EXCELLENCE IN TEACHING RESEARCH & PRACTICE

National Centre for Autism Studies
Literature Review of Autism
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Acknowledgments

A note about terminology

The terms autism, autism spectrum disorders and autistic spectrum disorders (ASD) will be used interchangeably in this report to mean the group of pervasive developmental disorders characterised by qualitative difficulties and differences in reciprocal social interactions, in reciprocal communication, and by a restricted repertoire of interests and activities. (World Health Organisation, 1993; American Psychiatric Association, 1994)

Scope of Review

The National Centre for Autism Studies was commissioned to provide an up to date literature review of autism, which will provide background to the investigation of the current provision for children with ASD in Scotland.
In accordance with requirements this review contains:

- Background to autism, its causes and diagnosis
- Information about the range of approaches used to teach children with autism, and the extent of use of each approach. This will include information from the United Kingdom and from international studies
- A collation of the published evidence of the effectiveness of the various approaches.

In recent years a number of reviews of the current knowledge base in autism have been undertaken. Usually reviews accompany policy documentation or needs assessment reports and provide the reader with a background against which to reference the key recommendations of such documents. Examples of such work include the Public Health Institute of Scotland's 'Autistic Spectrum Disorders. Needs Assessment Report' (PHIS, 2001), and the National Initiative for Autism: Screening and Assessment (NIASA)'s 'National Autism Plan for Children' (National Autistic Society, 2003). In 1998 the Department for Education and Employment commissioned a literature review of recent and current research into 'Educational Interventions for Children with Autism' (DfEE, Research Report RR77, 1998). It is therefore timely that HMIE should have commissioned an up to date literature review of autism, which will provide background to the investigation of the current provision for children with ASD in Scotland.

This review is different in that it seeks to not only to provide information about autism and about approaches, but also to evaluate the effectiveness of approaches to teaching children with autism. The DfEE Report (1998) highlighted that "There was no well conducted study of the effectiveness of any of the approaches that controlled for intensity, so the effectiveness of the particular approach itself was not measured"(p.1). In this report evidence and lack of evidence of effectiveness of approaches is addressed. Additionally the research team at the National Centre of Autism Studies is able to provide recent evidence of effectiveness under broader themes of social interaction and understanding, cognitive and behaviour approaches and joint play. This evidence augments evidence from the wider field.

The introductory section of this review covers the rising profile of autism spectrum disorders, considering the reasons for this area increasing greatly in importance both in society in general and in education in particular. This provides a context that demonstrates why ASD has become an issue of central concern in relation to educational provision.

An important feature within our coverage of the background to autism, its causes and diagnosis is the impact of autism upon interpersonal, communicative, cognitive, imaginative, sensory, perceptual, physiological and behavioural processes. Recent work

has extended our knowledge of the impact of autism in these areas, which has also informed our understanding of causes and the drive towards more refined diagnostic protocols, and has underpinned a widening range of interventions and approaches to the education of children with ASD.

In Section 2 the range of approaches is systematically presented in relation to key features of their application - understood causes and areas of impact; functional focus of the approach; the personal or interpersonal focus of the approach; the social context of the approach. Extent of use is addressed, and examination of available evaluative evidence to reveal strengths and weaknesses in the effectiveness of the approaches.

In drawing together the information presented in Section 2, Section 3 appraises the evidence of effectiveness of the different approaches. In doing so, this section also reveals any gaps in range of approach in relation to the areas of impact of autism upon an individual, and also any gaps in relation to existence, extent and adequacy of evidence of effectiveness of approaches used.

An overview of the evidence for intervention approaches is especially important for practitioners in the field of ASDs. Such an overview can provide accessible up to date information, can show which approaches have empirical support, and can provide a critical evaluation of approaches on the basis of published evidence. It can only be helpful that professionals in education are supported to ask about available evidence and to learn about the range of approaches that may be helpful in their practice. This evidence will also help them to assist parents' access to the nature and strength of evidence for the various approaches presented in this review.

Key findings

In terms of methodology few studies meet the requirements set out for an adequate evaluation. This has to do with the adequacy of the methodologies used to evaluate approaches, which show, on the whole, a lack of a suitably large number of participants, and the lack of adequate controls and control groups. Follow-up measures of sustainment, endurance and generalisation of outcome results for the participants are rarely included. A further methodological difficulty lies in the inconsistent use of terms in different studies, such as 'joint attention', and the lack of standardised outcome measurement systems, which would allow comparison of results across studies.

The power of the developmental and peer intervention comes through and is particularly relevant to the increasingly understood underpinnings of many behavioural outcomes in autism which result from social isolation. And with the identification of autism coming increasing early the need for social interventions is paramount.

What is known about autism endorses the need to intervene early, consistently and in an informed way with a pronounced focus on the generalisation of skills into understanding from the outset. A prolonged gap between identification and support can drive families to expensive and unproven alternatives: all children should have access to appropriate support from the time of parents' first concerns.

There is practice evidence of improvements for at least some children on all the intervention approaches discussed. The extent to which improvements can be attributed to the particular intervention is unknown: it is possible that any approach that focuses on social understanding will offer some success. Many other variables may be influencing outcome simultaneously with the specific approach/intervention.

There is no evidence that any specific approach brings greater benefit across the spectrum, nor that any sub-group benefits from any particular intervention. In broad terms the degree of autism determines the amount of structure needed by any individual. In a climate of social inclusion this is one of society's most vulnerable groups, and the emotional well-being of individuals with autism should be a main focus for all interventions.

In summary, in reviewing the evidence of effectiveness of approaches and the adequacy of evaluation studies the following key points have emerged:

- methodological difficulties within studies means that definitive evidence of the effectiveness of any given approach, and the contrastive effectiveness of one approach compared to another is not available;
- where professionals plan to make use of particular approaches they should look critically at the available evidence of effectiveness;
- most approaches offer some evidence of positive and useful intervention results, and an eclectic model to supporting a person with autism has emerged;
- a playful context has emerged as a widely used setting for supportive intervention;

- the use of peer mediated supports and social group contexts is increasing;
- environmental structure and socio-constructive teaching techniques tailored to the individual are an important component in support;
- intervention approaches which involve the child in prolonged periods of training, or long periods of interaction with only a trained adult, may preclude involvement of the child in other effective forms of support;
- the need for early intervention to meet the needs of a child when these are initially recognized is apparent;
- the involvement of parents has emerged as a crucial element in intervention approaches and the need for support for parents and family is emphasized.

SECTION 1

Overview of autism spectrum disorders.

"Autistic spectrum disorders are lifelong, complex, controversial, challenging to service providers, they can cause severe impairments and they are not uncommon."

PHIS Report (2001, p.7)

An overview of the current understanding of ASD is provided, with a short review of key research in the following five areas: definition, identification, prevalence, causes and outcomes. Our approach to presenting information on interventions is introduced, but the intervention evaluations are presented in a separate section since they are covered in much more detail and are central to this review. Section 1 will therefore provide the essential information required in order to understand the overall context of ASD and inclusion.

Background to autism

Autism spectrum disorders (ASD) have a rising profile in terms of recognition, definition and public knowledge, which has greatly increased the importance of ASD both in society in general and in education in particular. Research into autism has grown significantly in the last five to ten years. Prevalence figures have changed from showing autism as a low-incidence set of difficulties, to defining autism as 'not uncommon'. Indeed internationally figures suggest that ASD is now recognised as a major problem (Gerlai & Gerlai, 2003) demanding further research and informed intervention. In Scotland a policy focus on inclusive education has served to heighten awareness of ASD across the education profession, making it an issue of central concern in relation to educational provision. Recent work has extended knowledge of the impact of autism upon interpersonal, communicative, cognitive, imaginative, sensory, perceptual, physiological and behavioural processes. This has informed a growing understanding of causes and the drive towards more refined diagnostic protocols, and has underpinned a widening range of interventions and approaches to the education of children with ASD. In this climate of increased awareness of autism, history affords us the understanding that autism is not new (Frith, 1989). In 1906 the Swiss psychiatrist Eugene Bleuler (Ritvo, Freeman, Ornitz et al., 1976) used the word autism to describe patients in clinical reports. From the 1920s onwards, several concepts had appeared in the literature all referring to similar or over-lapping patterns of personality traits and problematic behaviours in children (mostly boys). However the main thrust to define autism began in the 1940s with the seminal work of Leo Kanner (1943) and Hans Asperger (1944). (For a historical literature review, see Gillberg, 1998 or Wing,1998).

Autism has been characterised as a pervasive developmental disorder (PDD), as a disorder of affective contact, as an organic dysfunction of biological origin, and as a neurological or brain disorder, that affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment, each in varying degrees. Those affected by autism fall along a spectrum of "high-functioning" individuals

to individuals who lack any means of communicating with others. This diverse and changing expression of autism and other PDDs over the course of development presents some of the greatest challenges for education.

- **Definition of Autistic Spectrum Disorders**

This section includes consideration of the origin and development of the concept of autism, focusing in particular on the contributions of Kanner and Asperger in the 1940s. It traces how these original concepts provided the foundation for what later became 'autism spectrum disorders', comprising autism, Asperger Syndrome and atypical autism, each of these being defined in its relationship to the triad of impairments in social development, in communication and in thinking and behaviour.

In his original paper Kanner (1943) presented 11 children (up to the age of 11) with unusual behaviour patterns that had been present from early childhood: his original paper gave detailed descriptions highlighting extreme autism, obsessiveness, good relationships with objects, a desire for sameness, stereotypy and echolalia in individuals each of whom he considered to have 'good cognitive potentialities' (p.247). All of the traits described were present to some degree in each of the eleven cases. A year later Asperger (1944) published his original paper in which he described 4 slightly older and very intellectually able individuals. In his summary of the typical features of the group Asperger writes about the children's appearance, their distinct intellectual functioning including their learning difficulties and attention problems, their problematic behaviour in social situations and their impairment of emotions and instincts: behaviour patterns that differed but overlapped with Kanner's autism group.

In 1956 Kanner modified his criteria and coined the term 'early infantile autism' (Eisenberg & Kanner, 1956) and so influenced perceptions of autism as a childhood disorder. His reformulated criteria were-
   1   "Extreme detachment from human relationships".
   2   "Failure to use language for the purpose of communication".
   3   "Anxiously obsessive desire for the maintenance of sameness, resulting in a marked limitation in the variety of spontaneous activity".
   4   "Fascination for objects, handled with skill in fine motor movements".
   5   "Good cognitive potentialities".

In a retrospective study analysing 74 clinical case records written by Asperger and his team, Hippler and Klicpera (2003) conclude that today's ICD 10 (World Health Organisation, 1993) and DSM 1V (American Psychiatric Association, 1994) criteria for Asperger syndrome (AS) do not quite fit for the individuals described by Asperger and his team. They feel that motor and social clumsiness and speech and communication 'deviances' (p.300) should be taken into account in future discussion of diagnostic criteria for AS. ICD 10 and DSM1V appear to differentiate between autism and AS mainly on the basis of onset criteria which points to a mixture of symptoms being regarded as common in AS and autism. This suggests that Asperger syndrome and autism cannot be clearly distinguished from each other, except in the case of 'classic' or Kanner's autism where areas of difference could be attributed to differences in intellectual function. The current concept of autism is broad. It ranges from those with severe disabilities to those with more subtle problems of understanding and limited social skills. Autism may exist alongside learning disabilities or other developmental disorders

and can also occur with other physical or psychological difficulties. Due to this range and the interaction with other difficulties, a concept of a spectrum has evolved and so the terms 'autistic spectrum disorders' or 'autism spectrum' are often preferred to autism.

Wing proposed a spectrum of autistic disorders with a triad of impairments, namely impairment of social interaction, communication and imagination. The term 'Triad of Impairment', coined by Wing and Gould (1979), describes the three key areas and the wide range of behaviours which are affected in individuals with ASD. Autism is defined using behavioural descriptions since no specific biological markers are known. Due to overlapping conditions, changes in individuals over time, the range of severity and the ways in which education, ability and temperament can modify individual presentation, the behavioural descriptions are very wide (Hill & Frith, 2003). The 'triad of impairment' (based on Wing & Gould and below drawn from Knott & Dunlop, 2005) represents three broad and interacting aspects of ASD, all of which will be inconsistent with the presenting individual's mental age. Many people with an ASD also have an increased sensitivity to sound, smells, touch, taste and visual stimulation. Changes also occur in individual presentation with age.

1) Social development is different, delayed or atypical. Social interaction difficulties are particularly seen during interaction with same-aged peers and as a result, developing and maintaining friendships is often problematic. These individuals also struggle with reciprocity, shown by lack of empathy or failure to adapt their behaviour according to social context.

2) Difficulties in communication may be pervasive and occur in both verbal and non-verbal modes. Pragmatic aspects of communication such as appropriate use of eye contact, facial expression, gesture and prosody may all cause difficulties . Functional use of language skills may present difficulties including reciprocal aspects of communication such as initiating and turn taking in conversation, negotiating a shared topics and topic maintenance, and in readily recognising what the listener knows. Those with good language skills may nevertheless interpret language in a literal manner, and may struggle to understand idiom, metaphor or sarcasm.

3) Difficulties with thinking and behaviour characterise the third element of the triad. Poor imaginative skills may lead to restricted repetitive, stereotyped patterns of behaviour. Impoverished imagination skills range from absence of functional or symbolic play to difficulties with the social use of imagination. Interests tend to be circumscribed and intense, often not reflecting cultural norms. A preoccupation with routine and structure is also common.

Christopher Gillberg defines these main three areas of difficulty in ASD as reciprocal social interaction, reciprocal verbal and non-verbal communication and imagination and behaviour. His emphasis on the reciprocal nature of typical human interaction is important for our understanding of autism, since ASD may be marked by lack of reciprocity.

Individuals diagnosed with high functioning autism or Asperger syndrome share difficulties on the triad of impairment, but usually attend mainstream school. Although their problems are considered to be 'subtle' in comparison to those with classic autism, their difficulties should not be underestimated. Their difficulties often impact on the 'ordinary' activities of life, while their academic abilities, particularly in their areas of special interest can be excellent. This makes it all the harder for individuals with ASD to integrate, as those they come into contact with at home or school may fail to understand the gap caused by ASD between their abilities, and their social naïvety or awkwardness. These individuals often experience difficulties making friends and can experience loneliness (Bauminger, 2003) and frustration as a result. Errors of judgment about social situations are common (for instance, failing to distinguish between friendly teasing and bullying) and individuals often do not recognise that their interests are not shared by others. They commonly experience difficulties organising themselves and comprehending day-to-day social situations for which the 'rules' are never made explicit.

- **Identification**

Autistic Disorder ('classic autism') is diagnosed principally in terms of the two international classification systems, ICD-10 and DSM-IV. Both describe behavioural criteria and specify expected age of onset. The International Classification of Diseases 10 (ICD-10) and The Diagnostic and Statistical Manual of Mental Disorders 4th Edition (DSM-IV) have similar criteria for the diagnosis of autistic spectrum disorders. These are both based on the triad of impairments described above, with certain diagnostic categories further expanded. ICD-10 is most commonly used in the UK and is endorsed by the World Health Organisation. In ICD-10 autistic spectrum disorders are included under the broader heading of pervasive developmental disorders (PDD).

The definition of Asperger Syndrome is less straightforward, and is confused by the introduction and use of several diagnostic criteria, including Gillberg and Gillberg's criteria of 1989 (outlined in Gillberg 1991), the criteria of Szatmari et al. (1989), ICD-10 (World Health Organization 1992, 1993) and DSM IV (American Psychiatric Association 1994) criteria. For a diagnosis of Asperger's disorder to be made, both ICD 10 and DSM IV require at least two manifestations of social impairment and one area of restricted interest or behaviour from a list of symptoms originally defining autistic disorder (Kanner syndrome). In contrast to autistic disorder, language development in AS is not supposed to be delayed and normal cognitive and self-help skills should be present in the first 36 months. Gillberg and Gillberg's (1989) and Szatmari's criteria do not require 'normal' early development for a diagnosis of Asperger syndrome to be made. Indeed they view language and communication differences to be a defining feature, and additionally the Gillbergs expect motor clumsiness, better theory of mind and higher intellectual functioning to be present in this group. However in many way diagnosticians are more readily able to identify the classic Kanner group at an earlier age than the Asperger or atypical individuals.

Debate over the diagnostic characteristics of Asperger syndrome continues. Leekam et al. (2000) found that of 200 individuals with autistic spectrum disorders, all met ICD-10 criteria for autism, whereas only 1% met criteria for Asperger disorder. However, 45% fulfilled Gillberg's criteria for AS. Again, the difference was due to the ICD-10 requirement for normal development of language, cognitive skills, curiosity and self-help skills before a diagnosis of Asperger syndrome may be given. The mainstream consensus, however, is that AS is not quantitatively or qualitatively different from autism and forms part of the spectrum of autistic disorders (PHIS, 2001).

Atypical autism is the term used when a disorder differs from classical autism due to a later age of onset, atypical or 'sub-threshold' symptoms, or all of these. This category is sometimes referred to as 'pervasive developmental disorders – not otherwise specified' (PDD-NOS).

The broadening of terminology to ASD has brought continuing diagnostic debate which adds to the complexities of understanding autism. Such debate includes discussion of children who appear to show variation in degrees of impairment at differing ages (Bishop & Frazier Norbury, 2002) and individuals who present with some of the core features of

autism, but have functional difficulties due to another disorder such as Attention Deficit Hyperactivity Disorder (ADHD). Autistic Spectrum Disorders are a lifelong, complex spectrum of disorders, with long term implications for those affected.

In the interests of supporting people with autism, there has been a longstanding debate about the perceived merits of identifying, diagnosing, and consequently assessing the support needs of individuals on the spectrum, and about the relative usefulness of defining sub-groups within the autism spectrum. This may be useful for research purposes, in practice the focus must be on the potential of any individual to benefit from intervention. It may be that some interventions are more appropriate according to sub-group, but as yet this is not widely reported. In the view of the authors the definition of autistic spectrum disorders should lead to common understandings of this spectrum amongst a wide range of professionals. Such understanding is essential if people with ASD are to be included in education, in services and in society.

The push for diagnosis occurs for several reasons, including to provide information to parents and caregivers; to give pointers to treatment, prognosis and other aspects of clinical practice; to link children and their parents with appropriate support groups; to provide professionals with short-hand descriptions; to facilitate record-keeping and to enable children to have access to specialist educational provision and other resources. However whilst generally there is a greater awareness of ASD, and increased rates of diagnosis, it is still considered to be under-diagnosed in Scotland (personal communication, MacKay, T., January 2005).

- **Prevalence**

In order to provide a full background we now turn to current evidence regarding the numbers of people with an ASD, including a discussion of gender issues. In particular, the fundamental changes that have taken place in reported prevalence levels from the classic early studies to the present time are highlighted. We briefly discuss how these changes are to be understood, with particular reference to current controversies in terms of suitable approaches, interventions and outcomes.

Recognition of individuals with ASD has increased markedly over the last decade and it is now known that there are significant numbers of individuals who need appropriate services and support (Fombonne, 1999). However as yet the prevalence of autism in the population is not well described. It was once thought that autism was relatively rare, for example in 1985 Rutter et al quoted two to four autistic children in every 10, 000. Wing and Gould's Camberwell Study (1979) had identified 5 per 10, 000 children ('classic autism') and 15 per 10, 000 children with a broader presentation of ASD. In a two stage total population study in 1993, Ehlers and Gillberg (1993) targeted children aged 7-16, and found a minimum of 6 per 10, 000. Chakrabati and Fombonne (2001) conducted a prevalence study (children aged 2.5-6.5 years) in which they found 62.6 per 10, 000 for all ASDs and 45.8 per 10,000 for other ASDs including Asperger syndrome. More recent estimations put the prevalence of autism in children at approximately 60 per 10, 000 (PHIS, 2001). Data on autism in adulthood is harder to access, but a commonly held view is that more children and adults are being identified as having disorders on the autistic spectrum than in the past.

Prevalence figures estimate numbers in a population and depend on the age of the people involved and on the assessment tools and ascertainment methods used. Variations across studies reflect the different approaches and criteria employed. Recent reviews provide agreement that ASD affect approximately 60 per 10, 000 under 8 years, of whom 10-30 per 10, 000 children have 'narrowly defined autism' (Baird, Charman & Baron-Cohen, 2000; Scott, Baron-Cohen & Bolton, 2001; Bertrand, Mars, and Boyle, 2001; Chakrabarti & Fombonne, 2001). In this group there is considerable overlap with a population that would previously have acquired a more general diagnosis of learning disability, and it may be that as figures for autism have increased figures for learning disability alone have gone down. Estimates confirm that ASD is far more common than was previously generally recognised (MRC, 2001).

Prevalence figures for presentation of ASD in boys and girls have consistently shown that ASD is more common in boys, and that there is a significant preponderance of boys (Ehlers & Gillberg, 1993) in more able individuals. Typically the literature suggests a ratio of 4: 1 for classic autism and 9:1 for AS. More recently Gillberg (University of Strathclyde, Course Conference, 2005) has speculated that there may be an under-diagnosis of more able females with Asperger syndrome whose presentation may be different in nature from their male counterparts. This would sit comfortably with Baron-Cohen's work on systematising and empathising mental domains associated by gender (Baron-Cohen, 2002). On this account females with Asperger are more likely to be able to relate to others, and therefore their social difficulties may be less pronounced.

Before leaving this section it is appropriate also to make comment on the extent of knowledge in Scotland about 'incidence' of autism: the known occurrence of ASD. Present figures on autism are incomplete, but data exists, for example in Local Authorities, and naturally these are fuller for the school population than they are for either pre-school children or the adult population. Inferences may be drawn from recent research, for example, in Webster et al's study (Webster, Feiler, Webster & Lovell, 2004) "*Reflecting a trend that has been observed in the UK and elsewhere, Bristol has seen a sharp rise in the numbers of children diagnosed with ASD from 125 in 1998–9, to 194 in 1999–2000, an increase of 30 percent per year and estimated to affect approximately 500 children in a school population of 51,400 (Bristol City Council, 2000)". (Webster et al, 2004, p.32)* Such figures have implications for the planning of services.

The prevalence figures also raise the question of whether there are interventions that are more or less suitable for particular sub-groups of individuals with ASD. Experience seems to suggest that the idiosyncratic nature of autism demands highly individualised approaches, however a more verbal population may be able to participate better in group settings, another group may require considerable visual support and individually there may be sensory issues which cut across all kinds of interventions.

- **Causes**

Autism has come to be recognised as a biological disorder affecting brain development, rather than the possible outcome of early life experiences such as parenting. This section considers the present understanding of the key biological processes that may be involved, together with how these then affect psychological functioning in relation to the main theories of central coherence, executive function, theory of mind and intersubjectivity.

The seminal papers of Kanner and Asperger speculated about the causes of autism. Kanner (1943) wrote that he had 'encountered a number of children whose behaviour from earliest infancy raises the question of an innate inability to form affective contact with people in the ordinary way to which the human species is biologically disposed' (1943, Co-Editor's introduction, p.216). He did not seek to give a finite answer to this question, but felt that an answer could not be found independently of a 'supporting consideration of children's earliest experiences with parental personalities and attitudes'. Kanner draws attention to few of his eleven subjects' parents being "really warmhearted" (p.250) and although he concludes that the children have 'inborn autistic disturbances of affective contact' it is possible to see how this first paper opened the door to psychogenic theories- now completely discredited. Asperger stated that his subjects' 'autistic psychopathy' presented with signs that broadly corresponded with Kanner's description, however Asperger emphasised his view that these disorders were genetic in origin and not caused 'exogenously'(Hippler & Klicpera, 2003).

As yet no specific biological marker for autism has been identified, though the neuropathology of autism suggests prenatal onset of the disorder (Nelson, 2001). The literature also suggests that whilst the evidence for genetic factors in ASD is overwhelming, it is clear that the environment may also contribute: the ways in which this happens is hotly debated, but toxins, infections, autoimmune problems, metabolic problems and exposure to vaccines have all been cited in what is currently both a scientific and a media debate. Indications in the literature suggest that further understanding of autism may come from the rapidly expanding knowledge of the biology of early brain development, and shared understandings across a range of disciplines including developmental neurobiology, neuroepidemiology, genetics, psychiatry and psychology. Research into the genetics of autism suggest familial links (Bailey, A. et al., 1998; Folstein & Santangelo, 2000), particularly where a broader phenotype of autism is concerned. With the exact causes of autism still unknown, lines of evidence suggest that 'autism is one of the most heritable complex neuropsychiatric conditions' (Spence, 2004, p.196).

Trevarthen (2000) in writing about autism as a neurological disorder that affects communication and learning, notes that neuropathy fails to show any one specific local problem in the brain of the autistic child to account for the way in which "the attentional and intentional motivation for a particularly human kind of learning that requires intricate communication of purposes, interests and feelings between individuals by expressive movement and mirroring of motive states" (p.41) may become dysfunctional in individuals with autism. Affected parts of the brain include the brainstem, limbic and neo cortex and cerebellum: affected sites include systems which play a part in perceptions of

human expression, states of mind of other persons and dynamic processes of consciousness and learning.

Gerlai & Gerlai (2003) discuss how the mechanism of ASD is not understood and call for further research of a condition in which a diagnosis may be made as early as, or under the age of two years of age (Trevarthen, 2000), and though changing, is lifelong. Currently there is consensus that autism is a neurodevelopmental disorder, with a strong genetic aetiology (Rutter, Bailey, Simonoff & Pickles, 1997).

In the absence of definitive understanding of the causes of autism, which may eventually allow the development of novel therapies and interventions, there is nevertheless a need to seek explanation of the behaviours that are presented in autism. The psychological literature has sought to provide such explanations, and this has led to two principal theoretical groupings: cognitive theorising and affective theorising, as well as theories in which these two groupings overlap. Here will share some insights into the theory of mind hypothesis, central coherence, executive functions, and consider the experiencing of self and intersubjectivity.

Trevarthen's early work with infants and their mothers in the 1970s (Trevarthen, 1977, 1979, 1980) convinced him "that an exceedingly complex innate mechanism foreshadowing the cooperative intelligence of adults, and more general than the mechanism of language, was already functioning in early infancy. The responses of the infants to persons were different in kind from those to objects, and they were pre-adaptive to reception and reply by persons". Later described by Trevarthen and others as 'intersubjectivity' these insights provide clear direction to understanding difficulties in communication found in autism. Trevarthen continues to study how the motives and emotions of a child are expressed to other people and their importance for psychological growth and education from birth. This leads to work on the interpersonal foundations of language and meaning, and on the development of problems such as autism that affect communication and thinking. Intersubjective communication implies intersubjective relatedness at a preverbal stage of development and this in turn entails sharing joint attention, sharing intentions and sharing affective states. Already in infancy these mechanisms can be observed to be different in children later diagnosed with autism. Trevarthen's work provides essential understandings through which to interpret failure to develop 'theory of mind'.

Much has been written about 'theory of mind', 'executive function' and weak 'central coherence'. Understanding of each can foster tailored interventions. The theory of mind hypothesis is the most documented of these three psychological explanations. It makes a connection between the inability to attribute mental states to others and the social interaction and communicative problems of individuals with ASD (Baron-Cohen, 2000; Baron-Cohen, Leslie & Frith, 1985). However in this focus on social and communication difficulties, non-social features are unexplained (Happé, 1999). Theory of mind goes some way to explaining difficulties in every day behaviour, including ability to predict others' behaviour; feelings of fear and avoidance; capacity to read the intentions and motivations of others; misunderstanding friendship; being able to understanding own and others' emotion; lack of empathy; understanding social interaction and understanding that

behaviour affects how others think and feel.

Executive functions and central coherence are held to offer a broader interpretation of a range of behaviours in ASD than does theory of mind. In terms of executive function, individuals may have problems with goal directed behaviour, with problem solving in a planned and strategic way, with flexibility in thought and behaviour and in self-monitoring. The evidence for other executive functions such as weak working memory is still contradictory (Ozonoff & Strayer, 2001). Executive functioning provides explanations for some of the non-social aspects of behaviour in ASD, such as repetitive and stereotyped behaviours, but does not provide any explanation for the documented special abilities that occur in ASD (Happé, 2000).

Kanner's early descriptions of autism demonstrated inabilities in experiencing 'wholes' because of detailed attention to constituent parts (Kanner, 1943). Frith proposed the central coherence theory in 1989 based on findings that children with autism showed a preference for focusing on detail at the expense of deriving meaning from the whole. In day-to-day terms this means that children with ASD have difficulty in seeing connections & generalising skills; in organising themselves, and in choosing and setting priorities. Often this is evidences in a preference for the known, inattentiveness to new tasks and an idiosyncratic focus of attention. For children in school situations an overview of what is going on, and some predictability is essential to being able making sense of everyday life. Being captured by details, individuals with ASD can find the world chaotic and confused, this can interfere in their being able to make adequate sense of their experiences (Noens & van Berckelaer-Onnes, 2005). Hermelin (2001) is of a view that weak central coherence may also imply certain strengths and facilitate focus and special talents. Happé (1999, 2000) suggests that weak central coherence should be considered a cognitive style rather than a cognitive deficit.

These three cognitive theories may each provide insight into behaviours in autism, and as such should not be considered mutually exclusive since all may be necessary to explain the variations in ASD (Hill & Frith, 2003; Frith, 2002).

The implications of current affective explanations of autism lead to a view that children with ASD need types of intervention that will 'systematically facilitate as much cooperative, negotiated and culturally relative learning as possible, intervention that is deliberately monitored with attention to the autistic learner's moment-to-moment motivational and inter-personal response.' (Trevarthen, 2002, p.45; Dawson & Galpert,1990; Marwick, 2001)

- **Outcomes**

Here we take a look at what is now known about how children with ASD develop on into adult life. The impact on siblings and families is also considered. The essential differences in outcome for autism and Asperger Syndrome are reviewed, as well as the key predictors of adult outcome present at early diagnosis. We begin with Kanner:

'He wandered about smiling, making stereotyped movements with is fingers, crossing them about in the air. He shook his head about from side to side, whispering or humming the same three note tune. He spun with great pleasure, anything he could seize upon to spin… when taken into a room he would completely disregarded the people and instantly went for objects, preferably those that could be spun… he angrily shoved away the hand that was in his way or the foot that stepped on one of his blocks'.

Donald aged 5 (Kanner, 1943)

'I was amazed at the wisdom of the couple who took care of him. They managed to give him goals for his stereotypies. They made him use his preoccupation with measurements by having him dig a well and report its depth. When he kept collecting dead birds and bugs they gave him a spot for a 'graveyard' and had him put up markers. When he kept counting rows of corn over and over, they had him count the rows while plowing them. He attended a country school where his peculiarities were accepted and where he made good scholastic progress'

Donald, aged 11 (Kanner, 1949)

'Don is now 36 years old, a bachelor, living at home with us…Since receiving his AB degree in 1958 he has worked in the local bank as a teller…His chief hobby is golf. .. He is dependable, accurate, shows originality… He owns his second car, likes his independence…. While Don is not completely normal , he has taken his place in society very well, so much better than we ever hoped for. If he can maintain the status quo I think he has adjusted sufficiently to take care of himself.' Donald, aged 36 (Kanner, 1971)

Outcomes for individuals on the spectrum

Kanner's 28-year follow up in 1971 showed that, of his original sample of eleven individuals of whom Donald was one, two were living at home with their parents and were in regular full time employment, five were in institutional care, one had developed seizures and had died aged 28 years, one was in sheltered employment and nothing was known about the remaining two.

New outcome studies are showing changes that reflect developments in diagnosis and trends in society since that time. Outcomes are very variable, with the areas most likely to show improvement being 'acting out' behaviour, educational skills and social skills and interests. Generally there is now enough evidence to predict adult outcomes in broad terms from age 4-5 years. The single best predictor is non-verbal IQ, followed by useful speech at age 5. The severity of the original symptoms is influential on outcome, and intervention has been shown to be important (Jordan, 1999).

Three studies serve to illustrate longer term outcomes: Kobayashi, Murata and Yoshinaka (1992); Howlin (2000), and Billsted, Gillberg and Gillberg (2003). Kobayashi et al followed up 201 children, in the range of 18-33 when followed up. 23.6% had IQs above 70. Figures were given for the percentage in employment (21.8%) in higher education (5.5%), in sheltered workshops (13.7%), in special units (49.6%), and at home (9.1%). These outcomes were deemed to be better than average, were based on IQ and speech level measured at age 6, and were attributed to therapeutic intervention.

Howlin (2000) summarised six outcome studies where individuals were either diagnosed with Asperger syndrome or high functioning autism. The studies were conducted between 1985-1999 (n= 123, range n=9 to n=43). Of the 123 individuals, 33 were living semi-independently, 4 were married, 35 were in paid work and 32 had mental health issues.

Billsted, Gillberg and Gillberg (2003) undertook a population-based 13-22 year follow-up study of individuals diagnosed in childhood, N=120, (83 males, 37 females) of whom 78 had a diagnosis of autism and 42 a diagnosis of atypical autism/autistic-like conditions. 20% of individuals with autism had IQs over 70%, whilst 14% of those with atypical autism had IQs over 70%. Criteria for outcome were:
- Good : (a) being employed or in higher education/vocational training and, (b) if over the age of 23, living independently; if 22 years or younger, having two or more friends/a steady relationship
- Fair : either (a) or (b) above
- Restricted but acceptable : neither (a) nor (b) above, and not meeting criteria for a major 'psychiatric' disorder other than ASD
- Poor: Severely handicapped, no independent social progress.
- Very poor: Unable to lead any kind of independent existence.

More than half those followed up had very poor outcomes, 13% had restricted but acceptable outcomes, and 0% had good outcomes. It was concluded that individuals diagnosed with autism in the 1970s-80s have an extremely poor outcome even in the presence of relatively well-functioning services, those diagnosed with atypical autism 15-30 years ago would now almost all receive a diagnosis of autism, people now diagnosed in the autism spectrum partly represent a different group, possibly with considerably better outcomes, however, low-functioning cases with autism probably still have outcomes similar to those found in this particular study.

Outcomes for families
There is some evidence of the impact of autism on family life. Stress in families of children with autism is well documented. It is worse where there are few support systems and the individual's problems are severe. Mothers of children with autism suffer more stress than mothers of children with Down's Syndrome (Holroyd & McArthur, 1976), and one third of mothers of children with autism suffer from depression with marital relationships often adversely affected (DeMyer, 1979). Many parents never get a break from their child and finding suitable childcare can be very difficult, and the chronicity of the disorder can leave parents exhausted, pessimistic and at risk for burnout (DeMyer & Goldberg, 1983). Bristol & Schopler, (1989) report that perceived adequacy of social

support is a significant factor in lower stress levels.

Sibling relationships when a child has autism

The particular experience of siblings of individuals with autism has attracted research interest for some time (Gillberg, Gillberg & Steffenburg, 1992). Findings are mixed as to the positive and negative experiences of having a sibling with ASD. Some have found higher levels of depression, loneliness and behaviour problems (Hastings, 2003; Verte et al, 2003), whereas others have found increased levels of pro-social behaviours and good adjustment (Kaminsky & Dewey, 2002; Pilowsky et al, 2004) An increasing amount of evidence is available on sibling experience of autism. For example, Wood, Rivers and Stoneman (2003) used family systems theory to study sibling relationships in 50 families with a child with autism. They found that typically developing siblings expressed satisfaction with their sibling relationships, that parents were somewhat less positive about the sibling relationship than were the siblings themselves, that stress in the marital relationship was associated with compromised sibling relationships, that informal social support buffered the deleterious effects of marital stress on positive, but not negative, aspects of the sibling relationship. Their findings reinforce the importance of considering family context as a contributor to the quality of the sibling relationship.

Practical aspects of outcomes for individuals

In terms of outcome for individuals with ASD, while there is generally a reduction in autistic symptoms over time, the severity of the social impairment may in fact increase (Starr, Szatmari, Bryson & Zwaigenbaum, 2003). Despite having good cognitive skills, children with Asperger syndrome report more loneliness than typically developing peers (Bauminger, Shulman & Agam, 2003) and are also more often subject to shunning and bullying by their peers (Little, 2002). Deficits in social communication skills may also be related to the increased risk of developing depression or anxiety disorders in this population (Kim, Szatmari, Bryson, Streiner & Wilson, 2000), possibly because these children and young people have a better awareness of their difficulties and of their consequences (Capps, Sigman & Yirmiya, 1995). The consequences of these impairments are far reaching. In adulthood, high functioning individuals with ASD are less likely than their typically developing counterparts to live independently away from home, to marry or have friendships, to complete college courses or to work independently (Howlin, 2000; Rumsey, Rapoport & Sceery, 1985; Szatmari, Bartolucci, Brnner & Bond, 1989). Mood disorders such as anxiety and depression are common (Gillot, Furniss & Walter, 2001; Green, Gilchrist, Burton & Cox, 2000; Hare, 1997), and this may relate to their ability to understand accurately their social difficulties (Capps, Sigman & Yirmiya, 1995). Social interest and skills are among the most crucial variables determining outcome (Matson, 1994) and have also been found to be the most disabling (Rogers, 2000). The challenge to understand and intervene in social communication and interaction in ASD is therefore undeniable. The right educational interventions are effective, not in removing the autism, but in creating a good environment for improvement.

Inclusion and autism

Work presented in this introductory section has made the case for autism as a complex set of inter-related behaviours which vary with age, severity and individuality. Whilst autism

is recognized as a neuro-developmental condition, it is also proposed that environment can make a difference. Given the diversity represented in the spectrum that is autism, the evidence presented here suggests that a diversity of educational provision will be needed. The ambition that is held by many educational providers to facilitate inclusive approaches by fostering independent participation in education and society is supported by legislation through the Standards in Scotland's Schools etc Act 2000 (Scottish Executive, 2000) and the Education (Additional Support for Learning) (Scotland) Act 2004 (Scottish Executive, 2004). The report, *Moving to Mainstream* (Scottish Executive Education Department, 2003) reveals some of the budget costs of an inclusive model of education. Barnard, Prior, and Potter's report *Inclusion and Autism: is it working?* (National Autistic Society, 2000) shares parental perspectives on inclusion and makes 16 recommendations (pp. 13 & 14), including: that awareness of autism should be part of the continuing professional development of all educational professionals, that earlier identification and diagnosis of autism should be promoted in the interests of making an early start to intervention; that local authorities should make autism-specific help available to mainstream schools whilst maintaining choice of autism-specific schools, and all in a context of meeting the individual needs and rights of pupils with autism.

In this context HMIE has been contracted by SEED to investigate and report on the current provision for children with ASD in Scotland and to make recommendations on how the provision can be improved.

- **Interventions**

It is clear from practice knowledge and from the review that follows that there is a very wide range of options for education and therapy for ASD. Rooted in different theoretical bases, all of these options lay claim to some success for some children (Howlin, 1998; Jordan et al., 1998). The assertion that intervention based upon a behavioural model currently enjoys the strongest research validation for effectiveness in ASD (Schreibman, 2000) remains largely unchallenged.

As early as 1977 Stedman claimed that relatively large and permanent gains in combating the effects of social disadvantage could be achieved if:
1) the child is enrolled in the programme from an early age
2) the parent is closely associated with the programme and used as a co-therapist, and if "home-rearing" is considered as a major variable in the programme/intervention
3) the programme has specifically and developmentally appropriate objectives and is based on relatively systematic teaching approaches rather than general enrichment.
4) the programme is maintained over long enough periods of time
5) steps are provided for generalisation of the learning to new situations.

In introducing the summary and evaluation of evidence for interventions into ASD that follow, these criteria drawn from intervention into social disadvantage remain informative for intervention into autism. However this review will add to them. Crucial to the overview and background to this review is an understanding of the effects of lack of, or delayed, intervention. Families are likely to seek help, but early specialist support is not always available to them. Indeed Sperry et al (1999) suggest that there is a disjunction between the increasing numbers of children diagnosed with ASD and the development of appropriate service delivery strategies. Current provision for young children with ASD appears to be 'patchy and underdeveloped' (Evans et al., 2001: 26). Support for families should ideally bring them into the system at an early stage in keeping with national policies on inclusion, and there is some evidence to suggest that suitable early intervention is likely to increase the likelihood of later inclusion in mainstream (Charman & Baird, 2002; Dawson & Osterling, 1997). The following sections of the review aim to share evidence about interventions and their effectiveness, but not to address the relative effectiveness of one against another since all approaches have been reported to offer success to at least some individuals on the spectrum.

Our experience of over 500 professionals studying with us on the Postgraduate Autism Courses at the University of Strathclyde underlines the use of a wide range of approaches to teach individuals with autism in Scottish schools. Practitioners display a great willingness to find approaches that suit both the individuals with whom they work and the group situations found in classrooms and schools. In the section on interventions that follows we have grouped these approaches and report on what research tells us about their efficacy.

The range of approaches used to teach children with autism, and the extent of use of each approach
In 1973, the work of Rutter and Bartak indicated that children with autism benefit from a more structured approach to teaching, providing a basis for a range of interventions to support the social interaction, communication and education of people with autism over the years. While it is acknowledged that people with autism should be supported for who they are, and their strengths recognised, reflecting what Baron-Cohen (2004) refers to as the 'triad of strengths', it is also recognised that intervention, and particularly early intervention can influence social, communicative and imaginative abilities in a child with autism and help with enabling social integration, friendships, self-esteem, well-being and access to education and employment. Earlier identification can lead to challenges for interventions (Volkmar, Chawarski & Klin, 2005), and although there can be concerns about labelling a young child with an ASD, the earlier the diagnosis of ASD is made, the earlier needed interventions can begin.

Approaches differ however, in their theoretical basis and consequent intervention paradigms, with a range including providing a structured education setting, behavioural approaches which shape and modify behaviours, developmental interactive approaches, which aim to develop social and communicative processes through naturalistic interaction, and cognitive approaches, which aim to teach the child through co-construction of shared meanings.

Structured Educational Setting
Division TEACCH (Treatment and Education of Autistic and Communication Handicapped Children) is described as a global approach based on close collaboration between parents and professionals, using structured and continuous intervention, environmental adaptations and alternative communication training, to minimize the difficulties for children and adults with autism and accommodate their strengths (Schopler et al., 1980). Visual and non-verbal aids are used to support planning, organisation and transitions between activities, to address cognitive and sensory processing, and to minimise anxiety. Founded in 1972 at the University of North Carolina (Lord & Schopler, 1994) the programme is state-wide and community based. Many TEACCH ideas have been adopted in specialist units and mainstream schools within the UK.

Behavioural approaches
Behavioural approaches rest on the theory of Skinner (1957) that learning is development, and all behaviour is learned. Using associative learning and operant conditioning, behavioural responses can be modified by positive and negative reinforcement. This approach was developed on the theoretical basis that persons with autism had not learned the behaviours of typically developing children because they could not respond to the typical environment, and, so, it was necessary for the environmental input to be altered to condition behavioural responses (Lovaas, 1987). A particular behavioural approach, 'Applied Behavioural Analysis', is used by Lovaas and colleagues (Lovaas, 1981) which involves breaking a skill into small steps and teaching each step a discrete trial technique. Other behavioural approaches have incorporated

developments in behavioural methodology, such as 'errorless discrimination learning' and 'functional analysis' (Smith, 1999). Prizant, Wetherby and Rydell (2000) draw a distinction between the earlier discrete trial training (DTT) behaviourist approach, and the contemporary applied behaviour analysis (CABA) approach, which involves behavioural reinforcement for appropriate responses but also uses naturalistic settings and minimally structured interactions. An intensive behavioural programme can involve 30-40 hours per week of one-to-one intervention

Some elements of behavioural approaches are included in other approaches such as Division TEACCH, but TEACCH would not use behavioural approaches in developing interpersonal understanding, considering them to be unsuited to promoting this type of development (Schopler et al, 1980).

Developmental Interactive approaches
The developmental interactive approach contrasts with a behaviourist approach in what is considered to be the processes of development. Informed by the insights into the social interactive processes in typical development shown by studies of infant development in the 1970's and 1980's (Trevarthen, 2001), the developmental and interactive approaches look at encouraging the motivation for the child to engage in the social settings required in typical development for social and communicative development and cognitive and emotional development to take place, and for encouraging these engagements in targeted ways to respond to the developmental needs of the child. Within this overall approach play therapy and play interaction approaches are used (Wolfberg & Schuler, 1993; Nind & Hewett, 1994), and also music interaction and drama interaction, and the impact of peer interaction is increasingly addressed. This type of approach has also been referred to as the social-pragmatic developmental interaction approach (Prizant et al, 2000)

Socio-constructive/cognitive approaches
Approaches such as Cognitive Behavioural Therapy, and Social Stories (Gray, 1994), aim to help a young person make sense of ideas and social conventions through co-construction of meaning (Vygotsky, 1978). These approaches can be used in combination with other supportive programmes and can be incorporated into inclusive practice.

Sensory and motor therapies
There is increasing recognition of the impact of sensory and perceptual processing upon social interaction and communication outcomes for people with autism (Bogdashina, 2003) which are addressed by therapies to integrated sensory processing or alter sensory sensitivities (Irlen, 1995).

Biomedical approaches
The role of physiological and biochemical factors, such as opiod excess (Whiteley & Shattock, 2002) are also addressed with, for example, exclusion diets and pharmacological interventions.

Issues around Effectiveness of Interventions

The intervention approaches outlined above indicate contrasts in theoretical approach – and in some cases would be mutually exclusive, and impact upon other daily events and opportunities for a child to socialize. Clearly it is important to know which interventions are effective, and which would suit any particular child, in relation to individual characteristics, age, and context, which would allow the child to develop friendships and social and communicative abilities, and to access the curriculum.

Jordan, Jones and Murray (1998) note that practitioners tend to use the 'best elements' of many approaches, however, with the range and possible approach types, some of which are mutually exclusive, some basis upon which to base a decision for deciding on the best approach for a particular child needs to be established.

Evaluating an intervention approach, however, can be difficult in relation to people with autism who form a heterogeneous group. Issues arise in relation to numbers of participants in an evaluation study, comparability of individual characteristics, the ethics and recruitment of a control group, the random assignment of participant to comparative groups – all of which pose methodological difficulties for comparative intervention paradigms.

Indeed difficulties have been found in the evaluative literature. In fact when reviewing the literature of the effectiveness of a range of interventions in this area in 1998, Jordan, Jones and Murray reported that <u>no</u> scientifically sound evaluation really had been done, a finding supported by other contemporary review studies also (Guralnick, 1997; Dawson & Osterling, 1997, Prizant & Rubin, 1999) and also more recent ones (Goldstein, 2002). Jordan Jones and Murray (1998) reported that there was no evidence that one approach was more effective than another. Looking closely at the methodologies involved in various studies they found that, while most approaches provided some evidence of effectiveness, they were very variable in scientific terms; some were just case studies, and most did not have a control group. Behavioural approaches in particular had claimed effectiveness for their approach (Lovaas, 1987), but various methodological problems questioned the validity of this claim (Gresham & MacMillan, 1998).

Evidence of effectiveness of approaches in supporting and teaching children with autism in more recent years needs further investigation, and this is the focus of this review.

SECTION 2
Evidence of the effectiveness of approaches

Review Method
The review includes information from the United Kingdom, international studies and common practice models, gathered from websites of research papers (such as Pubmed, and psycINFO), journals, books, and published reviews. The range of approaches outlined in the above section indicates the range of dimensions involved in intervention approaches – theories of development and learning, specificity of ability targeted, addressing causal processes, addressing behavioural responses. Information presented in this section on type, extent of use and effectiveness of approaches to teaching children with ASD will be organised in relation to-

- **understood causal processes and areas of impact** underpinning the formulation of the approach (one approach may aim to address communicative difficulties through promoting interpersonal engagement, another may aim to address communicative difficulties through adjusting perceptual sensitivities)

- **functional focus of the approach** (an approach may aim to address a wide range of functional abilities (e.g. TEACCH), or may be targeted to one specific skill (e.g. a strategy to indicate need for assistance)

- **the personal or interpersonal focus of the approach** (an approach may be 'child centred'(e.g.PECS), 'parent centred'(e.g. Hanen, EarlyBird), 'parent/adult and child' centred (e.g. the Joint-Play Method, the 'Options' approach), 'group' centred (e.g. social interaction groups, drama), 'child and peer centred'(e.g. 'buddies', peer supported play)

- **the social context of the approach** (e.g. home-based approaches, communication unit approaches, mainstream classroom approaches)

This allows the range of approaches to be systematically presented in relation to key features of their application. Extent of use is addressed, and examination of available evaluative evidence will reveal strengths and weaknesses in the effectiveness of the approaches.

In this way, the review starts with looking at an approach that centres on a structured educational environment to enable learning, in particular Division TEACCH, and then Behavioural approaches and other approaches which aim to influence 'product' of learning, rather than 'process' of development. These approaches focus on the learning of a child in an individual or group setting, and can be home or school based. Some behaviourally based communication approaches are also addressed.

Then developmental interactive approaches are considered, which work with encouraging the interpersonal processes and opportunities thought to underpin social, communicative and cognitive outcomes in children. Music therapies are included, and also, parental programmes. One area of support receiving much current interest is peer support, and peer mediated interventions, including drama, and art, are addressed, plus interventions addressing specific aspects of inclusive practice.

Socio-constructive/cognitive approaches are then addressed, including cognitive behaviour therapies, the 'social stories' approach, and computer based approaches. Approaches addressing sensory processes thought to impact on the social interaction, communication and imagination of children with autism are then considered, and biomedical interventions are also addressed.

Presentation of evidence of effectiveness of approaches
Each element in this section starts with a description of the approach used, including the theoretical assumptions, and containing, where applicable, previous evaluation information. Recent studies are then looked at, summarised, and critically appraised with evaluative points and strengths and weaknesses considered.

To allow us to make a comprehensive comparison we extracted the information systematically looking at the key features of the particular study including; sample size, method, design, control group (appendix 1.) Comparative studies, if applicable, were also looked at.

This then allowed us to appraise the data and look at adequacy of evidence on an individual study basis, on an approach type basis, and then on an overarching theoretical position basis. We were also able to identify gaps in evaluation research, and give an appraisal in relation to different areas, such as: transition processes, behavioural challenges, and friendships.

The approach areas under consideration are -

- **Structured education and environment**
- **Behavioural approaches**
- **Augmented Alternative Communication (AAC) systems/PECS**
- **Developmental and Interactive approaches**
- **Music therapy and interaction**
- **Parental programmes**
- **Peer mediated support**
- **Social interaction groups**
- **Socio-constructive/cognitive approaches**
- **Sensory and motor approaches**
- **Biomedical approaches**

- **Structured Education and Environment**

Division TEACCH
As described above, Division TEACCH, was originally a statewide program in North Carolina, and is now an intervention model implemented throughout the United States and Europe, and is considered to have been the most influential special education program for children with autism (Smith, 1999). The structured settings are designed to accommodate the strengths and weaknesses of the person with autism and would include, for example, visual cues, such as visual time-tables and structured routines. TEACCH is designed as a life-long approach, applicable from pre-school into adulthood, to equip a person with autism with life skills for employment and independent living.

The effectiveness of a structured teaching environment for supporting children with autism was indicated in early studies (Schopler, Brehm, Kinsbourne & Reichler, 1971; Rutter & Bartak, 1973). However, the higher mean initial IQ for the intervention group in contrast to the comparison groups in the latter study may have influenced the outcomes (Smith, 1993). Smith (1999) notes that all of the subsequent studies indicating the effectiveness of the TEACCH approach had methodological difficulties, being either uncontrolled (e.g.Panerai, Ferrante & Caputo, 1997; Keel, Mesibov & Woods, 1997), incompletely described (Schopler, Mesibov & Baker, 1982) or containing a confounding design element (e.g. Ozonoff & Cathcart, 1998).

Keel, Mesibov and Woods (1997) for example, reported on the 89% retention rate in employment for adults following the TEACCH employment support programme, and, responding to the need to provide a methodologically sound evaluation of this method, Ozonoff and Cathcart (1998) had carried out a matched control study of 22 children, with 11 children receiving a parent provided TEACCH programme at home in addition to their daily school behavioural based programme, and 11 children receiving only the daily behavioural based school programme. The children receiving the TEACCH programme showed increased development in non-verbal communication, imitation and motor skills, at three to four times the rate of the control group. However, Jordan, Jones and Murray (1998) point out that the impact of parent involvement alone, and intensity of treatment, were not controlled for, and these may have been influencing the results.

A more recent study by Panerai, Ferrante and Zingale (2002) compared the TEACCH educational treatment in a residential institute with an integration educational programme in mainstream schools in Italy with a support teacher. The two groups of eight subjects were matched by gender, chronological and mental age and nosographic diagnosis (autism associated with severe intellectual disability, DSM-1V criteria and Childhood Autism Rating Scale scored). Pre and post assessment scales were used with a one-year interval. Both groups showed significant development in hand-eye coordination, but the TEACCH group were found to also show significant development in the areas of imitation, perception, gross motor skills and cognitive performance. The authors argue that the outcome differences are due to the differences in the two treatments, but the effects of the programme alone cannot be separated from the effects of the settings in this study.

Mesibov (1997) points out the difficulties in attempting to evaluate the effectiveness of a programme like TEACCH, which is global, lifelong, and with moving outcomes,

'The problem is compounded by the organic basis of autism and the focus of Division TEACCH on lifelong adaptations which do not lend themselves to superficial cures or clearly defined milestones' (p.25).

Various studies continue to report on the effectiveness of a structured environment for people with autism. For example, positive outcomes are reported from applying a structured intervention to a high functioning autistic adult (Chang, 2004) where use of routines, scheduling, and establishing rules and expectations helped to reduce violent behaviour and improve social interaction. Use of a residential TEACCH based programme for adults with autism with severe disabilities was found to improve the quality of the treatment programme (with an increase in structure and individualized programming) in comparison to that of participants in control settings (Van Bourgondien, Reichle & Schopler, 2003).

Leppert and Probst (2005) report on the effectiveness of a TEACCH based training programme for teachers, which reduced the stress ratings for these teachers and had a positive affect on their assessment of child symptoms. Teachers' psychological adaptions and teacher-student interaction was found to improve. This study has no control group, but reflects findings on the impact on the philosophical commitment found with teachers using the TEACCH approach (Jennett, Harris & Mesibov, 2003).

Despite methodological difficulties in systematically evaluating this approach, Jordan (2004) draws out the strengths of structured teaching through visual aids and reducing stress through environmental adaptations. She indicates some potential difficulties in possible over-dependence on external structure and isolated learning.

- **Behavioural approaches**

As indicated above, Behavioural approaches rest on the theory of Skinner (1957) that learning is development, and all behaviour is learned. Using associative learning and operant conditioning, behavioural responses can be modified by positive and negative reinforcement. In 1987, Lovaas reported results for his method of Applied Behavioural Analysis used in his Young Autism Project with a group of subject over the previous two decades and involving the use of rewards and aversives with the experimental group. This study reported that 47% of the children in the experimental group, i.e. nine out of nineteen, achieved normal intellectual and educational functioning. This gave rise to much optimism about the effectiveness of this approach, but the methodology used has since been much criticized (Schopler, Short & Mesibov, 1989; Gresham & MacMillan, 1998; Shea, 2004).

Shea (2004) lists over 12 areas of methodological difficulties for this work including, lack of random assignment of subjects to control and experimental groups, experimental and control groups that were not equivalent (with aversives used in earlier stages with the experimental group), reliance on parental report measures and use of an unusual statistic.

Shea reports that other studies using an ABA approach over the past three decades have consistently shown results with lower improvement rates, a point also made by Smith (1999), and concludes that Lovaas's claims in the 1987 study are not sound. Nevertheless, she acknowledges that EIBI – early intensive behavioural intervention - can be useful. For example, in a study of 16 pre-school children with pervasive developmental disorders, Luiselli and O'Malley Cannon (2000) reported overall improvement in the areas of communication and cognitive and social-emotional functioning in proportion to the duration of time (months) that a child spent in home-based behavioural intervention programmes. Eikeseth and Smith (2002) studied 25 children with autism aged 4 to 7 years who were assigned to either behavioural or eclectic treatment and reported significant gains in favour of the behavioural group. In an extensive review of the literature on behavioural interventions for pre-school children with autism, McGahan (2001) concluded that cognitive and functional improvements may be gained through interventions using applied behavioural analysis. However, she approached the results with caution, noting that findings were limited, that it was not clear what components of intervention were linked to positive outcomes, that long-term benefits were uncertain, that studies in this area were marked by methodological flaws, and that it was not known whether the types of gain reported translated 'into happier people with greater functioning in the community'.

A widespread and coordinated evaluation of ABA has been undertaken recently, and has involved replication of the work of Lovaas across 25 international sites. Results have not yet been published.

Recent studies have used behavioural approaches to teach language and communication (Goldstein, 2002), joint attention (Whalen & Schreibman, 2003), and play (Kok et al. 2002). Whalen and Schreibman report that joint attention behaviours were successfully trained with 5 children with autism, however performance of a trained behaviour does not imply the mutual interpersonal understanding inherent in what is defined as 'joint attention' in infant development as described by, for example, Trevarthen (2001).

Kok et al (2002) compared structured play with facilitated play within a behavioural approach for pre-schoolers with autism mediated through trained peers. The use of discrete trials and incidental learning approaches was compared for eight participants in a crossover design, and both approaches were found to increase communicative behaviours and play, with more appropriate communicative initiations in the facilitated play and more appropriate communicative responses in the structured discrete trial play setting. Both setting resulted in a marked increase in spontaneous play initiation. The authors argue for a need to need to match treatment paradigm and mental age of child, and to match treatment goals to specific skill profile. The small number of children involved prevents generalized interpretation of the findings, and the crossover design resulted in cross-contamination of treatment content.

Hwang and Hughes (2000) reviewed 16 studies looking at the effects of social interactive training on early social communicative skills of children with autism. These studies used more naturalistic interactive teaching techniques such as contingent imitation, naturally occurring reinforcement and time delay, which are contingent upon the initiations of the child, and environmental arrangement. Positive changes were reported across these studies in social and affective behaviours, non-verbal and verbal communication, eye contact, joint attention and motor imitation, with some evidence of generalisation and maintenance. Numbers in these studies were, however, small, and although a multiple baseline design was used in many studies, large controlled studies had not been carried out.

While it can be useful to teach specific skills and responses in a particular context, the amount of time involved in an EIBI has yet to be justified, and could be a barrier to other forms of intervention. Aspects of behaviour modification could be useful *as part of* an intervention package, but modelling, imitation and interpersonal affirmation are strong processes within interactive development, and it is possible that gains reported in these studies derive from the more naturalistic interactional aspects of the activities rather than behavioural reinforcement aspects.

- **Augmented Alternative Communication (AAC) systems/PECS**

AAC systems, such as signing and symbol approaches, are used within the TEACCH approach and can be used within behavioural approaches. Jordan (NAS website) outlines both strengths and weaknesses in signing approaches, with, for example, echopraxia serving the same function as echolalia, but signing also helping to clarify deictic pronoun confusions, and stresses that signing must be demonstrated to have a communicative purpose and be used within functional communication. Signing can have limited number of communication partners, and sign training can result in 'prompt dependency, poor generalisation, limited total vocabulary or limited complexity (Bondy & Frost, 2001).

Signs are also used within Functional Communication Training (FCT) to express the communicative purposes underpinning challenging behaviour in a positive way. Reductions in challenging behaviours have been reported using this approach (Mirenda, 1997).

The Picture Exchange Communication System (PECS) devised by Bondy and Frost (1994) is an augmented alternative communication (AAC) system designed to teach functional communication to children with limited speech. PECS is based on behavioural principles following Skinner (1957), with communication defined as being 'under the stimulus control of the listener' and with 'subsequent reinforcement …mediated by the listener' (Bondy & Frost, 2001). The child is trained to initiate communicative interactions using a desired object as a motivator. Using a system of cards that illustrate objects, concepts, and activities, PECS begins by teaching requesting. Starting with shaping and reinforcing a response behaviour to become pre-requisite to achieving the reward, an initiating exchange of cards is trained. There are six phases in this system, with phase 1 teaching the child a physical behaviour that will be considered communicative, and the other phases training persistence, discrimination between symbols, using phrases, answering a direct question and commenting. Prompting, reinforcement and error correction strategies are used at each phase to teach spontaneous functional communication. The child does not have to have the ability to make eye contact, engage in joint attention, or to be able to imitate in order to learn how to use the technique. There are no verbal prompts used, so it encourages spontaneous communication that is not dependant upon verbal instruction by others. Semantically PECS is more like spoken language than signing, and independent speech is reported to occur in children trained in PECS (Bondy & Frost, 1994; Schwartz, Garfinkel & Bauer, 1998). This system is compatible with TEACCH.

Studies of the effectiveness of PECS report that children with limited communicative ability can be trained to use the system, and that independent speech also occurs for many of these children (Bondy & Frost, 1994; Schwartz , Garfinkel & Bauer, 1998; Charlop-Christy et al, 2002). There are, however, methodological problems of sample size and lack of control groups for such studies.

Charlop-Christy et al (2002), for example, studied the acquisition of PECS skills in three children with autism who were assessed as having no, or severely limited,

communication ability. The authors found that communication skills improved, including the use of verbal communication, as did social interactions among children taught PECS. Problem behaviour was found to decrease. Small sample size prevents generalisability of findings and lack of control group means that it cannot be determined the results were due to PECS or to naturally occurring developmental changes.

Kravits et al. (2002) reported on a study of a single grade-school-aged child with autism. The child was tested prior to the start of the study, and then repeatedly tested over time as each new aspect of the intervention was introduced. The child was found to show significant improvements in initiating interactions with peers and adults, and in her vocabulary. These abilities were reported to generalise to outside the teaching setting.

Ganz and Simpson (2004) in a study involving three young children with an ASD and developmental delay (DD), found that PECS was able to be used by the children and that word utterances increased in number of words and complexity.

A larger study was that of Magiati and Howlin (2003), who described a pilot study evaluating PECS in which teachers of 34 children with autism were trained in the approach. The children involved in the study had varying degrees of communication skills – some were nonverbal and others spoke in short phrases. Most participants were found to show improvements in their use of PECS, with rapid increases found, but the authors report that improvements in general communication skills were slower The children with the least communication skills at the start of the study made the most gains. The children who already had some communications skills seemed to plateau and did not show as much improvement. Parents' satisfaction with the technique was high with use of behaviours like the screaming previously used by one child to achieve needs reported to lessen. Setting affected the use of the system, with more use reported in the structured school setting than the home setting. The authors reported that a randomized controlled trial addressing some of the limitations of their pilot study is currently under way.

As a system which requires no prior engagement in joint attention, or imitative ability, or apparent communicative motivation, PECS can be a way of guiding the child into initiating a behaviour which will have an effect upon the world. As with all behavioural approaches the numerous repetitions of the behaviour can be difficult to sustain in a classroom environment, and the performance of trained behaviour does not imply the development of interpersonal communicative motivation. Numbers in most studies reported are too small to draw conclusion in relation to the general population of people with autism. Magiati and Howlin, in their larger study, report that general communicative improvements for the children were slower to occur.

Goldstein (2002) in a review of speech and language intervention procedures applied to children with autism reports that interventions incorporating sign language, discrete-trial training, and milieu teaching procedures have been used successfully to expand the communication of children with autism, and to replace challenging behaviours. He points out that use of discrete trial teaching techniques in more natural contexts in homes and schools has occurred in response to the lack of generalisability found for such techniques

on the everyday functioning of children with autism. He acknowledges need for further research in this area.

- ## **Developmental and Interactive Approaches**

The developmental interactive approach aims to encourage the motivation for the child to engage in the social settings required in typical development for social and communicative development and cognitive and emotional development to take place, and for encouraging these engagements in targeted ways to respond to the developmental needs of the child This reflects the current theoretical position that it is the impact of social isolation, which underpins many difficulties in social and communicative outcomes for a child with autism, rather than deficits in social and cognitive processes (Jordan, 2003). Within this overall approach play therapy and play interaction approaches have gained in use, and also music interaction and drama interaction, and the impact of peer interaction is increasingly addressed. Relevant also to inclusion are the 'Circle of Friends' and 'Buddies" approaches.

An early example of this type of approach is the Intensive Interaction approach of Nind & Hewett (1994). Intensive interaction is an interactive approach also based on a model of caregiver-infant interaction. The approach aims to facilitate the development of fundamental social and communication abilities. The practitioner uses imitation and develops turn-taking routines and scaffolds playful episodes in engagement. There is no fixed task or outcome focus and increases in sociability and communication have been reported (Watson & Fisher,1997; Hewett & Nind, 1998; Nind, 1999). Nind and Powell (2000) consider this naturalistic and supportive approach suitable for helping children with autism develop interaction and communication. Kellet (2004) presents a case study to illustrate the use of intensive interaction to support social and communication development for pupils who are 'hardest to reach' with little early communication abilities. A controlled evaluation of this approach has not been carried out with children with autism, but Cumine et al. (2000) suggest it could be used as part of a package of intervention strategies with young children

Scottish Centre for Autism (SCA) pre-school treatment programme
The SCA approach is a socio-developmental approach which is 'child-centred', with the adult initially following the child's lead.The programme aims to improve the child's early social communication and social interaction skills, and lead to the potential development of play and flexibility of behaviour. This is achieved by 1:1 intensive treatment by trained therapists, and a schedule of parent training. The treatment incorporates a child led approach; the use of imitation as a therapeutic strategy; using language contingent on activities; and the introduction of flexibility into play and social exchanges (Salt et al, 2001)

Salt et al (2002) evaluate the effectiveness of the programme. Two groups of children were compared, a treatment group (n=12) and a no-treatment control group (n=5), which comprised children on the waiting list for treatment. Standardized assessments were administered before and after the intervention period by an independent clinician. Pre-

treatment comparisons revealed that the control group had a significantly higher pre-treatment IQ; but the two groups were comparable for age, mental age, socioeconomic status and number of hours of non-experimental therapy. Results demonstrated that children in the treatment group improved significantly more than those in the control group on measures of joint attention, social interaction, imitation, daily living skills, motor skills and an adaptive behaviour composite. The authors point out that the allocation of children to the study groups was not randomised, and numbers are small.

DIR 'floor-time" approach (Greenspan & Wieder, 1998)
This naturalistic play approach follows a Developmental, Individual difference, relationship-based (DIR) model. The Floor Time model focuses on developing relationships and affect, and interventions are designed to accord with the child's developmental level and individual characteristics During spontaneous 'floor-time' play sessions adults follow the child's lead using affectively toned interactions through gestures and words to establish shared-attention, engagement, simple and complex gestures and problem solving. It is designed to help the child develop relationships and to help the child develop concepts, symbolic representation and abstract thinking through the interpersonal processes of shared affective interaction (Weider & Greenspan, 2003). Parents are trained to use the 'floor-time' model at home and to utilize spontaneous opportunities to engage in playful interactions, and engagement in 'floor-time' at home can range from two to five hours a day.

Greenspan and Wieder (1997) reviewed the charts of 200 children with autism spectrum disorders who had been involved with their approach over at least two years, and found marked improvements in relating and communicating and all areas of development. The progress of 58% of the children was described as 'good to outstanding' with significant improvements in affect, social behaviour, cognitive skills, symbolic play, and creativity, and a reduction in avoidant, self-stimulatory, or perseverative behavior. Scores for these children on the Childhood Autism Rating Scale (CARS) (Schopler et al., 1988) were found to no longer be at the autism level. Seventeen percent of the children were found to show little improvement in affect, symbolic ability, attention and avoidant behaviour and were described as having 'ongoing difficulties'. Greenspan and Wieder also examined the charts of a further 53 children who had received other interventions – speech therapy, occupational therapy, special education approaches and behavioural therapy - but had not yet used the 'floor-time' model, and found that 58% of these children would be described as having 'ongoing difficulties' with only 2% showing improvements that could be classed as 'good to outstanding'.

This study involved a large number of children, however the chart review design, although giving a detailed method of data gathering, does not provide the randomised controlled comparison groups necessary to give a sound evaluation of this approach. A randomised control trial (RCT) is needed.

This approach, however, does provide support for the effectiveness of naturalistic interactive play approaches, and several other studies also report similarly positive results

using this type of approach (Chandler et al, 2002; Marwick & Mackay, 2004). Control group comparisons, however, are necessary for evaluation of these approaches.

Reciprocal play approaches

Chandler et al (2002) describes outcomes from an interactive communication approach for 2-3 year olds with autism and reports clear developments using this approach. Similar developments are reported for pre-school children with autism using the Joint Play Intersubjectivity Assessment Method (Marwick, 2001, 2005). This method follows a shared regulation model for adult and child, reflecting typical development, using 2 sets of identical toys. Beyer and Gammeltoft (2000) also use a reciprocal play method, which connects social, emotional and cognitive developmental aspects of play. Although reporting positive developments this method has not been evaluated.

Options (Son-Rise Program) approach (Kaufman, 1976)

This is a child-centred interactive approach used mainly in a home setting with the adult following the child and completely accepting the child's focus and actions. The programme can be used intensively for up to 80 hours a week (Kaufman, 1994). Although influential in child-centred practice, effectiveness of the approach is documented only in a small number of case studies, with no randomly controlled evaluation having been carried out. Williams and Wishart (2003) note the lack of evaluative material on both the effectiveness of the method and on the effects of such an intensive interaction on the family as a whole. In their study, Williams and Wishart (2003) investigated family experiences with the Son-Rise Program intervention using a longitudinal questionnaire based design. Families who had attended an initial 'start-up' training course in the UK in 1998 were sent out three questionnaires ove rthe course of the following year. They found that the most commonly reported benefit was that the family felt more positive emotionally. An equal number of parents reported that family life was more or less stressful as a result of involvement in the intervention, and nearly half of the responding families reported the drawback of having less time to spend with other family members.

Comparative study of play approaches

Bernard –Opitz, Ing and Kong (2004) compared behavioural and natural play interventions for young children with autism. Using a small sample of eight children in matched groups of four in a crossover design to control for sequence of intervention, they found improvements in play, attention, compliance and communication measures following both types of approach. Improvements in attending and compliance measures were higher with the behavioural approach, but influences of each approach upon the presentation of the other were noted. The small number of participants and sequential design of this study prevent generalisation of the findings.

Wetherby and Prizant (2000) have developed the SCERTS model of service provision, which focuses on Social-Communicative Emotional Regulation and Transactional Support in intervention planning. This approach incorporates socio-pragmatic language

therapy, naturalistic play based strategies for promoting social relatedness and social-emotional reciprocity, sensory processing support, and support for the family.

These approaches rest on a theoretically strong developmental basis and also emphasis the increasing recognized importance of providing opportunities for interactive play in children's development (NRC, 2001).

- **Music Therapy and Interaction**

Music Therapy (e.g. Nordoff & Robbins, 1977, 1998) aims to enable the child to experience sound and change, motivation, inter-responsiveness, supporting spontaneity and intentionality in musical communicativeness. Musical Interaction Therapy (Christie, Newson, Newson & Prevezer, 1992) is an autism specific approach where a child's parent or key worker works with the child and a music therapist plays an instrument to facilitate interactions.

Many studies in this area are of single cases or small samples, and it is often the case the effect of music cannot be separated from other intervention variables (Whipple, 2004). In a meta-analysis of music in intervention for children and adolescents with autism (Whipple, 2004) a range of studies were included, she was able to include that 'all music interventions, regardless of purpose or implementation, has been effective for children and adolescents with autism'.

- **Parental programmes**

Parental involvement in the range of interventions described is of crucial importance. Some parent training programmes have been developed specifically to equip parents for supporting the communication and development of their child, such as the NAS 'Early Bird' programme (Shields, 2001), and the Hanen 'More than Words' programme (Sussman, 1999).

The NAS 'EarlyBird' programme is a three month parental programme, which involves weekly group training sessions and home visits to help parents understand about autism and support parents in developing communication and managing behaviour. Evaluations of this approach (Morris, 2002; Engwall & MacPherson, 2003) reported parental assessments to be very positive.

The Hanen 'More than Words' programme is a training programme for parents of pre-school children with autism which has a developmental interactive perspective and aims to help parents develop the communication of their child. Group sessions, home visits and video feedback are used. An evaluation of the effectiveness of this programme is in progress (Dixon & LeCouteur, 2003).

A randomised control trial (Aldren, Green & Adams, 2004) involving 28 children with autism and their families of an intervention to educate parents and train them in adapted communication tailored to their child's individual competencies found significant improvement in the parent trained group outcomes, particularly in reciprocal social interaction, and on secondary measures of expressive language, communicative initiation and parent-child interaction. The authors argue that a larger RCT is necessary.

A further pilot RCT parent training intervention programme focusing on joint attention skills and joint action routines was carried out (Drew, Baird, Baron-Cohen et al., 2002) which reports some evidence of more progress in language development for the parent trained group of children after one year. However several methodological difficulties were encountered, and the authors draw out the challenges inherent in carrying out an RCT for pre-school children with autism.

- **Peer mediated support**

Increasingly over the years interventions involving peers have been tried. Rogers (2000) in a review of studies facilitating social development in children with autism, draws together a number of studies involving peers, some of which have used behavioural principles in training peers to be therapists and tutors and others which use more naturalistic settings to integrate children with peers. The increased understanding that many communicative and social difficulties in behaviour for people with autism arise from their social isolation rather than lack of capacity, has resulted in several naturalistic approaches.

Integrated Play Groups (Wolfberg & Schuler, 1993)
This method follows the position of Vygotsky (1978) with children with autism playing with more 'competent' typical peers, and thereby mixing 'novice' and 'expert' players. An adult Playgroup guide is present. The settings are where play occurs naturally, and play would take place twice weekly, for about 30 minutes. The adult assesses, enhances, monitors and scaffolds play. In a recent study using this method (Yang et al, 2003) of two children over a period of 6 months (35 sessions, 40-60 minutes each), each child made notable gains in reciprocal social interaction and symbolic/pretend play. Further studies by Schuler (2003) with one child, and Zercher et al.(2001) with 6 year old twin brothers with autism, report marked improvements using this method.

'Circle of Friends' (Whitaker et al, 1998; Greenway, 2000, Whitaker, 2004) where peers are trained to initiate and positively interact with a focus child with autism in a group, and 'Buddies' (Dennison, 2000) approaches also report marked improvements in social interactions, communication and friendships. Studies of peer mediated support for children with autism provide promising results, but numbers are small and more systematic evaluation is needed.

- **Social Interaction Groups**

Researchers report some benefits from structured social skills groups for children, young people and adults with autism and Asperger syndrome. In the hierarchy of evidence, randomized controlled trials (RCTs) and their meta-analyses are considered to provide the best evidence of effectiveness of interventions. It is useful to note however that in some fields of practice the use of RCTs has been challenged, particularly in terms of types of participant or where the information produced has had limited generalisability to practice. RCTs may also fail to take account of the role of qualitative research, which for many engaged in day-to-day interventions with people with ASD provides essential research and practice information. The challenges encountered in the conduct of RCTs in

a parent training for pre-school children with autism are discussed by Drew, Baird, Baron-Cohen, Cox, Slonims, Wheelwright, Swettenham, Berry and Charman (2000), who attempted a pilot RCT for a parent training intervention with a focus on the development of joint attention skills and joint action routines. They highlight methodological challenges and strategies for future well-designed RCTs for autism interventions. Studies reported in this section make use of quantitative and qualitative data, but none involves RCTs.

Work presented in this section has drawn from a range of sources, but in particular the authors would like to acknowledge the usefulness of colleagues' recent work in this area in supporting this section of the review (Dunlop, Knott & Mackay, 2002; Dunlop, Knott & MacKay, 2005; Knott, Dunlop & MacKay, 2005; MacKay, Knott & Dunlop, 2005). Reported studies all have very small numbers of participants, consequently to be able to draw on the work involved in a study with 46 participants is very helpful.

Difficulties with social interaction and understanding present a major challenge to individuals on the autistic spectrum, and are considered to be the core deficit (Fein, Pennington, Markowitz, Braverman & Waterhouse, 1986). These difficulties often have overwhelming effects on the lives even of the most able. Previous interventions in this area have been subject to a number of limitations including small sample size, the teaching of isolated social skills, the lack of formal assessment measures and, most particularly, lack of generalisation to other settings (Dunlop, Knott & Mackay, 2002). We include several short examples of social skills group work with individuals with ASD, three more detailed recent examples of group approaches to social interaction and understanding and social competence, followed by a detailed review of literature in which we consider the implications of social interaction difficulties in ASD for education, from which we draw general conclusions and recommendations.

Short examples
Howlin and Yates (1999) in their study of '*The potential effectiveness of a social skills group for adults with autism'* aimed to understand the social difficulties in autism, and to find ways to overcome them. Although the study was conducted with adults, the outcomes are therefore pertinent to children and young people as well. A particular focus was made on conversation. A mixed format was used and included role play, video and structured games. Ten males, with an average age of 28 years met monthly for a year. Outcome measures for the project were based on interviews with participants and their families. Video-taped conversation in two situations (informal, and a job interview) was rated pre and post the project. Most participants and families reported improvement. Whilst video evidence showed improvement in conversational skills especially in formal situations such as job interviews, the generalisation of this improvement was poor.

In common with other social interaction interventions, techniques used in Marriage, Gordon and Brand's '*social skills group for boys with Asperger's Syndrome'* (1995) included the use of warm-ups, role plays, videotaping and watching tapes and movies. Show-and-tell techniques were used as a focus for talking about favourite subjects whilst having to gauge the response of the audience. Eight children aged 8-12 were involved in

two phases of this project, which was short life. During the first phase in term time, weekly 2 hour sessions were held. The second phase was 90 minutes of informal school holiday contact. Homework was included and involved 1-3 tasks per week: these tasks were not completed by all participants, but parents reported that it was useful to see how hard the activities were for the children involved. Outcomes were gathered through the use of 5 point Lickert scales with parents. The parents reported negligible change on various skills, but all the children seemed to be more confident. Generalisation was reported as very poor.

In a pilot social skills group for what the authors described as 'socially disorganised children', Savidge, Christie, Brooks, Stein and Wolpert (2004) included children who sometimes remained without a diagnosis because they did not fulfil all the criteria for autism or Asperger syndrome, but who nevertheless presented with the same pattern of social impairments in understanding and processing interpersonal cues and planning appropriate responses. The groups ran for only 6 weeks and the number of participants was small, comprising 11 boys, three of whom had a diagnosis of Asperger syndrome. Pre-post assessments pointed to positive changes in behaviour.

Williams' study (1989) was carried out at weekly meetings over a four year period. His '*social skills group for children with autism*' meetings involved social skill instruction for adolescents with autism. There was a total of ten participants who attended for varying lengths of time. Individual ages at start varied from 9-15 years of age. The aim of the meetings was to help participants develop friendships and try out their own ways of interacting. Approaches integrated modelling, coaching, recreational games and role playing. A different theme was addressed each term and included developing enjoyment of the group, role plays of increasing complexity, discussion of problems and understanding of feelings, conversation, voice tone, leave taking, temper control, flexibility and taking account of others' points of view. Outcomes were measured using the Spence questionnaires and parental self-reports. Improvements were noted in at least some areas for all children, but it remained unclear whether gains were due to maturation or attendance at the group meetings.

Three recent examples of group approaches to social interaction and understanding and social competence.

Bauminger, N. (2002) *The Facilitation of Social- Emotional Understanding and Social Interaction in High- Functioning Children with Autism: Intervention Outcomes.*
Summary
Bauminger recognises that social impairments: 'abnormalities in reciprocal social interaction and difficulties in emotional expression and recognition' (p.283) are considered as core difficulties in ASD. Children with autism who have normal intelligence may show different socio-emotional characteristics than less able individuals, perhaps due to their cognitive abilities. However difficulties in social initiation and social-emotional understanding present this group with major challenges, despite greater social sensitivity and interest than others with ASD (Bacon, Fein, Morris, Waterhouse & Allen, 1998; Sigman & Ruskin, 1999). This study evaluated the effectiveness of a 7-month cognitive behavioural intervention for the facilitation of social-emotional understanding and social interaction of 15 high-functioning children (8 to 17 years) with autism.
Method
Children were included on the basis of four conditions: they met both the DSM-IV and ADI-R criteria for autism, had a verbal IQ of 69 or above, and consent was given by professionals and parents. The group consisted of 4 girls and 11 boys. The teaching of interpersonal problem solving, affective knowledge, and social interaction were the focus of this study. Pre-intervention and post-intervention measures taken included: observations of social interaction; measures of problem solving and emotional understanding, and teacher-rated social skills. Each participants' individualised educational plan included work on the intervention curriculum 3 hours per week over a 7-month period. Peers and parents were involved in practice. A range of assessment measures were used.
Effectiveness
Progress was shown in the three areas of intervention. Participants were more likely to initiate positive social interaction with peers following the intervention (which is described as 'treatment'), this was shown by improved eye contact, showing interest in peers and sharing experiences with peers. In terms of affective knowledge, participants provided more examples of complex emotions, offered more specific examples, and were more aware and more frequently included an audience. More relevant solutions which made more human sense were provided in problem solving situations after intervention. Teachers rated participants' social skills of cooperation and assertion more highly.
Conclusions
Overall Bauminger's work offers a potentially positive model of cognitive-behavioural intervention aimed at facilitating social-emotional understanding and social interaction which includes peers, teachers and parents and occurs in situ. Intervention occurred as part of curriculum planning and measures were taken during school breaks to track the influence of peer and parental involvement and support.

Dunlop, A.W.A., Knott, F. and MacKay, T. (2002). *Developing Social Interaction and Understanding in Individuals with Autism.*

Summary

This recent Scottish study sought to address limitations of sample size, the teaching of isolated social skills, the lack of formal assessment measures and lack of generalisation to other settings. The work undertaken in this particular study on increasing social and emotional understanding, social interaction with understanding, communication, social integration and friendships through Social Interaction Groups showed marked success. The study also went some way to addressing the relative lack of information about the skills and competencies of children and young people who access ordinary community facilities including mainstream education, as seen through the eyes of those children and their parents (Knott, Dunlop & MacKay, 2005).

Method

A sample of 46 able children and young people with autism spectrum disorder (38 boys, 8 girls) was allocated to one of 3 primary (ages 6-11) or 3 secondary (ages 12-16) intervention groups. Each group comprised a 2-hour weekly session for a duration of 16 weeks, and aimed to promote key areas of social interaction and understanding, supported by home-based practice. An assessment framework was designed using the Vineland Adaptive Behaviour Scales (VABS) (Carter, Volkmar, Sparrow, Wang, Lord, Dawson, Fombonne, Loveland, Mesibov, & Schopler, 1998) to provide a profile of the sample, and pre-post testing using the Spence Social Skills Questionnaire (SSQ) and Social Competence with Peers Questionnaire (SCPQ) (Spence, 1995), together with an individual parent rating measure designed for the study. A key element of the programme was the mixed professional nature of the intervention teams who were drawn from speech and language therapy, teaching, nursing and psychology. In common with other studies in the area of social interaction, understanding and social competence, a control group was not established for ethical reasons. Originally the team attempted to set up controls by use of the waiting list for the next group, but the timescale of the project mitigated against this approach. However pre- and post-intervention data was generated through the measures taken.

Effectiveness: Significant gains were obtained for social skills and social competence in comparison with a normative population, and the individual parent ratings showed marked and sustained changes in the key areas targeted by the groups.

Conclusions: A focus on developing social interaction and understanding can enhance social skills and competence in children and young people with autism spectrum disorder in ways that significantly enhance quality of life. Skills and understanding developed in naturalistic contexts and practised at home are more likely to foster generalisation, and to increase social competence.

Webb, B. J., Miller, S.P., Pierce, T.B., Strawser, S. and Jones, W.P. (2004) *Effects of Social Skill Instruction for High-Functioning Adolescents with Autism Spectrum Disorders.*

Summary

Ten young people with diagnoses of ASD participated in social skills training in a group setting over a 10 week period. Attendance was in the evening and dependent on parental cooperation. Data was generated through questionnaire completion by the participants and by their parents. The aim of the study was to investigate the efficacy of using a particular approach to social skills training, the SCORE Skills Strategy (Vernon,

Schumaker and Deshler, 1996). Participants and parents rated the social skills group positively, however it is observed that whilst an outcome of such intervention aims that the participants social competence is more noticeable to others, in this case although the participants showed significant gains in their performance of targeted social skills in the classroom the generalisation of these skills was not noticeable to their parents.

Methods

The ten participants were recruited through school and community announcements, and observed six criteria for involvement: current educational eligibility for an ASD programme; being 12-18 years of age; receptive and expressive language ability above 70 standard score, as measured within the previous three years; currently attending mainstream for at least one period a day; deficit in social skills, and parental agreement to provide transport to and from sessions. The study took place in a community building. Role-play data was collected by video. An instructional programme, the SCORE Skills Strategy Program and associated materials were used. Instruction is based on five skills which children need in order to cooperate successful with others. Five social skills were targeted. These were: 'share ideas'; 'compliment others'; 'offer help or encouragement'; 'recommend changes nicely', and 'exercise self-control'. A high level of adult assistance was needed to facilitate interaction.

Effectiveness

The results reported from this study indicate that at least the participating high-functioning adolescents with ASD are able to master the particular skills in a cooperative group setting. Individuals made gains in the performance of the five targeted skills, and after teaching had been completed were able to generalise these skills into role play situations, though generalisation was not observed by parents beyond the group meetings.

Conclusions

An interesting study producing measurable gains in context, reported results demonstrate the need for a greater emphasis being placed on the generalisation of social skills to new contexts and different environments. Such generalisation may have been facilitated by parental involvement in the practice of skills at home.

Implications of Social Interaction Difficulties for Education

In ASD social interaction difficulties occur across the lifespan and reflect difficulties in engaging with others in ways that are truly reciprocal, in understanding others' minds, and with concepts such as friendship. More able individuals, often included in mainstream education, have difficulty using communication appropriately for social purposes, even when their functional language is good (Attwood, 1998; Landa, 2000). The consequences of these impairments are far reaching (see 'Outcomes' section). Later success in, for example, independent living, completion of college courses, capacity to sustain friendships or to work independently and sustain employment, are all affected by social competence. Social skills and interest are among the most crucial variables determining outcome (Matson, 1994) and are arguably, when poorly developed, the most disabling (Rogers, 2000). The literature reports frequency of mood disorders such as anxiety and depression in young people with ASD (Gillot, Furniss & Walter, 2001; Green, Gilchrist, Burton & Cox, 2000; Hare, 1997), and this may be more marked for more able individuals who equally are likely to participate in mainstream education.

Approaches that support the development of social competence by encouraging reflection and generalisation may support individuals in their ability to understand and cope with their social difficulties (Capps, Sigman, & Yirmiya, 1995). Research suggests that social skills training on its own is unlikely to result in lasting change in social competence, unless it is seen as part of a wider approach (Spence, 2003). Individuals with autism will typically benefit from approaches that develop a range of social skills augmented by support to interpret others' intentions and to focus on interpersonal problem solving.

There is a long tradition of social skills training for children with ASD (Rogers, 2000). Several approaches are evident: direct teaching of specific skills (McGee, Krantz & McClannahan, 1984); the involvement of typically developing peers or siblings (Celiberti & Harris, 1993; Kamps et al., 2002; Strain & Hoyson, 2000), and enhancing interactions skills of children with adults. Examples include teaching mothers to imitate their children in toy play (Dawson, Hill, Spencer, Galpert & Watson, 1990), and visual cueing system used to increase pre-schoolers' social initiations to teachers (Krantz & McClannahan, 1998).

The evidence for the benefits of social skills groups and other methods of social skills training is subject to a number of limitations. First, most studies are based on very small numbers of participants (e.g., Marriage et al, 1995; Savidge et al., 2004; Webb et al., 2004). This is particularly important in the absence of a control group and when the intervention lasts a long time. As Williams (1989) points out, although his study produced improvements in some areas, the children were involved for considerable periods of time and change could have resulted from maturation or other educational methods being used at the same time. Second, there are issues arising from the generally informal nature of the assessment measures used. Research is undermined if pre-post tests are not appropriate (Greenway, 2000) and the outcome measures reported in most of the above studies are primarily qualitative (Attwood, 2000). Sometimes also the personnel carrying out the intervention are also responsible for the evaluation, and parent and self-reports may be subject to the effects of social desirability, where answers may be given to 'please' the interviewer (e.g., Bauminger, 2000). Third, few social skills interventions have been based on a theoretical understanding of the mechanisms underpinning ASD. This parallels development in social skills training in other child populations (Spence, 1995). A good understanding of the theoretical underpinnings of ASD will be a key factor in developing effective interventions (Attwood, 2000). The recent shift in the focus of interventions from the teaching of splinter skills to those taking account of more fundamental deficits and their psychological bases is a welcome development (e.g., Swettenham, Baron-Cohen, Gomez & Walsh, 1996; McGregor, Whiten & Blackburn, 1998).

A fourth and crucial limitation is that most interventions, including most of the reported group studies, suffer from a lack of generalisation from the intervention setting to the day-to-day environment, or from isolated skills to a wider social understanding. This was particularly true of early approaches that focused n the teaching of 'splinter skills' (Howlin, 1998). In their review Hwang and Hughes (2000) argue that social interaction skills cannot be successfully developed in isolation from daily life, and some efforts have been made to overcome this, for example, by giving children the opportunity to practise

skills in a natural setting (Strain, 2001). While Bauminger's (2002) small sample showed encouraging indications that new social skills had been demonstrated in real-life settings, the key question again was whether improvement had exceeded the learned items and had indeed transferred into more global social competence with peers.

Whilst such studies report on individual gains, there is an under-reporting of the views of parents and their children about the skills and competencies of children and young people who access ordinary community facilities including mainstream education (Knott, Dunlop & MacKay, 2005).

Spence's distinction between 'social skills' (Spence, 2003). and 'social competence' (Spence, 1995), is invaluable in terms of outcomes for children and young people with ASDs. Dunlop, Knott and MacKay (2002) embedded this notion of competence into their project title of 'Social Interaction & Understanding'. It is possible to develop skills, and indeed a logical and abstract understanding of, for example, the way in which friendships form, that still appears to leave the individual with ASD with profound difficulties in putting this knowledge into practice (Green, Gilchrist, Burton & Cox, 2000). Indeed adolescents with Asperger's report more loneliness (Bauminger, Shulman & Agam, 2003) than their typically developing peers. Added to their vulnerability to bullying (Little, 2002), it is possible to see likely causes of the anxiety, tension and depression that is so often reported in this group (Kim, Szatmari, Bryson, Streiner & Wilson, 2000)

In concluding this section we should ask the question: what kinds of approaches to the development of social interaction are effective? Approaches which seem to be effective day-to-day in the hands of experienced practitioners with a sound knowledge of ASD, would seem to include a range of group work; the use of social stories and circle of friends; the Social Use of Language Programme (Rinaldi, 1992); peer mediated interventions, in which children with ASD are paired for play sessions with typically developing children; and attempts to develop social interaction skills by encouraging perspective taking. Good reviews have been provided by Rogers (2000), Weiss and Harris (2001) and Greenway (2000).

There are a number of features common to effective interventions. There has been a move away from teaching 'splinter skills' such as eye contact (Howlin, 1998) in isolation from normal use: the teaching of skills in this kind of a way is problematic as the number of skills to teach could be 'endless' (Strain, 2001 page 31). Such an approach is also particularly ineffective for children who have difficulties making connections as is commonly the case in ASD (Cumine et al, 1998) unless connections are specifically taught. Skills learned in one context or setting do not easily generalise to another setting: learning in ASD can be particularly 'context specific'. The issue of generalisation remains a challenge for researchers and practitioners, but focusing clearly and thoughtfully on skill generalisation has lead to more success (Dunlop, Knott & MacKay, 2002). Group work is one arena in which such skills may be developed (Knott & Dunlop, 2005). The tables in Appendix 2are provided to show key themes and methodologies for intervention in effective social interaction and understanding approaches in ASD. Evidence presented in this section reveals the small number of studies in this promising

area: where possible a gradual reduction of structure and an increasing focus on teaching understanding, reflection and internal cognitive control of skills needs to be developed for pupils with ASD in order for them to be able to benefit from inclusion.

- **Socio-constructive/ cognitive approaches**

This type of approach aims to help a young person make sense of ideas and social conventions through co-construction of meaning (Vygotsky, 1978). These approaches can be used in combination with other supportive programmes and can be incorporated into inclusive practice.

Cognitive Behaviour Therapy
Use of Cognitive Behaviour Therapy (CBT) is recent, and a few studies have begun to appear (Greig & Mackay, in press; Hare, 2004). A randomised control trial (Sofronoff & Attwood, 2003) included 65 children aged 10 to 12 years with Asperger's Syndrome, and reported positive results. A case series (Bauminger, 2002) included 15 high-functioning children and young people aged 8 to 17 years with a diagnosis of autism. Positive effects of CBT were found for problem solving, emotional understanding and social interaction. While these results show promise, a systematic review of the literature covering this area has concluded that early results require further evidence to indicate the extent to which any improvements are a direct result of the CBT (White, 2004).

Social Stories
Social stories (Gray, 1998) use a short story form to inform a child about a social skill or social meaning. They include features that currently are unanimously regarded as effective in the field of autism (Smith 2001). They incorporate visual cues in the form of drawings and words, which have been proved to be particularly effective with individuals with autism (Hodgdon 1995, Peeters 1997) in sharing meaning and ideas about behaviours, intentions and feelings. The stories will include descriptive and perspective sentences, and also a directive sentence. They can be considered as a stable source of information, as the individual can refer to them at any time he or she would like to (Jones 2002). Initially Gray and Garand (1993) argued that cognitively more able children with fundamental language skills would benefit more from a Social Story Later on Gray (1998) reported that they could be beneficial for more severely impaired children, too. Most of the published studies involve participants with mild to moderate ASDs, as well as Asperger syndrome. Additionally, there are a number of studies where non-reading children with additional learning difficulties benefited from the use of Social Stories (Smith 2001, Kuoch & Mirenda 2003, Barry & Burlew 2004).

Even though social stories have become increasingly popular for teaching appropriate behavioural skills to children with autism, little empirical evidence is available examining their effectiveness (Sansosti et al. 2004; Barry et al. 2004). However almost all the relevant studies report that this intervention has proved to be successful in dealing with the target behaviour (Alevra, 2004). But the factor of whether Social Stories were combined with other approaches which needs to be considered in relation to the evaluation of this method's effectiveness. For instance, Kuttler et al (1998) paired them with visual schedule and prompting. Consequently it is not clear to what extent the Social Story used contributed to the positive behavioural change which followed the intervention.

Social Stories appear to be a technique that could be easily adapted for work with a broad range of pupils, in a variety of settings. In most of the published studies participants are of a young age (Alevra, 2004). Chalk (2003) conducted the only study where a Social Story was presented to an adult with a diagnosis of an ASD and learning difficulties. However, there does not seem to appear a particular reason why this intervention would not be appropriate for adults with an ASD as far as the needs, the abilities and the general developmental level of each particular individual are taken into account.

Social stories were also implemented in a variety of settings. Some of them were conducted in a school setting (Swaggart et al 1995, Kuttler et al 1998, Rowe 1999, Bledsoe et al. 2003, Kuoch & Mirenda 2003, Barry & Burlew 2004), whereas others in a home environment, such as the one implemented by Alevra (2004) with an adolescent with autism and moderate learning difficulties.

Social Stories are written from the perspective of the child when describing the social rules, and not from the perspective of a non-autistic person (Attwood 1998, Smith 2003; Bogdashina 2003). Another element which can result in them being effective is that they are tailored made to each person with an ASD by incorporating his or her interests (Gray 1995, Smith 2003); in this way they may become particularly motivating. What is more, parents with appropriate guidance can implement this method themselves, at least if help has been provided to them during the creation of the Social Story material (script, drawings) or until they become more confident using this method entirely on their own. Social Stories can also be presented in a computer-based format, which often seems to be particularly appealing for an individual with an ASD (Jordan, 1995). In this case perhaps the child may also be facilitated by slow dynamic presentation of images, as Gepner et al. (2001) argue that this enhances facial expression recognition by children with an ASD, an ability which needs to be developed by them (Attwood,1998).

A possible weakness in using social stories in each case of challenging behaviour is in being able to identify its exact cause, in order to create the most relevant and effective Social Story, especially in settings where adults may not be given enough opportunities to develop a close relationship with the individual with ASD

Computer based programmes for communication and face and and emotion recognition

Social Stories can also be presented in a computer-based format, which often seems to be particularly appealing for an individual with ASD (Jordan, 1995), and computer based techniques (Heimann, Nelson & Tjus, 1995; Hetzroni & Tannous, 2004) report positive results in communication, and in recognition of emotions (Silver & Noakes, 2001). Further evaluative studies of such approaches are needed.

- **Sensory and Motor approaches**

It is recognised that people with autism can have sensory and perceptual sensitivities, unusual motor behaviours and altered sensory processing abilities (e.g. Bogdashina, 2003). Baranek (2002) presents a review of the efficacy of sensory and motor interventions for children with autism. She reviews studies across a range of interventions including visual therapies, Sensory Integration Therapies, sensory stimulation techniques, Auditory Integration Training (AIT), sensorimotor handling techniques, and concludes that the evidence is either inadequate or does not indicate effectiveness for such sensory and motor interventions. In one study (Mudford et al., 2000) of auditory integration training the results for the control group were better than for the intervention group.

Sinha, Silove, Wheeler and Williams (2004) examined evidence for the effectiveness of AIT or other methods of sound therapy in individuals with ASD. They found that no trials assessing sound therapies other than AIT met their criteria, and that these trials still contained methodological shortcomings. Of these, three trials did not demonstrate benefits of AIT over control conditions, and three did report improvement using an outcome measurement the validity of which the authors question. They conclude that more research is needed in this area.

The Higashi 'Daily Life Therapy" approach (Kitahara, 1983) emphasises strenuous exercise programmes as part of a holistic approach. This approach has not has systematic evaluation.

- **Biomedical approaches**

A number of biomedical approaches have been used to address particular symptoms or co-morbid disorders in individuals with autism. Roberts (2004) lists a number of medications for which some effectiveness has been demonstrated, such as Selective Seritonin Reuptake Inhibitors (SSRIs), and also lists a number of medications found to be ineffective or harmful for children and adolescents on the autism spectrum. Chez, Memon and Hung (2004) report that 'future research into rational medical treatment options is desperately needed' (p.229).

In a study of the efficacy of gluten- and/or casein- free diets as an intervention to improve behaviour, cognitive and social functioning in individuals with autism, Millward, Ferriter, Calver and Connell-Jones (2004) found that only one published trial met the inclusion criteria, with no effect being shown for outcomes for cognitive skills, linguistic ability and motor ability, but with a significant beneficial treatment effect reported for the outcome of 'reduction in autistic traits'. The authors conclude that good quality randomised control trials are needed.

Nye and Brice (2002) conducted a review to determine the efficacy of vitamin B6 and magnesium (B6-Mg) for treating social, communication and behavioural responses of children and adults with autism. They concluded that no recommendation could be advanced regarding the use of B6-Mg as a treatment for autism because of the small number of studies, the small sample sizes, and the methodological quality of studies.

SECTION 3
Appraisal

Appraisal

Drawing together the evidence presented in Section 2, it can be seen that definitive evidence of the effectiveness of any given approach, and the contrastive effectiveness of one approach compared to another remains elusive. This has to do with the adequacy of the methodologies used to evaluate approaches, which show, on the whole, a lack of a suitably large number of participants, and the lack of adequate controls and control groups (see Appendix 2 for summary table). Follow-up measures of sustainment, endurance and generalisation of outcome results for the participants are rarely included. This, however, reflects realistic factors in the area under study. As drawn out in the section on social interaction groups, Randomised Control Trials (RCTs), which are considered to provide the best evidence of effectiveness of interventions, present particular challenges in this area (Mesibov, 1997, Drew et al, 2002). As noted, in some fields of practice the use of RCTs has been challenged, particularly in terms of types of participant or where the information produced has had limited generalisability to practice. RCTs may also fail to take account of the role of qualitative research, which for many engaged in day-to-day interventions with people with ASD provides essential research and practice information.

A further methodological difficulty lies in the inconsistent use of terms in different studies, such as 'joint attention' and the lack of standardised outcome measurement systems, which would allow comparison of results across studies.

Nevertheless, studies within most approaches offer some evidence of positive and useful intervention results (although the evidence was not supportive of effectiveness in the area of, for example, auditory integration therapy). The extent to which improvements can be attributed to the particular intervention is unknown: it is possible that any approach that focuses on social understanding will offer some success. Many other variables may be influencing outcome simultaneously with the specific approach/intervention. Recent models of intervention, such as the SCERTS model of Wetherby and Prizant (2000) combine elements from various approaches to support the child and the child's family. Jordan (2004) advocates an eclectic approach to supporting a person with autism.

An important theme emerging across the different intervention approaches is the use of playful settings providing opportunities for shared interpersonal regulation of activities for the child with autism. This was evident not only in the developmental interactive approaches, but also in the contemporary behavioural approaches, where periods for play are interspersed with training periods. This helps to reduce dependence on external structures, and promotes generalisability of developing skills and understanding, and also can provide the interpersonally significant basis, which in typical development, enables role- play and symbolic and imaginative activity to develop.

Related to this is the increasing use of peer mediated supports and social groups, which seem to play a strong role in reducing social isolation and facilitating inclusion. Importantly, benefits are reported for all participants, and this type of intervention directly addresses the core difficulties of social relatedness and social understanding which impact so forcibly upon friendships and relationships and the inclusion of a person with autism within the social community.

Nevertheless, opportunities to learn and be specifically taught about social rules and meanings will also help to the child to interact socially and make sense of the world, and the socio-constructive techniques reviewed offer ways in which this can be tackled. Reduction in behaviour difficulties was reported to emerge from a number of studies across a range of approaches, which addressed the underlying cause or trigger for the behaviour or the function of the behaviour and responded by environmental adaptations to reduce pressure or by empowering an alternative behaviour and communicative ability.

The issue of time intensity of an approach remains to be addressed in evaluation studies. The emergence of an eclectic model of provision and the increasing emphasis on naturalistic play opportunities and peer support and group involvement, would suggest that intervention approaches which involve the child in prolonged periods of training, or long periods of interaction with only a trained adult, may preclude involvement of the child in other effective forms of support.

Many of the intervention approaches reviewed are formulated to promote fundamental social and communicative abilities and reduce and alter the consequential impact of not having these: the need for early intervention to meet the needs of a child when these are initially recognized is apparent. The involvement of parents has emerged as a crucial element in intervention approaches and the need for support for parents and family is emphasized. What is known about autism endorses the need to intervene early and consistently with a pronounced focus on the generalisation of skills into understanding from the outset. A prolonged gap between identification and support can drive families to expensive and unproven alternatives: all children should have access to appropriate support from the time of parents' first concerns.

There is no evidence that any specific approach brings greater benefit across the spectrum, nor that any sub-group benefits from any particular intervention. In broad terms the degree of autism determines the amount of structure needed by any individual. In a climate of social inclusion this is one of society's most vulnerable groups, and the emotional well-being of individuals with autism should be a main focus for all interventions.

The volume of writing about interventions and approaches shows that many of them are widely used, but, in this area, little on actual practice finds its way to the published literature, and a survey of actual use in Scotland would be needed to ascertain local extent of use.

Summary

In summary, in reviewing the evidence of effectiveness of approaches and the adequacy of evaluation studies the following key points have emerged:

- methodological difficulties within studies mean that definitive evidence of the effectiveness of any given approach, and the contrastive effectiveness of one approach compared to another is not available;
- most approaches offer some evidence of positive and useful intervention results, and eclectic model to supporting a person with autism has emerged;
- a playful context has emerged as a widely used setting for supportive intervention;
- the use of peer mediated supports and social group contexts is increasing;
- environmental structure and socio-constructive teaching techniques tailored to the individual are an important component in support;
- intervention approaches which involve the child in prolonged periods of training, or long periods of interaction with only a trained adult, may preclude involvement of the child in other effective forms of support;
- the need for early intervention to meet the needs of a child when these are initially recognized is apparent, and
- the involvement of parents has emerged as a crucial element in intervention approaches: the need for support for parents and family is emphasized.

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Appendices

Appendix 1.

Example of **sub – table** used for each approach

<div align="center">PECS</div>

Paper reference Information source	**Charlop-Christy MH, Carpenter M, Le L, LeBlanc LA, Kellet K (2002). Using the picture exchange communication system (PECS) with children with autism: Assessment of PECS acquisition, speech, social-communicative behaviour, and problem behavior.** **Journal of Applied Behavior Analysis**, 35(3): 213-231.
Abstract/summary	studied the acquisition of PECS skills in three children with autism who had either nonexistent or severely limited communication ability. In addition, the study examined the effects of PECS training on the emergence of speech in play and academic settings.
Author's appraisal of the approach in general, or previous work	Despite its common clinical use, no well-controlled empirical investigations have been conducted to test the effectiveness of PECS.
Sample:	
number	3
age	children
gender	
diagnosis	autism
Particular feature	nonexistent or severely limited communication ability
Setting of intervention	
Method/design	multiple baseline design
findings	communication skills improved, including the use of verbal communication, as did social interactions among children taught PECS. Problem behaviour decreased. all 3 children met the learning criterion for PECS
Paper author's appraisal	Problem behaviour decreased, apparently as frustration with the inability to communicate declined' Further study is needed to determine if this latter result was due to PECS or to naturally occurring developmental changes (e.g., maturation).
Other's published appraisal	Further study is needed to determine if this latter result was due to PECS or to naturally occurring developmental changes (e.g., maturation).
NCAS appraisal	

Appendix 2

Summary Table - Effectiveness and Appraisal of approach types in relation to teaching children with autism.

Approach/intervention area	Evidence of effectiveness	Possible strengths	Possible drawbacks
Structured educational environment	Studies tend to be uncontrolled or of confounding design, but positive outcomes are reported	Lifelong adaptations Individualized programming Visual aids and routines aid independence and Reduce stress	Dependence on external structure Lack of social/group learning experience
Behavioural	Methodological difficulties with studies.

Results report positive outcomes | Certain response behaviours can be trained and functioning improved | Response behaviour does not indicate understanding

Not clear what component of intervention is active

Time intensity may preclude involvement in other effective interventions

Long-term benefits uncertain |
| **PECS** | Studies tend to be uncontrolled or with small numbers and not randomized participants | Can provide an alternative means of expressive communication and promote communicative initiating behaviour | Requires consistency and structured contexts which may be difficult to achieve and may preclude spontaneous and playful interactions |

Approach/intervention area	Evidence of effectiveness	Possible strengths	Possible drawbacks
			Effectiveness may plateau
Developmental /interactive approaches	Studies tend to be uncontrolled or with small numbers and not randomized participants Very positive results reported	Directly address child's motivation to engage and be involved socially Developing self and relationships Can promote symbolic and imaginative abilities Parents can use spontaneous opportunities Based on fundamental processes of typical development Does not have to be time intensive	May involve a lack of structure May need targeted goals
Music therapy	Studies tend to be uncontrolled or with small numbers and not randomized participants Positive results reported	Can encourage interpersonal connnectedness and processes of communication without speech or content	Not always shared regulation of activity
Parental programmes	Limited forms of evaluative evidence Positive perceptions reported	Informing and empowering parents	May be time limited

Approach/intervention area	Evidence of effectiveness	Possible strengths	Possible drawbacks
Peer mediated interventions	Studies tend to be uncontrolled or with small numbers and not randomized participants Positive results reported	Addressing social integration. Can aid generalization of abilities Can promote friendships Can promote symbolic and imaginative abilities	Peers may require training Peer input may vary
Social interaction groups	Studies tend to be uncontrolled or with small numbers and not randomized participants Positive results reported	Can increase socio-emotional understanding, social competence communication and friendships can aid generalization of abilities	Need to avoid teaching 'splinter skills' in isolation
Socio-constructive/cognitive approaches	Studies tend to be uncontrolled or with small numbers and not randomized participants Positive results reported	Can help with problem solving, emotional understanding, understanding meanings and social interaction. Can teach about feelings and intentions and help to guide behaviour Individually targeted	Requires identifying the particular cause of a difficulty in context May require many versions made of a social story
Sensory and motor	Studies tend to be uncontrolled or with small	May improve aspects of functioning in	Can be time consuming to no effect

Approach/intervention area	Evidence of effectiveness	Possible strengths	Possible drawbacks
	numbers and not randomized participants Some results showed no positive effect of AIT	some individuals	AIT reported to have adverse effect in certain individuals
Biomedical	Studies tend to be uncontrolled, with small numbers and not randomized participants Mixed results reported	May improve aspects of functioning in some individuals	Some medications could be harmful Further research is needed

Appendix 3

The following tables are provided to show key themes and methodologies for intervention in social interaction and understanding in ASD. (Knott, F. & Dunlop, A-W. (2005) Developing Social Interaction and Understanding Pack, 2nd edition.)

Table 1: Shared themes in published reports and resources

Paper / resource	Emotional understanding	Conversation	Friendship
Mesibov (1984)	Understanding and expression,	Greetings, meeting others, topic choice & maintenance, questions	Humour
Williams (1989)	Posture, facial expression, non-verbal signals	Greetings, maintaining and finishing a conversation	
Hutchins (1991)		Proximity, saying how you feel, conversations	Dealing with emergencies, assertiveness
Kamps (et al, 1992)		Initiating, responding, greetings, topics,	Giving and accepting compliments, taking turns, sharing, asking for help, including others in activities
Rinaldi (1992)	Feelings	Eye contact, listening, turn taking, rate. volume	Self other awareness, friendship strategies, negotiating, compromising, saying no
Ozonoff & Miller (1995)	Read, interpret, express non-verbal signals,	Beginning, maintaining and ending, topic choice, listening	Sharing and negotiation, compliments, expressing interest in others
Spence (1995)	Identification of feelings	Basic skills include posture, facial expression, conversation, listening	Friendship skills (eg sharing), social problem solving, dealing with conflicts
Freeman & Dake (1996)	Emotions eg finding out about others feelings	Look, listen, comment, question, reciprocal comments	Problem solving, daily requirements (eg ordering food)
Kelly (1996)		Body language (eye	Skills such as

Paper / resource	Emotional understanding	Conversation	Friendship
		contact, distance, touch, volume, clarity), conversation (defining good and bad conversation, conversation openers, turn taking)	assertiveness, compliments
Aarons & Gittens (1998)	Awarenss of others, feelings	Attending, turn taking, looking, listening	Social understanding
Firth & Venkatesh (1999)		Eye contact, giving and listening to instructions, interpreting verbal and non-verbal communication, awareness of conversational rules,	Finding out about others
Barratt (2000)		Sharing attention, understand facial expression, starting and finishing talking, maintaining topic	
Broderick (et al 2000)		Eye contact, posture, expressing and recognising non-verbal signals, rescue comments	Conflict resolution,
Bauminger (2002)	Affective education (simple emotions and their rules, identifying emotion in self and others)		Concept of friendship, social interpersonal problem solving, (eg comforting a friend)
Baker (2004)	Emotion management	Non verbal skills such as voice tone, greetings, maintaining conversation	Friendship skills

Table 2: Shared methodologies for intervention in social interaction and understanding in ASD.

Paper or resource	Games	Modelling	Role play	*Miscellaneous*
Mesibov (1984)		√ with feedback	√	
Williams (1989)	√	√	√	
Hutchins (1991)			√ with video	Practical activities
Rinaldi (1992)	√	√	√	Stories
Ozonoff & Miller (1995)	√	√	√	Discussion to reinforce importance of skill
Spence (1995)	√	√	√ with feedback	Social problem solving, home tasks
Freeman & Dake (1996)			Drills – oral and written practice sheets	Self monitor by practising after session
Aarons & Gittens (1998)	√		√	Snack, table top activities, news time, discussion
Firth & Venkatash (1999)	√		√	Discussion, TV
McKay & Anderson (2000)		√	√	Discussion
Robins & Hall (2003)		√	√	Clips from Soaps, discussion, matching tasks

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