Chapter 16

WORKING WITH PEOPLE WITH AUTISM

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INTRODUCTION

The reported prevalence rates of Autistic Spectrum Disorders (ASD) have risen dramatically over the last few decades. The reason for this increase is not fully clear but is likely to be due in part to increased recognition by parents and professionals, improvements in diagnostic services and a greater understanding of the range of symptoms that would be included within diagnostic assessments. Current prevalence rates suggest 1 in 100 people will have a broad range of presentations across the Autistic Spectrum (Baird *et al*. 2006).

Initial research indicated that 70% of children with ASD had associated Learning Difficulties (Rutter and Schopler 1987) although it is now believed that 75% of people with ASD have IQ within the normal range (MRC 2001). However the co-morbidity of learning disability and ASD is high (Emerson and Hatton 2007) and as such, whilst working with children and young people with learning disabilities, you will find yourself working with someone who has a diagnosis of autism.

DEFINITIONS

Childhood Autism was originally described by Leo Kanner in America in the 1940s although other, less systematic accounts can be seen throughout the literature before this time.

Kanner identified a group of children who had difficulties with social interaction and communication and who had a need to maintain sameness in their environment and interactions (Kanner 1943). He also identified that these children had difficulties with the development of their play skills and he reported that their emerging skills lacked the level of creativity and imagination seen in typically developing children. Kanner used the term 'Early Infantile Autism' to describe these children.

At around the same time, Hans Asperger also described a group of children who had similar difficulties in the areas of social communication, obsessional interests and a need for routine and sameness (Asperger 1944). He reported that these children were also clumsy but that they did not have any obvious cognitive or language difficulties, being of average, or above average, intelligence. Asperger identified these children as having 'autistic psychopathology'.

The terms Childhood Autism and Asperger's Syndrome have subsequently been used to identify children (and adults) with a range of difficulties in the areas of social interaction, social communication and imagination/flexible thinking. This cluster of difficulties has been referred to as the 'triad of impairment' (Wing and Gould 1979). In addition to this triad of difficulties, children and adults may display repetitive behaviours, have a need for routine/sameness and have difficulties in processing sensory information.

Individuals will vary greatly in how they are affected by autism and each person will have particular strengths as well as difficulties that are caused by their autistic thinking styles and behavioural patterns. However, all individuals who are diagnosed with an Autistic Spectrum Disorder will have core difficulties within the triad and these will impact on their ability to link into the world around them.

Formal diagnostic descriptions of Autistic Spectrum Disorders are listed in DSM IV (American Psychiatric Association 1994) and ICD 10 (World Health Organisation 1993). The range of diagnoses considered includes: Autism, Asperger's Syndrome and Pervasive Developmental Disorder. There is debate regarding whether the diagnoses defined within these manuals are discrete disorders and it is more widely viewed that the range of difficulties presented fall within a spectrum of difficulties. Wing and Gould (1979) introduced the term 'Autistic Spectrum Disorders' (ASD) in order to encapsulate the wide variety of behavioural presentation that occurs across the triad of impairment. The view of a spectrum can help with understanding the range of difficulties experienced by people with ASD but can lead to a view that some forms of autism (e.g. classical autism) are more severe than others (such as Asperger's Syndrome). It is important to recognise that the impact of having ASD can vary significantly and underlying impairments may result in major difficulties for individuals that cannot be wholly mediated by greater cognitive ability. Debates over name continue as some

people with autism, would also much rather the term 'Autistic Spectrum Condition' was used as they feel that 'disorder' has unnecessarily negative connotations. Understandably and more accurately; they would prefer the autistic thinking style to be acknowledged as simply being 'different' and celebrated for that difference.

CAUSES OF AUTISM

At present, a single, specific cause for Autism has not been identified. More recently, it has been proposed that there is not a single cause of autism but that ASD is a complex disorder with a range of core difficulties that may have distinct, and differing, causes (Happé and Ronald 2008).

Early theories of Autism focussed on the parent-child relationship. Kanner (1949) proposed that children developed Autism as a result of lack of parental warmth and this was further developed by Bettleheim (1963) who suggested that the mothers of children with Autism were cold, distant and rejecting. These theories of 'refrigerator mothers' lead to parents of children with Autism feeling guilty and blamed but such theories have now been soundly discredited.

Research has suggested that pre-birth complications may increase the likelihood of children developing ASD (Deykin and MacMahon 1980; Glasson *et al*. 2004). The causal nature of this relationship is not clear however and other research suggests that, while pregnancy complications are common in women whose children are later diagnosed with ASD, this may result from the foetus already having genetic difficulties rather than the complications causing problems for the foetus. (Zwaigenbaum 2002).

More extensive research indicates that individuals with ASD show some differences in brain structure and development which may account for the range of difficulties that they experience (Courchesne *et al*. 2001; Sparkes *et al*. 2002; Acosta and Pearl 2004). There is no single primary structure or pathway identified in the literature but a number of different sites within the brain have been implicated (e.g. amygdala, orbito-frontal cortex, medial frontal cortex) and research is ongoing.

Running parallel to the research on brain function is research into genetic factors. Again, no single gene has been identified as responsible for Autism but a number of genes appear to be implicated in children and adults with ASD (Muhle *et al*. 2004). This is strengthened by clinical observation which highlights that many families appear to have family histories of ASD or other associated difficulties (e.g. speech and language impairment, dyspraxia). It is known that a number of individuals with other genetic syndromes also have an increased likelihood of having an Autistic Spectrum Disorder (e.g. Tuberous Sclerosis, Fragile X, Congenital Rubella Syndrome and untreated Phenylketonuria).

Wakefield (1998) suggested a link between Autism and MMR immunisations. This research led to much public debate but the article was fully retracted by The Lancet in February 2010. A population study of over 30,000 children in Japan (Honda *et al*. 2005) looked at the incidence of Autism following the withdrawal of MMR as a consequence of concerns of a link to meningitis. The incidence of ASD continued to rise in line with countries where MMR was still routinely given to children suggesting that MMR vaccination was not a causal factor in increased rates of ASD.

PSYCHOLOGICAL THEORIES OF AUTISM

There are three main cognitive theories of Autism that dominate the literature: Theory of Mind Deficit, Executive Dysfunction and Weak Central Coherence (Rajendran and Mitchell 2007).

Theory of Mind

'Theory of mind' is the ability to reflect on one's own, and other's mental states minds and allows an individual to read the intentions of others. It was proposed that people with Autism lack this ability and as such struggle to understand the thoughts and intentions of others. Various tests of theory of mind have been invented; the most well known of which is probably the 'Sally Anne' test. The interviewer animates two dolls; 'Sally' and 'Anne'. Anne has a marble that she puts in her basket. She then leaves the room and Sally moves the marble and puts it in a box. The interviewer asks the interviewee where Anne will look for her marble. To answer correctly, the interviewee has to be able to acknowledge that they have seen Sally move the marble but 'Anne' did not. Therefore Anne will look for the marble in the basket because that is where she left it. If the interviewee cannot put themselves in Anne's shoes they will say that she will look in the box because that is where they know it to be.

'Neuro-typical' children (children without ASD) have the ability to track what others are thinking by the age of four years (Wellman, Cross and Watson 2001), (Wimmer, and Perner 1983). When using a test of Theory of Mind, based on that developed by Wimmer and Perner, with a group of children with ASD, Baron Cohen *et al*. (1985) found that 80% of these children were unable to succeed at the task leading him to conclude that people with ASD had a deficit in this area. However, 20% of the group were able to complete the task and as such, Baron-Cohen later adapted his theory to suggest that this was an area of delay rather than

deficit in people with ASD (Baron-Cohen 1989). Further research has focussed on using more difficult theory of mind tests but again results have not always been conclusive with some researchers showing larger numbers of people with ASD being able to infer the states of minds of others (Bowler 1992).

As a result of differing findings from the Wimmer and Perner tests, further tasks have been developed to assess the ability to infer states of mind from contextual information focussing on language and face processing in ASD, e.g. The Strange Stories test (Happe 1994), The Eyes Task (Baron-Cohen *et al*. 1997) which again identify that people with ASD may have difficulties identifying the thoughts and emotions of others.

Executive Dysfunction

The Executive Dysfunction theory of Autism stemmed from research into Specific Brain Injury that hypothesised similar symptom presentation between people with Autism and those experiencing Dysexecutive Syndrome as a result of an Acquired Brain Injury (Ozonoff *et al*. 1991). 'Executive function' refers to the process underlying control of actions, namely attentional control, initiation, planning, inhibition of unwanted responses, flexibility of thought and action and decision making; all known to be areas of difficulty for people with autism.

Research findings have provided mixed support to the Executive Dysfunction theory of ASD; ranging from 96% of people with ASD showing deficits in Executive Function (Ozonoff *et al*. 1991) to only 50% (Pellicano *et al*. 2006). Research authors have also questioned the uniqueness of Executive Dysfunction to ASD, finding similar difficulties in groups of individuals with other psychiatric disorder including ADHD, OCD, Tourette Syndrome and Schizophrenia (Ozonoff and Jensen 1999).

Weak Central Coherence Theory

Central coherence explains the ability to integrate information into context and extract overall meaning from experiences and situations. For example, the person may find it difficult to integrate someone saying 'I'm sorry'; with a facial expression that indicates otherwise; in the context of the person complaining about something they find unacceptable. The theory of weak central coherence addresses the trait of attention to detail that is found in people with ASD and hypothesises that people with ASD process information by focussing on component parts as opposed to the

whole picture (Frith 1989). Tests used to identify central coherence include the 'Children's Embedded Figures Test' (Witkin *et al*. 1971) where researchers have found that people with ASD perform better than matched controls suggesting that they were able to focus on component parts of the test without being distracted by the global whole (Shah and Frith 1993). Again, researchers have found conflicting results when reviewing theories of central coherence and it is not considered to explain all difficulties experienced by people with ASD (Happe and Frith 2006).

In summary, the three main cognitive theories of Autism account for a number of the difficulties experienced by people with ASD but no single theory is able to account for the range of problems experienced. It is likely that no one theory will ever explain such a complex disorder (Ozonoff *et al*. 1991) but that a multiple-deficit account, drawing on a number of different theories will help understand the experiences of people on the Autistic Spectrum.

In addition to the peer reviewed literature, there are numerous first-hand accounts of ASD, which provide a valuable insight into the experiences of those with a diagnosis of ASD and propose alternative views on the underlying strengths and deficits experienced by people with ASD (Lawson 2000; Williams 1996; Grandin 2006). This literature tends to better convey the more positive aspects of the autistic experience and the strengths of the autistic thinking style (http://www.wrongplanet.net/postt40354.html; http://autism.about.com/od/postiveaspectsofautism/Postive_Aspects_of_Autism.htm).

ASSESSMENT AND DIAGNOSIS

The assessment process is often quite complex and sometimes families and individuals with autism are less interested in the eventual diagnosis at the end of assessment than in the process itself. Some people find the end diagnosis reassuring; having always felt 'different'. Unfortunately, some find that only a formal diagnosis will help them gain access to appropriate services and support. However, others take the view that the main aim of an assessment should be to give a better understanding of an individual's profile; their strengths and difficulties and the type of support they might need and that this, rather than a diagnosis per se, that needs to drive the assessment.

The development of good practice guidelines and tools to aid diagnosis has tended to focus on children and adolescents but much of the good practice can be extrapolated to adult settings. The National Autism Plan for Children (NAP-C; NIASA 2003), highlights a code of good practice for assessment in children. It suggests that assessment should be multi-disciplinary and should involve assessment by Child Psychiatrists/Community Paediatrician, Clinical Psychologists, Speech and Language

Therapists and Educational Psychologists. It sets targets for the length of an assessment process and gives families a guideline as to what an assessment should look like. It notes, for example, that as part of the process there should be:

- a medical overview – screenings as necessary;
- a developmental history;
- observations of the child across settings;
- use of semi structured interviews (such as the Autism Diagnostic Interview or the Autism Diagnostic Observation Schedule – see below);
- an assessment of communication.

and in some cases; a cognitive assessment.

The developmental history is essential to an assessment of Autism as it should highlight that problems with social communication and inflexibility have existed from the child being an infant or from the adult being a child. By its nature; autism takes a developmental path; therefore even with very young children; there may be areas of development that can be identified as being unusual. Filipek *et al*. (1999) identified a number of Red Flags for Autism and these can be used as a basis for questioning parents of young children who are being seen for assessment (see Table 16.1).

Questions also need to ascertain that the difficulties are pervasive across settings. For example; as children get older; information about social skills can be gained by asking about their relationships at nursery and at school. Is it just parents or do teachers and support workers show concern about the child and what exactly have they noticed that they feel is different?

Taking a developmental history will constitute at least two sessions as you will need to be absolutely sure that you have exact details about an individual's:

- social development;
- communication style;
- special interests;
- repetitive behaviours;
- ability to be flexible (in actions and thought);
- sensory issues;
- additional difficulties with learning;
- additional difficulties with coordination;
- strengths and motivators.

How does the individual fill their time? What happens when routines are changed? When there is a different route home from school or if they have to go and see the dentist rather than returning home as usual? What motivates the individual? What is the parent/carers experience of having a

Table16.1 Filipek's red flags for autism.

Key issues in early infant development

- No big smiles or other warm, joyful expressions by six months or thereafter.
- No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter.
- No babbling by 12 months.
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months.
- No words by 16 months.
- No two-word meaningful phrases (without imitating or repeating) by 24 months.
- Any loss of speech or babbling or social skills at any age.

Other indicators that may cause concern

- The child does not respond to his/her name.
- The child cannot explain what he/she wants.
- The child's language skills are slow to develop or speech is delayed.
- The child doesn't follow directions.
- At times, the child seems to be deaf.
- The child seems to hear sometimes, but not other times.
- The child doesn't point or wave 'bye-bye.'
- The child used to say a few words or babble, but now he/she doesn't.
- The child throws intense or violent tantrums.
- The child has odd movement patterns.
- The child is overly active, uncooperative, or resistant.
- The child doesn't know how to play with toys.
- The child doesn't smile when smiled at.
- The child has poor eye contact.
- The child gets 'stuck' doing the same things over and over and can't move on to other things.
- The child seems to prefer to play alone.
- The child gets things for him/herself only.
- The child is very independent for his/her age.
- The child does things 'early' compared to other children.
- The child seems to be in his/her 'own world.'
- The child seems to tune people out.
- The child is not interested in other children.
- The child walks on his/her toes.
- The child shows unusual attachments to toys, objects, or schedules (i.e., always holding a string or having to put socks on before pants).
- Child spends a lot of time lining things up or putting things in a certain order.

conversation with their child? Even for children without formal language; parents can often give evidence of conversational 'babble'; of turn taking in making noise. For individuals who can speak; ask parents/carers how it feels to have a conversation with them. Does it feel comfortable? Is there the normal to and fro quality of speech and is the person able to integrate gesture into conversation? Many people with autism find this kind of verbal/non verbal integration difficult. Some individuals can speak eloquently about topics they enjoy but do not converse about other things; others will talk in monologues leaving their conversational partner little room to join them. Carers may speak about conversations being 'one sided' and rather rigid and note that their individuals fails to pick up on their normal social cues that they need to end the conversation or that they want to inject a comment into it. How does the person express their emotions? What do they do well?

As with any assessment you will need to consider contextual factors such as the environment in which the child is living; their school experiences; any trauma or past history of neglect or abuse; factors which may provide alternative explanations to behaviours that may be puzzling or unusual. One must always consider differential diagnoses such as Specific Language Impairments, Attachment Difficulties or Developmental Co-ordination Difficulties and consider why these might be ruled out and why ASD is a better fit.

A good developmental history is often easier to obtain for children as they are usually still living with their parents who can give a fairly good account of the child's early years. However, it can be more complicated when assessing an adult as they may no longer have relatives who can remember their early years. In this instance; it is important to try and get hold of medical records to look for that developmental trajectory of difficulties. It is also helpful to talk to friends and carers who know the individual now to get a sense of current functioning. With adults, one can ask more questions about how social relationships have evolved; how the person has managed relationships with prospective partners; how they individual functions at work. Rather than discuss play, one can think about current leisure activities and interests and how the person pursues those. As we get older we have more choice over how and what we do and this can in itself be revealing as a person who finds social contact stressful may avoid that contact more easily and pursue gaming activities on the internet or more solitary leisure pursuits.

It is undoubtedly useful to be aware of semi structured interviews such as the Diagnostic Interview for Social Communication DisOrders (DISCO; Wing *et al*. 1999, 2002) or the Autism Diagnostic Interview (ADI-R); (Rutter *et al*. 2003) both of which can be used to guide good history taking. Both these tools require further training in administration and can be lengthy to administer but both ensure that detailed, relevant information about current and past functioning is gathered from carers who know the individual well.

Whilst vital, of course; the developmental history is not the whole picture and it is also important to undertake observation of the individual under assessment in a variety of settings. Most people can be seen in clinic and whenever appropriate it is helpful to interview the individual directly who is being assessed to gain first hand feedback about their social communication skills as well as gather information about interests, etc. However, it is also helpful to observe individuals at home and with children and young adults; to see them at nursery, school or college. This provides additional information regarding the individual's social communication skills in a much more naturalistic way. Observations should include the individual's responses to those around them; how much do they initiate contact and how responsive are they when others make social overtures? It is important to note whether people respond to their name, whether they understand whole group instructions as being relevant to themselves and how they act in both structured and unstructured times within their everyday settings. Observers may want to watch for the individual showing sensory sensitivities, obsessions and rituals and consider how easily they follows social cues in the environment (e.g. in a school; if everyone lines up to go outside do they understand they need to line up too?). If possible, it can be helpful to have a sense of others' experiences of the individual and their views of any difficulties being experienced. For a child in school, for example, on might ask a teacher to complete a questionnaire (e.g. the Australian Scale for Asperger's Syndrome; Attwood and Garnett 1995; Attwood 2002).

The ADOS (Autism Diagnostic Observation Schedule Lord *et al*. 1999, 2000) is a semi structured interactive measure that can be used with children or adults which is designed to draw out the kinds of difficulties in social communication that one sees in ASD. It again requires further training but can be a useful guide to observation and assessment. For adults; it takes the form of a semi structured interview but for children it is more like a play session. It looks, for example, at how children develop their own play themes as well as how they interact to other's themes and ideas in their play (e.g. Will they let the therapist join the play for example, or do they have set repetitive ideas which the therapist has to join in with? Is the play a verbatim copy of a favourite TV show or is it self generated?).

INTERVIEWING PEOPLE WITH ASD

Whether during assessment or intervention, you will need to interview the person with social communication difficulties. The principles that apply to interviewing people with intellectual disabilities also apply to interviewing people with autism, however there are some additional factors that relate to Autism which you might want to consider. For example, it is important to check how 'Autism friendly' your environment is

(http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=2004). Pay attention to sensory issues and try to have an environment that is as distraction free as possible to ensure that the individual has the best chance of understanding the session.

Make sure that you have the person's attention before asking questions. They may have difficulty filtering out stimuli from their environment and may not hear what you are saying. Be consistent with the words you use and ensure that body language is clear. Hold a facial expression that is congruent with your verbal communication and try and avoid ambiguity, sarcasm or irony. It may take longer for the individual with ASD to process verbal information so adjust the assessment/intervention to their speed. It may be that the individual has difficulties with physical proximity or eye contact that need to be taken into account when planning sessions.

The social interaction inherent in Clinical Psychology work may be stressful and anxiety provoking for people with ASD. It may be necessary to provide sessions with breaks or to have sessions that are much shorter in length and it is helpful to use a visual timetable to let clients know what the session will be about.

INTERVENTIONS AND ASD – GENERAL PRINCIPLES

People with ASD have a range of difficulties within the 'triad of impairment' and the strengths and challenges that individual experiences will vary widely. Moreover, while individuals vary widely between each other, the presentation of each individual also changes over time so it is necessary to be flexible with approaches to assessment and intervention. No single intervention works for all people with ASD and no single intervention will work consistently with one individual over time. There are, however, a number of general principles which are important to consider in intervention:

- View difficulties through an 'autism lens'; identify the individual, autism specific reasons for behaviour/difficulties. Autism specific or sensitive interventions are much more likely to be successful than those that remain unadapted.
- Encompass the individual's strengths and skills, utilising routines and special interests/obsessions where appropriate.
- Take account of possible communication difficulties and include the use of visual support whenever necessary.
- Question the social norms. Why does something have to happen in a certain way? Is there scope to change an environment or an experience so it fits better with the person with autism? It doesn't have to be down to the person with ASD to make all the change.
- Take your time; make small changes that are less likely to phase the person with ASD and give them time to accommodate to these changes

Table 16.2 SPELL – the NAS framework for intervention.

Structure – Make the world more predictable and accessible.

Positive – Assessment and interventions should account for the strengths, interests and abilities of people with ASD in order to help develop potential whilst providing an appropriate level of support based on an accurate assessment of need.

Empathy – It is necessary to explore the issues from the perspective of the individual with ASD.

Low Arousal – Environments should be managed to provide calm and ordered experiences for individuals that reduces anxiety and encourages attention.

Links – links need to be made across aspects of an individual's life to ensure communication between support networks and increase consistency and communication.

e.g. with eating difficulites; if someone has a very restricted diet; try and introduce very similar foods first; just change the type of pasta someone eats for example; rather than try and introduce a whole new range of food (Legge 2002).

- Utilise the skills, knowledge and expertise of the individual themselves, their parents, carers and other professionals who know that person well. Evidence suggests that working in a multiagency way, in partnership with the person with autism and their carers, produces more accurate diagnoses and more successful interventions (National Autism Plan for Children 2003).
- Promote generalisation; a significant issue for children and adults with ASD is difficulty generalising skills across a range of settings. Ensure that strategies are in place to help the individual to transfer skills across environments.
- Provide information regarding ASD and support organisations for individuals and their families, e.g. information about the National Autistic Society (NAS); Contact a Family, etc.
- Ensure all staff and carers supporting people with ASD have appropriate training on autism so they too can better understand the individual.
- Consider the NAS framework (SPELL) when organising clinical work (see Table 16.2).

BEHAVIOURAL INTERVENTIONS

As for people with intellectual disabilities who do not have autism; behaviour theory is key to providing evidence based interventions for those people who do have Autism (Howlin and Rutter 1987). The most

common reason for referral to a clinical psychologist is likely to be related to a person exhibiting some kind of challenging or problematic behaviour. Whether it be feeding, sleeping or self injury; the key principles remain the same (see Chapter 11 on behavioural interventions). In essence, one needs to think about the STAR approach Settings, Triggers, Action and Response (STAR; Zarkowska and Clements 1994 – see Clements and Zarkowska 2000). What are the environmental or wider contextual factors in which this behaviour is occurring (Setting)? What exactly seems to trigger the behaviour (Trigger)? What does the person do (Action)? What is the response to the behaviour (Response)? This format helps the clinician to think through the possible function of the challenging behaviour and in doing so, find solutions for change. Rather than a linear ABC model; it can be drawn out as a STAR shape to help parents or carers understand that behaviours do not happen out of the blue but are part of a larger system of interactions.

Often, with people with autism; the setting events and context to the behaviour is key. With carers and parents, we often talk about putting on autism glasses and imagining for a moment how the world felt just before a difficult-to manage behaviour occurred. Bearing in mind that between 45% and 95% of people with ASD are thought to have some sensory sensitivities (see Ben-Sasson *et al*. 2009 for overview); the person's reaction to their sensory environment is a good example of how setting might influence behaviour (see also Williams 1996; Holliday-Willey 1999).

Sensory sensitivities can take different forms:

- **Visual sensitivity** – individuals may become very interested and engaged in visual information, patterns and shapes, e.g. the light coming through the trees, the pattern of the carpet. They may also have a dislike of certain visual information, e.g. fluorescent lights, bright lights
- **Auditory sensitivity –** Individuals can either be over-sensitive to certain sounds or under sensitive to noise. For example, it may be that the sound of the vacuum cleaner or the traffic outside is unbearable and individuals with ASD are frequently observed to place their hands over their ears to block out the noise. Equally, they may be fascinated by certain sounds and want these played repeatedly.
- **Pain –** for some individuals with ASD they appear to have a high pain threshold and there are reports of people with extremely painful injuries of which they seem unaware. These reports are complicated however, in that it may be difficult for the individual to demonstrate the social behaviour that usually accompanies pain. Contrastingly, some individuals seem to have heightened pain experiences and may find it painful to have their hair cut/brushed.
- **Taste –** Individuals report both heightened and lowered senses of taste and this may well relate to some of the difficulties with feeding detailed above.

- **Smell –** Again, sense of smell can be affected and individuals with ASD indicate that many smells may become overpowering – this can have an impact on areas such as toilet training and feeding.

By recognising, for example, that someone has sensory sensitivities; one might think about a supermarket differently. How many senses might be assaulted by the strong smells, bright overhead lights, background 'muzak' and smells of fresh bread? Thinking about the wider context, one can see how the person with autism might feel quickly overwhelmed in a supermarket and how a seemingly innocuous event (e.g. being pushed by someone else's trolley) might lead to a behavioural outburst. Thinking about the situation in these terms can help parents, carers and individuals themselves to come up with ideas for managing the original anxiety and sensory overload – does it help to wear glasses? Your own MP3 player with your own music on? Does it help to know that the shop will be brief; does it help to have a visual reminder of what you need; a list that you can tick things off and so see that the end of the shop is coming?

Aside from sensory sensitivities; one might also want to consider if the person is experiencing any communication difficulties and if; as part of a broader set of interventions; they might need support to express themselves better or to understand the demands of those around them. Working alongside colleagues in speech and language therapy; it can be helpful to consider alternative communications strategies such as Picture Exchange Communication System (PECS) (Bondy and Frost 2001) to aide expression and understanding.

Once you have thought about settings, it is important to consider key triggers to behavioural change. Whilst the setting event may be that a person does not like change; the trigger could be that something unexpected has happened e.g. if a person likes to take a familiar route to a favourite place and that route is diverted due to roadworks. It is often useful to think about how much visual information the person is given at these times to help them understand what is happening and what is likely to happen next. Ensuring that people with Autism have the right information in the right format can help to reduce anxiety levels at such times and may avert behavioural challenge.

Finally, one needs to think about the response and how this impacts on the person. If, for example, the STAR reveals that a bout of self injury usually results in the individual being removed from a stressful environment into a calmer one; then one might want to consider if the individual is engaging in self injury in order to get to that calm space. Perhaps it would be better to try and reinforce an alternative way of them asking for a break e.g. 'I need a break' cards. When trying to alternative behaviours, you may have to be inventive as standard reward strategies are often socially based and may not be that effective. The challenge is to be creative and to use whatever the individual finds rewarding. For instance, you may grant the

individual five minutes to flap their hands if that's what they enjoy, or time to look at a web page or book that is related to their special interest whatever that may be.

COGNITIVE-BEHAVIOUR THERAPY

People with ASD are at increased risk of developing mental health difficulties (Melville *et al*. 2008) with particular evidence to suggest that the incidence of anxiety and depression in this population may be higher than in the general population (Gilliot *et al*. 2001; Kim *et al*. 2000). In some cases, as noted above, changing the environment may help to reduce stress and anxiety. However where direct work with the individual is indicated, Cognitive Behaviour Therapy (CBT) is the most appropriate intervention to offer. CBT is based on the underlying principle that our interpretations and understanding of events are mediated by our beliefs about ourselves, others and the world (Beck 1976). Faulty or negatively biased beliefs lead to misinterpretations, in turn leading to negative emotional or behavioural responses. Intervention aims to challenge and change faulty beliefs and biased thinking, leading to more adaptive responses. CBT is the psychological treatment of choice for managing both anxiety and depression in adults (NICE 2004) and children (Cartwright-Hatton *et al*. 2004; NICE 2005). In recent years there has been a growing acceptance that people with intellectual disabilities can engage in CBT and there is an increasing body of research suggesting its effectiveness for people with ASD (Hare and Paine 1997; Sofronoff *et al*. 2005; Lang *et al*. 2010; Wood *et al*. 2009). CBT has certain characteristics that play to the strengths and preferences of people with ASD, such as using logical argument to challenge faulty cognitions, that make it particularly applicable and acceptable (Hare and Paine 1997).

SPECIFIC INTERVENTIONS WITH AUTISM

When searching the internet for references relating to 'autism' and 'interventions', thousands of potential sites are available, many claiming to have found a cure for ASD. Many of these sites have no research evidence for their claims and have not been subject to systematic analysis. These sites are understandably seductive to parents, carers and families of people with ASD and part of the clinician's role is to help carers of people with ASD and individuals themselves to negotiate this minefield. It is important to help people to understand the available research and to assess the claims that support different interventions.

Helpful information is available from the NAS website on how to understand research articles and there are also summary sheets on various

common approaches or interventions such as TEACCH (Mesibov *et al*. 1997, 2005), Social Stories (Gray 2002, 2010; Lorimer *et al*. 2002; Smith 2001) which are used to support people with ASD.

CONCLUSION

In conclusion, no single chapter is going to tell you all you need to know about autism nor can it encapsulate the exciting and challenging clinical work that ensues from getting to know those with autism. However, we hope that we have conveyed the main skills that you need; to keep an open mind; wear your autism glasses and celebrate the strengths of the autistic experience and the fortitude and creativity that people with autism show whilst managing that experience within a neuro-typical world.

References

Acosta, M.T. and Pearl, P.L. (2004) Imagery data in autism: from structure to malfunction. *Seminars in Pediatric Neurology*, **11**(3), 205–13.

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

Asperger, H. (1991/1944) "Autistic Psychopathology" in Childhood. Translated and annotated by Frith, U. In Frith, U. (ed.) *Autism and Asperger syndrome*. New York: Cambridge University Press.

Attwood, T. (2002) *Asperger's Syndrome: a guide for parents and professionals*. London: Jessica Kingsley Publishers.

Attwood, T. and Garnett, M. (1995) *The Australian Scale for Asperger Syndrome*. Paper presented at the 1995 Australian National Autism Conference. Brisbane, Australia.

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. and Charman, T. (2006) Prevalence of disorders of the autistic spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *The Lancet*, **15**, 210–16.

Baron-Cohen, S. (1989) The autistic child's theory of mind – a case of specific developmental delay. *Journal of Child Psychology and Psychiatry and Allied Disciplines*. **30**(2), 285–97.

Baron-Cohen, S., Joliffe, T., Mortimore, C. and Robertson, M. (1997) Another advanced test of theory of mind: evidence from very high functioning adults with autism or Asperger Syndrome. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **38**(7), 813–22.

Baron-Cohen, S., Leslie, A. and Frith, U. (1985) Does the autistic-child have a theory of mind? *Cognition*, **21**(1), 37–46.

Beck, A. (1976) *Cognitive Therapy and the Emotional Disorders*. International Universities Press.

Ben-Sasson, A., Hen, L., Fluss, R., Cermack, S., Engel-Yeger, B. and Gal, E. (2009) A meta-analysis of sensory modulation symptoms in individuals with autism spectrum disorders. *Journal of Autism and Developmental Disabilities*, **39**(1), 1–11.

Bettelheim, B. (1963) *The Empty Fortress*. Chicago: Free Press.

Bondy, A. and Frost, L. (2001) The picture exchange communication system. *Behavior Modification*, **25**, 725–44.

Bowler, D. (1992) Theory of mind in Asperger's Syndrome. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **33**(5), 877–93.

Cartwright-Hatton, S., Roberts, C., Chitsabesan, P., Fothergill, C. and Harrington, R. (2004) Systematic review of the efficacy of cognitive behaviour therapies for childhood and adolescent anxiety disorders. *British Journal of Clinical Psychology*, **43**(4), 421–36.

Clements, J. and Zarkowska, E. (2000) *Behavioural Concerns and Autistic Spectrum Disorders: Explanations and Strategies for Change*. Jessica Kingsley Publishers.

Courchesne, E., Karns, L.M., Davis, H.R., Ziccardi, B.S., Carper, R.A., Tigue, Z.D., Chisum, H.J., Moses, P., Pierce, K., Lord, C., Lincoln, A.J., Pizzo, S., Schreibman, L., Haas, R.H., Askhoomoff, N.A. and Courchesne, R.Y. (2001) Unusual brain growth patterns in early life of patients with autistic disorder. *Neurology*, **57**(2), 245–54.

Deykin, E. and MacMahon, B. (1980) Pregnancy, delivery, and neonatal complications among autistic children. *American Journal of Diseases of Children*, **134**(9), 860–4.

Emerson, E. and Hatton, C. (2007) Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry*, **191**, 493–9.

Filipek, P., Accardo, P., Baranek, G., Cook, E., Dawson, G., Gordon, B., Gravel, J., Johnson, C., Kallen, R., Levy, S., Minshew, N., Prizant, B., Rapin, I., Stone, S., Teplin, S., Tuchman, R. and Volkmar, F. (1999) The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, **29**(6), 439–84.

Fitzpatrick, M. (2004) *MMR and Autism: What Parents Need to Know*. London: Routledge.Taylor and Francis.

Frith, U. (1989) *Autism: Explaining the Enigma*. Oxford: Blackwell.

Frost, L. and Bondy, A. (1994) *The Picture Exchange Communication System Training Manual*. Cherry Hill, NJ: PECs.

Gilliot, A., Furniss, F. and Walter, A. (2001) Anxiety in high-functioning children with autism. *Autism*, **5**(3), 277–86.

Glasson, E., Bower, C., Petterson, B., De Klerk, N., Chaney, G. and Hallmayer, J. (2004) Perinatal factors and the development of autism. A population study. *Archives of General Psychiatry*, **61**, 618–27.

Grandin, T. (2006) *Thinking in Pictures*. Bloomsbury Publishing.

Gray, C. and Leigh-White, A. (2002) *My Social Stories Book*. London: Jessica Kingsley Publishers.

Gray, C. (2010) *The New Social Story Book*. Arlington, TX: Future Horizons Inc.

Happé, F. (1994) An advanced test of theory of mind – understanding of story character's thoughts and feelings by able autistic, mentally-handicapped and normal children and adults. *Journal of Autism, and Developmental Disorders*, **24**(2), 129–54.

Happé, F. and Frith, U. (2006) The weak coherence account: detail-focused cognitive style in autism spectrum disorders. *Journal of Autism and Developmental Disorders*, **36**(1), 5–25.

Happé, F. and Ronald, A. (2008) The 'fractionable autism triad': a review of evidence from behavioural, genetic, cognitive and neural research. *Neuropsychological Review,* **18**(4), 287–304.

Hare, D. and Paine, C. (1997). The use of cognitive-behavioural therapy with people with Asperger Syndrome: a case study. *Autism*, **1**(2), 215–25.

Holliday-Willey, L. (1999) *Pretending to be Normal: Living with Asperger's Syndrome*. Jessica Kingsley Publishers.

Honda, H., Shimizu, Y. and Rutter, M. (2005) No effect of MMR withdrawal on the incidence of autism: a total population study. *Journal of Child Psychology and Psychiatry*, **46**, 572.

Howlin, P. and Rutter, M. (1987) *Treatment of Autistic Children*. Chichester: John Wiley and Sons, Ltd.

in treatment of sleep Disorders in children with autism. *Journal of Autism and Developmental Disorders*, **36**, 741–52.

Kanner, L. (1943) Autistic disturbances of affective contact. *Nervous Child*, **2**, 217–50.

Kanner, L. (1949) Problems of nosology and psychodynamics in early childhood autism. *American Journal of Orthopsychiatry*, **19**(3), 416–26.

Kim, J., Szatmari, P., Byrson, S., Streiner, D. and Wilson, F. (2000) The prevalence of anxiety and mood disorders among children with autism and Asperger Syndrome. *Autism*, **4**(2), 117–32.

Lang, R., Regester, A., Lauderdale, S., Ashbaugh, K. and Haring, A. (2010) Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: a systematic review. *Developmental Neurorehabilitation*, **13**(1), 53–63.

Lawson, W. (2000) *Life behind Glass: a personal account of autism spectrum disorder*. Jessica Kingsley Publishers.

Legge, B. (2002) *Can'tEeat, Won't Eat: dietary difficulties and autistic spectrum disorders*. Jessica Kingsley Publishers.

Lord, C., Risi, S., Lambrecht, L., Cook, E., Leventhal, B., DiLavore, P., Pickles, A. and Rutter, M. (2000) The autism diagnostic schedule-generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, **30**, 205–24.

Lord, C., Rutter, M., DiLavore, P. and Risi, S. (1999) Autism diagnostic observation schedule – generic. Los Angeles, CA: Western Psychological Services.

Lorimer, P.A., Simpson, R.L., Myles, B.S. and Ganz, J.B. (2002) The use of social stories as a preventative behavioural intervention in a home setting with a child with autism. *Journal of Positive Behavior Interventions*, **4**(1), 53–60.

Melville, C., Cooper, S., Morrison, J., Smiley, E., Allan, L., Jackson, A., Finlayson, J. and Mantry, D. (2008) The prevalence and incidence of mental ill-health in adults with autism and intellectual disabilities. *Journal of Autism and Developmental Disabilities*, **38**, 1676–88.

Mesibov, G.B. (1997) Formal and Informal Measures on the Effectiveness of the TEACCH Programme. *Autism*, **1**(1), 25–35.

Mesibov, G.B., Shea, V. and Schopler, E. (2005) *The TEACCH Approach to Autism Spectrum Disorder: Issues in Clinical Child Psychology*. Kluwer Academic/Plenum Publishers.

MRC (2001) *Review of Autism Research: Epidemiology and Causes*.

Muhle, R., Trentacoste, S.V. and Rapin, I. (2004) The genetics of autism. *Pediatrics*, **113**, 472–86.

National Autism Plan for Children (2003) *Review of Autism Research: Epidemiology and Causes*. NIASA.

National Institute for Clinical Excellence (NICE) (2005) *Depression in Children and Young People: Identification and Management in Primary, Community and Secondary Care*. London: National Institute for Clinical Excellence.

National Institute for Clinical Excellence (NICE) (2004) *Depression: Management of Depression in Primary and Secondary Care*. London: National Institute for Clinical Excellence.

Ozonoff, S. and Jensen, J. (1999) Brief report: specific executive function profiles in three neurodevelopmental disorders. *Journal of Autism and Developmental Disorders*, **29**(2), 171–7.

Ozonoff, S., Pennington, B. and Rogers, S. (1991) Executive function deficits in high functioning autistic individuals – relationship to theory of mind. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **32**(7), 1081–1105.

Pellicano, E., Mayberry, M., Durkin, K. and Maley, A. (2006) Multiple cognitive capabilities/deficits in children with an autism spectrum disorder: 'weak' central coherence and its relationship to theory of mind and executive control. *Development and Psychopathology*, **18**(1), 77–98.

Rajendran, G. and Mitchell, P. (2007) Cognitive theories of autism. *Developmental Review*, **27**, 224–60.

Rutter, M. and Schopler, E. (1987) Autism and pervasive developmental disorders: concepts and diagnostic issues. *Journal of Autism and Developmental Disorders*, **17**, 159–86.

Rutter, M., LeCouteur, A. and Lord, C. (2003) Autism Diagnostic Interview – Revised (ADI-R). Los Angeles, CA: Western Psychological Services.

Shah, A. and Frith, U. (1993) Why do autistic individuals show superior performance on the block design task. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **34**(8), 1351–64.

Smith, C. (2001) Using Social stories to enhance behaviour in children with autistic Spectrum Difficulties. *Educational Psychology in Practice*, **17**(4), 337–45.

Soffronoff, K., Attwood, T. and Hinton, S. (2005) A randomised controlled trial of a CBT intervention for anxiety in children with Asperger Syndrome. *Journal of Child Psychology and Psychiatry*, **46**, 1152–60.

Sparks, B.F., Freidman, S.D., Shaw, D.W., Aylward, E.H., Echelard, D., Artry, A.A., Maravilla, K.R., Giedd, J.N., Munsen, J., Dawson, G. and Dager, S.R. (2002) Brain structural abnormalities in young children with autistic spectrum disorder. *Neurology*, **59**(2), 184–92.

Wakefield, A.J., Murch, S.H. and Anthony, A. (1998) Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet*, **351**, 637–41.

Wellman, H., Cross, D. and Watson, J. (2001) Meta-analysis of theory of mind development; the truth about false belief. *Child Development*, **72**(3), 655–84.

Williams, D. (1996) *An Inside-out Approach*. London: Jessica Kingsley Publishers

Williams, D. (1998) *Nobody Nowhere: the remarkable autobiography of an autistic girl*. Jessica Kingsley Publishers.

Wimmer, H. and Perner, J. (1983) Beliefs about beliefs – representation and constraining function of wrong beliefs in young children's understanding of deception. *Cognition*, **13**(1), 103–28.

Wing, L. and Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, **9**(1), 11–29.

Wing, L. (1999) *Diagnostic Interview for Social and Communication Disorders, DISCO*. Bromley, Kent: The National Autistic Society.

Wing, L., Leekam, S.R., Libby, S.J., Gould, J. and Larcombe, M. (2002) The DISCO: background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry*, **43**(3), 307–25.

Witkin, H. *et al*. (1971) *A Manual for the Embedded Figures Test*. California: Consulting Psychologists Press.

Wood, J., Drahota, A., Sze, K., Har, K., Chiu, A. and Langer, D. (2009) Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: a randomized, controlled trial. *Journal of Child Psychology and Psychiatry*, **50**(3), 224–34.

World Health Organisation (1993) *The ICD-10 Classification of Mental and Behavioural Disorders. Diagnostic Criteria for Research*. Geneva: World Health Organization.

Zwaigenbaum, L., Szatmari, P., Jones, M.B., Bryson, S.E., MacLean, J.E., Mahoney, W.J., Bartolucci, G. and Tuff, L. (2002) Pregnancy and birth complications in autism and liability to the broader autism phenotype. *Journal of the American Academy of Child and Adolescent Psychiatry*, **41**(5), 572–9.