

Autistic Spectrum Disorders | **Good Practice Guidance**

01 Guidance on Autistic Spectrum Disorders

Contents

Section one

Introduction	4
About this guidance	4
How to use this guidance	4
Further Information	5

Section two

What are ASDs?	6
How does an ASD affect the individual?	6
The core areas affected in ASDs	6
What are the strengths of children with an ASD?	7
What are the intellectual abilities of children with ASDs?	8
When are children with an ASD usually diagnosed?	8
What type of information might be collected when it is thought that a child might have an ASD?	10
Is the diagnosis important?	11
Prevalence: How common are ASDs?	11
What are the causes of ASDs?	12
Are ASDs caused by illness or damage to the brain?	12
Do children grow out of ASDs?	13
Does medication help?	13
Can children with an ASD benefit by following a special diet?	13

Section three

Educational provision for children with ASDs	14
What type of educational placement might an LEA support for children with an ASD?	14
Which principles are important in practice?	15
Knowledge and understanding of autistic spectrum disorders	15
Early identification and intervention	16
Policy and planning	16
Family support and partnership	16
Involvement of children	17
Co-operation with other agencies	17
Clear Goals	18
Monitoring, evaluation and research	18
Appendices	
Glossary	19
Appendix 1	
Publications on current educational interventions	21
Appendix 2	
Publications which give guidance on the educational needs of children with an ASD	22
Appendix 3	
Useful Addresses	25
Appendix 4	
The Autism Working Group	27

Ministerial foreword



Catherine Ashton



Jacqui Smith

Autistic Spectrum Disorders (ASDs) are complex. As more people have been diagnosed with an autistic spectrum disorder over recent years there has been a growing awareness of the challenges of meeting individuals' needs and making provision for the increasing population as a whole. The Government is determined to see improvements in the understanding of autistic spectrum disorders and in the provision that is made for children and adults with the condition and their families. The nature of autistic spectrum disorders calls for different agencies to work together to ensure that needs are properly addressed. On a broader front, co-operation between all those with an interest helps us to develop national policy in a way which promotes improvements in provision for those with autistic spectrum disorders.

During childhood it is the education service which makes the most sustained intervention for children with autism. This guidance, therefore, concentrates on educational provision, while still taking account of the important role of other agencies. Early identification and early intervention to meet a child's special educational needs – whether in mainstream, special, autism-specialist or home settings – is crucial to helping the child realise potential and lead a productive adult life. This guidance is in line with the principles set out in 'Together from the Start', the draft guidance from the Children with Disabilities (Birth to 2) Working Party, which is currently out for consultation.

In many areas of the country good provision is already being made for children identified with autistic spectrum disorders but, nationally, there is still room for improvement. The Autism Working Group was established in recognition of the part central government has to play in helping meet the challenges of making provision for this group of children. The Group has brought our two Departments together with parent support organisations, practitioners, government agencies, local education authorities and researchers to collect examples of good practice and produce guidance based on that good practice and the expertise within the Group.

Meeting the diversity of needs of children within the autistic spectrum requires a diversity of provision, based on sound common principles. We believe that this is already happening in many areas. We are confident that this Guidance will provide an impetus to raising awareness and the standards of support for children with ASDs and we commend it to you.

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Introduction

This section provides information on using this guidance.

About this guidance

- 1.1 The guidance in this booklet is intended to give practical help to those who make provision for children¹ with autistic spectrum disorders (ASDs). It is based on and aims to spread more widely some of the excellent practice occurring across the country. It also aims to help those who are already demonstrating good practice principles to monitor and reflect on their practice with a view to securing continuous improvements. The principles of multi-agency support to meet the assessed needs of disabled children and their families do of course equally apply to many other children with special needs and disabilities. It is important that all families with disabled children receive help and support when it is needed.
- 1.2 Following identification and/or diagnosis and a more detailed assessment of special needs, most active intervention for children with an ASD is provided by the education service. This guidance is therefore largely directed at schools, education outreach and support services and LEAs, voluntary, independent and early years education providers. It gives advice on organising and delivering educational provision for children with an ASD. However, health and social services have an important, interactive role to play in co-ordinating provision

with education services to ensure that children with an ASD and their families receive the multi-agency response to their needs which is most beneficial for them. This guidance gives advice on creating strong links between these services. In addition, since parents² play a critical role in their children's education, it will also be of interest to them.

How to use this guidance

- 1.3 The guidance is organised in two parts. The first part – sections 1-3 – offers an introduction for teachers and others to the nature of autistic spectrum disorders and the range of educational interventions used to support children with ASDs. It sets out the principles underlying effective provision for these children. It is intended to be read as a whole. The second part of the guidance offers a set of pointers to good practice covering aspects of educational provision for children with ASDs. It is not intended to be read as a whole but to be used by service providers as an audit tool to review and evaluate their practice and select particular aspects for development, according to their own needs and priorities.
- 1.4 The guidance sets out principles of good practice in the field of ASDs. An expanded version, available on-line at www.dfes.gov.uk/sen, illustrates the pointers with examples of good practice from around the country. The pointers are drawn from the examples of good practice and from wide consultation

with parents, practitioners and specialists in the field. Good practice evolves as we learn more about ASDs and interventions to meet needs. The on-line version is a 'live' version. It allows you to give your views on the guidance and allows providers the opportunity to send in further examples of the pointers in practice. It enables us to keep the guidance under review and share up-to-date examples of developing practice. The illustrations of the different pointers on the on-line version are examples only. There are many other providers who demonstrate good practice principles or are devising their own solutions or strategies for meeting children's needs successfully.

- 1.5 The pointers, taken together, may look very challenging. The Autism Working Group³ would not expect any individual school, local education authority or regional grouping of service providers to reflect in their practice all of the pointers that are relevant to them. The provision aspired to by these pointers collectively is something to work towards over a period of time from the resources available. Providers whose practice is not identical to that in this guidance should not be seen as failing to make good provision. Practice will inevitably vary. The most important consideration for each provider is that individual children's needs should be met.

Further information

- 1.6 This guidance is not intended to be a text on different approaches or interventions for children with an ASD, or comment extensively on medical debates. There are many publications on these topics. A select bibliography is given at Appendix 1.
- 1.7 Information contained in this guidance is Crown copyright. Extracts from this document may be reproduced for non-commercial education or training purposes on condition that the source is acknowledged.
- 1.8 Throughout this guidance, the term autistic spectrum disorders (ASDs) will be used to describe all children and young people with the triad of impairments⁴. Autistic spectrum disorders will include individuals who have a diagnosis of: autism, autistic disorder, Kanner's or classical autism, childhood disintegrative disorder, Asperger's syndrome, pervasive developmental disorder (PDD), pervasive developmental disorder not otherwise specified, and semantic pragmatic disorder⁵. See the Glossary for an explanation of these terms and others related to autistic spectrum disorders.

¹ In this guidance 'children' refers to children and young people.

² In this guidance 'parents' refers to parents and carers.

³ The membership of the Group is listed at Appendix 4.

⁴ See Chapter 2 for further information on ASDs.

⁵ See World Health Organisation (1992), ICD-10 Classification of Mental and Behavioural Disorders for clinical definitions, apart from semantic pragmatic disorder.

What are ASDs?

This section provides a brief introduction to autistic spectrum disorders.

How does an ASD affect the individual?

2.1 Autistic spectrum disorder is a relatively new term to denote the fact that there are a number of subgroups within the spectrum of autism. There are differences between the subgroups and further work is required on defining the criteria, but all children with an ASD share a triad of impairments⁶ in their ability to:

- understand and use non-verbal and verbal communication
- understand social behaviour which affects their ability to interact with children and adults
- think and behave flexibly – which may be shown in restricted, obsessional or repetitive activities.

2.2 Some children with an ASD have a different perception of sounds, sights, smell, touch and taste, which affects their response to these sensations. They may also have unusual sleep and behaviour patterns and behavioural problems. Children of all levels of ability can have an ASD and it can co-occur with other disorders (for example, with sensory loss or Down's syndrome).

2.3 Some commentators on ASDs have moved away from a deficit model to viewing people with an ASD as having a different perspective and experience of the world. This view redirects the focus away from trying to change the child with an ASD. It encourages people to value the child's abilities and

the child to develop their interests and activities. Professionals and parents are encouraged to see situations from the child's point of view. However, this requires a balanced and empathetic approach. It may be necessary to adopt specific strategies in relation to particular areas of difficulty in order to assist a child to maximise their potential and preserve their dignity: from toilet training for a child who is profoundly affected to supported social skills guidance for a child who wishes to engage with his or her peers.

The core areas affected in ASDs

2.4 There are several core areas affected in ASDs:

Non-verbal and verbal communication

Children and young people with an ASD have difficulty in understanding the communication and language of others and also in developing effective communication themselves. Many are delayed in learning to speak and some do not develop speech. Many children with speech have difficulties in using this to communicate effectively. It is likely that they will need to be taught the purpose of communication, a means to communicate (using pictures, photos, gestures, spoken or written words) and how to communicate.

Social understanding and social behaviour

A key characteristic of those with an ASD is their difficulty in understanding the social behaviour of others and in behaving in socially appropriate ways.

Other children develop this understanding without being explicitly taught and do so fairly easily. Children with ASDs are very literal thinkers and interpreters of language, failing to understand its social context. For the child with an ASD, other people's opinions may have little or no influence on their behaviour and the child may say and do exactly as they want. Children with an ASD often find it hard to play and communicate effectively with other children who may be confused by their behaviour and may avoid or tease them. Adults who do not know the child or know about autism, may misunderstand the child's behaviour and view it as naughty, difficult or lazy, when in fact, the child did not understand the situation or task or did not read the adult's intentions or mood correctly.

Thinking and behaving flexibly according to the situation

Children with an ASD often do not play with toys in a conventional way, but instead spin or flap objects or watch moving parts of toys or machinery for long periods and with intense concentration. Their play tends to be isolated or alongside others rather than with others. Some children develop a special interest in a topic or activity which may be followed to extreme lengths. Any new skills tend to be tied to the situation in which they were taught which means that children with an ASD will need specific help to generalise skills. They will also have difficulty adapting to new situations and often prefer routine to change.

Sensory perception and responses

From accounts of adults with an ASD, it is evident that some children are over-sensitive or 'under-sensitive' to certain sounds, sights and textures. This has implications for the child's home and school environment and may explain their response to changing clothes or food and their response to noise. In addition, the child may not make appropriate eye contact, looking too briefly or staring at others. In the past, there has been a focus on teaching the child to look when communicating but it may be that some children are unable to talk and look at the person at the same time.

What are the strengths of children with an ASD?

2.5 All children with an ASD are individuals and their areas of strength will vary. Many children with an ASD will have an ability to focus on detail and they may be able to concentrate for long periods on a single activity, if it is of interest to them. They can give their sole attention to a task and therefore can often achieve a high level of skill, or work on tasks way beyond the point at which others would tire of them. Those with an ASD are generally able to process visual information better than that given orally. Children who are more able often succeed in academic areas that do not require high degrees of social understanding and where the language used is technical or mathematical (for example, science, engineering, music and information technology).

¹ 6 See Wing, L (1996) *The Autistic Spectrum: A guide for Parents and Professionals*. London. Constable.

What are the intellectual abilities of children with ASDs?

2.6 Paragraph 1.8 listed many of the different diagnoses which are encompassed within the term 'autistic spectrum disorders' and referred readers to the Glossary. Children within the spectrum display a range of needs and a range of intellectual abilities. Many children with ASDs also have severe learning difficulties and multiple and complex needs. Other children within the spectrum have a higher level of ability. Asperger's syndrome is generally used to describe those with autism who are of average or above average ability and have good spoken language, even though the ability to use this for communication is still affected. The term 'high-functioning' autism has also been given to this group of individuals. Some professionals argue that there are important differences between those with Asperger's syndrome and those who are termed high-functioning, in that the former are also likely to be clumsy, more sociable and more likely to have special interests and the latter to have been delayed in developing speech and language. Others argue that there is no difference between the two terms and that they can be used interchangeably.

When are children with an ASD usually diagnosed?

2.7 The majority of children with an ASD will have shown signs of the condition during the first three years of life but their needs may not be identified within this period. It is possible to recognise and diagnose an ASD by the age of 18 months but, in practice, the diagnosis

is rarely made until after the age of 24 months and the average age is 5 years⁷. For children whose speech and academic skills develop at the usual age or who are in advance of their peers in some areas (for example, maths, reading accuracy and memory for facts), the ASD may not be recognised and so the diagnosis may not be made until after the child begins compulsory schooling. In some cases, children are not diagnosed or recognised as having an ASD until after many years in education. There are many adults who may have an ASD which is not recognised or who were only diagnosed as having an ASD in adulthood. Having a diagnosis as early as possible benefits people with ASDs as it helps to focus the interventions and support they receive.

- 2.8 The kind of behaviours professionals look for in diagnosing an ASD are:
- delay or absence of spoken language (but not true for all children with ASD), including loss of early acquired language
 - unusual uses of language – pronoun reversal (for example, saying 'you' instead of 'I'); prolonged echolalia (that is, repeating others' words beyond the usual age); 'playing' with sounds
 - difficulties in playing with other children
 - inappropriate eye contact with others
 - unusual play activities and interests
 - communicating wants by taking an adult's hand and leading to the desired object or activity
 - failure to point out objects/third parties with the index finger when sharing communication

- failure to share in the interests or play of others
- unusual response to certain sounds, sights and textures
- resistance to changes in familiar routines
- repetitive actions or questions
- a preference for following their own agenda.

2.9 There is, however, no conclusive diagnostic test and it is quite common for professionals to disagree over the diagnosis given to a particular child, which can add to the parents' distress. In practice, paediatricians, psychiatrists, speech and language therapists, clinical or educational psychologists, or General Practitioners (GPs) may contribute to a diagnosis of an ASD. Others who see the child and family regularly such as pre-school staff and teachers may already have suspected the child has an ASD and referred them for further assessment. To make a diagnosis, detailed observations are needed of the child at home and in other situations, and it is good practice to take an account from the family of any difficulties with the pregnancy and about the child's early history up to the present day. Other investigations should be made to check whether the child has any additional difficulties (for example, epilepsy, severe learning difficulties, hearing or visual problems, low muscle tone, fine motor difficulties and severe constipation or other bowel problems). Some additional difficulties may not be apparent at the time of diagnosis so there should be a strategy for ongoing assessment with further investigations as necessary.

2.10 Guidelines for screening, identification, assessment and diagnosis of autism are being developed by an independent, non-governmental, multi-disciplinary group of professionals, commissioned by the Royal College of Paediatrics and Child Health and the Royal College of Psychiatry, called the National Initiative for Autism: Screening and Assessment (NIASA). The group is publishing guidelines for health, education and social services on identification, assessment, diagnosis and access to early interventions for pre-school and school age children with an ASD.

2.11 NIASA's report will make a large number of recommendations to service providers. Its key general principles underlying a service for children with ASDs will be adapted from ones which were published as part of the work of the West Midlands SEN Regional Partnership which concentrated on identification, training and provision for children with ASDs and their families. They were as follows:

- any proposed code of good practice/protocol needs an environment that accepts and understands autism. It requires that the awareness of autistic spectrum disorders continues to increase across everyone professionally involved with children/ young people with autistic spectrum disorders
- specialist professional training in autistic spectrum disorders for staff involved in the identification of ASDs should take place both during qualification and post qualification and should build on an understanding

of the breadth of the spectrum needs to be achieved

- active family involvement is essential – there needs to be high-quality, accurate information for families, which begins as soon as difficulties are recognised. Provision of information should be seen as a two-way process. It is important that families are listened to and their views and the information they provide, is seen as central to the identification/diagnostic process. Support should begin, and should continue throughout the assessment process
- communication and co-ordination of all services is vital. Ideally there should be a single referral point to identification and assessment services. All parties involved should know who the key personnel are and the pathways to referral
- there should be an identified multi-disciplinary/multi-agency team of professionals with specialist skills to whom open referral is possible. Teams should be available to assess individuals across the age range. More than one team may operate in the same area depending on the age of the individual being assessed
- early response to concerns should enable early identification of need and timely intervention
- identification of needs should lead to a consensus regarding the terminology used to describe these needs. There should be an ownership of the diagnosis and procedures by all concerned.

What type of information might be collected when it is thought that a child might have an ASD?

- 2.12 Information could be collected under the three main areas affected in ASDs – communication, social skills and understanding and flexibility of thought and behaviour. Parents are a key source of information, and with their consent, other information can be obtained from:
- past reports on the child
 - discussions with professionals who know the child
 - analysis of the child's work and response to tasks
 - asking the child for their views, where appropriate
 - observing the child in different situations and while playing and interacting with others.
- 2.13 Observing the child in different situations, particularly during interactions with others, is extremely useful. These situations can include working at a task on their own, with a partner, in a small group, interacting with an adult with and without materials, and playing indoors and outdoors.
- 2.14 Staff within an early education or school setting can collect this information and discuss it with the early education setting's or school's Special Educational Needs Co-ordinator (SENCO). The SENCO can talk to the parents and visiting professionals such as the Speech and Language Therapist (SLT), the Educational Psychologist (EP) or, where available, the school doctor. Decisions can be made as to whether further assessment and action is required.

Is the diagnosis important?

- 2.15 Having a diagnosis can help to focus and inform the support that is given to the child. It has the potential to help the child and the family in a number of important ways. It gives access to the relevant literature, to other parents and professionals and the opportunity to investigate useful forms of support. Knowing the underlying reasons for the child's behaviour is very important in helping parents and professionals to devise strategies to help the child, rather than merely reacting to and speculating on the causes of their behaviour as it occurs. It is important though, that the ASD is seen as just one of the factors involved in influencing the child's behaviour. Other factors include the child's personality, the environment, family characteristics and the child's strengths and interests. It is also common for children with an ASD to have the disorder in combination with other conditions. A diagnosis can point the way to the type of difficulties a child will have but effective support can only be based on identification of the particular profile of the individual child's needs and strengths.

Prevalence: How common are ASDs?

- 2.16 It is difficult to know exactly how many children have an ASD as it is not always easy to identify; indeed, some will never have been diagnosed. ASDs can be masked by other needs. As our knowledge, understanding and awareness increase, more children are

being identified. The Medical Research Council's (MRC) *Review of Autism Research: Epidemiology and Causes* states that "according to recent reviews there appears fairly good agreement that autism spectrum disorders affect approximately 60, and narrowly-defined autism 10-30, per 10,000 children under 8"⁸.

On this basis it can be predicted that the majority of mainstream schools will have one or more children with an ASD.

- 2.17 The All Party Parliamentary Group on Autism's report *The Rising Challenge*⁹ noted that many LEAs responding to the Group's questionnaire reported that they felt there had been an increase in the numbers with an ASD. We cannot, however, be sure that this feeling reflects a 'real' increase. The MRC report states that factors which may give rise to an increase in prevalence over time include "changing diagnostic thresholds, better case ascertainment, survival, population flows and finally changes in the prevalence of causal factors. Methodological differences between studies and changes in diagnostic practice and public and professional awareness are likely causes of apparent increases in prevalence. Whether these factors are sufficient to account for increased numbers of identified individuals or whether there has been a rise in actual numbers affected is as yet unclear...".

⁸ MRC (2001) *Review of Autism Research: Epidemiology and Causes*. London. Medical Research Council. p. 18.

⁹ Loynes, F. (2001) *The Rising Challenge. A survey of Local Education Authorities on educational provision for pupils with autistic spectrum disorders*. Report prepared for the All Party Parliamentary Group on Autism. London. The National Autistic Society.

2.18 ASDs are more common in boys than in girls, particularly at the high ability end of the spectrum. Research by Lorna Wing in 1981¹⁰ found that among people with high-functioning autism or Asperger's syndrome there were up to 15 times as many males as females. For those with severe learning difficulties as well as autism, the ratio of males to females was 2:1. Overall, the Scottish Needs Assessment Programme publication *Autistic Spectrum Disorders Needs Assessment Report* refers to "a generally accepted ratio of 4:1".¹¹

2.19 Children from all cultures and social groups have been diagnosed, although there is much work to be done to improve awareness within the relevant professions of the needs of ethnic minority children and their families. They are under-represented in terms of referrals for diagnosis and attendance at support groups and workshops.

What are the causes of ASDs?

2.20 The MRC Review of Autism Research: *Epidemiology and Causes* gives an authoritative overview of the current state of knowledge of the causes of autism. The MRC report notes that "research over the last half century has established autism as a neurodevelopmental disorder. Early suggestions that ASDs might result from abnormal parenting have been abandoned in the face of overwhelming evidence of a biological basis and a strong genetic component. Most researchers believe that ASDs

have a variety of causes, perhaps all affecting the same brain systems or impeding development through disruption of different abilities necessary for social and communicative development." It is highly likely that a number of different genes are involved but it is not yet known which these are. The MRC report acknowledges that environmental risk factors have been suggested for autism, for example illness during pregnancy, childhood illness and food intolerance. It is often difficult to untangle real causes from events which occur at the same time as the child's difficulties become most apparent. It concludes that: "Whether environmental factors interact with genetic susceptibility is as yet unclear"¹².

Are ASDs caused by illness or damage to the brain?

2.21 Some people have proposed a theory that ASDs may be related to the presence of viruses which persist in the body throughout life. The MRC report notes that at present there is no evidence that such infections cause ASDs. Measles can persist in the body but again the report notes that there is no definitive evidence that it is associated with autism. The MRC report says that current evidence suggests that many people with ASDs may have larger, heavier brains and notes that studies to date have found under-activity in areas associated with planning and control of complex action, and in areas associated with processing socio-emotional information.

Do children grow out of ASDs?

2.22 As children with an ASD grow older, particularly higher functioning children, so their social understanding and use of communication will improve, with appropriate teaching and support. This progress continues throughout their adulthood, so that an adult with an ASD may be much harder to identify than when they were younger. There have been claims that some children have recovered and that their ASD is no longer evident, but long-term studies suggest that the great majority will continue to experience the features associated with an ASD throughout their lives. Some adults live independently, may have a partner and children. Some may be employed, often in jobs which do not involve a high level of social understanding, although even higher functioning adults may still find it more difficult to find and keep jobs. Others may live semi-independently, with support from their own families or services. Many will continue to live with their family or in supported living environments and attend a range of educational, employment and leisure facilities. Children and adults with an ASD are at above average risk of developing mental health problems, especially depression. Individuals who are doing well may find conforming to social norms very stressful and will continue to need support in developing coping strategies.

Does medication help?

2.23 There are some drugs which have been prescribed to those with an ASD, but there is no autism-specific medication available. A number of adults with an ASD have reported benefits in taking anxiety-reducing medication in very small

doses. This can enable them to function in a confusing and anxiety-provoking social world. But, medication can be over-prescribed and misused as a means of controlling behaviour, often with serious short-term and long-term side effects (for example, weight loss or gain, sinus problems, sleep disorder, nausea and tremors), so great caution is needed. Alternative methods of reducing anxiety and managing behaviour should be considered first. Whether medication or alternative methods are used it is important that mental health problems which may first present in adolescence are identified and addressed. Where 'co-morbidities', that is additional medical difficulties, exist (for example, epilepsy which can present as disordered behaviour rather than obvious stereotypic fits) it is important that people with autism have access to diagnosis and any appropriate medication.

Can children with an ASD benefit by following a special diet?

2.24 There has been a considerable amount of interest recently in abnormalities affecting the gastro-intestinal tract. Casein and gluten-free diets have been tried but although there are some reports of improvements, the MRC notes that no properly controlled studies have been described in peer reviewed medical journals to date. Given the potential widespread benefits if any of these reports were to be substantiated, the MRC stresses that it is important that further research should be undertaken. In the meantime it is very important that any decision to alter a child's diet is discussed with medical staff or with a qualified dietician.

¹⁰ Wing, L. (1981) Sex ratios in early childhood autism and related conditions. *Psychiatry Research*, 5, 129-137.

¹¹ PHIS (2001) *Autistic Spectrum Disorders Needs Assessment Report*. Glasgow. Public Health Institute of Scotland.

¹² MRC (2001), p. 21.

Educational provision for children with ASDs

This section sets out some of the educational interventions used for autistic spectrum disorders and the key principles which are important in practice.

- 3.1 Current educational interventions or frameworks and parent training programmes include:
- Applied behavioural analysis (ABA) (including Lovaas and Verbal Behaviour)
 - Child's Talk
 - Circle of friends
 - Daily Life Therapy
 - EarlyBird programme
 - Gentle teaching
 - Hanen (ASD-specific adaptation) programme
 - Intensive interaction
 - Music therapy
 - Musical interaction therapy
 - Option (Son Rise) programme
 - Picture Exchange Communication System (PECS)
 - Portage programme (modified)
 - Speech and language therapy
 - SPELL – Structure, Positive approaches, Empathy, Low arousal and Links
 - Social stories
 - Treatment and Education of Autistic and related Communication handicapped Children (TEACCH)

The above listing should not be taken as an endorsement by the Group of the particular programmes within it. The frameworks and interventions are

also not mutually exclusive. Schools often use a mix and some develop approaches or have a framework which underlies their practice that may not have a particular name.

Relevant literature on most of the above interventions are given in Appendix 1.

What type of educational placement might an LEA support for children with an ASD?

- 3.2 The educational needs of children with an ASD vary considerably depending on their intellectual ability and their profile of strengths and needs. It is not possible without an assessment of the individual child to determine the provision they require. In addition, the policy and practice in how, and in what type of placement, to meet those needs varies between LEAs depending on professional experience, opinion and historical factors.
- 3.3 At present in England, children with an ASD might attend an ordinary mainstream school or a special unit or school for children with learning difficulties or an autism-specialist school. A minority of children may attend residential schools offering a consistent programme both during and after normal school hours. Some children with an ASD are educated at home for a variety of reasons. The majority of children with an ASD will be recognised within a mainstream school as having additional or different needs from their peer group and will have an Individual Education Plan or individual

targets and interventions planned as part of the class or school curriculum. Some may require more support than is usually provided from within a mainstream school's or early education setting's resources and may need a formal assessment, which, where necessary, leads to a Statement of Special Educational Needs, specifying their needs and the provision to meet them. Children whose needs are identified before statutory school age may receive a statement to support early intervention, either in specialist or mainstream settings, or in the home.

- 3.4 Staff within all types of school and early education settings where children with an ASD are educated will need to understand the implications of ASDs for teaching and learning and should look to modify the environment and how the curriculum is planned and taught to enable the placement to succeed. There are aspects of pre-school and school education and the curriculum which require special attention, whatever the type of educational placement and whatever the nature of a child's difficulties. If staff are not aware of the ways a child is affected, then the child might be seen as naughty, lazy or non-compliant.
- 3.5 A number of books have been written on how to meet the educational needs of children with an ASD with learning difficulties and the needs of able children with an ASD. Details of some of these are given in Appendix 2.

Which principles are important in practice?

3.6 Key principles

There are several key principles that should underpin all aspects of practice when providing for children with an ASD. These can be brought together under the following headings:

Knowledge and understanding of autistic spectrum disorders

As knowledge grows about how children with an ASD think and learn, so the approaches used are constantly modified and developed. People with an ASD will have a unique learning style and we cannot assume their learning takes place in a linear fashion. Without at least a background knowledge of the challenges that having an ASD can create, a child's behaviour can be misinterpreted and their needs will not be met in the most appropriate way. A teacher or early years practitioner will, therefore, need a knowledge of ASDs and how to structure situations to promote learning as well as observational skills and the capacity to motivate and involve. They will also need flexibility and resourcefulness as, although children with ASDs share core deficits, they do not all think and learn in exactly the same way.

All those who plan or provide for children with an ASD should have some knowledge and understanding of autism. LEA staff training programmes help to spread knowledge and understanding of the disorder and should

be open to all relevant staff, not just teachers. LEA audits will need to identify training needs in this area and take appropriate action.

Early identification and intervention

It is important that a child's individual needs are identified as soon as possible so that they can be met in the most appropriate way. Assessment over time may indicate an ASD but early intervention appropriate to a child's identified needs should not be dependent on diagnosis of an ASD. However, a diagnosis may help to guide families and professionals to the most appropriate sources of information and support networks.

Professionals should be aware of the referral pathways to follow when an ASD is suspected. There should always be clear channels of communication between families and professionals.

The draft guidance from the Birth – 2 Working Party *Together from the Start*¹³ aims to provide practical guidance promoting good practice in relation to the delivery of services to very young children with disabilities and their families by a range of professionals.

Central themes of the guidance are:

- the importance of active partnership with parents, and of communicating news of a child's difficulties in a sensitive way
- prompt and co-ordinated assessment of needs, leading to a written Family Service Plan

- the importance of key workers, and
- effective support for parents, in terms of advice and information, practical support and childcare.

Policy and planning

Forward planning at all levels is vital when working with children with an ASD. At the operational level, children will benefit from planned and predictable activities on a day-to-day basis. In the longer term, there should be planning for phase and environment change (for example, from pre-school to school or secondary to further education).

At an LEA/regional/strategic level there should be close liaison with health and social services in order to build up a clear picture of the size of the cohort of children with an ASD in an LEA or region and a clear inter-agency policy on provision for children with an ASD. Whatever the reason for the increasing number of children being identified with ASDs (discussed in paragraph 2.17) planning should include planning to meet expected future demand on services and support networks, and aim for a spectrum of provision for the spectrum of need.

Family support and partnership

The emergence of difficulties associated with an ASD in a child places particular stress on the family in addition to the general challenges associated with being a parent.

Families (including siblings and the extended family) should have their emotional and material needs addressed by professionals who know about ASDs and how to access family support. Asking families what type of support they would value in addition to providing information on existing services is important.

It is essential that families are provided with information about ASDs and that professionals liaise closely with parents so that the home environment supports any intervention in the school or pre-school setting and vice versa. Parents should be given clear advice and information about the special educational needs system and any available services and how to access these if necessary.

Involvement of children

Children with an ASD should be consulted about their education just as other children are. Difficulties with communication may mean that alternative methods of communication need to be sought. Where a child has particular communication difficulties, (for example, if they are non-verbal and have restricted use of augmentative communication systems) then the child's views may need to be mediated through parents, carers and others who know the child well. However, as a principle, self-advocacy must be the goal for all.

Co-operation with other agencies

ASDs are complex and will undoubtedly require the input of different agencies. There should be multi-agency co-operation and intervention which recognises the multiple demands ASDs place on providers. Interagency discussion is crucial and is particularly important at the pre-school stage and at the transition to adult services. For children with an ASD and their families to receive a co-ordinated flexible and seamless service, statutory, voluntary and independent providers need to link and liaise across organisational boundaries.

Professionals in the health services may be the first to hear the parents' concerns (for example, General Practitioner (GP), health visitor and speech and language therapist) and so have a vital role in diagnosis, assessment and intervention. Professionals in social services may be involved in assessing the needs of the family and the child for support and in providing or arranging short term breaks or befrienders for the child. Health and social services may be involved in supporting the funding of a package of provision where a child has particularly complex needs. Where a child has associated gross and fine motor difficulties (involving large and small bodily movements), the child may need access to additional health services such as occupational and physiotherapists and in some cases GPs may be asked to make arrangements for appropriate

¹³ DfES and DH (2002) *Together from the Start – Practical guidance for professionals working with disabled children (birth to 2) and their families*. London, Department for Education and Skills and Department of Health.

referrals and support. Voluntary agencies have several roles including the provision of information, advice and advocacy, through to running nurseries, schools and outreach and out-of-hours services.

Clear goals

Clear short and long-term goals for teaching and learning should be agreed with the children with an ASD, their parents and professionals. The goals should include a clear rationale for practice and challenge children to realise their potential as learners.

Individuals with an ASD should be given the skills to enable them to choose how to live within society, whether that is at the level of teaching them the skills necessary for an independent adult life or at the level of making basic choices and conveying preferences.

Social skills as well as academic skills should be high on the priority list. Some young people with an ASD may leave school well equipped academically but unable to function in the real world through a lack of social skills.

Monitoring, evaluation and research

Continual monitoring and evaluation of provision for children with ASDs, will facilitate better practice. Sharing practice and knowledge of recent research findings will enhance the services provided. Professionals and families need to be willing to adapt in order to meet the changing needs of the child and the situation.

Effective programmes for individual children appear to be characterised by the following:

- a programme with a focus on communication, regardless of the language ability of the child
- a programme which involves social interaction, play, leisure and life skills
- access to the academic curriculum in ways that do not depend on social or communicative skills and takes account of the particular difficulties of children with ASDs in learning how to learn. These may emphasise structure, visual learning and modelling of activities and behaviours
- an approach to managing behaviour which involves assessing the function of a behaviour and teaching an acceptable alternative to achieve the same result.

Glossary

Asperger's Syndrome

Similar to autism except that children with the syndrome have higher intellectual abilities and better language development than the majority of children with a diagnosis of autism. There is theoretical debate over whether Asperger's syndrome is the same as high-functioning autism. The main clinical features of Asperger's syndrome are a lack of empathy and difficulties in understanding the reciprocal nature of conversations and relationships. Individuals can be pedantic with repetitive speech and develop an intense fascination for certain topics. Many also are clumsy and have co-ordination problems and difficulties in attending to more than one aspect of a task simultaneously. Diagnosis is usually later than for children with autism.

Attention Deficit/Hyperactivity Disorder (ADD or ADHD)

Children with the disorder display inattentiveness and impulsiveness and those with the ADHD diagnosis, hyperactivity. There is a strong genetic basis but environmental causes have also been associated with the disorder including brain damage and food intolerances. Treatments include stimulant medication and exclusion diets.

Autism (Classical or Kanner's)

Characterised by the 'triad of impairments' – impairments of non-verbal and verbal communication; social understanding and social behaviour; and thinking and behaving flexibly according to the situation. Onset is before 30 months. 75-80% of children with a diagnosis of autism will also have severe or moderate learning difficulties. Many children also have 'co-morbidities', such as epilepsy or ADHD. A small proportion of children with autism have islets of, sometimes exceptional,

ability in areas like drawing, music and mathematics. This tends to be over-represented in lay literature and films.

Autistic Spectrum Disorder

The term autistic spectrum disorder was suggested by Wing in 1996 to acknowledge that there are different subgroups, and that all individuals within these subgroups share the triad of impairments.

Fragile-X Syndrome

Fragile-X syndrome is the most common cause of inherited learning difficulty, with an incidence of about 1:4500 in males and 1:8000 in females. The name derives from a defect of the X chromosome of affected individuals so the condition is genetically inherited although its expression can be very variable. Learning difficulties range from mild to severe. Affected males tend to show more of the impairments found in ASDs, and be overactive and impulsive. They have language difficulties and poor short-term memory skills.

Obsessive-compulsive Disorder

Obsessive-compulsive disorder is characterised by recurrent obsessional thoughts and compulsive acts. Obsessions are thoughts or images that are involuntary, intrusive, and anxiety-provoking. Compulsions are impulses to perform a variety of stereotyped behaviours or rituals. Clinical symptoms tend to present at certain stages of life; counting and sorting and "evening out" usually start during childhood, "grooming" compulsions usually start at puberty, and obsessions usually begin during adulthood. Some mental disorders may include obsessions and compulsions among their symptomatology but it is inappropriate to diagnose OCD in such cases.

Pervasive Developmental Disorder

Incorporates the whole spectrum of autism and atypical autistic disorders.

Phenylketonuria

An inherited metabolic disorder which affects the normal development of the brain causing learning difficulties. Carefully controlled dietary measures counteract the effects of the disorder. Affected children may show some of the symptoms of autism. PKU has been virtually eliminated in the UK by screening all children immediately after birth so proper dietary measures can be taken.

Rett's Syndrome

A pervasive developmental disorder that occurs only in girls. The girls develop normally for the first year and then development begins to slow with a reduction in head growth. There follows a gradual or sudden regression with deterioration in speech and social withdrawal. The girls develop hand clapping or wringing and many have seizures. Growth retardation, muscle wasting and severe learning difficulties are evident.

Semantic-pragmatic Disorder

This is a term originally coined by Speech and Language Therapists for children who have difficulties in understanding the meaning of language and its social use, which affects their communication. These children also have difficulties with social interaction and imaginative play and have restricted interests. Like those with Asperger's syndrome, children with semantic-pragmatic disorder will have average and above average intelligence. There is debate currently as to whether children with semantic-pragmatic disorder and children with Asperger's syndrome are the same or different sub groups within the autistic spectrum.

Tourette's Syndrome

A condition characterised by multiple tics, including facial and vocal tics. Onset is usually between 5-11 years of age. Some severely affected children involuntarily say obscenities or make obscene gestures. Three to four times as many boys as girls are affected.

Tuberous sclerosis

A genetic disorder, characterised by the development of small benign tumours which may affect many bodily systems and by various skin lesions. Brain function may be affected and epilepsy and behaviours seen in ASDs are common.

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(The interventions covered are given in brackets after the reference.)

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Bondy, A. and Frost, L. (1994) The Delaware autistic program, in SL Harris and JS Handleman (Eds.) *Preschool education programs for children with autism*, Austin: Pro-Ed (PECS and TEACCH)

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Maurice, C. and Green, G. *et al.* (1993) *Behavioural Intervention for Young Children with Autism*, Austin, Texas: Pro-Ed (APPLIED BEHAVIOUR ANALYSIS)

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Shields, J. (2001) The NAS EarlyBird Programme: partnership with parents in early intervention, *Autism*, 5, 1, 49-56 (PARENT TRAINING PROGRAMME)

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A selection of publications which give guidance on the educational needs of children with an ASD

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Jones, G (2002) *Educational provision for children with autism and Asperger syndrome*, London: David Fulton

Jordan, R (2001) *Autism with severe learning difficulties*, London: Souvenir Press

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Early Intervention

DfES and DH (2002) *Together from the Start – Practical guidance for professionals working with disabled children (birth to 2) and their families*. Consultation document available from DfES Publications Centre. Tel. 0845 6022260. Ref. No. 0184/2002. Also available at www.dfes.gov.uk/consultations

Evans, J, Castle, F and Barraclough, S (2001) *Making a difference: early interventions for children with autistic spectrum disorders*. LGA Research Report. Available from Publications Unit, NFER Tel. 01753 747281 Ref. SRO34

Teaching

Seach, D (1998) *Autistic Spectrum Disorder: Positive Approaches for Teaching Children with ASD*. Publications Department NASEN, Tel. 0800 0182998 Ref. ASD or email welcome@nasen.org.uk

QCA (2001) *Planning, teaching and assessing the curriculum for pupils with learning difficulties*. http://www.qca.org.uk/rs/equal_ops/equal_opps.asp

Teaching Assistants

DfES (2001) *Teaching Assistant File: Induction training for teaching assistants in secondary schools*. Available from DfES Publications Centre, Tel: 0845 6022260. Ref. DfES/0601/2001. Also available via http://www.teachernet.gov.uk/Teaching_Assistants_Secondary_TA_File (Contains brief guidance on ASDs and Asperger's syndrome. Primary TA File will do in the future).

The Curriculum, Literacy and Numeracy

ACCAC, Qualifications, Curriculum and Assessment Authority for Wales, (2000) *A Structure for Success: Guidance on the National Curriculum and Autistic Spectrum Disorder*. Available from ACCAC Publications PO Box 2129, Erdington, Birmingham B24 0RD Ref. AC/GM/0091. Website www.accac.org.uk

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Inclusion

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Physical Intervention

British Institute of Learning Disabilities (BILD) (2001) *BILD Code of Practice for Trainers in the Use of Physical Interventions: Learning Disability, Autism, Pupils with special educational needs*. Available on 01562 850 251

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DfES (2001) *Promoting Children's Mental Health within Early Years and School Settings* (Contains a section on Asperger's Syndrome/ Autistic Spectrum Disorders). DfES Publications Tel: 0845 6022260 Ref. 0112/2001

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Teacher Training Agency (2001), *The National SEN Specialist Standards*. Available via <http://www.canteach.gov.uk/info/sen/national.htm>. CD ROM TTA (2002) *SEN: Identify your Training Needs*, which includes the Specialist Standards, is available via publications@ttalit.co.uk

Careers and Post-16

Connexions (2001), *Directory of Career Resources for Special Needs*. Available from the DfES Publications Tel: 0845 6022260 Ref. 814-0

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Bob Budd, *ASD RESKU Pack*. City of Sunderland Careers Service, ESPA, Thornhill Park Schools and Colleges and One North East.

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Learning Disabilities

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Published by The Stationery Office Limited and available from The Stationery Office, PO Box 29, Norwich NR3 1GN. Fax orders 0870 600 5533; Email book.orders@theso.co.uk or via the Internet <http://www.ukstate.com>

General Services

Jordan R, Jones, G and Morgan, H. (2001) *New Guidelines on Services for children with autistic spectrum disorder*. Mental Health Foundation/Foundation for People with Learning Disabilities. Available via 020 7535 7441 or books@mhf.org.uk

Department for Education and Science, Dublin (2001) *Educational Provision and Support for Persons with Autistic Spectrum Disorders: The Report of the Task Force on Autism* (Chairperson Professor Sheelagh Drudy). Available from Government Publications, Postal Trade Section, 51 St. Stephen's Green, Dublin 2, Tel: 01 6476000. Fax 01 6476843. Version without reference list, bibliography etc. is available at www.gov.ie/educ/publications/autism_report

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Medical Research Council (2001) *MRC Review of Autism Research: Epidemiology and Causes*. Available via www.mrc.ac.uk

Diagnosis

APA (1994) *Diagnostic and Statistical Manual of Mental Disorders* (4th edition). Washington, American Psychiatric Association

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Useful addresses**Journals**

Autism (from Sage Publications, 6, Bonhill St., London, EC2A 4PU)

The Autism File (from PO Box 144, Hampton, TW12 2FF)

British Journal of Special Education (from NASEN, 4/5 Amber Business Village, Amber Close, Amington, Tamworth, Staffs, B77 4RP)

Good Autism Practice (from BILD, Campion House, Green Street, Kidderminster, Worcs DY10 1JL 01562 723010)

Journal of Autism and Developmental Disorders (from Plenum Publishing, 233, Spring St., New York, NY 10013 USA)

SLD Experience (from BILD)

Special! (from NASEN)

Special Children (from Questions Publishing, 27, Frederick St, Birmingham B1 3HH)

Support for Learning (from NASEN)

Contacts

Association of Head Teachers of Autistic Children and Adults (AHTACA)
1 Aston Road, Ealing, LONDON W5 2RL
Tel: 020 8998 2700

Autism Cymru
National Office
6 Great Darkgate Street, Aberystwyth,
Caeredigian SY23 1DE
Tel: 01970 625256

Autism Research Unit (NAS)
School of Pharmaceutical and Chemical Sciences
Faculty of Science, University of Sunderland
SUNDERLAND SR2 7EE
(marked: Autism Research Unit)
Tel: 0191 510 8922, Fax: 0191 515 2557

Centre for Social & Communication Disorders (NAS)
Elliot House, 113 Masons Hill
BROMLEY, Kent BR2 9HT
Tel: 020 8466 0098, Fax: 020 8466 0118

Contact a Family (National Centre)
209-211 City Road, London EC1V 1JN
Tel: 020 7608 8700, Fax: 020 7608 8701

Makaton Vocabulary
Makaton Vocabulary Development Project
31 Firwood Drive, CAMBERLEY, Surrey
Tel/fax: 01276 61390

MENCAP
MENCAP National Centre
117-123 Golden Lane, LONDON EC1Y 0RT
Tel: 020 7454 0454, Fax: 020 7608 3254

National Autistic Society (NAS)
393 City Road, LONDON EC1V 1NG
Tel: 020 7833 2299, Fax: 020 7833 9666

National Autistic Society (Wales)
William Knox House, Suite C1, Brittanica Way,
Neath, PORT TALBOT SA10, 6EL
Tel: 01792 815915, Fax: 01792 815911

National Portage Association
127 Monk's Dale, YEOVIL, Somerset BA21 3JE
Tel: 01935 71641

Parents' Autism Campaign for Education (PACE)
1 Floral Place, off Northampton Grove,
LONDON N1 2FS
Tel: 020 7226 5525, Fax: 020 7359 8996

Royal College of Speech and Language Therapists
2 White Hart Yard, LONDON SE1 1NX
Tel: 020 7378 1200, Fax: 020 7403 7524

Websites

Websites on resources in ASDs
<http://autismconnect.org>
<http://www.asperger.org/>
<http://www.autism-awareness.org.uk>
<http://www.autism-resources.com>
<http://www.autismuk.com>
<http://www.autism-uk.ed.ac.uk/>
<http://www.autistic.net/>
<http://www.lookingupautism.org>
<http://www.mental-health-matters.com/autism.html>
<http://www.mugsy.org>
<http://www.udel.edu/bkirby/asperger/>

National Autistic Society

<http://www.nas.org.uk>

Parents for the Early intervention of Autism in Children

<http://www.peach.org.uk>

Autism Research Unit

<http://osiris.sunderland.ac.uk/autism/>

Education

Inclusion
<http://inclusion.ngfl.gov.uk>

Resources for teaching
<http://members.aol.com/room5/welcome.html>

Interventions

Daily Life Therapy
<http://www.musashino-higashi.org/english.htm>

Hanen
<http://www.hanen.org/>

Lovaas
<http://www.Lovaas.com>

Option
<http://www.Son-Rise.org/>

PECS
<http://www.pecs.com>

Play
<http://www.aristotle.net/theraplay/>

Social Stories
<http://www.thegraycenter.org/>

TEACCH
<http://www.unc.edu/depts/teacch/>

Appendix 4

The Autism Working Group

The Autism Working Group was established following a DfEE Autism in Education seminar hosted by Jacqui Smith. The Group has representation from central government, government agencies, parent groups, LEAs, early years, researchers and academics. The following people have been involved, either throughout or for part of the Group's existence:

Autism Working Group Facilitator

Annette English, Regional Facilitator,
West Midlands SEN Regional Partnership

DfEE/DfES Chairs (SEN Division)

Jeanette Sinclair, Stephen Dance and Phil Snell

DfEE/DfES Secretariat

Nigel Fulton, Jason Dedman and John Gormley

DfEE/DfES Early Years Division

Michael Collins and Paula Hurst

Department of Health

Elaine Cooper, Clive Marritt, Kevin Woods, Julia Ritchie and Sally Jones (both Speech and Language Therapy advisers at DH), Hilarie Williams (DoH/DfEE)

National Autistic Society

Paul Cann, Mike Collins and Rosemary Siddles

Parents' Autism Campaign for Education

Virginia Bovell

Pre-School Learning Alliance

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at the PSLA, now an SEN consultant

Community Practitioner and Health Visitor Association

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HMI/Ofsted

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Qualifications and Curriculum Authority

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Glenys Jones and Rita Jordan

National Foundation for Educational Research

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Institute of Education

Leicestershire LEA

Christine Cassell, Senior Educational Psychologist
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Worcestershire C. C. Education Directorate

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Teacher Autistic Spectrum Disorders

Notes

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<http://inclusion.ngfl.gov.uk>

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