Autism

A Guide for Parents

autism
wellbeing

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About this booklet:

This booklet has been co-produced by a team of practitioners with lived experience of autism, dyspraxia, ADHD and dyslexia. It includes professional input from health and social care management, education and speech and language therapy, the latter informed by the principles of Sensory Attachment Intervention.

About Autism Wellbeing CIC:

Autism Wellbeing CIC is a not-for-profit social enterprise based in Carmarthenshire. We are a team of professionals working collaboratively with Autistic individuals and their families. We recognise that life can be complex and that individuals and families often have to overcome barriers in order to access the information and support services they need and to which they are entitled. For this reason, we work closely with and for Autistic people, remaining alongside them as partners on their journey.

The Autism Wellbeing team includes highly skilled professionals with specialisms in autism, sensory processing, education and psychology. We positively value neurodiversity and recognise the benefits it brings to our team. Amongst Autism Wellbeing's directors, we have lived experience of autism, dyslexia, ADHD, dyspraxia and sensory impairment.

We have co-produced a range of services that combine our expertise with that of our partners — Autistic individuals, their families and carers and the professionals who support them. None of our services requires the person to have a diagnosis of autism.

You can find out more about us on our website:
www.autismwellbeing.org.uk

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Understanding Each Other

When they are born, babies enter a new environment which they come to know and understand through their different sense systems. Sensory information comes in from the world around the baby, as well as from sensations originating within their own body.

As new parents, we have only our own lived experience to draw upon and, understandably, presume that our newborn infant will experience the world in just the same way as we do. Most people are able to interact with their physical and social environment without experiencing any pain or discomfort. However, for some of us, including for most Autistic people, interactions between our sensory processing systems and the physical and social world may be unpredictable, uncomfortable, distressing and even painful .

In order for us to understand our children's sensory processing patterns, we need to develop a deeper understanding of our own sensory processing patterns — how we process sensory information coming in from the world around us as well as sensations arising within our own body.

If we are non-Autistic and have an Autistic child who processes sensory information differently to us, it may be difficult for us to understand why our child responds or acts in a particular way. Given that we most likely interpret our Autistic child's way of being in the world from the perspective of our own lived experience (itself informed by societal norms), we may fail to understand – or only partially understand – our Autistic child's lived experience of their sensory environment.

We may be present in the same environment as our Autistic child yet have a radically different experience of a particular event or interaction taking place in that environment. Equally, our child may experience an event or interaction on Tuesday and be perfectly okay — for example, hearing the doorbell ringing — but then that same experience on Wednesday may cause them to become distressed.

Autistic people frequently communicate to those around them, via spoken language or via their way of being in the world, that our sensory experiences differ from those of other people, even when we are in the same environment.

You may hear this door slam and it might make you jump slightly and look up. Your brain and sensory processing system have perceived it as a slight annoyance, nothing more.

Your response is proportional to your experience. You carry on with what you were doing.

I may experience the same door slam as sudden, severe auditory pain. Perceiving the door slam as a threat, I might cower, fall to the floor in a foetal position or lash out at you if you're too close.

Just like you, my response is proportional to my lived experience.

We've both responded authenitically and genuinely to our experience – our responses differ because our neurologies and experiences differ.

My reaction is not an over-reaction or over- sensitivity – you probably respond in a similar way to me when you perceive threats too.

Each of us has our own sensory preferences or sensory profile — those sensory experiences that we either like or dislike, seek out or find difficult to tolerate. When our sensory profile is similar to our child's, we may have a good understanding of our child's sensory experience. Alternatively, it may be that our child seeks or needs sensory experiences that we find difficult to provide or to tolerate because those same sensory experiences for us cause discomfort, distress or pain.

For example, a child may feel the need to move their feet and tap their pencil on the table in order to regulate themself and so be able to focus on doing their homework, but their parent may be distracted and made to feel uncomfortable by their child's tapping and moving.

This booklet is offered as a guide to help us consider and make sense of our own and our child's sensory experiences and how these may differ. A deeper understanding of sensory experience may help us to identify changes that support both parent and child to create a more connected, responsive relationship that accounts for potentially different sensory experiences of our shared environment. This, in turn, may help us to reduce the discomfort, distress and pain associated, for many Autistic people, with sensory experience.

Stepping away from the medical model of autism

When your child was diagnosed as Autistic, in all likelihood you were told about the 'impairments', 'abnormalities' and 'deficits' your child supposedly has in relation to their Autistic Spectrum 'Disorder'. For decades, the medical model of autism has defined it as a 'triad of impairments' in social interaction, communication and imaginative play. At Autism Wellbeing, we contest the medical model of autism because it both pathologises and fails to reflect the lived experience of Autistic people. There is no denying that many Autistic people experience considerable difficulties in their lives. However, not all these difficulties are related to being Autistic and nor do they necessarily have to do with social interaction, communication or imaginative play. For many Autistic people, the difficulties they experience in their lives have to do with being Autistic in a world designed by and geared to the needs of non-Autistic people. A focus on 'deficits', as set out in the medical model of autism, fails to acknowledge the resources of courage, strength, resourcefulness and persistence that Autistic people draw upon as they lead their lives in a world not set up for their way of processing sensory information.

Here is a short film we made about neurodiversity:
https://www.autismwellbeing.org.uk/resourcesforparents/our-neurodiverse-classroom

The language we use at Autism Wellbeing

The language we use to talk about Autistic experience and autism in general can have a profound impact on Autistic people's lived experience. For example, when a clinician says that an Autistic person is 'hypersensitive' to sound, this implies there is a 'normal' or 'standard' way to experience sound. At Autism Wellbeing, however, we believe that each person's lived experience is different and equally valid. According to the Concise Oxford Dictionary, 'hypersensitive' means 'abnormally or excessively sensitive'. An Autistic person, responding to an auditory sensation (a sound), does so proportionately and in accordance with their sensory processing system. They are not 'over-hearing', 'hearing excessively' or 'hearing too much'. They simply process sound differently to how the clinician processes sound.

The language typically used to talk about Autistic lived experience portrays Autistic people as categorically different to a supposed 'norm'. For example, to describe Autistic sensory differences as 'sensitivities' implies that the Autistic person is not resilient enough, not robust enough to cope with something as benign as a mere sound, taste or texture. Talk to an Autistic person, however, who had a survival response (fight, flight or freeze) when they heard a fire alarm going off and they'll tell you they experienced the sound as acutely painful and responded in a way commensurate with the intensity of what they experienced.

Focusing on a supposed 'difference from the norm' in this way has resulted in certain ideas about Autistic people becoming set in stone, a kind of 'accepted truth'. These ideas colour the general public's perceptions of autism and, to a large extent, determine how Autistic people are perceived, responded to and treated. If we go into an interaction with an Autistic child and expect to see certain 'traits' of autism, then that is what we will see. In so doing, we may fail to take into account what is actually happening from the Autistic child's perspective. We may fail to see acts of friendship, kindness, love and empathy that are there but are perhaps being expressed in a way we weren't expecting.

Your Autistic child may not use speech to communicate — perhaps they use gestures, vocalisations or some other method. They may nonetheless understand spoken language — indeed they may even be able to hear a conversation taking place in a different room. Perhaps they simply take a while to process and respond to language.

Be mindful of how you talk about your child and their communication and sensory differences – especially if they are with you but you are not including them in the conversation.

Commonly used language....	We prefer....
Person with autism This is person–first language, as used by many professionals and practitioners. Person–first language is disliked by many Autistic people because they consider autism as inseparable from their identity.	Autistic person This is identity–first language, as preferred by the majority of Autistic people and their allies.
Autism Spectrum Disorder Use of the term “disorder” makes many Autistic people feel like there is something wrong with them or that they need fixing.	Autism
Sensory Processing Disorder Abnormal sensory processing Atypical sensory processing Words like disorder, abnormal and atypical suggest that there is one, standard sensory processing norm from which Autistic people deviate. This is not the case. Each of us, Autistic and non–autistic alike, has our own individual way of processing sensory information.	Sensory processing differences
Over–responsive Hypersensitive Hyperreactive Again, over– and hyper– suggest the existence of a sen–sory processing norm from which Autistic people deviate. This is not the case. When an Autistic person responds to sensory experience, they do so proportionately, in line with their own, unique sensory processing system. Their sensory processing system is unique, just as yours and mine are.	Heightened sensory signals Intense sensory signals
Under–responsive Under–reactive Hyposensitive See above.	Muted sensory signals
Neurotypical The notion of neurotypicality suggests the existence of a neurological norm from which Autistic people deviate. This is not the case.	Non–Autistic
	Neurodiversity This term encompasses all of humanity. All the diverse human neurologies that exist in the world are included and valued equally.

Learning from Autistic Adults

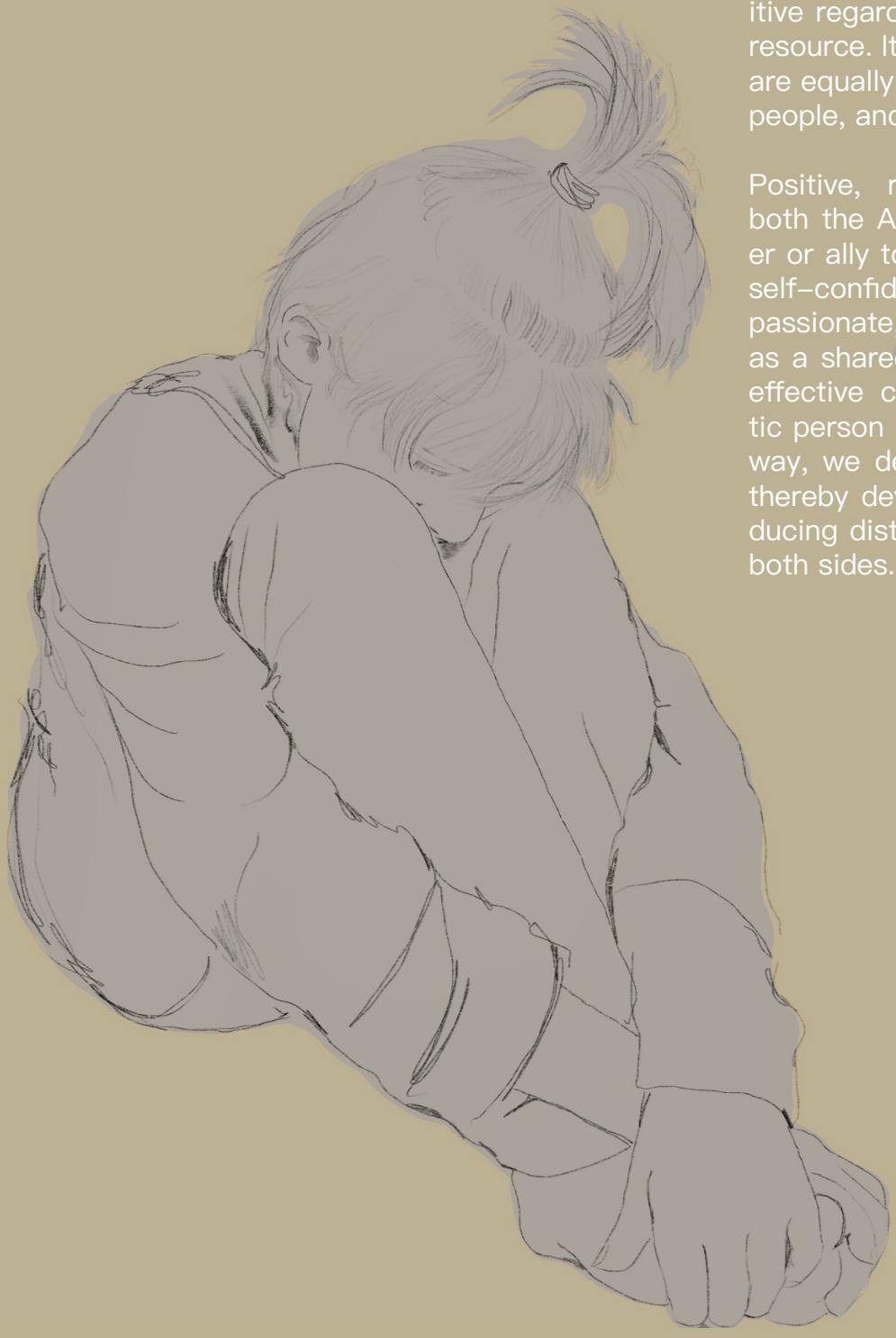
A resource available today that was not available previously is Autistic adults' own, unmediated accounts of their lived experience. People like Donna Williams and Temple Grandin began writing accounts of their lived experience over thirty years ago. When we read, listen to or watch Autistic testimony in books, blogs and films, it is clear to see that Autistic people do experience emotions, they do express empathy and they do use and appreciate humour. They can be sarcastic, eloquent and capable and yes, they do indeed have a so-called "theory of mind" — all capacities and attributes that tend to be denied them because of the myths and stereotypes that have grown up around autism.

By allowing the testimony of Autistic adults to guide us, we gain insight into what our Autistic children may be experiencing in their lives. In so doing, we deepen our understanding of how we might connect with and respond to our Autistic children more effectively.

Understanding and Mental Health

The testimony of Autistic adults asserts unambiguously that the most effective protection against mental ill health across the lifespan comes in the form of relationships with those around us — the validation, empathy and understanding of family members and allies and their willingness to accept and value the Autistic person just as they are.

As parents, we know that validation, empathy and understanding are sometimes easier said than done. In addition, our Autistic child's way of being in the world may make them particularly vulnerable to teasing, ridicule, bullying and abuse in the wider community, as well as, potentially, within their own extended family and social networks.



However, for Autistic people, compassionate, reciprocal relationships of mutual respect in which each person can express their true self and experience unconditional positive regard are an essential, transformative resource. It is worth noting that relationships are equally important for non-autistic people, and for just the same reasons.

Positive, reciprocal relationships support both the Autistic person and their caregiver or ally to develop enhanced self-esteem, self-confidence and self-efficacy. Compassionate, reciprocal relationships function as a shared scaffold, creating openings for effective collaboration between the Autistic person and their caregiver or ally. In this way, we deepen mutual understanding and thereby develop effective strategies for reducing distress and increasing wellbeing on both sides.

Living in a world designed for non-autistic people presents Autistic people with all sorts of difficulties, including stigma and discrimination. However, thinking of our Autistic children, they do not experience these difficulties alone — each child is, of course, a family member. As such, parents and siblings may also experience stigma and discrimination from the wider community. This can be expressed as open hostility or as subtler behaviours that make us feel ashamed, embarrassed and excluded from community life. As parents and siblings, we too may feel lonely and isolated at times.

Masking

Many Autistic people grow up masking their autism in order to reduce their exposure to discrimination, teasing, bullying and worse. Many Autistic people mask their autism in order to be able to take part in activities and friendships with their peers. As parents, we are often desperate for our children to be accepted and to avoid some of the difficult experiences we might have had as children because we were different. Creating opportunities for Autistic people to take part without having to mask their autism can be beneficial for Autistic children as well as for their peers and communication partners. When we create conditions in which our Autistic child no longer feels the need to mask their autism in order to take part, their peers and communication partners meet the child on a level playing field where, who knows, they might become friends and allies.

We know from first person testimony that many Autistic adults feel that they are seen as somehow "other" or less human on account of their autism — like being a square peg trying to fit into the round hole of so-called "normality". As caregivers and allies of Autistic people, we need to advocate for our children and do what we can to make the 'holes' more square. By working to modify the attitudes and environments with which our children come into contact in the course of their daily lives, we can support our Autistic children to feel that it is okay to be who they are.

Masking is known to be detrimental to an Autistic person's mental health and a significant factor in suicide and self-harm. Having access to social settings where it is safe to be authentically Autistic can have a hugely positive impact on Autistic people's wellbeing and mental health.

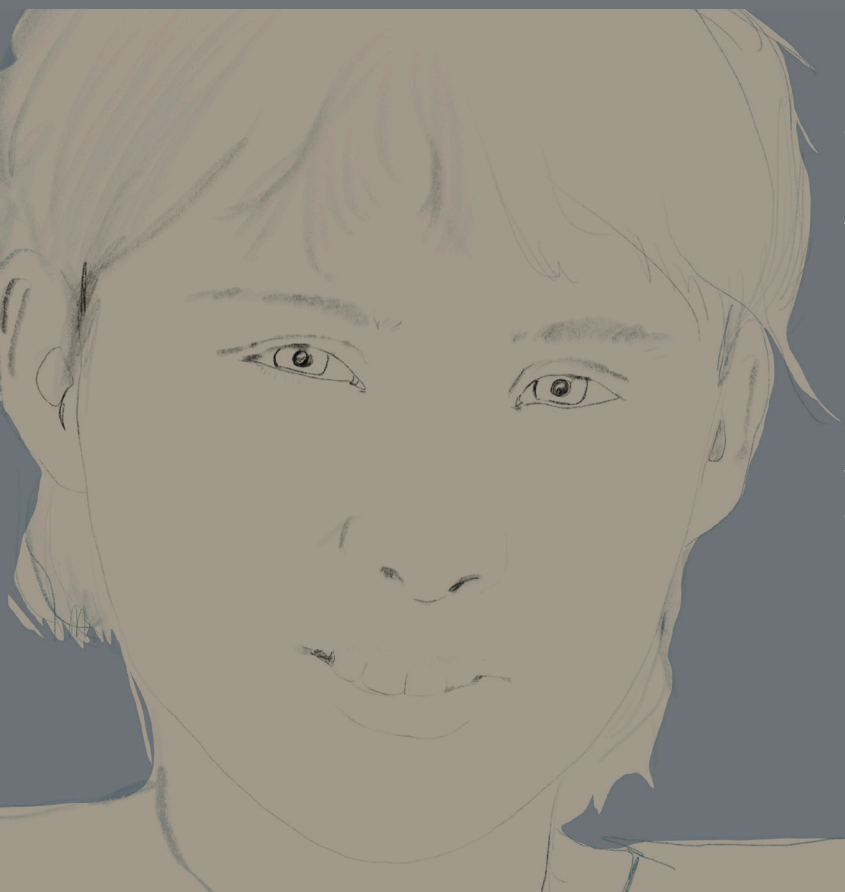
Communication

Many of our Autistic children communicate differently to their non–autistic peers. While most Autistic children use spoken language, albeit possibly idiosyncratically or with some difficulty, some may not use formal language to communicate. With these children, our interactions are focussed more on connection, emotion and body language. Some Autistic children may not use formal language to communicate but may be able to process and understand spoken and written language. Others may, over time, learn to communicate expressively using a communication aid or through signing or writing.

Some Autistic children may be able to use single words or short phrases, whilst Autistic children who use spoken language to communicate may need lots of time both to process what has been said to them and to formulate what they are going to say in response. And of course, many Autistic children are fluent speakers.

Some Autistic children take time to figure out how to formulate speech sounds using their vocal chords, lips, teeth and tongue. As a result, their fluency may be disrupted and this can affect the spontaneity and timeliness of their spoken interactions. Some Autistic children may be able to speak freely with specific family members and close friends but struggle speaking to certain known others, to people they don't know or to people they meet in the community. We know from the first person testimony of Autistic adults that, no matter how able they are verbally, in stressful or unpredictable situations or environments, even the most competent speakers may find themselves struggling or even unable to use verbal language.

In an ideal world, all forms of communication would be recognised and equally valid. There are many examples of good practice happening across the UK in terms of communicating with Autistic people, but the pace of change is slow. At Autism Wellbeing, we use an approach called Responsive Communication.



Responsive Communication is a disposition, a way of being and interacting rather than a set of techniques to learn.

At the heart of Responsive Communication is the concept of 'autism from the inside out' – learning from Autistic testimony and developing an empathetic understanding of how our child's lived experience may be different from our own.

We believe that, for meaningful connection to take place between us and our Autistic children, we need to reduce negative, distressing sensory inputs and increase positive, regulating sensory inputs, thereby promoting feelings of safety.

Responsive Communication

Responsive Communication is founded on the recognition that all behaviour is communicative and all ways of being in the world are equally valid. What this means is that, when we communicate with our Autistic children, we are listening not only to what they are 'saying' verbally, we are also 'reading' their whole-body expression and responding to their emotional state (their affect). For example, think of a child who repetitively asks the same question over and over again. This child may not necessarily be seeking an answer to his question. He may be working on the assumption that, by repeating his question in this way, he will get some kind of response from his parent. He may be using the question as a way of initiating interaction with you, and if you 'listen' to the emotion behind his persistent questioning, it may be that the child is signalling to you that he feels scared, anxious, worried or out of control, or simply that he needs comforting.

Using Responsive Communication with our non-speaking Autistic child means we tune in to their vocalisations and non-spoken communication, we take into account and respond to their body language and behaviour (their way of being in the world) and we connect with them by joining in with what they are doing in a responsive and empathetic way.

By responding to our child in this way, we signal that we see them, we are with them and we value any and all forms of communication they might use. For example, a child picking up handfuls of Lego and letting them drop through her fingers may be seemingly cut off from the rest of the world. However, sitting alongside her, letting Lego drip through your fingers or miming a similar action with the same rhythm and emotion behind the action, signals to your child "I see what you are doing, I value what has meaning for you and I will validate your calm pleasure by joining in with that meaningful activity". As Phoebe Caldwell says in her book Finding You, Finding Me: "[i]n being for each other, we become ourselves".

We know from Autistic adults that when someone takes the time to 'learn their language', to connect with them in a way they are comfortable with, then relationships are easier to initiate, negotiate and enjoy. For all of us, Autistic and non-autistic alike, when we feel accepted in this way, we are more able to be our true self.

To find out more about Responsive Communication, please visit

http://thecaldwellautismfoundation.org.uk/index.php/responsive-communication-the-films/

Sensory Processing

All of us, Autistic and non-autistic alike, experience the world through our senses. Sensory processing is the process by which the nervous system receives, organizes and interprets sensory information.

Sensory processing helps us figure out how to respond to environmental demands based on the sensory information available to us.

As humans, we are constantly picking up sensory information from our environment via our sense receptors. As part of this subconscious process, our brains filter out sensory information that is safe to ignore so that it can focus on information important to tune in to. We also process sensory signals arising from within our body that help us to know how we are feeling, where our body is in space and where our body is in relation to gravity.

Sensory information is vitally important for each of us because it drives our physical, cognitive and emotional development. We are motivated to learn and explore through our interactions with and interest in the sensory world around us. Our senses also play an essential role in keeping us safe. For example, if food smells rancid, we know not to eat it, and if we feel unstable on a structure, we climb down from it. Similarly, if we see a threat coming towards us, we take action to avoid it, and the pain of touching a hot surface makes us quickly move our hand away. Sensory information tells us how to act in and adapt to the environment. Sensory processing also plays a role in regulation, activating us to evade a threat or calming us so that we feel safe.

Survival Responses

When we feel threatened — when our senses perceive a threat in the environment — we instinctively take action in response to that threat. Our three main survival responses are fight, flight or freeze. Sometimes, when we are feeling regulated and in a safe place, we may be able to override these survival responses and cognitively weigh up the extent to which we are actually threatened.

On account of their sensory differences, our Autistic children may live their daily lives in a state of heightened stress and anxiety, many of them experiencing Sensory Trauma. Sensory Trauma may arise from painful and distressing sensory experience. For many children, these painful or distressing sensory experiences are associated with activities that are typically part of normal everyday life.

As Sensory Trauma and the potential for Sensory Trauma are ever-present over the course of their day, our Autistic children may spend their waking hours constantly on edge, hypervigilant and at risk of tipping over at any time into one of the three survival responses.

The longer the Autistic child lives in a state of heightened anxiety, the more their nervous system becomes used to functioning in that mode or on that “setting”. The child becomes habituated to being on the look-out for the next potentially distressing sensory experience.

Survival Responses

An Autistic child's account of how a "FLIGHT" survival response feels when they are in the supermarket:

"I feel too hot – uncomfortable and itchy and prickly with the heat – a sort of needing to keep moving kind of too hot, rather than a 'I could lie here all day it is so lovely' type of heat. My clothes feel unbearable and if only I could get them off my skin. Everything is too bright and won't keep still, the pattern on the floor is moving up and down and I can't judge where the floor is – I can't even sense where my feet are – I am beginning to detach from my body completely….
I am so jumpy and aware of everything that is happening. Every time someone speaks over the tannoy I feel deafened and as if they are shouting directly at me – I am terrified. I have to leave NOW or I will die!!!

I lock my eyes onto the exit door and my tunnel vision guides me like a missile down the aisles and out into the fresh air. The shelves flash by as if illuminated by strobe lighting. I am pulling my top away from my neck again and again because it is going to choke me, but I can't even feel how much force to use and oh no – I've ripped my top...

My hands feel grippy and tight and I am squeezing and clenching and unclenching my fists and that makes me know I am alive because I can feel the tension and the pressure of each of my fingertips digging into my palms. I can't think in words, I feel very unsafe and scared, like something really bad is about to happen to me, but I'm not sure what. I have been making a noise…I hadn't realised but I just needed to not hear all the people."

What other people may say when they don't understand what is going on for this child:

"No matter how many times I tell her to keep her clothes on, she rips them off whenever we go in the supermarket – she knows how to behave so why is she doing this? I can't simply not go into the supermarket just because she doesn't like it!"

"That mother clearly can't control her child!"

"That rude girl has just barged into people without looking where she's going"

"Why is that child making such an annoying noise?"

"That girl looks dangerous – look at her clenching her fists when the security guard is trying to help her, it looks like she's going to punch him."

What was actually happening

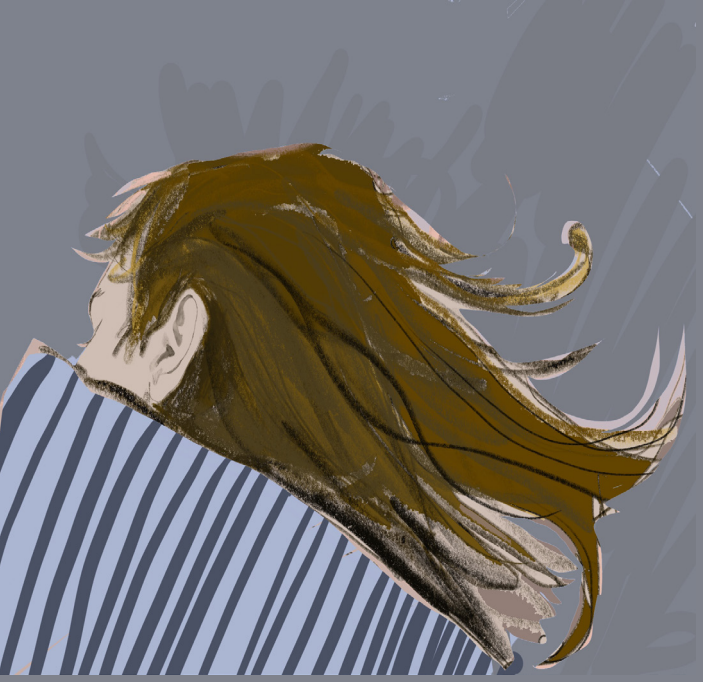
This Autistic child has described how her brain processed the sensory information in the super–market and automatically responded with a FLIGHT survival response. She requires only a small amount of sensory input for it to register in her brain, so places like supermarkets can be over–whelming because they are designed to be colourful, busy places.

Here are some other ways that a person experiencing a FLIGHT survival response might act:

» Restless and fidgety
» Constantly moving, unable to sit still, moving their legs
» Breathing quickly
» Running or climbing without any concern for their own safety.

How our Autistic child might appear when experiencing a FIGHT response:

- Hypervigilant, darting eyes, scanning the environment for threats
- Screaming
- Clawing at the air
- Glaring
- Clenching fists
- Gasping for breath
- Raising voice
- Saying things like ‘I hate you’
- Moving towards people in an apparently threatening way
- Verbally abusive
- Physically hurting their caregiver or sibling
- Kicking
- Biting
- Pushing
- Throwing things
- Physically hurting themselves.



What a FREEZE response might look like in an Autistic child:

- Breath–holding
- Crying or whining
- Day–dreaming
- Heart pounding or decreased heart rate
- Losing bowel or bladder control
- Not being able to hear when spoken to
- Not being able to use or process speech
- Feeling numb
- Turning in on themselves, escaping into their own mind
- Unable to move
- Going pale
- Fainting

Some Autistic children are able to describe how they feel when they are in a freeze state:

- Lost, spaced out, not really there
- Disconnected from themself
- Disconnected from their body
- Physically frozen, numb, they literally can't move
- Feeling like they are stuck in a part of their own body
- Unable to tell you or to articulate how they feel, they may just honestly respond that they 'do not know' where they are or what is going on
- Unable to speak.

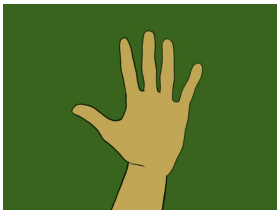
Our Sense Systems

We are taught in school that there are five sensory systems, however, there are three more sensory systems that we tend not to learn about. When we are thinking about autism, there are eight sensory systems we need to consider:

Visual
(Sight)

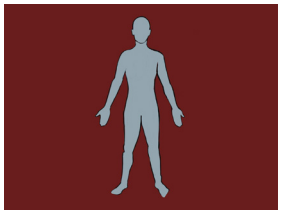
Gustatory
(Taste)

Auditory
(Hearing)

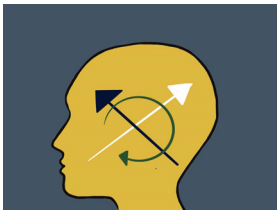


Tactile
(Touch)

Olfactory
(Smell)



Proprioception
(Body/position sense)



Vestibular
(Relation to gravity)

Interoception
(Sensation originating in the body)

Each of us has sensations that we like or are able to tolerate, as well as some we do not like and find difficult to tolerate. Many Autistic people process sensory information differently to their non–autistic peers. For Autistic people, their sense receptors (eyes, ears, taste buds and so on) may work perfectly well but there may be differences in the way their brain processes the incoming sensory information.

For Autistic children, the experience of sensory processing in the brain may include:

- Struggling to process too much sensory information to be able to function effectively
- Not receiving enough sensory information to function effectively
- Struggling to filter out unnecessary sensory information
- Sensory signals are experienced as heightened
- Sensory signals are experienced as muted
- Sensory signals are distorted during processing
- Sensory signals fragment during processing
- Sensory signals are delayed during processing
- Sensory perception in one or more senses shuts down, resulting in an incomplete picture of what is happening in, to or around your body.

Variability in sensory processing

Our Autistic children's sensory processing patterns may be confusing for us as parents. Our child may seem to cope well with a particular sensation on one occasion, but another time they may become distressed and struggle to cope with that sensation at all. Sensory processing does not happen in isolation, it is not just about the child's ability to process that particular piece or kind of sensory information. Sensory processing is dynamic and highly context specific – it is about the child experiencing that specific sensation, at that particular time (in light of what has come before and anticipation of what may come next), in that particular environment, in the company of those particular people, whilst in that particular emotional state.

This can make it very difficult for us as parents to understand and support our child's sensory experience, with the result that their responses to sensory experience may catch us off guard. Unpredictable sensory responses can make it difficult to be empathetic if our Autistic child is dis–tressed about a particular sensory experience which, yesterday, they coped with comfortably. We question whether the child is 'putting it on' or 'doing it for attention', because to us (and maybe to other people as well), that's exactly how it looks. Sensory distress or sensory pain often looks like a 'temper tantrum' but what is actually happening for the child is quite different.

We have seen that, whatever the reason for our Autistic child's distress, by responding to them calmly and empathetically we provide the reliable, consistent support they need. More often than not, your child may not be able to tell you the source of their distress.

We know from Autistic adults that many of them experienced or were made to feel acute shame after becoming distressed as children. Happily, things are changing (albeit slowly) and nowadays more and more parents and teachers have a greater understanding of autism. However, a key part of protecting our Autistic children's mental health is supporting their capacity for self-compassion and self-care. When we refrain from judging our child's way of being in the world, we provide an opening for them to practise such self-compassion and self-care.

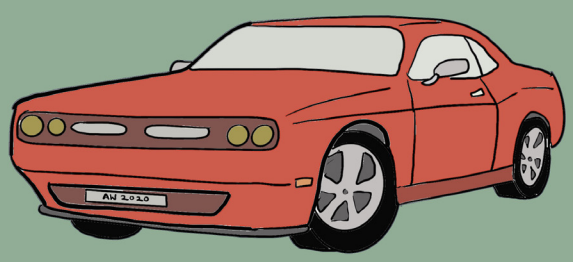
Sensory Modulation

Sensory modulation is an ongoing process — it's how our brain fine tunes incoming and internal sensory signals so as to make sure we are in our 'just right state'. Sensory information is constantly being registered in the brain and sensory modulation continuously makes adjustments to help us feel in the 'just right state', meaning we are able to function, learn and connect with others optimally. Being in the 'just right state' means feeling calm and alert, being open to new experiences and available for intellectual challenge, social interaction and emotional connection. For many of us, sensory modulation goes on all the time, ticking along subconsciously in the background. For our Autistic children, the process is not always so smooth and many children (consciously or unconsciously) develop idiosyncratic ways of being in the world that support their sensory regulation.

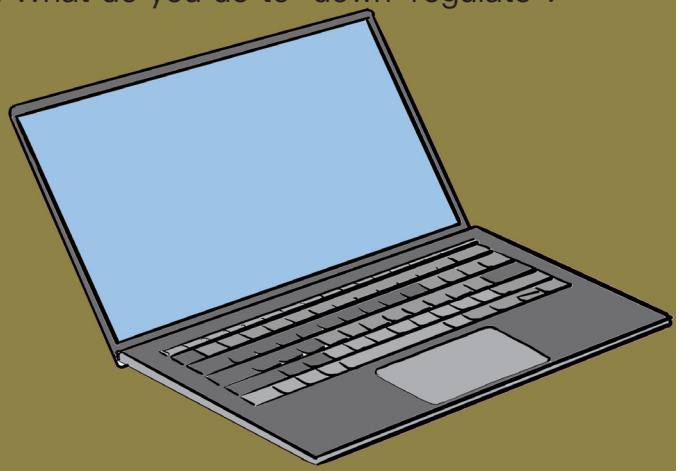
The things our children do to make themselves feel in their 'just right state' may not be things we would ever do. This can make it quite difficult for us as parents to understand why our child does some of the things they do, especially when these behaviours — these ways of being in the world — may be socially frowned upon. Most of the strategies our children devise to keep themselves regulated, or in their 'just right state', are sensory strategies. Examples include rocking, head banging, hitting their ears, flapping, jumping, spinning or hitting objects. Repetitive sequences of activities and sorting things into categories may also be part of our child's attempts to regulate themself. By engaging in such activities, our Autistic child is seeking sensory input into their body that will regulate them or at least give them a sense of where their body is. Autistic children engage in such sensory activities in an attempt to help them feel embodied and safe.

When we are in the 'just right', regulated state, we are open to new experiences and available for intellectual challenge, social interaction and emotional connection. If we are anxious or overstimulated, to get into our 'just right state' we need to do things to calm or down-regulate ourself. Conversely, if we are feeling disconnected from those around us or from our own body, we need to do things to awaken or up-regulate ourself.

You're driving down the motorway, you're tired and the services are ten miles away: what do you do to 'up-regulate' yourself?



You need to do a presentation for work but you're feeling really anxious about it. What do you do to 'down-regulate'?



Our brain's information filter

Our brain continuously filters out sensory information in our environment to which we do not need to attend, for example the sound of the fridge humming or the whirr of the computer. Sometimes, our Autistic children are unable to filter out certain sensations and may experience all sensory information in their environment with equal intensity. Conversely, their sensory "filter" may be so effective that it filters out too much information and the child may appear disconnected from the world around them. For some children, these sensory processing differences may vary both within and across sense systems. In addition, sensory processing differences may depend on the setting as well as the child's emotional state.

Have you noticed that when you're stressed or trying to concentrate, you notice other sounds more and you find things distracting that you didn't before?

Have you noticed that when you're hungry you find it harder to concentrate, as the sensation of hunger seems to take over your attention?

Do you find that when you're tired, you're more likely to bump into things, and that small injuries seem to hurt more?

Heightened Sensory Signals

Some Autistic children have heightened sensory experiences in one or more sense systems. Which sensory experiences are heightened will depend primarily on the child's neurology, but also on their emotional state and social and physical environment. The child's heightened sensory experiences may range from mildly uncomfortable to excruciatingly painful. Heightened sensory experiences arising from activities and interactions that are part of everyday life may be experienced as Sensory Trauma and may activate a survival response in the child (fight/flight/freeze). The fear of repeated exposure to the traumatising sensation may lead to increased anxiety and a desire to avoid situations in which the traumatising sensation might be re-experienced. For example, an Autistic child who experiences heightened sensory signals in their tactile (touch) sensory system may become distressed during everyday activities such as teeth brushing, hair brushing, nail cutting or wearing clothes. Anticipation of such everyday activities may increase the child's stress levels which may, in turn, further heighten their sensory distress.

Muted Sensory Signals

Some Autistic children may not be able to detect sensation in a particular sensory system with enough intensity for it to register in their brain. This may be the case in one or more sense systems and is likely to vary depending on the context and the child's emotional state at the time. When we experience muted sensory signals, we may feel disconnected from ourself and from what is going on around us. An Autistic child may need to give themself really strong sensory experiences in order to begin to register a particular type of sensation. For example, they might bend their fingers or their hands back, pinch or hit themself or bite their hand as a way of embodying themself and thereby gaining a stronger sense of where their body is in space.

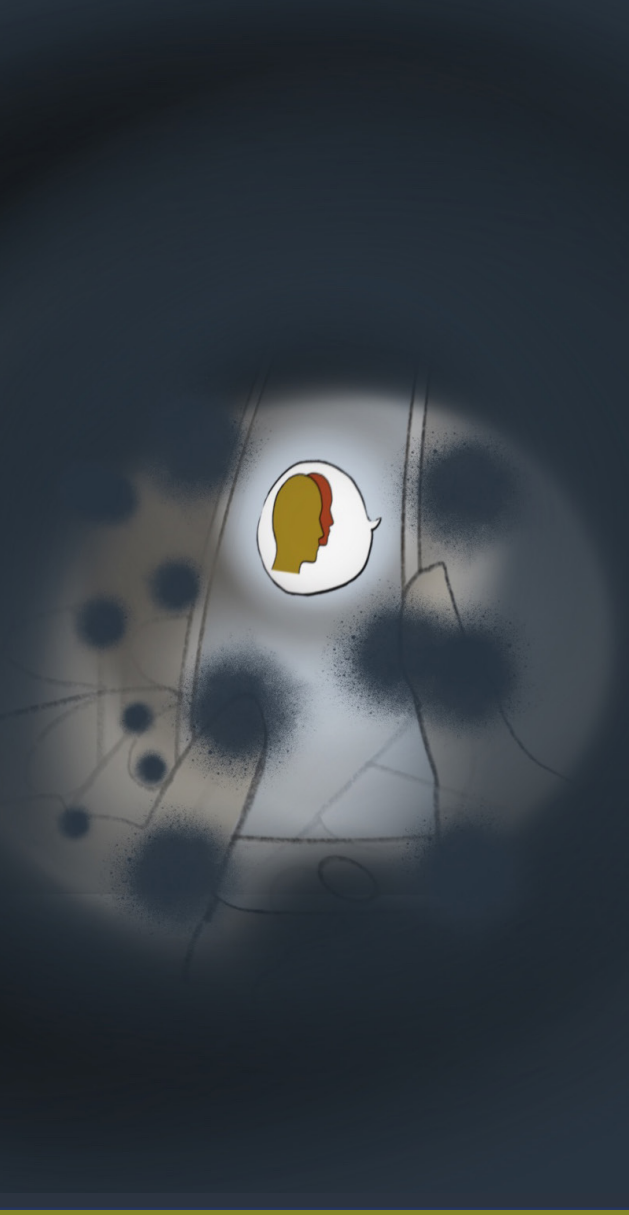
Distortion, Fragmentation and Delay

For some Autistic children, sensory signals may become distorted as they are processed in the child's brain. For example, when an Autistic person becomes stressed or overloaded, their capacity to perceive dimensional depth may diminish with the result that their environment may appear flattened and two-dimensional.

We know from Autistic adults that, owing to their different sensory processing, spaces (rooms, environments) may appear larger or smaller than they actually are. Similarly, objects may appear to change size and shape, to move or to change texture or form. Some Autistic people report losing the capacity to identify or distinguish between their interoceptive sensations.

Sometimes our Autistic children may be able to see a part of their body but not feel it. Whole sense systems may shut down as processing of incoming sensory information becomes too much for the brain to manage.

Delays in processing sensation may occur because the sensory information takes time to register in and be processed by the brain. This can often be clearly seen in Autistic children who experience delay in processing pain signals, with the result that they may react to an injury and its associated pain minutes or even hours after the injury occurred.



What follows is an account of an Autistic adult's lived experience:

"My fingers aren't there! I'm sat scrolling through my newsfeed on social media, trying to tap on a message to open it and my fingers have disappeared. I can read the screen of my phone but there are blank, blurry patches where my fingers should be. I move them – or do I? I can't see them and I'm never quite sure, when I can't see bits of my body, whether I can actually move them or not. I slowly move my phone around and realise that I have tunnel vision with a ring of pixelated, almost kaleidoscopic vision around it. If I move my head, I can fix what I am looking at into the centre of my vision so that I can see it. This isn't right, but I feel OK. I quickly scan through my body: head – OK, no pain, no dizziness; limbs – OK, no pain, they can move; body – my heart isn't doing anything unusual, no pain or fluttering or sickness from my tummy. I can think normally; I'm not worrying; I'm not preoccupied; I'm just going about my business as usual and this has happened. This visual disturbance lasted for a few minutes and then disappeared as suddenly as it came. It happened a few times over the next few days…. My dad died the day before I experienced this visual disturbance for the first time" (from Good Autism Practice Journal, May 2020).

Our Interoceptive System (Interoception)

Interoception is the sense that tells us what is going on inside our body. Our interoceptive sense tells us when we are hungry or need the toilet, for example, as well as how we are feeling emotionally. The interceptive sense receptors are found in our organs, bones, muscles and skin. Interoception tells us about our internal experience of emotional states such as:

- hunger/fullness
- thirst
- temperature
- pain
- needing the toilet
- sexual arousal
- happiness
- enjoyment
- boredom
- sadness
- frustration
- anger
- fear
- alarm

Interoceptive signals allow us to label and understand our emotions. When we experience an emotion, our interoceptive system sends signals to our brain to help us understand that emotion. We need to be able to detect and recognise these interoceptive sensations in our body in order to be able to label the particular emotion we are experiencing. Knowing the emotion that we're feeling, we can then, if necessary, take appropriate action to regulate ourself.

If we are unable to detect or label interoceptive sensations arising in our body, we may not recognise our changing state of arousal until we have actually responded physically to a perceived threat. For example, an Autistic child may not pick up on their internal signals telling them that they are scared or angry until the point when they actually hit out at someone, whether verbally or physically.

If you are unable to detect or recognise your internal sensations, it follows that you may have difficulty actually processing how you're feeling. When an Autistic person is unable to detect or recognise the interoceptive signals arising in their body, they may also find it difficult to self-regulate.

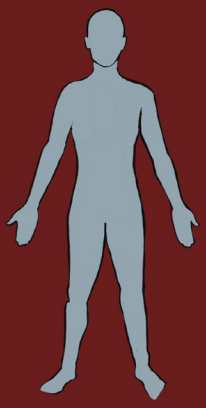
Some Autistic children experience heightened interoceptive signals, feeling the sensations associated with different emotions so acutely that they become distressed and go into a survival response. For example, many Autistic children find being hugged uncomfortable or even painful, not simply because it is experienced as an intense touch sensation, but also because of the emotion associated with being hugged. Experiencing such emotion may make the child feel sick, anxious and wanting to push back, flee or collapse.

The interoceptive system tends to be little known about or understood. For example, many Autistic children are enrolled in "social skills" or "emotional intelligence" programmes at school. Such programmes are of little use to an Autistic child who is unable to reliably detect, label or interpret the interoceptive signals arising in their own body. Indeed, such programmes may be counter-productive for many Autistic pupils.

Praise and the emotions that may go with it.

A significant number of Autistic children find the experience of being praised difficult to deal with. Being praised can give rise to heightened interoceptive signals in the child's body that may feel uncomfortable, distressing or even overwhelming. Being praised may bring unwanted attention to the child that may also feel uncomfortable, distressing or intolerable. As such, it is important to find ways of recognising the child's achievement without the child becoming distressed or overwhelmed. One way to do this is to acknowledge the child's achievements indirectly. For example, you could tell a third party how pleased you are with your child's efforts, expressing this in such a way that the child can hear your positive affirmation but does not feel that the praise is directed at them.

Our Proprioceptive System (Proprioception)



The term proprioception comes from the Latin meaning ‘to understand oneself’.
Our proprioceptive sense receptors are in our muscle spindles, joints and ligaments.
Sensory signals from these receptors tell us about:

- Joint angle
- Muscle length
- Muscle tension
- Movement

Proprioception tells us where our body is in space, where our limbs are in relation to each other and where our body ends and our environment begins.

It is our proprioceptive sense that allows us to walk along a footpath without looking at our feet, or to make the ongoing micro–adjustments necessary to maintain our seated position.

Proprioception also plays an important role in our sense of self. It is by mapping all these subtle proprioceptive signals from our muscles, ligaments and joints that we distinguish between “me” and other people. The proprioceptive system functions in collaboration with our other sense systems, most notably the vestibular and visual systems.

Many of our Autistic children may experience muted proprioceptive signals and so find it difficult to generate and sustain a coherent sense of self. If you detect only muted proprioceptive signals, you will have only a weak or blurry sense of where your body is.

When you wake up in the night and you’ve been lying on your arm and it’s gone numb, the sensation you get in that arm is one of disconnection, the slightly panicky feeling that your arm no longer fully belongs to you. In this scenario, you fail to detect the proprioceptive signals that tell you where your arm is that it is connected to the rest of your body.

Many Autistic children experience muted proprioceptive signals which means they need to seek out proprioceptive input that will help them to feel embodied. This is precisely what you do when you wake up having slept on your arm: you shake your arm, pinch it, rub it, squeeze your palm, open and close your fist — you do what you have to in order to get proprioceptive sensation back in your arm.

Close your eyes and bring your index finger to the tip of your nose, stopping just before you get there. The proprioceptive signals from your muscles, ligaments and joints tell your brain precisely where your finger is in relation to your nose. This is proprioception in action!

Things you may see if your child experiences muted proprioceptive signals.

Your child may:

- Be constantly on the move, jiggling their feet, rocking, fiddling with their fingers
- Run into furniture, run into walls
- Use more force than a task or activity requires
- Have poor body awareness, bump into things, stray into other people's personal space
- Kick, bite, hit
- Like to be squeezed – in clothes, in hugs, under heavy bedding, in corners or small, enclosed spaces
- Chew clothing, pencils, fingers
- Tighten and flex their muscles
- Tend to be rough and physical in play
- Have ways of being in the world that end up with them getting hurt (so-called 'self-injurious behaviours').

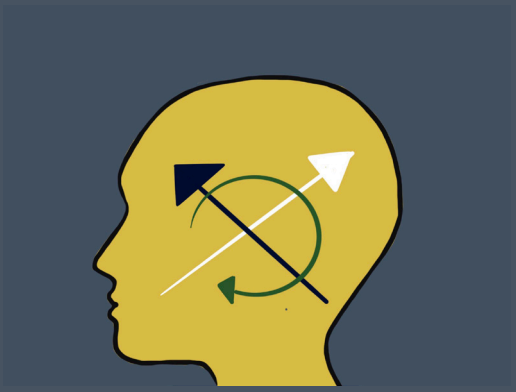
Ways of increasing proprioceptive input if your child has muted proprioception:

- Provide regular opportunities for them to be active, to move around
- Activities where the child bears their own body weight such as wheelbarrow walks, animal walks, crawling
- Heavy work – lifting, carrying, digging, dragging, pulling
- Basic resistance exercises – jumping jacks, wall press-ups, push-ups
- Inversion – handstands so that all the weight of their body is felt through all of their joints
- Deep tissue massage or full-body massage with a therapy ball
- Oral proprioception: chewy/crunchy snacks, chewing gum, chew tubes, sucking thick drinks through a straw
- Vibration for example from hand-held massager, vibrating snake, vibrating pillow or mattress
- Compression: tight clothing, bear hugs, being rolled up in blankets, squashed between mattresses.
- Sports: swimming, cycling, climbing

Many Autistic children need to chew on things or to spit as a way of getting increased proprioception in their jaw muscles. Telling our Autistic children not to bite on clothing, toys or furniture may not work as they are attempting to regulate themselves by seeking heightened proprioception in their jaw, muscles and ligaments. Instead, try offering an alternative means of getting increased proprioception in their jaw muscles.

When you have a muted, unreliable or inconsistent sense of self, you have to work harder at carrying out tasks and activities, at paying attention and learning. It can be exhausting, frustrating and scary.

Our Vestibular System



Our vestibular system tells us where we are in relation to gravity. It tells us about head position, body movement and balance. The vestibular sense receptors are found in the inner ear.

The vestibular system is closely linked to our visual system. For example, if we are on a boat and feeling seasick because of the movement, looking at the horizon may help us to feel more steady.

Autistic children with heightened or muted vestibular processing may live in a state of anxiety a lot of the time because their unreliable vestibular sensations make them feel unsafe.

Linear rocking provides calming and regulating vestibular input. We do it instinctively to calm ourselves or to provide regulating sensory input. For example, when we pick up a new–born baby we instinctively rock the baby in our arms in a linear fashion.

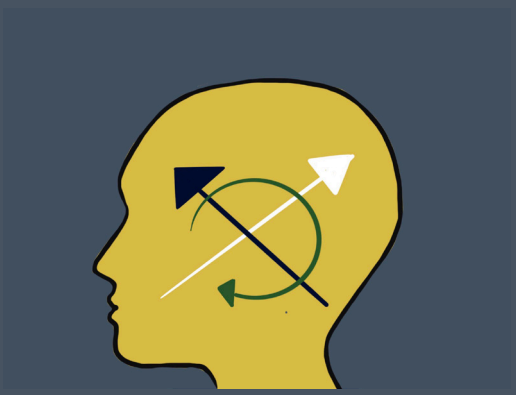
By contrast, rotary movement (turning round and round) is alerting or activating, so an Autistic child who has muted vestibular signals may frequently feel the need to spin. Some Autistic children will spin fast on a roundabout in the play park and then step off the roundabout without feeling remotely dizzy.

Inversion (turning your body upside–down) provides heightened vestibular input. Many of our Autistic children with muted vestibular signals will spend lots of time upside–down on sofas or hanging upside down from a tree or climbing frame in the garden.

Autistic children with muted vestibular signals may take risks such as climbing really high or going really fast. They engage in activities that provide heightened vestibular sensation (the pull of gravity) so as to make them feel more embodied and more regulated.

Autistic children with heightened vestibular signals are the opposite, they will be cautious and sensitive to any changes in their relationship to gravity. In extreme cases, the sensation of being on the first floor of a building may feel too intense and activate a survival response in the child. Movement, for example travelling in a car, may cause a child who experiences heightened vestibular signals to feel nauseous very quickly. As babies, some of our Autistic children may have become highly distressed when having their nappies changed because being tipped backwards onto their back felt alarming for them. Feeling unsafe if tipped backwards is an example of gravitational insecurity. Some Autistic children with heightened vestibular sensation may even struggle with having their feet off the ground.

We don't tend to give our vestibular system much thought as we're generally not consciously aware of our relationship to gravity. Times when we are aware of our vestibular system (when we feel the pull of gravitiy) are, for example, when we are taking off in an aeroplane, when we're on a roller coaster or a high balcony or going up in a lift.



Things you may see if your child has muted signals in their vestibular and proprioceptive senses.

Your child may:

- Appear “clumsy”
- Lack awareness of their body position in space, have ‘odd’ body posture
- Appear resistant to learning new movement activities
- Have difficulty standing in line without touching their neighbours
- Love rough and tumble play
- Rock frequently, hang upside–down frequently, move constantly
- Jump on furniture, bounce, spin, be unable to ‘sit and listen’

Ideas that may help if your child has muted vestibular signals (these ideas involve providing lots of vestibular input):

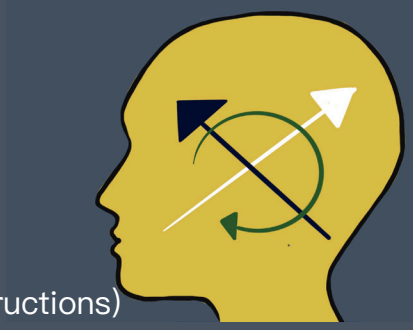
- Give the child as much opportunity as possible to move, including opportunities to jump, spin and turn upside–down
- Provide regular pauses during ‘thinking’ activities so as to give your child ‘body breaks’ for vestibular and proprioceptive activities
- Ensure the child’s chair lets them have their feet on the ground
- Do chair push–ups (holding onto the arms or frame of your chair and straightening your arms so as to lift your body weight)
- Full–body activities such as jumping jacks
- Squeeze a stress ball
- Do push–ups against the wall
- Provide seating that gives ‘wiggle’ opportunities — gym ball seats, wedge or wiggle cushions, Sit and Fit cushions
- Spinning, swinging, roundabouts, rides, somersaults, hanging upside down, sit–n–spin, hammock
- Trampolining

Vesitbular activities such as spinning and trampolining may need to be done in moderation as some children may become overstimulated and this may cause them to experience after–effects for up to six hours following intense vestibular input. Getting the right balance of input can mean the difference between the child being regulated or over–stimmulated.

Planning and Sequencing (Praxis)

Some Autistic children have difficulty with praxis, meaning a difficulty with motor–planning and sequencing actions. This can mean the child finds it difficult to carry out both ‘gross’ and ‘fine’ motor actions (large movements [kicking a football] and small, delicate movements [threading a needle]). The child may have difficulty with ‘ideation’ (coming up with an idea of what needs to be done), planning how to use their body to carry out the intended action, actually carrying out the action and, finally, reviewing how the action went after they have completed it. Difficulties with motor planning and sequencing may be formally diagnosed as Developmental Co–ordination Disorder (DCD) or Dyspraxia.

Things you may see if your child has motor planning difficulties (dyspraxia/developmental coordination disorder)



Your child may:

- Have poor body scheme and body awareness
- Have difficulty following instructions (particularly multi-step instructions)
- Have difficulty starting tasks
- Have difficulty completing tasks efficiently or in a timely fashion
- Take a long time to learn new tasks
- Have a preference for familiar play routines, ones they can predict and where they know what to expect
- Repeat tasks which they feel they're good at
- Become frustrated with or or avoid new tasks and have a corresponding fear of failure
- Avoid tasks requiring manual dexterity (eg puzzles, intricate construction or fine motor tasks such as writing, cutting with scissors)
- Appear "clumsy"
- Find the action more difficult the harder they try to do it.

If you're keen to explore sensory processing further and gain a greater understanding of your child's sensory experience, you might like to become a member of Autism Wellbeing. Membership starts at £1 a week and provides access to an extensive and growing database over one hundred resources to support you to 'Notice' and 'Think' about your child's way of being being in the world, as well as how to 'Attend' to their needs and support their regulation.

In addition to our Notice-Think-Attend database of resources, as a member you will also have access to:

- Autism Wellbeing's Making Sense App
- Autism Wellbeing's Members Forum where you can requests topics for us to cover in our Notice-Think-Attend database as well as seeking peer support.
- Discounts on on Autism Wellbeing's online training courses
- Priority booking and discounted rates for Autism Wellbeing's online workshops, discussion and peer support groups.

All of this for less than half the price of a posh coffee each week!
Our membership is literally cheaper than chips!
And you also get the warm, cosy feeling of supporting Autism Wellbeing to keep on doing what we're doing. To find out more about becoming a member, contact Rorie at roriefultonaw@gmail.com

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