A Practical Approach to Managing Children and Young People with Autism Spectrum Disorder

Dr Chinnaiah Yemula
Consultant Community Paediatrician, Bedford
SEPT: South Essex Partnership NHS University Foundation Trust

Professor Frank M C Besag
Consultant Neuropsychiatrist, Bedfordshire
SEPT: South Essex Partnership NHS University Foundation Trust

Jennifer Wilson
Counselling Psychologist, Bedfordshire
SEPT: South Essex Partnership NHS University Foundation Trust

Natalie Hopkins
Senior Community Nurse, Luton, Bedfordshire,
SEPT: South Essex Partnership NHS University Foundation Trust

Dr Shalini Rajendran
Specialist Paediatric Registrar
East of England Deanery

Abstract

Managing a child or a young person with autism spectrum disorder (ASD) often requires coordinated multidisciplinary input and support from a number of professionals from paediatrics, mental health, learning disability, education and social care. Behavioural and sleep problems are common. Psychoeducation of parents, carers and teachers is the first step in enabling an understanding of what strategies are likely to be effective. In addition, ongoing individual support along with the provision of a conducive and supportive environment at home, school and places of leisure are typically needed. Prompt identification and treatment of comorbid medical and mental health conditions is imperative and should be an integral part of the overall management.

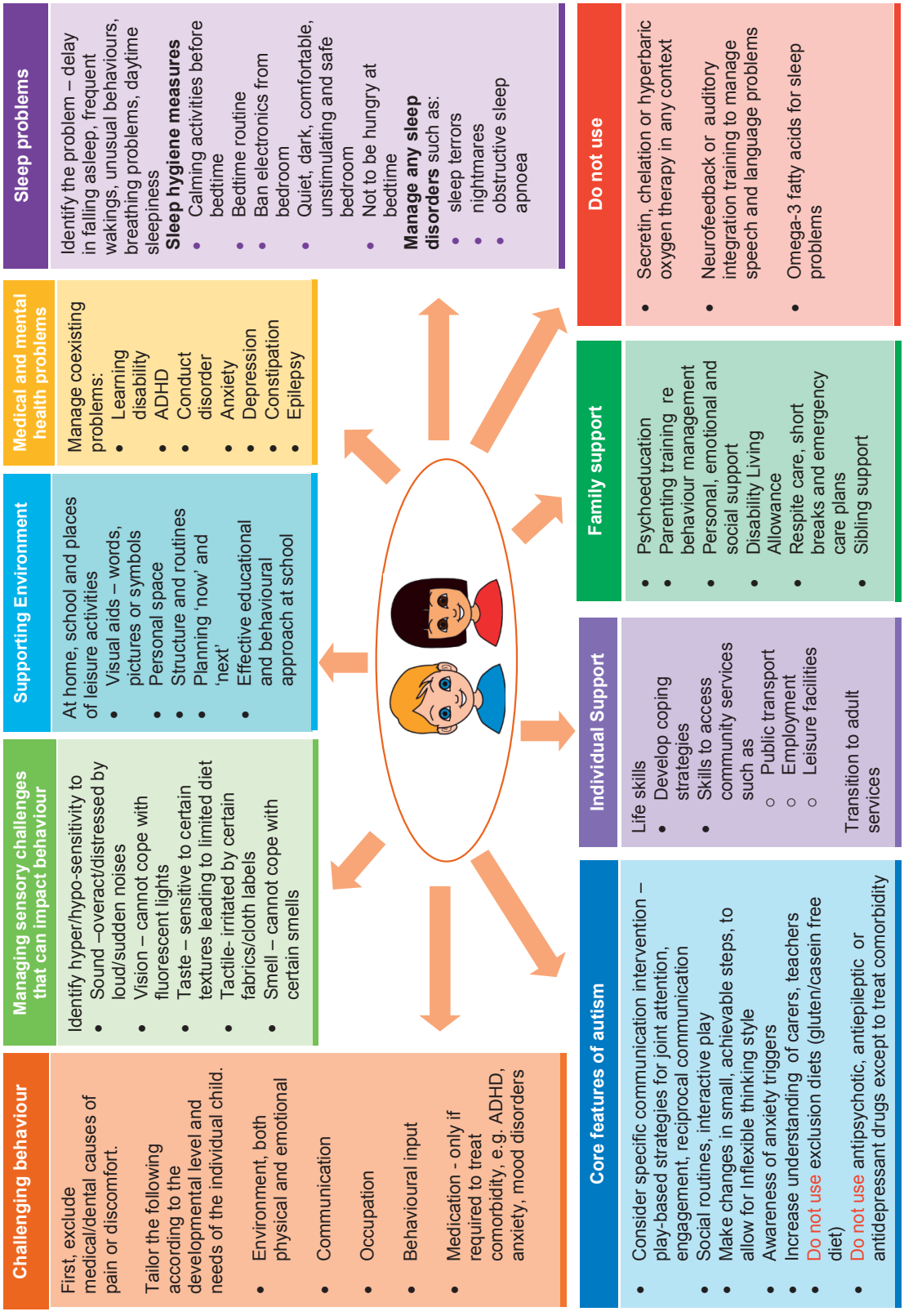
Background

Autism spectrum disorder in children and young people is a common condition that is being recognised increasingly by various professionals from health, education and social care. The NICE guidelines (1) recommend that the diagnosis of autism should only be made after a detailed and structured assessment by an autism team consisting of a group of professionals such as a paediatrician/child psychiatrist, clinical or educational psychologist and a speech and language therapist. In addition to the core features of autism, there are often a number of comorbid conditions that can have an enormous impact, not only on the affected individual but also the parents/carers, siblings and other family members.

Care should also be coordinated through a multidisciplinary team which, depending on the nature and complexity of the child's needs, may include professionals from mental health, learning disability, speech and language therapy, occupational therapy, education and social care, together with voluntary agencies such as parent support groups and the National Autistic Society. It is important to ensure that the child and the family have full access to health and social care services. Professionals from the various disciplines may have differing degrees of experience. This may add to the difficulty of providing the necessary coordinated treatment, education, support and care that the individual requires.

The aim of this paper is to provide a practical and simplified approach to managing autism, based on NICE guidelines (1) and the experience of experts (please see figure1)

Figure 1: Autism management



An overview of interventions and support

The NICE guidelines on managing ASD in children and young people (1) indicate that children and young people with ASD need interventions and support that can be categorised in the following areas.

Areas of interventions and support
• Psychoeducation about the core feature of autism
• Individual support
• Family support
• Supporting environment at home, school and places of leisure facilities
• Strategies to mange sensory challenges
• Management of challenging behaviour
• Management of comorbid medical and/or mental health conditions

What can help in the management of the core features of autism?

- **Psychoeducation; it is essential that all who have regular contact with the individual should have a clear understanding of the nature and implications of the core features of autism.**
- **Play-based strategies implemented by the parents/carers and teachers to improve joint attention, engagement and reciprocal communication of the child or the young person. These include social routines, interactive play.**

Core features of autism

- Impaired reciprocal socal communication and socal interracation
- Restricted and repetitive behaviour patterns, interests and activities

The NICE guidelines also list interventions that should not be used. Exclusion diets such as avoiding gluten or a casein free diet are not recommended. Treatments such as antiepileptic, antidepressant and antipsychotic drugs should only be used for comorbid conditions and not for core features of autism.

Individual and family support

Again, appropriate psychoeducation regarding ASD features and coexisting conditions should be provided both to the child/young person, taking into account their developmental level, and to the parents/carers.

- Written information about the local services and support groups can be very valuable.
- Offer families (including siblings) and carers an assessment of their own needs, including the following.
  - Personal, social and emotional support.
  - Support in the form of Disability Living Allowance, respite care, short breaks, emergency plans.
  - A care plan and transition to adult services.
- Offer children and young people with autism the support for the following.
  Developing coping strategies in social situations.
  Opportunities to develop skills to access community services such as public transport, leisure facilities and employment.

Supportive environment at home, school and places of leisure activities

Children and young people with ASD can experience high anxiety if their routines are changed or

they cannot predict the outcome of a social situation. High anxiety is often manifested as anger or aggression if it is maintained over a long period. Visits to unfamiliar places can be daunting. The anxiety can be decreased greatly if the individual can be enabled to learn the rules, social expectations and boundaries of their new environment in advance. This teaching is continuous. Because individuals with ASD have significant social communication difficulties they are liable to misinterpret social situations, and generally require support to adapt their behaviour accordingly. Those working with people who have ASD in these settings need to be aware of their own communication style and should be prepared to manipulate the environment where necessary to help the child or young person to maintain lowered anxiety. The following approaches can be helpful.

• Visual aids
The use of visual aids such as words, pictures or symbols to improve communication is recommended. Children and young people with ASD are often visual thinkers. Social stories and comic strip conversations (see the National Autistic Society website http://www.autism.org.uk/, & publications by Carol Gray) give the individual the opportunity to communicate visually and verbally how they have experienced a situation, helping them to identify the intent or expectation of others and to adapt their own behavioural response.

• Structure and predictability
Structure and predictability help the individual to feel emotionally secure and contained. A personalised visual schedule gives that reassurance that they have some predictability in their day. They may take some time to process what they have experienced. It helps to reduce anxiety if they are aware of where and how they may access a quiet space throughout their day. Because they may have a different tolerance to proximity and touch, together with a limited social awareness of the intent of others, carers and teachers must be considerate of their need for personal space.

• Planning 'now' and 'next'
Visual schedules for individuals who struggle with transitions from one task to the next can be broken down into short manageable steps. This enables them to focus on the current activity and the next one, the "now and next" approach, rather than worrying about the whole day ahead.

• Effective educational and behavioural approach at school e.g. the TEACCH approach (Treatment and Education of Autistic and related Communication handicapped Children). Please see paper in this issue on the TEACCH program.

Sensory challenges

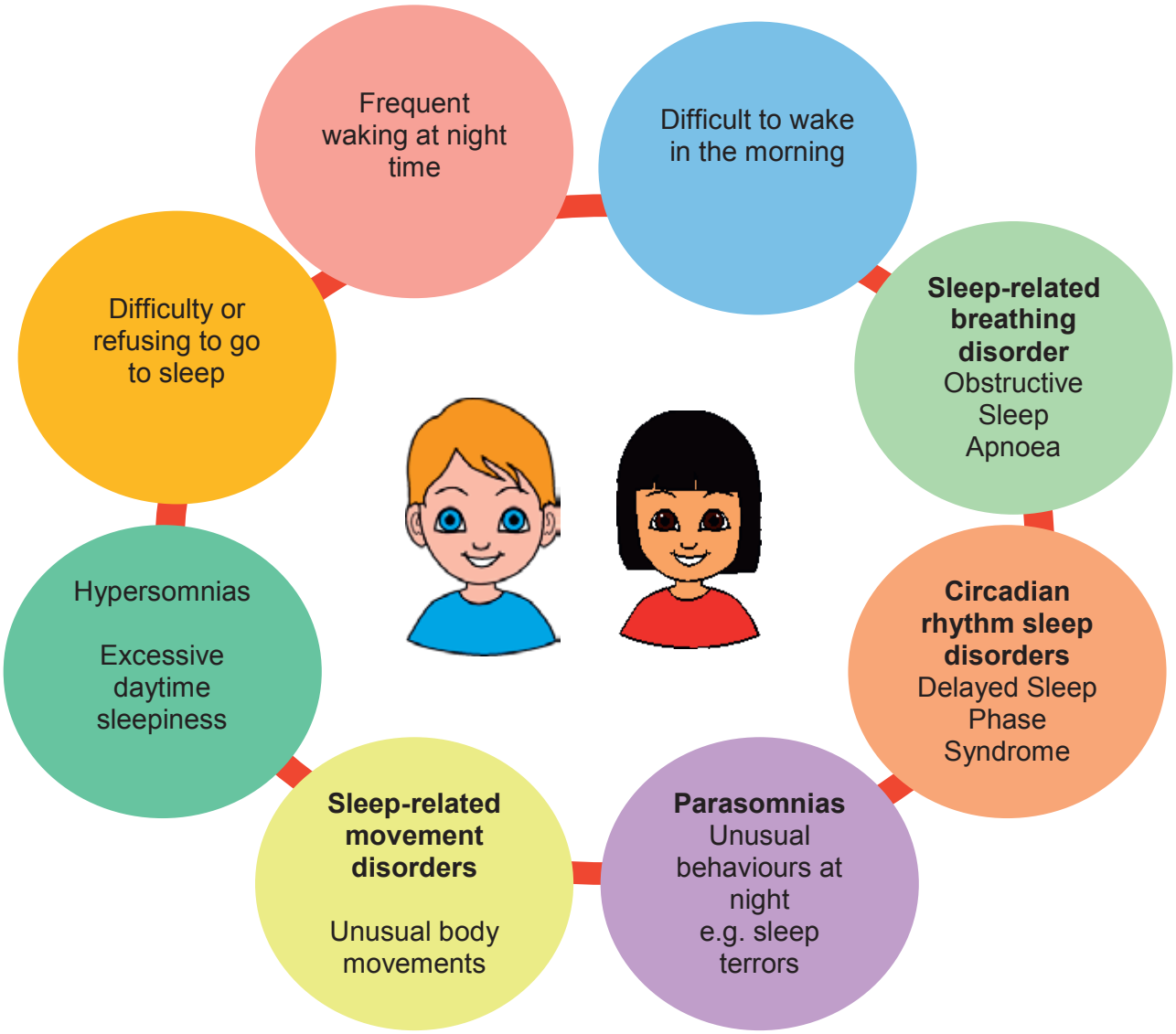
Although children and young people with ASD often experience sensory processing difficulties and challenges, these are not always recognised or assessed in clinical practice.

- The sensory difficulties can include hyposensitivity or hypersensitivity to one or several sensations such as sound, smell, vision, taste, touch, movement and body awareness.
- Sensory information overload from hypersensitivity can result in anxiety, emotional problems and consequent challenging behaviour.
- Interventions are based on individual needs; they include identification of the sensory issues, psychoeducation, adapting the environment and sensory integration therapy.
- There are several things parents can do to help their children who experience sensory difficulties. For example, activities to improve body awareness which work for those over-sensitive or under-sensitive include obstacle courses, moving in different ways; deep pressure – rolling in blankets/squeeze between pillows; swimming, trampolines.
- A simplified list of sensory difficulties and possible solutions that can be tried by parents/carers is provided in table 1.
- Please refer to the paper 'Autism and sensory processing problems' in this issue for additional information.

Table 1. Sensory issues and helpful strategies

Sensory area	Individual's response		Some helpful strategies for parents/carers
	Over-sensitive - tend to avoid or get upset by specific sensory inputs	**Under-sensitive** - tend to seek out specific sensory inputs	
Sound	• Distressed by loud/sudden noises, e.g. hoover, fireworks, school bell, and covers ears • Easily startled/ distracted	• Loves noisy environment • Poor localisation of sounds/voices • Doesn't pick up expected cues	**Over-sensitive:** prepare the child before visiting noisy/crowded places, wear ear defenders, listen to music, adapt environment, e.g. provide quiet space in classroom **Under-sensitive**: use visual cues to complement verbal cues
Touch	• Dislikes or only tolerates cuddles on their terms • Irritated by certain fabrics/cloth labels • Dislikes messy play • Oversensitive to pain, temperature	• Likes to touch/stroke other people's clothing or hair • Sometimes stands too close to others • High pain/temperature threshold • Needs firm touch to respond to others • Poor fine and gross motor skills	**Over-sensitive**: warn the child before touching, approach from the front, introduce different textures gradually **Under-sensitive**: weighted blankets, weighted jacket/vest may be helpful but follow professional advice
Smell	• Cannot cope with certain smells of foods, deodorants, toothpaste • Overreacts to new smells • Gags easily	• Under-reacts to bad or good smell • Cannot distinguish between good and bad smells	**Over-sensitive**: use unscented detergents or shampoos, avoid fragrances in the environment **Under-sensitive**: use strong smelling products as rewards and to distract from strong smelling stimuli such as faeces
Taste	• Sensitive to certain flavours & textures, leading to limited diet • Likes bland taste	• Licks, mouths, eats edible as well as nonedible items e.g. toys or clothes	**Over-sensitive**: Encourage varied diet and introduce changes gradually **Under-sensitive**: provide safe alternatives e.g. Chewy-chews and work on reducing the need for these
Sight	• Cannot cope with fluorescent lights or bright sunshine • Easily distracted by visual stimuli • Closes eyes as objects e.g. ball approaching	• Likes bright rooms • Stares at bright lights • Needs more visual cues to respond • Seeks flickering movements, spinning objects	**Over-sensitive**: reduce fluorescent lighting- use deep coloured light bulbs, wear sun glasses, work station in class to reduce visual distractions **Under-sensitive**: provide appropriate activity to help them focus but not distract
Movement	• Hates spinning or jumping • Fearful of heights • Hates busy place full of movement • Avoids swings (feet off ground)	• Always on the go • Cannot sit still • Uncoordinated (Do not confuse with ADHD - also common in ASD)	**Over-sensitive**: break down activities into small and easily manageable steps, allow child to be in control of activity e.g. swing, especially being able to stop **Under-sensitive**: encourage activities: swings, roundabouts, wobble cushion, fidgety toy
Body awareness	• Does not like people being too close • Difficulty standing in queues – better to be at the end • Avoids busy crowds- stands at the edge at playtimes or in P.E.	• Stands too close to others Bumps into/trips over things/people • Spills drinks • Seeking hugs • Heavy handed • Chews on objects	**Over-sensitive**: appreciate their body awareness, stand at arm's length but work on acceptable boundaries - coloured tape on the floor to show boundaries, arrange furniture at the end of the room, cushion/ carpet to sit on, visual cues/pictures **Under-sensitive:** work on acceptable boundaries/distances

• Common sleep problems can be categorised broadly into the following groups: (adapted from ICSD, 2005) (2)



How to manage sleep problems

Sleep problems due to behavioural insomnia are more common than other sleep disorders in children and young people with ASD. Other causes include environmental, medical and mental health conditions (e.g. anxiety). Good sleep hygiene advice to parents/carers (3) is often helpful (see table 2).

Table 2. Sleep hygiene advice

During daytime	Before bedtime	Bedtime and wake-up time	Bedroom
Make sure the child spends time outside and has regular exercise and activities. Young children can have a nap as appropriate. However, discourage long naps or too many naps as this may affect the child's ability to fall asleep at night or reduce the amount of night-time sleep	Avoid food or drinks containing caffeine such as chocolate, coffee, tea, and cola in the late afternoon and evening. Make sure the child is not hungry before going to bed. A warm bath may be helpful before bedtime. Ensure a pre-bedtime routine with a period of 'winding down' to prepare the child to go to sleep. Introducing calming activities 30 minutes before bedtime such as reading a story, massage or listening to soothing music can be very helpful.	Set a bedtime to be maintained every night; this should be age appropriate to the child and manageable for the family. However, it should be somewhat flexible to suit the family's normal lifestyle. Bedtime and morning waking time should be about the same every day, both during school term and holidays or weekends. There should be no more than one hour's difference between a school night, weekend or a holiday.	The child's bedroom should be safe, quiet, dark and comfortable. There should be no TV, internet or computer games in the child's bedroom (ban the electronics from the bedroom). A child can easily develop a bad habit of needing the TV to go to sleep. A child cannot relax and sleep easily if he or she is excited after playing computer games before bedtime. Avoid using the child's bedroom for 'time out' or punishment.

In addition to good sleep hygiene and managing specific sleep disorders, there are some specific behavioural strategies that parents/carers can implement to manage their child's sleep difficulties. However, they will often need support from a trained professional such as a specialist sleep nurse/ sleep counsellor. Helpful behavioural strategies for sleep problems include the following (3, 4):

Bedtime settling difficulties

• Extinction (crying out). Parents/carers need to put their child to bed at a predetermined time and ignore the child's crying or screaming until the morning, but they should ensure the child is safe and monitor for any illness (4). There is usually a good response within 7 days.

• Graduated extinction (controlled crying). This strategy may be less stressful and involves parents ignoring bedtime crying before checking on the child at specific periods of time, either on a fixed schedule (e.g. every 3 min.) or on a graduated schedule (e.g. 5 min., then 10 min.). The aim is to enable the child to self-soothe and fall asleep independently (4).

• Positive routines and bedtime fading. Parents need to establish a set bedtime routine with enjoyable and quiet activities. Bedtime fading involves parents delaying bedtime temporarily to coincide with the child's natural sleep onset time, then moving the bedtime earlier once the child is able to sleep quickly (4).

• Graded withdrawal: The goal is to enable the child to fall asleep independently by gradually withdrawing from the child's bedroom. This strategy can be particularly helpful if the child has become reliant on the parent lying with them until they fall asleep (3).

Night-time waking

• Robotic parent return strategy. This requires the parent to avoid communication and interaction with the child when they wake up, cry or call out for parents. The only communication, if needed, is to repeat the 'magic phrase' such as 'Time for Sleep' (3).

Sleep terrors, sleepwalking and frequent night-time awakenings

• Scheduled waking. This strategy involves parents recording the pattern of night awakenings, then waking the child 15 to 30 minutes prior to a spontaneous awakening and eventually fading this out over a period of time (4).

Delayed sleep phase syndrome (DSPS)

• Phase delay and phase advancement. DSPS occurs mainly in teenagers and young adults. They have severe difficulty in falling asleep and trouble waking in the morning, although they sleep soundly once asleep. Phase delay (chronotherapy) involves delaying the bedtime by 2 to 3 hours on successive nights, until the desired bedtime is reached. In phase advancement, bedtime is shifted earlier by 15 minutes every 1 to 3 nights.

Relaxation strategies such as visual imagery and listening to soothing music can also be useful.

It is important for parents to reward the child for a better night's sleep with praise and positive interaction in the morning.

Melatonin medication

• Whilst melatonin can improve sleep latency (time to fall asleep), the recent MENDS study (5) concluded that melatonin does not significantly increase the total sleep time in children with neurodevelopmental problems such as ASD.

How to manage challenging behaviours

We must ask ourselves: "Who is it challenging for?"

Those who misunderstand the communication

- The child who is misunderstood
- Those who are not aware of the behavioural function
- The child who has no alternative way of communicating
- The person working on a tight time schedule
- The person who is exhausted
- The person who has different expectations of the child's ability
- The person with similar difficulties to the child

Before choosing, if it needs eliminating or adapting, we must consider

- Medical explanation for the behavioural presentation
- Functionality of the behaviour
- Observe where, when and frequency of the behaviour to ascertain what the behaviour is communicating
- Check if the environment is maintaining the behaviour. Does the environment need to be manipulated?
- Does the behaviour need to be eliminated or modified?

The outcome of this consideration will dictate the behaviour management approach.

Key Principles of management

- Pain relief and treating coexisting conditions
- Environmental manipulation
- Communication
- Occupation
- Behavioural input
- Medication to treat comorbid conditions

Devising appropriate strategies for managing difficult or challenging behaviours in individuals with ASD relies on the following.

- Accurate identification of the function of the behaviour.
- Identification of any precipitating or maintaining factors.
- Effective preparation of the parents/carers.

Behavioural strategies

A behaviour programme will only be successful if the caregivers are aware of what is expected of them and if they feel both confident and empowered to implement the programme. They need to be supportive of each other and to remain consistent.

Lavigna & Willis (6) developed a multi-element approach to devising behavioural programmes, made up of proactive and reactive strategies. Proactive Strategies focus on long-term support to effect behaviour changes over time and reactive strategies are identified to manage the behaviour at the time it occurs.

Proactive Strategies			Reactive Strategy
Ecological manipulations	Positive programming	Focussed support	Situational agreement

Proactive strategies are made up of Ecological Manipulations, Positive Programming and Focussed Support.

Ecological Manipulation focuses on how the environment affects the individual, and identifies the changes required to 'smooth the fit' between the individual and their environment (Lavigna & Willis (6)). This could include changing the physical environment, for example, reducing noise levels or making the room less stimulating, offering choices of appropriate activities, implementing consistent routines, and providing quality interaction and realistic expectations.

The Positive Programming element aims to teach the individual skills which are functionally equivalent, but socially acceptable, to help them cope within their environment. This could be coping skills, daily living skills and communication strategies.

Focussed Support effects change through antecedent control, increasing engagement and reinforcement of appropriate behaviour. Reinforcement requires careful planning to ensure the reward is very motivating for the individual and that inappropriate behaviours are not inadvertently reinforced.

Behaviour management aims to prevent the behaviour from occurring, rather than having to manage it when it is occurring. Reactive strategies are devised to support when the behaviour is occurring. Being able to recognise the 'early warning signs' is a key element of reactive strategies so that strategies such as de-escalation techniques, redirection, distraction, environmental management, active listening and as a last resort, physical intervention can then be implemented.

When planning a programme, the 'target behaviour' needs to be identified clearly and the frequency with which it occurs should be recorded, along with the time between incidents of behaviour. This

can ensure the most effective programme is put in place to promote success for the individual. If the reinforcer or reward cannot be achieved, the individual will not be motivated to try again. It is suggested that the average time between incidents is calculated and divided by half as a time-frame of frequency in which the reward is presented. For example, if the behaviour occurs one hour apart, the reward should be presented every half hour. Careful consideration also needs to be given to the reward to ensure it is motivating to the individual; for example, food items, time spent in a desired activity, music, smells, tastes, physical activities. The reward needs to be presented to the individual immediately on successful completion of the target behaviour and is something they do not have access to at any other time.

It is not necessary, in all cases, for the individual to understand the programme in order for it to be effective, although their involvement can produce improved results, and written or visual contacts can support this.

Token systems are frequently used, as they can be visual and assist the individual in understanding what is expected of them, helping them to monitor their own progress. Frequently used are sticker or tick charts, or the collection of items such as money or pebbles in a jar. The item itself may be enough of a reinforcer for the individual. However, they can also be 'collected' to exchange for something that is not easily available such as a trip to the shop, or appropriate as a frequent reward, such as a chocolate. Each reward should be accompanied with verbal praise so that over time the reward can be phased out and replaced with just verbal praise. Some individuals find direct praise difficult to accept and respond better to indirect praise, e.g. overhearing someone praising them to another.

There are a number of reinforcement programmes which can be considered. Some of the most popular are:

• Differential Reinforcement of Other Behaviour (DRO) is a term used to describe reinforcement programmes which reward the absence of the target behaviour. For example, if the target behaviour of hitting does not occur during a ten minute period, the individual is rewarded with a motivating reinforcer.
• Differential Reinforcement of Lower Rates of Behaviour (DRL) is a term used to describe reinforcement programmes which best target high frequency behaviours. They work by reinforcing a time period in which fewer than a set number of behaviours occur. For example, if an individual spits ten times in an hour, they may be rewarded if they spit less than eight times in the hour.
• Differential Reinforcement of Alternative Behaviours is a term used to describe reinforcement programmes in which a reward is presented when a more appropriate behaviour is used. For example, an individual who hits out at others when anxious in order to 'escape' from a situation, should not be reprimanded for walking away from the situation but should be reinforced for 'escaping' the situation in an appropriate manner.

Managing an outburst of behaviour can be extremely stressful for all involved. The family/carers need to be provided with strategies on how to manage the situation following an incident to prevent it escalating again, and have some support in place from professionals, friends or family to be able to 'debrief' afterwards.

The Process in Practice – A case history

Adam, a thirteen year old boy diagnosed with learning disability and ASD lived at home with his mother and three siblings. His mother reported that at times he would hide under his bed, defecate and smear faeces. A Functional Analysis identified that he engaged in the behaviour at times when his siblings were playing loudly and chaotically, suggesting he found it difficult to cope with this. The Multi Element approach was implemented. Although some Reactive Strategies were identified in the form of recognising and responding to 'early warning signs' and encouraging him to go to a quiet area, the main focus of the intervention focussed on Proactive Strategies. Initially Focussed Support was employed to reduce noise levels when early warning signs were detected. Ecological Manipulations included supporting his mother to be more aware of the noise levels in the home and balancing the

needs of all her children. Boxes were placed under his bed to restrict his access and a small tent was erected in his bedroom as an alternative 'place of escape'. Using Focussed Support in the form of a reinforcement programme, Adam was introduced to a yellow card which became an object cue to associate with the tent. A raisin and verbal praise were given as reinforcement of acknowledging the card. Over a period of time, the yellow card was presented to Adam moving closer toward the tent, encouraging Adam to follow to receive the raisin and praise, until the reinforcement was given when he was sat in the tent. Ultimately, Adam learnt to go to his tent when his mother produced the yellow card at the identification of his Early Warning Signs. Through Positive Programming Adam learnt to take himself to his tent when his home environment became too stimulating for him, and alternative, appropriate activities were provided for him whilst he was there to replace the smearing behaviour. The long term aim then changed in order to teach Adam coping strategies that could be employed in all environments.

Coexisting medical and mental health conditions

It is essential to screen for comorbid conditions that occur with ASD. Managing these conditions appropriately usually requires multidisciplinary/multiagency support and input.

The comorbid conditions may include some of the following.

- Learning disability.
- ADHD.
- Conduct disorder.
- Anxiety.
- Depression.
- Constipation.
- Epilepsy.

Interventions that should not be used

There are some interventions that should not be used in the management of children and young people with ASD. Do not use the following treatments which have no evidence base to support their efficacy.

- Hyperbaric oxygen therapy.
- Chelation.
- Secretin.
- Neurofeedback or auditory integration training to manage speech and language problems.
- Omega-3 fatty acids for sleep problems.

Conclusion

Management of children and young people with ASD remains a challenge in clinical practice. Multidisciplinary care, support and therapy are usually necessary in order to achieve a good quality of life for the affected individual and the family. Education that is appropriate for the needs of the child is essential. All those who have contact with the individual should be trained to understand how both the core features of ASD and any comorbidities will influence the approach to management. Diagnosing and managing conditions such as ADHD, sleep problems, constipation and sensory problems should be an integral part of management. A careful and systematic analysis of the causes of any behavioural problems followed by consistent multidisciplinary behavioural intervention can yield remarkably positive results. The sooner intervention can be provided the more likely it is to succeed. However, even problems that had been present for long periods can respond well. The key to success of practical management is input from a multidisciplinary professional team working very closely with parents, teachers and carers, always guided by a sensitive understanding of how ASD affects that particular individual.

Acknowledgement
The authors would like to thank Jennie Oliver, Paediatric Occupational Therapy Team Manager, for her contribution to reviewing the information about sensory issues.

GP Comment.

What have I learned from this paper?

1. I found this paper very interesting. I was fortunate to attend a GP update course last year which included a brief presentation on ASD and this added to the things I had learned there.

2. What I found particularly useful was the clear identification of behaviours associated with hypo or hypersensitivity to various stimuli and strategies for helping to deal with these. The very clear direction with regard to treatments which are not evidence based was also useful - parents are always coming to ask if they should try something they have read about on the internet and it is helpful to be able to say Yes - I do know some people advocate that but unfortunately there is no evidence that it helps. Now I can add, however: "Have you tried .....", and suggest reviewing some of the strategies outlined here!

3. The clarification about the inappropriateness of the use of antipsychotic, anticonvulsant or antiepileptic medications as treatments for the individual's ASD is very valuable. We see so many people with ASD on these meds and it is important to realise these are for co-morbidities which unfortunately often add to the challenging environments these individuals are trying to navigate.

4. This has been added to my portfolio and will be referred to readily when I see youngsters whose presentation suggests ASD.

Dr Christiane Harris,
GP, Luton.

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