

NEURODEVELOPMENTAL CONDITIONS BREAKDOWN

AUTISM SPECTRUM DISORDER

Autism Spectrum Disorder is a condition that affects how a person approaches everyday activities. An Autistic child or young person possesses a spectrum of strengths and weaknesses using communication skills for social interaction and shows some atypical behaviours, including restricted interests, repetitive behaviour, and unusual sensory responses.

There is a wide variety in how Autism is expressed, and the condition affects each person differently. (Aspergers Syndrome and High or Low Functioning Autism diagnoses are no longer given as they have been included in the diagnosis label of Autism Spectrum Disorder. Therefore, if your child or young person has an Aspergers or High or Low Functioning diagnosis, the following information will still apply to them).



CLINICAL DIAGNOSTIC CRITERIA AND FEATURES

The child or young person may present with the following;

Developmental levels;

- ▶ Delayed speech and language
- ▶ May be non-verbal
- ▶ May have delayed fine motor skills
- ▶ May have delayed social-emotional skills such as difficulty tolerating frustration, becoming overwhelmed very quickly and confused about how to respond to other's emotions.

Social-emotional exchanges;

- ▶ Not recognising what's appropriate behaviour in different social situations
- ▶ Shows little interest when others talk about topics outside of the child's interests. It is difficult to speak with the child about anything other than the child's interests
- ▶ Being unable to have a back-and-forth conversation
- ▶ Having less shared interests with others, so the dialogue is stilted
- ▶ Struggling to understand the other person or people's emotions
- ▶ Difficulty initiating or responding to social interactions.

Communication during social interaction;

- ▶ Their hand gestures, facial expressions, and body language may not match with what they are saying
- ▶ Struggling to make or maintain eye contact
- ▶ Difficulties in understanding and using gestures
- ▶ Possible lack of facial expressions and nonverbal communication (stands very still with a blank face whilst talking and socialising)
- ▶ Struggles with imagination in play or communication.
- ▶ Does not understand what's funny when others joke around
- ▶ Difficulty with language that includes multiple meanings or when others use metaphors. Understands best when language is concrete
- ▶ May not be able to identify deception or lies.

The child may present differently, depending on their age, intellectual level, language ability, and other factors such as treatment history and current support. Many Autistic children and young people have language difficulties, ranging from complete lack of speech to language delays, poor understanding of speech echoed speech or stilted and overly literal language.

Relationships;

- ▶ Difficulty making friends
- ▶ Not having any interest in their peers
- ▶ Having little interest in making friends or being sociable
- ▶ Maybe passive and quiet
- ▶ May approach others inappropriately, that may appear aggressive or disruptive
- ▶ May insist on playing games by very fixed rules
- ▶ May prefer to play alone or with either much younger or older people than themselves
- ▶ May have a lack of understanding of what friendship involves
- ▶ This should be judged against the norms for age, gender, and culture.

Restricted or repetitive patterns of behaviour, interests, or activities;

- ▶ Hand flapping
- ▶ Rocking
- ▶ Banging head against surfaces or walls
- ▶ Intense interest in patterns such as lining up toys or objects
- ▶ Spinning wheels on a toy vehicle or a spinning toy. Using toys differently from their intended purpose (removing the limbs of a doll and putting it back together)
- ▶ Repeating words or phrases a lot
- ▶ Echolalia; they repeat words or phrases they have heard (from other people, the TV, etc.)
- ▶ Insistence on sameness such as playing a game by only one set of rules, even when it would make sense to alter the rules for different players; eating the same food every day; Having to greet someone in the same way, every time they see them
- ▶ Dependence on routines
- ▶ Extreme distress at any changes in their routine
- ▶ Difficulties with transitions
- ▶ Rigid thinking patterns
- ▶ Highly focused and intense special interests (strong attachment to or preoccupation with an interest or item)
- ▶ Sensory difficulties (**Please see the Sensory Needs section PAGE 20).**



First Person Perspective by Chris Bonnell – Autistic Advocate, writer, speaker, and the author of the website and Facebook group Autistic Not Weird;

After a long history of non-autistic people deciding how the autistic experience should be described – to parents, professionals, and the general public – it is a huge sign of progress that people are now relying more and more on autistic perspectives to accurately describe what Autism is genuinely like. And whereas it's different for each one of us, here are some of the more common elements of the autistic experience.

Perhaps the most striking part of being autistic is our alternative perspective. We process the world differently, we interpret the world differently, we experience the world differently. Often, this is quite beautiful, and leads to us seeing wonder in the “little things” where others may not expect.

Because of our behaviours in response to how we see the world, we are often interpreted as “weird” or “lesser” or even “disordered”. But if 98% of humanity thought like us, guess who'd be given the disorder? In my experience, autistic people are not weird – we're just outnumbered.

This can be quite tricky in a world where neurotypical people seem to have established a monopoly on what behavioural expectations are. Often, being autistic feels like taking part in a sport where nobody has explained the rules to you; you're just expected to magically know them like everyone else does. And when you inevitably make mistakes or have misunderstandings, the pain of being judged feels quite awful for us. (In a similar way, a lot of autism-related challenges aren't really the result of Autism itself, but rather the result of how others treat autistic people. If we were offered the same dignity and respect that most people are afforded, half of our problems would vanish into thin air.)

Some of the differences in how we see the world are driven by sensory issues. We don't just ‘see and hear things differently’ in a metaphorical sense; some of us literally do interpret lights as being brighter, or noises as being louder. This can be something of a nightmare in a society that has already decided how bright is “too bright” and how loud is “too loud”; where noise levels that are painful to us are considered “not too loud” by the general population.

You may have already heard about autistic people's “intense focus”, “narrow interests”, or even “blinkered vision” in terms of what motivates us. It's quite true that we can become very focused on topics we find interesting – if not obsessed on occasion – but I've always seen this as a positive rather than a negative. Our special interests give us plenty of opportunities to improve our wellbeing: they are anxiety relief, escapism, a source of pure joy, and occasionally even a route to a future career.

There is plenty to love about the autistic experience. There are plenty of challenges too. The same can be said for the human experience in general, but the particular difference for autistic people is that we're living in a world that's been built for everyone else. Schools, workplaces, the recruitment process, social situations and wider culture have all been designed by and for the neurotypical population, which in turn makes the difficulties of autistic people stand out rather than our strengths. There's quite some irony in this, given the contribution autistic, dyslexic and otherwise neurodiverse people have contributed to human progress – not least the wide range of tools we've invented over the centuries. And these contributions also demonstrate the enormous capability of autistic people, when we're in environments that allow us to play to our strengths.

For a long time, Autism has been defined by its weaknesses rather than its general characteristics. But the tide is beginning to turn in the direction of autism acceptance, and little bit by little bit the world is becoming more Autism friendly. And the more opportunities we have for their strengths to be recognised, accepted and appreciated, the better our lives will be.

Pathological Demand Avoidance (PDA – An Autistic Profile)

PDA is not diagnosed by any local NHS service as it is not currently recognised as a separate condition by any of the diagnostic frameworks used by the services. In a Multidisciplinary assessment, concerns around avoidant behaviour will be explored. The assessment will be an opportunity to try and understand how a child's weaknesses may be linked to the avoidant pattern of behaviour. When trying to understand avoidant behaviour, it is important to look for patterns that might provide information about what is causing stress for the young person. Thinking about how to reduce stress, develop skills for managing stress and strategies for increasing cooperative behaviour should be considered in any assessment of avoidant behaviour.

However, PDA is a lot broader than just demand avoidance, as you will learn from the description below, provided by Harry Thompson, a renowned expert in PDA and an Autistic & PDA Writer, Public Speaker, Educator, Self-Advocate & Consultant, and author of Harry Thompson – PDA Extraordinaire Facebook page.

PDA stands for 'Pathological Demand Avoidance' and is regarded by many as an Autistic profile. PDA was first recognised by Elizabeth Newson, a Neurodevelopmental Psychologist, in the 1980s. Newson observed 12 children who were referred to the Child Development Clinic at the University of Nottingham who all displayed characteristics that she noted were similar to Autism but different at the same time. Namely, these children had a tendency to avoid or resist the everyday demands of life.

It is important to note that PDA does not currently feature in either the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V), or the International Classification of Diseases, Eleventh Revision (ICD-11). Because of which, PDA is not considered an "official" diagnosis. Given that the recognition of PDA is relatively recent, it has not yet met the evidence threshold required for it to be admitted to either diagnostic manual.

PDA does, however, receive a footnote of a mention in the National Institute of Care and Excellence (NICE Guidance) Appendix K, and therefore any reputable diagnostician ought to recognise demand avoidance as a potential feature of Autism.

PDA is steeped in controversy, and many clinics across the UK refuse to diagnose it on the basis they are dubious about its existence. There are a number of clinics throughout the UK who do vouch for PDA's existence, and diagnosed PDA as a profile of ASD, or note during an ASD assessment that the person being assessed may exhibit 'PDA traits'.

The Main Characteristics, or 'proposed criteria', of PDA are as follows:

- ▶ Resists and avoids the ordinary demands of life
- ▶ Uses social strategies as part of avoidance
- ▶ Appears sociable but lacks understanding
- ▶ Experiences excessive mood swings and impulsivity
- ▶ Appears comfortable in role play and pretence
- ▶ Displays obsessive behaviour often focussed on other people.

PDAers (as they are colloquially known amongst people within the PDA community) have an anxiety-driven need to be in control, or (as I prefer to call it) 'an instinctual desire to be free'.

PDAers or PDA people resist or avoid the demands of everyday life. So, this is anything from getting out of bed, to brushing one's teeth, to leaving the house, to preparing a meal, to eating meals. To be honest, ANYTHING can be demanding. If we detect a demand in the environment, we will avoid it accordingly, on the basis the demand poses a threat to our sense of freedom, which means it poses a threat to our sense of safety.

Other PDA characteristics include having a highly developed imaginary world - for example, coming up with highly elaborate excuses which are used as demand avoidant strategies. PDAers are predominantly people-focussed, and so the special interests - which are so fundamental to Autistic experience - are usually in people, either real or fictional.

Things I would add are abstract thinking and love for mischief, controversy and humour. PDAers enjoy eliciting a shock response from people.

Whilst a lot of Autistic people enjoy structure and routine, PDAers tend to prefer spontaneity and novelty.

PDAers do not recognise authority or a pecking order, and because of this, school as children and the workplace as an adult can be extremely difficult to navigate. PDAers are intrinsically motivated and learn best and work more efficiently when left to their own devices.

For further reading on PDA, please follow this link to find a list of academic papers constituting PDA's current evidence base:

www.pdasociety.org.uk/resources/resource-category/research/

<https://www.harryjackthompson.com/>

www.facebook.com/HarryThompsonPDAExtraordinaire

Attention-Deficit/Hyperactivity Disorder

Attention-Deficit/Hyperactivity Disorder is a pattern of behaviours that affects children in many areas of their life. While many preschoolers can be very active and eventually settle down, the child with ADHD will continue to find it hard to pay attention and sit still beyond the age when they start school. ADHD can impact the child's achievement in school, peer relationships, confidence and family life, especially if not recognised.

Clinical Diagnostic Criteria and Features

The child or young person may present with the following;

Inattention;

- ▶ Difficulty in staying focused on a task or activity
- ▶ Does not give close attention to details
- ▶ May make careless mistakes in their schoolwork, at work, or during other activities
- ▶ Often does not seem to listen when they are spoken to directly
- ▶ Their mind often appears to be ‘elsewhere’
- ▶ Does not follow instructions and fails to finish schoolwork, chores, or duties in the workplace (I.e. starts tasks but quickly loses focus and is easily side-tracked)
- ▶ Often has difficulty organising tasks and activities
- ▶ Usually avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (I.e. schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers)
- ▶ Often loses things necessary for tasks or activities (I.e. school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones)
- ▶ Is often easily distracted by unrelated stimuli (may include irrelevant thoughts for older adolescents and adults)
- ▶ Is often forgetful in daily activities (I.e. doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).

Hyperactivity and impulsivity;

Impulsivity refers to hasty actions that occur in the moment without forethought and have a high potential for harm to the child or young person (I.e. darting into the street without looking). Impulsivity may reflect a desire for immediate rewards or an inability to delay gratification. Impulsive behaviours may present as making important decisions without considering long-term consequences (I.e. taking a job without adequate information).

- ▶ Often fidgets with or taps hands or feet or squirms in seat
- ▶ Often leaves seat in situations when remaining seated is expected (I.e. leaves their place in the classroom, in the office or other workplace, or in different situations that require staying in place)
- ▶ Often runs about or climbs in situations where it is inappropriate. (Note: In adolescents or adults, it may be limited to feeling restless)
- ▶ Often unable to play or engage in leisure activities quietly
- ▶ Is often “on the go,” acting as if “driven by a motor” (I.e. is unable to be or is uncomfortable being still for an extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with)
- ▶ Often talks excessively
- ▶ Often blurts out an answer before a question has been completed (I.e. completes people’s sentences; cannot wait for turn in conversation)
- ▶ Often has difficulty waiting for their turn (I.e. while waiting in line)
- ▶ Often interrupts or intrudes on others (I.e. butts into conversations, games, or activities; may start using other people’s things without asking or receiving permission; for adolescents and adults, may intrude into or take over what others are doing).

First Person Perspective by James; An Adult with ADHD from Southend

All of my life I have had difficulty in being able to focus on, or even start a task. I always procrastinated, or paced the floor back and forth; trying to put things in my mind in order. I've always paced; I can't sit still for any length of time without needing to get up and move around. When I was able to sit down and start a task, I'd become very quickly bored and would leave the task, or if a part of the work involved any sort of complex thought, I'd stop and walk away from it. I could never stay motivated enough to complete anything.

The only thing that I could stay focused on was playing console games; I guess it's because it gave constant rewards and achievements, so I didn't get bored as quickly.

I found that minimalising my life helped; I can function a lot better in a clear environment with plenty of space and not having things that may distract me, around.

With learning, I've only ever been able to process little bits of information at a time, and then have difficulty in linking the little bits of information together. I find that I need to get all of the little bits of information together, once everything I'm learning has been covered, and then need to piece all the pieces together like a jigsaw puzzle.

My memory is terrible, and I don't seem to be able to retain much information once I've taken it in, and I have trouble linking past memories to present day things. Like, I have been doing Boxing training for the past 5 years and the way I stand has always felt unnatural and wrong, though I have stuck with it. 2 days ago, I had a flashback to when I was young and I did Martial Arts training from the ages of 6-11 and the way I was trained to stand then, was the opposite of how I have been standing in Boxing training. I tried standing in the way I was trained to as a child when Boxing and have found it so much more natural and flexible. I don't know why my brain kept this memory away from my current day thinking, as this would've really helped my training over the past 5 years!

Since being diagnosed and prescribed medication, I have found that I can focus so much more now, my head feels a lot clearer and I still pace a lot, but I've found that it's directed towards a task rather than my mind flitting between lots of different things.

Specific Learning Disorder (Dyslexia, Dyscalculia, Dysgraphia)

Specific Learning Disorders are conditions affecting a child's ability to learn. The child's teacher will observe that the child is finding it very difficult to learn specific skills and can seek assessment to understand what is interfering with their learning of these skills.

Clinical Diagnostic Criteria and Features

The child or young person may present with the following;

- ▶ Difficulties learning and using academic skills
- ▶ Inaccurate or slow and difficulties with word reading (i.e. reads single words aloud incorrectly or slowly and hesitantly, frequently guesses words, has difficulty sounding out words).
- ▶ Difficulty understanding the meaning of what is read (i.e. may read text accurately but not understand the sequence, relationships, inferences, or deeper meanings of what is read).
- ▶ Difficulties with spelling (i.e. may add, omit, or substitute vowels or consonants).
- ▶ Difficulties with written expression (i.e. makes multiple grammatical or punctuation errors within sentences, employs poor paragraph organisation, written expression of ideas lacks clarity).

The specific learning difficulties are not part of a more general learning difficulty caused by intellectual disability or global developmental delay.


Specific learning disorders may also occur in individuals identified as intellectually “gifted.” These individuals may continually display adequate academic abilities by using strategies to compensate for their difficulties, such as using extraordinarily high effort or support.

The learning difficulty cannot be attributed to more general external factors, such as economic or environmental disadvantage, chronic absence, or lack of education.

With impairment in reading: Word reading accuracy, reading rate or fluency, and reading comprehension - Dyslexia is an alternative term used to refer to a pattern of learning difficulties characterised by problems with accurate or fluent word recognition, poor decoding, and poor spelling abilities.

With impairment in written expression: Spelling accuracy, grammar and punctuation accuracy, clarity or organisation of written expression – Dysgraphia is an alternative term used to refer to a pattern of learning difficulties characterised by problems with the above.

With impairment in mathematics: Number sense, memorisation of arithmetic facts, accurate or fluent calculation, and accurate math reasoning - Dyscalculia is an alternative term used to refer to a pattern of difficulties characterised by problems processing numerical information, learning arithmetic facts, and performing accurate or fluent calculations.



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First Person Perspective by Pat; an Adult with Dyslexia from Southend

I have always had trouble with reading, ever since I was a child. I have a very slow processing speed when it comes to reading and understanding words. I would get frustrated, angry, and embarrassed at school, especially when I was asked to read aloud, as each word that came out painstakingly slowly made me feel really self-conscious. I was frequently called 'dumb' and 'stupid' even though I excelled in other subjects, which was hard to deal with.

When I read them, some words just don't make sense compared to how I see and understand the word in my head, and it takes a lot of focus to be able to work them out when I'm reading. The letters don't look like they're in the right order, and the whole word just looks wrong.

When a word in a sentence doesn't make sense, it makes the whole sentence confusing, which increases the amount of time and focus that it takes to read through things. This affects my spelling as well as when I'm writing. I spell things how they look in my brain, which isn't always how the word is actually spelt! I also spend so much time focusing on getting the spelling right or using the right words that my grammar and punctuation go out of the window completely, or I put them in the wrong places by accident.

But when I do learn something (it can take 3 or 4 times of reading something for it to sink in), it locks in my brain, and it stays in my memory for years, which is definitely a bonus!

Understanding why I have these struggles has helped combat the insults and put-downs of my youth; knowing that I'm not dumb or stupid, just Dyslexic and that I just need extra time to read and understand things made a big difference for me.

Developmental Coordination Disorder - Dyspraxia Clinical Diagnostic Criteria and Features

The child or young person may present with the following;

- ▶ Motor skills development and use are significantly lower than their expected level for their age.
- ▶ Appears clumsy (i.e. dropping or bumping into objects)
- ▶ Slow and inaccurate use of motor skills (i.e. catching an object, using scissors or cutlery, handwriting, riding a bike, or participating in sports).
- ▶ May experience delays in motor milestones (i.e. sitting, crawling, walking)
- ▶ May find walking up and down stairs challenging
- ▶ May have difficulty in pedalling a bicycle
- ▶ They May have trouble dressing themselves (i.e. buttoning shirts, using zippers, etc.)
- ▶ Movement may appear awkward, slow, or less precise than their peers
- ▶ May display slow speed or inaccuracy with motor activities such as assembling puzzles, building models, playing ball games (especially in teams), handwriting, typing, driving or carrying out self-care.
- ▶ May have poor handwriting ability

First Person Perspective by Ruth; Mum (Dyspraxic) of a Dyspraxic Child in Southend

When my daughter was diagnosed as having DCD – Developmental Co-ordination Disorder – aged nine, I quickly realised this was a new name for what I'd always known as Dyspraxia. I knew Dyspraxia well as I had been in early years & SEND teaching for almost two decades, but what I hadn't realised was that I knew it even more intimately than that... because I am also dyspraxic. Not clumsy, not an idiot that can't walk through a doorway without getting her belt-loop stuck in it, but dyspraxic. A common co-morbidity with Autism and, in our case, also paired with the connective tissue disorder, Joint Hypermobility Syndrome – JHS – Dyspraxia doesn't have a great deal of positives that come with it. Unless you count becoming adept at avoiding and working around situations that find physically challenging as a positive skill!

For us, Dyspraxia is one of the key factors that makes us disabled. Trouble distinguishing left and right, struggling with multi-tasking activities that require different movements on the opposite side of the body simultaneously, challenges with coordination and balance. Trouble reading analogue clocks. Falling over more often than the average person. Not being able to ride a bike, drive a car, anything with wheels, to be honest! Finding it difficult to navigate a new space, building, street or town, remembering how to get somewhere, giving or following directions... it's hard to get where you need to go when you can't work out the journey, and if you work out the journey, then you've physically got to get there. It means a lot of public transport or relying on others to get you to your destination. So sometimes, you just don't go.

The accommodations that Dyspraxia can require to prevent limitations on us are often not considered. I have learnt to brush off the 'what do you mean you can't (insert challenging activity here)?' comments and self-advocate. It's frustrating when you have to explain what you can't do well without help and embarrassing sometimes too – 'clumsy' people aren't cool, are they? How could you possibly be intelligent and yet not be able to tie up your shoelaces? If you're not laughed at, then you're patronised and even occasionally disbelieved.

My daughter makes it quite clear when she needs help, and if she doesn't get it, then that's on you! Maybe I ought to take a leaf out of her book?

