Nurturing Neurodiversity Network

Masking & What We've Learned As Parents About Neurodivergence

Nurturing Neurodiversity

Sidcot
Live Adventurously

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Masking Autism

Attending school for my Autistic boy is, metaphorically, like asking him to carry hot coals. Every busy corridor, every shouty lesson, the teacher who smells of coffee, the difficult social interactions; they all add extra coals to the pile. 'Learn resilience!' actually means 'you'll get used to the burning eventually!'. But every time he's complained about the hot coals in the past, peers have teased him and adults have ignored him or not believed him. So he's learnt to pretend that the coals don't bother him, not to complain, not to 'stim' or use other coping strategies; to put on a mask so he doesn't stand out. He's so good at pretending, teachers say 'he's fine in school!'. All the while, the coals are burning and uncomfortable, so he struggles with learning, and with friendships, and he's exhausted because it's hard to function 'normally' when there's this constant background pain. When he gets home, he can put the coals down, and for a while he can hang upside down, shout, sing, flap, let it all out... but then he remembers the coals and that he'll have to pick them up again tomorrow and do it all again, and that makes him sad and anxious. I hope eventually he'll be able to put the coals down for good, but I worry what scars they will leave behind.

Diary of a Dyslexic Kid

The teacher asked what I did this weekend handing over a crisp blank page,
It's stark whiteness glowing harshly bright,
A daunting empty stage.
After the words, "pick up your pencil" I have no idea what was said,
My heart was sinking
I felt so alone
Facing the gargantuan task ahead.

Nonetheless, I show willing and I light my creative spark,
It fills my head with magical words that illuminate the dark.
"Why are you not writing?", the teacher came and said...
However, I knew whatever I wrote would be marked in a sea of corrected red!
"Make it legible!"
"Make it neat!"
"Sit down on your bottom!"
"Stop tapping your feet!"
"Remember the rules of punctuation!"
"Come on lad, use that imagination!"
I feel sick, confused and angry. Why? Although I try my best
what I put down on the paper doesn't look like all the rest.

I sit there trying to focus
Trying to complete this massive test
But all my ideas have burned away
Leaving an anxious void inside my chest.
Could the cause be his barrier to learning?
But apparently it isn't so
It's just my idle attitude making my writing so messy and so slow,
I want the world to know I will never use dyslexia as an excuse,
But if people don't stop and understand this thing then really what's the use?

I am William, I am dyslexic,
I am kind and fun and smart,
I am driven and I am capable of more than games and art.
To all those people who sit and judge
Who are neurotypical and educationally conform
I will find my key, to let me be me and will take the world by storm.

The Toll It Takes On Everyone

Still exhausted from the day before, and not having nailed – exactly – the necessary bedtime routine, leading to poor sleep, a Morning Meltdown ensues before my 10-year-old daughter even lifts her head from the pillow...

Even after 40 minutes of gentle empathetic coaxing, she's too tired to get out of bed; it's too cold to get out of bed. She doesn't want to go swimming later. Then she doesn't want to go to school at all.

It escalates. She declares she won't go swimming and/or won't go to school. My gentle coaxing becomes negotiation: I'll pick her up early if she's still tired. It gets nowhere. Patience wears thin. My tone of voice becomes sharper, more matter of fact, more heated. Snap! I shout, "I'm done! I've had enough! If you won't listen to reason and you won't even try, I'll just have to tell your teacher you're refusing to go to school."

It works. Sobbing and shouting, my daughter remonstrates that she'll get out of bed only when she has another hug first.

Riddled with guilt for deploying emotional blackmail, I squeeze her and hold her tight, marvelling at how my child needs and wants me, even when I'm shouting at her and making her feel guilty for something she can't control. But my state of high alert keeps my thoughts buzzing and focussed on all that still needs to be done to get everyone out of the door and how little time there is left to achieve it. It's impossible to be completely present in the embrace.

Finally, my daughter is up, but she still insists she's not going to school. I start grabbing stuff she'll need, to make progress. Kit that should have been got together the night before; but there were too many distractions, and it was too hard to process what was needed and where to find it, being so exhausted from her day. In her determined fury, my daughter snatches bags and belongings from me, preventing even the practical help to get her off to school.

I can't cope with the obstinacy, the physical lashing out, the temper. So, Dad intervenes and dresses his daughter while she screams and sobs.

Now everyone is angry and stressed.

Older brother in the senior school, all ready to go, shouts and stomps angrily as he must arrive earlier than his siblings and hates being late. Younger brother dawdles, too distracted and bemused by the unfolding drama to finish getting ready himself, until he ends up on the receiving end of his sister's temper and is shoved out of the way. Tears for him too.

Dad is increasingly agitated and curt with everyone: he must go straight to work after drop-off and there's only just time to do the school run and get there – provided everyone is on time.

I, still in a state of hypervigilance and oozing cortisol, fret about what activities everyone has today, whether they have everything they need, what still needs to be done to get everyone in the car – and how my daughter's meltdown threatens to impede that; all while simultaneously feeling conflicted and guilty for forcing my daughter into something she really doesn't seem to have the energy and capacity for.

By the time she is finally ready to get in the car, where her brothers are already strapped in and waiting, my daughter seems quiet and contrite. She calmly asks me to put her hair in a ponytail, picks up her bag and throws her arms around me for another hug. Then, holding her father's hand, she leaves the house, gets in the car and goes to school.

It takes me most of the morning for my overstimulated nervous system to regulate and recover. Yet less than 15 minutes later, my daughter walks into school without any fuss. Mask on, she sits at her desk and gets on with her day just like everyone else in the class, her teacher none the wiser of what the family has already been through by 8:30 am. It is not obvious to anyone in the room how hard and exhausting it is for this dyslexic ADHD child – already hiding the dysregulated emotions she's feeling inside – to keep up with the information and instructions she's being given, to process the words printed on the page in front of her, and to write the sentences which can't keep up with her ideas. Only her family will know about it when she gets home: where it's safe to lift the mask of pretence, and she loses control again...

When this happens several times a week or more, it's exhausting for everyone in the family. My daughter has to experience, process and recover from these incidents with their overwhelming, uncontrollable, feelings as much as I do. It takes its toll on her wellbeing, ultimately manifesting in anxiety and sleep disorder.

Her two brothers must witness her meltdowns and/or bear the brunt of them if she targets them to shout at or shove. They are often forced to concede more than their fair share of things (like who sits where at the dinner table, or who gets the front seat in the car) as it becomes the only way to bring their sister's defiant non-cooperation to an end.

The siblings also miss out on getting their parents' time and attention while they 'deal' with their daughter. The youngest needs someone to help with homework, play with him, help him get ready for the next day and bed, read stories to him, tuck him in and check on him after lights out – a lot of which gets cut short because there isn't enough of me or my husband to go around. The eldest likes – needs – to chat to me about his day and download on a 1:1 basis later in the evening when his siblings aren't around; but I'm too exhausted by that point to listen properly or at all – I just need to fall into bed myself.

I live in a permanent state of high-alert, stress, anxiety and overwhelm – not just when my daughter is so emotionally dysregulated, but with the uncertainty and fear around when and how the next outburst will erupt. Consequently, I often feel too overwhelmed to get things back under control or focus on other needs for the family.

So, if he's not at work, my husband finds himself trying to keep the rest of the show on the road, meeting usual day-to-day family demands and taking responsibility for household tasks – often after a long day at work which will have started with a report time somewhere between 5:00 and 6:30 am. Or he must step into the fray and take over to try and 'reset' the disintegrated dynamic. This often means he just does everything with or for our daughter to get us where we need to be, since she can't be reasoned with, and he too is depleted.

Our Experience of Austic Burnout

This is a picture that my daughter drew two weeks after she started back at school, having spent the previous 20 months in what we now know was autistic burnout.

It wasn't actually until about two years later that we were able to talk about it as burnout. We just didn't have the vocabulary at the time… especially as we were told that she was not autistic, that she had social anxiety, that lots of children were anxious post-Covid.

It didn't sit quite right with us. And the problem was, our wonderful autistic daughter, who was finally diagnosed in December last year, is a master masker. She is SO good that she has fooled teachers, psychologists, therapists, friends, family… us.

But in November 2021, age eight, she completely ran out of batteries and couldn't mask any more. Her demand avoidance was through the roof. Her nervous system was completely overwhelmed. And she was unable to do simple daily things that we take for granted.

To go to school. To play with her friends. To go for a walk. To get dressed. To brush her teeth. To wash. To leave the house. To communicate…
We had many days when these things felt impossible for her to do. We had many days in which she sat in the living room with the curtains drawn, watching back-to-back Teen Titans, eating melty cheese Birdseye potato waffles. To be honest, we still have quite a few days like this, but they've progressed to melty cheese on any type of potato and bac- to-back American Office.

We had many days in which the only way we could communicate with her was using post it notes and emojis. It was heartbreaking and traumatic not just for her, but for the whole family.

She was effectively in recovery. She needed autonomy and control. A zero-demand environment. A chance to recharge her social, emotional and physical energy in whatever way she needed to.

And it's really hard as a parent to shift your mindset and trust in that process. It goes against everything society impresses upon us to raise healthy and happy children… Don't let them have too much screen time. Ensure they have a balanced diet. Give them plenty of fresh air and exercise. SLEEP! Oh and of course, why isn't she in school?

As she slowly started to be able to meet some of her regulatory needs, I became a facilitator… buyer of enough slime making ingredients that I should have taken out shares in Elmer's glue. Chief trampoline cheer leader. Bedroom decorator - around every 3 months, but choosing paint meant going to B&Q, leaving the house and being around people, so even

if she hadn't washed for weeks and was still in her pyjamas, that was worth its weight in gold.
The thing about recovering from burnout is that you just don't know how long it's going to take. We went from days, to weeks, to months, to what was nearly a quarter of her life.

And for us as her parents we had very little support at that time. She didn't have her diagnosis. She wasn't at school. We were both trying to keep our businesses running. We had two other children to support. We were doing as much reading and listening as possible to try and understand what was happening, but we just didn't have the language to be able to articulate to anyone what was really going on.

The irony of course is that every day, through all of this, I put my own mask on to be the best mum I could be to all three of our children, to be a good partner, to go to work, to be a friend, a daughter, a sister, an aunty... While inside I felt like I was stuck in a washing machine and couldn't get out. I was exhausted, and I didn't have enough headspace to process what was happening. As much as you want that pause button, life just doesn't stop!

We are incredibly lucky to have amazing friends and family around us, but the 20 months that it took for her to get to a place where she was ready to re-engage with life and school and friends… they were really, really tough.

But. That time was also a really amazing opportunity and in many ways I'm incredibly grateful for it. It allowed us to better understand our daughter and what she needs to be regulated and able to engage with the world. And most importantly it gave her a chance to better understand herself.

When she decided that she wanted to go back to school, we had a much clearer idea of what she needed out of a school environment. It was so important that the school was able to support us all, and we will be forever grateful that they took a chance on us... I mean on paper we weren't a great bet!

We're now just over a year on from that return to school. Our daughter still masks. And we still don't always get the balance right. She burnt out again in February this year, but returned to school eight weeks later thanks to our experience and knowledge of what she needed, and the incredible support that we received from school.

Starting a new school year has been challenging, but we have another superb teacher who understands and accommodates far beyond our expectations, a hugely supportive Head of Learning Support, and we have also just started working with a wonderful Speech and Language Therapist. But we have yet to manage a full week of school.

As a family, we are on a huge learning curve, and I know that we have a long and pretty bumpy road ahead. But what I've realized over the past few years is that for us, educating our children must also be about teaching them to understand and listen to what they need as individuals.

It's so important that they feel empowered to make choices for the good of their own mental and physical health. And that as parents we feel empowered to support them in this.

Our daughter, like me, might always need to keep her mask handy to live in the world that we do, but I hope in time and with the support of a safe, accommodating and empowering school, that she will be able to take it off and be herself a little more.

Unmasking and Exploding

My take on masking, especially where my son is concerned, is to think of it like a lid; a saucepan lid if you will, on top of a pan of water.

Looking back at his time in the Junior school, my son's 'lid' managed to keep in all the steam and pressure that built up as that water heated up, all day long.
All sorts of things would have heated it up; different demands, expectations, a lesson he did not want to do, a PE lesson with physical challenge that he could not do, food he did not want to eat, an unexpected change of timetable etc. the list is quite endless but as an Autistic boy with Sensory Processing Disorder, Dyspraxia and probable PDA, I am sure you can imagine the energy, effort and determination to keep that lid on all day long. The lid was kept so tightly closed that he would present to everyone as a quiet, well behaved, helpful, friendly and sociable boy.

The release of that lid would start as he left his classroom and met me in the playground or found my car. Sometimes it could stay on until he was inside the car, sometimes not, but often we would still be on our way out of school when the lid finally flipped. The release would be dripping rage, physically spilling out, spiralling and lashing out, often at me, himself or the car. Sometimes it lasted way beyond getting home and shutting the front door. It would be like a temper tantrum leaving his body until he was totally exhausted. The toll of the day needed immense processing, which as a younger child was so very difficult to do. As a parent, life was traumatic and felt totally helpless, as the demands on him seemed so 'normal' and expected, yet these outbursts were daily. I am sure you can also appreciate the sense of shame we feel as parents that this is happening and the sheer dread of sharing these scenarios with school.

I can totally understand the confusion around how a child can behave so well at school all day and then explode on their way home. To go one step further my son would often refuse to come in altogether, which was also so confusing to school as he could be happy and content in school one day - and then having no energy left to put the mask or lid back on, refuse to come in the next - leaving the teachers looking for reasons and logic when it was all hidden under the lid.

We have had a huge amount of support with our son in all sorts of ways, but I really wanted to focus on what school have done so well that, bit by bit, have eased his day and the build-up of that steam! Over his years in the Junior School simple things like allowing him to come in 10 mins early and help sort the chairs, gave him focus and calm before others arrived. He was given an 'ear' card to show teachers when he was 'just listening' so that he could feel extra control in deciding to do a task (I was told 9/10 he would then complete it as normal, but perhaps take a couple of minutes to get going). He could wear his PE kit so that he was comfortable and consistent each day. His teacher would help him to find food in the canteen that he could eat or I would send in a packed lunch. We filtered out PE and trips, and any extra curricular actives that were just too much. Any assemblies/shows were mostly missed. He had theraputty and a stress ball at his desk. He often sat very near the teacher so he felt connected to them and away from possible distractions from others. He even had time with the SEN teacher to give him a heads up on the following weeks topics in Maths and English, so that he felt more familiar with them when he then heard them in class.

School have supported us in SO many ways that showed huge empathy and understanding towards him and us. They have allowed us to try things, kept an open mind, regularly reviewed how things were working and always kept in close contact with us to ensure we were all on the same page.

My son is now in Yr 8 and has happily returned after a long summer holiday with no particular anxiety. He still wears his PE kit everyday, but he no longer needs the 'ear' card. Other adjustments are still made for him, such as limited pressure to complete homework and very limited extra curricular activities such as Camp. His teachers have as much information about him as I can provide! Which I know is a lot! He can still refuse school when putting that lid on just feels too much but again, I can see that school are fully aware of his situation and quite often he is back the next day, rather than it becoming a longer period of absence. Picking him up from school now is so different! He can still occasionally get in the car and growl 'just drive!' And I know that he will need a few minutes and now lots of expletives! to get whatever has gone wrong that day off his chest, and I can be known to join in (to show empathy of course!) but it is brief and over with and then he can happily chat about all the good or at least ok things that have happened.

When I look back there have been SO many times I could never have imagined him still being in mainstream school, but I hope we can be an example to show it is possible to accommodate and allow our

Quotes from Maskers

"I feel like I don't know who I am, what I like, or what to think."

"I don't know how to be myself and make new friends. I want to be myself, I just don't know how to do that and it be ok."

"I am exhausted! I cannot do this anymore."

"No-one really knows the real me."

"I have to act differently at school or people think I'm weird."

"I have to pretend things don't bother me when they're really all I can think about. Like the sound of someone jigging their knee up and down; or when someone's humming to themselves while they concentrate. And while I'm pretending it doesn't bother me, I have to make my brain think about the sum in front of me so I don't fall behind."

"I feel so lonely even when I am with other people and I don't know why."

"I feel like I am lying to people every day. I don't want to, and I want to stop I just don't know how."

"It's like I am two different people."

"I don't even realise I'm doing it. I just know I must have been, because when I stop, it all catches up with me. I feel overstimulated, overwhelmed and exhausted."

Accommodations or Adjustments

An accommodation or an adjustment is a change or intervention that removes a barrier to learning or getting work done. It can describe an alteration of environment or equipment that allows an individual with a disability to gain access to content and/or complete assigned tasks.

Anxiety

An emotion characterized by feelings of tension and dread, worried thoughts, and physical changes like increased blood pressure, headaches or stomach aches. For many, this is an occasional and temporary state. When it is experienced persistently (for several months or more) and interferes with daily life or ability to sleep, a formal diagnosis of Generalised Anxiety Disorder can be made. Anxiety is a common comorbid condition (see Comorbidity) for people with ADHD or Autism.

Attention Deficit Disorder (ADD)

The term used in the DSM-III (see "DSM"), published in 1980, for the disorder which is now officially called Attention Deficit/Hyperactivity Disorder.

Attention Deficit Disorder was officially divided into "ADD with hyperactivity" and "ADD without hyperactivity". Although it has not been used as a diagnostic term since 1987, many still prefer to use the term ADD to describe predominantly inattentive ADHD (see Attention Deficit/Hyperactivity Disorder) as they don't feel the hyperactive element is relevant to them.

Attention Deficit/Hyperactivity Disorder (ADHD)

A neurological disorder which means the nervous system, including the brain, develops and functions differently to neurotypical brains.

The attention 'deficit' refers to an inability to regulate attention – that is, to control the intensity of focus or what the brain focusses on. This sometimes results in struggling to pay attention at all, sometimes in hyper focussing (see Hyperfocus), and often in broader difficulties with executive function and impulsivity.

The 'hyperactivity' can manifest itself physically (for example, unable to sit still or stop talking) and mentally (for example, with many crowding buzzing thoughts which distract focus or prevent sleep). In the DSM-V, ADHD falls into three 'types': predominantly hyperactive (manifesting mainly physical high energy and impulsive behaviour), predominantly inattentive (mainly affecting cognitive function), and combined.

Asperger's Syndrome

Sometimes also referred to as Asperger's Disorder. Asperger's is an outdated term, which is used for those with a "high functioning" form of autism (i.e. still able to function well in society despite autistic difficulties), which is now encompassed within the current definition of the Autism Spectrum (see Autism). Asperger's Syndrome is no longer used for new diagnoses, although people with an existing diagnosis using the criteria in DSM-IV (see "DSM") still retain this term of reference for their diagnosis.

Auditory Processing Disorder (APD)

Auditory Processing Disorder, also known as CAPD (Central Auditory Processing Disorder), is a neurological processing issue that affects the way the brain receives, recognises, processes, organises and interprets sounds, especially speech. Hearing function itself is not usually impaired. Tone and volume of individual sounds are usually within normal range when delivered in isolation (for example, in a hearing test sound booth), which makes it very difficult to diagnose. People with APD have a hard time hearing small sound differences in words, difficulty understanding words spoken quickly or in strong accents, and struggle to prioritise the most relevant sounds in an environment which has lots of different noises (like a classroom or playground) or poor acoustics. It is a condition which often coexists with other neurodivergent conditions including ADHD, autism, and dyslexia. It is also sometimes mistaken for ADHD because it affects concentration.

Autism (ASD, ASC)

Autism Spectrum Condition/Disorder (ASC/ASD) is a neurological and developmental disorder that affects how people behave and interact with the world around them. Autism is known as a "spectrum" disorder because there is wide variation in the type and severity of symptoms people experience. Autism difficulties include how people communicate with others and interact socially; a need for restricted or repetitive behaviours; over- or under-sensitivity to light/sound/touch/taste; an intense focus on a particular interest or hobby; extreme anxiety; and overwhelm leading to loss of control (see Burnout, Meltdown, and Shutdown).

Burnout

An intense state of physical, mental or emotional exhaustion, often accompanied by a loss of skills and functions. It is a syndrome recognised by the World Health Organization. Burnout can affect anyone and occurs when someone is subject to repeated and prolonged high demands that exceed resources. It is less immediate that a shutdown (see Shutdown), building up over time and typically involving a much longer recovery process. It can affect people with Autism or ADHD because, for them, navigating a world designed for neurotypical people is extremely demanding and it takes a disproportionate level of mental and cognitive resources to achieve the same level of 'performance' as a neurotypical person every single day.

Comorbidity

A medical term to describe the existence of more than one disease or condition within the body at the same time.

Condition

A preferred term over "disorder". In the context of neurodiversity, it is a general term used to describe any difference of neurological experience.

Developmental Language Disorder

Developmental Language Disorder (DLD) is a long-term neurological condition that affects the learning, expression, and comprehension of spoken and written language in people of all ages causing difficulties with learning and achievement at school and beyond. Challenges for someone with DLD include (among other things) remembering certain words or things people say, having limited vocabulary, understanding written and spoken language, expressing themselves and communicating with others. DLD is often a comorbid condition alongside Autism, ADHD or a SEN.

Disability

In the UK, Disability under the Equality Act 2010 is defined as a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on the ability to do normal daily activities. Many countries around the world have an equivalent act, protecting disability characteristics.

Disorder (mental)

A medical term used in the DSM (see "DSM") describing a behavioural or psychological pattern that significantly disturbs an individual's cognition, emotional regulation, or behaviour. When used in common vernacular, it can have negative connotations making those with symptoms or a diagnosis feel inadequate. A preferred term might be "condition" or "difficulty".

"DSM"

The Diagnostic and Statistical Manual of Mental Disorders (DSM). The American Psychiatric Association's professional reference book on mental health and brain-related conditions. This is used by psychiatric professionals worldwide, including the UK. It sets out criteria for diagnosing many conditions, including ADHD, Autism, and Specific Learning Disorders.

The most recent edition of the manual is version 5 which was published in 2013, with a 'text revision' in 2022. It is often referred to as "the DSM 5" or referenced in writing as DSM-V-TR.

Dyscalculia

The term used to describe the Specific Learning Disorder where people have difficulties with learning number number-related concepts, processing numerical information, learning arithmetic facts or using the symbols and functions to perform accurate or fluent math calculations.

Dysgraphia

The term used to describe the Specific Learning Disorder where people have difficulties with putting thoughts on to paper. This could be due to differences on a physical level on hand functioning making the formation of words difficult, and/or on a neurological level making sequencing of words and sentences or accurate punctuation and grammar difficult.

Dyspraxia

Also known as Developmental Co-ordination Disorder. Dyspraxia is a difference in the learning of motor skills, leading to difficulties with movement and co-ordination.

Dyslexia

The term used to describe difficulties with one or more of the reading subskills including word reading accuracy, decoding or spelling; reading rate or fluency; and/or reading comprehension. Dyslexia affects the temporal lobe in the brain.

Education Health and Care Plan (EHCP)

An Education, Health and Care Plan (EHCP) is for children and young people in the UK, aged up to 25, who need more support than is available through special educational needs support. It is a legal document issued by the child or young person's local authority/council which describes their special educational needs, the support they need, and the outcomes they would like to achieve.

Emotionally Based School Avoidance (EBSA)

The (current) official term used to describe the situation where a child or young person routinely becomes so anxious and fearful that they become unable to attend school. Previously known, and often still referred to, as "school refusal" (see School Refusal).

Emotional dysregulation

An inability to flexibly respond to and manage emotional states, resulting in intense and prolonged emotional reactions (see Meltdown)

Fine Motor Skills

Fine motor skills involve using your hands and fingers to control small objects.

Gross Motor Skills

Gross motor skills involve using the large muscles in your body to make large movements.

Hyperactivity

Hyperactivity is a state being unable to be still or silent, continually acting impulsively and being easily distracted.

Hyperfocus

A tendency or ability for a person to become deeply and completely immersed in an activity with intense concentration for long periods, sometimes to the point that they become oblivious to everything around them, including time. This could be highly beneficial for a productive activity, or at the expense of more important or pressing responsibilities.

Hypersensitivity

Hypersensitivity is to have significantly increased awareness of stimulation to one or more senses.

Impulsivity

Impulsivity is to tend to act without thinking things through properly first.

Inclusion

Inclusion is about offering the same activities to everyone, while providing support and services to accommodate people's differences.

Interoception

Interoception is a sense that provides information about the internal condition of our body—how our body is feeling on the inside. Interoception allows us to experience many body sensations such as a growling stomach, dry mouth, tense muscles or racing heart. The interoceptive system can be impacted in autistic individuals, with studies showing that some autistic people have significantly lower awareness of their interoceptive signals.

Irlen Syndrome

Irlen Syndrome (also referred to at times as Meares-Irlen Syndrome, Scotopic Sensitivity Syndrome, and Visual Stress) is a problem with the visual cortex part of the brain's ability to process visual information. For people with Irlen Syndrome words may move, blur, shift, change, and distort, and individuals may experience headaches, eye-strain, nausea, fatigue or other physical symptoms. It is often confused with dyslexia (see Dyslexia) because, like dyslexia, it can affect a person's ability to acquire reading skills. However, it is a separate condition which also affects a person's ability to utilise existing reading skills. Spectral filters or overlays can be used when reading to counter the visual distortion and associated physical discomforts experienced with Irlen Syndrome.

Mainstream

The term 'mainstream' refers to educating children with special needs in regular education classes and schools (as opposed to special needs classes or schools).

Meltdown

A meltdown is an intense reaction that happens when someone's mind or body becomes completely overwhelmed by their current situation and they temporarily lose behavioural control. This loss of control can be verbal (e.g. shouting, screaming, crying) or physical (e.g. kicking, lashing out, biting) or both. Meltdowns in children are often mistaken for temper tantrums.

ND

Abbreviation of Neurodiverse/Neurodivergent.

Neuro-inclusion

Neuro-inclusion is acknowledging different neurological perspectives and making the environment, processes, and other factors comfortable for neurodivergent people.

Neurodivergent

Refers to an individual who has less than typical cognitive variation, such as autism, ADHD, dyslexia, dyspraxia etc.

Neurodiverse

Is a recognition that not all brains think or feel in the same way and that these differences are natural variations in the human genome. A group of people are neurodiverse, an individual is not.

Neurodiversity

“Neuro” relates to the brain. “Diversity” relates to the state of being varied. The concept of ‘neurodiversity’ therefore recognizes that no two brains are alike.

Neurominority

A neurominority is a population of neurodivergent people who share a similar form of neurodivergence. Examples of neurominority groups include autistic people and dyslexic people.

Neurotype

A type of brain, in terms of how a person interprets and responds to social cues, etc.

Neurotypical

Refers to an individual of typical development and intellectual/cognitive functioning.

NT

Abbreviation of Neurotypical.

Obsessive Compulsive Disorder (OCD)

Obsessive Compulsive Disorder (OCD) is a common mental health (as opposed to neurodevelopmental) disorder where a person has obsessive thoughts and compulsive behaviours. It can be distressing and significantly interfere with life. OCD can occur comorbidly (see Comorbid) with Autism or ADHD.

Overstimulation

(See Sensory Overload.)

Pathological Demand Avoidance (PDA)

Pathological Demand Avoidance (PDA) is a profile of autism spectrum disorder and a proposed sub-type. Characteristics ascribed to the condition include greater refusal to do what is asked of the person, even to activities the person would normally like, due to extreme levels of anxiety and lack of autonomy.

Proprioception

A set of sensory receptors in our joints and muscles shape the proprioceptive system, responsible for building full-body awareness. The proprioceptive system has an important regulatory role in sensory processing as proprioceptive input can assist in controlling responses to sensory stimuli. Autistic individuals often seek proprioceptive input in order to regulate their emotional and behavioural responses to sensory stimulation. Examples include: Biting/chewing on objects e.g. sleeve of jumper, pen/pencil; banging body parts e.g. hands together, jaw with hand; holding objects with excessive pressure e.g. pencil; writing heavily on a page; preferring to run, jump or stamp heavily when they should be walking.

Reasonable Adjustments

In the UK, reasonable adjustments are changes that organisations and people providing services or public functions must make - as directed by the Equality Act 2010 - if a person’s disability puts them at a disadvantage compared with others who are not disabled. The duty is anticipatory which means that plans must be made in advance to ensure accessibility by disabled people. See ‘Adjustments’.

Retained Primitive Reflex

Primitive reflexes are automatic/involuntary movements fundamental for keeping a newborn alive. At birth, these are controlled by the brain stem, as this is the first part of the brain to develop in utero. As an infant’s brain develops and matures after birth, these primitive reflexes ‘integrate’ into other parts of the brain, where they can be voluntarily controlled and manipulated, and develop into more complex movements as neural pathways are created and cemented. Most primitive reflexes will have disappeared by the age of 12 months. If some or all of those primitive reflexes do not integrate with the more sophisticated parts of the brain (they are ‘retained’), it can affect a specific area of development for someone, involving difficulties in social, educational, and psychomotor skills. Retained reflexes can be integrated with occupational therapy using multi-sensory activities.

Rejection Sensitive Dysphoria (RSD)

People with rejection sensitive dysphoria have an emotional reaction to negative judgments, exclusion, or criticism beyond what most people feel. Other people may see those with RSD as overly perfectionistic, over-sensitive, or overly reactive to even the mildest types of criticism.

School 'Refusal'

A term often used to describe the situation where a child or young person routinely becomes so anxious and fearful that they become unable to attend school.

There can be many causes and contributing factors for this anxiety and response, and it can affect anyone at any time – though it can be more common among children with SEND.

While this situation often presents as 'refusal' – and can often feel like refusal to those trying to encourage school attendance, the term 'refusal' unfairly implies that children make a choice not to attend school when in reality they simply cannot control their response. School has become too overwhelming or too daunting for their nervous system to be able to cope: their mental motivation, emotional reasoning and/or physical energy is too depleted to function and meet the demands of a school day.

To acknowledge this lack of control over the situation, the term Emotionally Based School Avoidance has more recently been adopted. However, "avoidance" still has negative connotations which can exacerbate a child's anxiety, making difficulties attending worse.

Preferred terms of reference might be 'school phobia', 'school related anxiety' or 'anxiety related absence'.

SENCo

SENCo stands for 'Special Education Needs Coordinator. SENCos are qualified teachers responsible for delivering the special educational needs provision within a school. Every school in the UK is required to have a SENCo to ensure that every child who has Special Educational Needs (SEN) are supported as well as to help them reach their full educational potential.

Special Educational Needs (and Disabilities) (SEN or SEND)

This stands for Special Educational Needs and Disabilities and covers a range of different disabilities and conditions such as specific learning disorders/difficulties like dyslexia and dyspraxia, recognised disabilities such as having a hearing impairment, emotional and social difficulties, and speech and language difficulties. The needs of children with SEND vary from requiring very little additional support through to needing significant support and adjustments. They may require support for a short period or throughout their educational careers.

Sensory Meltdown

A sensory meltdown is a fight, flight or freeze response to sensory overload.

Sensory Overload

Sensory overload occurs when one or more of your five senses becomes overstimulated. For instance, a person's sense of hearing may become overloaded when music is too loud or their vision may be impaired if lights are too bright. Anyone can experience sensory overload, but it is most common with people who have post-traumatic stress disorder (PTSD), are autistic, or have a auditory processing, sensory processing and/or other neurodevelopment disorders.

Sensory Processing Disorder (SPD)

Sensory Processing Disorder occurs when the brain perceives and processes sensory information in an atypical or inconsistent manner. A person with SPD will demonstrate hypo- or hypersensitivity in one or more of the senses or a combination of both. SPD often occurs concurrently with other forms of neurodivergence, such as autism, ADHD, and more.

Shutdowns

Shutdown is when a person's brain goes into protective mode when it becomes overwhelmed as a result of overstimulation or extreme levels of anxiety and distress.

To the outside world it appears as though a person as 'gone quiet' or 'switched off'; for the person experiencing it, it cannot be controlled and is extremely debilitating.

Specific Learning Disorder (SpLD)

A neurodevelopmental disorder characterized by a persistent impairment in at least one of three major areas: reading, written expression, and/or maths (see Dyslexia, Dysgraphia and Dyscalculia). While "disorder" is a clinical term, "difficulties" might be a more preferred term to use around those affected.

Stimming

Self-Stimulation. The repetitive performance of certain physical movements or vocalisations, as a form of behaviour by autistic people or others with neurodevelopmental conditions. This behaviour is thought to serve a variety of functions, such as calming or expressing feelings.

Tourette's Syndrome (TS)

Tourette's Syndrome (TS) is a condition of the nervous system which causes people to involuntarily make sudden twitches, movements or sounds (called "tics") which goes on for more than a year. It's not clear what causes tics. They're thought to be due to changes in the parts of the brain that control movement. TS is often comorbid with other conditions such as OCD (see Obsessive Compulsive Disorder) and ADHD (see Attention Deficit/Hyperactivity Disorder).

NEURODIVERSITY INFORMATION RESOURCES

ADHD

Additude Magazine (a mine of information on all things ADHD related)
Website: www.additudemag.com
Podcast: ADDitude ADHD Experts
Useful article: "Rejection Sensitivity Dysphoria and ADHD" (https://www.additudemag.com/rejection-sensitive-dysphoria-and-adhd/?src=embed_link)

ADHD_Love (living with ADHD – Roxanne Pink (has it!) & Richard Pink (doesn't!))
Website: https://www.adhd-love.co.uk
Podcast: ADHD Small Talk
Book: 10 ADHD Lies and How to Stop Believing Them
Also on multiple social media platforms

ADHD UK (support charity run by people with ADHD for people with ADHD)
Website: https://adhduk.co.uk

How to ADHD (a host of information on all things ADHD, including helpful coping strategies)
YouTube: https://www.youtube.com/@HowtoADHD
Book: "How to ADHD: An Insider's Guide to Working With Your Brain, Not Against It" by Jessica McCabe

Books:

- "ADHD 2.0: New Science and Essential Strategies for Thriving with Distraction – from Childhood Through Adulthood" by Edward M. Hallowell & John J. Ratey
- "Help, My Grandchild has ADHD: What Children and their Parents Wish You Knew" by Judy M. Kirzner
- "Scattered Minds: The Origins and Healing of Attention Deficit Disorder" by Dr. Gabor Maté
- "The Parents' Guide to ADHD Medicines" by Peter Hill
- "Understanding ADHD in Girls and Women" edited by Joanne Steer

Podcasts:

- ADHD for Smart Ass Women with Tracy Otsuka
- The ADHD Women's Wellbeing Podcast with Kate MoryousseF

Autism and related (including Pathological Demand Avoidance & Rejection Sensitive Dysphoria)

Autistic Girls Network (a campaign and information sharing group to promote acceptance and awareness of autism and associated mental health difficulties)
Website: https://autisticgirlsnetwork.org
Also on multiple social media platforms

Declarative Language (how we can use language so it is less demand based)
Website: https://www.declarativelanguage.com
Book: "Declarative Language Handbook: Using a Thoughtful Language Style to Help Kids with Social Learning Challenges Feel Competent, Connected, and Understood", by Linda K. Murphey

Dr. Naomi Fisher (Low Demand Parenting/PDA/Autism)
Website: www.naomifisher.co.uk (information and access to webinars)
Webinars can also be booked on Eventbrite
Book: "Changing Our Minds: How Children Can Take Control of Their Own Learning"

National Autistic Society (charity supporting autistic people in the UK)
Website: https://www.autism.org.uk

PDA Society (UK charity providing awareness, training, support and resources for Pathological Demand Avoidance)
Website: https://www.pdasociety.org.uk
Useful support infographic: https://www.pdasociety.org.uk/resources/helpful-approaches-infographic/

Books:
- "The Family Experience of PDA: An Illustrated Guide to Pathological Demand Avoidance" by Eliza **Fricker**
- **"The Panda on PDA: A Children's Introduction to Pathological Demand Avoidance" by Glòria Durà-Vilà**
- **"The Secret Life of Rose: Inside an Autistic Head" by Rose Smitten & Jodie Smitten**
- **"The Superhero Brain: Explaining Autism to Empower Kids" by Christel Land**

SEN(Dyslexia, Dysgraphia & Dyscalculia)

Made by Dyslexia (Global awareness charity)
Website: www.madebydyslexia.org
Useful self-advocacy tool: https://www.madebydyslexia.org/wp-content/uploads/Childrens-Passport.pdf

Irlen Syndrome Foundation (global awareness charity)
Website: https://www.irlensyndrome.org
Useful infographic explaining dyslexia vs. Irlen: https://www.irlensyndrome.org/irlen-vs-dyslexia/

Books:
- "Dyslexia. Wresting with an Octopus: 10 Tips to Help Your Child" by Beth Beamish & Sarah Pitts
- "Overcoming Dyslexia: The Essential Programme for Reading Problems at Any Level" by Sally Shaywitz, M.D. & Jonathan Shaywitz, M.D.
- "The Dyslexic Advantage" by Brock Ede and Fernette F. Ede

Podcast episodes:
- "Is the SEND System Working for Children with Special Educational Needs and Disabilities?": https://www.bbc.co.uk/sounds/play/m0022ss7

Sensory Processing Difficulties (Retained Primitive Reflex, Dyspraxia, Auditory Processing Disorder)

Harkla (Information, digital training, helpful products)
Website: https://harkla.co
Useful article: https://harkla.co/blogs/special-needs/what-are-primitive-reflexes?srsltid=AfmBOorlI1ITe4a2BZ-YIqq3sPO156AnVNcjJ7mNCtgQoifliE4uWfMI

Books:
- "Integrating Primitive Reflexes Throughg Play and Exercise" (5 book series) by Kokeb Girma McDonald

Wider Support Organisations & Information Resources

Mental Health UK (charity challenging the causes of poor mental health)
Website: https://mentalhealth-uk.org
Useful explanations of different mental health conditions: https://mentalhealth-uk.org/help-and-information/conditions/

Neon Daisy (support group for parents & carers of neurodivergent and gender non-conforming girls in Bristol, Bath, South Gloucestershire, North Somerset and surrounding areas)
Website: www.neondaisy.org.uk
Also on Facebook

Neurodiversity Week (resources and webinars)
Website: https://www.neurodiversityweek.com

NeuroWild (Resources to help explain and understand the challenges neurodiverse people experience)
Facebook page: https://www.facebook.com/p/NeuroWild-100087870753308/?locale=en_GB
Also on Instagram

North Somerset Parents and Carers Working Togeth er (support charity)
Website: www.nspcwt.org
Also on Facebook, Instagram & X/Twitter

Once Upon an Upset (stories to help make sense of being neurodivergent in a neurotypical world)
Facebook page: https://www.facebook.com/story.php?story_fbid=838055041675658&id=100064135088770&mibextid=WC7FNe&rdid=zrC7qQp9KzC95ptx
Podcast: Once Upon an Upset

Books:
- "Wonderfully Wired Brains: An Introduction to the World of Neurodiversity" by Louise Gooding

Podcasts:
- The Neurodivergent Woman Podcast

Podcast episodes:
- "Understanding learning and behavioural difficulties with Sarah Warley": https://lizearlewellbeing.com/podcast/understanding-learning-behavioural-difficulties-sarah-warley/

ACCOMMODATIONS - CREATING A SAFE ENVIRONMENT TO REDUCE THE NEED TO MASK

School / Classroom

Provide a rest area for children to regulate in a relaxed environment.

Limit any changes to the layout of the classroom, including where a child sits.

Ensure the seating plan allows the child to feel safe and comfortable e.g. near the door, close to the teacher, front or back of the class, who they are sitting next to – allow the child to choose.

Many neurodivergent children do not want to feel different so allow accommodations to be subtle and do not draw attention to them.

Adjust attendance and behaviour policies to accommodate needs, especially related to executive functioning or processing issues e.g. being late, forgetting equipment, being slow to get changed etc.

Take time to learn, understand and share your knowledge to develop a whole school understanding of neurodiversity and how different people experience the world in different ways.

Where possible use passionate interests to help learning.

Break / Lunchtime

Make a trusted adult available for a child to talk to if needed.

Offer structured play to support social interactions, including clubs that will be interesting to your neurodivergent students!

Consider an alternative to eating in the main lunch hall – children with sensory processing difficulties may find this environment challenging to be in.

Relaxation of ‘food rules’ if a child needs to eat ‘safe foods’ only.

Support interoception challenges by reminding to eat, drink, go to the toilet etc. as necessary.

Communication

Keep communication and instructions clear and precise.

Limit any ambiguity e.g. quantify activities, use visual timers etc.

Give plenty of warning of any changes or transitions e.g. seating, display boards, trips, events etc.

Do not enforce eye contact. Support and accommodate children who need to listen and learn in different ways e.g. while doodling, fidgeting, looking out the window etc.

Use different communication methods, codes, or cards to allow children to feel safe, in control and able to communicate directly with the teacher e.g a card to allow a rest break, or to just listen during the lesson when participation feels overwhelming.

Use Declarative Language to support and encourage choice and autonomy. https://www.declarativelanguage.com/

Organisation

No Surprises!

Keep your promises. If you say something is going to happen, make sure it happens.

Provide a copy of the timetable to parents ahead of term start.

Adjust timetable so that days are shorter or perhaps a regular shorter day midweek that can help a child recover from over stimulation or burn out.

Limit changes to timetable / routine. Give as much warning as possible if there are any changes to timetable or teaching staff.

Visible timetables in the classroom for the day, week and for upcoming events such as trips.

Avoid particular lessons that cause extra pressure, demand or sensory overload.

Allow a child to come into school early in order to settle while it is quiet.

Understand and support children through any transition or change, however small or big.

- Encourage and engage in open communication with parents/carers to support families and fully understand the child's needs.

Sensory

Create movement opportunities for children who need this to regulate by asking them to run errands or hand out books (be aware of not creating too much demand)

Encourage heavy pressure in the body to help calm a child's nervous system e.g. sitting chair pushups, therabands around chair legs, carrying heavy things (within reason!).

Self-Stimulation (STIM): Provide opportunities for stimming with Theraputty, stress balls, fidget toys, a doodle book, or even Blu-tak. Far from a distraction these can enable focus and concentration.

Light sensitivity: Sit a child away from windows, avoid use of strip lights, dim smart boards, encourage blue light glasses.

Noise sensitivity: Accommodate use of noise reduction headphones/ear plugs e.g. loops, flares, music

Keep shouting or raising your voice to a minimum.

Relax uniform regulations to accommodate sensory needs.

Find this document online at Sidcot.org.uk:

https://www.sidcot.org.uk/media/572