

## Autism Spectrum Disorders

### *Guidance for Inspectors - National Care Standards Commission*

This document gives an indication of the range of initial knowledge about autism needed by Inspectors. It also gives you pointers to further information and to the skills which are needed to build on this knowledge-base.

#### **Principles and Context**

##### What is autism?

The autism spectrum is wide, from those who withdraw from social contact and use little or no language to those who are articulate and want to engage with others but don't know how to. There is also great variation within this spectrum in the degree of the severity of the effects of autism experienced by individuals.

A person with autism has a different view of the world from someone whose brain functions in a typical way. Their life-long core differences in cognitive functioning have a wide range of effects. Their capacity for social understanding is especially limited. This lack of intuitive awareness of what other people may be thinking and feeling, or of why they may behave as they do, puts the onus on us to develop our understanding of how they experience the world.

The term Autism Spectrum Disorders includes Asperger's syndrome, which affects people at the higher functioning end of the autism spectrum. They are of average or above average intelligence and generally have fewer problems with language, but may experience significant difficulties in social functioning.

People with ASD experience difficulties in three specific areas (the triad of impairments):

- a. ability to understand and use non-verbal and verbal communication
- b. ability to understand social behaviour and to interact with other people
- c. ability to think and behave flexibly.

These impairments go hand-in-hand with the need for repetitive routines and resistance to change. People with autism may also have unusual (i.e. heightened or lowered) sensitivity to sound, smells, touch, taste and visual stimulation.

##### Cause

The exact cause of autism is still unknown but genetic factors are clearly predominant in current research findings. It is also evident that autism is associated with various conditions affecting brain development which occur before, during or soon after birth.

### Incidence/prevalence/diagnosis

The National Autistic Society (NAS) estimates that 91 people in 10,000, or almost 1 per cent have ASD. Prevalence rates vary, but they have risen substantially in recent years, wherever they are measured around the world. The main reason for the lack of accuracy is that there is no medical diagnostic test for autism. Diagnosis depends on observation of behaviour, which cannot be entirely objective. There has also been a rapidly increasing ability to recognise autism since the early 1990s, and many clinicians in children's services have been trained to make a diagnosis. This has led to many more children than adults being recognised as autistic. So adults with autism who are using services are unlikely to have had access to a diagnosis.

If a person's behaviour seems to have features of autism, then lack of diagnosis should not be used as an excuse not to put in place autism-friendly ways of working, e.g. clear communication and structure, or to make suitable adaptations, e.g. to the sensory environment. These measures would be good practice with all service-users, but they are essential practice for those with autism.

### 'Challenging behaviour'

People with autism often create difficulties for others as they react to situations they find painful, chaotic or confusing, but difficult behaviour is not a defining element of ASD. Instead, it may be caused by an inability to communicate effectively and the resulting frustration, or a lack of awareness of more socially appropriate behaviour, or an inability to cope with excessive or confusing demands, or an inability to tolerate some aspect of the sensory environment or a response to an unexpected change in routine. Self-injurious behaviour also requires an assessment of the purpose it serves for the person. It may be that they are stimulated by the physical effects, such as the brain's reaction to endorphins or the colours they can see by poking into their eye. People with autism often have a very limited understanding of their body and how it functions. Appropriate interventions are to ensure that our behaviour and communication are helpful, to focus on managing the environment – not the individual - and to help them to develop their self-awareness.

### Distinctive features

Autism is pervasive in its effects on a person's development. It is a hidden disability - with no obvious physical signs - and it usually causes the person to have high levels of anxiety.

Features of **communication** are:

- Not responding consistently to their own name
- Difficulty communicating wants
- Poor use of gesture

- Echolalia (repeating words or phrases used by others)
- Frequent repetition of the same words or phrases

In Asperger's syndrome, further **communication** features are:

- Taking what people say very literally
- Difficulty in understanding gestures, body language and facial expressions
- Lack of awareness of what is socially appropriate and difficulty in choosing topics to talk about
- Little motivation to engage with others, because of difficulties in communication.

**Social** concerns are:

- They may prefer their own company
- Poor eye-contact
- In their own world
- Inability to have or show empathy
- Less use of and lack of understanding of facial expressions, body language, tone of voice etc

In Asperger's syndrome, further **social** concerns are:

- Repetitive speech
- Difficulties expressing themselves, especially when talking about emotions
- Anxiety in social situations, and consequent nervous tics
- Difficulties in group situations, especially where there are rules of behaviour
- Finding 'small talk' very difficult
- Problems in understanding double meanings and irony
- vulnerability to teasing
- Not choosing appropriate topics to talk about

**Behavioural** concerns are:

- Repetitive movements e.g. hand flapping, bouncing or sequences of movement
- Over-sensitivity to certain textures, sounds or smells
- Obsessive attachments to particular objects, activities or people

In Asperger's syndrome, further **behavioural** concerns are:

- An obsession with rigid routines and severe distress if routines are disrupted
- Problems with making plans for the future and with organising themselves
- Problems with sequencing tasks, so that, for example, preparing to go out can be difficult because they can't remember what to take with them.

## **Support and Interventions**

Myths and misconceptions about autism abound, despite the recent widespread raising of awareness about the condition and its effects. They include the following beliefs: autism is a low incidence disability; it is a withdrawal into fantasy life or a mental illness; it stems from parental rejection or family dysfunction; people with it do not make eye-

contact and are always aloof; it is misunderstood genius; and it is curable. None of them is true.

Staff with generic training whose background is in mainstream services usually have a sense of culture shock when they begin to work with people with autism, and they need to have access to specialist training. The wide ranges of autism-specific courses and of training-providers are of varying quality. This briefing document can be used as a basis for understanding the effectiveness of any training which has been undertaken.

Autism has also attracted a wide range of therapies and interventions. Each of these approaches has seemed to be of benefit to some people on the autism spectrum but very few of them have been systematically and independently evaluated. Some have become controversial or are thought to be ineffective. Holding therapy, for example, provides no evident lasting benefit and may cause distress to someone with autism who finds such enforced close physical contact aversive. Facilitated communication is used to help someone to communicate by pointing, often by typing on a keyboard. Although still widely used in Europe, it is not clear in using this form of communication whether it is initiated by the person with autism rather than by the facilitator. It is in disrepute in the USA following accusations of abuse, and in the UK as ineffectual.

### **Common Approaches with Adults**

People with autism need most help in:

- predicting what might happen to them
- communicating and understanding what others are trying to communicate to them
- developing social skills
- managing stress.

All the approaches which work well emphasise **structure, consistency, and a calm, well-organised environment**. The *SPELL* framework (Structure, Positive, Empathy, Low arousal and Links), which is used in all NAS services, has these qualities, as does the *TEACCH* approach (Treatment and Education of Autistic and related Communication-handicapped Children), which creates an autism-friendly environment in which to teach in a highly-structured way. The use of schedules and timetables gives the necessary structure and visual cues to people with autism, and it is good practice to employ them.

Two common autism-specific approaches, which focus on social communication, are *PECS* (Picture Exchange Communication System), which relies on the preference of people with autism for visual cues to teach them to exchange pictures for things they want, and *Social Stories*, an approach which uses short personalised stories to help them to understand what is required of them in social situations. For those with limited communication or who are very withdrawn, *Intensive Interaction* helps them to develop fundamental abilities in these areas. Details of all these and other approaches are in 'Approaches to autism' (2001).

To manage stress, regular exercise within daily routines is emphasised in many therapeutic approaches. Music and art therapies, light-rooms and sensory integration

programmes have all proved to be valuable in counteracting the effects of autism. For those who can communicate more easily, especially those with Asperger's syndrome, *Dramatherapy* and *Cognitive Behavioural Therapy* are increasingly being used successfully.

Autism is often associated with dietary problems, both because of a common preference for only a limited diet of familiar food and because of gastro-intestinal problems, which affect a substantial proportion of people with autism. Allergic reactions, especially to gluten and casein, but also to colouring and flavouring chemical additives and to excessive yeast in the intestine are all common in autism. Gluten- and casein-free diets, detoxification and nutritional support and anti-fungal treatments have all been used effectively but may be difficult to apply, because there may be a craving for the very foods which are causing the problems and inadequate labelling of foods makes it difficult to ensure that diets are free from them.

Medication is a controversial issue. No psychoactive drug can 'cure' autism, nor can any other therapy or approach. No medication has been found to be effective in the treatment of autism as a whole, since its effects are wide-ranging and individualised. Finding an effective medication for a particular individual can only be a matter of trial and error, and all drugs should be used for short periods at low doses, if at all. Some antidepressants and anti-anxiety drugs can reduce unwanted behaviour, but their effects on people with autism are unpredictable, and they may increase hyperactivity and aggression.

Antipsychotics in low doses may reduce aggression and self-injury, but common distressing effects are weight gain, tremors, continence problems, blunting of emotional and cognitive reactions and restlessness. One-third of people with autism have developed epilepsy in early adult life, so there is a strong association between the two conditions. Carbamazepine and valproic acid are considered to be the drugs of first choice in the treatment of epilepsy in autism, but both require regular blood monitoring. The use of homeopathy and alternative therapies are widespread in autism. They include megavitamin therapy, cranial osteopathy, G therapy and Dimethylglycine.

### **Aide Memoire**

Inspectors can use the following framework to help them to assess the quality of a service for an adult with autism and to make good practice suggestions and recommendations. It makes reference to the National Minimum Standards for Care Homes for Younger Adults.

#### **■ Recognition**

Autism and Asperger's syndrome are classified as pervasive developmental disorders in ICD-10 (International Statistical Classification of Diseases – 10<sup>th</sup> revision). However, many adults who are on the autism spectrum have not had access to a diagnosis because the rapid development of awareness of autism has been comparatively recent. In every local authority area, there are many more children with a diagnosis of autism than there are adults. So adults with autism who are using services are likely not to have a formal diagnosis, but will rely on the staff who work closely with them to recognise their core disability. It is often not their autistic behaviour which leads to recognition, but their

difficult and challenging behaviour which is a result of their high anxiety. It is important to question whether there has been consideration of autism as a possible cause when someone's behaviour is challenging and confusing to staff. The NAS has developed a short screening instrument for adults which will be available on its website for use by frontline staff in any service. It will clarify whether further assessment is advisable in order to establish whether the person has autism.

### ■ Staff Training

The service should provide specialised staff training so that autism is included both in an induction programme and in a continuous programme to develop, reinforce and update the skills needed. Staff need to have a thorough understanding of the underlying impairments and to be able to attune themselves to how the person with autism sees the world.

The SPELL training framework for autism, developed by the NAS, provides both introductory and more specialised training. It will be made increasingly available to care staff in generic settings. Four new LDAF units are relevant - 'Contribute to the support of people with Autistic Spectrum Disorders' and 'Support people with Autistic Spectrum Disorders' at levels 2 and 3 respectively, and 'Understand Person Centred Planning' and 'Support Person Centred Planning' also at levels 2 and 3.

The NVQ modules CL7 on Promoting Independence, and Z8 and Z9, are also relevant to autism and should be taught by reference to it. Staff taking the second unit in the LDAF framework's induction phase on 'What are learning disabilities' should also have learned about autism, including the anomaly that people with autism who are using learning disability services do not necessarily have learning disabilities. LDAF Unit 3

'Understand positive communication' at Foundation Level is also relevant to autism.

Training programmes on managing difficult behaviour, such as SCIP or Studio III, are provided in services used by people with autism and some social services departments have recruited specialist trainers for these programmes.

Autism-specific training courses in H.E. are provided by Birmingham, Manchester Metropolitan and Lancaster and Sheffield Hallam Universities, among others. The range is from Certificate to Masters level, and there are some post-experience courses for front-line staff and parents, who do not have prior academic qualifications.

### ■ Care Plans

Person-centred care plans are particularly important in autism, because its effects are so wide-ranging yet so individualised. Allocation to key workers is also good practice in autism for these reasons (Standard 6.8). The plan should make specific reference to how the person is affected across the triad of impairments and to any differences from the norm in their sensory experiences, of sound, smells, touch, taste and visual stimulation. Any specific dietary needs and problems should be made clear (Standard 17.1).

Healthcare needs should be addressed (Standard 19.1), recognising that awareness of bodily functioning is limited or may be distorted, so the person will need to be carefully prepared for and informed about each health check and treatment, and about any consent needed (Standard 20.2). Physical and mental health problems experienced by adults with autism are often missed or misdiagnosed.

All operational records, including behaviour support plans, incident recording and risk assessments/risk management strategies (Standard 9.2), should recognise the distinctive effects of autism. There should be detailed and specific strategies to achieve social interaction, communication and independence skills, highly planned structured activity and an appropriate physical environment. Appropriate staff levels for implementation of care plans and the necessary staff training should be made clear and methods of selecting staff should be assessed against the needs of those who use the service.

### ■ Flexibility of Provision

Choice should be offered to people with autism in a structured and limited way, or it will cause them additional stress. Staff must take account of the core impairments in autism in applying the principles of offering a range of choices and supporting risk-taking as part of an independent lifestyle (Standards 7 and 9). Difficulties in thinking flexibly mean that concrete choices should be offered, which are within the range of their experience. Difficulties in processing information mean that they need more time than their level of intelligence may suggest, to deal with information before a response is expected. Difficulties in coping with change mean that time to prepare for it, and essential information about what the change will mean must be given in the form, ideally visual, that the person can understand.

Inspectors may find that practice which appears to be poor can be understood through the difficulties associated with autism. A young man who insisted, for instance, on having no furniture in his bedroom other than a bed, did so because of his literal interpretation of 'bedroom', and needed gradual support to change it. Another who wore only light trousers and shoes in winter, did so because of his sensitivity to touch, and he had previously insisted on being naked. Most people with autism become very anxious when there is a change in routines, such as having the same breakfast every day.

### ■ Communication

All people with autism need unambiguous language to be used, since they will normally take the literal meaning of what is said. Staff should always use a person's name, when beginning to speak to them, since they are unlikely to pick up any other cues that they are being addressed. They should always be given time to process the meaning of language (Standards 7.2 and 11.1). All need a careful assessment of their individual preferred means of communication (Standard 3.5). For example, some find it much easier not to look at someone who is speaking to them, so that they can avoid sensory overload and focus on understanding the verbal communication.

### ■ External Input

Services need strong links with relevant, external professionals and with significant family members, particularly parents. Autism is so complex that input from speech and language therapists, psychologists and psychiatrists is usually necessary, although all are in short supply. Protocols for multi-disciplinary work should be in place, as they should for work with parents and family, whose contribution and knowledge should be explicitly valued. Any close relationship developed by someone with autism will have been hard-

earned. So staff support to maintain family links and friendships is of vital importance (Standard 15)

### ■ Environment

A low arousal environment should be given high priority. Sensory issues are emphasised in personal accounts by adults with autism and over-arousal is a major source of stress. A regular audit of noise levels should lead to a minimum of intrusive noise, and to noisy activities, such as vacuum cleaning, being carried out when residents are absent. A sense of personal space and lack of clutter in the environment is helpful, as is the use of colours which are not vivid or clashing. Fluorescent lights, where they are needed, should be 'day light' tubes and the use of aerosol air fresheners should be limited. Sensory rooms are helpful in reducing anxiety, and it is always necessary to assess the individual's particular sensory sensitivities.

Visual cues help to create an autism-friendly environment. A range of signs, symbols and photographs will communicate form and function much more successfully than use of language, and the person can refer back to them if confused or can use them to communicate with others.

### ■ Activities

All activities should be well-structured and planned to take account of the person's need to predict the nature of the activity; when and where it will take place; when it will end; and what will happen following the activity. Unless they are helped in this way, people with autism follow very rigid routines, both to reduce their anxiety about what lies ahead and because they do not know how to be flexible to change. If a resident has spent a long time on a particular activity, this will need to be justified by staff as part of an agreed plan.

People with autism tend to excel in activities which do not involve following social rules, such as games, and which are logical and well-structured. Many value the opportunity to use computers. They often develop and become expert in an area of special interest, focussing on what makes sense to them. It can be anything from sport statistics to the stars in the galaxy. Skilled staff can use this interest as a springboard for other related activities by building on their motivation to learn more about it. Social inclusion is a particularly difficult aim in autism, and it is essential that it has a positive meaning for the person concerned (Standard 13.2)

### ■ Accreditation

The NAS established Autism Accreditation in 1993. It is a peer review process which is compatible with and complimentary to Care Standards and other quality monitoring systems. It has developed a set of core and specialist standards for assessment of competence re. autism, and it supports the development of the quality of the service as a whole. By contrast, the other autism-specific programme in the UK – the Quality Network, which was set up in 2003 - focuses on the person's experience of using the service. Contact details are in the final section of this document.

## ■ Advocacy

Advocacy is vitally important in autism. The widespread misunderstanding of the condition and its effects and the particular forms of impairment - in social relationships and communication - mean that advocacy is both very necessary and difficult to achieve. Self-advocacy is still virtually non-existent, despite the great advances that have been made by people with other forms of disability speaking up for themselves. Until this issue is properly addressed, there will continue to be a heavy reliance on independent assessment of the quality of the services provided.

There is a debate about the best way forward. Some argue that only specialist advocacy services can meet the complex and distinctive needs of people with autism, others that it should be the responsibility of general advocacy services to meet these needs. In any event, there is a great shortage of any form of advocacy which has expertise in autism. So if service users have not been given access to independent advocacy schemes (Standard 3.7), this is not necessarily an indication of poor practice by the care service provider.

## ■ 'Respite' Placements

Preparation for change and time to adjust to it are essential to people with autism but are difficult to ensure in short or emergency placements. 'Respite' placements (Standard 3.10) should take account of their difficulties and pay particular attention to planning and preparation. Emergency admissions (Standards 4.4 and 4.5) should recognise the distinctive issues for the person with autism.

Any period of transition in the life of an adult with autism requires detailed planning and support strategies.

## **Views of Service Users**

Some of the distinctive issues about appropriate ways of accessing the views of service users who have autism are:

### ★ Tips for interaction

When making personal contact, remember that perfume or aftershave may affect the person adversely, and jewellery or other distracting aspects of your appearance may become the focus of their attention. So they should be avoided. You should take advice from someone who knows them well before entering their personal space. They may find close proximity difficult or the offer of an introductory handshake may not be accepted.

### ★ Forms of Consultation

This should be guided by information you can gain at the outset about the forms of communication which the service user is able and willing to use. Many people with autism use little or no language, and all have difficulties in reciprocal interaction. One-to-one or group discussion should be tailored to the needs of the individual. If comment

cards are used, they may help the person by avoiding the anxieties experienced in conversation with a stranger, but questions must be concrete and specific. Relatives, representatives or advocates should be consulted about the effects autism has had on the person, and their views should be sought about how you can interact with them, and about how far the service meets their needs.

★ **Privacy**

When Inspectors are able to meet service users alone, you should first be briefed on trigger words which should be avoided with that individual. The person may also have areas of obsessive interest which should be avoided in discussion. There may be personal safety issues for Inspectors in meeting service users privately without the support of service staff. If senior staff advise that there are risks to your safety, this is not likely to be an attempt to limit your access to the person.

★ **Aids to Consultation**

Although there are endemic problems in communication and self-advocacy, visual cues are clearly helpful and they should be the basis of direct work with the person, whatever their level of intelligence. A computer programme, which they could work through, would probably be the most effective way to consult them. But cue cards or pictures will also help them to understand what information is being sought from them and to give a response

### **References and Contact Details**

Websites:

[www.nas.org.uk](http://www.nas.org.uk) (The National Autistic Society)

[www.ldaf.org.uk](http://www.ldaf.org.uk) (The Learning Disability Awards Framework)

Accreditation Programmes:

Autism Accreditation, The National Autistic Society, Church House, Church Road, Filton, Bristol, BS34 7BD. Tel: 0117 974 8429

The Quality Network, BILD, Campion House, Green Street, Kidderminster, Worcestershire DY10 1JL. Tel: 01562 723018

Introductory reading:

Approaches to autism (2003) £6.

Autism: preparing for adulthood (1998) by Patricia Howlin £17.99

Behavioural concerns and autistic spectrum disorders: explanations and strategies for change (2000) by John Clements and Eva Zarkowska £15.95

Nobody Nowhere (1998) a personal account by Donna Williams £12.95

All the above books are available from The National Autistic Society and can be ordered through the website above.

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