this is unconventional and using more natural activities and events as contexts to support the development of the child's communicative abilities. The DSP approach differs from the contemporary ABA approach in its emphasis on sequences of language development and reduced emphasis on eliciting and measuring discrete trial behavioural responses. DSP focuses on successful participation in extended interactions as the measure of success with greater emphasis on enhancing communication abilities within meaningful events and routines. Research indicates there are some advantages to this approach.

Floor time or the Developmental Individual-Difference, Relationship-Based Model (*DIR*) is a developmental approach for early intervention with infants and children with a disability. The program includes interactive experiences, which are child directed, in a low stimulus environment. Proponents contend that interactive play, in which the adult follows the child's lead, will encourage the child to "want" to relate to the outside world.

Relationship Development Intervention
Relationship Development Intervention (RDI) is a series of techniques and strategies built upon the typical developmental processes of social competence. The goal of RDI is to increase motivation and interest in social relating in individuals with autism and provide activities and coaching to assist them to enjoy and become competent in social relationships. There appear to be no independent peer-reviewed, published studies of RDI's effectiveness.

Learning Experiences-An Alternative Program for Preschoolers and Parents (*LEAP)*
is a comprehensive preschool service, designed for both children with autism and typically developing children. LEAP has the components of an integrated preschool program and a behaviour skills training program for parents. The program contains aspects of behavioural analysis, but it is primarily a developmentally based approach. There appear to be no independent peer-reviewed, published studies of LEAP's effectiveness for children with autism.

Communication Therapies

Visual Supports/Alternative and Augmentative Communication (AAC) There is considerable research evidence to support the use of visual strategies and visually cued instruction for children with autism. Augmentative systems of communication in autism, are used not just to replace speech, but to assist learning and communication, regardless of the level of speech. Symbols, pictures, photographs and objects of reference, are all well established as helpful for people with autism in supporting the comprehension of what is said and in getting needs met.

Picture exchange Communication System (PECS) is a program that teaches children to interact with others by exchanging pictures, symbols, photographs or real objects for desired items. The goals of PECS include the identification of objects that may serve as stimuli for each child's actions and the learning of responses to simple questions with multi-picture systems. It is a highly structured program that uses behaviourist principles of stimulus, response and reward to achieve functional communication. There are some studies that have evaluated PECS and show positive gains for participants.

Facilitated Communication (FC)
Proponents of FC claim that autism is primarily a motor disorder involving difficulty producing voluntary movement, (apraxia) and therefore precluding the production of speech. Therapy involves teaching communication by physically prompting to form a pointing finger, supporting the hand as a point is made and assisting withdrawal from the point. Extensive research has been done to determine the efficacy of FC for people with autism. No evidence has been found of consistent, useful or spontaneous communication using this method.

Functional Communication training (FCT)
FCT is a behavioural strategy of teaching people with autism to use signs or other AAC techniques as substitutes for the 'messages' underlying their challenging behaviour. FCT

interventions teach the individual to communicate one or more functional messages, while at the same time they provide a positive alternative to his or her challenging behaviour(s). A review of FCT studies published between 1985 and 1996 (Mirenda, 1997) found that for those participants with autism, there was an immediate and substantial reduction in challenging behaviour after the FCT interventions were initiated.

Sensory/motor therapies

Sensory integration
Sensory Integration (SI) therapy is a sensory-motor treatment based upon theories that children with autism and other developmental delays experience dysfunction in which sensory input is not integrated or organized appropriately by the brain. Sensory integration is described as providing the child with planned and controlled sensory experiences that aim to produce adaptive and functional responses to sensory stimuli. Current research does not support SI as an effective treatment for children with autism, developmental delays or mental retardation; nor has the limited research to date been able to identify SI as an independent variable responsible for positive change in a child's behaviours or skills. In at least one study, SI was shown to actually increase self-injurious behaviours.

Auditory integration training (AIT)
Auditory integration training is said to address the hearing distortions, hyperacute hearing, and sensory processing anomalies, which cause discomfort and confusion in people with disability, including autism. According to the American Academy of Paediatrics Committee on Children with Disabilities, current information does not support the use of auditory integration training and, therefore, its use is not yet warranted other than in research protocols.

Combined Approaches

TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children)
This approach is one of the most widely used approaches in autism. The major feature of the TEACCH approach is structure. Some of the difficulties in autism, which the TEACCH program identifies and addresses, are organisational difficulties, memory problems, difficulties with auditory processing and making transitions from one activity or topic to another. The environment is organised to help the child or adult understand and remind them what they are to do. The emphasis is on positive strategies of behaviour management and visually, rather than verbally, mediated teaching strategies. Types of intervention include structured teaching, communication training, leisure and social skill development and stress reduction. There is extensive research into the outcomes of the program however there are few peer-reviewed studies of outcome replications conducted by researchers not affiliated with TEACCH.

Autism Association NSW Satellite class program
The Autism Association of NSW satellite class program is a program designed to include children with autism in regular school settings, while meeting their specific needs. The content and delivery of the program is similar to the TEACCH model with heavy emphasis on visual supports, structure and routine, specific teaching of communication and social skills in the regular school setting. There is no empirical research into the outcomes of the satellite class program.

Other Therapies
These include: Higashi/Daily Life Therapy, The Option Method (also known as 'Son-Rise'), Connect Therapy (this is a derivative of the Options Program) and Music therapy. There is little if any empirically sound research evaluating outcomes of these programs

Elements of successful programs.
Research suggests that program directors, regardless of philosophical orientation, describe the same key components of a successful program as follows:
- Autism specific curriculum content focusing on attention, compliance, imitation, language and social skills
- Need for highly supportive teaching environments and generalisation strategies
- Need for predictability and routine
- A functional approach to problem behaviours
- Transition from the preschool classroom
- Family involvement

Therefore there is no one program that will suit all children with autism and their families. Research suggests that there are substantial short and long term benefits from early, intensive, family-based treatment programs, whatever their theoretical basis, so long as these are appropriately adapted to the child's pattern of strengths and weaknesses and take account of family circumstances (Webster, Webster & Feiler, 2002).

Cost benefits
Information about the cost benefits of treatment programs in terms of funding, treatment times, short-term outcomes and benefits over time is reviewed. To date, no studies have reported on the cost benefits associated with treatment programs in terms of funding, treatment times, short-term outcomes and benefits over time. Rather, reviewers in this field have provided a description of the aims of the intervention or treatment program available, the target population, treatment times, associated costs and how the treatment was being funded. Information about costs provided by service providers in Australia and internationally are included in the review.

Supporting Families
The research is examined for evidence to support best practice models in supporting families at the time of diagnosis and assessment and an overview of the nature of comprehensive supports that help reduce stresses that may be experienced by families of a child with autism and promote inclusion in community activities. Evidence to support best practice models to assist families at the time of diagnosis is scarce. Factors identified

as contributing to the reduction in stress experienced by families when receiving a diagnosis of autism, were identified as: early disclosure of a diagnosis, increased understanding of autistic behaviour, the accumulated experience of how to communicate with their child and the existence of a self-care group to support parents.

Programs focusing on parents and families, increasing their knowledge of autism and building their competence and confidence through different strategies are reviewed. The research into outcomes for these programs is variable with little independent peer-reviewed research done by researchers unaffiliated to the programs, however what information there is about outcomes for these programs is positive.

Several programs designed to support and inform families are reviewed including:
The Help! Program *(UK) is for parents of newly diagnosed children,*
Family-centred positive behaviour support (PBS) programs, *PBS is a collaborative, assessment-based approach to addressing problem behaviour. A number of studies have demonstrated the efficacy of combining family-centred intervention with PBS*
NAS EarlyBird Program *(UK and NZ), is a parent-focused model of early intervention. The EarlyBird Program was utilized by the Leicestershire Education Authority as a service provided to support families of preschool children with autism. Parents reported several benefits from the program.*
The Hanen Program *'More Than Words' is an intensive training program for parents of pre-school children with autism. The program derives its theoretical framework from a social-pragmatic developmental perspective. The Department of Health at the University of Newcastle (UK) is currently conducting a longitudinal evaluation of the More Than Words Program. Preliminary results show an improvement in the interactive skills identified as impacting on children's language development.*
Autism Early Intervention Project *(AUST) is a parent-focused model of early intervention focusing on the provision of parent training and support. The program is currently being evaluated with initial results showing a significant improvement in mental health of parents participating in the intervention.*

The review concludes with a description of autism programs in NSW and other States/Territories.

AUTISM TREATMENT REVIEW

Introduction

The Centre for Developmental Disability Studies (CDDS), The University of Sydney was asked to undertake this literature review as part of the 2003 funded work plan with The Department of Ageing, Disability and Home Care (DADHC). Jacqueline Roberts was engaged by CDDS to undertake the review with support from Roger Stancliff of CDDS. The project was managed by the Prevention and Early Intervention Unit of DADHC.

About the author

Jacqueline M.A. Roberts, BA (Hons), Dip. Teach, B Applied Science (Sp Path), Ph.D. Jacqueline is a consultant specialising in autism spectrum disorders. Jacqueline worked for the Autism Association of NSW for 20 years as a teacher, speech pathologist, school principal and Director of Services with overall responsibility for the provision of all professional services delivered by the Association. As a lecturer and educator Jacqueline has worked extensively in New South Wales and overseas delivering both specialised programs in autism, and general training in Special Education and Speech Pathology. Jacqueline has a Doctorate in Linguistics, Macquarie University (Sydney, Australia). Jacqueline currently works as an early intervention teacher with young children with autism, as a researcher and postgraduate supervisor and teaches the autism strand in the postgraduate program in Developmental Disability Studies at the University of Sydney and is the coordinator of the graduate program in autism in the Faculty of Education at the University of Canberra. She holds the position of Clinical Lecturer in the Faculty of Medicine, The University of Sydney and is a Clinical Associate.

Background

In recent years it has been suggested that there is an "epidemic" of autism spectrum disorders. There is also a strong indication that this group has very specific support needs and that early intervention is beneficial to building skills that will enable effective participation within the community and increased independence throughout life. Areas of particular importance include the development of socio-communicative processes, the prevention of challenging behaviours and increased adaptive functioning within inclusive settings.

Concern also exists for the support needs of families where there is a family member with autism. There is a need to identify strategies that will help families through the experience of diagnosis and assessment and to find the most effective way to provide information about available treatments. In addition, comprehensive service provision requires family centred practices that acknowledge the specific needs of individuals within families, for example fathers and siblings, and identify strategies to promote family participation in their community.

Brief from DADHC: Terms of reference

Identification of recommended best practice models for intervention and therapy is critical for DADHC. A strong evidence base will enable DADHC to build the capacity of the existing service system to cater for the needs of children and young people with autism spectrum disorders within a family centred framework.

This review of the key international articles and any ongoing research projects sets out to identify:

- The definition of autism spectrum disorders
- Comparative evidence supporting a range of treatment and intervention models, for example intensive behavioural interventions, naturalistic mainstreaming strategies, combined therapy support and parent training programs, across the range of individuals included within autism spectrum disorders.
- Cost benefits of treatment programs in terms of funding, treatment times, short-term outcomes and benefits over time.
- Evidence to support best practice models in supporting families at the time of diagnosis and assessment (including the provision of information) and an overview of the nature of comprehensive supports that help reduce stresses that may be experienced by families of a child / young person with autism spectrum disorder and promote inclusion in community activities.
- Review of autism policies and programs in other States/Territories. It is understood that this section of the review will be illustrative rather than exhaustive

Definition of Autism Spectrum Disorders.

What is autism?

Autism is a life long neurological disability of unknown aetiology (Volkmar, 1998). In terms of pathophysiology it is generally accepted that,

> Taken together the available evidence in autism suggests that although certain aspects of brain functioning are often spared in autism, the syndrome never-the-less involves widespread brain dysfunction at both cortical and sub-cortical levels. The originating site of brain injury has not been identified (Bristol et al., 1996, p. 137).

The diagnosis of autism has been remarkably consistent and stable over the past several decades since its identification by Leo Kanner in the 1940's (Kanner, 1943). Rutter (1996, p.257) suggested that there is …"a high degree of consensus on the diagnostic criteria for autism and consistency in the evidence on the validation of autism as a diagnostic category".

Kanner (1943) referred to autism as 'a disorder of affective contact' and identified criteria in terms of deficits in interpersonal development, communication and imagination. Currently there are two major diagnostic systems in use which have common criteria for a diagnosis of autism based on a triad of impairments in social interaction, communication and a lack of flexibility in thinking and behaviour. These are DSM IV: American Psychiatric Association, (1994) and ICD 10: World Health Organisation, (1992). The term 'autism' is synonymous with the term 'autistic spectrum disorders' (ASD) (Wing, 1996) and with the term used in DSM IV 'Pervasive Developmental Disorders' (PDD). The autistic spectrum covers a number of different conditions with different diagnostic criteria, but which share those common developmental difficulties described as the triad of impairments. Autistic Spectrum Disorders or Pervasive Developmental Disorders as defined in DSM IV (1994), include:

- Autistic Disorder (also referred to as Classic or Kanner's autism. Some people with Autistic Disorder with IQ in the typical range may also be described as having High Functioning Autism (HFA)
- Asperger Syndrome (also known as Aspergers Disorder) There is some dispute about the validity of the distinction between Asperger's Syndrome (AS) and HFA
- Retts Syndrome
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS), also known as Atypical Autism

While current diagnostic formulations (DSM-IV: APA, 1994; ICD-10: WHO, 1992) support the concept of Asperger Syndrome as a distinct syndrome (Trevarthen, Aitken, Papoudi & Robarts, 1996) there is some debate in the research about the validity of a distinction between high functioning autism (HFA) and Aspergers Syndrome as two distinct conditions (Jordan, 2001). Wing (1996) has maintained that HFA and Aspergers syndrome are more alike than different and that educational distinctions between the groups may not be valid or helpful.

The diagnosis of an autistic spectrum disorder is based on the observation of behaviour in the three areas of the triad; social behaviour, communicative behaviour and repetitive or ritualistic behaviour/resistance to change. There is no definitive physiologically based test to reliably indicate the presence of autism and no one particular behaviour is a definitive indicator of autism. The diagnosis is predicated on the observation of behaviours in all clusters of characteristics described by the triad. In a review of educational intervention for children with autism conducted in the UK Jordan, Jones and Murray (1998) discuss the difficulties associated with the assessment and diagnosis of autism spectrum disorders:

> Because of difficulties in diagnosis, a range of descriptions might be used by professionals to describe a child on the autistic spectrum. Such descriptions will include 'autistic tendencies', 'autistic features', 'Kanner's Syndrome', 'Asperger Syndrome', 'autistic behaviours', 'atypical autism' and so on. Sometimes, one of the diagnostic features is emphasised ('semantic pragmatic disorder', for example,

or 'rigid and obsessional behaviour') and then it will be necessary to look at the other two classifying features to determine whether this is an autistic spectrum disorder or whether the difficulties are limited to that one area of functioning.

Incidence and Prevalence

How common is autism?

The prevalence and incidence of autism continues to be an area of contention amongst researchers and service providers. Prevalence rate refers to the number of people with autism in a particular age range, living in a defined area. Birth Prevalence refers to the number of babies born with a particular condition in a prescribed area. Clearly it is not possible to establish birth prevalence for autism in the same way that it is possible to establish birth prevalence for Down's Syndrome (Williams, 2003). Incidence refers to the number of **new** cases in a specified time in a specified population (Wing, 1996). The incidence rate is also difficult to study in autism because of the variable criteria for autism used by different researchers, for example studies which include Aspergers Syndrome will have a higher prevalence rate than those looking only at Autistic Disorder. DSM-IV lists the prevalence of autism at 2-5 cases per 10,000 people.

In a comprehensive review of the research Fombonne (1999) found that autism spectrum disorders were reported to affect between 0.7-21.1 per 10,000 children. Fombonne (2003, p.379) in a recent review of epidemiological studies reports that, "…autism is associated with intellectual disability in about 70% of the cases and is over represented amongst males (with a male/female ratio of 4.3:1) A comprehensive review conducted by the Medical Research Council (MRC) of the United Kingdom for the Department of Health (2001) found that autism spectrum disorders affect approximately 60 per 10,000 children under 8 years of age. In Victoria, in a recent report Crewther, Goodyear, Bavin, Lawson, Wingenfeild and Crewther (2003) suggested that the prevalence rate of ASD in 2002 in Victoria was estimated at 27 per 10,000. Of these only 10% were reported to be HFA or AS. A recent report commissioned by the Department of Developmental Services, State of California (2003) states that in the state of California in the four years from 1998 to 2002 the number of autism cases nearly doubled (increased by 97%). As of December 2002, estimated prevalence in California reached a high at 31.2 per 10,000 for birth year 1997. It is important to note that these figures are drawn from the department's data collection of service demand and are not the product of a valid and reliable epidemiological research study. Wing (1996) has proposed that broadly defined autism spectrum disorders might be as prevalent as 100 in 10,000 children.

The MRC review suggests that differences in rates reported in the literature are likely to be the result of a number of factors: methodological differences between studies, changes in diagnostic practice, and increasing professional and public awareness of autism. What is not clear is whether there has been an actual increase in the prevalence of the disorder, and if indeed there has, whether the factors outlined previously are sufficient to account for the increase. It appears that the possibility of other aetiological factors cannot definitively be ruled in or out at this stage.

Currently there is no single known cause for autism or autism spectrum disorders. Most experts would contend that autistic symptoms are the result of a variety of aetiologies affecting the developing brain (Gillberg & Peeters, 1999). It is well established that there is a genetic component to autism, (MRC report, 2001) although the mechanism is not yet understood. Neither is it known how genetic susceptibility interacts with environmental factors.

TREATMENT AND INTERVENTION MODELS FOR CHILDREN WITH AN AUTISM SPECTRUM DISORDER.

Complexities and background considerations

Cultural Perceptions
The impact of cultural perceptions of autism needs to be taken into account in any discussion of intervention outcomes. Every disorder is perceived differently by society and different cultures may define and relate to a given disorder in different ways. The social definition of a particular disorder or aspects of that disorder may influence specific interventions and reflect different societal beliefs and values. For example differences in the amount and 'type' of eye contact, is subject to different cultural norms within Australian society in different cultural groups. Lack of eye contact and/or unusual quality of eye contact are characteristic of autism. There is a view of autism as a feature of normal biological variation which may have evolutionary advantages as well as disadvantages (Jordan, 2001).

In addition many able adults with autism question the validity of imposing non-autistic or 'neurotypical' standards, beliefs, attitudes and judgements on ways of being in society.

Need for a Multi-Dimensional Framework
Autism itself is a condition that straddles many different disciplines in its definition, diagnosis, education and care. As a result it is inevitably best approached in a multidisciplinary way (Jordan, 2001). When considering assessment and intervention for children with autism it is essential that we adopt a multi-dimensional framework involving people working in different disciplines. It is essential that our understanding of autism is based on an ecological concept of the disorder and that intervention strategies include parents, teachers, peers, the person with autism and other professionals.

We are not dealing with a person in isolation,

> All attempts at planning intervention and treatments should involve a close working relationship between the professional and the family, always keeping in mind the need to bridge the gap between science, beliefs, culture, and the individual needs of children and their families (Schulman, Zimin & Mishori, 2001 p. 233).

Individual Differences
The range of the autism spectrum and individual variation in autism is a key issue. Is the autism spectrum a series of subgroups or a continuum? "The effects of autistic spectrum disorders are pervasive, affecting the way a person thinks, feels, understands and acts; but the effects are not uniform (Jordan, 2001). Given that the autism spectrum encompasses a wide range of age and ability, which is reflected in the often considerable, individual differences among children with autism, it is unlikely that one intervention will fit all.

> Possible systems for classifying children with autism into subgroups based on their profiles …can be invaluable in planning more appropriate interventions in order to better service individuals with autism and their families (Schulman et al., 2001 p. 234).

Claims of 'Cure' and 'Recovery'

Although autism is a life long pervasive developmental disorder, treatment programs exist that claim to provide a cure for autism. Howlin (1998) mentions a number of these therapies, including Holding Therapy, the Options or 'Sonrise' program (Kaufman, 1976), Auditory Integration Therapy (e.g. Bettison, 1996), Facilitated Communication (FC), and Applied Behavioural Analysis (ABA) (Lovaas, 1987). Despite being the subjects of a range of published testimonials (e.g. Maurice, 1993), internet articles, anecdotal accounts and research studies, none of these therapies and associated claims have been shown to be supported by **adequate** research (Howlin, 1998). It is clear that there is insufficient empirically sound research evaluating outcomes of programs for children with autism, despite the range of treatments available to parents and the claims made by the exponents of some of these programs.

The Challenges Inherent in Measuring Outcomes

This gap between program claims and empirically validated outcomes, the 'research-clinic gap' (Schopler, 2001) arises because the criteria for good science are based on rigorous experimental methods such as random assignment to experimental and control groups and tight control of dependant and independent variables. In order to provide compelling evidence for the effectiveness of a particular intervention, a range of experimental criteria must be met, however intervention programs cannot readily meet such empirical criteria, for example random assignment of subjects to an experimental and control group may not be feasible or even legal, and complex variables cannot be easily controlled for. 'Superimposing artificial research criteria on intervention programs may not result in the most useful measures of treatment effectiveness' (Schopler, 2001 p. 11). However without research to evaluate interventions outcome claims cannot be substantiated. It is possible, although difficult, to design scientifically rigorous research to evaluate outcomes of intervention. The extent to which sound research criteria are met, in particular the replication of the research findings by different researchers, is an indicator of the confidence with which the findings can be treated. Unfortunately in the field of autism there is a tendency for research containing major errors in the selection and interpretation of the evidence to be used to substantiate claims for a particular intervention, or in some cases claims are made in a "flagrant perversion or disregard for evidence" (Schopler, 2001, p. 13).

Historically the picture is clouded with decades of psychotherapy for families and children with autism occurring without any empirical evidence to support its efficacy. Today families are spending significant resources in terms of time and money on programs that have not been evaluated and which may even pose risks of harm to children with autism and their families. Examples of treatments that have potentially harmed children with autism include Facilitated Communication (Perry & Condillac, 2003) where research showed that the presence of the facilitator made the child more

passive and less likely to initiate communication, in addition in the USA in a number of schools or educational districts there was a major transfer of resources into Facilitated Communication to the detriment of the wider curriculum and children were transferred into mainstream classes on the basis of remarkable 'facilitated' typescripts resulting in unrealistic expectation of students and subsequent stress for all concerned (Howlin, 1997). There are also a range of biomedical treatments not recommended due to minimal evidence and potential risk (Perry & Condillac, 2003) including the administration of high doses of vitamin B6 and magnesium. A study by Pfeiffer, Norton and Shott (1995) found that 5% of participants demonstrated side effects such as sensory neuropathy, headache, depression, vomiting and photosensitivity.

Significant issues for any researcher looking at treatment outcomes are:
- The variables measured to assess change
- The type of autism spectrum disorder of the participants involved in the evaluation

Variability or lack of precision in terms of the description of the nature of the autism spectrum disorder of participants, and variability in the outcome measures make comparison of studies of different treatment evaluations difficult. The challenge addressed in this review is to summarise the research evidence available, to consider and discuss the empirical soundness or otherwise of this research evidence and where possible to suggest how this research evidence might relate to the programs available in NSW for children with autism and their families. The goal of this chapter is to promote understanding of what has been done in terms of research into treatment and management of autism in children, and to highlight the need for more empirically sound research to inform families and professionals.

Classification of treatments

The range of treatments available for autism is extensive with treatments classified in several different ways by different authors. Mesibov, Adams & Klinger (1997), classify intervention approaches into three main groups:
- Psychodynamic
- Biological
- Educational/Behavioural

This review will deal briefly with the psychodynamic and biological treatments and focus on the educational/behavioural interventions. While educational/behavioural interventions are the primary focus of this review, brief reviews of the research into psychodynamic and biological approaches are included because it is likely that families will pursue more than one approach, often simultaneously, for example many children with autism in NSW are in educational programs and are also receiving one or more biological intervention such as medication, modified diet, or treatment for 'heavy metal poisoning'. It is important to keep in mind the dilemma for families faced with many, often expensive and sometimes invasive, potential treatments for their child, especially when empirical evidence of the efficacy of these treatments is lacking.

PSYCHODYNAMIC TREATMENT/MANAGEMENT

Introduction

When Kanner (1943) first described autism he initially speculated about potential biological/genetic aetiology. However he also commented on the lack of warmth shown by the parents of the children he studied and their tendency towards "mechanisation of human contacts". Probably as a result of the prevailing psychoanalytic climate of the time, Kanner and other influential theorists, assumed that autism was an emotional disorder caused by emotionally 'cold' parents, especially mothers, who subconsciously rejected their off spring. This developed into the theory of 'refrigerator parents' or 'refrigerator mothers' despite the lack of empirical evidence to support the theory (Jordan, 1999). These theories and the treatments that sprang from them were popularized by Bettleheim (1967) who was himself a concentration camp survivor. He had observed first hand the extreme symptoms of social withdrawal, anxiety, depression and stereotyped behaviour resulting from trauma to the concentration camp inmates. When he observed similar behaviours in children with autism in America he assumed that these children had suffered a similar extreme trauma which could only have happened at home at the hands of the people the child spent most of his or her time with, their parents. Because parents were assumed to be the primary source of the child's disorder, removal from the home and placement in residential institutions ('parentectomy') was often recommended as treatment.

There is some evidence that severely traumatised children demonstrate behaviours that are initially compatible with a diagnosis of autism. This was observed in children who had suffered severe abuse and deprivation in Eastern Europe before they were adopted into British families (Rutter, 1999), however, the response of these children to treatment showed a very different pattern to the treatment outcomes for children with autism.

Severing all ties with their 'toxic' parents and psycho-dynamically oriented play therapy were key components in the psychodynamic therapeutic process (Mesibov, et al 1997). Although the psychoanalysts claimed dramatic cures and recoveries as a result of this treatment there is virtually no supporting evidence to support the efficacy of either removal from the parents or traditional play therapy (Jordan, 1999; Mesibov, 1997).

There continues to be some support for a psychoanalytic approach to autism today from researchers such as Hobson (1990) who suggests it may be useful because of it's emphasis on object relations and affective contact. Howlin (1997) points out that for older more able individuals with autism individual psychotherapy or counseling may help them deal with anxiety and depression arising from recognition of their difficulties and differences. There is some evidence to support the effectiveness of Cognitive Behavioural Therapy (CBT) with some high functioning individuals with autism (Perry & Condillac, 2003), however unless therapy is combined with practical advice on how to deal with problems in a functional sense the outcome is unlikely to be effective.

Examples of Specific Psychodynamically Based Treatments/Therapies:

Holding Therapy.
This therapy based on the work of the Tinbergens (Tinbergen & Tinbergen, 1983) who claim that autism is caused by "an anxiety dominated emotional imbalance, which leads to social withdrawal and ….. a failure to learn from social interaction". This imbalance was said to result from a lack of binding between mother and infant, which could be ameliorated by Holding Therapy. Howlin describes Holding Therapy as a "process [which] involves holding the child tightly, to ensure eye contact, with the aim of deliberately provoking distress, until he or she needs and accepts comfort." (Howlin, 1997 p. 58).

Pheraplay.
This approach was developed by DesLauriers (1978), who essentially proposed that autism was a failure of emotional attachment compounded by sensory impairments. Pheraplay was advanced as the best way to provide stimulating experiences intense enough to overcome autistic children's basic sensory deficits. The therapy focused on providing highly stimulating interpersonal interactions rather than learning specific play skills (Mesibov, et al 1997).

Summary
Today, clinicians in the field of autism infrequently use psycho-dynamically oriented approaches. The evidence that autism is a developmental rather than an emotional disorder is strong and there is now empirical evidence demonstrating the ineffectiveness of these interventions (Mesibov, et al 1997).

BIOLOGICAL TREATMENTS

Medication

Medication has been found to be useful in disorders such as epilepsy and depression. Although behavioural approaches to intervention are usually the most favoured form of treatment for younger children, consideration of the treat-ability of disorders such as anxiety and the biological nature of autism have resulted in hope that pharmacological treatments may be found to treat and possibly even cure autism. There have been announcements of such treatments; such as secretin (a hormonal compound) (Dempsey & Forman, 2001) and a consequent rush to secure them by families. However, to date, with subsequent scientific examination, none of the claims for substantial treatment or cure have been substantiated (Sikich, 2001). While no medication has been found to affect the core symptoms of autism to date, there are often associated problems that may respond to pharmacological treatment. For example, there are times when because of severe behavioural disturbance including aggression and self injurious behaviour, sleeping problems, over-activity, anxiety, depression or marked obsessive/compulsive behaviours, medication may be considered (Howlin, 1998). Gringas (2000) describes this as 'a tailor made' approach and stresses that the agents used do not impact on the primary social impairments that underlie autism. This is in contrast to the 'one suit fits all' approach when there is a belief that there is one underlying biological cause for autism and claims are made for treatments that impact on the core social impairments of autism (Gringas, 2000).

In the USA pharmacological interventions are very common. In a 1995 survey it was found that over 50% of the children studied were taking some form of drug or vitamin treatment (Aman, van Bourgondien, Wolford & Saphare, 1995). Ratings of parental satisfaction with the different forms of treatment indicated that anticonvulsants, antidepressants and stimulants were the most popular. Least popular were the vitamins, mood stabilizers, neuroleptic, antihypertensives and sedative/hypnotic (Howlin, 1997). It is not known what the figure would be for pharmacological interventions in Australia, however a recent straw poll of 20 families in one of the Autism Association NSW services suggests that the figure is likely to be similar (50% +).

The major pharmacological treatments used in autism are summarised as follows:

Typical Anti-psychotics.
These were developed to treat schizophrenia. This class includes drugs such as haloperidol, fluphenazine, thioxene and thioridazine. Empirically sound studies conclude that these drugs may be useful in modestly improving the overall functioning of children with autism however there are significant side effects on the extrapyramidal motor system associated with these medications including stiffness (dystonia), restlessness (akathisia) and involuntary movements (dyskinesias). Long-term use is not recommended because of the possibility of developing permanent tardive dyskinesia. If the medications

are to be stopped they should be gradually withdrawn to avoid withdrawal dyskinesias. (Sikich, 2001)

Atypical Anti-psychotics.
These have been developed in the last 20 years to minimise the effects on the extrapyramidal system of the typical antipsychotics outlined above. This class of drugs includes: clozapine, risperidone, olanzapine, ziprasidone, quetiapine. These drugs have fewer extrapyramidal side effects than the typical antipsychotics. Clinical trials of risperidone with adults with autism show reduction in repetitive behaviours, aggression, irritability and anxiety. No changes in language or social behaviours were observed. Similar positive findings have been found for olanzapine but not for quetiapine, which suggests not all atypical antipsychotics are equally efficacious. The usefulness in children of this class of medications is not yet clear. The most common side effects in those on these medications are weight gain and sedation. (Sikich, 2001)

Serotonin Reuptake Inhibitors
This class of drugs was developed as antidepressant and has proved useful in the management of obsessive-compulsive disorder. Serotonin reuptake inhibitors include the tricyclic antidepressant clomipramine, and the mixed antidepressant venlaflaxine and all selective serotonin reuptake inhibitors, fluxetine, sertraline paroxetine, fluoxamine, and citalopram. The effect of serotonin reuptake inhibitors in reducing the severity of the characteristics of autism is likely to be linked to serotonergic abnormalities in many people with autism, and altered patterns of brain serotonin synthesis. There is significant clinical evidence to suggest that this class of drugs is effective for many adults with autism. Mesibov et al (1997) suggests however that clomipramine should be used with caution because of an association with lowering of seizure thresholds. Evidence supporting efficacy in children is more equivocal and no randomized control studies have been undertaken with this population. (See Sikich 2001 for a comprehensive review).

Beta blockers.
The use of beta-blockers to reduce anxiety and aggression in autism has not been well researched, however atenolol and propranolol are used to reduce anxiety in some people with autism. (Mesibov et al 1998)

Anti-convulsant medications.
It is estimated that up to 30% of people with autism have seizures, which often develop during adolescence (Mesibov, 1997). For those who do suffer from seizures anticonvulsant medication is indicated in the same way as in any person affected. In the case of autism however there is one anti convulsant medication, carbaramazepine (Tegretal), which is sometimes used to modify aggression in highly aggressive people with autism who do not show signs of seizures (Mesibov, 1998).

Naltrexone.
Naltrexone is an opiate antagonist that has been hypothesised to be helpful in reducing the symptoms of autism by blocking endogenous opiods that may be released during self-injurious repetitive behaviours. Sikich (2001) suggests that there is fairly consistent

evidence that Naltrexone is possibly to probably efficacious in reducing hyperactivity and impulsivity to a limited degree in children with autism, however there have been problems reliably replicating study findings and results for adults have been mixed and negative at times. Overall the results suggest that Naltrexone may be useful in some autistic children with significant hyperactivity who are able to tolerate the very bitter taste of the medication. Perry and Condillac (2003), suggest that Naltrexone has not been demonstrated to be effective.

Stimulants e.g. Methylphenidate (Ritalin TM)
Sikich (2002) suggests that because children with autism have significant problems with attention, hyperactivity and impulsivity, stimulants may be helpful in some cases. One clinical trial has been done which shows modest but statistically significant improvements in hyperactivity. No adverse effects were demonstrated.

Summary
In conclusion, psychopharmacologic research in autism is punctuated by initial case reports and open studies that demonstrate dramatic treatment benefits. However when these treatments have been examined more rigorously, the benefits appear much more modest and often cannot be substantiated in randomised controlled trials. The best treatments seem to work in only 50 – 60 % of participants. One issue is the lack of agreement on the standards of rating scales that are used to assess change. No treatment has yet been rigorously shown to change the core features of autism to a sufficient extent that the affected individual is able to achieve levels of functioning within the typical range. In general medications are most beneficial for people with autism who also exhibit levels of hyperactivity, aggressiveness, self-injurious behaviours, withdrawal, impulsive behaviours and anxiety that significantly interfere with daily functioning.

Other biological treatments

Secretin
Secretin is a peptide hormone secreted by the small intestine, which increases the pancreatic secretions. To date secretin has not been reported to have an activity in the brain. Reports of dramatic reductions in autistic symptomatology subsequent to treatment with secretin to assess the gastrointestinal function in some children with autism evoked extensive interest in secretin as a potential treatment for autism. However, clinical trials have failed to demonstrate its efficacy. Results are described in the Cochran review of research into the efficacy of Secretin in the treatment of autism (Williams, Wray & Wheeler, 2003). Perry and Condillac (2003), state that Secretin, Fenfluramine, Naltrexone and Adrenocorticotrophin (ACTH) have been demonstrated to be ineffective and/or harmful for children and adolescents with autism

Vitamin B6 and magnesium.
Interest in mega doses of vitamins to treat autism arose from a 1960's theory that some psychiatric disorders might be the result of relative deficiencies in certain vitamins and minerals. There has been particular interest in Vitamin B6 because it is involved in the synthesis of several neurotransmitters. Magnesium is administered with mega doses of

Vitamin B6 to reduce toxic side effects. The Cochran review of the research into the effect of this therapy did not find any studies that met the standard for clinical control trials (Nye & Brice, 2003). Sikich (2001), suggests that an overview of what research evidence there is, indicates that vitamin B6 and magnesium are possibly to probably efficacious in some autistic individuals. There are potential difficulties in administering the agents (bitterness) and the effect appears to be relatively small, even in individuals who do respond (Sikich, 2001). Howlin (1997) suggests that there are reported side effects such as sensory neuropathy, headache, depression, vomiting, and photosensitivity and urges caution in the use of large doses of vitamins.

Diet
It has been suggested that food intolerance or allergic responses may be responsible for at least some of the behavioural disturbance seen in autism (Howlin, 1997) While there are numerous anecdotal accounts of reduction in autistic symptomatology from families of children on gluten/casein free diets, there is no research to date to support this. A systematic review (Cochran) of gluten and casein free diets is being done; to date the authors have indicated that no RCTs (Randomised Control Trials) had been found. While there is growing literature describing the benefits of a range of dietary manipulations in the form of small group trials and anecdotal reports published in peer-reviewed journals, the scientific validity of these is questionable due to small sample size, lack of blinding and inconsistent outcome measures (Dr Katrina Williams, personal correspondence).

Cranial osteopathy
This involves very gentle manipulation particularly of the head. Treatment may last several months and effects are said to range from minor reductions in hyperactivity to major improvements in communication. However there are no adequate evaluative studies of this approach (Howlin, 1997).

Anti-yeast therapy,
This is based on the theory that autism may be caused by toxic effects of an over growth of yeast, particularly Candida, in the gut. Treatment involves the use of an anti-yeast agent such as 'Nilstat' to destroy the yeast in the gut to reduce the 'toxic effects'. There appears to be no empirical research to support the presence of abnormally high levels of yeast in the gut of children with autism, e.g. Candida, or the efficacy of anti yeast treatment. Perry and Condillac (2003), in a review carried out for Children's Mental Health, Ontario, state that exclusion diets (casein and gluten free) and anti-yeast therapies are not recommended due to minimal evidence and potential risk.

'Chelation treatment' for 'heavy metal contamination'
This treatment is based on the theory that autism is caused by the accumulation of toxic heavy metals in the systems of children with autism. Practitioners claim that higher than normal levels of mercury and other heavy metals show up in hair and faecal analysis. It is recommended, by some medical practitioners in Sydney, as the next step for children who show only a little improvement on a gluten/casein free diet. (Dr Katrina Williams, personal correspondence). No research evidence or reference to 'chelation' treatment was found in any of the recent international reviews or journals.

EDUCATIONAL/BEHAVIOURAL INTERVENTIONS

Introduction

The primary aim of this paper is to provide a synthesis of the published research for particular interventions and a description of the programs available in NSW and other Australian states. For this reason the primary focus of this section of the report will be on research relevant to programs currently available in NSW. However research into the efficacy of some other interventions is also summarised as intervention approaches from other countries may become available in Australia in the future. An example of this is the Options or 'Son-Rise' program, which has been available for many years in the USA but was only recently set up in South Australia. Similarly Connect Therapy, which appears to be a variant of the Options program, is now available in NSW. Dempsey and Foreman (2001), noted that sensory motor therapies, applied behaviour analysis, communication therapies, and multi treatment programs were available in New South Wales.

See Table 1 for the grouping of educational / behavioural interventions.

Table 1:   *Educational/Behavioural Interventions*

Behavioural Approaches	• Applied Behaviour Analysis (ABA • (Early) Intensive behavioural interventions (EIBI/IBI)
Naturalistic Developmental Approaches	The Hanen Program Floor time Relationship Development Intervention Developmental Social-Pragmatic Model (DSP) Learning Experiences – An Alternative Program for Preschoolers and Parents (LEAP)
Combined Therapy	**Communication Therapies** Visual Supports/Alternative and Augmentative Communication (AAC) Picture Exchange Communication System (PECS) Social Stories Facilitated Communication (FC) Functional Communication Training (FCT) **Sensory/Motor Therapies** Sensory Integration Auditory Integration Training Doman-Delacato method Giant Steps Scope Topics Sensitivity training
Combined Approaches	**SCERTS** (Social-Communication, Emotional Regulation and Transactional Support) TEACCH (Treatment and education of autistic and related communication handicapped children)
Other Therapies	Higashi/Daily Life Therapy The Option Method Music Therapy Spell Campbell Miller

Educational/Behavioural treatments and programs can also be viewed in terms of their position on a continuum of discrete trial traditional behavioural approaches to the social pragmatic developmental approaches (Prizant & Wetherby, 1998) – See Figure 1. It is acknowledged that this is only one dimension of treatments and programs. While the continuum shown below may be an over simplistic generalisation, given the controversy and debate about the efficacy of one approach compared to another, it is useful to examine how significant these assumed differences are.
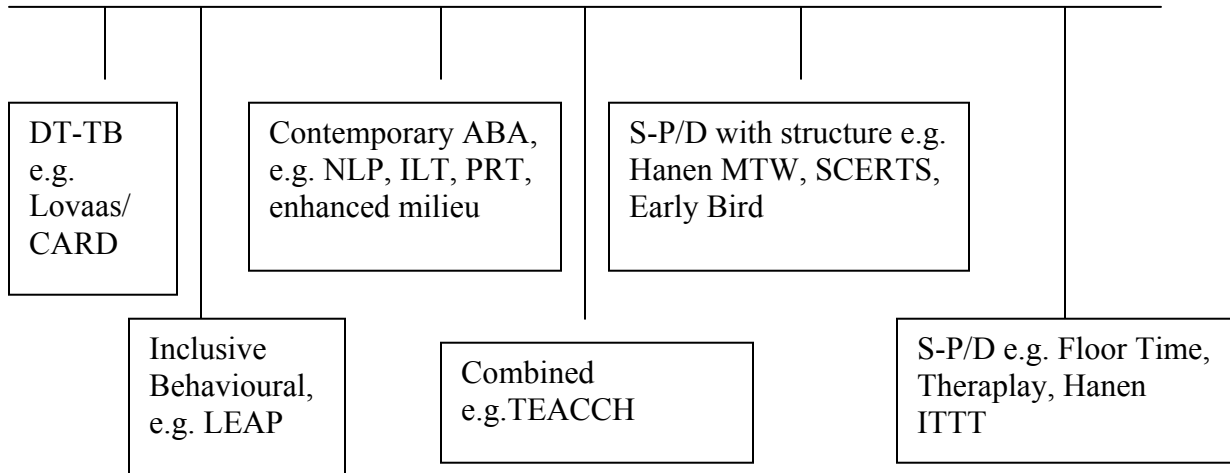
DT-TB e.g. Lovaas/ CARD	Contemporary ABA, e.g. NLP, ILT, PRT, enhanced milieu	S-P/D with structure e.g. Hanen MTW, SCERTS, Early Bird
	Inclusive Behavioural, e.g. LEAP	Combined e.g.TEACCH
		S-P/D e.g. Floor Time, Theraplay, Hanen ITTT

Figure 1: *The Continuum of Discrete-Trial Traditional Behavioural to Social-Pragmatic Developmental Approaches.*[1]

Finally in this section comparative research on different approaches is discussed.

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[1] Key:

ABA	Applied Behavioural Analysis
CARD	Centre for Autism and Related Disorders based on the UCLA Young Autism Project Lovaas and operating from Los Angeles with branches internationally
DT-TB	Discrete Trial traditional Behaviour
ILT	Incidental Language Teaching
ITTT	Takes Two To Talk Finally in this section comparative research on different approaches is discussed
LEAP	Learning Experiences: an alternative program for preschoolers and their parents
MTW	More Than Words
NLP	Natural Language Paradigm
PRT	Pivotal Response Training
SCERTS	Social-Communication, Emotional Regulation and Transactional Support
S-P/D	Social Pragmatic Development
TEAACH	Treatment and Education of Autistic and related Communications Handicapped Children

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Behavioural Interventions

The following section provides an overview of the considerable body of research and academic writing in this area. In addition to the large body of published research on behavioural interventions, there are several recent comprehensive reviews of behavioural intervention research commissioned by various government agencies internationally. Some of these reviews are included as part of more general reviews of treatment and management of children with autism (Jordan, Jones & Murray, 1998; MADSEC, 2000; Perry & Condillac, 2003), some such as the Canadian review are reviews of behavioural interventions in general, and one from British Columbia is a review of the Lovaas Program specifically. Several of these reviews are cited in this section.
See **List of Key Reviews**, (Appendix Two, P.137).

In this section on behavioural interventions; a) the key terms are defined and described, b) key international behavioural programs are described, including the Lovaas Program, c) research evidence for a variety of behavioural interventions is considered, d) some conclusions are drawn and emerging trends in behavioural programs are outlined.

Definitions

Behavioural Interventions refer to behaviourally based therapy developed to improve the symptoms associated with autism (McGahan, 2001). In contrast to psychologically and biologically based approaches, behaviour intervention is based on the idea that most behaviour is learnt through the interaction between an individual and the environment. Behaviour modification therapy is based upon the principles of learning theory, that is, the idea that human behaviour is learned and that it is governed by its antecedents and its consequences. The theory assumes that children can learn new skills by modification of stimuli and the presentation of reinforcement. This is based on Skinnerian operant conditioning theory developed in the 1960's, which assumes that learning results in the repetition of responses that in the past have led to reward, and the elimination of responses that have led to punishment. Behaviour modification therapy is designed to affect this interaction and change the behaviour of the individual (Jordan, Jones & Murray, 1998).

> 'There is little doubt that the use of behavioural procedures has resulted in major improvements in the education, management and treatment of children with autism in the last three decades. The benefits are particularly striking when parents are involved in therapy and such techniques are now widely accepted as playing a crucial role in intervention' (Howlin, 1997 p. 9).

Early behavioural interventionists considered autism as a syndrome of specific behaviours related to environmental determinants. Hence, it could be possible to change or modify behaviours by manipulating environmental events. Antecedent interventions such as integration with typical peers; implementation of highly structured environments, activities, and daily schedules; as well as behaviour modification procedures and those

offering the opportunity for choosing the task to be taught have been used to reduce problem behaviours and treat non-compliance. Behavioural assessment consists of careful measurement of discrete behavioural and environmental events allowing precise determination of target behaviours, specificity in therapy implementation and evaluation of intervention effects (McGahan, 2001).

Behaviour modification methods can be divided into three general approaches:
- operant conditioning,
- respondent conditioning,
- cognitive approaches (New York State Dept report, 1999).

Behavioural strategies can also be divided into three categories:
1. *Antecedent* interventions that are implemented before a target behaviour is likely to occur;
2. *Consequence* interventions that are implemented following the occurrence of a target behaviour;
3. *Skill development* interventions or *behavioural techniques* that are designed to teach new skills and alternative, adaptive behaviours to reduce the frequency and severity of maladaptive behaviours (Cohen & Volkmar, 1997).

Current behavioural therapy employing operant conditioning, involves the presentation of a stimulus or antecedent to a child and then providing a consequence such as a reinforcer based on the child's response. A reinforcer could be anything that, when presented as a consequence of a response, increases the probability or frequency of that response, such as a desired item. As part of operant conditioning approaches, a functional assessment of possible reinforcers is required periodically to determine which reinforcers are most effective in shaping each child's behaviours (McGahan, 2001).

Applied Behaviour Analysis

Applied Behaviour Analysis (ABA) is a type of behavioural intervention first defined by Baer, Wolf and Risley (1968) as "the process of applying sometimes tentative principles of behaviour to the improvement of specific behaviours and simultaneously evaluating whether or not changes noted are indeed attributable to the process of application".

The goal of ABA is to improve socially significant behaviours to a meaningful degree (Sulzer-Azaroff & Mayer, 1991). "Socially significant behaviours" may include reading, academics, social skills, communication and adaptive living skills. Adaptive living skills include gross and fine motor skills, eating and food preparation, toileting, dressing, personal self-care, domestic skills, time and punctuality, money and value, home and community orientation, and work skills. ABA focuses on the objective measurement of, and change in observable behaviour, i.e., before and after intervention. Reliable measurement requires that behaviours are defined objectively (Sulzer-Azaroff & Mayer, 1991). An ABA program designed to change behaviour is likely to contain the following elements;
- selection of interfering behaviour or behavioural skill deficit

- identification of goals and objectives
- establishment of a method of measuring target behaviours
- evaluation of the current levels of performance (baseline)
- design and implementation of the interventions that teach new skills and/or reduce interfering behaviours
- continuous measurement of target behaviours to determine the effectiveness of the intervention
- ongoing evaluation of the effectiveness of the intervention, with modifications made as necessary to maintain and/or increase both the effectiveness and the efficiency of the intervention (MADSEC 2000).

For children with autism ABA methods are used to:
- *Increase* behaviours (e.g., reinforcement procedures increase on-task behaviour, or social interactions);
- *Teach new skills* (e.g., systematic instruction and reinforcement procedures teach functional life skills, communication skills, or social skills);
- *Maintain behaviours* (e.g., teaching self control and self-monitoring procedures to maintain and generalize job-related social skills);
- *Generalize* or to transfer behaviour from one situation or response to another (e.g., from completing assignments in the resource room to performing as well in the mainstream classroom);
- *Restrict* or narrow conditions under which interfering behaviours occur (e.g., modifying the learning environment);
- *Reduce* interfering behaviours (e.g., self-injury or stereotypy) (MADSEC, 2000).

Discrete Trial Training

One of the instructional methodologies frequently used in ABA-based programs is Discrete Trial Training (DTT). In DTT each training trial, regardless of the skill objective, consists of four major components: The teacher or therapist presents a brief, distinctive instruction or question (stimulus), the instruction is followed by a prompt, if the child needs one, to elicit the correct response, the child responds correctly or incorrectly (response), the teacher or therapist provides an appropriate "consequence." Correct responses receive a reward, which may be an edible treat, a toy, hugs or praise; incorrect responses are ignored and/or corrected, data are recorded (MADSEC, 2000).

> In discrete trial training, the therapist chooses the stimuli to be used in training and the nature of the interaction, only correct responses are reinforced, indirect reinforcers (e.g., tokens, food) are typically used, several consecutive trials on a new task are presented, and the therapist initiates trials (Schreibman, Kaneko & Koegel 1991, p. 480).

Proponents of discrete trial training state that DTT and ABA are not synonymous; rather DTT represents one of several of teaching strategies within the field of ABA. For example, other methods of teaching used within ABA-based programs include; chaining,

shaping, and graduated guidance. (MADSEC, 2000). However, the most frequently cited and recommended **intensive** behavioural programs (Lovaas, 1981; Maurice, Green & Luce, 1996) focus on DTT as the initial and predominant strategy for teaching children with autism.

Intensive Behavioural Intervention (IBI) or Early Intensive Behavioural Intervention (EIBI).

Early, intensive behavioural intervention (IBI or EIBI) appears to be a generic term that refers to behavioural interventions that are intensive and comprehensive. Severe behaviour disorders may be treated with intensive behavioural intervention. Proponents point out that children with autism typically do not learn from their environment spontaneously, and therefore need to be taught virtually everything they are expected to learn (Green, 1995). Intensive programs refer to more than the number of hours of treatment the child receives per week. Training, curriculum, evaluation, planning, and coordination are also "intensive." Consequently, an effective IBI/EIBI intervention requires numerous hours of child: therapist sessions per week. According to Green (1995), "For young children with autism, the treatment of choice is intensive application of the methods of applied behaviour analysis". "**Intensive**" means one-to-one treatment in which carefully planned learning opportunities are provided and reinforced at a high rate by trained therapists and teachers for at least 30 (preferably 40) hours a week, 7 days a week, for at least two years. Because true generalization of therapy effects means that newly acquired behaviours need expression in a variety of settings with a variety of people, behavioural interventions require the expansion of the role of therapy provider to include parents, teachers, siblings, and peers. If therapy is consistently provided when the child is with parents, siblings, peers and at school, a complete therapeutic environment is created to support generalisation (McGahan, 2001).

The primary elements of the traditional behavioural approach typified by the Lovaas Program, are described by Prizant, Wetherby and Rydell (2000) as follows:
- "The teaching structure is highly prescribed including choice of the stimuli presented, the responses targeted, and the consequences provided. Physical arrangements such as seating are often predetermined.
- There is a focus on teaching discrete and objectively defined behaviours. Traditionally, there has been a focus on speech as a primary communicative mode, beginning with vocal imitation and followed by word imitation.
- The learning context involves a 1:1 child teacher ratio, with the adult determining the activity and focus of attention and following a prescribed sequenced curriculum.
- Predetermined criteria are provided for correctness of response. Each response is evaluated as correct or incorrect, with predetermined consequences following the response. 'Off-task' responses, even if communicative or relevant to some aspect of the training context, are ignored, or the child's behaviour is redirected.
- The initial focus is on adult control and child compliance. In a section of *Teaching Developmentally Disabled Children: The 'Me' Book*, entitled 'Adult is

Boss,' Lovaas (1981) outlined his rationale for initially providing 'structured and authoritative' environments followed by lessening adult control.

- Curricula used in discrete trial programs may not be informed by literature on sequences or processes of child language and communication development, unless the curricula chosen are developmentally based.
- There is minimal use of contextual supports, such as accompanying use of gestures by the clinician/educator (unless specified in a hierarchy of prompts), activity boards, or picture schedules. Teaching is largely organized and directed through oral language" (Wetherby & Prizant 2000, pp.198-199).

It is of interest to note that the focus on oral language training typical of the traditional IBI programs such as The Lovaas Program appears to have shifted in contemporary ABA programs to incorporate augmentative and alternative communication strategies such as the PECS program (see communication section).

Examples of Key Behavioural Intervention Programs

Douglas Developmental Disabilities Centre Program
Established at Rutgers University, this program is based on principles of ABA and behaviour intervention approaches. Children progress through three classrooms from a segregated class to a highly structured group to an integrated preschool classroom. The segregated class provides intensive 1:1 DTT largely based on the Lovaas model (see below). The highly structured group maintains a 2:1 child: teacher ratio and focuses on the skills needed to function in an integrated classroom. The integrated class is partially based on the Learning Experiences-An Alternative Program for Preschoolers and Parents (LEAP) as described in the section on naturalistic/developmental approaches. The program is developmentally based; recommended hours per week are 25 with the goal of the program being inclusion in a mainstream educational setting after 1-2 years. The mean age in months of children enrolled in the program in 1997 was 50; range 30 – 62 (Dawson and Osterling, 1997). The program serves both children with autism and typically developing peers. Families are visited by a member of staff twice a month and are offered parent and sibling support groups (McGahan, 2001). There was a program at Rutgers University called the Rutgers Autism Program which was discontinued in June 2001. The Douglass Program was set up to replace it and involves many staff from the Rutgers Program.

Autism Preschool Program
This program is based at the University of Manitoba and uses a variety of behavioural and language development methods similar to the Rutgers Autism Program (see above). It is a collaborative program staffed by a multidisciplinary team and involves the university hospital, the provincial government, and local community resources. The intervention is directed by parents and day care staff who are taught how to perform functional analysis of behaviour and to plan and evaluate strategies for changing behaviour (McGahan, 2001).

Princeton Child Development Institute Program (PCDI)
The program at the Princeton Child Development Institute for children with autism is based on principles of ABA and intensive behaviour intervention (IBI) approaches. The mean age in months of children enrolled in the program in 1997 was 43 months; range 30 – 58 months. Children are first evaluated so that individualised behaviour programs that target basic skills can be designed. Children in the day education and treatment program attend school 5.5 hours per day, five days per week, for 11 months of the year. Children participate in 30-minute classes with changes in activity and a change of classroom and teacher. Children are taught to use picture schedules to assist them with transitions throughout the day. It has been suggested that this arrangement of the school day assists in generalization. Picture schedules also help children to learn to initiate activities, make choices and encourage independence. Progress is periodically assessed and specific goals are revised. A home programmer may visit the family twice a month to help families implement behaviour programs that have been successfully achieved at school to maximize the generalisation of these skills at home (Dawson & Osterling, 1997).

May Institute.
The May Institute in Boston offers a developmentally sequenced program based on the principles of ABA and behavioural intervention approaches. The mean age of the children enrolled in the program in 1997 was 47 months; range 36 – 62 months. Intensive in–home training (15 hours per week) is provided to children and their families for a period of six months. The in-home therapist and parents provide one-to-one intervention focusing on basic skills such as self-care, language, and the reduction of problem behaviours. Following completion of home-based treatment, the children attend one of the Institute's two preschool programs, the "Step 1" class or the integrated classroom. Children attend the Step 1 class, comprised only of children with autism, learn basic skills such as how to follow instructions, develop imitation, and work in highly structured small groups for the duration of a year. The integrated class, in contrast, includes typically developing children as well as those with developmental disabilities. The curriculum focuses on teaching skills that children need in general kindergarten. A service coordinator visits families every month, during which time the child's progress and the parents' concerns are discussed. The program offers group support and respite care for families as well as outside referral information (Anderson, Campbell & Cannon, 1994).

Lovaas Program
The Lovaas Program is also known as the 'UCLA model', 'Home Based Behavioural Intervention' or the 'Lovaas Technique' (National Autistic Society, 2002). The Lovaas Program was developed by the University of California Los Angles Young Autism Project under the direction of O. I. Lovaas, a psychologist who began researching methods of applied behaviour analysis and their application to autism in the 1960's. Based upon his research, Lovaas concluded that intensive behavioural intervention (primarily using discrete trials) is the treatment of choice for children with autism. The Lovaas Program uses time intensive (40 or more hours per week) behavioural intervention techniques to treat children 2-3 years of age over a 2-3 year period. First stages of the program focus on teaching self-help and receptive language skills,

nonverbal and verbal imitation, and the foundations of appropriate play through 1:1 DTT 40 hours per week. More recently Lovaas (1993) has indicated that in the first six months of intervention the majority of the forty hours should consist of rectifying speech and language deficits. Parents are trained to apply the intervention during most of the child's waking hours. The second stage of the intervention emphasises the teaching of expressive and early abstract language and interactive play with peers. Advanced stages, taught at home and school, involve learning early academic tasks; socialisation skills, cause and effect relationships; and learning by observation. Aggressive and self-stimulatory behaviours are managed by ignoring, time-out, and the delivery of a loud 'no' or slap on the thigh. However it should be noted that the use of aversives is no longer recommended as part of the Lovaas program (Schopler, 1998). The treatment strategy requires the presence of a therapist trained at the Lovaas Institute (McGahan, 2001).

Other ABA programs internationally include the Eden Programs, The Childhood Learning Centre, Yale Child Development, Bancroft, and Horizon. Another ABA approach is the Comparative Applied Behavioural Analysis to Schooling Program (CABAS).

In the Sydney metropolitan area, ABA programs are offered by four private service providers (Learning to Learn website, www.learningtolearnsydney.com.au, accessed August 2003). See also Appendix One Services in Australia for Children with Autism and their Families (NSW).

There are a variety of ABA curriculum instructional and training materials available for use by families and health care professionals. Social Stories and social skill development packages are also behavioural interventions used with children with autism (Heflin & Simpson, 1998) (see communication section).

Research Evidence

In this section the research studies reporting on, a) The Lovaas Program and other intensive IBI programs are discussed, including the claims and counterclaims for the outcomes of the programs focusing on issues such as 'recovery rate' from autism and the intensity of the programs, b) research into outcomes of parent managed home-based programs in the United Kingdom is presented, no research into outcomes for parent managed home-based programs in Australia was found, c) research evaluating other behavioural interventions is briefly reviewed, d) conclusions and emerging trends in behavioural intervention are presented.

The Lovaas Program and other Early Intensive Behavioural Interventions

In 1987, Lovaas published his report of research conducted with 38 children with autism. The children were divided into 2 groups, an experimental group of 19 children and a control group of 19 children. The experimental group received one to one behavioural treatment using methods of applied behaviour analysis for 40 hours per week over 2-3 years. Treatment occurred in the home and school setting. The control group received 10 hours of treatment a week or less. There was a second control group in this study of 21 children with autism who were followed over time by a nearby agency but who were never referred for this study, giving a combined total of 40 control participants.

All of the children in the study were re-evaluated between the ages of six and seven by independent evaluators who were blind as to whether the child had been in the treatment or control groups. The findings of the study are set out below:

> In the treatment group, 47% passed "normal" first grade and scored average or above on IQ tests. Of the control groups, only one child had a "normal" first grade placement and average IQ.

> Eight of the remaining children in the treatment group were successful in a classroom for children with language disorders and scored a mean IQ of 70 (range = 56-95). Of the control groups, 18 students were in a class for children with language disorders (mean IQ = 70).

> Two students in the treatment group were in a class for children with autism or intellectual disability and scored in the profound intellectual disability range. By comparison, 21 of the control students were in a class for children with autism and intellectual disability with a mean IQ of 40.

> In contrast to the treatment group, which showed significant gains in tested IQ, the control groups' mean IQ did not improve. The mean post-treatment IQ was 83.3 for the treatment group, 53.3 for the control groups.

McEachin, Smith and Lovaas (1993), investigated the nine students who achieved the best outcomes in the 1987 Lovaas study. After a thorough evaluation of adaptive functioning, IQ and personality conducted by professionals blind as to the child's treatment status, evaluators could not distinguish treatment subjects from those who were not (i.e. typically developing adolescents).

The Murdoch Early Intervention Program
The Murdoch Early Intervention Program (Birnbrauer & Leach, 1993) set out to replicate the EIBI designed by Lovaas. There were 11 participants aged from 24 to 48 months at the start of the study. The goal of the program was to provide an intensive program of 30

hours per week, however this proved difficult to achieve, the range of hours provided was 8.7 – 24.6 with a mean of 18.7 hours per week. Four of the nine children in the experimental group and 1 from the control group made substantial improvements within 24 months, although scores continued to be below average and children continued to display 'autistic' characteristics.

Smith (1996) reviewed studies (published prior to 1996) which met the criteria of including: Children averaged five years of age or younger at treatment onset; children receiving direct services as part of a study, comprehensive services aimed at addressing multiple problems, reporting of data on treatment outcome, and appearance in a peer-reviewed journal. Based on these criteria, Smith reviewed 12 peer-reviewed outcome studies that included nine studies of behaviour intervention programs. Smith reviewed the results found for the UCLA Young Autism Project (see The Lovaas Program above) and partial replications of the UCLA project come from the May Centre, Murdoch University (Western Australia, see above), and the University of California San Francisco (UCSF). Services at these sites were less intensive, averaging 18-25 hours per week, and less frequently supervised than services at UCLA; however, children at these other sites displayed gains. While small in number, the children receiving 25 hours per week of intervention in the UCSF study scored an average of 28 IQ points higher than those who were matched on cognitive ability and mental age, yet did not receive such treatment. Two-year follow up at the May Centre revealed average increases of 20-22 points. At Murdoch, less improvement was noted; the results may be attributed in part to staffing problems. The programs Douglass, LEAP and Princeton Child Development Program (PCDI) were school based, with 15-27.5 hr/week of service. Children in the school-based programs tended to enter group settings at an earlier stage than did children in home-based settings. The most favourable outcomes occurred in programs that provide the most intensive services; otherwise, no clear correlations were evident among treatment intensity, treatment model and outcome (McGahan, 2001).

Anderson, Avery, Dipietro, Edwards and Christian (1987), who applied the Lovaas treatment method more rigorously than any but the original trial itself, concluded that while 6 of 14 children studied showed IQ gains of 20-22 points over 2 years, all children continued to need special education services and none were mainstream in a regular kindergarten or school.

Two other uncontrolled studies, Harris, Handleman, Kristoff Bass and Gordon, (1990) and Fenske, Zalenski, Kranz and McClannahan (1985), reached similar conclusions. Harris et al. (1990) report on a centre-based intensive behavioural therapy program for nine children after one year, and conclude that "all treated children continued to demonstrate impairments after treatment" (p175). Fenske et al., (1985) reported on nine pre-school children after 2 years of intensive treatment at the Princeton Child Development Centre.

Smith (2000) reports on a randomised trial of intensive early intervention for children with Pervasive Developmental Disorder. He compared groups of participants who were randomly assigned to intensive treatment groups (using the Lovaas treatment manual) or

parent training groups. The intensive treatment group averaged nearly 25 hours per week of treatment for 12 months, gradually reducing hours over the next 1-2 years. The parent training group received 3-9 months of parent training. At follow-up the intensive treatment group scored significantly higher than the parent training group on measures of intelligence, visual-spatial skills, language and academics. There were no significant differences for adaptive functioning or behaviour problems. Participants with less severe forms of autism (PDD-NOS) appear to have gained more. While outcomes for the treatment group were favourable the differences between the groups were not as large as those reported in earlier studies such as that by McEachin et al., (1993).

Specific Concerns about the Lovaas and McEachin Studies

These studies have generated considerable controversy and criticism, primarily because one at least (Lovaas, 1987), claims to have 'cured' or 'recovered' children from autism. The Lovaas study in particular has been subjected to a great deal of critical evaluation, the main points of which are set out below. It should be noted that more recent studies of intensive behavioural programs (Smith, 2000) do not claim to have 'recovered children from autism'.

Jordan et al (1998) details many of the criticisms of the Lovaas (1987) study and the McEachin et al. (1993) follow-up study. The key criticisms can be summarised as follows:
- The treatment for Control Group 1 was delayed so that they were 6 months on average older when their treatment started
- The two outcome measures used (IQ and educational placement) are gross measures and do not reflect improvements in the key areas of difficulty in autism
- The IQ of the children is assessed with 7 different tests with publication dates and norms from 1948-1974. Even more crucially, the same test is not necessarily used with the same child at follow up (either at 7 years old or at later follow-up)
- There is a discrepancy in the long-term follow-up data in the time period considered for the two groups; Control group 1 is followed up at 6-14 years of age, whereas the experimental group ages at follow up are 9-19 years making comparison unreliable
- There are doubts about the matching of the experimental and control groups. At a gross level, there are many more girls in the control group and this may introduce bias
- The allocation of children to different groups for treatment was less than random assignment (Gresham & MacMillan, 1998; Rutter, 1996; Schopler, Short & Mesibov, 1989). However, Lovaas' (1989) rejoinder that random assignment is seldom appropriate (in terms of practicality and ethics) in educational research is reasonable. The problem is that the groups used in the Lovaas study are only matched on gross (and somewhat inadequate) measures, so that systematic bias remains a possibility
- Fifteen per cent of the referred children were excluded on the basis of their prorated mental age (PMA), which affect its interpretation and generalisation to

other children with autism. Thus, the findings are not representative of *all* children with autism

- In the experimental group that excluded 16% of the referred children, less than half showed 'recovery' and there are no indications of the child variables that affected this outcome

General issues arising from the evaluation of EIBI programs and the Lovaas Program in particular.

Staff expertise.
Smith (1993) emphasises the importance of prolonged and expert training for therapists. This may not be generally available. There are issues of the expertise, training and close supervision required to maintain treatment integrity. Smith (2000), suggests that staff shortages, scheduling conflicts and illness make the logistics of arranging for intensive treatment 'formidable…and may pose more of an obstacle to replication than …previously acknowledged" (p283). The difficulties in finding adequately trained and experienced staff is also highlighted in a review of parent managed IBI programs in the UK (Mudford, Martin, Eikeseth & Bibby, 2001).

The use of aversives
Lovaas (1987) himself states that,

> ...In the within-subjects studies that were reported, contingent aversives were isolated as one significant variable. It is therefore unlikely that treatment effects could be replicated without this component.   (p.8)

In the Lovaas, Smith and McEachin (1989) response to the Schopler, Short and Mesibov (1989) criticisms, the authors specifically claim the use of contingent aversives as one of the distinguishing factors that can account for the success of this program over others. Current statements about Lovaas style EIBI programs emphasise that aversives are no longer used (Schopler, 1998). This is acceptable on ethical and legal grounds, but it does mean that current interventions do not have the treatment integrity of the original study and this in turn undermines the claimed scientific basis of the treatment.

Intensity of IBI programs
There is no conclusive evidence for the optimal intensity of IBI/EIBI programs. Several researchers have suggested that the smaller gains made by the participants in their studies compared to the original group in the Lovaas study (1987) were a result of less hours of treatment per week (Anderson, et al, 1987; Smith, 2000; Sheinkopf & Siegel, 1998). For example participants in two controlled trials of Lovaas therapy (Birnbauer & Leach, 1993; Sheinkopf & Siegel, 1998) failed to achieve 'a normal development stage' by the end of therapy. In both these instances the children received about half (20 hours per week) the intervention intensity described in the original Lovaas study (1987). The authors attribute this reduced effect to the reduced intensity of the program however there are other potential contributing variables in addition to the issues related to the claims of 'recovery' and the achievement of 'normal functioning'.

Claims for 'recovery'

Claims for 'recovery' or 'cure' have led to the most controversy. There seems little contention that IBI programs produce positive outcomes for children with autism. Mesibov (1993) states that it is not surprising that such intensive intervention should result in positive and lasting results, particularly as behavioural approaches have been used effectively with children with autism for many years. Green, (1995) in a systematic review of Lovaas treatment states that "applied behavioral analysis is the treatment of choice, … should have at least 30 hours of 1:1 therapy per week by individuals with extensive training" (p. 42). However the extent of the positive outcomes reported in studies of some IBI/EIBI programs, particularly those that claim to produce 'normal' functioning is frequently questioned. BCOHTA (2000) states Lovaas and his research colleagues have not limited their effectiveness claims to achieving developmental gains. Instead, they have permitted and even fostered the premise that appears throughout the published literature associating their therapy with a notion of achieving 'normal functioning' for as many as half a given population of children with autism. Mesibov (1993) also queries the magnitude of the changes reported by Lovaas (1987) and McEachin et al. (1993) and what they mean. More recent evaluations have been unable to replicate the magnitude of the gains made by the participants in the original Lovaas study (1989). (See above). Tristan Smith, a co-author of the McEachin study along with Lovaas, provides a somewhat more cautious interpretation of the research evidence in terms of achieving normal functioning: "It is encouraging that debates over how much and what kind of early intervention children with autism should receive have largely replaced debates over whether such intervention merits particular attention at all." (p. 45). He also states in relation to his study (McEachin et al., 1993) that while.

> … some outcome studies indicate that a major breakthrough may have occurred. Nevertheless, these studies require replications with improved research methodologies and, even if interpreted in the most favorable possible light, reveal substantial shortcomings in the interventions under investigation. Therefore, much research remains to be done (p. 42).

Definition of 'normal functioning'

Mundy(1993) takes issue with the fact that McEachin et al. (1993) describe their best outcome group as having 'normal functioning'. He cites the work of Dykens, Volkmar and Glick (1991) and of Szatmari, Bartolucci, Bremner, Bond and Rich (1989) which shows that high-functioning people with autism may display relatively good adaptive skills and social outcome, yet still have a significant disability related to unusual thought processes and obsessive thoughts and concerns.

It is noted that in a more recent publication, Smith, McEachin and Lovaas comment on the Lovaas 1987 study:

> First, our best-outcome subjects appear to have made significant gains. Second, we have made a plausible case for attributing these gains to our treatment instead of extraneous factors such as spontaneous recovery. Third, this finding needs to be replicated because no single study by itself can give conclusive evidence on the efficacy of a treatment. Finally, replications should not simply rehash what has already been done (BCOHTA, 2000).

Howlin (1997) concludes:

> For the present, Lovaas program clearly confirms the power of behavioral interventions. The true extent of the benefits, however, still requires greater exploration and longer term evaluations, covering many other aspects of functioning are needed if the true cost-effectiveness of the time, effort and energy expended by families is to be adequately assessed. (p.10).

Research into Parent Managed Home Based Behavioural Interventions

In a study summarising child and program data from 75 young children with autism receiving IBI through 25 individual behavioural consultants in the UK, the authors (Mudford, Martin, Eikeseth & Bibby, 2001) found that the majority of children started treatment later than in the Lovaas study (1987) and 16% failed the minimum IQ criterion. Children experienced fewer hours of treatment (mean 32 hours per week compared to 40 hours) in their programs and were relatively infrequently supervised. Only 21% of the programs received supervision from individuals accredited to provide the Lovaas program. They conclude that none of the IBI programs in their sample were following the UCLA program that produced the 1987 results with the potential outcome that the UCLA levels of 'normal functioning' were unlikely to be replicated. This study demonstrated the difficulty inherent in faithful replication of the Lovaas program outside a university setting. This has significant implications for the potential outcomes of parent managed home-based IBI programs and suggests that parents who initiate and manage these programs may require more assistance from IBI service providers to bring their children's programs closer to the empirically supported UCLA protocols. Johnson and Hastings (2002) examined facilitating factors and barriers to the implementation of home based IBI programs and found that recruiting experienced, trained staff, funding and personal/family resource constraints were the most frequently cited barriers; while a supportive committed team, financial resources and the support of family and friends were the most frequently cited facilitators. The program team was the most frequently cited barrier and facilitator. In particular the paucity of supervisory and consultant level staff with ABA expertise was found to be a problem.

In a second study Bibby, Eikeseth, Martin, Mudford and Reeves (2002) examined outcomes for the group of parent managed behavioural interventions in the UK in the study discussed above and analyse outcome data after a mean of 31.6 months of intervention. There was no change in IQ scores, scores of adaptive functioning

(Vineland) had increased significantly as had scores of mental age (Merrill Palmer). No children had attained 'normal' functioning'.

Research evaluating other behavioural intervention programs

There is a vast body of research in different disciplines dealing with the theory and practice of behavioural intervention. Documentation of the efficacy of behavioural interventions with people with autism emerged in the 1960s, with comprehensive evaluations beginning in the early 1970s.

DeMeyer, Hingtgen and Jackson (1981) reviewed over 1,100 studies that appeared in the 1970s. They examined studies that included behaviourally based interventions as well as interventions based upon a wide range of theoretical foundations. Following a comprehensive review of these studies, the authors concluded

> . . .the overwhelming evidence strongly suggest that the treatment of choice for maximal expansion of the autistic child's behavioural repertoire is a systematic behavioural education program. (p.435).

Baglio, Benavidiz, Compton, Matson, and Paclawskyj (1996) reviewed 251 studies of behaviourally-based interventions with people with autism from 1980 to 1995, noting in their review that categories of target behaviours included; aberrant behaviours (i.e. self injury, aggression), language (i.e. receptive and expressive skills, augmentative communication), daily living skills (self-care, domestic skills), community living skills (vocational, public transportation and shopping skills), academics (reading, maths, spelling, written language), and social skills (reciprocal social interactions, age-appropriate social skills) (MADSEC). Mesibov (1998) concludes that of all the interventions available to date for children with autism evidence suggests that behavioural interventions have been the most effective to date. This includes the early behavioural programs emphasising operant conditioning and more recently developed cognitive behavioural approaches focusing on observable behaviours and following learning theory.

Conclusions

It is essential to specify the nature of the behavioural intervention being discussed. Behavioural interventions may range from a social story to a discrete trial training program but all behavioural interventions have in common the underlying assumption that the symptoms associated with autism can be reduced by manipulation of the observable interaction between the individual and his/her environment and in particular by the objective measurement of change in observable behaviour.

There is universal agreement that behavioural interventions have produced positive outcomes for children with autism that are well supported by research. However there continues to be a great deal of controversy about particular behavioural interventions and programs and differences in the interpretation of research findings. IBI/EIBI programs

exemplified by the Lovaas program which use ABA and DTT are among the most controversial intervention strategies for children with autism. This controversy revolves around outcome claims, exclusivity, extensive use, and personnel. There is controversy as to whether ABA and DTT can lead to recovery. Controversy related to exclusivity pertains to whether ABA and DTT should be used to the exclusion of all other methods. While 40 hours of weekly DTT has been used, controversy exists regarding the extensive use of DTT and the appropriateness for some children and families. Most communities lack the resources, and families experience limitations that prevent delivery of services as intensive as those of Lovaas (1987). Issues related to personnel have also made ABA and DTT controversial, in that school administrators are being requested for one-to-one implementation of DTT programs in cases where such intensity may not be appropriate for the child. Concern has been raised about the changes to contemporary ABA programs from the traditional approach, as well as the contributions of different disciplines and intervention approaches. Additional concerns have been raised on the tenet that ABA can be used to address virtually all aspects of the challenges associated with autistic spectrum disorder when minimal consideration has been given to the fact that different abilities and challenges may require different intervention approaches.

The authors of the BCOHTA (2000) systematic review draw the following conclusions in relation to IBI programs:
- The Lovaas (1987) and McEachin et al. (1993) studies, while methodologically stronger than published reports of alternate comprehensive therapies, are inadequate to establish the degree to which this form of therapy results in children achieving 'normal' functioning, however defined.
- There is insufficient evidence of effectiveness to establish a relationship between the amount (per day and total duration) of any form of early comprehensive treatment program and overall outcome.
- Randomized trials of alternative early intensive treatment programs are ethical and feasible to advance research knowledge.
- There is insufficient evidence of effectiveness to conduct a cost-benefit analysis of early, intensive treatment programs in terms of 'normalization' of children diagnosed with autism. It remains the case that without a soundly based determination of the extent to which the intervention may result in benefit, and the degree of any such benefit, cost-benefit analyses have no basis on which to proceed. (BCOHTA, 2000)

Emerging Trends in Behavioural Interventions

Current and emerging trends in ABA include positive behavioural support, functional assessment and functional communication training.

Positive Behavioural Support
(PBS) is a process whereby individuals are assisted in acquiring adaptive, socially meaningful behaviours and encouraged to overcome maladaptive behaviours. The primary goal of positive behavioural supports is to teach functional skills as a replacement for problem behaviour. Positive behavioural support plans typically involve

changing existing environments in a manner that makes problem behaviours irrelevant, ineffective and inefficient (Horner, O'Neill & Flannery, 1993). ABA based methods of instruction are emphasized within positive behavioural support interventions to increase pro-social behaviour, while concurrently decreasing maladaptive behaviours.

Functional assessment
Functional Assessment is the process of gathering information that can be used to maximize the effectiveness and efficiency of behavioural support interventions. Primary outcomes of functional analysis include: a description of the problem behaviour; identification of events, times and situations predictive of problem behaviour; identification of consequences that maintain behaviour; identification of the motivating function of behaviour; and collection of direct observational data (O'Neill et al., 1997).

Several studies have demonstrated that interventions based on the results of comprehensive functional assessments have a much higher probability of being effective than those interventions based upon traditional forms of assessment (e.g., norm-referenced, intellectual/achievement/behavioral, projective personality, anecdotal observations and unstructured interviews) (Repp, Felce & Banton, 1988; O'Neill, et al., 1997).

The goal of *functional communication training* is to teach an individual to use appropriate communication to obtain a desired item instead of engaging in problem behaviour. "Errorless" teaching used in some programs is used to teach new or challenging information or skills. ABA is used to maximize learning by ensuring that the individual experiences success and is somewhat dependent upon the skill and expertise of both the program developer and the therapist (see section on Communication therapies).

Contemporary Applied Behaviour Analysis approaches: Incidental teaching Natural Language Paradigm (NLP) Pivotal Response Training (PRT)

In response to the problem of lack of generalisation of trained skills noted time and time again in the behavioural literature, behaviourally oriented researchers introduced teaching strategies in the 1980s that diverged significantly from earlier discrete trial traditional behavioural (DT-TB) approaches. Incidental teaching (Hart, 1995), NLP and PRT were developed as methods of achieving a more naturalistic approach to enhancing language and communication development for children with autism. These approaches were based, in part, on principles and interactive processes drawn from the developmental literature on caregiver-child interaction and developmental pragmatics, as well as ABA (Wetherby & Prizant, 2000). The most striking differences between DT-TB approaches and contemporary ABA approaches are as follows:

- The control of the interaction is either shared or shifted from the trainer to the child. Child preferred and child selected activities provide the primary contexts and topics for communication exchange.
- Choices are offered rather than trainer imposed selections.

- Play and group therapy incorporating PRT (Schreibman & Pierce, 1993) focuses on increasing motivation to learn in children with autism by allowing them choices, reinforcing attempts at correct responding, using adequate modeling, and providing natural consequences (Dempsey & Foreman, 2001).

PRT has also been used to assist participants to develop an understanding of social roles and social events. Positive changes have been reported in play, language and social skills, but with limited generalisations to others and to other settings (Thorp, Stahmer, & Schreibman, 1995). Interestingly Sigman (1998) contends that "representational play skills as a predictor of gains in language over time has strong theoretical and empirical support" (p. 822).

Naturalistic/Developmental/Interventions

Generally naturalistic interventions follow a developmental approach, which is relationship based and aims to help the child to learn to,

> attend, relate, interact, experience a range of feelings, and, ultimately, think and relate in an organized and logical manner (Atchison et al., 1997, p. 50).

Naturalistic interventions are also known as normalised interventions.

Developmental Social-Pragmatic Model (DSP).

DSP approaches take a step further than the contemporary ABA models in the emphasis on the importance of initiation and spontaneity in communication, following the child's attentional focus and motivations, building on the child's current communicative repertoire even if this is unconventional and using more natural activities and events as contexts to support the development of the child's communicative abilities (Wetherby & Prizant, 2000). DSP approaches are defined by the following characteristics:

- The focus is on enhancing spontaneous social communication within a flexible structure and varied and motivating activities
- There is an emphasis on building multimodal communicative repertoires (e.g. speech, gestures, Augmentative and Alternative Communication (AAC) to enable children to have a range of strategies to express intentions (see section on communication programs)
- The extent to which possible interactions are characterised by; shared control, turn taking, and reciprocity
- Learning contexts involve meaningful activities or events, chosen for interest and motivation
- The relevance of the child's response is considered in reference to the ongoing context and activities, including acknowledgment of unconventional means or behaviours as legitimate attempts to communicate
- Use of a variety of social groupings is desirable because the child's life experiences will involve increasingly complex social experiences
- Information about sequences and processes of child development is used to frame the sequence of goals and to measure progress in a broader developmental context
- Contextual (visual, gestural) supports are seen as essential to help children make sense of activities and interactions rather than to 'strip down' learning contexts
- There is a focus on helping children acquire socially acceptable means for social control (e.g. means to protest, means to make choices) to preclude behavioural difficulties
- Emotional expression and affect sharing are seen as central to the interactive and learning process

The DSP approach differs from the contemporary ABA approach in its emphasis on research of sequences of language development in children with autism, reduced emphasis on eliciting and measuring discrete trial behavioural responses as a primary measure of success. Rather DSP focuses on successful participation in extended interactions as the measure of success. DSP targets multiple goals within one activity rather than counting isolated behaviours and focuses on the interdependency of different aspects of development. DSP places greater emphasis on enhancing communication abilities within meaningful events and routines and finally most DSP approaches emphasise developing communication skills within the context of developing relationships and socio-emotional growth. In contrast the role of affect and emotional expression in motivation and learning is minimised in contemporary ABA as well as traditional behavioural approaches (Wetherby & Prizant, 2000).

Delprato (2001) completed a review of the literature comparing DT-TB approaches and 'normalised language interventions' and concluded that "normalised language intervention' seems capable of producing more successful acquisition and generalisation performance" (p 322) when compared with discrete trial training. In addition, studies reviewed by Delprato, such as Koegal, Bimbela and Schreibman (1996;) and Schreibman, Kaneko and Koegel (1991) found that naturalistic interventions had a positive effect on the parents of children with ASD. Parents using naturalistic techniques were happier, less stressed and communicated better with their child than parents trained in discrete trial training (Koegal et al., 1996).

Greenspan's DIR/"Floor Time"

Over the past 20 years, Stanley Greenspan and colleagues have published numerous articles on theories of child development. Only one relates specifically to children with autism; others may include references to autism among an array of disabilities. At the National Centre for Clinical Infant Programs, Greenspan and colleagues have worked with children with a wide range of disabilities from infancy through to age 10. Greenspan and others have created a developmental approach for early intervention with infants and children with disabilities, titled Developmental Individual-Difference, Relationship-Based Model (DIR). This is also commonly referred to as the "Floor Time" approach (Greenspan, 1998).

Floor Time is based upon Greenspan's theories of six functional milestones necessary for a child to succeed in further learning and development. According to Greenspan, these are:
- The dual ability to take an interest in the sights, sounds and sensations of the world and to calm oneself down
- The ability to engage in relationships with other people
- The ability to engage in two-way communication with gestures
- The ability to create complex gestures, to string together a series of actions into an elaborate and deliberate problem-solving experience
- The ability to create ideas

- The ability to build bridges between ideas to make them reality-based and logical (Greenspan, 1998)

DIR/Floor Time includes interactive experiences, which are child directed, in a low stimulus environment, ranging from two to five hours a day. During a preschool program, DIR/Floor Time includes integration with typically developing peers. Greenspan contends that interactive play, in which the adult follows the child's lead, will encourage the child to "want" to relate to the outside world. Furthermore, Greenspan stipulates "In this model, the therapeutic program must begin as soon as possible so that the children and their parents are re-engaged in emotional interactions that use their emerging, but not yet fully developing capacities for communication (often initially with gestures rather than words). The longer such children remain uncommunicative and the more parents lose their sense of their child's relatedness, the more deeply the children tend to withdraw and become perseverative and self-stimulatory" (Greenspan, 1998).

According to Greenspan (1998), intervention must "transform this perseveration into interaction". Once this occurs, Greenspan theorizes that the child becomes purposeful, and can imitate gestures, sounds and play. Greenspan reports,

> We have worked with a number of children diagnosed with autism or PDDNOS between the ages of 18 and 30 months who, now older, are fully communicative (using complex sentences adaptively), creative, warm, loving, and joyful (p.3).

There appear to be no independent peer-reviewed, published studies of Greenspan's DIR/Floor Time's effectiveness for children with autism.

In NSW DIR is available in the Sydney metropolitan area. "Theraplay" is the name of the program. See table of Programs for contact details, no web site available.

Relationship Development Intervention

Relationship Development Intervention (RDI) (Gutstein, 2000; Gutstein & Sheeley, 2002) is a series of techniques and strategies built upon the typical developmental processes of social competence. The goal of RDI is to increase motivation and interest in social relating in individuals with autism and provide activities and coaching to assist them to enjoy and become competent in social relationships. There are 6 levels in RDI: Novice, Apprentice, Challenger, Voyager, Explorer, and Partner, which are subdivided into a total of 24 developmental stages. Programming is individualised and based on the Relationship Development Assessment designed by Gutstein. Once a child's relationship level is determined, an individualized program is prepared, and coaches are trained to implement the program and support the acquisition of skills. To date there is no published research regarding the efficacy of this approach, though Gutstein suggests it might be a useful approach for higher functioning children and adolescents with ASDs, or for lower functioning children after they have learned some basic relating through IBI. The effectiveness of this should be carefully evaluated for the individual child, and because of

lack of empirical evidence, it should be considered an adjunct to other interventions proven effective (Perry & Condillac, 2003).

Learning Experiences-An Alternative Program for Preschoolers and Parents (LEAP)

LEAP is a comprehensive preschool service, developed in Pennsylvania, by Phillip Strain, designed for both children with autism and typically developing children. LEAP has the components of an integrated preschool program and a behaviour skills training program for parents. The program contains aspects of behavioural analysis, but it is primarily a developmentally based approach. Services include parent involvement and training. The program does not provide one-to-one intervention; instead services consist of 15 hours per week of classroom instruction provided by a teacher with a master's degree and an assistant who both implement the program with 10 typically developing children and 3-4 children with autism. A full time speech therapist and contracted occupational and physical therapists also work with the children in specially arranged classrooms designed to support child-directed play. Individualised curricula are updated every 4 weeks. The primary goals of the curriculum is to expose children with autism to typical preschool activities and to adapt the typical curriculum for the children with autism only when necessary. Independent play skills are facilitated by using peer models and by prompting, fading and reinforcing target behaviours (Strain & Hoyson, 2000).

There appear to be no independent peer-reviewed, published studies of LEAP's effectiveness for children with autism.

Combined Therapy Approaches

Communication therapies

Visual strategies & visually cued instruction

While not a program in itself, the use of visual strategies as part of communication and behaviour programs may be of benefit. Quill (1997) outlines the rationale for using visual strategies for a variety of activities. She suggests that the use of stable, iconic symbols match the processing style strengths and cognitive profile features of children with autism, such as difficulty shifting attention, better visuo-spatial skills than auditory skills and better memory for non-verbal material. In addition, Tager-Flusberg, (1991; cited in Quill, 1997) found that retrieval cues supported children's recall of language information and thus visuals may have a facilitating effect on language and conversation. Visual strategies also play a major role in several programs for children with autism including the SCERTS program and the Division TEACCH program discussed in the section 'Combined Approaches' and the behaviourally oriented PECS program described below.

Augmentative communication

Although augmentative systems of communication (e.g. sign, pictures, symbol or written words) are generally used as an alternative to, or a precursor of, speech in children who have no or inadequate spoken language skills, they have an additional role in autism. Even when children with autism have apparently good speech, comprehension may be poor and speech may not focus attention or be as meaningful to the child with autism as a visual form of communication. Written language may serve the same purpose for the more able child with autism or Asperger syndrome. Augmentative systems of communication in autism, then, would be used not just to replace speech, but to assist learning and communication, regardless of the level of speech. Augmentative communication systems are forms of visual support (see above). Mirenda and Schuler (1989) point out that in order for teaching communication skills to children with autism to be successful, there needs to be a strong communicative foundation for these skills.

> It is simply not sufficient to teach individuals with…limited interest in communication how to say or sign something, or how to point to or show a picture or another visual display. Instead attempts should be made to extend the current nonverbal means and to diversify the existing communicative functions across contexts (p.29).

Jordan et al (1998) report that in the UK signing was the most common form of augmentative system used in the 1990's by people with autism, at least in those with additional learning difficulties, Makaton (Walker, 1980) was the most common form used. The use of signing with people with autism has been advocated (Jordan, 1985) but

there are also reservations (Jordan, 1993) and it is generally regarded as only marginally easier to understand and use than spoken language for many people with autism (Peeters, 1997). Jordan (1998) suggests that symbols, pictures, photographs and objects of reference, however, are all well established as helpful for people with autism in supporting the comprehension of what is said and in getting needs met. The use of 'visual supports,' that is, visual means of communicating and of facilitating the person with autism's ability to understand and function in their environment, is fundamental principle of programs such as the TEACCH program reviewed below.

Picture Exchange Communication System (PECS)

Picture Exchange Communication System (PECS), developed by Bondy and Frost in 1994 (Bondy & Frost, 2002) is a program that teaches children to interact with others by exchanging pictures, symbols, photographs or real objects for desired items. The goals of PECS include the identification of objects that may serve as stimuli for each child's actions and the learning of responses to simple questions with multi-picture systems. It is a highly structured program that uses behaviourist principles of stimulus, response and reward to achieve functional communication. The program claims to teach children to initiate communication and to generalise these skills to a variety of objects and communicative partners (Schwartz, Garfinkle & Bauer, 1998). The manual that accompanies this method of teaching describes procedures as empirically tested and describes very positive results (Atchison et al., 1997; Bondy & Frost, 1994). The PECS is an example of a behaviourist program that uses ABA to teach functional communication via the strong visual modality characteristic of children with autism. This is in contrast to the oral/aural focus on speech development of the more traditional behaviourist programs (e.g. Lovaas, 1987).

There are few well controlled studies that have evaluated PECS. Schwartz, Garfinkle & Bauer (1998) conducted two studies that looked at the rate of acquisition of PECS and the program's effect on communication across settings and modalities in children with a range of disabilities including autism. All the children mastered the stages of PECS but the study was limited by the lack of a control group, the reliance on pre-school records for information and the heterogeneous group of children studied. The second study indicated that the children increased their communicative functions and showed generalisation to settings outside the teaching situation. About half of this group developed spontaneous speech by the end of the PECS training and were found to continue to make gains in their verbal skills during observations after the end of the PECS teaching. Charlop-Christy, Carpenter, Loc, LeBlanc and Kellet (2002) studied three children with ASD to determine the rate of acquisition and the effect on the children's verbalisations. They found that the three children acquired the skills in an average time of 170 minutes and the all three children showed increases in their mean length of utterance. The findings of increased verbal speech in the latter two studies is an interesting phenomena given that functional communication, rather than verbal speech is the aim of the program and that the program has been criticised for the lack of emphasis on verbal skills (Richards, 2000).

Social Stories

Social stories were originally developed by Carol Gray (The Gray Center website, 2002) in order to explain social situations to children with autism and help them to learn appropriate responses to social cues. A basic social story consists of descriptive sentences, which help children understand and pick up on cues in their environment (e.g., *"The bell rings and then the children go to class")*, perspective sentences that explain how the situation affects other people (*"My teacher is happy when the children listen"*) and directive sentences that tell children how to respond (*"I can try to use a quiet voice in class").* While social stories may help to teach children with autism how to manage their own behaviour, there are few independent empirically sound studies into the efficacy of this approach.

Richards (2000) suggests that social stories can be effective with a range of children and situations but cautions that children's comprehension of the language and format of the story must be carefully evaluated and the story adjusted appropriately. Richards (2000) also points out that as the social story format is published and accessible, teachers, parents and professionals alike are able to learn and apply the format.

Facilitated Communication

Facilitated Communication (NAS, 1994) is a form of assisted communication first introduced to the US in 1990 by Donald Biklin. It is based on the work of Rosemary Crossley in Victoria with people with cerebral palsy. Crossley's therapy involved teaching communication by physically prompting to form a pointing finger, supporting the hand as a point is made and assisting withdrawal from the point. The rationale for the therapy was based on the difficulty experienced by people with cerebral palsy in making and controlling movements. The claim that communicative purposes and thoughts of the person with a disability can be revealed if sensitive support is given to directing hand movements, has received widespread publicity and led to considerable controversy. Biklin and others proposed that people with autism could also communicate using FC. Proponents proposed a reconceptualisation of autism (Mesibov, 1997). Autism was suggested to be primarily a motor disorder involving difficulty producing voluntary movement, (apraxia) and therefore precluding the production of speech (Howlin, 1997). Rather than accepting that 70% of people with autistic disorder also have intellectual disability, proponents suggested that FC reveals at least average intelligence and great sensitivity in virtually all people with autism (Mesibov, et al 1997).

The person with autism is facilitated to point to a communication board or (more commonly) to type using a word processor and under such facilitation people with autism without speech have 'written' about a range of esoteric topics, including their distress at being 'locked inside their own body'. The aim is usually not to produce independent typing or pointing but to 'release' the hidden potential through a facilitator. Many professionals and parents initially believed (and some still do) that the person with autism

was the author of the work. Others had strong doubts, however. At the peak of its use in some states in America, children with autism, who had been assessed as having additional severe learning difficulties and who had no speech, were being taken out of special schools and put into mainstream classes to follow an age-appropriate mainstream curriculum with the help of their facilitator.

Extensive research has been done to determine the efficacy of FC for people with autism. No evidence has been found of consistent, useful or spontaneous communication using this method (Edelson, Rimland, Berger & Billings, 1998). Howlin (1997) reviewed the research into the efficacy of FC and found that across 45 studies independent communication was confirmed in only 6% of a total of 359 participants in that in the majority of the 6%, responses were often only partially correct and generally consisted of minimal one word answers. Howlin concludes that the negative outcomes associated with the widespread use of FC (in the US and UK) are cause for major concern. These outcomes include increasing passivity, channeling of educational resources to FC to the detriment of other programs, unrealistic mainstreaming of students and most disturbingly unfounded allegations of physical/mental/sexual abuse against parents or carers. As a result of these concerns in 1994 the American Psychological Association adopted the resolution that 'Facilitated Communication is a controversial and unproved procedure with no scientifically demonstrated support for its efficacy.' Jordan (1998) points out that in the UK, FC has been tried by some schools and parents as another tool to foster communication. Other parents (not involved in Facilitated Communication) have reported anecdotally, that their child appears to be helped to write if they place their hand on their arm or shoulder. At least one university department is researching the processes involved (Grayson & Grant, 1995).

Functional Communication Training (FCT)

FCT is a behavioural strategy for teaching people with autism to use signs or other AAC techniques as substitutes for the 'messages' underlying their challenging behaviour. FCT interventions teach the individual to communicate one or more functional messages, while at the same time they provide a positive alternative to his or her challenging behaviour(s). A review of FCT studies published between 1985 and 1996 (Mirenda, 1997) found that for those participants with autism, there was an immediate and substantial reduction in challenging behaviour after the FCT interventions were initiated. These gains were maintained for as long as 12 months for those participants for whom follow up data were available

Sensory/Motor Treatments

Introduction

Sensory integration is the ability to process, immediately and simultaneously, the many different sensory messages that result from even the simplest action. It has long been established that children with autism have problems in dealing with complex sensory stimuli and that they may be sensitive to particular kinds of stimuli such as noise or texture (Howlin, 1997). Children with autism appear to have difficulties modulating their response to sensory input and maintaining optimal arousal and focused attention. These deficits have been attributed to neuropathology of the limbic and cerebella brain systems. As many as 40% of children with autism are reported to have some form of sensory difficulty (Atwood, 1998; Rimland, 1990; Talay-Ongan & Wood, 2000). Some theorists suggest that it is always present in autism and that it is the primary deficit (Anzalone & Williamson, 1997). The sensory motor theory of autism proposes that motor problems in autism are related to praxis, the formation of a motor goal, the motor planning to carry out the goal and the execution of the motor movement to complete the goal. The cognitive and sensory characteristics of autism affect the first two steps in particular and can result in significant motor problems, or dyspraxia (Anzalone & Williamson, 1997). Developmental dyspraxia relates to fine and gross motor performance and in turn affects sensorimotor exploration, play and functional tasks. Oral/verbal dyspraxia interferes with the proper development of speech and eating skills.

Sensory Integration therapies

Sensory Integration (SI) therapy is a sensory-motor treatment based upon theories developed over the last 30 years by Dr. A. Jean Ayres. Proponents theorize that sensory integration is an innate neurobiological process (Hatch-Rasmussen, 1995), and that children with autism and other developmental delays experience dysfunction in which sensory input is not integrated or organized appropriately by the brain. Fisher and Murray (1991) describe sensory integration as both "a neurological process, and a theory of the relationship between the neurological process and behaviour." Sensory integration is described as providing the child with planned and controlled sensory experiences that aim to produce adaptive and functional responses to sensory stimuli (Dawson & Watling, 2000).

According to Fisher and Murray (1991) there are five major assumptions upon which SI theory is based. These are:

- there is plasticity within the central nervous system. Plasticity refers to the ability of the brain structure to change or be modified
- .the sensory integrative process occurs in a developmental sequence. In normal development, increasingly complex behaviors develop as a result of the circular process, and behaviours present at each stage in the

> sequence provide, in turn, the basis for the development of more complex behaviours
> - the brain functions as an integrated whole, but is comprised of systems that are hierarchically organized
> - evincing an adaptive behavior promotes sensory integration, and, in turn, the ability to produce an adaptive behavior reflects sensory integration
> - people have an inner drive to develop sensory integration through participation in sensorimotor activities (Fisher & Murray 1991).

Sensory integrationists theorize sensory dysfunction is rooted in the central nervous system, and that successful integration of sensory input requires treatment. This treatment is comprised of vestibular, proprioceptive, and/or tactile stimulation.

Ayres (1979) describes sensory integration therapy as sensory stimulation and subsequent adaptive responses which evolve according to the child's neurological needs. Therapy techniques include vestibular stimulation such as swinging in a hammock, and tactile stimulation achieved by brushing parts of the child's body (Smith, 1996). SI therapy is viewed as a direct intervention that can improve nervous system function. This is done by providing the child with enhanced levels of sensory information gleaned during physical activities that are meaningful to the child, and that elicit adaptive behaviors (Koomar & Bundy, 1991).

Sensory integrationists theorists also postulate that children with sensory dysfunction are either over- or under-responsive to sensory input. Children with autism may be startled by a slight sound (hypersensitivity), or may totally tune out external stimuli, such as language (under-responsive or hyposensitive). SI practitioners further postulate that self-stimulation and stereotypic activities characteristic of many autistic children may be related to sensory dysfunction, and that therefore SI therapy may reduce the rates of self-stimulation and self-injurious behaviors.

According to a critique by Arendt, Maclean and Baumeister (1988), SI therapy does not seek to teach higher order skills, but rather to rearrange brain functioning (sensory processing capability) as a precursor to learning. Arendt challenges basic SI theory in his critique; he also asserts that even if Ayres' theories of nervous system hierarchy and neural plasticity are valid, the SI treatment model does not inherently address them (Arendt et al, 1988).

Research into Sensory Integration

Despite recommendations for use of Sensory Integration therapy with children with autism (e.g. Mailloux, 2001; Richards, 2000) and anecdotal reports (e.g. Sachs, 1995), little experimental evidence of its benefits have been reported in the literature. Dawson and Watling (2000) reviewed the evidence regarding sensory integration, auditory integration and traditional occupational therapy and found only poor quality evidence

providing no, or at best equivocal support for Sensory Integration therapy and found no empirical evidence on the practice of occupational therapy in autism.

Ray, King and Grandin (1988) examined the effect of vestibular stimulation (swinging) on speech sounds in children with autism. The researchers found a 15% increase in vocalizations while the child was on a swing than in the absence of this vestibular stimulation.

Cook (1991) presents anecdotal case studies of on-task behavior and attending skills in three children with autism who received sensory motor interventions. Cook reported both teachers and parents noted significant improvements in both domains, in all three children. However, these reports are based upon parent and teacher impressions, not empirical data, and therefore could be vulnerable to reporter bias and failure to establish SI as an independent variable responsible for the reported improvement.

According to Murray and Anzalone (1991),

> care is required not to overstep the boundaries of sensory integration theory when applying these procedures to children and adults with autism (p.378).

In a study designed to test the effectiveness of SI on self-injurious behaviors (SIB), Mason and Iwata (1990) found that SI was less effective than behavioral treatment in reducing SIB; in one case, the rate of SIB actually increased with SI treatment. A review of the literature did not yield any study concluding SI is an effective treatment for SIB or self-stimulation.

Arendt et al (1988) examined the effectiveness of SI therapy as it applied to individuals with mental retardation. Arendt found that the database of studies was small, and that the methodology in most of the studies under his consideration had serious flaws. These flaws included examiner bias and uncontrolled variables.

Ottenbacher's analysis concluded that SI had a positive effect on the participants receiving the therapy (1982). However, he later reports that his study had several limitations associated with interpretation of the data (Ottenbacher, 1991); there was no consistency in participant's areas of improvement, and much of the sub-analysis was confounded. Ottenbacher concludes in a 1991 textbook on sensory integration,

> previous attempts to synthesize and interpret existing sensory integration research reveal that a clear empirical consensus does not exist regarding the validity of sensory integration theory, or the effectiveness of sensory integration practice (p.389).

Ottenbacher further concludes more research is needed to reach empirical consensus.

Smith examined several investigations evaluating SI's effectiveness for children with developmental disability (Smith, 1996). Smith concludes SI did not decrease self injury,

did not reduce ritualistic behaviors and did not show increases in motor development. Like Arendt, Smith concludes "studies on sensory integration therapy are sparse, but they have consistently yielded adverse findings" (Smith, 1996).

Conclusions

Current research does not support SI as an effective treatment for children with autism, developmental delays or intellectual disability; nor has the limited research to date been able to identify SI as an independent variable responsible for positive change in a child's behaviours or skills. In at least one study, SI was shown to actually increase self-injurious behaviors.

According to Smith (1996),

> Though Sensory Integration Therapy does not appear to enhance language, control disruptive behaviors, or otherwise reduce autistic behaviors, it may offer enjoyable, healthy, physical activity (p.50).

Anecdotal reports suggest SI may show promise, but it is not yet objectively substantiated as effective for children with autism subject to the rigors of good science. The lack of research supporting SI places the role of this therapy in the treatment of autism in a difficult position. It effectiveness is unsubstantiated at this point and yet SI therapy enjoys wide mainstream acceptance in NSW (e.g. Autistic Association of NSW services, Giant Steps).

Giant Steps
This program originated in Canada and has two centres in Australia in Sydney NSW and in Tasmania. Giant Steps uses a holistic overview integrating sensory-motor theory with a behavioural approach. This program claims a 95% success rate in teaching children to speak within three years though 'there is currently no in-house or independent research to substantiate these claims' (Dempsey & Foreman, 2001, p. 112).

Doman Delacato
Glen Doman and Carl Delacato originally designed a sensory integration training program for children with brain injuries but used it with a wide variety of disabilities. The program advocated 'patterning' or the hands on, systematic exercising of autistic children by their parents and usually teams of volunteers. The program was advocated as a cure for autism. By stimulating muscle activity in a controlled and intensive manner, it was claimed that neural networks were repaired. There has been no systematic appraisal of the effectiveness of this program for children with autism, and serious criticisms about the use of such methods have been raised by a number of authors. (Howlin, 1997). According to Cummins (as cited in Dempsey & Foreman, 2001, p. 105) the research studies had serious methodological flaws, which precluded reaching any conclusions about the effectiveness of this approach.

Auditory Integration Training (AIT)
Hypersensitive hearing of persons with autism has been widely recognized by many professionals (e.g. Con don, 1975; Delacato, 1974; Grandin & Scariano, 1986; Hayes & Gordon, 1977; Rimland, 1964.) Auditory Integration Training (AIT) was developed in France, by otolaryngologist Guy Berard, on the theory that human behavior is largely conditioned by the manner in which one hears (Berard, 1993).

AIT is said to address the hearing distortions, hyper-acute hearing, and sensory processing anomalies, which cause discomfort and confusion in persons suffering from learning disabilities, including autism (Stehli, 1995). Auditory training seeks to retrain the auditory system by correcting hearing distortions. During 20 half-hour training sessions which take place over 10 to 14 days, participants listen with headphones to a musical program modified and filtered through an electronic device called an AudioKinetron (Stehli, 1995).

Research into Auditory Integration Training (AIT)

Berard reports using AIT with over 8,000 individuals with hearing impairments at his clinic in France. Forty-eight of these patients were diagnosed as having autism (Berard, 1993). One patient is reported to have recovered from autism after receiving auditory integration training (Stehli, 1991). Three studies have been conducted to determine the efficacy of this approach in the education and treatment of children with autism (Link, 1997; Rimland & Edelson, 1995; Rimland and Edelson, 1994).

Link (1997) presented case studies of three boys with autism that received 20 half-hour sessions of auditory integration training. The study looked at the impact of AIT on sound hypersensitivity, as well as on cognitive and behavioral problems. Link found no change in hypersensitivity to sound, and few beneficial effects on the behavior or cognitive skills of the three boys.

Rimland and Edelson (1995) conducted a study of 18 children, ages 4 to 21 years, using a multiple criteria assessment over a three month period. Assessment tools included the Rimland E-2 Diagnostic Checklist, Aberrant Behavior Checklist (ABC), the Fisher's Auditory Problems Checklist (FAPC), and Hearing Sensitivity Questionnaire. Results indicated a significant decrease in aberrant behaviors of the experimental group, compared to those of the control group (ABC ($p<.01$); FAPC ($p<.05$)). However, these results were not consistently significant in the areas of hypersensitivity to sound or cognitive skills involving comprehension and language (Rimland & Edelson, 1995).

Rimland and Edelson (1995) concluded that the main hypothesis for this research was the premise that hypersensitivity to sound was directly related to aberrant behaviors, cognitive deficits and poor social interaction skills. Therefore the lack of significant data on sound hypersensitivity did not support the use of auditory integration training (Rimland & Edelson, 1995). Howlin (1997) questioned this conclusion, contending that

researchers often seek high p values, but that professionals and clinicians are responsible for determining therapeutic value to individual children, and these children did demonstrate some lessened hypersensitivity and a reduction in aberrant behaviors (Howlin, 1997).

Rimland and Edelson (1994) conducted a follow-up study, which surveyed 445 parents of children with autism who had undergone AIT. Results indicated most parents felt auditory integration training was beneficial to their child (Rimland & Edelson, 1994).

Conclusions

There are few validated studies regarding the use of Auditory Integration Training. According to Smith (1996), there is no scientific evidence to substantiate the theory that hypersensitivity to sound causes aberrant behaviors, interferes with social skills, and is a basis for cognitive deficits. In addition, there is currently no scientific evidence to support the effectiveness of AIT in reducing hypersensitivity to sound in children with autism. According to the American Academy of Pediatrics Committee on Children with Disabilities, current information does not support the use of AIT and, therefore, its use is not yet warranted other than in research protocols. Preliminary research and anecdotal reports suggest AIT may show promise (Rimland & Edelson, 1994; Rimland & Edelson, 1995; Stehli, 1991; Stehli, 1995), but it is not yet objectively substantiated as effective subject to the rigors of good science. In NSW AIT has also been described as a cure for ASD (e.g. www.auditoryintegration.net) with claims made about its positive effect on language, communication, behaviour, energy levels, self-esteem and sound sensitivity.

Scotopic sensitivity training/Irlen lenses

According to Irlen (1995), abnormal sensitivity to certain wave lengths of light results in Scotopic Sensitivity Syndrome. This produces a variety of symptoms, including dyslexia, and deficits in recognition and attention. Irlen specially designed glasses incorporating lenses of different colours to provide optimum tint for each individual, and claimed thereby to improve their reading skills, body and spatial awareness, eye contact, communication and self-control. Donna Williams, a young woman with autism whose autobiographical writings are well known is said to have found the results 'close to miraculous….she was able to listen and concentrate better, her speech became more fluent and spontaneous' (Williams, 1996). However other than reports from a small number of individuals who have worn the spectacles, and the writings of Irlen herself, little is known about the relative merits of this form of treatment and nothing about its long term effectiveness (Howlin, 1997).

Other Interventions

Daily Life Therapy/Higashi School
The Boston Massachusetts Higashi School was opened in 1987 by Dr Kiyo Kitahara and was run along the lines of the school she founded in Tokyo in 1964 (Kitahara, 1984). The term Daily Life Therapy (DLT) was given to the educational model that Kitahara developed over a 20 year period. She was convinced that this model could be successfully implemented in other cultural settings (Quill et al., 1989). A major difference between the original school in Tokyo and the Boston school is that the latter has only children with autism on the roll, whereas the former has typically developing children as well. Some children from the UK attend the Boston school, often from an early age. The school provides a totally integrated 24 hour curriculum comprising a concentration on daily living skills, physical education, music and craft. The teaching approach is embedded in the Japanese culture of group performance and identification with the group. The curriculum content and mode of delivery is based on age rather than developmental level and the aim is to teach the child at a level that will allow integration into mainstream. The Boston school now has an overlay of the American system (e.g. individual educational plans and the use of computers) and there are plans to establish schools in the UK following Daily Life Therapy principles. There has been almost no published research on outcomes of Daily Life Therapy and no well matched controlled study. One study (Hardy, Henrichs & Edwards, 1991) with a comparison (not control) group showed differential improvement in the children undergoing Daily Life Therapy in just those areas focused on in the curriculum. Richardson and Langley (1997) do have a control group, but insufficient details are given to assess how well matched it is and exactly which aspects of DLT are being controlled. The data from this study is inadequate in that it is derived from parental and teacher questionnaire and (in many cases) asks for retrospective information. The opportunities for bias are clear. This paper also was only published as a 'research in brief' section in a peer-reviewed journal, so does not give full information (Jordan, 1998).

Music therapy

Music therapy provides a framework in which a mutual relationship is set up between the child and the music therapist. The growing relationship enables changes to occur, both in the child and in the form that the therapy takes. It is suggested that music may afford opportunities for expressing emotions and may open up channels of communication (Storr, 1993). Music therapy includes directive and non-directive strategies.

Musical interaction therapy
Musical interaction therapy (Christie, Newson, Newson & Prevezer, 1992; Prevezer, 1990; Wimpory, Chadwick & Nash, 1995) is an autism-specific approach that has been developed over a number of years at an autistic society school in the UK. It forms part of the school's curriculum, which prioritises the development of communication skills. It is

also being used in clinical practice with families by a clinical psychologist in North Wales (Wimpory et al., 1995) and has been adopted by many speech and language therapists in the UK as part of their practice in working with children with autism. The intention of the work done in these sessions is to develop early communication and interactive skills. The child's key worker or parent works with the child and a musician plays an instrument to support and facilitate the interaction between the two.

Musical interaction has also only been evaluated through small case studies. Radhakishan (1991) reviewed music therapy in general and concluded that the literature on music therapy research showed consistent methodological weaknesses, principally the absence of adequate control groups and the potential presence of observer bias.

Option approach
Also known as the Son-Rise program (Kaufman, 1976). In NSW 'Connect Therapy' is based on the Option program.

The Option method is based on the premise that the child with autism finds the world 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 principle underlying treatment is to make social interactions pleasurable for the child. The approach also emphasises the importance of acceptance and recognising that the children's behaviours are not deviant or inappropriate, but an understandable reaction to their difficulties in making sense of or controlling their world (Howlin, 1997).

The Option approach is an interactive approach, which started through the intensive work of parents with their child with autism through which they claimed to affect a 'cure' for their son (Kaufman, 1976; 1994). While not promising this as the goal of intervention, the approach emphasises hope and uses intensive 1:1 intervention in which the child is put in charge of the situation, but is continually enticed to join in interaction with the adult. In the system as practised in America, the child will spend months or years away from the disturbing influences of the outside world, in its own suite of rooms into which volunteers come to engage with the child for one or two hours at a time, throughout the day, seven days a week.

The Option Program puts more stress on the adult showing complete acceptance of the child and their actions than is typical of other interactive approaches. The approach includes staff debriefing sessions in which they are taught to recognise moments when they were not comfortable with the child and, therefore by implication, not as responsive as they should be. Staff and parents are taught the difference between wanting change (which is acceptable) and needing change in order to approve of the child (which is not). Every action of the child is accepted (although some extreme actions may be re-directed or ignored). The adult uses enthusiasm, energy and excitement to involve the child in the interaction.

The Option approach is used by some families in the UK, largely in the home setting, but there are examples where parents have asked the staff if they will work in this way for part of the school day. Some schools in the UK which have developed an interactive, child-centred approach, offering choice and letting the child take the lead, have ascribed their practice to the influence of the Option approach.

The Option approach has been evaluated in terms of its rationale and practice, but not its outcomes (Jordan, 1990), although the proponents have published some detailed case studies (Kaufman, 1976; 1994). There are no controlled investigations of this form of treatment and apart from the Kaufman's own writings, no reports of long-term effects of intervention (Howlin, 1997). There is research evidence for some of the principles underlying this approach; Dawson and Adams (1984), for example, and Koegel, Dyer and Bell (1987) found that the quantity and quality of social responsiveness in children with autism improved considerably when strategies similar to following the child's lead were employed. Dawson and Lewy (1989) found that children with autism under six years spent more time socially engaged when adult play behaviour closely followed and was contingent on their own behaviour.

The research of Dawson and Galpert (1990), reported above, lends some support to the rationale behind this approach, but make it clear that there is no convincing research based evidence to suggest that the Option approach as such, is effective. There was anecdotal evidence in their study, for example, that one child became fixated on gaining his mother's eye contact suggesting that the danger of distorting the overall development of a child by focusing on a single aspect, is always present when dealing with children with autism.

SPELL (Structure Positive Empathetic Low arousal Links)
This program has been developed by the (National Autistic Society, 2001) and aims to 'reduce the effects of the impairments of imagination, communication and social skills that underlie autism' (p. 1). This is additional to the accepted emphasis on structure, consistency, reduction of disturbing stimuli, and high degree of organisation, and involves collaborative design of education and care plans to encompass all of the child's time 24 hours 7 days per week. The National Autistic Society (2001) indicates that SPELL is still an approach in the developmental stages and as such is continually being monitored and assessed. To date there appear to be no independent validated scientific or empirical studies of this method.

The Camphill Movement
This approach incorporates the 'Waldorf' or 'Rudolf Steiner' curriculum and has three guiding principles, namely importance of community life, sharing of experiences and resources, and development of a social, educational, and therapeutic approach (Smith, Laird, & Smith, 2001). There are 600 Waldorf schools worldwide, however there appears to be no research based evidence to its effectiveness for those with autism or other developmental disability.

The Miller Method

In 1965, Arnold and Eileen Eller-Miller founded the Language and Cognitive Development Center (LCDC) in Boston, Massachusetts. The LCDC is a school, for students with autism/PDD ages 3 - 14. The LCDC specialises in a particular approach to teaching children with autism, the Miller Method. The founders of the LCDC have also developed a reading program, the "Symbol Accentuation Reading Program".

The Miller Method assumes that some children with autism have "system-forming disorders" which impair the child's ability to organize, understand and egage with their surroundings. The Millers further theorize that other children with autism/PDD have "closed system disorders" which enable the child to interact with the environment, but only in a repetitive and ritualistic manner (Miller & Eller-Miller, 1989). An objective of the Miller Method is to expand these systems by keeping the child on task, as well as helping the child to transform stereotypic behaviors into functional interactions.

The Miller Method extensively uses adaptive equipment, including platforms (that elevate the child in hopes of increasing eye contact), large swinging balls (to expand the child's reality system), and Swiss cheese boards (to teach motor planning, as well as to increase the child's understanding of his or her relation to environment and space.) (Miller, 1998).

The Miller Method Symbol Accentuation Reading Program is designed to teach reading and writing by transforming pictures of objects into words. American Sign Language is used to teach communication (Miller, 1997).

According to the Millers, there are five factors which determine how well a child will progress using the Miller Method. These include:
- Age at which the intervention begins (ideally, before age 3)
- Extent of neurological involvement
- Evidence of a relationship with at least one parent
- Characteristics of system-forming disorders
- Degree of parental support (Miller & Eller-Miller, 1998)````

Conclusions

Only one study has been conducted to validate overall effectiveness of the Miller Method. This study was weakly controlled, in that it did not evaluate the direct effects of the intervention, only the post-educational placements of the students.
The single study surveying educational placements of children who leave the Language and Cognitive Development Center is insufficient to validate the program's effectiveness in helping individuals with autism build a wide range of skills, or to further posit theories regarding outcomes.

TEACCH & Other Combined Approaches

The SCERTS model

The SCERTS model (Wetherby & Prizant, 2000) focuses on Social-Communication, Emotional Regulation, and Transactional Support as the principal dimensions for intervention planning. The goal of the program is to directly address the core deficits observed in children with autism based on a highly individualised approach which addresses the primary deficits affecting each child. The emphasis is on communication, social relatedness, sensory characteristics and family centred practices that reflect acknowledged 'best practices' in contemporary literature on autism (Dawson & Osterling, 1997). SCERTS is a model of service provision rather than a program and as such has not been independently validated. However Wetherby and Prizant (2000) state that the model draws from a variety of empirically supported treatment methodologies. Key components of the model are as follows:

- Communication and language deficits are addressed through social-pragmatic language therapy, which emphasises the functional use of pre-verbal and verbal communication skills in natural and semi-structured interactions. The model includes the use of validated and effective strategies to support the use of non-speech communication systems such as picture symbols. Social-pragmatic approaches are now practiced in both contemporary ABA programs as well as developmentally based programs.
- Deficits in social relatedness and social-emotional reciprocity are addressed through strategies developed as part of Greenspan's floor time approach. See section on developmental/naturalistic approaches.
- Sensory processing deficits are addressed through sensory integration therapy and environmental adaptations and supports. Many children with autism also have motor planning issues affecting daily living skills, which are also addressed.
- The model also emphasises supporting and educating family members, to best enhance the child's development.

The authors (Wetherby & Prizant, 2000) stress that the whole of the SCERTS model is greater than the sum of the parts. The developmental challenges experienced by children with autism do not occur in an isolated manner and cannot be treated as such. For example daily activities such as mealtimes involve the full range of skill areas outlined above. In addition the SCERTS program draws on the child's developmental strengths and natural motivations to address areas of weakness.

Division TEACCH
(Treatment and Education of Autistic and Related Communications Handicapped Children)

Division TEACCH was founded in 1972 at the University of North Carolina (Lord & Schopler, 1994). The program is state wide and community based for children and adults with autism and communication disabilities. TEACCH services are both centre and outreach based. There is a demonstration preschool classroom within the medical school, and other educational services and programs within regular schools and in the communities of the children.

A major goal of the program is to provide continuity of services from preschool to adult life. A total of about 250 new preschool children a year are seen at the 6 TEACCH centres, so at any one time, about 650 to 700 preschool children are receiving TEACCH services. Over 4,500 children and adults have been served by TEACCH during the first 20 years of its existence. Most were first seen during their preschool years and have moved through the program. The age of referral to TEACCH has been decreasing over the last ten years. They may be referred by the age of three and quite a number at the age of two years. Types of intervention include structured teaching, communication training, leisure and social skill development and stress reduction. Schople & Mesibov (1994) and their staff utilize components of behavioural approaches in teaching self-care skills and managing aberrant behaviours. The program focuses on the student's strengths and interests and works on emerging skills. There is a detailed assessment which identifies 'emerging skills' and uses these as the first teaching goals. Children are taught functional (even vocational) skills from the start to enable them to function as independently as possible. TEACCH provides a 'prosthetic environment' for people with autism whereby many of their difficulties can be circumvented and they are able to live and learn without undue stress and anxiety. However the staff believe there is value in providing learning and play experiences with typically developing children and set up reverse integration opportunities and full inclusion into mainstream classes.

The major feature of the TEACCH approach is structure. Schopler (1991) showed that children with autism learned better in a structured learning environment and that children at earlier developmental levels needed structure more than children at higher levels of functioning. Some of the difficulties in autism, which the TEACCH program identifies and addresses, are organisational difficulties, memory problems, difficulties with auditory processing and making transitions from one activity or topic to another. The environment is organised to help the child or adult understand and remember what they are to do. The emphasis is on positive strategies of behaviour management and visually rather than verbally mediated teaching strategies. Mesibov (1998) comments,

> Structured teaching is an important priority because of the TEACCH research and experience that structure fits the "culture of autism" more effectively than any other techniques. Organising the physical environment, developing schedules and work systems, making expectations clear and explicit, and visual materials have

been effective ways of developing skills and allowing people with autism to use these skills independently of direct adult prompting and cueing. Some can work effectively and benefit from regular education programs, while others will need special classrooms for part or all of the day where the physical environment, curriculum, and personnel can be organized and manipulated to reflect individual needs (p.3).

Developing a student's communication skills in terms of their understanding and their ability to express themselves is a key part of the approach. A number of ways of communicating are acknowledged and taught depending on the individual concerned, these include using objects of reference, photographs and pictures, symbols and words. Visual cues for instruction and prediction assist students in gaining independence (Trehin, 1998).

Additionally the program includes concepts of sensory integration therapy in determining the cause of behaviour problems or lack of skill acquisition. For example, staff theorise that pain is at the root of many aberrant behaviours. If a child is over-stimulated in an environment, the child may be in physical pain and display aberrant behaviours (Trehin, 1998).

TEACCH is one of the most widely used approaches in autism. European (Flemish) versions of TEACCH incorporate a cognitive element (Gillberg & Peeters, 1999) and prefer to call the approach 'visually mediated instruction'. Later versions from America also involve a cognitive element, at least for the more able child (Schopler & Mesibov, 1994). Parents are involved as equal partners in the program throughout. The most commonly seen TEACCH strategy is the use of visual timetables and the use of other visual clues (e.g. pictures, photographs, symbols, sequenced diagrams) to clarify what it is the students are to do, in a work, home or leisure setting. TEACCH principles are fundamental to the educational programs offered in NSW by the Autism Association of NSW although the Autism Association has not formally adopted TEACCH methodologies.

Research into the TEACCH program

Schopler, Mesibov and Baker (1982) evaluated the outcomes of 647 students graduated from or presently enrolled in the TEACCH program, ranging in age from 2 to 26 years of age. Fifty-one percent of these students have a diagnosis of autism. One group of students received only a diagnostic evaluation; one group received an evaluation and parent training; and a third group received an evaluation and placement in the TEACCH classroom. Questionnaires were mailed to participants' homes to be filled out by parents of participating students. Results indicated that persons most involved in the program saw the most improvements. Additionally, adults and adolescents in the study were found to have an institutionalisation rate of only 7%. This was compared to the rate of institutionalisation of adolescents and adults with autism prior to the introduction of Division TEACCH in the 1960s of 39% to 74% (Schopler, Mesibov & Baker, 1982).

Ozonoff and Cathcart (1998) conducted a study of the effectiveness of a TEACCH home-based program. In the program, parents were taught how to work with their preschool child with autism in the home setting. Two groups of 11 children were matched by age, diagnosis, and severity of autism characteristics. The control group received no programming, and the treatment group received four months of home-based intervention. Each group was given a pre- and post-test. Results indicate that children in the treatment group made significant progress and demonstrated overall improvement that was three to four times greater than that of the control group (Ozonoff & Cathcart, 1998). Three additional follow-up studies have been conducted to document outcome data of students who received TEACCH services (Lord, 1991; Venter, Lord & Schopler, 1992; Lord & Schopler, 1989).. These studies have indicated substantial increases in IQ scores. Children that received services beginning at the age of three, who were non-verbal and had IQ scores ranging from 30 - 50, demonstrated a 22 to 24 point increase in IQ scores by the age of seven (Lord & Schopler, 1989). In each of these studies, gains were most significant in very young children who were non-verbal prior to intervention (Lord & Schopler, 1994). However, this research includes few peer-reviewed studies of outcome replications conducted by researchers not affiliated with TEACCH. Mesibov et al (1997) concedes the difficulty in objectively substantiating the effectiveness of TEACCH based upon the scope and quality of scientific research:

> Demonstrating the effectiveness of a large and complex program such as Division TEACCH is difficult. The problem is compounded by the organic basis of autism, and the focus of Division TEACCH on lifelong adaptation, which do not lend themselves to superficial cures or clearly defined milestones (p.56).

The UK review of treatment programs concludes that 'Research conducted by TEACCH and anecdotal reports suggest TEACCH shows promise (Lord, 1991; Lord & Schopler, 1989; Lord & Schopler, 1994), but it is not objectively substantiated as effective by independent researchers' (Jordan et al., 1998). In contrast the (Autism-PDD Resources Network, 1997) describes the TEACCH program as a throw-back to the failed models of behaviour management recommended in the Seventies and early Eighties, which mentally shield a subject from their surroundings and curb social acceptance. They do mollify this by suggesting that it is 'incorrect implementation which proves to be the most dangerous aspect of the program' (p. 1).

The Denver Model:

The Denver Model is a developmentally based program using behavioural techniques, which began in 1981 at the University of Colorado Health Sciences Center, Denver. Similar to the TEACCH program, the Denver Model aims to build upon the skills the child with autism has already gained. The child's individualized curriculum is developed around quarterly meetings between the parents and the treatment team. Goals, objectives, instructional plans and activities are discussed for the child's instruction across all settings. The Denver Model includes several teaching elements: shaping of natural gestures followed by conventional gestures; teaching motor-imitation skills related to

language; and teaching the meaning and importance of speech. This model uses the tools of functional behavioural analysis; communication training; positive teaching of alternative, more conventional behaviours; and redirection to provide new behavioural strategies by which the child can achieve their goals.

The Autism Association of NSW Satellite Class Program.

The Autism Association of NSW (AANSW) operates six schools from the Illawarra to the Hunter. All Association schools operate satellite classes (autism support classes) in other less specialised educational settings; Department of Education and Training (DET) regular primary schools and one regular DET high school, Catholic Education Office regular primary schools and high schools, and one DET school for specific purposes. The first Association satellite class opened in 1992 in Belrose Primary school. Currently there are 32 AANSW satellite classes in operation. New classes open each year. Approximately half of the total enrolment in Association schools is in satellite classes. Staffing ratios for satellite classes are 4-5 students per teacher. The following factors have been identified in determining the success of satellite classes.

- Climate of the receiving school, particularly the attitude of the school principal
- Careful and thorough preparation of the receiving school
- The skills and experience of the Association staff in the satellite class
- The support and ongoing training from the base school
- The careful selection of children who are known to have the potential to benefit from the placement.

Satellite classes have a clear transition focus and cater for students with autism who can benefit from the placement and who will in time move into a local regular class or a generic local support class (regular class). The selection of students for satellite class placement is made by the Principal of the AANSW school after careful assessment of the child and consultation with the child's family. Entry criteria include the ability to manage a mainstream playground with support and the potential to benefit from the academic, communication and social opportunities offered by the placement. Exit criteria include; breakdown of the placement, and transition into a less specialised educational placement. Transition into the next educational placement, local school or generic support class, involves AANSW staff working with the receiving school and integrating the child. The Association continues to provide consultative support as required to the receiving school for 12 months after the student has been enrolled. Students on average transition from the satellite class after one to two years. There is no limit to the period the student may need placement in the satellite class and it is possible that for some students a support class set up specifically for students with autism may be the optimal setting for that student throughout his/her school career.

There is no research to date into the satellite class program operated by the Autism Association of NSW.

Comparative Evaluation of Educational/Behavioural Programs for Children with Autism.

Several authors have comprehensively reviewed key programs available internationally for children with autism, (Dawson & Osterling, 1997; Howlin 1997; Marcus, Garfinkle & Wolery 2001; Rogers 1996). Based on their reviews of the research, these authors have all defined the common elements they consider necessary for effective intervention, regardless of the theoretical framework underlying any one particular approach. Dawson and Osterling (1997) found that the directors of the programs they reviewed agreed on many of the key elements they believed are essential for a program to be effective regardless of theoretical perspective. However the methods employed by different programs to address each of the elements listed below may vary due to differences in the philosophical approaches.

The key elements described in the literature for effective programs are:

Curriculum content: Within this element there are five basic skill domains; ability to attend to elements of the environment, ability to imitate others, ability to comprehend and use language (Howlin, 1997), ability to play appropriately with toys (Howlin, 1997), and ability to socially interact with others (Dawson & Osterling, 1997). Marcus, Garfinkle & Wolery (2001) suggest that effective programs utilise the following intervention strategies based on the learning characteristics of children with autism: Clarifying meaningful information, organisation and scheduling, teaching across settings and people, active directed instruction, individualisation of teaching materials and curriculum, provision of visual supports, teaching imitation at a developmentally appropriate level, using strengths and interests to help with weak areas of development.

*Need for highly supportive teaching environments and generalisation strategies***:** The core skills outlined above are taught in a highly supportive teaching environment and are then systematically generalised to more complex, natural environments. Howlin (1997) stresses the need for behaviourally oriented strategies.

Need for predictability and routine. Research shows that children with autism become more socially responsive and attentive when information is provided in a highly predictable manner and, conversely, that their behaviour is severely disruptive when the same stimuli are presented in an unpredictable manner.

A functional approach to problem behaviours: Most programs focus on the prevention of problem behaviour by means of increasing the child's interest and motivation, structuring the environment and increasing positive reinforcement for appropriate behaviour. Should the problem behaviour persist despite ecological management, the behaviour is analysed to determine what the function of the behaviour is for the child. The environment is then adapted in specific ways to avoid triggers and reinforcers for the problem behaviour and appropriate behaviour is taught to give the child an alternative more acceptable behaviour. Howlin (1997) stresses the importance of recognising the

communicative function of problem behaviour and the need to teach the child more appropriate alternative means of communication.

Transition from the preschool classroom: Most programs recognise that transition to school is a time when children with autism need a great deal of support. Effective programs actively teach school skills to enable the child to be as independent as possible. Programs frequently take an active role in finding school placements that will best suit the child and then actively integrate the child with autism into the new setting.

Family involvement: Effective programs recognise that parents are a critical component in early intervention for children with autism. Most programs support parents to choose the type and intensity of their involvement in their child's program. Effective programs are sensitive to the stresses encountered by families of children with autism and provide parent groups and other types of emotional support. (Dawson & Osterling, 1997)

In addition reviewers discuss important strategies or methods not utilised by all models but utilised by a significant number and worth noting:

Visual Supports
Dawson and Osterling (1997) note that the provision of augmentative communication methods is a characteristics of many programs reviewed. In addition both Howlin (1997) and Quill, (1997) stress the importance of visually cued instruction to provide the child with a predictable and readily understood environment.

Number of hours of treatment per week
Dawson and Osterling (1997) note that programs reviewed recommend a minimum of 15 hours of treatment per week. The authors stress the point that the concept of intensity as discussed in the research is complex and not necessarily conveyed solely by the 'number of hours per week'. Focusing exclusively on the number of hours per week detracts from the amount of actual meaningful engagement, which is the key factor. Marcus, Garfinkle and Wolery (2001) suggest that while it is unfortunate that the early intervention movement emphasises the number of hours per week, a lower limit of 15 hours minimum per week is sensible in that the focus should be on the importance of more relevant factors of curriculum and content of instruction rather than on hours of treatment alone (Marcus, Garfinkle & Wolery, 2001).

Occupational Therapy
Several programs provide occupational therapy services for those children who can benefit from them (Dawson & Osterling, 1997).

Inclusion of peers
Many include typically developing peers (Dawson & Osterling, 1997).

Independent functioning
Marcus, Garfinkle and Wolery (2001) note that many programs emphasise child independence, initiative and choice making

Obsessions and rituals
Howlin (1997) suggests that a good program will recognise the importance of obsessions and rituals as underlying causes of many problem behaviours. However, these may have a vital role in reducing anxiety and may act as a powerful source of motivation and reward.

Individual Variation

It is important to account for the spectrum of autism disorders and to recognise that while the core characteristics of autism spectrum disorders are consistent, no one child with autism will have the same pattern of strengths and needs as another. In addition families differ in their goals and resources, strengths and needs. Therefore, there is no one program that will suit all children with autism and their families. Research suggests that there are substantial short and long term benefits from early, intensive, family-based treatment programs, whatever their theoretical basis, so long as these are appropriately adapted to the child's pattern of strengths and weaknesses and take account of family circumstances (Webster, Webster & Feiler, 2002).

COST BENEFITS OF TREATMENT PROGRAMS

To date, no studies have reported on the cost benefits associated with treatment programs in terms of funding, treatment times, short-term outcomes and benefits over time. Rather, reviewers in this field have provided a description of the aims of the intervention or treatment program available, the target population, treatment times, associated costs and how the treatment was being funded (Table 3). In the case of treatments available in Australia, no reports have been published on the cost-effectiveness of the programs. However information has been accrued on the types of programs available, treatment times, funding sources, associated costs and expected short-term outcomes and benefits over time (Table 4, p.94).

Studies that have evaluated the costs or cost effectiveness of intervention programs for autism have used cost-benefit models to provide tentative estimates of the overall costs and benefits of early intensive behavioural intervention (EIBI) to society (Jacobson et al., 1998; Hilderbrand, 1999; Jacobson & Mulick, 2000; Jarbrink & Knapp, 2001). These studies have generally shown that the majority of savings accrue from children who receive EIBI and achieve normal functioning rather than partial benefit.

These studies have highlighted the need to examine more closely the family costs of having a child with autism, service utilization rates and associated costs, and an individual evaluation of the cost-effectiveness of early intervention programs.

FAMILY SUPPORT MODELS AND PROGRAMS

Evidence to support best practice models in supporting families at the time of diagnosis and assessment (including provision of information):

The family's needs

Evidence to support best practice models to assist families at the time of diagnosis is scarce. In Futagi and Yamamoto's (2002) study of mothers' views on the disclosure of a diagnosis of autism, the following factors were identified as contributing to the reduction in stress experienced by families when receiving a diagnosis of autism:

- early disclosure of a diagnosis relates to early acceptance
- increased understanding of autistic behaviour
- the accumulated experience of how to communicate with their child and
- the existence of a self-care group to support parents were important factors for the acceptance of the disability.

Family forums that were held in the state of Indiana, USA, to gather information concerning the diagnostic process, stated the need for more training on how to individualise education programs and on advocacy (Indiana Resource Center for Autism, 1998). Many parents reported that it was hard to know what intervention to use and indicated that it would be useful to have one central location for information about various approaches. Families also indicated that they would prefer that information provided "would be more optimistic in the beginning", and stressed the importance of training for siblings and for the entire family unit.

Provision of parent guides

The importance of providing parents of children with autism with information on all aspects of autism, including the diagnostic and assessment process, is well recognised. Families have emphasised the need to have information that is easily accessible in physician's waiting rooms and/or at the point of diagnosis (Indiana Resource Center for Autism, 1998). The document should be a quick guide that would provide family members with a checklist for future action, practical information about their child's disability, and the names and phone numbers of important organisations and resources. They have also stated the need for basic information and training on issues such as nutrition, toilet training and behaviour support. Such information could be compiled into 'parent guides' consistent with the guide recommended by Ozonoff, Dawson & McPartland (2002). The guide would also include;

- strategies to help the child to learn to interact more comfortably with siblings and peers, understand the rules of appropriate behaviour, and become a more active participant in school and family life
- strategies to capitalise on the child's strengths, and minimize their weaknesses
- how to find best educational placement
- exercise the child's educational rights
- maximise the benefits of therapy
- teaching parents behavioural strategies
- involvement with family support groups
- addressing financial concerns, and
- medication

Recommendations for professionals and the interview process

Research has identified key factors that should be considered by professionals when informing parents of their child's diagnosis; in particular ways to improve the interview process (Nissenbaum, Tollefson & Reese, 2002; Hazell, Tarren-Sweeney, Vimpani, Keating & Callan, 2002).

These include;
- become knowledgeable about autism
- establish a family-friendly setting
- understand families' needs
- communicate effectively
- provide lists of resources and interventions
- provide follow-up, discuss prognosis and provide hope, and
- recognise that personal reactions are common when communicating a diagnosis of autism

Another study identified that paediatricians need expertise in assessing family needs, strengths and situations, along with counseling skills to offer strategies and resources to families (Committee on Early Childhood, Adoption, and Dependent Care, 2001). Continuing medical education programs on paediatric family interviewing and psychosocial issues in paediatric practice can enhance the paediatrician's skills and opportunities for counseling families. Rather than place all the emphasis on the paediatrician or health professional to provide the required support, particularly at the time of diagnosis, another approach may be to communicate a diagnosis of autism to a family using two multi-professional groups: one in a medical setting and one in an educational setting (Bartolo, 2002). By using this approach, professionals at both sites have been shown to apply a parent-friendly frame which was complemented by a hopeful-clinical/diagnostic-formulation frame at the medical site and a defocusing-of-bad-news frame at the educational site.

The Help! Program

An example of a post-diagnostic support program for parents and carers of autistic children is the Help! program developed by the National Autistic Society of the United Kingdom (http:www.nas.org.uk/family/help.html). This program aims to provide parents and full-time carers with post-diagnostic information and advice, to develop their knowledge and understanding of autistic spectrum disorders, positive management strategies and local support services. The program targets parents/carers of children with autism aged 5+ or in full-time education, and young people or adults who have received a diagnosis of an autistic spectrum disorder within the last 12months. The program is delivered flexibly to respond to local circumstances and consists of an introductory 'getting to know you' session, six three-hour core sessions, and a closing/farewell session.
The six core sessions include

- information about autism and Asperger syndrome
- communication and social interaction
- strategies for behaviour support
- education and transitions or adult life and transitions
- legislation and rights, and
- developing partnerships with professionals and local support networks and the ways in which to access these

Each program supports ten families and a parent manual including handouts, information booklets and leaflets, together with a child/adult life folder accompanies the program.

Comprehensive supports
Research into the nature of comprehensive supports that help reduce stresses that may be experienced by families of a child / young person with autism spectrum disorder and promote inclusion in community activities, was reviewed. Apart from facing the enormous stress of having their child diagnosed with autism, families also experience the complex stress associated with increasing social and behavioural difficulties of the child, prolonged dependency on the parents for care, and guilt arising from others labeling the parents 'mismanagement' of the children. There is also the accumulation of stressors experienced by individual family members as they try to adapt to the situation. If not provided with the right support, many parents and siblings are at risk of developing negative outcomes (depression, social isolation, and spousal relationship problems). Parents have rated their spouse as their most frequently used support for coping with their child, followed by family, and professionals (Neil, 2002). For this reason a number of intervention programs have focused on parents and families, increasing their knowledge of autism and building their competence and confidence through different strategies.

Family-centred positive behaviour support (PBS) programs
Family-centred behavior interventions that involve a collaborative relationship between professionals and families and consideration of families needs and strengths in addition to

child needs and strengths, were found to increase parental sense of competence, increase parents factual knowledge of autism and issues related to advocacy and to buffer the effects of child adaptive functioning on stress related to parenting (Sirbasku-Cohen, 2001; Zaldo, 1996; Everett, 2001).

A number of studies have demonstrated the efficacy of combining family-centred intervention with PBS which is a collaborative, assessment-based approach to addressing problem behaviour (Fox, Benito & Dunlap, 2002; Marshall & Mirenda, 2002; Lucyshyn et al, 2002). Family-centred PBS is often conducted within the context of natural routines that occur regularly in home or community settings. It typically requires professionals and family members to participate in five successive phases that include;

- building relationships between the family and the professionals,
- conducting a functional assessment of the behaviours of concern,
- identifying natural routines as contexts for intervention,
- developing behaviour support plans related to each of the routines, and
- implementing and revising the support plans as needed.

A PBS plan includes the following components: a) strategies for teaching and increasing skills that are intended to replace the problem behaviours, b) strategies for preventing the problems before they occur, c) strategies for dealing with the problems if or when they do occur, and d) strategies for monitoring progress. As time goes on, the supporting professional and family members meet to evaluate progress and make adjustments to the plan, as necessary. Families that have used this approach have shown that children with autism and their siblings show decreases in their disruptive behaviours, and the family experiences other family-wide collateral positive effects, including decreased stress and increased positive interactions among family members (Boettcher, Koegel, McNemey & Koegel, 2003).

NAS EarlyBird Program
This is a parent-focused rather than family-focused model of early intervention which combines group sessions with the one-to-one support of a professional during home visits (Shields, 2001). Parents learn first to understand their child's autism: to appreciate how people with autism experience the world and how the underlying triad of social deficits influences thinking, development and learning. The goal of the program is to build parents' confidence by explaining why development and behaviour may be different in autism, so that parents can work out how best to help their child. Parents then learn about communication and how to build interaction and social communication with their child. Lastly, parents are helped to analyse their child's behaviour: examining underlying triggers and the possible functions of inappropriate behaviours. They learn to use structure and visual cues to prevent or minimize problem behaviour.

The program content targets the needs of parents living with a preschool child with autism, but may be suitable for children across the spectrum and the resultant spread of developmental stages. This program is much less intensive (only three months in length) than some of the other models for early intervention (Lovaas, 1987).

The EarlyBird Program was utilized by the Leicestershire Education Authority as a service provided to support families of preschool children with autistic spectrum disorders (Whitaker, 2002). Parents of children with autism who had utilized the service were interviewed once their children had entered full-time education and left the service. As part of the interview, parents identified which aspects of the program that they found particularly useful. These included the information that was provided about autism and the specific management and intervention techniques, strategies for promoting expressive and receptive communication and the opportunity for contact with other parents. Embedding the package in the context of an on-going home visiting service by a support worker offered significant additional benefits. A significant proportion of the support worker's time was spent in helping parents apply this knowledge- devising, reviewing and refining specific strategies tailored to their child and their situation. This in turn increased parental confidence in applying the suggested strategies. The support workers were also recognized for providing moral support and encouragement to keep going and their role in liaising and working with the staff of nurseries and playgroups that the children attended. There has been considerable interest in the Early Bird program in New Zealand where it is being implemented and evaluated. It appears that extensive litigation initiated by the Hanen Program is currently an issue for the Early Bird Program.

The Hanen Program

The Hanen Centre is a government-funded agency in Toronto, Canada, that specialises in training caregivers to facilitate language development in children from birth to six years of age. 'More Than Words' is the Hanen program for parents of children with autism. It is an intensive training program for parents of pre-school children with autism. The program derives its theoretical framework from a social-pragmatic developmental perspective (see previous section). The program emphasises the blending of aspects from both behavioural and naturalistic child-centred programs: the breakdown of activities into structured, small steps found in an ABA program and the provision of opportunities to use language for functional purposes that are built into more naturalistic approaches. The aim of the program is for parents to learn how to use their child's everyday activities as the context for learning to communicate. In addition, the Hanen website claims that 'More Than Words' incorporates current best practice guidelines and emphasises the importance of affect, predictability, structure and the use of visual supports to enhance learning in children with ASD. The program applies the principles of adult learning to teach a group of parents in eight interactive classes and three individual in-home videotaping and coaching sessions. Through knowledge and practical, hands-on training, the program aims to enable parents to turn everyday activities into learning experiences and support other treatments that their child may receive throughout his life.

The Department of Health at the University of Newcastle (UK) has undertaken a longitudinal evaluation of the *More Than Words* Program, of which the first major analysis of data took place in June 2002. Professor Ann Le Couteur presented preliminary results of this research at the World Autism Congress in Melbourne in November 2002. She reported that parents changed their behaviours significantly on the Joy and Fun

Assessment (JAFA), showing an improvement in the interactive skills identified as impacting on children's language development.

Autism Early Intervention Project

Currently under trial is another parent-focused model of early intervention developed by the Centre for Developmental Psychiatry & Psychology at Monash University, Melbourne (Brereton, 2003). This project aims to determine whether a parent education and skills training early intervention (PET) improves the outcome for preschool children with autism. The research compares outcomes of parent education to a general parent education and support intervention (PS), and an age and developmental level matched community sample of children who do not receive these interventions. In addition the project assessed the maintenance of therapeutic gains.

Parents in the intervention group were recruited from consecutive referrals to the Melbourne southern region autism assessment service. Parents were randomly assigned to either parent education and behaviour management (PET) or parent education and support (PS). The families in the non-intervention group were recruited from consecutive referrals to two other Victorian regional autism assessment services (Geelong, Wangaratta). Outcome measures included assessments of parent mental health, family functioning, child psychopathology, cognitive adaptive behaviour and language skills measured pre and post intervention and at 1 or 2 year follow-up. The intervention (PET, PS) involved ten small-group parent education sessions where two or three families join with a clinician to discuss and learn more about autism, managing difficult behaviour and parenting skills (90 minutes in length). On alternate weeks, ten individual sessions offer parents the opportunity to apply what has been learnt in the group sessions to their own family situation. The project met recruitment targets (N=120). At one year follow-up, the participation rate was 96.3% for the intervention groups and 95.2% for the non-intervention groups.

Results at this point indicate that there was a significant improvement in mental health of parents participating in the intervention versus control groups (P<0.000; General Health Questionnaire, Goldberg & Williams, 1988). The parents in the intervention groups also experienced less stress, though this result was not significant (P=0.38). There was a trend toward significant improvements in family function in the intervention group (P=0.07; Family Assessment Device, Epstein et al, 1983). Overall behaviour was less disturbed in children whose parents received intervention (P=0.01; Developmental Behaviour Checklist, Einfeld & Tonge, 1995) and these children also showed significant improvements in daily living skills (P=0.001; Vineland Adaptive Behaviour Scale, De Lemos, 1989). Preliminary analysis also indicated that the outcome of PET intervention at one year follow-up was superior to the PS intervention, with parents in the PET group showing significant improvements in mental health (P=0.013, anxiety and insomnia domain (P=0.003)). Parents have revealed a high level of satisfaction with the program. The researchers are currently completing a two year follow-up.

Evaluation and efficacy of research into parent/family-centred interventions

As parent/family-centred interventions have become the preferred approach to behaviour support for children with autism, it is important to determine the effectiveness of these programs and whether these approaches result in identifiable benefits. What are the family outcomes? How are they measured? Are the preferred outcomes achieved? Which family support is the most efficient in achieving long-term positive outcomes for the family as well as for the child? Which family support is practical to instigate as well as cost-efficient? One study examining family outcomes in early intervention, developed a framework for program evaluation and efficacy research of parent/family-centred interventions (Bailey et al., 1998).   Based on previous literature and interviews with professionals and family members, the authors identified eight questions that could serve as a framework for determining the extent to which early intervention has accomplished the goals inherent in a family-centred approach. The questions could serve as a stimulus for discussion among professionals, parents, and policymakers engaged in fundamental inquiry into the purposes and anticipated benefits of early intervention. Conceptual issues and methodological considerations associated with documenting these outcomes were also presented.

The questions are:

Does the family see early intervention as appropriate in making a difference in their child's life?
Does the family see early intervention as appropriate in making a difference in their family's life?
Does the family have a positive view of professionals and the special service system?
Did early intervention enable the family to help their child grow, learn, and develop?
Did early intervention enhance the family's perceived ability to work with professionals and advocate for services?
Did early intervention assist the family in building a strong support system?
Did early intervention help enhance an optimistic view of the future?
Did early intervention enhance the family's perceived quality of life?

Conclusion

In summary, the success of all these programs is clearly dependent on the establishment of a good parent-professional relationship. In particular the ability of health professionals, social and support workers to enhance the well-being of children with autism and their families by addressing the needs of the entire family, facilitating family choice and control of supports, and helping families to navigate the complex service system. Also of key importance are:

- The recognition of informal support available through family, friends, and neighbours

- Consideration of family context in the assessment and intervention planning process
- Improved recognition within families of their resources and successful coping effort
- Acceptance that negative events occur and they need to be dealt with
- The need for professionals to provide a more positive "spin" on problems so as not to unnecessarily discourage family members (Whitaker, 2002; Hastings, 2003; Weiss, 2002; Dunn, Burbine, Bowers & Antleff-Dunn, 2001; Freedman & Boyer, 2000; Hastings & Johnson, 2001)

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Table 2 Summary of information about programs for children with autism

Type of program	Type of Program	Name of program
Psychodynamic treatment/management		Holding Therapy Pheraplay
Biological treatments		Vitamin B6 and magnesium Diet Cranial osteopathy Anti yeast therapy 'Chelation treatment'
	Medication	Typical Antipsychotics Atypical anti psychotics Serotonin Reuptake Inhibitors Beta blockers Anti-convulsant medications Naltrexone Methylphenidate (Ritalin TM) Secretin
Educational/ behavioural intervention	**Applied Behaviour Analysis** **Discrete Trial Training** **Intensive Behavioural Intervention (IBI) or Early Intensive Behavioural Intervention (EIBI).**	Douglas Developmental Disabilities Centre Program http://gsappweb.rutgers.edu/dddc Autism Preschool Program Princeton Child Development Institute Program (PCDI) http://www.pcdi.org/programs May Institute. http://www.mayinstitute.org Lovaas Program http://www.geocities.com/luznmymind2/autism2.html

Table 2 cont

Educational/ behavioural intervention	Naturalistic/ develop-mental interventions	Developmental Social-Pragmatic Model (DSP). Greenspan's DIR/"Floor Time" Learning Experiences-An Alternative Program for Preschoolers and Parents (LEAP) Relationship Development Intervention RDI http://www.kennedykrieger.org
EDUCATIONAL/ BEHAVIOURAL INTERVENTIONS	TEACCH & other combined approaches	The SCERTS model Division TEACCH http://www.teacch.com/ The Denver Model http://www.jfkpartners.org/ The Autism Association of NSW Satellite Class Program.
Combined therapy approaches	Communication-Social therapies	Augmentative communication PECS Social Stories Facilitated Communication Functional Communication Training (FCT)
Sensory/motor treatment	Sensory Integration therapies	Doman Delacato Auditory Integration Training Scotopic sensitivity training/Irlen lenses

Table 2 cont

Other interventions		Daily Life Therapy Music therapy Musical interaction therapy Option approach SPELL (Structure Positive Empathetic Low arousal Links) The Camphill Movement The Miller Method
Family Support models and programs		The Hanen Program NAS EarlyBird Program Autism Early Intervention Project

Table 3 A Summary of available information re the Cost/Benefit of autism programs internationally.

Treatment	Cost/year ($US) (approximations)	Funding	Treatment time Hrs/week	Short term outcomes and Benefits over time[1]
Music therapy	Staff salaries per session	Education/ Health Authority or parents	2	For information on outcomes refer to report.[1]
Option approach	Not known	Parents	~56hrs/wk	For information on outcomes refer to report.[1]
Communication -social therapies:				
Picture Exchange Communication System (PECS)	Salaries of professionals involved	Education/ Health Authority	Daily, across all situations	For information on outcomes refer to report.[1]
Augmentative communication	Salaries of professionals involved	Education/ Health Authority	As appropriate	For information on outcomes refer to report.[1]
Facilitated communication	Salaries of facilitator (parent my be facilitator)	State Government	As appropriate	For information on outcomes refer to report.[1]

Table 3 cont

Treatment	Cost/year ($US) (approximations)	Funding	Treatment time Hrs/week	Short term outcomes and Benefits over time[1]
Educational/ Behavioural				
Learning experiences: An alternative program for Preschoolers and their Parents (LEAP)	$25,000/school year to cover Salaries of professionals involved	State Government	15	Post-program placements: Approximately 50% in regular education.[2] Significant increases in language, cognitive and motor skills. Doubling of developmental rate in several areas.[2] refer to report for more information.[1]
Douglas Developmental Disabilities Centre Program	Not known	State Government	25	Post-preschool placements: after a three year program, 14% children "fully integrated' into a general educational setting and 76% in classes for children with neurological or communication disabilities.[2] Specific developmental gains in IQ after 1 year of treatment. For more information on outcomes refer to report.[1]

Table 3 cont.

Treatment	Cost/year ($US) (approximations)	Funding	Treatment time Hrs/week	Short term outcomes and Benefits over time[1]
TEACCH	$5,000 to $15,000	State Government	30	Children starting treatment at 4 years showed increases in IQ of 15-19 points by 9 years of age.[2] For more information on outcomes refer to report.[1]
Higashi/Daily life therapy	$86,000 (44wks (boarding at school) $30,000 (day pupil/yr)	State, Local Education Authorities, parents	24hr day approach, taking into account all areas of daily life	For information on outcomes refer to report.[1]
Lovaas therapy	UCLA- $810/day Non-Local- $1,350/day May Institute- $100,000 (residential) $30,815 (young child) $40,000 (home-based)	Parents	40	For information on outcomes refer to report.[1]
Rutgers Autism Program	$1,000/day (6hours/day)	parents	40	For information on outcomes refer to report.[1]
Denver Program	Not known		22-35	For information on outcomes refer to report.[1]

Table 4 Cost benefits of Autistic Spectrum Disorder treatment programs in Australia*

*The information presented in this table was provided by the service providers in response to a consistent set of questions (see Appendix) sent to services in writing and followed up verbally if necessary. Information is reported as provided by services.

Victoria				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/wk**	**Expected short term outcomes and benefits over time[3]**
Early Childhood Autism Services-Northern (ECAS-N), Victoria	$480	Department of Human Services, Victoria	48hrs/wk. (out of home), ongoing in home	Speech, communication skills, problem and adaptive behaviour skills, everyday living skills, adaptability to family and community settings, reduction in family stress and cohesion in family unit
WestArc Autism Program, Victoria	$320-$400	Noah's Arc Family Resources (non-profit organisat'n), Victoria	24hr day approach, taking into account all areas of daily life	Child inclusion in early childhood services and their communities, family confidence in parenting a child with autism and community awareness/understanding
Illoura Early Childhood Intervention Services, Victoria	$400-$600	Knox City Council, Victoria	-	Achievement of goals set by parents, parental knowledge of service and options and parental well-being
Autism Victoria Family Counselling and Information Service, Victoria	$27.50 (member fee)	Department of Human Services, Victoria, donations and philanthropic grants and fees in equal proportions	As required	Provide information, guidance, emotional and practical support for families with a child diagnosed with autistic spectrum disorder

Table 4 cont

Autism Behavioural Intervention Service (ABIA)	$40,000 for ABA service providers organised by ABIA	Parents fund child. ABIA funding provided by fundraising and philanthropic Organisations	30-40hr/wk	Same as CARD except ABIA actually organises the ABA service providers for families rather than provides a program itself.

Queensland				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
"KidStart" Family Involvement Program, Queensland	$450 per program-subsidised fee	Autism Queensland (AQ) funds large part of costs through its grant from C'wealth. Special Education – Non-Schools Organisations.	15hrs/wk. (hrs. may be flexible for each child)	Increased knowledge of ASD in parents, increased awareness of appropriate strategies in parents, increased awareness of available services in parents, increased coping ability in parents, report recommendations that provide information for utilising strategies and implementing programs for key concerns of parents and report recommendations for future appropriate AQ services

Table 4 cont

Queensland				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
"Focus" Family Involvement Programs, Queensland	$450 per program-subsidised fee	AQ funds large part of costs through its grant from C'wealth. Special Education – Non-Schools Organisations.	12-15hrs/wk	Increased knowledge of ASD in parents, increased awareness of appropriate strategies in parents, increased awareness of available services in parents, increased coping ability in parents, report recommendations that provide information for utilising strategies and implementing programs for key concerns of parents and report recommendations for future appropriate AQ services

Table 4 cont

Queensland				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
AQ group placement, Queensland	$20 per day fee charged subsidised fee;	Family charged $20 per day-remainder of costs met through service agreement with Education Queensland, some funds from non-state school grants and fundraising	3 days/ wk. for a period of up to 2 years	Improvements in child's functioning as measured through achievement of IEP goals, increased ability of family to cope with and implement strategies for behavioural challenges, increased ability of home school staff to modify environment and provide strategies to meet child's individual needs, increased understanding of all involved of what ASD is, particularly in relation to this specific child and achievement of home school IEP goals
Early Intervention Group Placement, Queensland	$60 per week fee subsidised AQ meets remainder of costs out of its own funds	Family charge $60 per week fee; AQ meets remainder of costs out of its own funds	48hrs/wk.; 1yr program	Achievement of IEP goals, smooth transition to school setting, positive relationship between AQ, home and scho / other educational settings, awareness and implementati of appropriate strategies by parents and school staff
"Stronger Families and ASD" Project, Queensland	No Fee	Family and C'wealth. Services, C'wealth. Govt. and University of Qld.	Families participate in weekend workshop followed by 5 weeks home facilitation	Parental satisfaction on use of techniques learned at workshop

Table 4 cont

Western Australia

Information re the funding situation in Western Australia was sought from the CEO of the Autism Association in W.A. Historically funding for early intervention services for children with autism was allocated to families who could 'go shopping' for services for their child; now funding is provided to eligible services (block funding) based on number of eligible cases identified by that service. $6,000 per program place is funded annually. The number of program places is negotiated with service providers on the basis of a three-year contract with DSC. The definition of a program place is linked to 250 operative days per annum, therefore if due to late diagnosis or other reasons, a child only receives 6 months of intervention before reaching the ceiling age for intervention (6 years as stipulated by the contract) this child is counted as half a program place.
In 2003 the Autism Association WA had 80 places funded, in 2004 the figure will be 106. Services must meet a number of requirements to be eligible to receive funding. For example services must be multidisciplinary and provide family centred practice. Services must integrate what is known about best practice (the govt. funders do not look favourably on 'mono' therapies).

Treatment	Cost/yr.	Funding	Treatment time Hrs/week	Expected short term outcomes and benefits over time[3]
Home-based autism service: preventative service for children in year one, WA	No fee	Disability Services Commission, Govt. WA	An initial 3 months of intensive intervention followed by 3 months of intermittent support and the ongoing support and review and modification of the program.	Reduction in target behaviours and maintenance of new behavioural management strategies over time Percentage achievement of objectives specified by families Parent satisfaction rates Maintenance of children in home settings – cost savings Disability Services Commission standards monitoring
Metropolitan Autism Services, WA	No fee	Disability Services Commission, Govt. WA	As required	Parent reports of level of information acquired and satisfaction with delivery of services

Table 4 cont

Western Australia				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
Mildred Creak Early Intervention Service	No fee	Disability Services Commission, Govt. WA	As required	Satisfaction by parents in meeting objective set in individualized family service plans
Intervention Services for Autism & Developmental Delay (ISSADD)	Sort term intensive intervention program: $110. Cost of required therapy extra: Psychological services (Assessment, therapy/Counsell-ing) $166.00 p.h. Program manager $71.50 p.h. Case Manager $35.20/hour. Advanced therapist $22.00 p.h. Senior therapist $18.70 p.h. Therapist $14.85 p. h. Trainee therapist $11.00 p.h. Training workshops for parents (6 hrs) $100 per person. Support groups (2 hours) $44.00.	Parents, Some Govt. funding may be provided	30-40hrs./wk.. consistent with that required for Applied behaviour analysis, Discrete trial training	Achievement of individualised program goals Reduction of family stress Empowerment of parents to direct child's behaviour and development

Table 4 cont

South Australia- See Summary of Australian services below

New South Wales (Rural)

Treatment	Cost/yr.	Funding	Treatment time Hrs/week	Expected short term outcomes and benefits over time[3]
Hunter School for children with autism, Hunter Region, NSW		Autism Association of NSW (AANSW)	As appropriate for the child concerned	Achieve student goals and Board of Studies outcomes
Building Blocks, Hunter Region, NSW	$640 at centre; $400 for home-based program	AANSW (2003 Budget $35,000)	Centre-based (3-5yrs): 2x2hr weekly sessions. Home-based (0-3yrs): 2hr visit per fortnight	Achieve short and long term objectives specific to child. Monitor data recording and checklists.
Central Coast School Early Intervention Service, NSW	$300 (for 1.5days/wk. at centre); $20 per home-based visit	AANSW (2003 Budget $31,000)	Centre-based (3-5yrs): 1.5days/wk. Receive occupational and speech therapy every fortnight. Home-based (0-3yrs): every fortnight	Achieve short and long term objectives specific to child. Monitor data recording and checklists.
AANSW Outreach Hunter region, NSW	$125-initial consultation; $95-follow-up consultation; $50-report; customised training available for a fee	Education authorities, parents (Those requiring assistance with children with autism in the area)	Service provided as required by schools, preschools, homes, support services.	Achieve objectives discussed at consultation and follow-up. Increased awareness of the service provided to a wide range of clients in the area.

Table 4 cont

New South Wales (Rural)

Treatment	Cost/yr.	Funding	Treatment time Hrs/week	Expected short term outcomes and benefits over time[3]
School Program, Early Childhood class, South Coast, NSW	Fee $1900	AANSW	School-based as required	Number of children achieving mainstream education
Early Intervention Program – Pambula, South Coast, NSW	Free	AANSW	Centre-based program (hours as required)	Achievement of individual objectives, including placement in mainstream preschool settings
Outreach-behaviour intervention and family support, South Coast, NSW	Free (nominal charge to be introduced)	Outreach Service (AANSW)	3days/wk. outreach service provided to children up to 20yrs with autism or Asperger's syndrome, and their families	Number of families using the service. Constant monitoring of services provided.
Kaleidoscope, Hunter Region, NSW	No fee	Hunter Children's Health Network	Not applicable	Not applicable An assessment and referral service only (see Autism Services description in Appendix)
Vacation Care, South Coast, NSW	Fee payable (means tested)	Illawarra Children's Services	3 days/wk. to children with autism up to 12yrs, needs based (waiting list)	Number of children using service. Monitor number requiring service.

Table 4 cont

New South Wales (Rural)

Treatment	Cost/yr.	Funding	Treatment time Hrs/week	Expected short term outcomes and benefits over time[3]
Saturplay, South Coast, NSW	Fee payable (means tested)	Interchange Illawarra	Saturdays only (9.00am-3.00pm) for children with autism up to 12yrs, needs based (waiting list)	Number of children using service. Monitor number requiring service.
After School Care, South Coast, NSW	Fee payable	Illawarra Disability Trust	After school care: 2days/wk (3.00pm-5.30pm) for adolescents with severe autism	Number of children using service. Monitor number requiring service.
Community access from home-base, South Coast, NSW	Fee to discuss with provider	C'wealth. Respite Carers	Limited availability-needs based	Number of children using service. Monitor number requiring service.
Home-based respite, South Coast, NSW	Fee to discuss with provider	Interchange Illawarra	Limited availability-needs based (autistic children up to 12yrs)	Number of children using service. Monitor number requiring service.

Table 4 cont

New South Wales (Metro)

Treatment	Cost/yr.	Funding	Treatment time Hrs/week	Expected short term outcomes and benefits over time[3]
"Building Blocks" Early Intervention Service, NSW	Early Play: $350 for 3 terms; Building skills: $350/ term (2 terms); Transition to school: $350/term (2 terms); Starting Blocks: $10/session (3 terms)	AANSW	See "Building Blocks", Hunter region (above)	Number of children provided with appropriate services; Number of children moving on to less segregated settings or mainstream school placements; number of children increasingly integrated into regular preschool settings with minimal support.
Jigsaw Preschool programs, Metro, NSW	$50/day	AANSW	Centre-based: 1day/wk for autistic children aged 3-5yrs.	Achievement of individual objectives, focussing on communication, social interaction and sensory processing.
School Outreach Service, NSW Includes Behaviour intervention service for children (0-19 yrs), Western Sydney Area.	Fee varies accord-ing to service	AANSW (2003 Budget $120,000)	Services for diagnostic and functional assessment as required. Assistance with interventions for children (K-12) in mainstream education. Provisions of social skills and anxiety management program as required.	Maintenance of integrated mainstream placements (approaching 100%)

Table 4 cont

New South Wales (Metro)				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
Lifestart Program, Metro, NSW	Joining fee (minimal)	DADHC, Charitable institutions, Dept. Education and Training	As appropriate centre- and home-based	Achieve reduction in family stress through family support/parent training. Individual goals achieved by child in terms of behaviour, social, communication, education.
Stepping Stones and Giant Steps, Gladesville, NSW	No fee	Part funding from State Govt. and parent fundraising	Stepping Stones: Centre-based program for young children (3-5yrs), 3hrs/day, 3 days/wk. Giant Steps: School-aged children, K-12, hrs. dependent on child's needs	Achieve functional living, a degree of independence, integration into mainstream education
Together Hand in Hand, NSW	Staff salaries: $20-60/hr	Parents or schools involved	3-4hr block/day, morning or afternoon. Home-based or school-based	Achieve functional living, inclusion in community settings, best educational alternative

Table 4 cont

New South Wales (Metro)				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
Starting Points, Campbell-town, NSW	Free	DADHC, Comm. Dept. Family & Community Services, Suppl. Funding from Comm. Intervention Support Program through NSW Dept. Education and Training	First Steps: child (0-6yrs), Sat. mornings, every 6wks, home visits and fathers group sessions. Stepping Stones: 8children up to 5yrs, 3hrs x 2days/wk. Stepping out: time as required.	Integration into mainstream education, family support, help parents to become advocates for themselves and their child.
Learning Links, Liverpool, St George, Fairfield/ Sutherland, NSW	Inclusive preschool: $27/day	DADHC Dept. Education and Training I.S.P. funding Fundraising by parents	Inclusive preschool 5hr/wk. to 3 days/wk (20/class, 1-3 have autism). Outside intervention may also be used as required. Individual programs at centre as required (fee will apply)	Inclusion in community settings, educational placement, personal development/independence, family support/stress reduction, empowerment.

Table 4 cont

New South Wales (Metro) cont'

Treatment	Cost/yr.	Funding	Treatment time Hrs/week	Expected short term outcomes and benefits over time[3]
Southern Sydney Therapy Centre, Miranda, NSW	Centre-based Early Intervention program: $250:1day/ term $500: 2days/ term. Extra: $55 members fee	NSW Dept. Education and training, Charities	1or 2 days/wk./term	Inclusion in community settings, educational placement, personal development/independence, family support/stress reduction, empowerment.
Early Education Clinic, Rosehill, NSW	$3.50pperson/Group session; $7 /individual session	Charities	Group or individual sessions, dependent on child's needs	Achieve goals in personal development, appropriate education, provide family support
Pathways, Marrickville, NSW (not specific to autism, all disabilities)	$20/day: Preschool program	DADHC, DOCS, NSW Dept. Educt'n. and Training, Small grants	Preschool program: 1-2days for children up to 5yrs of age. Home-based visits per/fortnight. Extra therapies as required.	Improvement in social, communication, behavioural and educational skills of child. Provide respite to families where possible.
Focus, Parramatta, NSW	$3.50/wk	Sydney Day Nurseries Child Services, DADHC, NSW DET NSW, Commonwealth FAES	Centre-based Early learning program (0-5yrs), 1.5hrs/wk for 10 wks. Some home visits.	Improve quality of life for child and family. Adequate provision of training and resource staff to aid families and support Childcare centres.

Table 4 cont

	New South Wales (Metro) cont'			
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
McCarthur Early Childhood Learning Service (was CEEPS), NSW	Free, a voluntary contribution of $5/wk from families attending	DADHC, AANSW	Early learning playgroup 2hrs/wk. Individual special; Educt'n. and group play therapy, hrs dependent on child's needs	Integration into community setting, achieve mainstream education, increased social, play skills using visual supports.
Catholic School System, NSW	School fees if attending mainstream school	AANSW	Satellite classes for children (K-2), within school day.	Achieve individual objectives in language, behaviour, play and social skills, to optimise inclusion in mainstream education
Sylvanvale, NSW	Free	DET, NSW	1-3 days/week for children aged from 3.5yrs.	Achieve individual objectives in language, behaviour, play and social skills, to optimise inclusion in mainstream education
C.A.R.D. (Centre for Autism and Related Disorders), NSW	$30,000-$60,000/yr dependent on choices	Parents	35-40hrs/wk., 1st year Children (2-4yrs.) homebased:25-30hrs/wk. at school, 10-15hr/wk. at home	Achieve individual objectives using ABA principles, focussing on problem behaviour, social, play, language and communication skills, integration into mainstream education and reduced stress in family setting
Diverse Abilities[4]	Variable depending on child's requirements	Parents	As appropriate	Education using the principles of ABA for children from 18months to 12 years

Table 4 cont

New South Wales (Metro) cont'				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
Lizard Children's Centre (formerly Elizabeth Watson Speech Pathology)	~$15,000-20,000[5]	Parents	25hr/wk minimum is recommended. Parents receive initial training from Elizabeth Watson, Speech Pathologist. Senior therapists from Centre visit families every week.	As for CARD
Early Autism Project[6]				
Connect Therapy, NSW	$2,200 for 9 week program	Parents	Program may happen anytime during the day. Requires child to be with parent/ professional in designated Connect therapy room in home for 45mins.	Train and empower parents to be able to direct their autistic child to achieve everyday life skills.
Hanen Program	Fees apply	Parents	Parents attend a training course on language acquisition	

Table 4 cont

New South Wales (Metro) cont'				
Treatment	**Cost/yr.**	**Funding**	**Treatment time Hrs/week**	**Expected short term outcomes and benefits over time[3]**
Tomatis Method[7]	$3,000-$3,600 for 60hr program	Parents	60hrs program Mother and child receive a program of sound therapy at the same time	More information see web-site: http://www.thedaviscenter.com Identifies various sound programs available (Tomatis, Auditory Integration Therapy and Samonas therapy)
Auditory Integration therapy[8]	$1200-$1800 for 10hrs of therapy	Parents	As required	See web-site above

[1] Roberts JR. Review of models of best practice in the management of children with autism spectrum disorders

[2] Dawson G. and Osterling J. (1999) Early intervention in Autism. In: Guralnick M.J. (Ed). The effectiveness of early intervention. Baltimore, Brookes Publishing, pp 307-326.

[3] Currently no published reviews on the effectiveness of outcome measures of these programs or on the benefits over time

[4] Diverse Abilities is moving its focus from providing ABA style services for children with Autism and will be setting up a practice to provide Relationship Development Intervention (http://www.connectioncenter.com).

[5] Families may pay $40,000 per year which includes private therapy as well as the therapy provided by the Lizard Centre. Families meet with the Lizard Centre team every 4 weeks to review child's progress.

[6] Please refer to appendix One for information on the Early Autism Project

[7] Three people practicing the Tomatis method in Australia, one based in Sydney, contact: Kay Distel, Ph. 02 9634 2510, Mob. 0425 242 123.

[8] Auditory Integration Therapy, currently know of 1 practicing in Melbourne, 1 in Sydney and 1 visiting US trainer who travels around (QLD).

Appendix One: Services in Australia for children with autism and their families

VICTORIA

The name of the program
Early Childhood Autism Services-Northern (ECAS-N)
Year of commencement:1999
Lead agency name and contacts
ECAS-N resulted from the establishment of a partnership between the Yooralla Early Childhood Intervention Program and the Broad Insight Group, Northern Metropolitan region and funded by the Department of Human Services.
Description of program, in terms of type and age range
Early childhood intervention program providing specific and tailored programs for pre-school children with an Autistic Spectrum Disorder (ASD) and their families. Programs focus on communication, behaviour, sensory processing and play.
Evaluations or evaluation strategies
Parent evaluation-questionnaire format
Individual program plans for child are evaluated regularly
Evaluation of family service programs is ongoing
Outcome measures
Speech, communication skills
Problem and adaptive behaviour skills
Everyday living skills
Adaptability to family and community settings
Reduction in family stress
Cohesion in family unit
Budget/Fees for program
Fees are $120 per term or $480 per year. Budgeting for the program (~$70,000 per annum) is shared equally between the two partnering organizations.

The name of the program
WestArc Autism Program
Year of commencement:
1992
Lead agency name and contacts
Noah's Ark Family Resources.   Jenny Bott is the Coordinator of the WestArc Program.
Description of program, in terms of type and age range
Early childhood intervention program for children (0-6 years) with Autism, Pervasive Developmental Disorder –Not otherwise specified (PDD-NOS) and Asperger's Syndrome (AS). A family-centred practice and supportive of inclusion of children in local kindergarten and childcare.
Evaluations or evaluation strategies

Family reviewed by annual questionnaire
Ongoing evaluation of child and family goals
Outcome measures
Child inclusion in early childhood services and their communities
Family confidence in parenting a child with autism
Community awareness and understanding
Budget/Fees for program
Fees are $80-100 per term (four terms per year).

The name of the program
Illoura Early Childhood Intervention Services
Year of commencement:
1977
Lead agency name and contacts
Knox City Council
Janelle Swalwell
illoura@knox.vic.gov.au
Description of program, in terms of type and age range
Early Childhood Intervention program (zero-six years), inter-agency, trans-disciplinary
Evaluations or evaluation strategies
Goal attainment scaling
Parental appraisal (achievement of goals set by parents evaluated six monthly)
Other services appraisal
Outcome measures
Achievement of goals set by parents
Parental knowledge of service and options
Parental well-being
Budget/Fees for program
$100-$150 per term.

The name of the program
Autism Victoria Family Counselling and Information Service
Year of commencement:
1991
Lead agency name and contacts
Autism Victoria-Amanda Golding-Executive Officer, Ph. 03 9885 0533
Description of program, in terms of type and age range
Support is primarily to families/primary carers-all ages, all ASD diagnoses. It comprises
information, guidance, emotional and practical support, library delivered via small group
sessions or electronic/phone/personal contact.
Evaluations or evaluation strategies
We complete the annual Department of Human Services Disability Self Assessment
process, as well as collect Quarterly Contact Data for Department of Human Services.
We also complete periodic evaluations by random selection, or at conclusion of specific
programs.
Outcome measures

Not relevant

Budget/Fees for program

Autism Victoria budget for provision of the above service is approximately $200,000. Annual membership fee of $27.50. Small services fee if required. Funding from Department of Human Services, Victoria, donations and philanthropic grants and fees in equal proportions.

The name of the program

Autism Behavioural Intervention Service (ABIA)

Year of commencement:

Originally early 1970s

Lead agency name and contacts

ABIA, contact: Julia Seedman, Ph. 03 9885 7463

Description of program, in terms of type and age range

ABIA organizers established ABA service providers to work with families that request assistance. ABA principles applied as for CARD.

Evaluations or evaluation strategies

Outcome measures

Budget/Fees for program

$40,000 per annum paid by families for provision of ABA services. No fee paid to ABIA. ABIA receives funding through parent fundraising and philanthropic organisations (see Table 4).

SOUTH AUSTRALIA

The name of the program
School Program
Year of commencement:
1975
Lead agency name and contacts
Autism Association of South Australia (AASA)
Manager: Liz Cohen
Description of program, in terms of type and age range
Children with autism or Asperger's Syndrome attend either state, catholic or independent mainstream school. AASA Multi-disciplinary team provide consultancy services to these schools. Areas covered include behavioural management, social skills development, communication, classroom management and curriculum issues.
Evaluations or evaluation strategies
Outcome measures
Budget/Fees for program
$712,545.00 (2002/2003).

The name of the program
Early Development program
Year of commencement:
1963
Lead agency name and contacts
AASA
Description of program, in terms of type and age range
For children with autism or AS: 0-school age- Families can access either A or B. A: Group sessions- 8 children to 4 staff (2 teaches, 1 speech pathologist, 1 occupational therapist). Focus on communication, gross and fine motor, sensory integration, social skills, behaviour. B: Consultancy services from teacher, speech or occupational therapists, given in home or at a centre. Family support offers Post Diagnostic visits, phone and home visits if families are having problems that cannot be addressed through A or B.
Evaluations or evaluation strategies
Group sessions: Group program with individual aims for children. Evaluations are made weekly after each session with term reports outlining progress in development. Aims are developed for the next term.
Outcome measures
Social/play development
Meal time behaviour
Fine/ table activities
Gross motor/ movement
Self-help/ snack time

Relaxation
Music/ movement
Sensory
Communication
Budget/Fees for program
$398,147.00 (2002/2003)

The name of the program
Diagnostic team
Year of commencement:
1973
Lead agency name and contacts
AASA
Coordinator: Amanda Harris
Description of program, in terms of type and age range
Conduct diagnostic assessments of individuals suspected of having autism or AS. (Referrals accepted in writing from parents or health/ disability/ education professionals. Age range: youngest referral was 16months; oldest 63. Main age range 2 to 12yrs. Assessment is multi-disciplinary focusing on early history/ play based assessment/ observation of individuals interactions/ behaviours and responses, then rated against internationally recognized criteria for ASD.
Evaluations or evaluation strategies
Scope for review/ reassessment at request of parent/ professionals
Outcome measures
Budget/Fees for program
$75,000 form State Government. $20,000 from private fees as Government funding does not cover cost of service.

The name of the program
Social skills
Year of commencement:
1980
Lead agency name and contacts
AASA
Coordinator- Jan Martin
Description of program, in terms of type and age range
8-16yr olds, focus on higher functioning autism and AS. Attendance for 12months (groups of 8 children).
Evaluations or evaluation strategies
Parent and participant feedback
Outcome measures
Budget/Fees for program
$70,000 per annum

The name of the program
Intensive intervention

Year of commencement:
2001
Lead agency name and contacts
AASA-Jan Martin
Flinders University-Verity Bottroff
Description of program, in terms of type and age range
Cognitive, behavioural and sensory intervention for school aged children with AS
Evaluations or evaluation strategies
Evaluation conducted by Flinders University in relation to psychological assessments of children and parental feedback
Outcome measures
Increased ability to integrate into community
Budget/Fees for program
$70,000 per annum for up to 6 participants

The name of the program
Pyramid approach to education Picture Exchange Communication System (PECS)
Year of commencement:
2002
Lead agency name and contacts
Pyramid Educational Consultants of Australia P/L
Amanda Reed (Director)- 08 8331 7727
Description of program, in terms of type and age range
The pyramid approach is a model for teaching students with autism based on the principles of ABA. PECS is a method for teaching functional communication. Both are relevant across all ages
Evaluations or evaluation strategies
Pyramid and PECS are data driven intervention approaches. Data is collected and analysed on a session by session basis
Outcome measures
Budget/Fees for program
Direct intervention starts at $200 per hour. Training for professionals and parents/ carers is also available. Fees for training sessions very, but parents are half price.

The name of the program
Occupational therapy for children P/L
Year of commencement:
1989
Lead agency name and contacts
Veronica Steer (Director)
Email: cvsteer@bigpond.net.au
Ph: 08 8410 4522 FAX: 08 8410 4622
Description of program, in terms of type and age range
Occupational therapy incorporating: sensory integration therapy, samonas integration therapy, PECS and COMPICS, developmental skills training, preparation for school, school skills (fine motor, gross motor, visual motor, playground skills)

Evaluations or evaluation strategies
Outcome measures
Formal tests as appropriate: Miller assessment of pre-schools, Peabody test, visual motor and handwriting tests, sensory profile and Southern Californian ST test Battery, Occupational therapy home, school, kindergarten, childcare rating scales
Budget/Fees for program
1hr consultation $110, 45min consultation $82, 30min consultation $55, add $555 to each for inclusion of written report

The name of the program
The Briars Special Early Learning Centre (formerly Kent Town Pre-school)
Year of commencement:
1975
Lead agency name and contacts
The Briars School
Contact: Ms Raymond
Ph: 08 8379 6976
Email: aasa@autismsa.org.au
Description of program, in terms of type and age range
Pre-school children, 4-5yrs of age receive 2 full days. Early entry for children 3.5-4yrs of age receive 1 full day. Extension for children 5-6yrs dependent on child's individual needs. Curriculum based on the DECS curriculum document and knowledge of individual child's and families needs. It s a play based program with a strong focus on sensory integrated learning.
Evaluations or evaluation strategies
All children have a Negotiated Education Plan that is relevant and appropriate, ideally within the first six months of attendance. This is then reviewed within a regular and agreed time frame. This NEP includes the child's Individual Learning Plan which states outcomes and strategies to be used. It is reviewed and updated at each meeting.
Outcome measures

The name of the program
ChiroPartners, SA
Year of commencement:
Lead agency name and contacts
ChiroPartners, SA
Ph: 08 8373 3896
Fax 08 8373 0223
Description of program, in terms of type and age range
Chiropractic adjustments on children with autism.
Evaluations or evaluation strategies
Outcome measures
Monitoring of progress by changes in medication intake, communication skills, reduction in head banging, parental feedback, social behaviour, appetite and self confidence
Budget/Fees for program

The name of the program
Learning through Play Playgroup
Year of commencement:
2001
Lead agency name and contacts
Cyone Whiting- Special Needs Officer, Playgroup Association of S.A.
Ph: 08 8346 2722
Description of program, in terms of type and age range
Playgroup for children with a disability or developmental delay, 0-5yrs of age. Parent or Carer attends the group with the child
Evaluations or evaluation strategies
Outcome measures
Continued family attendance
Budget/Fees for program
Funded through Special Needs Program at Playgroup, S.A.

The name of the program
Aquatic Therapy for children with autism
Year of commencement:
1998
Lead agency name and contacts
South Australian Sport and Recreation Association for People with Integration Difficulties Inc. (SASRAPID). Aquatic therapy for children operates within the Rapid Swim project which is auspiced by SASRAPID.
Contact: Annette Redman, Ph. 08 8410 6999
Description of program, in terms of type and age range
Description of program, in terms of type and age range
One to one water based therapy to children aged 3-12yrs who have been diagnosed with ASD
Evaluations or evaluation strategies
Children involved in the program are assessed on a regular basis by therapists who work with them. Progress reports are written on a weekly basis
Outcome measures
Outcomes are measured by the development of the child's social skills, aquatic skills, physical development, alertness and awareness levels. Many participants progress into the Rapid swim program where they participate in more structured swim lessons
Budget/Fees for program
Participants pay $14.30/session. Rapid swim (via SASRAPID) receives funding from HACC and Dept. of Human Services to assist with the operation of the programs

The name of the program
Kid Sense Occupational therapy (and private practice)
Year of commencement:
1999
Lead agency name and contacts
Director: Joanna Buttfield, Ph. 08 8272 7522

kidsense@ozemail.com.au
Description of program, in terms of type and age range
Cater for students of all ages. Provide both assessment and treatment of sensory and motor skills. Treatment is both consultative and hands-on
Evaluations or evaluation strategies
Parent/ teacher reports. Use of "sensory profile" questionnaires.
Evaluations or evaluation strategies
Outcome measures
Test/ re-test scores of motor skills and behavioural changes
Budget/Fees for program
Parents pay fee that is dependent on requirements

The name of the program
Social Skills and Behaviour Therapy
Year of commencement:
March, 2001
Lead agency name and contacts
Ms Madhavi Nawana (BA Psych Grad Dip Rehab)
Ph: 08 8211 6445
Description of program, in terms of type and age range
Program is for children aged 5yrs and greater and adults with ASD, in particular those with AS. Includes social skills training, counselling, behaviour support strategies, observations at home and school, training and development for parents and professionals (eg. Teachers, SSO's, nurses, psychologists).
Evaluations or evaluation strategies
Outcome measures
Program goals are set for individual and progress is measured by reports from teachers and parents.
Budget/Fees for program
$45 for 50minute session initial interview. Then 30 per head for 50minute session of small group training (3/group). $90 per 50mintue session- external rate (eg. home/ school) and $90 per 50minute session for training and development rate. Currently 8-12month waiting list

The name of the program
Early Intervention Research Program
Year of commencement:
February, 2003
Lead agency name and contacts
Director: Dr Robyn Young, Senior Lecturer, School of Psychology,
Faculty of Social Sciences, Flinders University, Adelaide
Robyn.young@flinders.edu.au
Ph. 08 8201 5104
Manager: Ms Carrie Johns
Carrie.johns@flinders.edu.au
08 8201 5261

Description of program, in terms of type and age range
The Flinders University Early Intervention Research Program (EIRP) provides intensive behavioural intervention to children with Autistic Disorder (AD) or those at risk of developing autism (either through genetics or early signs in development) between 1 and 4 yrs of age. This program provides assistance to those children and families who have typically been unable to access suitable levels of intervention due to costs of such intense therapy. By developing ways to intervene with the core-deficit (primary) behaviours of autistic children at an early age, we hope to reduce the development of secondary outcomes which include inappropriate social behaviours, poor communication, and other behaviours which arise from these deficits.
The EIRP is research based and aims to evaluate the effectiveness of intensive behavioural intervention in children with AD under the age of 4. Following acceptance into the EIRP, an intervention program is developed targeting the needs of each child based on initial assessment. An intervention program utilising behavioural techniques in
Description of program, in terms of type and age range
then implemented under the supervision of a trained therapist for 15 hr per week over a 2 week period. Following this initial training period, a home-based program is followed for a minimum of 15 hrs each week over a minimum period of 20 weeks.
Evaluations or evaluation strategies
We aim to investigate the efficacy of the behavioural program specifically targeting the early difficulties operationalised in the Flinders Observation Schedule for Pre-Verbal Autistic Characteristics (Revised) (FOSPAC_R). Assessments employ a staggered baseline design; that is the children are assessed on four occasions:
1) an initial assessment
2) a pre-intervention assessment
3) a post-intervention assessment, at 2 weeks
4) a follow-up assessment, at 20 weeks
Outcome measures
Assessments are conducted by blind raters so that the condition of each child is unknown. The dependent measures on which the children are assessed include:
i. *The Flinders Observation Schedule for Pre-Verbal Autistic Characteristics (Revised).* This is an instrument designed to assess early manifestations of the disorder otherwise referred to as the core-deficit linked behaviours (Young, Brewer, & Patterson, 2003).
ii. *Developmental Behaviour Checklist.* This is an assessment tool that looks at challenging behaviours including 'autistic related' behaviours.
iii. *Childhood Autism Rating Scale*
iv. *Vineland Adaptive Behaviour Scale*
v. *Autism Treatment Evaluation Checklist*
Budget/Fees for program
The EIRP is a free program. However, a condition of acceptance into the program require children to participate in intervention for a minimum of 15hrs per week for 2o weeks following the initial fortnight training period. Parents may choose to provide the intervention themselves or to pay a trained therapist.

QUEENSLAND

The name of the program
"KidStart" Family Involvement program
Year of commencement:
1999
Lead agency name and contacts
Autism Queensland (AQ) – Bernadette Newport, Assistant Director of Services, co-ordinates these programs.
Description of program, in terms of type and age range
Specifically for children aged under five. Parents and child attend all sessions. Total number of direct contact hours approximately 15 (varies according to format (see next point)). Flexible in format according to child's / family's needs (eg., individual or small group; number of hours per day / sessions per week, etc.). Run by teacher and/or occupational therapist (OT) and/or speech pathologist (SP).
Evaluations or evaluation strategies
Parents, AQ staff and staff from other setting (if there is one) complete evaluation forms
Outcome measures
Increased knowledge of ASD in parents
Increased awareness of appropriate strategies in parents
Increased awareness of available services in parents
Increased coping ability in parents
Report recommendations that provide information for utilising strategies and implementing programs for key concerns of parents
Report recommendations for future appropriate AQ services
Budget/Fees for program
$450 fee per program – subsidised fee, AQ funds large part of costs through its grant from Commonwealth Special Education – Non-Schools Organisations.

The name of the program
"Focus" Family Involvement Programs
Year of commencement:
Early 1980's
Lead agency name and contacts
AQ – Bernadette Newport, Assistant Director of Services, co-ordinates these programs
Description of program, in terms of type and age range
Available for children aged five –16 years. Two main formats at present – individual or group. Twelve - 15 hours of direct therapy provided (depends on format). Staffed by teachers. Usually includes a visit to child's school. Often a visit to the child's home takes place as well.
Evaluations or evaluation strategies
Parents, AQ staff and staff at other educational setting complete an evaluation form

Outcome measures
Increased knowledge of ASD in parents
Increased awareness of appropriate strategies in parents
Increased awareness of available services in parents
Increased coping ability in parents
Report recommendations that provide information for utilising strategies and
implementing programs for key concerns of parents
Report recommendations for future appropriate AQ services
Budget/Fees for program
$450 fee per program – subsidised fee, AQ funds large part of total costs through its
service agreement with Education Queensland

The name of the program
AQ Group Placement
Year of commencement:
1970's
Lead agency name and contacts
AQ– Valerie Preston, Director of Services co-ordinates these placements
Description of program, in terms of type and age range
Three-day per week placement for period of up to two years in a class at one of AQ's two
Autism Therapy and Education Centres. Six children per class, one teacher, one or two
aides, weekly OT, physiotherapy (PT) and SP sessions, psychologist input by referral.
Available for children aged five – 16 years. Focus on working on particular deficits of
ASD as displayed by each child. Strong emphasis on working collaboratively with
parents and other educational setting/s ("home school"). Term school visits. Home visits
as required.
Evaluations or evaluation strategies
Ongoing process of reporting, development of IEP goals, then subsequent reporting on
achievement of those goals
Assessment by AQ, OT, PT, SP or psychologist when specifically requested
Videoing of children at start, middle and end of placement
Implementation in near future of battery of testing at beginning and end of placement
Outcome measures
Improvements in child's functioning as measured through achievement of IEP goals
Increased ability of family to cope with and implement strategies for behavioural
challenges
Increased ability of home school staff to modify environment and provide strategies to
meet child's individual needs
Increased understanding of all involved of what ASD is, particularly in relation to this
specific child
Achievement of home school IEP goals
Budget/Fees for program
$20 per day fee charged – subsidised fee; remainder of costs met through service
agreement with Education Queensland, some funds from non-state school grants and
fundraising

The name of the program
Early Intervention Group Placement
Year of commencement:
2001
Lead agency name and contacts
AQ– Valerie Preston, Director of Services co-ordinates these programs
Description of program, in terms of type and age range
Available to children aged between three and five years. Twelve month program of two days per week attendance at AQ's Sunnybank Autism Therapy & Education Centre. Third day per week teacher goes to other educational settings and homes. Six children, one teacher, one aide, weekly SP, OT & PT. Focus is on deficits of ASD. Heavy emphasis on preparing child for school, both through acquisition of pre-requisite skills and supporting parents through appropriate Education Queensland processes such as ascertainment, selecting a school, providing information to school.
Evaluations or evaluation strategies
Ongoing process of reporting, development of IEP goals and reporting on achievement of IEP goals
Feedback from parents and other settings during visits
Videoing of children at beginning and end of placement
Outcome measures
Achievement of IEP goals
Smooth transition to school setting
Positive relationships between AQ, home and school / other educational settings
Awareness and implementation of appropriate strategies by parents and school staff
Budget/Fees for program
$60 per week fee – subsidised; AQ meets remainder of costs out of its own funds

The name of the program
"Stronger Families and ASD" project
Year of commencement:
2002
Lead agency name and contacts
University of Queensland – Deb Keen, Michelle Braithwaite (07) 3255 0651
Description of program, in terms of type and age range
Funded by Family and Com services Commonwealth, University of Qld, four years or less, not necessary to have diagnosis of autism but needs to demonstrate characteristics from all three sections of triad. Use modified checklist CHAT. Family centered approach: Families participate in weekend workshop followed by five weeks home facilitation, visit twice per week both parents, help parents work out priorities, support to decide on and implement approach to meet goals.
Evaluations or evaluation strategies
Outcome measures
Video data prior to and after workshop and after home visits, for analysis of parent and child outcomes, e.g. child initiation of interaction towards parents, number of interactive turns.
Parents give feedback on use of techniques learned at workshop.

Budget/Fees for program
None

The name of the program
Applied Behaviour Analysis (ABA)
Year of commencement:
Lead agency name and contacts
Autism Behavioural Intervention Queensland (ABIQ) – 3892 2347
(Other information not available)

The name of the program
Various Education Queensland autism-specific programs
Year of commencement:
Lead agency name and contacts
Education Queensland – Natalie Swayn, Statewide Advisory Visiting Teacher for Autism
Spectrum Disorder – (07) 3240 9328
(Other information not available)

NEW SOUTH WALES

The name of the program
Autism Association, NSW (AANSW)- Outreach- Hunter region
Year of commencement:
1997
Lead agency name and contacts
Lydia Meem- School Coordinator/ clinical psychologist
Lara Cheney- School Coordinator-Outreach Consultant ph. 49556266
Description of program, in terms of type and age range
Catering for people 0-99yrs of age. Providing support to schools, preschools, homes, support services. Liaising with other agencies. Training (customized and from training calendar).
Evaluations or evaluation strategies
Client/ family/ service feedback
Outcome measures
Number of clients receiving our service, area we cover
Objectives achieved from consultations and follow-ups.
Budget/Fees for program
$125-initial consultation
$95-follow-up consultation
$50- report
Training (variable)

The name of the program
Hunter School for children with autism
Year of commencement:
Lead agency name and contacts
AANSW
Description of program, in terms of type and age range
Program covers children aged three years, nine months to ~eight years. Provides a transition setting to develop skills before making the transition to a less specialized setting.
Evaluations or evaluation strategies
Observations, videotape, anecdotal evidence
ABC analysis
Discussion with parents/carers and other involved professionals
Outcome measures
Individual student goals
Board of studies outcomes
Budget/Fees for program

The name of the program
Kaleidoscope
Year of commencement:
2002
Lead agency name and contacts
Hunter Children's Health Network (work in collaboration with Autism Association, NSW
Sean Fardell (psychologist) Ph. 0249246400
Description of program, in terms of type and age range
Assessments for children (0-18years)- both diagnostic and intellectual. Referrals are made to other relevant services.
Evaluations or evaluation strategies
Outcome measures
Budget/Fees for program
Free

The name of the program
Central Coast School Early Intervention Service
Year of commencement:
1997
Lead agency name and contacts
AANSW
Description of program, in terms of type and age range
Program for children aged two-six years. Home-based, fortnightly visits for zero-three years. Centre-based for three-five years (also fortnightly occupational and speech therapy).
Evaluations or evaluation strategies
Observations
Developmental checklist
Consultation with other service professionals
Observe Individual Family Support Plan's (I.F.S.P.s) where possible and parental feedback
Outcome measures
Achievement of short and long-term objectives
Data recording
Cross-checking with checklists
Budget/Fees for program
$75/term (one-five days/week)
$20/home-based visit
Funded for 2003: $31,000

The name of the program
"Building Blocks", Hunter region
Year of commencement:
1997
Lead agency name and contacts

AANSW-Hunter
Beth Gerondis, Ph. 49556266
Description of program, in terms of type and age range
Centre-based program for children, aged three-five years, two x two hr sessions/week.
Home-based program for children, aged 0-three years, one x two hr visit/fortnight.
Evaluations or evaluation strategies
Observations
Review of objectives
Consultation with other professionals involved and parents/caregivers
Outcome measures
Achievement of short and long-term objectives
Data recording
Cross-checking with checklists
Outcome measures
Budget/Fees for program
$160/term for centre-based program
$100/term for home-based program (5 fortnightly visits)
Funded for 2003 for $35,000

The name of the program
School Outreach Service
Year of commencement:
1990
Lead agency name and contacts
AANSW
Anthony Warren, Jane Cotter
Description of program, in terms of type and age range
Diagnostic and functional assessment, consultancy services, school and home-based interventions for children (K-12) (mainstream), social skills and anxiety management group program, Behaviour intervention service for children (0-19yrs), Western Sydney area.
Evaluations or evaluation strategies
Quality assurance project
Adult Social Communication Group. 2002
Outcome measures
Maintenance of integrated mainstream placements for clients (~100%)
Budget/Fees for program
Free
Budget funded 2003, $120,000

The name of the program
"Building Blocks" Early Intervention Service
Year of commencement:
1970
Lead agency name and contacts
AANSW

Description of program, in terms of type and age range
A number of home-based and centre-based program options for children aged zero-five years with a diagnosis of ASD:
Home-based Early Play Program (zero-three years)
Building Skills Program (three-five years)
Transition to School Program (four and half-five years)
Centre-based Starting Blocks Groups (zero-three and half years)
Evaluations or evaluation strategies
Parent questionnaires for each program
An external review of all Building Blocks Programs commenced in 2003
Outcome measures
Number of children provided with appropriate services
Number of children moving on to less segregated settings or mainstream school placements Number of children successfully integrated into regular preschool settings with minimal support
Budget/Fees for program
Early Play Program:$350/ term (for three terms)
Building Skills: $350/ term (for two terms)
Transition to School: $350/ term (two terms)
Starting Blocks: $10/session (three terms)

The name of the program
Jigsaw Preschool program (Metropolitan)
Year of commencement:
1998
Lead agency name and contacts
AANSW
(Vern Barnett School for Children with Autism) Ph. 89778360
Fax. 99727046
Email: vbschool@autismnsw.com.au
Description of program, in terms of type and age range
A centre-based early education service operating one day/week for children aged three-five years who have characteristics associated with ASD. There is an associated Parent Training Service. Program is based on the AANSW curriculum with an emphasis on 1:1 and small group instruction.
Evaluations or evaluation strategies
Jigsaw program being evaluated by AANSW in 2003
Outcome measures
Assessment of individual education plan
Functional assessment of communication skills
Curriculum based checklist
Anecdotal data
General observations of play and communication
Sensory assessment and plays skills Checklist.
Budget/Fees for program
$50/day

The name of the program
South Coast, NSW Services:
a) School program
b) Early intervention- Pambula
c) Outreach- Behaviour intervention and family support
d) Vacation care
e) Saturplay
f) After school care
g) Community access from home base
h) home based respite
Year of commencement:
a) 1986
b) 2000
c) 2002
d) –
e) –
f) 2003
g) –
h) –
Lead agency name and contacts
a) Autism Association, NSW- South Coast School for Children with Autism- Principal
b) As above
c) South Coast School for Children with Autism- Outreach worker
d) Illawarra's Children's Services- Ms Leanne Micallef, Ph. 4227 1079
e) Illawarra Disability Trust- Ms Lisa Wardell, Ph. 42284500
f) Commonwealth respite carers, Ph. 4233 1923
h) Interchange Illawarra- Mrs Glenda Pearce, Ph. 4227 1079
Description of program, in terms of type and age range
a) School based program for children with a diagnosis of Autism Spectrum Disorder (ASD) or Asperger's Syndrome (AS) focusing on core competence (behaviour, communication, sensory, social skills) integrated into NSW Board of Studies Key Learning Areas. Age range four-16 years. Transitory education setting: students may start at base school and then move to a satellite class and then to the next least restrictive setting that may be in either a NSW Department of Education and Training school, Catholic or private school
b) Early intervention centre-based program for child to the age of five years
c) Three day per week outreach service for people with ASD or AS aged to 20 years and their families and other services
d) Provide leisure activities during school holidays- three days per week. Open to children to 12 years who are moderately affected by autism. Access to service is needs based and there is a waiting list
e) Community access service providing respite on Saturdays, 9am -3pm. This is a community access program from the base school. Open to children to 12 years who are moderately affected by autism. Access to service is needs based and there is a waiting list

f) After school care provided from base school for adolescents with severe autism, two days per week (3pm to 5.30pm)

g) Limited respite available for all students with a disability

f) Limited respite available for all children up to 12 years

Evaluations or evaluation strategies

a) Board of Studies curriculum based assessment, functional skills assessment

b) Functional skills assessment

c) Statistical evaluation completed at quarterly intervals

d) –

e) –

f) –

g) –

h) –

Outcome measures

Number of children provided with appropriate services

Number of children moving on to less segregated settings or mainstream school placements Number of children successfully integrated into regular preschool settings with minimal support

Budget/Fees for program

a) $475 per year

b) Free

c) Free (nominal charge to be introduced)

d) Fee payable- means tested

e) Fee payable- means tested

f) Fee payable- means tested

g) –

h) –

For more information regarding the following services, please see the Cost-benefit Table:

The name of the program

Learning Links, Liverpool, St George, Fairfield/Sutherland

Year of commencement:

Lead agency name and contacts

Kerry Butler, Ph. 9534 1710

Description of program, in terms of type and age range

Centre uses a multi-disciplinary approach. Inclusive preschool may have 30% of children with special needs of which up to three may be autistic.   Preschool runs classes of two children with three professionals (speech pathologist, occupational therapist, psychologist) teaching. Teachers trained in Hanen program and More Than Words program. Do not use PECS approach or Shadows approach. Outside intervention from speech pathologists, occupational therapists and psychologists as required.

Linking with preschool program involves professionals going out to preschools to assess individuals and provide support. Use a trans-disciplinary play based assessment.

Early start program involves home visits from an educator for 1.5hours/week for a baby to two hours/week for children aged two-three years. Educator may request the involvement of a speech pathologist, occupational therapist or psychologist as required. Program is for 12 months and in the first instance and leads into preschool programs. Learning Links may receive children from A.B.A. programs and Giant steps at Gladesville. Staff at the Centre run an in-house program called Hands up and practice the Hanen program. Intend to utilize the NCP program from Noah's Ark is funds become available.
Evaluations or evaluation strategies
Outcome measures
Budget/Fees for program

The name of the program
Connect Therapy, NSW (Brochure supplied)
Year of commencement:
Lead agency name and contacts
Monique Simpson, Ph. 9460 9838
Description of program, in terms of type and age range
Nine week program involves professionals going to autistic child's home to teach parents connect therapy. Aim of program is to train and empower parents to be able to direct child in every day life skills. First visit with speech therapist, child is present with parents. Remaining eight visits by speech therapist, only parents are present, for one hour session per week. Occupational therapist is present for three sessions. Parents watch instructional videos and discuss videos with therapists in session. Outside of sessions, parents carry out teaching (interactive play-based) relevant to their child and situation, in a designated connect therapy room each day for 45mins. At end of course, extra therapy can be provided as required. Speech therapist visits on a monthly basis, until no longer required. Some aspects of teaching are consistent with the Sonrise program in the US. Currently seven families are on the program. Intention is to have 80 families on the program at any one time as more staff are employed.
Evaluations or evaluation strategies
Outcome measures
Budget/Fees for program

The name of the program
The Early Autism Project P/L
Year of commencement:
The Early Autism Project was established in March 2001. The Early Autism Project is closely affiliated with the Wisconsin Early Autism Project (in the U.S.). WEAP has been providing services since 1995 (I began work as an ABA therapist in 1995).
Lead agency name and contacts
Margot Squire (Director), Ph. 02 9331 5807
Email: margotsquire@bigpond.com.au
Description of program, in terms of type and age range
We provide services to children 2 – 8 years of age. EAP Consultants are responsible for developing a child-specific curriculum, teaching the child (in a one-to-one fashion),

training and supervising therapists as well as liaising with other professionals. We offer two supervision models; the supervision models differ only in intensity of supervision hours.

Workshop Model:

Training of the team and supervision of the program is accomplished at workshops scheduled every two months. The initial workshop is 9 hours in length (1.5 training days) and follow up workshops are 6-9 hours in length. Team leadership and supervision between workshops is provided by parents or by a particularly skilled team member chosen by the parents. Fortnightly phone consultations between the parents and the EAP Consultant are required to ensure the success of the program.

In addition to the workshops, children on this program are required to see a WEAP Consultant twice yearly for a progress review. The WEAP Consultant is a clinical psychologist.

Fortnightly Supervision Model:

Training of the team and supervision of the program is accomplished during visits held fortnightly (three hour visits with the child, his/her parents and line therapists). Fortnightly phone consultations between parents and the Consultant are required to ensure the success of the program. In addition to the Consultant's fortnightly supervision, children on this program are required to see a WEAP Consultant twice yearly for a progress review.

Budget/Fees for program

The cost of treatment per year for the child concerned

The following estimates are high estimates based on the greatest number of hours recommended for a child. Every program is individualised to meet the specific needs of the child. The samples are estimates only and based on a 48 week year.

Annual Cost for EAP Workshop Model

6 workshops (9 hours per workshop)	$ 8,100
18 phone consultations (30 minutes each)	$ 900
Progress Reviews by WEAP Consultant (2 visits @ 1.5 hours each)	$ 750
A Portion of the Airfare, Accommodations WEAP Consultant	$400
Total	$ 10,150

All supervision is provided in the family's home. Travel is billed at $50 per hour.

Annual cost for EAP fortnightly model

24 supervision visits (each 3 hours)	$ 10,800
24 phone consultations (30 minutes each)	$ 1,200
Progress reviews by WEAP consultant (2 visits @ 1.5 hours each)	$ 750
A Portion of the Airfare, Accommodations WEAP Consultant	$400
Total	$ 13,150

All supervision is provided in the family's home. Travel is billed at $50 per hour.

Additional costs

Initial Workshop $150.00/hr x 9 hours (one time cost)	$1,350.00
Travel costs for Supervisor	$50.00/hour

Families receiving Early Autism Project services are responsible for hiring the therapists for their child's program. Parents pay the therapists directly according to their level of experience, qualifications and the financial restraints of the family.

Therapist costs

Families pay therapists according to prior experience or relevant qualifications. New therapists are generally paid $15 per hour for the first six months. After six months, their rate of pay increases; the wage increase depends on the family and skill of therapist. Most children receive 35 hours of therapy per week for the first 6 – 12 months of treatment. When they have acquired the language and social skills to benefit from a group learning environment, the hours of one-to-one intervention decrease and pre-school/play group hours increase. Often, it is recommended that, a 'shadow' attends with the student during school hours to assist the child in participating in group instruction and interacting with other children. These 'shadow' hours have been included in the estimated costs for the first two years.

Cost of therapists (first 2 years of treatment)

35 teaching hours each week ($17 / hour) = $630 per week x 48 weeks $ 28,560
1.5 hour team meetings (4 therapists at $17 / hour) = $102 x 24 meetings $2,448
Total $ 31,008

Costs of therapists (third and fourth year)

15 teaching hours each week ($17 / hour) = $255 per week x 48 weeks $12,240
1.5 hour team meetings (4 therapists at $17 / hour) = $102 x 24 meetings $2,448
Total $14,688

Total cost for Workshop Model per year (first & second year)
Supervision costs $ 10,150
Cost for therapists   31,008
Total cost $ 41,158*

Total cost for Workshop Model per year (third & fourth year)
Supervision costs $10,150
Cost for therapists   14,688
Total cost $ 24,838 *

Total cost for Fortnightly Supervision (first & second year)
(recommended model)
Supervision costs $ 13,150
Cost for therapists   31,008
Total cost $ 44,158 *

Total cost for Fortnightly Supervision Model (third & fourth year)
Supervision costs $ 13,150
Cost for therapists   14,688
Total $27,838*

* Many families have found ways to reduce the cost of ABA programs including:
a.)   In Home Care
Federal government program provides a subsidy for the cost of care of disabled children in the home. It subsidises about one-third of the cost of therapy (therapists costs)
Carer Allowance
Carer allowance accessed through Centrelink ($87.50 per fortnight)

Tax Rebate
Taxpayers can claim a tax rebate for all medical expenses. ABA is considered a "medical expense" provided families have a letter of referral from a medical practitioner. The rebate is for 20% of expenses after the first $1,000.

The main agency or fund provider for your service
Families pay the majority of costs themselves. Families have been also to access assistance through: In Home Care, Carer Allowance and Medical Tax Rebate.

Evaluations or evaluation strategies
Specific pre-treatment assessment of cognitive, language and adaptive skills is required for children receiving EAP services. Follow-up assessment every twelve months is also recommended to monitor progress in all areas of development.
Regular discussions with parents and classroom teachers are organised. Feedback from other professionals including speech pathologists and occupational therapists is also appreciated. The comments and criticisms are used to identify specific difficulties and guide the course of the program.

Outcome measures
Each child's curriculum is individualised according to his or her strengths, challenges and response to treatment. The curriculum typically emphasizes language skills, communication, social interaction, play skills, cognitive and daily living skills. Complex skills are broken down into small steps, each step taught one at a time. New skills are taught using simplified instructions and positive reinforcement. Once mastered, generalisation of teaching materials, instructions and settings is prioritised.
Data is collected on a daily basis in each of the target areas and used as a means of identifying difficulties and advancing programs. Goals are reviewed each fortnight and strategies are modified as needed. The treatment is based on the work of Dr. Lovaas in the late 1980's at UCLA. This approach is the only treatment for autism supported by controlled studies and post treatment follow-up data. It develops communicative speech and improved social relatedness in 90% of those treated.
This program produces virtually normal social interaction, communicative and cognitive abilities in 40% to 50% of autistic children (Lovaas, 1987, Smith, 1993[2]). The Early Autism Project is closely affiliated with the Wisconsin Early Autism Project. WEAP is the largest replication site for Dr. Lovaas' work. Preliminary results from an ongoing research project show that the WEAP is well on the way to replicating Lovaas' 1987 results.

The name of the program
Relationship Development Intervention (RDI) program
Year of commencement:
Lead agency name and contacts
Elizabeth Scherrer
Diverse_abilities@msn.com.au

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[2] McEachin, J.J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioural interventions. American Journal of Mental Retardation, 97, 359-372.

Description of program, in terms of type and age range
RDI is a parent-based clinical treatment for individuals with ASD and other relationship-based disorders. The primary goal of RDI is to systematically teach the motivation for and skills of 'experience sharing' interaction (the means by which typical children become competent in the world of emotional relationships). The RDI program teaches people with ASD to learn friendship, empathy and a love of sharing their world with others. Language comes alive when integrated with real emotion. People with Autism and AS learn to tolerate and enjoy change and transition. It begins at the edge of each person's current capability and carefully teaches the skills needed for competence and fulfillment in a complex world (http://www.connectionscenter.com)
Evaluations or evaluation strategies
Outcome measures
Budget/Fees for program

The name of the program
Lifestart Program, Metropolitan area, NSW
Lead agency name and contacts if possible
Libby Marr Ph. 94400344

The name of the program
Southern Sydney Therapy Centre, Miranda, NSW
Lead agency name and contacts if possible
Danielle Stokes, Ph. 95403011

The name of the program
Starting Points, Campbelltown, NSW
Lead agency name and contacts if possible
Lorraine Brown, Ph. 46200091

The name of the program
McCarthur Early Childhood Learning Service (originally CEEPS)
Lead agency name and contacts if possible
Trish Coombs, Ph. 46t289332

The name of the program
Together hand in hand, NSW
Lead agency name and contacts if possible
Ann Cross, Ph. 0414 642 245

The name of the program
C.A.R.D. (Centre for Autism and Related Disorders), NSW
(Brochure supplied)
Lead agency name and contacts if possible
Karen Wong, Ph. 93104411

The name of the program

Early Education Clinic, Rosehill, NSW
Lead agency name and contacts if possible
(Jacqui) Ph. 999232727

The name of the program
Focus, Parramatta, NSW
Lead agency name and contacts if possible
(Nina) Ph. 9687 9878

The name of the program
Pathways, Marrickville, NSW
Lead agency name and contacts if possible
Sylvana Mahmit, Ph. 9572 8840

The name of the program
Giant Steps, Gladesville, NSW
Lead agency name and contacts if possible
Karen Marr, Ph. 98794971

The name of the program
Koorana
(Integrated preschool program for children with special needs)
Lead agency name and contacts if possible
Ph. 9750 4100
(No information available)

The name of the program
Hanen Program
(Language acquisition program for children with autism and other language disorders.
Parents participate in a training course and work from the More Than Words book).
Lead agency name and contacts if possible
Contact through Learning Links

WESTERN AUSTRALIA

The name of the program
Home-based autism service: preventative service for children in year one
Year of commencement:
Home-based autism services- 2000
Preventative service for children in Year One- 2003
Lead agency name and contacts
Disability Services Commission
Metropolitan Autism Services
Contacts: Bronwynn Comerford, Ph. 08 9472 1598 and Diana Peters
Description of program, in terms of type and age range
These services are for primary-school aged children with ASD, intellectual disability and challenging behaviours at home (Brochure supplied). The goal of the program is to prevent the development of challenging behaviour through pro-active parent training. The intervention is based on principles of ABA applied within daily life schedules. The service is provided by an initial three months of intensive intervention followed by three months of intermittent support and the ongoing support and review and modification of the program.
Evaluations or evaluation strategies
Multiple pre- and post- rating scales
Parent questionnaire, eg. Similar to battery used in Triple P Positive Parenting Program
Outcome measures
Reduction in target behaviours and maintenance of new behavioural management strategies over time
Percentage achievement of objectives specified by families
Parent satisfaction rates
Maintenance of children in home settings – cost savings
Disability Services Commission standards monitoring
Budget/Fees for program
Government – no fee
Note: $6,000 per program-place is funded annually. The number of program places funded is negotiated on the basis of a three year contract with the Disability Services Commission. The definition of a program place is linked to 250 operative days per annum. Therefore, if due to late diagnosis or whatever, two children only receive 6 months intervention prior to the ceiling age for intervention, as stipulated by the contract (6yrs), these two children are counted as one program place i.e. they shared 250 operative days. In addition to the number of places contracted over three years, a service provider can tender for growth to these places on an annual basis.

The name of the program
Metropolitan Autism Services (Brochure supplied)
Year of commencement:

1960's
Lead agency name and contacts
Disability Services Commission
Contact: Kate Smith
Description of program, in terms of type and age range
Assessment and diagnosis of children aged 2-17 years with ASD. Consultation with Psychology and SP. Provision of workshops and information in regard to the impact of ASD and intervention strategies.
Evaluations or evaluation strategies
Parental evaluation- ratings of the workshops compared across time
Disability Services Commission annual standards monitoring
Outcome measures
Parent reports of level of information acquired and satisfaction with delivery
Budget/Fees for program
Government – no fee (see Home-based autism service: preventative service for children in year one)

The name of the program
Mildred Creak Early Intervention Service
(Brochure supplied)
Year of commencement:
1960's
Lead agency name and contacts
Disability Services Commission
Contact: Adam Sullivan
Description of program, in terms of type and age range
Comprehensive assessment of skills, needs and priorities for intervention. Individual programs designed by professional staff. Parent training programs and group based programs. One-to-one teaching, if required. Visits to day care or pre-school, including staff training and input to conferences. Intensive programming for specific difficulties. Consultation with other agencies. Assistance with transition to pre-school and school.
Evaluations or evaluation strategies
Daily evaluation of children's progress and parent skills
Pre/post measures on standardized tests/ interviews
Disability Services Commission annual standards monitoring
Outcome measures
Satisfaction by parents in meeting objective set in individualized family service plans
Budget/Fees for program
Government – no fee (see Home-based autism service: preventative service for children in year one)

The name of the program
Intervention Services for Autism & Developmental Delay (ISSADD P/L)
(Brochure supplied)
Year of commencement:
Lead agency name and contacts

ISSADD, Ph. 08 9397 5970, 08 9381 9661
Description of program, in terms of type and age range
In depth assessment and diagnosis to establish accurate level of functioning. Intensive individualized programs aimed at behavioural, educational and developmental goals, including access to individualized therapy conducted in home school or daycare (30-40hrs per week). Parents trained in ABA / discrete trial training (DTT). Counselling for family members. Involvement with parent groups. For more information, see web-site: http://www.isadd.org
Evaluations or evaluation strategies
Outcome measures
Reduction of family stress
Empowerment of parents to direct child's behaviour and development
Achievement of individualised program goals
Budget/Fees for program
Mainly Parent funded, some assistance provided by Government (Disability Services Commission)
Sort term intensive intervention program administration fee $110.00. Extra to this fee is the cost of required therapy:
Psychological services (Assessment, therapy/Counseling) $166.00 per hour

The name of the program
ABA/DTT Program- Supervision, Case Management and Therapy:
Year of commencement:
Lead agency name and contacts
Description of program, in terms of type and age range
Evaluations or evaluation strategies
Outcome measures
Budget/Fees for program
Program manager $71.50 per hour
Case Manager $35.20/hour
Advanced therapist $22.00 per hour
Senior therapist $18.70 per hour
Therapist $14.85 per hour
Trainee therapist $11.00 per hour

Training workshops for parents (6 hours) $100 per person
Support groups (2 hours) $44.00 per person

Appendix Two List of key reviews

Bassett K, Green CJ, Kazanjian A. (2000). Autism and Lovaas treatment: A systematic review of effectiveness evidence. Vancouver: B. C. Office of Health Technology Assessment, Centre for Health Services and Policy Research, University of British Columbia.. 2000. 57. British Columbia Office of Health Technology Assessment (BCOHTA). Also registered as: Autism and Lovaas treatment: A systematic review of effectiveness evidence. NHS Centre for Reviews and Dissemination.

Campbell J, Cawthon L, Keenan T, Lyons D, Schrager L. (1998). Evaluation of early intervention in Washington State: Options and Issues. Research and Data Analysis Section, Department of Social and Health Services, Olympia, Washington, US.

Crewther S.G., Goodyear M.J., Bavin E.L., Lawson M.L., Wingenfield S.A., Crewther D.P., (2003) Autism in Victoria: An investigation of prevalence and service delivery for children aged 0-6 years. Victorian Government Department of Human Services, Melbourne, Victoria.

Jordan R, Jones G, Murray D. (1998). Educational Interventions for Children with Autism: A literature review of recent and current research. School of Education, University of Birmingham, UK.

Ludwig S, Harstall C. (2001). Intensive intervention programs for children with Autism. Health Technology Assessment Report. Alberta Heritage Research Foundation for Medical Research, Canada.

Autism: Epidemiology and Causes. **Medical Research Council**, UK.

McGahan L. (2001). Behavioural intervention for preschool children with Autism. Ottawa: Canadian Coordinating Office for Health Technology Assessment. Technology Report.

Perry A., Condillac, R., (2003). Evidence-based practices for children and adolescents with autism spectrum disorders: Review of the literature and practice guide. Report commissioned by Children's Mental Health, Ontario, Canada. www.cmho.org/autism_training.shtml

Appendix Three Searches performed

Database searched	Subject Headings	Textwords	Results
Medline 1966 to May 2003	exp autistic disorder AND Treatment programs: exp early intervention exp treatment effectiveness evaluation/ or exp treatment outcomes Family support programs: exp family support exp diagnosis	autism or autistic AND Treatment programs: intervention OR treatment OR model OR program AND language or speech OR communication OR social OR behaviour OR functional OR educational OR play Family support programs: diagnosis OR assessment	517 (Treatment) 29 (family support)
Psycinfo 1974 to May 2003	Treatment programs :As for Medline Family support programs: exp family relations exp treatment exp caregiver burden exp social support networks exp health care services exp diagnosis	As for Medline	846 (Treatment) 303 (Family support)
Embase 1988 to 2003	As for Medline	As for Medline	827 (Treatment) 216 (Family support)
PubMed -May 2003	autism spectrum disorder AND Treatment programs: intervention OR treatment OR program OR model Family support programs: family support OR		343 (Treatment) 35 (Family support)

	social support		
ERIC 1985-May 2003	autism AND Treatment programs: intervention OR treatment OR program OR model Family support programs: family support OR social support		20 held
Cochrane database of Systematic Reviews HTA*	Autism Autistic Spectrum Disorder		3 protocols (3 HTA)
Web searches of government sites and research establishments worldwide	Autism Autism Spectrum Disorder		4 reviews

* Health Technology Assessment Report

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