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# The Autism Act 2009: developing specialist skills in autism practice



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## ESSENTIAL GUIDE

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## Introduction

People with autism are 'falling through gaps in services' (Loynes 2001, Department of Health (DH) 2006, National Autistic Society 2010). The All Party Parliamentary Group for Autism (APPGA) was formed in 2000 to work with the main political parties to raise awareness of the difficulties that people with autism and their families face, and to campaign and lobby for legislation change. The National Autistic Society drafted the Autism Act, which was taken forward by Cheryl Gillan as a private member's bill in November 2009. The bill was supported by a coalition of 16 autism organisations and had all-party support.

The bill was passed and required the publication of an autism strategy paper *Fulfilling and Rewarding Lives* in March 2010 (DH 2010a); this was followed by the publication of a three-year delivery plan in April 2010 (DH 2010b) and statutory guidance to implement *Fulfilling and Rewarding Lives* in December 2010 (DH 2010c). The Autism Act 2009 seeks to give health and social care organisations specific legislative responsibility to:

- ▶ Provide all staff with statutory training in autism, with front line staff required to have more specialist training in meeting the specific needs of adults with an autism spectrum disorder.
- ▶ Ensure that the diagnosis of autism is accompanied by an assessment of need. Before the act, few more able people with autism were accessing community care assessments, and of those who did only 45 per cent were receiving services specified in the assessment (Loynes 2001).
- ▶ Provide all children with a statement of an autism spectrum disorder with a drawn-up 'transition plan' for progression into adult services. Before the act, an inquiry into 'transition' found that: 'Transition services are still failing most young people on the autism spectrum', and that: 'Getting it wrong for a young person on the autism spectrum can have catastrophic consequences that may be irredeemable because of their inherent difficulty with new situations' (Allard 2009).
- ▶ Ensure that adults with autism are involved in local service planning. Local authorities are not aware of the number of people with an autism spectrum disorder living in their locality, which they need to be to identify and adequately plan ways to work with people with autism.

The Equality Act 2010 replaced most of the Disability Discrimination Act 1995. The Equality Act requires 'reasonable adjustments' to the way things are done in public services – for example, changing a policy, changing the structure of the building or providing information in an accessible format. It is not appropriate to wait until a person with a disability seeks to use a service – the act requires public sector organisations be proactive in identifying the needs of disabled people. This guide will explore how services might anticipate the needs of people with autism. Its aims are to:

- ▶ Explore an understanding of autism in adulthood (or transition to adulthood) that helps practitioners to provide a positive experience for people with autism seeking to access services in health and social care.
- ▶ Review how this knowledge might help to identify and plan to meet the needs of adults with autism, while making 'reasonable adjustments' to the services to enable this to occur.

- ▶ Provide a clear pathway for the development of leaders in the field of autism in health and social care who will 'champion' the implementation of the Autism Act 2009.

This guide is aimed at people in a specialist role who will lead the planning, development and commissioning of services with local authorities and GP consortia. A report from the National Audit Office (2009) stated that '80 per cent of GPs feel they need additional guidance and training to manage patients with autism more effectively'. Although the employment, police and probation services are not legally required to respond to the Autism Act 2009, the Autism Strategy (DH 2010a) and Statutory Guidance (DH 2010c) could help improve the services in these areas. The vision of the act is that:

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'

The Autism Strategy (DH 2010a) outlines the need for staff to have training in autism. But, unless training helps staff to develop their skills in making reasonable adjustments under the Equality Act 2010, little will change in the lives of people with autism and their families. Simply providing training using a medical model is insufficient, because this will only provide information about the condition of autism in isolation from the environment that defines the characteristic behaviours that are part of the autism spectrum condition. Some environments

can be enabling, while others can be disabling (Swain *et al* 1993). A social model of understanding autism is needed to understand how barriers in health and social care can have a disabling and distressing effect on the person with autism if service providers lack knowledge of autism and fail to make some level of reasonable adjustment.

People with autism are sometimes referred to as having an 'invisible' impairment, and identifying how reasonable adjustments can be made to make services more accessible may not be easy. But, reasonable adjustments need to be made to:

- ▶ Premises – by exploring how the environment can be better accessed by people with autism.
- ▶ Processes – by exploring how appointments can be scheduled better.
- ▶ Communication – by exploring how documents can be presented in a way that can be better processed by people with autism.

This guide also discusses the development of skills and knowledge in autism practice to explore:

- ▶ Autism as an impairment of sensory perception.
- ▶ The use of an environmental audit to ensure organisation-friendly access for people with autism.
- ▶ The use of a communication profile to develop a personalised pathway through health and social care and to make reasonable adjustments as part of the person's care plan.
- ▶ A systematic approach to understanding the meaning of behaviour.

## A note about terminology

Many websites and autobiographical accounts written by people with autism are available. Some of these suggest that people with autism are dissatisfied with the term 'autistic spectrum disorder' (Gerland 2000, Jackson 2002, Lawson 2000). A movement away from the medical model of defining autism as a disorder towards an understanding that it is a condition characterised by certain behaviours (some idiosyncratic) that may be seen and evidenced in some environments but not in others has emerged. This suggests that people with an autism spectrum condition are disabled by factors external to themselves, recognising autism as an impairment, which will have positive and negative aspects depending on the stimuli present in particular environments. The official diagnostic criteria (Diagnostic Statistical Manual [DSM-IV], International Classification of Diseases [ICD-10]) refer to autistic spectrum disorders, whereas people with autism and their families may prefer the term autism spectrum condition. This guide will use the term autism and autism spectrum condition throughout.

## Defining autism to guide best practice

To understand autism spectrum conditions through the social model, we need to understand autism differently from the more clinical definition used in DSM-IV (American Psychiatric Association 1994). Practitioners need a definition of autism to help them to identify the problems faced by people with the condition, and for this knowledge to be used to improve the experience for service users and to challenge barriers that prevent access to services by

people with autism and their families. This section of the guide will explain the likely barriers raised by:

- ▶ Environments and sensory issues.
- ▶ Communication and information, and cognitive processing issues.
- ▶ Attitudes from health and social care workers.

It will identify possible 'reasonable adjustments' that could give people on the autism spectrum greater access to health and social care services.

**Environments and sensory issues** Autism can cause people to experience high levels of stress and distress, particularly when they are in highly stimulating and demanding environments (Williams 1998a, 1998b, 1998c). This is the area in which 'reasonable adjustments' might most improve access to services for people on the autism spectrum. People with autism show excessive physiological reactivity to environmental stressors compared with their non-autistic peers. Despite growing awareness of stress in autism, little work has been done to develop tools that assess reactions to stressors in this population (Goodwin *et al* 2007). The only instrument to assess stress in people with autism is the Stress Survey Schedule (Grodén *et al* 2001), an informant-rated, 49-question instrument. Goodwin *et al* (2007) tested the instrument's validity with a sample of 180 people on the autism spectrum. They identified stress in eight specific areas, as shown in Table 1.

Gillott and Standen (2007) used the Stress Survey Schedule and found that fear of change, anticipation and certain sensory stimuli were the main precipitators of stress for people on the autism spectrum. Fear of change was

**TABLE 1****Eight areas of stress identified by the Stress Survey Schedule**

Area of stress	Example situations
1. Changes and threats	Having a cold; change in task and new directions; going shopping; change in environment; transition in locations; transition from preferred to not preferred activity; engaging in an activity not liked; being unable to communicate; needing to ask for help; participation in group activity.
2. Anticipation and uncertainty	Having a change in plans; waiting for an activity; having unstructured time; waiting generally.
3. Unpleasant events	Waiting to talk about a desired topic; having personal objects missing; following a diet; receiving criticism and being told 'no'; having something marked as incorrect; a change in teacher; losing at a game.
4. Pleasant events	Receiving a present; playing with others; receiving reinforcement; having something marked correct; receiving tangible reinforcement; having a conversation; receiving verbal reinforcement.
5. Sensory/personal contact	Being in the vicinity of noise or disruption by others; being touched; receiving hugs and affection; feeling crowded.
6. Food-related activity	Waiting at a restaurant; waiting for food.
7. Social/environmental interactions	Being in the vicinity of bright lights; being unable to assert oneself with others; someone else making a mistake.
8. Ritual-related stress	Having personal objects or materials out of order; being prevented from completing or carrying out a ritual; being interrupted while engaging in a ritual.

(Grodén *et al* 2001, Goodwin *et al* 2007)

prominent and could apply to people or locations. Williams (1998a), in *Nobody Nowhere* writes: 'The constant change of most things never seemed to give me a chance to prepare myself for them. Because of this I found pleasure and comfort in doing the same things over and over again.'

The study by Gillott and Standen (2007) also identified elevated levels of anxiety in adults with autism compared with adults with intellectual impairments. The types of anxiety with high scores were panic/agoraphobia, separation anxiety, obsessive-compulsive disorder and generalised anxiety disorder.

This stress experienced by people with autism has been referred to as 'exposure anxiety', which describes the way people with autism protect themselves from stimuli in the environment (Williams 2002). Exposure anxiety explains why a person with autism may be able to communicate verbally and through other effective means in an environment that is quiet and without high levels of distracting stimuli. However, in a busy environment with high noise levels and bright lights the person may 'shut down' and be unable to speak, sitting in a corner and rocking. Others might simply seek to run away. Many of the services provided to people across health and social care are in environments that are often busy, noisy, stimulating and demanding.

#### **Autism as a sensory perceptual impairment**

Approximately 70 per cent of people with autism will have a 'sensory perceptual impairment' (Cascio *et al* 2008). Leekam *et al* (2007) found that 90 per cent of children with autism had sensory abnormalities, while 94.4 per cent of Crane *et al's* (2009) sample reported extreme levels of sensory processing on at least one part of the sensory assessment. Bemporad (1979), writing of Jerry, a young man with autism, states that: 'The recurrent theme that ran through all Jerry's recollections was that of living in a frightening world presenting stimuli that could not be mastered. Noises were unbearably loud, smells overpowering, nothing seemed constant, everything was unpredictable and strange.'

Sensory abnormalities will exist across all five sensory modalities, as well as kinaesthetic and proprioceptive sensation (Harrison and Hare 2004). Table 2 (page 8) summarises the

particular sensory difficulties. A sensory perceptual impairment is different from a sensory impairment, which suggests a loss of sight or hearing, and has been defined as being more complex as it encompasses all the senses (Shabha 2006). A sensory perceptual impairment is characterised by 'turbulent, fluctuating, inconsistent and unreliable perception where individuals cannot make connections with their own environment' (Shabha 2006).

A sensory perceptual impairment can affect the person in different ways:

- ▶ The person may struggle to remember information in a different environment. Grandin (1984) explains how she processes information visually and how this affects her remembering certain basic information: 'Learning sequential things such as maths was very hard. My mind is completely visual and spatial work such as drawing is easy. I taught myself drafting in six months. I have designed big steel and concrete cattle facilities but remembering a phone number or adding up numbers in my head is still difficult.'
- ▶ Perception may be delayed in a new and different environment, which means that people may need to pause outside or inside a door for a few seconds while they adjust their perception.
- ▶ For some people, the sensory inputs get mixed up and the person goes into 'sensory overload'. At this point they will not be able to process verbal instruction and will need support to come out of this state of sensory overload.

**TABLE 2****Sensory difficulties in people with autism**

Sensory abnormality	Examples
1. Hyper- and hyposensitivity to stimulation and fluctuation between the two	'Noises that would make me cover my ears or avoid them were: shouting, noisy crowded places, polystyrene being touched, balloons being touched, noisy cars, trains, motorbikes, the sound of felt tip or marker pens when colouring in' (Joliffe <i>et al</i> 1992).
2. Distortion – for example, depth may be wrongly perceived or still objects may be seen as moving	'At home I would spend hours in front of the mirror, staring into my own eyes and whispering my name over and over, sometimes trying to call myself back, at other times becoming frightened at losing my ability to feel myself' (Williams 1998a).
3. Sensory tune-outs – for example, sound or vision may suddenly black out and return	'Usually I claw large chunks of skin and flesh from my upper arms or sometimes my thighs and shins. The pain is so intense that I am totally incapable of focusing on anything else around me... It puts me in total control. Rather than "out there" penetrating and "hurting me" it is now me hurting me' (Blackburn 2000).
4. Sensory overload	'Many conversations going on at once will become a confusing blur. As the person with autism can't process them to decipher their meaning' (O'Neill 1998).
5. Difficulties in processing from more than one channel at a time	'These people had, uninvited, tried to take away my choice at being touched, though to them it was more a tap on the shoulder. These were the people who out of their own selfishness, would rob me of my sense of peace and security' (Williams 1998a).
6. Multi- and cross-channel perception. For example, the perception of sound may be accompanied by perception of colour or taste	'Sometimes there are also perception difficulties because autistic people are concerned with the space immediately surrounding their bodies, they tend to prefer proximal senses: touch, taste, smell to their distal senses sight and hearing' (O'Neill 1998).
7. Difficulties in identifying the source channel of the sensory stimulation	Williams (1998a) describes herself as having a 'mono-channel', not being able to see and hear at the same time, while Blackburn (2000) talks about how touch (used as a prompt) can severely distract from the verbal request, as the energy required to process touch is more overwhelming than that to process auditory instruction.

(Adapted from Harrison and Hare 2004)

## BOX 1

**Example of use of the Sensory Behaviour Scale**

Rory is 29 years old. He has an autism spectrum condition and lives at home with his parents and sister. His family depends on respite care services for Rory as his mum is his full-time carer.

The family uses respite care services from the adult learning disability service, but often tensions exist between Rory's needs and the values of the learning disability service. On the Sensory Behaviour Scale, Rory scored high on the following:

- ▶ Auditory – ongoing.
- ▶ Olfactory – ongoing.
- ▶ Kinaesthetic – ongoing.
- ▶ Proprioception – ongoing.
- ▶ Vestibular – ongoing.

A planning meeting for Rory identified that he flaps his wrists and jumps up and down (kinaesthetic) and that he does this while watching his favourite DVDs. The respite care service has only one television, so the service agrees for Rory to have access to a TV in his bedroom; he will need to learn to use the remote control.

Some of the DVDs have music and are based on repetitive routines. Some staff have questioned if the videos are 'age appropriate for Rory', and more work is needed to help the staff team to understand the core elements of the Sensory Behaviour Scale.

All activities for Rory at the respite care service need to relate to the Sensory Behaviour Scale.

'Reasonable adjustments' in the service require consideration of the vestibular needs of Rory and his unsteadiness of gait.

Appropriate planning is needed for him to avoid crowded areas.

Various tools are available to assess sensory dysfunction, including the Sensory Profile (Kern *et al* 2007, Dunn 1999) and the Diagnostic Interview for Social and Communication Disorders (DISCO) (Leekam *et al* 2007). Both instruments are complex and will usually be used by a trained psychologist or psychiatrist. A more accessible instrument for practitioners is the Sensory Behaviour Scale (Table 3, page 10) (Harrison and Hare 2004), which can help with screening and individual assessment. The authors argue that its use should 'facilitate the development of more appropriate environments for people with autism'.

Using the Sensory Behaviour Scale across teams and with carers can help to identify requirements for adaptation in the environment or for support, as well as to explore relevant and enjoyable leisure activities. Box 1 gives an example. Some people with kinaesthetic needs may enjoy trampolining or visiting a snoezelen room. Harrison and Hare (2004) argue that the instrument be used to create more appropriate environments for people with an autism spectrum condition. It would be expected that a 'sensory curriculum' could be created to ensure that the service commissioned on behalf of the individual is suitable and appropriate.

**Barriers in the environment** For example, lighting, sound (acoustics) and patterned flooring and walls or stripes on the radiators – will affect some people with autism in different ways. People are unlikely to be able to communicate the effect the environment has on them and instead may display stereotypical and self-stimulatory behaviours. Such behaviours may suggest that the person is being overwhelmed

**TABLE 3****Outline of the Sensory Behaviour Scale**

Does the person:	Ongoing	In past	No or N/A	Don't know
<b>1. Visual</b> a. Watch bright lights? b. Twirl his or her fingers in front of his or her eyes?				
<b>2. Auditory</b> a. Make unusual vocalisations?				
<b>3. Olfactory</b> a. Smell other people? b. Smell parts of his or her own body?				
<b>4. Taste</b> a. Put objects in his or her mouth? b. Engage in play with saliva or other bodily substances? c. Like any unusual foods/tastes (please give details)?				
<b>5. Tactile</b> a. Hold and manipulate small objects? b. Like to be tightly wrapped up in clothes and/or bedding?				
<b>6. Kinaesthetic</b> a. Flap his or her wrists? b. Jump up and down on the spot? c. Twirl round and round?				
<b>7. Proprioception</b> a. Have difficulty in dressing and feeding him/herself?				
<b>8. Vestibular</b> a. Walk with a noticeable gait?				
<b>9. Temperature</b> a. Seem to be unaware/tolerant of temperature extremes				
<b>10. Sensory preferences</b> a. Tend to use touch/taste/smell to examine objects and situations more than using vision and hearing?				
(Adapted from Harrison and Hare 2004)				

sensorially, and this will make it difficult for the person to process and retain instructions or information. Consider Hale's (1998) thoughts on lighting: 'To add to my problems, the sun comes streaming through the window, the brightness is blinding and very long spikes of sunlight come out towards me from places where the sun hits shiny surfaces. Everywhere I go there is the dreaded fluorescent tube lighting. Both sunlight and fluorescent tube lighting increase the rate at which my eyes become tired and augment all my visual distortions (for example, there are many more little white bits flying around). Spending more than about half an hour under fluorescent lighting gives me a headache and eye ache. My ideal after dark lighting is from "daylight" bulbs (these are light bulbs often used for interior photography or needlework after dark) and during the daylight hours I like natural light which comes through a north facing window.'

The source of light (natural daylight is better in appointment rooms or college or university classes) and the intensity of light should be examined. High levels of light intensity and flickering lights are triggers for self-stimulating behaviours (Shabha 2006). Fluorescent lighting causes severe problems for people with autism, as they see a '60-cycle flicker' and reflections bounce off everything. Under the Equality Act 2010, a 'reasonable adjustment' would be to purchase appropriate light bulbs for a person who is using a day service or attending a college class or university course.

It is not always easy for adults with autism to recognise the difficulties they encounter in environments and then explain these difficulties to staff. Staff members need to be proactive to

identify factors that cause people distress and to suggest a course of action under the Equality Act 2010. Some adults with an autism spectrum condition might develop management strategies when in these environments because they may have been supported in the past to reflect on ways to deal with such situations with family members and support staff. Others may need help to manage these situations, and staff will need to recognise when the person is being 'saturated by stimuli' so that they can enable the person to withdraw and adjust to a more moderate environment.

Some people may not be able to cope with additional stimuli in these already difficult environments. For example, Hale (1998) reflects on living in a university halls of residence: 'The carpet and duvet cover in my study room are highly patterned. This causes me to see a whirling mesmerizing mess which hurts my eyes. The patterns are hard to escape in this small room. Any highly contrasting pattern is a problem. For instance trying to have a conversation with someone who is wearing a black and white striped shirt is almost impossible. The pattern appears to be jumping around in a mesmerising fashion and can cause my vision to go fuzzy and remain fuzzy long after the pattern is out of sight.'

It would be a 'reasonable adjustment' to request that staff wear clothing without patterns while supporting Alison at university.

**Use of reasonable adjustments to enable access to the environment** First, the physical environment should be reviewed as part of the impact assessment in relation to the Equality Act (2010) (Box 2). Second, people with autism can

be desensitised to the environment (and gradual exposure to new people) before the day they attend the hospital appointment, the new college class or the induction day at the university. The process of desensitisation will vary from person to person, but ideas for doing this include:

- ▶ Introducing photographs in a schedule to prepare the person for what is going to happen at the hospital or social services appointment.
- ▶ Taking the person on a trial visit to meet the

staff and see the environment (without any intervention occurring).

- ▶ On the day of the planned intervention, introducing the person to photographs of the people who will be carrying out the procedure.
- ▶ Using a virtual visit to the hospital with software that orientates the person to the environment (and replicates acoustics).

### **Communication, information and processing**

Some 'reasonable adjustments' can be made to the communication methods used by staff. In unfamiliar environments, a lot of verbal information will not be processed by the person and will sound like 'blah blah blah'. Visual information is a good way to enable easier access to people with autism.

Visual information, including photographs, videos and diagrams, is easier than written or verbal information for people with autism to process. Visual input is the primary source of information for people with autism (Quill 1995). Cihak (2011) found no single preferred means of visual communication that was more effective (between static picture scales and video-based schedules). This suggests that visual schedules need to be tailored to individuals, or generalised to enable better access rather than relying on verbal or written instruction. This is important for people with autism attending appointments, where they will need some sort of visual scheduling of the stages in the process. How many stages to make available to the person at once will depend on the person's cognitive ability. Letters might be better set out in a landscape format, so that the events of an appointment can be scheduled from left to right. Department

## **BOX 2**

### **Environmental audit for access**

#### **1. Lighting**

- ▶ Some flickering lights can cause difficulties if present in a consulting room.
- ▶ Is there natural light in the consulting room? Natural light may have a more relaxing effect.
- ▶ Is there fluorescent tube lighting?

#### **2. Flooring**

For example, large black and white floor tiles may cause difficulties with orientation and movement for some people.

#### **3. Acoustics**

This can cause the person to have sensory overload and be unable to process standard information.

#### **4. Spatial**

The room needs to be large enough for people to define the spatial distance between themselves and the hospital staff member. A small confined space can cause excessive stress. People need to have some control over their environment.

#### **5. Transition**

The person should be supported to take an item of interest that will help to calm him or her when in a strange environment.

of Health guidance has been issued on best practice in producing 'easy read', this can be accessed at [www.valuingpeoplenow.dh.gov.uk/webfm\\_send/377](http://www.valuingpeoplenow.dh.gov.uk/webfm_send/377).

More effort should be made to listen to the person's behaviour, exploring if a communication profile is in place that recommends how best to communicate with the person. Not touching the person unless the person is asked is important, as: 'When touched unexpectedly, we usually withdraw, because our nervous system does not have time to process the sensation' (Grandin 1996). Encouraging a rapport by talking about the person's area of special interest can act as a 'de-stressor' for some people in some environments. This information might be provided in the communication profile (Table 4). It is important to:

- ▶ Avoid excessive verbal communication (which is without instruction).
- ▶ Avoid the use of sarcasm and unnecessary body language.
- ▶ Focus on listening to the non-verbal communication of the person.

Sensory perceptual difficulties mean that some people with autism will fail to orientate themselves when their name is called (Cascio *et al* 2008).

People should always be referred to by the name they recognise. When a request is made, the person should be allowed a few seconds to orientate him/herself without the instruction immediately being repeated or the language that is used in the instruction being changed.

**Understanding behaviour** Not all behaviour presented by a person with autism will have a sensory origin. Behaviour often serves as a way of communicating when a person may not have

the necessary language. With a growing awareness of the role of sensory perceptual difficulty in autism, differentiating between four possible functions for behaviour will be important. These are:

- ▶ Avoiding contact (escape).
- ▶ Seeking contact (attention).
- ▶ Serving the purpose of communication (tangible).
- ▶ Sensory.

The 16-question Motivation Assessment Scale (Durand 1990) (Table 5, page 20) is an excellent place to start a functional analysis of the person's behaviour. Sometimes this instrument can be completed with teams of staff to obtain some sort of consensus about the function that a particular behaviour may have for the person. A lack of understanding of the function of a behaviour may lead to dissent in the team. For example, believing a person is attention-seeking when the function of the behaviour is to avoid contact. Consider the following situation with Mary:

Mary lives in a supported living environment with two other people with autism. Staff members are worried about Mary's behaviour and that her behaviour seems to be getting worse. They explain that every time a member of staff approaches Mary, she starts to spit at them. Mary has learnt that when she spits at staff they leave her alone. Staff members believe that the reason Mary spits is to gain attention and have decided to ignore Mary when she spits at them and to praise the positive times that they engage with her when she is not spitting. Over the past two weeks, Mary's behaviour has worsened because as soon as she spits the staff retreat and

**TABLE 4****An example of a communication profile**

(This is based on a real person who had a minimum of two male staff members on each shift to work with him in his flat. Staff often expressed difficulties they experienced in understanding his communication.)

<b>Question</b>	<b>Example</b>
1. Does the person use verbal communication? If so, how is this used in communication with others and how effective is it as a means of communication?	John Brown makes his needs known by vocalising various sounds. The sounds used vary in loudness and pitch depending on his mood. John uses sounds that can communicate happiness and sadness. If staff do not attend to the noises, the sad ones will escalate and result in some form of negative behaviour. His most commonly used sad sound is 'na-na, na-na'. If the na-na sound continues and he starts to grind his teeth and to rock back and forth, he is becoming even more unhappy about something.
2. What non-verbal methods of communication are used?	John claps his hands to let staff know that he wants something. If staff do not understand, he may take them by the hand to show them what he is trying to communicate. If staff have still not listened, he will become agitated and start to sit on his hands and rock backwards and forwards. He may then start to make a na-na sound if he continues to be unhappy. After grinding his teeth, he may become frustrated and try to attack a member of staff.
3. Does communication change when anxiety levels increase? If yes, how does this change?	As John becomes more anxious, his Makaton signing becomes more vague and difficult to interpret and understand. The sounds he makes become louder and higher pitched.
4. What is the person's special interest?	John loves garden tools; he likes the variation in form rather than using them. He likes to visit garden centres and look through catalogues.
5. What is the meaning of the person's non-verbal communication? (When they do X, they mean Y)	John will point to the vehicle's keys and sign for you to give him some money; he will stand by the window and sign for driving a car. He will also do drawings of past trips to garden centres. All the above suggests that he would like you to drive to the garden centre to buy new tools.
6. Does the person have his or her own words for things?	No.
7. How does the person express anxiety?	Grinding teeth; grunting sounds becoming louder and louder; repetitive Makaton signing for garden tools; rolling eyes; sucking in cheeks and biting the side of his mouth; pulling at his ears and teeth; flapping his hands in the staff's faces; swinging his arms and body from side to side; shallow breathing; pallor and clammy skin.
8. What needs to be in place in the environment to help the person not to feel anxious?	John's day needs to be structured. If the planned activity does not occur, an alternative needs to be done instead because he does not understand cancellation. Staff working with John need to support him in a confident manner and include him in all aspects of the daily routine.

ignore her. Staff have had no opportunities to engage with Mary when she is not spitting, so Mary has had no positive feedback. The autism specialist explains to the team that their management strategy might be wrong and that all should complete a Motivational Assessment Scale to find out the function of Mary's behaviour.

Only after the team members have agreed on the possible function can an appropriate behavioural management strategy be devised. Sometimes the presentation of behaviour will have no pattern and no single reason for it. This should alert staff to the possibility that the behaviour is caused by pain. Carr and Owen-DeSchryver (2007) found that the frequency and intensity of problematic behaviour were higher when the person was sick. It is not easy to know how to ask the right questions of a person without verbal communication who presents with severe self-injurious behaviour. For example, a young man, David, banged his head so much that he fractured his jaw. X-rays showed that he had a serious abscess on his tooth, which had been undetected for some time. It was only discovered when he was X-rayed as a result of the injury caused by his self-injurious behaviour. Carr and Owen-DeSchryver (2007) developed assessment tools that can be used to identify any underlying ill health if no pattern is discernable through presenting behaviour.

#### **Use of reasonable adjustments to change**

**personal behaviour** Staff will sometimes need to adapt their behaviour, when communicating with the person with autism. This can be done by reading the communication profile and communicating to other professionals via the

patient's notes. Every effort should be made to explore the function of behaviour. People with autism may not have the words to explain pain, even if they have spoken language. The young man with the broken jaw was described as 'revolting, difficult and very challenging', because he would play with his spit, and as a result staff members were not motivated to provide support to him.

Training on autism from a sensory perspective is vital to help staff understand that some people relate to their proximal senses more than their distal senses because this is a way to cope with a confusing world. Kern *et al* (2007) explain that even though sensory dysfunction is mentioned in DSM-IV (American Psychiatric Association 1994), which is the diagnostic manual for diagnosing autism, it remains excluded from the indicative profile. This is problematic because not all training in autism will focus on the sensory domain of autism as a key defining area of the condition. However, understanding the sensory impairment would help caregivers to overcome their prejudices in caring for people who relate to the senses close to their body. It would also help to ask the right questions when an understanding about complex and challenging behaviour is needed.

Guidance is needed on desensitising the person with autism to the member of staff. This may take time. The person may need to process the member of staff before he or she speaks; otherwise, this may lead to overload and ineffective social relating.

**Attitudinal barriers** People with autism report negative experiences of other people's attitudes towards them. Williams (1998a) writes: 'I told him how I'd been called crazy, stupid, disturbed and just plain weird.' Reading the

autobiographical accounts gives a sense that the pressure is on people with autism to become 'normal'. Williams (1998a) writes: 'These "helpful" people were trying to help me to "overcome my ignorance" yet they never tried to understand the way I saw the world.'

While many people with autism have exceptional talents, a general societal prejudice about autism spectrum conditions suggests that people ascribe a negative social role to autism as 'difference' rather than a positive one. The positive aspects of autism should be explored and the abilities promoted rather than the disabilities. Encouragingly, the first-year delivery plan *Towards Fulfilling and Rewarding Lives* (DH 2010b) outlines a long-term vision for adults with autism to develop an increasing awareness and understanding of autism in the wider community. This document contains plans to 'develop a nationwide campaign to tackle stigma so often attached to autism' (DH 2010b).

### Diagnosis and services

The Autism Strategy (2010a) recognises the stigma present in the wider society for people with autism and their families, and the Autism Act seeks to remove that. How the diagnosis is given to people with autism and their families can be unsatisfactory. Beresford *et al* (2007), in their study of 25 families (with a total of 28 children with an autism spectrum condition aged between three and 19 years), found that parents had experienced negative communication about their child's diagnosis of autism. National Institute for Health and Clinical Excellence (NICE) guidance on the diagnosis of autism will be published in 2012.

Under the NHS Community Care Act 1990, all people with a learning disability are entitled to a community care assessment, although this does not guarantee that a service will be provided. However, once a diagnosis has been made people with autism have not previously been automatically entitled to this assessment, as local authorities argued that some people with autism did not have a learning disability. In a National Autistic Society (2010) survey of 1,400 adults with autism and carers, 63 per cent stated that they did not receive support to meet their needs. The Autism Act 2009 now makes it clear that this assessment cannot be denied on the basis of IQ. People who have a social impairment clearly need support, and this will be the responsibility of the lead professional for autism in local areas.

A diagnosis of autism will give people who go to university the right to learning support. The number of university students with autism increased more than fourfold between 2003 and 2008 (National Audit Office 2009), and appropriate support will need to be developed.

A diagnosis of autism is a catalyst for a carers' assessment under the Carers Recognition and Services Act 1995. Carers and families live in an environment with high levels of stress, and they should be made aware of their right to request an assessment. Social services should draw up a plan for the carer and communicate it to their GP.

**Transition** Children with autism need a transition plan between the ages of 13 and 19 years. A health action plan can also aim to develop social skills and strategies to enable self-care and independent living. Multi-agency

planning is required to meet the needs of children going through the transition to adult services. The white paper *Equity and Excellence* advocates 'no decision about me without me', which emphasises the engagement of all children in the process of transition planning (DH 2010d).

Transitions must be considered from a micro-scale (everyday perspective) to larger-scale planning. Transitions for people with autism can be complex and require key observations. The observation with James (names changed) in Box 3 illustrates how a 14 year old with complex communication difficulties tries to express his need to have an item of his own interest in the transition from home to a summer school. The observation shows how his communication was picked up by the teaching assistant but not the teacher.

The example in Box 3 illustrates how until James's stress and anxiety were dealt with, he was not going to concentrate on other tasks required of him. His stress acted as a sufficient distracting mechanism, and he was not able to process any other information. In this example, James's stress was generated from 'anticipation' and from the prospect of a 'change' in environment, and this was not acknowledged by the teacher. The classroom assistant was able to reassure James so that he could get on with his work.

Effective means need to be in place to communicate with children, and the use of visual cues in scheduling, is an important component of helping the person to understand what is going on. A study by Cihak (2011) found that children with autism began transition between activities

in the classroom more independently after being exposed to visual schedules. The use of scheduling should be a standard process of enabling communication for micro activities in a day service, an employment placement or respite care; it should also be used to explain larger scale events such as a transition to different services.

Leaving communication to the last possible opportunity to avoid the person becoming anxious is not good practice. Best practice should be engaging people in the transition in a way that helps them to understand the planned process of change. This varies from person to person, but even people with severe

### BOX 3

#### Example of transition

**9.30am:** James says: 'I will take four videos.' The teacher says: 'No, I have said no videos to be taken to Bewley Camp.' James says: 'Just one video, please, just one video, okay Mr Adams?'

Mr Adams gets on with taking the class: 'Yes, now Jack, you will be a prison officer, Simon a pig farmer, and Sam Clarke is going to be a photographer'. James says: 'Mr Adams is being silly'. James is still unconvinced that the teacher will let him take a video with him to Bewley Camp. Almost ten minutes later James initiates communication with Mr Adams.

**9.39am:** James calls 'Mr Adams', the teacher looks over to James, and James lifts his shirt showing his abdomen. The teacher says 'Put it away', and James says: 'Just one video for Bewley Camp, just one more, just one more, just one video, just one video.'

**9.43am:** Lesley, the support assistant, comes in and hears James. She says: 'Yes you can keep it in your bag,' and she prompts him to get on with his work.

learning difficulties and autism should be engaged in the transition process through the use of ideas such as:

- ▶ A visual long, thin map, such as a wallpaper border, with events that the person recognises, such as birthdays and Christmas, which is used to count down to an event such as changing services or respite care locations.
- ▶ A large wall calendar with marked monthly or weekly events (depending on the person's

ability to understand), which could be in the form of photographs. People could be helped to understand what they will be doing that day. The photographs could be removed at the end of the day and new photographs put in the next morning.

- ▶ Others may be at the point of understanding 'now' and 'later'. The use of Makaton signs of now and the picture of an activity can be presented, then a Makaton sign of later with an alternative picture presented.

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## Summary

This guide highlights the need for more training in autism awareness for people who have a specialist role working in learning disability and mental health services. A move beyond 'basic' awareness to understanding autism from a sensory domain is needed, and this includes the areas required for 'reasonable adjustments' under the Equality Act 2010. Training in autism should be facilitated with people with autism so that real examples can be used to illustrate the key areas of support.

Enabling access to services requires challenging barriers in the environment, with the use of communication and information, and challenging general societal attitudes. It is, however, the vision of the Autism Strategy and within the jurisdiction of the Autism Act that the legislation is in place to promote a greater enablement and contribution of people's talents. The challenge will be to argue and lobby for the use of 'reasonable adjustments' (Equality Act 2010) which will be the driver to enable effective long-lasting change to occur.

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**TABLE 5**

**Motivation Assessment Scale (Durand 1990)**

Name \_\_\_\_\_ Rater date \_\_\_\_\_

Behaviour description  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Setting description  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Instructions: The Motivation Assessment Scale is a questionnaire designed to identify those situations in which an individual is likely to behave in certain ways. From this information, more informed decisions can be made concerning the selection of appropriate prevention, distraction and management strategies. To complete the questionnaire, select one behaviour that is of particular interest. It is important that you identify the behaviour very specifically. 'Aggressive', for example, is not as good a description as 'hits his sister'. Once you have specified the behaviour to be rated, read each question carefully and circle the one number that best describes your observations of this behaviour.

0 = Never, 1 = Almost Never, 2 = Seldom, 3 = Half the Time, 4 = Usually, 5 = Almost Always, 6 = Always.

Questions	Never 0	Almost never 1	Seldom 2	Half the time 3	Usually 4	Almost always 5	Always 6
1. Would the behaviour occur continuously, over and over, if this person was left alone for long periods of time? For example, several hours.	0	1	2	3	4	5	6
2. Does the behaviour occur following a request to perform a difficult task?	0	1	2	3	4	5	6
3. Does the behaviour seem to occur in response to your talking to other people in the room?	0	1	2	3	4	5	6
4. Does the behaviour ever occur to get a toy, food or activity that he or she has been told they cannot have?	0	1	2	3	4	5	6
5. Would the behaviour occur repeatedly in the same way for very long periods of time if no one was around? For example, rocking back and forth for over an hour.	0	1	2	3	4	5	6
6. Does the behaviour occur when any request is made of this person?	0	1	2	3	4	5	6
7. Does the behaviour occur whenever you stop attending to this person?	0	1	2	3	4	5	6

Continued over page

**TABLE 5**

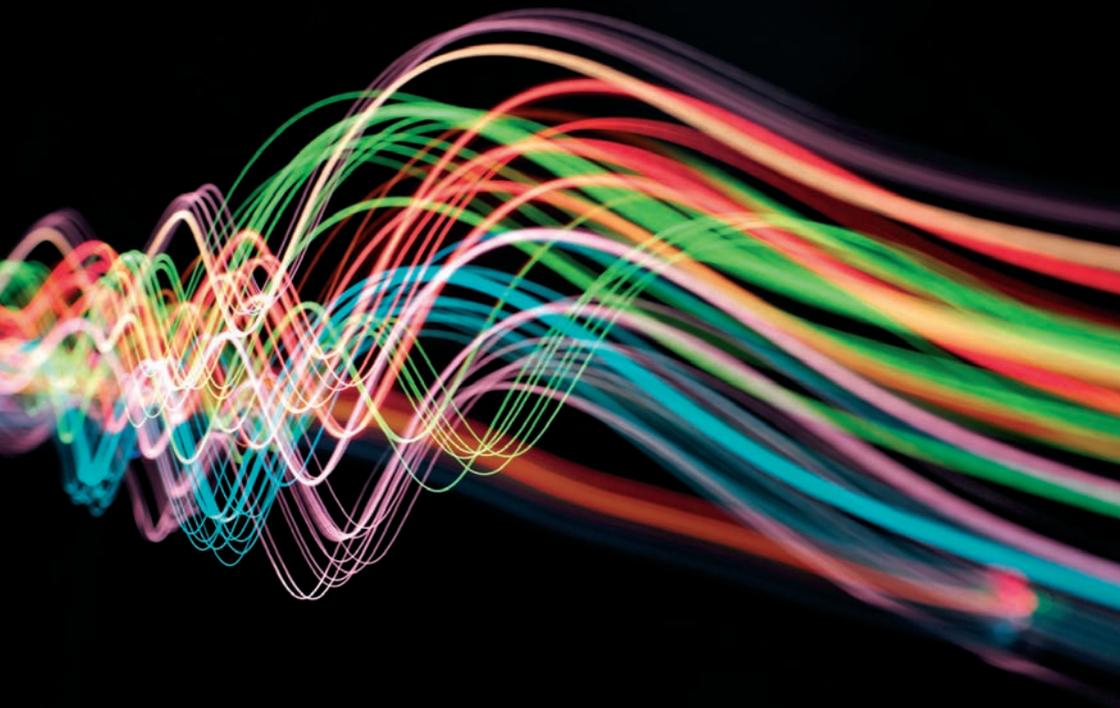
**Motivation Assessment Scale**

Questions	Never 0	Almost never 1	Seldom 2	Half the time 3	Usually 4	Almost always 5	Always 6
8. Does the behaviour occur when you take away a favourite toy, food or activity?	0	1	2	3	4	5	6
9. Does it appear to you that this person enjoys performing the behaviour? (It feels, tastes, looks, smells and/or sounds pleasing?)	0	1	2	3	4	5	6
10. Does this person seem to do the behaviour to upset or annoy you when you are trying to get him or her to do what you ask?	0	1	2	3	4	5	6
11. Does this person seem to do the behaviour to upset or annoy you when you are not paying attention to him or her? For example if you are sitting in a separate room, interacting with another person.	0	1	2	3	4	5	6
12. Does the behaviour stop shortly after you give the person the toy, food or activity he or she has requested?	0	1	2	3	4	5	6



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