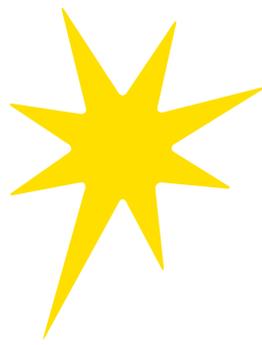




Sensory processing

A Guide for Parents



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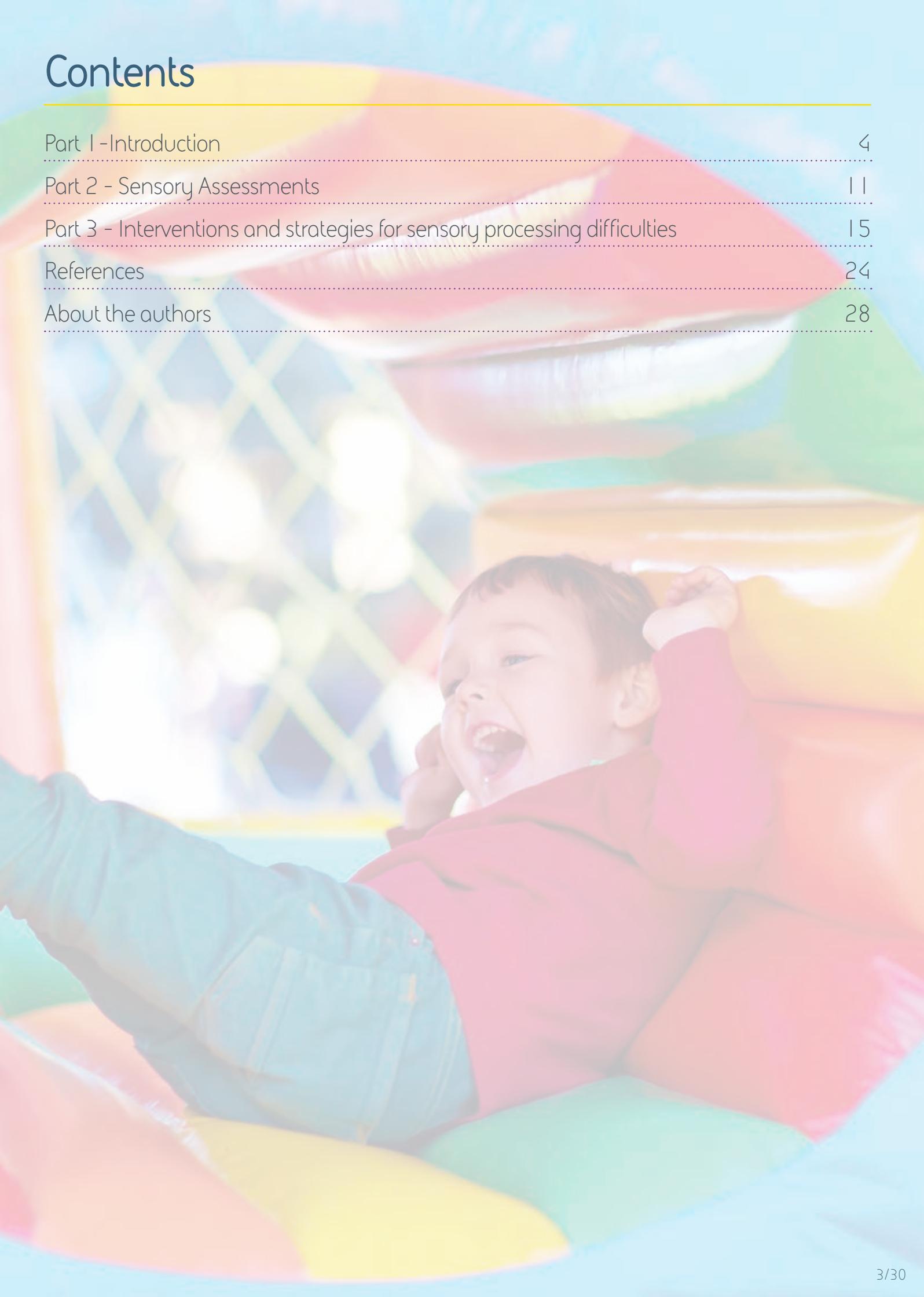
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Thank you.

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Part I - Introduction

What is sensory processing?

Sensory processing refers to how people experience, interpret and use their senses to guide their day-to-day behaviour. We receive sensory information from many different sources, including our vision, hearing, touch, tastes and smells.

Other senses include proprioception, (senses of body awareness and position), vestibular, (awareness of movement, balance, and coordination), and interoception, (our internal sensory system that tells us what is happening inside our body e.g. noticing when we are tired or hungry).

Some people may have difficulty processing information from one particular sense (e.g. hearing), whereas other people may have difficulty with more than one of these types of sensory inputs.

People with high levels of sensory processing difficulties can show different responses in their brains and behaviour following sensory input. They can also show different physiological responses (e.g. heart rate and sweat responses)^{1,2}, suggesting that their brains are processing incoming sensory information in a different way.

Sensory processing difficulties are different from sensory impairments (e.g. blindness/hearing loss).

This guide will outline the most common sensory processing difficulties people can experience, but it is important to know that there may be other difficulties that your child experiences that are not covered in this guide.

Common types of sensory processing difficulties include:

- Experiencing too much stimulation from incoming sensory information (**hyper**reactivity)

- Experiencing too little stimulation from incoming sensory information (**hypo**reactivity)
- Needing to seek out sensory experiences (sensory seeking)
- Having difficulty combining sensory inputs from different senses (often referred to as problems with multi-sensory integration).

"He really cannot stand loud noises. If somebody is speaking loudly or with intonation in their voice, he really doesn't like it."

Hyperreactivity can lead to avoidance of certain sensory inputs, in an attempt to avoid the overwhelming experience of sensory information. On the other hand, a **hyper**reactive person may seek out sensory stimulation to 'drown out' another input that is overwhelming for them e.g. rocking when there is too much noise.

Hyporeactivity is when a person does not respond or register sensory input when you might usually expect someone to respond. A **hypo**reactive person may seek additional sensory stimulation to help improve alertness.

It is important to note that **hyper**reactivity and **hypo**reactivity can both be linked to sensory seeking.

People may also be sensory seeking because they enjoy certain sensations or because it can make them feel calm in stressful situations. Every child is different and will have a different profile of sensory needs; an individual may seek one type of input but avoid another. **Box I** outlines what **hyper**reactivity, **hypo**reactivity and sensory seeking can look like in terms of observable behaviours.

Box 1		
Hyperreactivity	Hyporeactivity	Sensory Seeking
<ul style="list-style-type: none"> ● Become distressed by bright lights or loud noises (e.g., hoovers, sirens) ● Cannot tolerate the feeling of certain types of clothing or labels within the clothes ● Often distracted by background noises that most people are able to ignore (e.g., the sound of a flickering lightbulb) 	<ul style="list-style-type: none"> ● May not respond to certain sensations where most people normally would (e.g., another person touching their hand or their calling name, no differentiation when touching very hot or very cold objects) ● May have a high tolerance for pain 	<ul style="list-style-type: none"> ● Enjoying deep pressure or other types of stimulation ● Often touching items with interesting textures, even when socially unacceptable (e.g., a strangers clothing) ● Have difficulty understanding personal space and be overly physically affectionate ● May seek out and seem to enjoy extreme sensory experiences (e.g., climbing high buildings or trees)

When do differences in sensory processing become an issue?

It's very common for people to occasionally feel over or under sensitive to different sensory inputs. For example, some people can feel that lights that don't normally bother them are too bright when they have a headache. Others may feel less sensitive to things going on around them when they are over-tired. These feelings usually don't last that long, and don't have a large impact on everyday life functioning. However, when sensory processing difficulties get in the way of everyday life, or are present most of the time, they may have reached a level that requires clinical support or advice.

Currently, there are no formal diagnostic labels or criteria for sensory processing disorders, meaning you cannot receive a formal diagnosis of Sensory Processing Disorder (SPD) in the UK. However, many people use this term (SPD) to describe

sensory processing difficulties that are so severe and/or prevalent that they have a clear negative impact on a person's day-to-day life. Although not currently a formal disorder, a professional may assess and treat difficulties in sensory processing to support and improve a person's everyday functioning.

It is important to note that there are certain sensory behaviours that are part of the diagnostic criteria for autism.

"He doesn't like the sound of his sister speaking because she is higher pitched. Especially if we are in smaller environments like the car, the sound is more intense for him."

Important information for families

Many parents go online to find out about sensory processing disorders. There are a lot of internet bloggers and other individuals online that push parents to go and get a Sensory Processing Disorder diagnosis. This can be confusing for families because many professionals won't give this diagnosis because there are no formal diagnostic labels or criteria for sensory processing disorders in the UK.

It is also important to be aware that if a therapist is offering a SPD diagnosis, this should be a warning sign because of the lack of a formal diagnostic process. A good professional should know this.

In the general population, studies find that around 16% of children are classified as having elevated reactions to sensory input³. Other studies find that 66% of autistic children (65-90% of autistic children, depending on the research study), and 32% of children with special education needs (who were not autistic) show definite differences in sensory processing⁴. Although researchers are still trying to agree on the exact rates of different types of sensory processing problems in different groups of people, it is generally believed that people with a diagnosis of autism, and people with genetic syndromes and/or intellectual disability are more likely to experience sensory processing difficulties. These difficulties are also present in people without developmental disorders. Other risk factors for sensory processing difficulties include prenatal complications, complications during birth and premature birth.

How can sensory processing difficulties impact upon behaviour?

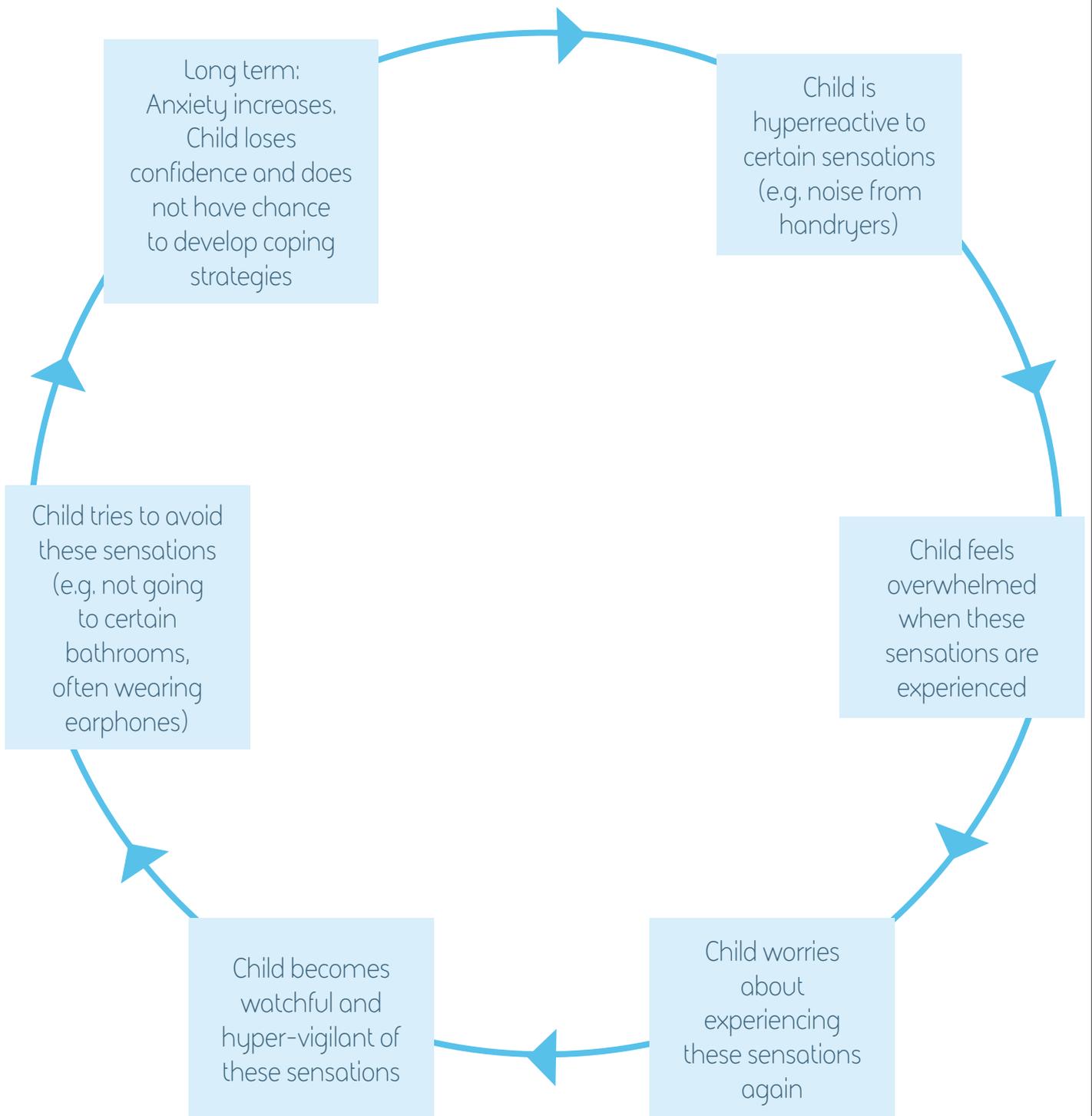
There are three main areas of a young person's life which can be affected by sensory processing difficulties that will be covered in this guide; anxiety, behavioural problems and sleep. However, there are other areas of life that might be impacted too. If you feel a specific area of your child's life is being impacted by sensory processing difficulties (e.g. feeding, toileting, physical health issues) then this should be

discussed with your child's doctor or health care provider. When reading information in this guide, it is important for you to know that most of the research looking at the impact of sensory processing on anxiety, behavioural problems and sleep has been conducted with autistic people. Whether there are similar patterns found in individuals with intellectual disability and other genetic syndromes is less well tested.

Anxiety

Research suggests a link between sensory **hyper**reactivity and anxiety problems^{5,6}. This could be due to **hyper**reactivity to certain sensory inputs leading to over-arousal and problems regulating negative emotions (like anxiety). This in turn can lead to worry around experiencing certain sensory inputs in the future. In addition, children with neurodevelopmental disorders, such as autism, are often poor at predicting what is going to happen next, and this can lead to these children worrying even more about sensory inputs they may experience. Children may then try and avoid situations where they think they may experience those sensory inputs⁷ (see **Box 2**). Although most research suggests **hyper**reactivity may lead to anxiety, high levels of anxiety may also make people feel more sensitive to certain sensory information.

Box 2. Links between sensory hyperreactivity and anxiety.



Behavioural problems

Sensory processing difficulties, specifically movement sensitivity, have also been linked to behaviour problems⁸. Although more research has focused on sensory **hyper**reactivity, children who are **hypo**reactive may also be at risk of developing emotional and behaviour problems. Adults with intellectual disability and autism, who are under-sensitive to sensory input experience more emotional disorders, anxiety, irritability and aggressive behaviour⁹.

Sleep

Others also suggest there is a link between sensory processing and sleep^{10,11}. For example, being **hyper**reactive can lead to sensitivity to the feel of bedsheets or pyjamas, or sensitivity to background noise. **Hypo**reactivities could result in not feeling stimulated enough during the day, and therefore not feeling tired by bedtime. Interoception difficulties can cause errors in our interpretation of bodily signals necessary for optimal sleep e.g. when a child is not able to read body clues that indicate they are tired¹². Sensory processing may therefore be important to consider when exploring factors affecting sleep quality. It's likely that sensory processing and sleep impact on each other. For example, sensory processing difficulties may make sleep more difficult, but poorer sleep may also make sensory sensitivities worse.

The family

It is important to consider how sensory processing difficulties impact the whole family. Sensory processing difficulties can create significant anxiety for families and has been linked to parenting stress¹³. Whole family working (including parental self-care) is key to ensure appropriate and sustainable intervention and support. Research suggests that sensory processing difficulties are likely to persist over time^{14,15}, so appropriate advice (e.g., from a clinician or healthcare provider), should be sought if these difficulties are beginning to impact on a young person's day-to-day life and/or the well-being of the family.

Sensory processing and specific genetic syndrome groups

There are certain genetic conditions that can cause developmental differences, including intellectual disabilities and/or autism.

These are sometimes known as genetic neurodevelopmental syndromes. Some of the better-known, and better-researched, syndromes include Down syndrome, Fragile X syndrome, Angelman syndrome and Williams syndrome. Each of these is caused by a specific type of genetic alteration in an individual.

The number of known genetic neurodevelopmental syndromes is growing year on year as the availability of detailed genetic testing, and knowledge of genetics increases. Many children for whom the cause of developmental differences might not have been identified in the past are now receiving diagnoses of genetic conditions.

Of course, having a diagnosis of a genetic syndrome in itself tells us relatively little about a person. There are just as many differences between people with a specific diagnosed genetic syndrome as there are for people without a genetic syndrome – everyone is different. However, it can sometimes be useful to know which characteristics or difficulties are more likely for people with certain genetic conditions. This may help parents and professionals to spot any issues early, and provide appropriate support.

For a number of the better-researched genetic neurodevelopmental syndromes, there is evidence of increased rates of sensory processing difficulties (see below). For other genetic conditions, where less research has been done (including rarer or more recently-discovered genetic syndromes and genetic variants of unknown causes), it may be that the direct evidence base remains limited. However, it can still often be useful to consider whether sensory processing difficulties are present for individuals. There are a few potential reasons for this. First, having a genetic syndrome increases the overall chance an individual will have autism, which is diagnostically linked to difficulties with

sensory processing. For some syndromes, a large proportion of people may meet diagnostic criteria for autism (e.g., Phelan–McDermid syndrome; Fragile X syndrome)¹⁶. For others (like Down syndrome), rates of autism are lower (around one fifth), but still greater than in the general population.

In some syndrome groups, many individuals have difficulties with issues such as anxiety (e.g., in Williams syndrome; Cornelia de Lange syndrome; Fragile X syndrome), sleep difficulties (e.g., Smith–Magenis syndrome), self-injurious behaviour (e.g., Cornelia de Lange syndrome; Smith–Magenis syndrome), or repetitive behaviours (e.g., Angelman syndrome; Fragile X syndrome). These problems might sometimes relate to sensory processing difficulties^{17,18,19}. This means that sensory processing may be investigated for that individual by clinical professionals.

It can be helpful to know the specific problems associated with a genetic syndrome your child has – you might want to look out for these, or alert clinicians to relevant problems that might need further assessment. However, remember that just because certain difficulties are more common for people with a specific syndrome than those without the syndrome, it does not mean everyone with the syndrome will be affected in the same way.

The genetic syndromes reviewed here are included because they are associated with elevated rates of autism¹⁶, and/or because more is known about sensory processing in these syndrome groups. Just because a syndrome isn't mentioned here doesn't mean sensory processing difficulties aren't present, or even prevalent, for people with this syndrome. The information here isn't intended as a comprehensive summary of the research for any given syndrome group; the evidence base is expanding all the time.

Fragile X syndrome (FXS)

Research suggests that men and boys with FXS have heightened risks of sensory processing difficulties, especially if they also have autism²⁰. **Hyper-** and **hypo**reactivity sensory processing has been noted in this group. It may be that **hyper**reactivity becomes more obvious as people with FXS get older. **Hyper**reactivity may be related to people with FXS not getting used to sensory stimuli, so they may respond more^{21,22}. **Hypo**reactivity is more apparent in younger people and people with more limited ability²³.

Some of the differences in **hyper**reactivity in FXS may be linked with poor eye contact, hyperactivity, tactile defensiveness (disliking being touched), avoidant behaviours, aggression, anxiety, verbal tics and repetitive motor behaviours. Children who show more avoidance of sensory inputs may also perform more poorly in school and have lower independence in daily living skills²⁴.

Little is known about sensory processing for females with FXS (although research with this group is now growing). It may be worth considering whether sensory processing is an issue if, for example, a female with FXS has high levels of anxiety and avoidance behaviours (which are known to be common in girls with FXS).

Williams syndrome (WS)

A high proportion of children with WS have sensory processing difficulties, with hypersensitivity to sound being the best-researched area²⁵. Children with WS may also be hypersensitive to tastes and proprioceptive information (body awareness and position)²⁶. Some research has found that people with Williams syndrome who have greater sensory processing difficulties have more difficulties in other areas, such as “executive functioning” and behaviours that challenge²⁷. (“Executive functioning” refers to the set of processes by which we control and monitor behaviour. These processes include control of attention, inhibiting behaviours which aren't currently useful, and holding relevant information in mind). Anxiety,

which is known often to be a problem for people with WS, might also be related to sensory processing difficulties and repetitive behaviours²⁶. Therefore, anxiety and repetitive behaviours may sometimes be a sign of sensory processing difficulties in people with WS.

Angelman syndrome (AS)

The majority of children with AS have differences in sensory processing. This is often in the form of **hypo**reactiveness to touch and vestibular sensation (movement, balance, coordination), alongside (perhaps leading to) sensory seeking behaviours^{28,29}. However, the same individual may show signs of **hyper**- and **hypo**reactivity.

Down syndrome (DS)

Individuals with DS may be more likely to have sensory processing difficulties in a number of areas. These include low energy/weakness, **hypo**reactivity and sensation-seeking, and difficulties with filtering of sounds³⁰. Sensory processing difficulties may relate to decreased muscle tone in people with DS, and possibly to lower participation in school activities and daily living skills³¹.

Phelan-McDermid syndrome (PHMDS)

A study of 24 children with PHMDS³² found that children had possible sensory processing differences. Children were mainly more **hypo**reactive and less **hyper**reactive compared to children with idiopathic autism, (autism with unknown genetic cause).

PHMDS is very strongly associated with autism, and one of the most common forms of autism caused by a single gene. Compared with children with autism that have no single known genetic cause, children with PHMDS may have fewer difficulties with **hyper**reactivity (specifically not being hyperactive to taste, smell, vision, hearing, and touch) but greater difficulties with **hypo**reactivity and low muscle tone.



Part 2 - Sensory Assessments

The following section on assessment has been written focusing on children with autism. However, much of the information below is relevant for children with learning disabilities who do not have a diagnosis of autism.

Many autistic children perceive the world in a different way compared to their peers. The most recent diagnostic criteria (Diagnostic and Statistical Manual of Mental Disorders; DSM-5) included sensory reactivity symptoms, such as **hyper**reactivity (stronger response to sensory stimuli such as lights), **hypo**reactivity (slower or less of a response) and sensory seeking (unusual sensory interests), as a recognised symptom of autism³³. However, few advances have been made in the diagnostic process since the DSM-5 has started to be used.

Individual services vary regarding assessments for autism; best-practice, gold-standard evaluations generally consist of a combination of direct diagnostic assessments such as the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)³⁴ and an interview with the caregiver such as the Autism Diagnostic Interview-Revised (ADI-R)³⁵. While the ADOS-2 and ADI-R provide important information on social communication difficulties and repetitive or restricted behaviors and interests, these assessments do not focus much on sensory processing. For example, the ADOS only includes one sensory item, 'unusual sensory interests,' which captures sensory seeking behaviour.

Sensory assessments/evaluation

Early sensory assessments can be beneficial as they can lead to early interventions which have been shown to be most efficient, however assessments and learning about your child's sensory needs at any stage are useful³⁶. You can then start making adjustments at home or educational settings to allow your child to reach

his/her full potential. Understanding of your child's sensory experiences and needs could also lead to a better family life³⁶.

Sensory assessments are, however, not regularly included in the autism diagnostic process and vary greatly depending on the individual service and commissioning. Ideally a comprehensive sensory assessment should consist of gathering information from several sources; a combination of both a caregiver report or interview and a direct observation and assessment of the child^{37,38}. The evaluation might, for example, include a talk with the caregiver first without the child present, followed by an observation of your child, sometimes standardised tests and questionnaires will also be used. These assessments should be conducted by trained experts such as Occupational Therapists. Standardised sensory assessments, such as the parent reports and observations listed below, are recommended³⁹.

Caregiver/parent reports

Many different parent report measures are used for assessing sensory symptoms^{40,41}. In general, parent reports and/or interviews will ask about sensory experiences your child might have, such as being overwhelmed by sounds, or seeking out bright and coloured objects. The Sensory Profile and Sensory Processing Measure seem to be the most widely used clinical caregiver reports. New tools are under development and will become available, and it is important for healthcare professionals to be aware of those⁴².

One of the most widely used parent reports is the The Sensory Profile that assesses an individual's responses towards sensory stimuli encountered in everyday life^{43,44,45}. The Sensory Profile-2 has several versions depending on the age of your child. An example item for **hyper**reactivity to sensory stimuli, such as sounds is: 'My child becomes upset or tries to escape from noisy settings'. An example item for **hypo**reactivity is:

'My child only pays attention if I speak loudly'. An example for seeking out sensory stimuli could be: 'My child looks carefully or intensely at people'. The Sensory Profile shows differences in 60–90% of autistic children and adults^{44, 45}. While the Sensory Profile is widely used to measure sensory symptoms in autistic individuals, not all questions are applicable to minimally verbal children.

Another commonly used parent report for measuring sensory symptoms is the Sensory Processing Measure (SPM), which is a parent or teacher rating scale that measures sensory functioning in preschool and school-aged children⁴⁶. The SPM will look at different modalities, such as vision, hearing and touch and also includes body awareness, balance, planning and awareness and social participation. The Sensory Profile, Sensory Processing Measure's and other parent reports have made significant contributions to the clinical understanding of sensory symptoms and are critical for a "trait-based" assessment. Caregiver reports are important and have made important contributions to understanding of sensory processing. However, they can be influenced by parent's views and feelings. This is why the assessment of sensory processing should include a combination of parent report questionnaires and direct assessments with the child.

Performance-based sensory assessments and standardised observations

Several standardised sensory observation tools exist, including the *Sensory Integration and Praxis Tests (SIPT)*⁴⁷. The SIPT offers several tasks assessing vision, touch and motor perception in children between the ages of 4 and 8⁴⁷. The whole assessment takes around two hours to complete, however, individual tests can be administered (10 minutes per test). During the SIPT your child might show sensory **hyper**reactivity, e.g. strong response to touch.

Other assessments you may come across are the *Sensory Processing Scale Assessment (SPS)*⁴⁸, the *Tactile Defensiveness and Discrimination Test—Revised (TDDT-R)*⁴⁹, the *Test of Sensory Functions in Infants (TSFI)*^{50, 51} or the *Sensory Assessment for Neurodevelopmental Disorders (SAND)*⁵². All performance-based tests and standardised observations include a direct interaction of your child with a clinician or healthcare professional. The healthcare professional should be trained in these direct assessments and have an adequate level of qualification to be able to conduct these assessments.

Multidisciplinary team

First and foremost, you as the caregiver are a crucial member of the team, you will learn how to become a 'sensory detective'. Given that a sensory evaluation only covers a snapshot of time, it can be useful to prepare for the assessment in advance, e.g. use a diary to note down any sensory symptoms (e.g. putting hands over ears when blender is used), or even taking a video when symptoms occur³⁶. Your input in the assessment is important and will provide healthcare providers with the information they need to evaluate your child's sensory needs.

BOX 3. Julie, David & Alice's story

Alice is a young person with Kleefstra syndrome; Alice is very sensory seeking. Alice and her parents, Julie and David, have had two experiences with sensory assessments. Their first experience was through a self-referral to an Occupational Therapist, who was part of a special needs parent group and was keen to get parents to take part in assessments. After the assessment, Alice and her family received a report detailing Alice's sensory profile. David and Julie did not feel the report was an accurate reflection of Alice and her sensory needs, and that some symptoms and information reported were inaccurate. Whilst the report itself was not so helpful for Julie and David they were able to get more ideas for equipment and avenues to pursue to help engage Alice such as brushing and sensory-rich toys.

The second assessment came from Alice's school, who referred Alice to an Occupational Therapist for odd posture and chewing. Not all parents would be able to access support in this way as in some places in the country, services are not commissioned to work with sensory issues. This referral was school specific and as can sometimes happen with school-based assessments, David and Julie were not invited to be involved. However, Julie pushed to be included in the process and was eventually. Whilst the process of assessment in the case of Alice, Julie and David may appear negative, it allowed Julie to be able to understand Alice's needs and behaviours better and gave her the starting point to start doing her own research into helping Alice.

As described in Box 3, David and Julie's story, snapshot assessments may not accurately reflect what you think your child's sensory needs are. Despite this, some aspects of the assessment may still be helpful. A multidisciplinary professional team is recommended for the sensory assessment³⁷. Different health professionals will be able to evaluate different aspects of your child's development. A GP, paediatrician or family doctor for example can evaluate your child's general health to see if there is an underlying medical condition. A psychologist or psychiatrist could check your child's mental health and see if they have other conditions. There are other health care professions which might be useful to consult with. For example, a developmental optometrist can check your child's visual perception of the world. Whereas a paediatric ophthalmologist can test the health of children's eyes. An Occupational Therapist can provide expertise on sensory processing and is best suited to test for sensory symptoms. Occupational Therapy is a healthcare profession that helps with everyday activities, such as eating, learning, playing, self-care, that are

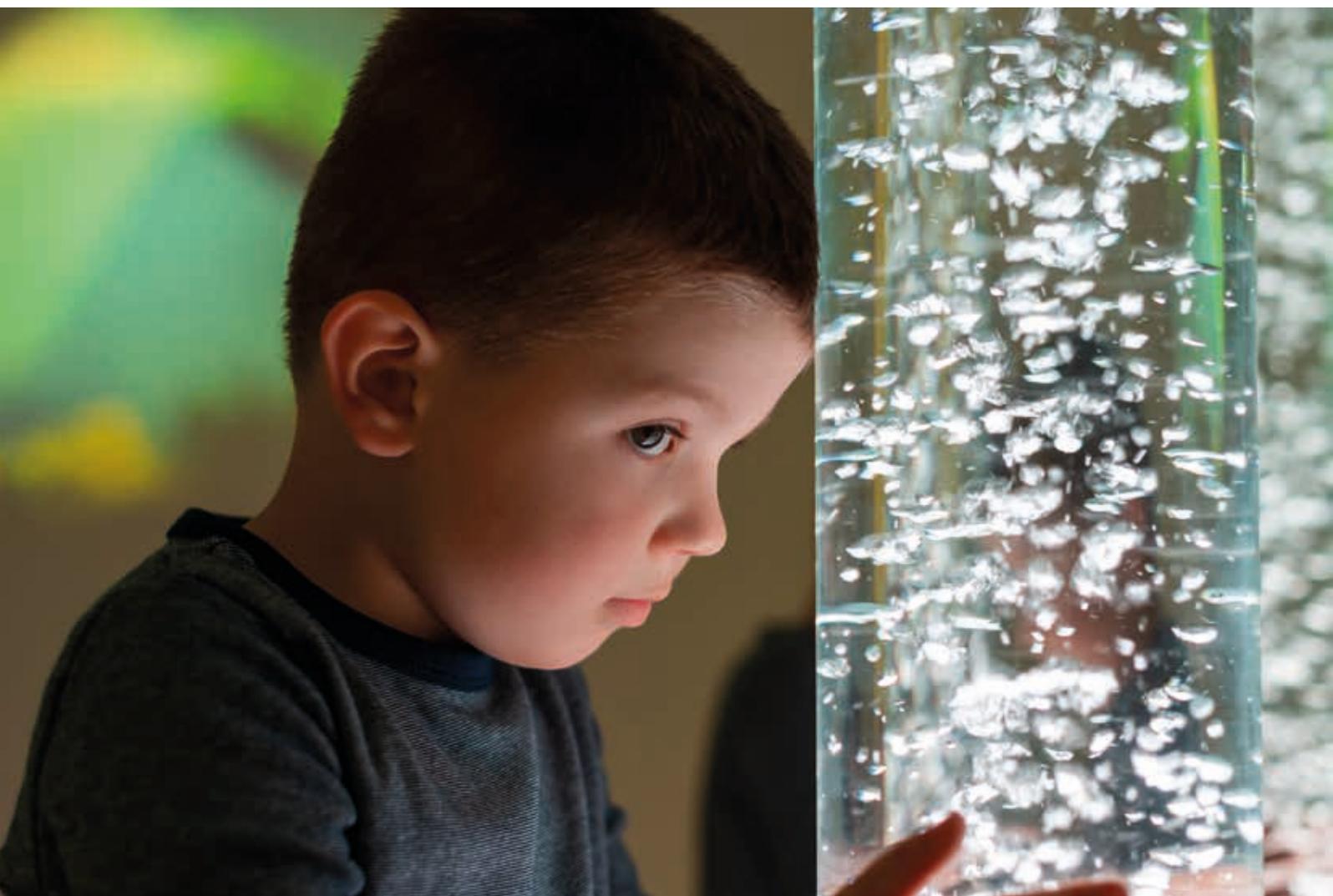
classified as occupations. Ideally, the sensory assessment should be conducted with an OT or other healthcare professional who has extra training related to sensory processing. After the assessment a report should be sent to you. Again, the report may vary depending on the service that will provide it. The report should include a description of symptoms, as well as strengths and weaknesses, and what intervention is recommended³⁶. The NHS, for example will recommend evidence-based practice. The report takes information gathered and interprets these in light of how sensory symptoms might affect daily living, participation in social and family activities³⁹. A report will often include a more comprehensive picture of your child's development, including motor function as well as sensory processing.

Accessing NHS services

As mentioned above, the type of assessment varies depending on the individual service. The availability of sensory assessments through the NHS also varies dependent on where you live in the UK. Some Learning Disability Child and

Adolescent Mental Health Services (CAMHS-LD), Learning Disability Teams in primary care settings, Child Centre's and specialist autism services have Occupational Therapists who work within these services who could offer sensory assessments. Schools, especially special needs schools, may also offer Occupational Therapy services as well as some private Occupational Therapists. Private Occupational Therapists may vary in quality, so make sure to check that necessary qualifications (e.g. registered with HCPC) and training are in place. If you feel your child would benefit from a sensory assessment, it is important to thoroughly investigate what NHS services are available to you in your local area and to get your child's name on a waiting list. GPs are usually the professionals who are able to refer you to your local learning disability or autism services, although they may not always know about the specific assessments that will be available to you from these services.

When discussing getting an assessment with your child's health team, it is important to say how sensory reactivity symptoms are impacting your child's well-being and family life, particularly when sensory sensitivities appear to be linked to anxiety. Some services may be only open to children with specific characteristics, such as children who may be experiencing mental health problems or those who have a diagnosis of autism. If your child has a genetic syndrome associated with autism but does not have an official diagnosis of autism, you may need to make your child's health team fully aware of how autism characteristics are associated with the syndrome and be prepared to advocate for input.



Part 3 - Interventions and strategies for sensory processing difficulties

Should interventions always be based on a thorough assessment?

While sensory assessments can be difficult to access, the current recommendation is that all sensory interventions should be informed by a thorough assessment. Interventions that are not based on a thorough assessment are less likely to be effective because they may not be matched to your child's sensory needs^{53, 54}. In addition, there is very little research on the adverse effects of an intervention that is not well-matched to a child's profile of needs. Well-planned interventions are delivered at a time that is right for your child and your family and, while all interventions can place some stress on families, it is important that the timing of the intervention does not put more stress than necessary on your child or you. If this is a busy period for your family, it may be worth postponing the intervention for a short time to ensure you have the maximum emotional and physical resources before making changes.

Can parents do anything to help improve their child's sensory processing or well-being related to sensory processing difficulties?

Despite a thorough assessment being an important component of any intervention, many families choose to adapt the environment around their child or implement their own strategies to support and manage the sensory inputs that their child experiences.

In addition, some children's activity centres and cinemas provide sessions specifically for children with autism where adaptations are made to the environment to make it more suitable to the needs of these children. Some examples of environmental adaptations are shown in Box 4 (pages 16-18) for **hyper**- and **hypo**reactive children, although this is not an exhaustive list. Kate and Laura's story in Box 5 (page 18) describes some strategies they have implemented to support Laura's sensory processing difficulties.

"The use of sensory activities keep him calm and alert and then we don't see those swings. We think it works really well, the chewy tube and supporting Annabel with the environment."

"He's started using ear defenders. I think more of a comfort thing rather than the actual like loud noises but I can't say for sure because he can't tell me. I've had them for a few years but then he was anxious over the summer holidays I was trying lots of different ways to help him and calm him down and this actually worked and now he's asking for them."

Box 4. Strategies that may be helpful for children with sensory sensitivities

Hyper-reactivity	Ideas
Auditory	<ul style="list-style-type: none">● Headphones or listening to music may be calming● Reducing noise in a busy environment e.g. turn off the TV● Install carpets to avoid the clatter of footfalls and to stop sound travelling● Some children may find constant background noise, such as white noise calming
Visual	<ul style="list-style-type: none">● It may be helpful to wear a baseball cap or sunglasses● Use a dimmer switch● Fluorescent lighting may be particularly unpleasant to some children with autism, therefore, where possible try to ensure children are in naturally lit rooms or are not seated directly under these lights
Tactile	<ul style="list-style-type: none">● Avoid unexpected touch. Tell your child or show them a picture card or cue to let them know that you are about to touch them● If you have to queue in a line your child may feel more comfortable being first or last
Olfactory (smell)	<ul style="list-style-type: none">● Make the environment as fragrance free as possible, for example, use un-perfumed toiletries● Keep rooms well ventilated● Teach your child appropriate coping strategies e.g. covering nose with tissue, informing others that a smell is unpleasant, either verbally or using a picture card or cue
Gustatory (taste)	<ul style="list-style-type: none">● Involve your child in food shopping and food preparation. This introduces your child to the texture and smell of food items without having to eat them● Allow preferred food items at mealtimes and ensure that your child is eating in a calm environment

Hypo-responsivity	Ideas
Auditory	<ul style="list-style-type: none"> ● Gain the person's attention before speaking to them ● Remove other distracting background noise ● Break down instructions into several smaller steps
Visual	<ul style="list-style-type: none"> ● Provide visual structure e.g. colour code books and timetables/schedules ● Allow access to preferred types of visual stimulation for certain periods in the day
Tactile	<ul style="list-style-type: none"> ● Gain the person's attention before touching them ● Consult with an Occupational Therapist regarding activities to increase tactile awareness e.g. messy play activities
Olfactory (smell)	<ul style="list-style-type: none"> ● Provide activities that stimulate the olfactory senses e.g. using scented play dough, cooking with strong smells ● Provide appropriate scented items such as hand cream or aromatherapy oils and direct your child to them when he/she attempts to smell people or potentially harmful materials
Gustatory (taste)	<ul style="list-style-type: none"> ● Allow your child to add strong flavours to meals or to choose strongly flavoured food e.g. chilli flakes, black pepper, citrus fruits, strong cheese ● If your child tries to eat non-food items, teach your child to discriminate between edible and non-edible items e.g. using a green box for edible items and a red box for non-edible items ● You could also try to select items which are similar in taste/texture to the non-food item that your child seems to be seeking e.g. chewy tubes, chewy sweets, dried fruit, raw vegetables ● Encourage your child to engage in oral activities e.g. blowing bubbles, blowing up a balloon, playing a wind instrument

Sensory seeking	Ideas
Auditory seeking	<ul style="list-style-type: none"> ● Listening to music through headphones may be helpful
Visual seeking	<ul style="list-style-type: none"> ● Ensure your child has access to lots of visually stimulating toys or objects
Tactile seeking	<ul style="list-style-type: none"> ● There is evidence that massage and pressure may be helpful to some children ● Make sure you have lots of different materials around the house e.g. tactile bath mats
Olfactory (smell)	<ul style="list-style-type: none"> ● Your child could carry a tissue or piece of material with a preferred scent and they could be prompted to smell this instead of smelling people or potentially harmful materials
Gustatory (taste) seeking	<ul style="list-style-type: none"> ● Allow your child to consume meals with strong flavours

BOX 5. Kate and Laura's story

Laura is a young person with Cornelia de Lange syndrome and has a broad profile of sensory processing difficulties. She did not get a sensory assessment until she was in her 20s, although her mum Kate would encourage parents to get one as early as possible even if it means going private (if possible). Laura has particular difficulties with proprioception (problems with understanding where her body is and positioning). This means that she likes to pace to help fulfil her sensory needs. At times this may be viewed as inappropriate or disruptive (e.g. in the middle of class). However, accommodating Laura's needs by accompanying her for a 5 minute walk means she can get her required sensory feedback and that her behaviours and anxiety do not escalate.

Laura likes deep impact pressure to help regulate her sensory processing, so she carries around a weighted doll whilst she paces to help. Other strategies used to help Laura with her sensory processing include a sensory bed cover, which really improved her sleep and sensory beads that her doll wears so that Laura can chew them when she needs.

Strategies for sensory hyperreactive children

Does your child have a self-regulation strategy?

Some children may be able to learn self-regulation strategies so that they can use these to help manage the environment around them by themselves. An example of this is a **hyperreactive** child learning to put on their headphones and listen to music when the environment becomes over-whelming. Another is a child learning to point to a picture card to request a five-minute break before returning to the activity they were doing. At first a child may need to be prompted to do this with a verbal prompt and a gentle physical prompt if necessary; these prompts can be reduced as a child learns what to do in a given situation. For example, a parent who noticed their child was showing signs of discomfort because the lights are too bright might put words to their experience and then provide the tool to help e.g. 'the lights are very bright. Let's put on your glasses'.

"He is a sensory seeker and has high levels of sensory needs. He has chewers and a ball and trampoline which he bounces on. If he doesn't have enough opportunity to explore his sensory interests, he can become very anxious."

Is your child prepared in advance?

Children often experience fear and anxiety in unfamiliar situations where they are not sure what is going to happen next. If children have sensory sensitivities they may be anticipating that unpleasant sensory experiences could occur at any point. This fear or anxiety may be made worse if unpleasant sensory experiences have occurred in the past in an unpredictable way. This can be compounded when a person was not

able to make sense of why, leading them to learn that all unfamiliar environments are potentially dangerous. It is not possible to control and predict all elements of the environment (unpredictable things will always happen). However, for children who can understand phrases, it's often helpful to let a child know what to expect when they are going into unfamiliar situations. Importantly, you can also let them know strategies they can use to manage when an unpleasant sensory experience occurs. As children with intellectual disability often have difficulty with problem solving, knowing that there is a plan to manage a situation can reduce anxiety. This can often be achieved by using a story format (see Daniel's Story, Box 6 on page 20).

Avoid avoidance

Keeping your child away from, or avoiding, sensory experiences can sometimes be an effective short-term strategy to avoid distress caused by hyperreactive to stimuli. For example, if a child gets over-whelmed by being in a loud and busy shopping centre, choosing to shop at less busy times may mean that your child can still participate in the activity without experiencing discomfort or distress. However, avoidance is a double-edged sword. There is evidence to suggest that the more people avoid sensory input, the more they can become sensitive to that stimulus, meaning they are more likely to notice it⁵⁵. In addition, if children avoid situations or experiences because they make them feel anxious, the anxiety can deepen overtime. More information on anxiety can be found in the Cerebra Anxiety Guide (see Box 8 on page 23). For example, a child who is given ear muffs to block out noise without real cause may become more sensitive to sound overtime as well as very anxious about being in situations where they cannot wear the defenders. Therefore, while avoidance of sensory stimuli may be useful for specific situations, strategies that encourage avoidance should be applied only when absolutely needed.

BOX 6. Daniel's story

Daniel is an eleven-year-old autistic boy who has started to go to the football with his mother, which he loves to do. He communicates with his mother using short restricted phrases, although he understands more words than he can speak. Daniel can sometimes be hyper-sensitive to sounds, particularly when they are sudden and unpredictable. The first time Daniel goes to the football and a goal is scored, Daniel is overwhelmed when the crowd stand up suddenly and there is a lot of noise. He becomes very distressed and starts to cry, shout and lash out, and his mother wonders whether it was the right thing to continue to take Daniel to the games. Despite this, she persists on taking Daniel and the second time she prepares him for what is likely to happen. She uses an illustrated story that she created on her computer to prepare Daniel for what happens at the football match to explain to Daniel why the crowd stands up and cheers. She also gives Daniel a strategy by telling that he can cover his ears with his thick woolly hat when this happens to help block out the sound. She practices this with him at home when they watch the football on the TV. The next time Daniel goes to the football and the crowd cheers, Daniel starts to show signs of distress although he is a little less distressed than last time. His mother prompts him to use his strategy of pulling down his hat to cover his ears, and once he is showing signs that he is calmer, she reminds him of why the crowd cheers to help him make sense of what has just happened. Over several matches, he starts to cover his ears without his mother prompting him and starts to show signs he is enjoying the goals. Daniel becomes more confident and his distress reduces, despite not always getting his hat down in time over his ears. The fact that he now understands why the crowd cheers and that he feels more in control of the situation has had a significant impact on his level of distress. He has also learnt to tolerate a greater level of noise than before and has learnt a strategy he can generalise to other situations (e.g. fireworks night). Not every child would cope with this situation as well as Daniel, however, preparing a child for what will happen, giving them a strategy to reduce stimulation, and helping a child make sense of a situation can all be helpful.

For a description of what a social story is and how to create one, follow the link below.

<https://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx>

Develop a plan to help your child build resilience to sensory stimuli

While avoidance is sometimes used as a short-term strategy for children who are **hyper**reactive to stimuli, research has indicated that interventions that are child-led but pose gentle challenges to a child's sensory processing abilities may lead to improved outcomes for children⁵³. Parents may be able to support their child feel more comfortable with sensory stimuli overtime. By no means does this mean that parents should take their child into situations that cause them clear discomfort or distress. It means trying to gradually support your child to explore more varied environments where they encounter new sensory stimuli. For example, if a child has difficulty being in loud busy places, it may be that visiting a quiet shopping centre is necessary at first; it is important not to stay at this level for too long and to try and very gradually build your child's tolerance to busier shopping centres again. You could combine a very short trip to a slightly louder environment while practising some of the self-regulation strategies above (e.g. listening to white noise through headphones if the noises of the shopping centre get too much). Importantly, there will likely be limits to this approach and not all children will be able to learn to tolerate all environments, nor should they. The important thing is to try to strike a balance between avoidance of experiences and providing opportunities for your child to

experience gentle sensory challenges that build their confidence over time. Flexibility is key.

Can you reduce the impact of sensory sensitivities on your child's sleep?

Individuals who are over-responsive to sensory input are likely to be especially sensitive to the effects of stimuli in the sleep environment such as lights, noise, temperature and tactile input⁵⁶. Therefore, adapting the individual's sleep environment may help the individual to fall asleep and stay asleep⁵⁷. For example, the use of white noise machines can help mask sounds in the environment that may disturb the sleep of an individual³⁶. Another example is to choose calming and neutral colours within the individual's bedroom, as some colours can be over-stimulating for children³⁶. There is a very limited evidence-base for sensory interventions specifically designed to improve sleep in individuals with neurodevelopmental disorders and/or autism. Most of the interventions suggested are based on clinical experience and a trial and error approach, especially given that sensory processing problems can vary hugely across individuals. For more information on how to adapt the sleep environment and improve sleep hygiene, see the Cerebra Sleep Guide (See Box 8 on page 23).

Strategies for sensory hyporeactive children

Children who are **hypo**reactive, may often not respond to stimulation around them. For these children, it is important to ensure that you get their attention before you start communicating fully with them. This could be done by pairing their name with a gentle touch to the hand, or by supplementing speech with visual communication aids to give a clear prompt or cue that you have started to communicate with them. As with many children with intellectual disability and communication difficulties, it is important to use short phrases and to break down instructions into small steps. Distracting

noises, sounds, lights or smells should be reduced when you are communicating with your child to give your child the best chance of responding to you.

Strategies for sensory seekers

Children who are sensory seekers often benefit from more opportunities to interact with their surroundings. This allows them to obtain the type of stimulation that they find enjoyable or soothing. For these children, providing lots of toys that provide sensory input may be beneficial. Occasionally, sensory-seeking behaviours may become concerning to parents because they may pose a danger to their child e.g. a child who turns on the hot taps to watch the water flow. In these situations, parents should work with an Occupational Therapist to try to find an activity that gives their child the same type of sensory experience but in a safe way (e.g. water play or watching sand move in a sand timer). This means the child is no longer motivated to engage in the dangerous behaviour to obtain this stimulation. It is always important to rule out other reasons why dangerous behaviour might be occurring too. For example, sometimes children may engage in dangerous behaviour because it produces a strong reaction from their parents and leads to another consequence that they may find rewarding (i.e. attention from parents, removal from a situation they would rather not be in, or delivery of a preferred item such as an iPad). Over time, children can learn that a specific behaviour (e.g. turning on a hot tap) reliably leads to this reward. Therefore, when introducing an activity to replace a behaviour presumed to be due to sensory seeking, make sure that you consider whether the behaviour could be a 'learnt' behaviour for another reason. You can find more information about how behaviour is learnt overtime by visiting the Challenging Behaviour Foundation or by watching the Cerebra video about behaviours that challenge (see Box 8 on page 23).

What other types of other interventions are available, and do they work?

Sensory Integration Therapy

There are some clinic-based interventions that have been developed for children with sensory sensitivities. The evidence for the effectiveness of most of these interventions is limited; however, there is now several research studies that provide some evidence that clinic-based sensory interventions, in particular Ayres Sensory Integration Therapy (SIT), may help families achieve their individual goals for their child. The interventions may also improve a child's sleep and caregiver well-being⁵⁴. SIT is delivered in a clinic with a variety of equipment (e.g. trampolines, climbing walls etc). The child is provided with activities that challenge their sensory processing to help them to integrate sensory stimuli⁵⁴. SIT focuses on improving the child's self-regulation and motivation for engaging with stimuli. If your child is going to receive SIT, it is important to ensure that this is delivered by a trained therapist (see Box 7 below that covers some of the things you should ask your therapist). Importantly, parents should be aware that if they seek out a therapist to deliver SIT, they may have to pay for the service as it is not likely to be offered by the NHS due to the evidence base for this therapy only just starting to emerge.

Box 7. (adapted from ³⁶)

Questions to ask your Occupational Therapist or any other therapist who claims they can offer a sensory intervention:

- What formal training do you have in the assessment of and intervention for sensory processing difficulties?
- What experience do you have working with children who have intellectual disability or neurodevelopmental conditions such as autism?
- What sort of assessments do you use? (pay attention to whether the types of assessments map on to what is described in this guide).

What's the evidence base for the type of interventions you might implement at home?

Single sensory interventions are when one strategy or device is tried at a time. Examples of this may be giving a child a massage. Some of the strategies that were listed in Box 4 (pages 16-18) are single sensory interventions. At the current time, there are very few good quality research studies on the effectiveness of these interventions.

The research that exists indicates that these interventions may not be very effective⁵³. However, there is some tentative evidence that movement related (vestibular) single sensory interventions, such as bouncing up and down, may be effective for some children, particularly prior to settling to do academic work⁵⁸. There is also some evidence that massage may be helpful for improving sensory responses and behaviours that challenge associated sensory issues⁵⁹. One review of the scientific literature states that the evidence base for massage was highest when it was applied three times a week in the afternoon for 15-30 minutes⁶⁰. However, it is important to remember that behaviours that challenge can be caused by a broad range of factors, including unrecognised pain or discomfort, the

child's learning history and anxiety^{61,62}. Massage should never be used without a thorough behavioural assessment. It is also important that the child's comfort levels and preferences for tactile stimulation are considered before implementing massage to ensure that the child and therapist are safe during the therapy⁶³. For more information on the other causes of behaviours that challenge you can access the Cerebra Self-Injury Guide, Cerebra Pain Guide or Cerebra Anxiety Guide (see Box 8 below). Finally, weighted vests and blankets have very little evidence base and can be dangerous if not implemented correctly, so these should only be

ever trialled with guidance from an Occupational Therapist and removed if they are of no benefit to the child. The Royal College of Occupational Therapists has specific guidelines on the use of weighted items, which are often viewed as unsafe⁶⁴.

Psycho-education

Sensory processing difficulties can be complex and confusing. Box 8 includes some resources that may be helpful for families who wish to learn more about sensory processing and how to support their children.

Box 8. Resources

Books

- **How does your engine Run – A Leaders Guide to The Alert Program for Self-Regulation**, Williams & Shellenberger (Therapy Works Inc)
- **Raising a Sensory Smart Child**, Biel & Peske (Penguin Ltd)
- **Alert at Home and School**, Williams & Shellenberger (Therapy Works)
- **Building Bridges through Sensory Integration**, Yack, Aquilla & Sutton (Future Horizons)
- **Sensational Kids: Hope and Help for Children with Sensory Processing Disorder**, Miller, Fuller, Roetenberg (Penguin Group USA)
- **No Longer a Secret: Unique Common Sense Strategies for Children with Sensory or Motor Challenges**, Bialer & Miller (Future Horizons)
- **The Out-of-Sync Child: Coping with Sensory Integration Problems**, Kranowitz (Perigee)
- **The Zones of Regulation**, Kupers (Think Social Publishing)

Websites

- The Challenging Behaviour Foundation <https://www.challengingbehaviour.org.uk/>

Cerebra Parent Guides and video

- Anxiety : A Guide for Parents <https://www.cerebra.org.uk/help-and-information/guides-for-parents/cerebra-anxiety-guide-guide-parents/>
- Pain: A Guide for Parents <https://www.cerebra.org.uk/help-and-information/guides-for-parents/pain-in-children-with-severe-intellectual-disability-a-guide-for-parents/>
- Self Injurious Behaviour in Children with Intellectual Disability <https://cerebra.org.uk/download/self-injurious-behaviour-in-children-with-intellectual-disability/>
- Sleep: A Guide for Parents <https://www.cerebra.org.uk/help-and-information/guides-for-parents/sleep-a-guide-for-parents/>
- Behaviours that challenge in people with intellectual disabilities (video) <https://youtu.be/ozeAyJCMtMQ>

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Dr Teresa Tavassoli

Teresa Tavassoli is an Associate Professor at the University of Reading. Her main research interest is sensory processing in autism spectrum conditions (ASC), which has progressively developed during her studies. During her doctoral studies she conducted a systematic study of different senses in ASC. Her research investigated sensory processing in ASC using self-report questionnaires, such as the Sensory Profile, as well as psychophysical measures of sensory detection, across multiple sensory modalities (vision, hearing, touch, smell and taste). She is interested in elucidating underlying mechanisms explaining variations in sensory processing in ASC and across the whole population.

Dr Virginia Carter Leno

Virginia Carter Leno is a Postdoctoral Research Fellow at the Institute of Psychiatry, Psychology and Neuroscience (IoPPN) at King's College London. Her PhD, also conducted at the IoPPN, explored different individual characteristics associated with mental health problems in youth with ASC. She is interested in delineating risk factors for mental health problems in ASC populations, and understanding why mental health problems are so much more prevalent in individuals with ASC as compared to those without ASC.

Ms Tara Rossow

Tara is an Occupational Therapist specialising in children with additional and complex needs. She trained in Australia (Bachelor of Occupational Therapy) and has worked in a variety of settings, both in Australia and overseas. She has worked extensively with children and adults with various disabilities and abilities, including with ASC, learning disability, sensory processing difficulties, physical challenges and challenging behaviour. Her interests lie in child- and family-centred practice, including pre and post diagnosis intervention and occupational performance.

Dr Jo Tarver

Joanne Tarver is a Research Fellow at Aston University. Joanne completed her PhD at the University of Nottingham where she led a small-scale randomised controlled trial of a self-help intervention for parents of children with Attention Deficit Hyperactivity Disorder (ADHD). Following this, Joanne worked as a post-doctoral researcher on the development of a clinical assessment tool for concerning behaviour in ASC and a feasibility and pilot trial of a novel parent intervention for emotional and behavioural problems in autistic children. Currently, Joanne is working on research projects aimed at improving the identification and treatment of mental health problems in individuals with ASC and intellectual disability.

Ms Georgina Edwards

Georgina Edwards is a doctoral researcher at Aston University, working with Dr Jane Waite and Professor Chris Oliver. Her PhD focuses on identifying the correlates of anxiety in children and adults with moderate to profound intellectual disability. Her main research interests include intellectual disability, ASC and mental health.

Dr Effie Pearson

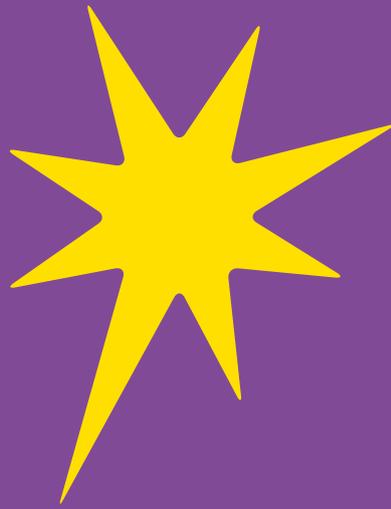
Dr Effie Pearson is a Postdoctoral Research Fellow currently working with Dr Jane Waite at Aston University. She completed her PhD looking at communication in Angelman syndrome under Prof. Chris Oliver at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham. Her research interests include understanding behaviours in individuals with an intellectual disability who speak few or no words, particularly communication, challenging behaviour and mental health difficulties. Effie has also worked with Jane Waite on developing online resources (Further Inform Neurogenetic Disorders (FIND); www.findresources.co.uk) to provide accessible information for families and professionals working with individuals with a range of rare genetic syndromes.

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