ESSENTIAL GUIDE

Developing specialist skills in autism practice

RCNi LEARNING DISABILITY PRACTICE MENTAL HEALTH PRACTICE

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Introduction

The Autism Act 2009 was a remarkable outcome of a campaign to lobby for a change in the way services are planned for, and delivered to, people with autism and their families.

The act was drafted by the National Autistic Society supported by a coalition of 16 autism organisations and the All Party Parliamentary Group for Autism. A strategy paper, Fulfilling and Rewarding Lives (Department of Health (DH) 2010a), was produced with a three-year delivery plan (DH 2010b) and guidance to implement the strategy (DH 2010c). However, a critique of the implementation of the Autism Act 2009 to date suggests that local authorities are not required to measure themselves against the outcomes and ambitions in the implementation guidance, which may result in varying levels of implementation of the act (Walsh and Hall 2012).

Walsh and Hall (2012) also question the level of integration across mental health and intellectual disabilities services of the strategy paper and of signposting to specialist services.

A review of Fulfilling and Rewarding Lives (DH 2010a) was undertaken and The Strategy for Adults with Autism in England: An Update (DH 2014) was produced. This report generated 15 priority challenges for action that reflected a more personalised care and choice agenda. These priority challenges were expected to deliver the specific legislative requirements of the Autism Act 2009, which seeks 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 (ASD).
- Ensure that the diagnosis of autism is accompanied by an assessment of need. Before the act, 'more able' people with autism were accessing community care assessments, and of those who did only 45% were receiving services specified in the assessment (Loynes 2001).
- Provide all children who have received a diagnosis and thereby a statement of ASD with a '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 were unaware of the number of people with an ASD living in their locality, despite having to be able to identify them to plan to meet their individual needs adequately.

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 a building or providing information in an accessible format. It is inappropriate to wait until a person with a disability seeks to use a service because the act requires public sector organisations to 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 may help professionals to identify and plan to meet the needs of adults with autism, while making 'reasonable adjustments' to the services.
- Provide a clear pathway for the development of leaders in the field of autism in health and social care to 'champion' the implementation of the Autism Act 2009.

This guide is intended for people in specialist roles who will lead and influence the planning, development and commissioning of services with local authorities and clinical commissioning groups. Most GPs think that they need additional guidance and training to manage patients with autism more effectively (National Audit Office 2009) and the Royal College of General Practitioners (RCGP) has identified autism as an area of clinical priority.

The RCGP has various resources on its website shared and updated by champions who share best practice in this area (www.rcgp.org.uk). In addition, a comprehensive clinical text book has been produced for GPs (Durand 2014) as well as more autism-specific resources to promote 'well health' among people with autism (Geslak 2014).

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 number of people diagnosed with autism has increased globally and in one Scandinavian study has been found to have increased eightfold (Idring *et al* 2014) with the increase attributed to diagnosis of ASD in people without intellectual disabilities. There has been a broadening of the diagnostic criteria for autism (Idring *et al* 2014, Chamak and Bonniau 2013) as well as an increase in the diagnosis of adults.

The rise in the rate of diagnosis of autism in England has been influenced by increased awareness raising through the introduction of three National Institute for Health and Care Excellence (NICE) guidelines (NICE 2011, 2012, 2013) and one quality statement (NICE 2014) on autism.

It is hoped that the guidelines and the quality statement will reduce variations in clinical practice by requiring every district to set up a multi-agency team with responsibility for providing an autism diagnostic service. A single point of referral should be made to the team and all team members should be clear about the process. Diagnosis should start within three months of referral. In addition, the team should provide training to professionals to ensure that they are aware of the signs of autism. This should include training for GPs.

The widening of the diagnostic criteria has generated some concern that the condition of autism is still overwhelmingly defined through the lens of a 'medical model'. The medical model has been critiqued for emphasising deficiencies, 'pathologising difference' and ignoring each person's qualities (Mogensen and Mason 2015).

Mogensen and Mason (2015) also argue that the findings from their research suggest too much focus on the negative connotations attached to the diagnosis and they call for a minimising of stigma and marginalisation associated with the diagnosis of autism. This is supported by Dr Temple Grandin (Grandin 1996), a woman with autism, who calls for a rejection of the stigma associated with autism and for the condition to be recognised as 'difference' rather than 'detriment'. If good information is provided by professionals at an individual level, a diagnosis of autism can be positive and can help the person so diagnosed form a better understanding of the condition (Mogenson and Mason 2015).

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. Training based on a medical model is insufficient because it provides information on the 'condition of autism' with insufficient emphasis on how the environment influences the behaviours presented.

Some environments can be enabling while others can be disabling (Swain *et al* 1993). A social model of understanding autism is needed (Aylott 2003), therefore, so that professionals can understand how barriers in health and social care can have disabling and distressing effects on people with autism, especially if service providers lack knowledge of autism and fail to make reasonable adjustments.

People with autism are sometimes said to have an 'invisible' impairment, and identifying how reasonable adjustments can make services more accessible is not always easy. But, reasonable adjustments can 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.
- Written communication, by exploring how this can be better presented to enable more effective processing by people with autism.
- Verbal communication, by exploring how this and non-verbal communication can be adapted to ensure better understanding by the person with autism.

This guide also discusses the development of the skills in, and knowledge of, autism practice. These include:

- Autism as a sensory perception impairment.
- 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 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). There is a movement away from the medical model, in which autism is defined as a disorder, towards an understanding of it as a condition characterised by specific behaviours, some of which are idiosyncratic, that may be seen in some environments but not in others. This definition suggests that people with autism spectrum conditions are disabled by factors external to themselves, and so recognises autism as an impairment that can have positive and negative aspects depending on environmental stimuli.

TABLE 1

Eight areas of stress identified by the Stress Survey Schedule

Area of stress	Example situations
1. Changes and threats	Having a cold; changes in tasks and new directions; going shopping; changes in environment; transitions in locations; transitions from preferred to not preferred activities; engaging in disliked activities; being unable to communicate; needing to ask for help; participating in group activities.
2. Anticipation and uncertainty	Changes in plans; waiting for activities; having unstructured time; waiting generally.
3. Unpleasant events	Waiting to talk about desired topics; personal objects being missing; following diets; receiving criticism and being told 'no'; having things marked as incorrect; changes of teacher; losing at games.
4. Pleasant events	Receiving presents; playing with others; receiving reinforcements; having things marked as correct; receiving tangible reinforcements; receiving verbal reinforcements; having conversations.
5. Sensory/personal contact	Being in the vicinity of noises or disruptions by others; being touched; receiving hugs and affection; feeling crowded.
6. Food-related activity	Waiting at restaurants; waiting for food.
7. Social/environmental interactions	Being in the vicinity of bright lights; inability to be assertive with others; someone else making mistakes.
8. Ritual-related stress	Having personal objects or materials out of order; being prevented from completing or carrying out rituals; being interrupted while engaging in rituals.

(Adapted from Groden *et al* 2001, Goodwin *et al* 2007)

The official diagnostic criteria offered in the latest Diagnostic Statistical Manual (DSM-5) (American Psychiatric Association 2013) and International Classification of Diseases (ICD-10) (World Health Organization 2015) refer to autistic spectrum disorders, but people with autism and their families may prefer the term autism spectrum condition. This guide uses the term autism spectrum condition.

Defining autism to guide best practice

The diagnostic criteria for autism spectrum conditions changed between DSM -IV and DSM-5 (American Psychiatric Association 2013) and there is now a broader diagnostic framework to help understand the complexity of the autism spectrum (Young and Rodi 2014).

A diagnosis of an autism spectrum condition will help to signpost appropriate services, and enable recognition and awareness that barriers in the environment may need to be challenged to ensure effective access to health and social care services.

This section explains barriers presented by: :

- Environments and sensory issues.
- Communication and information, and cognitive processing issues.

- Attitudes of health and social care workers.

The section 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' can 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 a growing awareness of stress in people with 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 (Groden *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 prominent and could apply to people or locations. In Nobody Nowhere, Williams (1998a) 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.'

A study by Gillott and Standen (2007) also identifies elevated levels of anxiety in adults with autism compared with adults with intellectual impairments. The types of anxiety with high scores were panic or 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 or 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 become unable to speak, instead sitting in a corner and rocking. Other people with exposure anxiety may 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

About 70% of people with autism have a 'sensory perceptual impairment' (Cascio *et al* 2008). Leekam *et al* (2007) found that 90% of children with autism had sensory abnormalities, while 94.4% 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.'

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 *et al* 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 (synaesthesia). 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)

Sensory abnormalities exist across all five sensory modalities, as well as kinaesthetic and proprioceptive sensation (Harrison and Hare 2004). Table 2 summarises the specific 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 people in different ways:

- A 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 be unable to process verbal instruction and will need support to come out of this state of sensory overload.

Various tools to assess sensory dysfunction, including the Sensory Profile (Dunn 1999, Kern *et al* 2007) and the Diagnostic Interview for Social and Communication Disorders (Leekam *et al* 2007), are available. Both of these instruments are complex and are generally used by trained psychologists or psychiatrists.

A more accessible instrument for practitioners is the Sensory Behaviour Scale (Harrison and Hare 2004) (Table 3), 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, page 11, gives an example of this. 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. A 'sensory curriculum' could ensure that the service commissioned on behalf of the individual is suitable and appropriate.

Barriers in the environment

Lighting, sound (acoustics), patterned flooring and walls or stripes on radiators can 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 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

TABLE 3

Outline of the Sensory Behaviour Scale

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

(Adapted from Harrison and Hare 2004)

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 and 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 the surroundings. In appointment rooms or college or university classes natural daylight is preferred and, 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. Individuals on the autism spectrum have difficulties self-initiating the use of learning and memory strategies, and need support from others to organise information (Couzens *et al* 2015). This suggests a more pro-active strategy of support ios needed, using a range of different prompts to encourage independent thinking. Recent work in this area supports young people to develop self-prompting of daily living skills with the use of iPods and iPhones (Cullen and Alber-Morgan 2015).

Staff members must be proactive to identify factors that cause people distress and to suggest courses of action under the Equality Act 2010. Some adults with autism spectrum conditions may develop management strategies in these environments, perhaps because they have been supported by family members and support staff to reflect on ways to deal with such situations. Others may need help in managing these situations, and staff will need to recognise when the person is being

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. Rory's mother 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 auditory, kinaesthetic, olfactory, proprioception and vestibular categories.

It was identified in a planning meeting that Rory flaps his wrists, and jumps up and down (kinaesthetic), while watching his favourite DVDs. The respite care service has only one TV, 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.

'Reasonable adjustments' in the service require consideration of Rory's vestibular needs and his unsteadiness of gait. Appropriate planning is needed for him to avoid crowded areas.

'saturated by stimuli' so that they can enable the person to withdraw and adjust to a more moderate environment

Some people may be unable to cope with additional stimuli in environments they already find difficult. 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.'

BOX 2

Environmental audit for access

1. **Lighting** Some flickering lights can cause difficulties if present in a consulting room, whereas natural light may have a more relaxing effect.

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 become unable to process standard information.

4. **Spatial** Rooms should be large enough for people to define the spatial distance between themselves and the hospital staff member. Confined spaces can cause excessive stress.

5. **Transition** People with autism should be supported to take an item of their 'special interest' that can calm them in strange environments.

One reasonable adjustment would have been to request that staff wear clothing without patterns while supporting her at university.

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 to new people, before the day they attend the hospital appointment, the new college class or the induction day at 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 hospital or social services appointments.
- Taking people on trial visits to meet the staff and see the environment without any intervention occurring.
- On the day of planned interventions, introducing people to photographs of those who will carry out the procedures.
- Undertaking virtual visits to hospitals using software that orientates people to environments, and replicates the level of sound and acoustics in that environment.

Communication and processing

Some 'reasonable adjustments' to staff members' communication methods can be made. In unfamiliar environments, a lot of verbal information sounds like general noise and is not processed by people with autism. 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) compared static picture scales and video-based schedules and found no single preferred means of visual communication that was more effective.

This suggests that visual schedules should be tailored to individuals, or generalised to enable better access rather than relying on verbal or written instructions. 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. Appointment letters can be better set out in a landscape format so that the events of an appointment can be scheduled from left to right. DH guidance has been issued on best practice in producing 'easy read' (DH 2010d).

More effort should be made to listen to people with autism, and all services should create 'communication profiles' with people with autism and their families to find out how best to communicate with them. Not touching people without asking first 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 can be provided in the communication profile (Table 4, page 14). It is important to:

- Avoid excessive verbal communication that is without instruction.
- Avoid the use of sarcasm and unnecessary body language.
- Focus on listening to the person's non-verbal communication, and watch for signs of increasing stress and exposure anxiety.

Sensory perceptual difficulties mean that some people with autism will fail to orientate themselves when their names are called (Cascio *et al* 2008). People should always be referred to by the name they recognise. When a request is made, people with autism should be allowed a few seconds to orientate themselves without the instructions being repeated immediately or the language being changed.

Understanding behaviour

Not all behaviour presented by people with autism has a sensory origin. Behaviour often serves as a way of communicating when people may not have the language necessary to communicate. As an awareness of the role of sensory perceptual difficulty in autism grows, differentiating between four possible functions for behaviour becomes important. These functions 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 in teams 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. This is illustrated in the following examples.

Mary lives in a supported living environment with two other people with autism. Staff members are worried about Mary's behaviour. They explain that every time a member of staff approaches Mary, she

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.)

Question	Example
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 understood, 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.

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 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.

Changing personal behaviour

Staff need to adapt their behaviour, when communicating with the person with autism. Agreements about how staff change their behaviour should be informed by communication profiles. Every effort should be made to explore the function of behaviour.

People with autism may not have the words they need to explain pain, even if they have spoken language. A young man with a 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.

Understanding sensory impairments can help caregivers to overcome their prejudices in caring for people who relate to the senses close to their bodies. It can also help to ask the right questions when developing an understanding about complex and challenging behaviour. Guidance on desensitising people with autism to members of staff can take time and should be explained in communication profiles.

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 some people with autism have exceptional talents there is still a tendency to stereotype people with autism as having some form of genius. This results in a general societal prejudice about autism, suggesting there is a need to provide a more mainstream understanding about autism as 'difference'.

Diagnosis and services

The Autism Strategy (DH 2010a) recognises that there is a stigma associated with autism that affects people with the condition and their families, and the Autism Act seeks to remove it. How the diagnosis is given to people with autism and their families can be unsatisfactory.

In a study of 25 families with a total of 28 children with autism spectrum conditions aged between three and 19 years, Beresford *et al* (2007) found that parents had experienced negative communication about their children's diagnosis of autism. NICE guidance in this area has been published (NICE 2011, 2012, 2013).

In a National Autistic Society (2010) survey of 1,400 adults with autism and carers, 63% 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 social impairments clearly need support, which will be the responsibility of lead professionals 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.

While a diagnosis might provide a signpost for support, there is still no post-diagnostic service in most areas. Carers and families live with high levels of stress, and they should be made aware of their right to request an assessment. As GPs become aware of the needs of people with autism, individuals should be encouraged to discuss issues with them. Guidance on this is available on the RCGP website (www.rcgp.org.uk).

Transition

Children with autism between the ages of 13 and 19 years need transition plans. Health action plans 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 2010e).

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 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 that James's needs were not addressed in a communication profile, which caused general confusion and inconsistency when staff communicated with him. The names of the people in this example have been changed to preserve their anonymity.

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. 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. This varies from person to person, but even people with severe learning difficulties and autism should be engaged in transition processes by use of, for example:

- 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.

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

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.

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

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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 (Durand 1990)

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

13. When the behaviour is occurring, does the person seem calm and unaware of anything else going on around him or her?	0	1	2	3	4	5	6
14. Does the behaviour stop occurring shortly after (one to five minutes) you stop working or making demands of this person?	0	1	2	3	4	5	6
15. Does this person seem to do the behaviour to get you to spend some time with him or her?	0	1	2	3	4	5	6
16. Does the behaviour seem to occur when this person has been told that he or she can't do something he or she had wanted to do?	0	1	2	3	4	5	6

Results	**Sensory**	**Escape**	**Attention**	**Tangible**	
	1.	2.	3.	4.	
	5.	6.	7.	8.	
	9.	10.	11.	12.	
	13.	14.	15.	16.	
Total score					
Mean score					
Relative ranking					

The questionnaire is designed so that you look at what response you gave to each question and you insert the number for that question next to it. You then complete this process for all 16 questions and add up the total score in each of the four columns. The column with the highest number is the likeliest function of the behaviour. This is, however, not a definitive answer and other forms of data collection, such as ABC charts, should to be used to gain a wider picture.