Supporting Your Neurodiverse Child

Written for parents, by parents

pinpoint
for parents by parents

Cambridgeshire & Peterborough Integrated Care System

NHS

Cambridgeshire County Council

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Introduction

When you first realise that your child experiences the world in a different way it can feel overwhelming, but once you begin to understand their way of thinking it can be rewarding and you can learn so much from your child.

We are a group of parents, at various stages on this same journey. We were desperate for guidance and didn't know where to look to find what we needed. A few years on, our knowledge has grown. We now know there is a lot of information available, but it can be hard to find the bits that are factually correct and relevant to your own situation.

We have provided an overview of what we have found to be the most relevant information from sources such as the NHS website, national charities and IPSEA but we aren't trying to recreate textbooks that are already available. There are links included that you could follow to find out more on specific topics. We have also recommended some books, videos and blogs, which are all resources that we have used ourselves.

We are extremely grateful to the parent carer groups and Forums in Essex that first created this resource, using funding from health. Without them sharing the core document, funded by our local health services, we simply wouldn't have been able to provide this to you in Cambridgeshire.

We don't intend for you to read this whole pack in one go, but dip in and out when each section becomes relevant to your family's situation.

Just as every child is unique, every family's experience will be different, but we hope there will be some information here that will help you. Books and websites can provide very useful guidance but we believe it is equally important to find your own 'tribe' of other SEND parents, who will understand how you are feeling and provide emotional, as well as practical, support.

Pinpoint aims to empower parent carers and we hope this booklet does just that.

Good luck on your journey from Sarah, Fay, Janet and the Pinpoint Team

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for parents by parents

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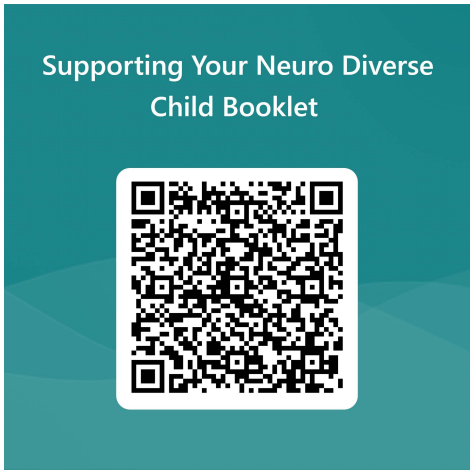
Integrated Care System

www.pinpoint-cambs.org.uk

Please give us your feedback!

We wouldn't have been able to produce this booklet without the funding we've had from Cambridgeshire and Peterborough Integrated Care Partnership. They, and we, need to know what you think about the booklet, how useful it is and what else you might want to support you and your child. The survey takes just a few minutes and we would be grateful for your time to complete it.



Use the QR Code to access the survey

Or use **this link** to the survey

Section 1

What is Neurodiversity?

What is Neurodiversity?

‘Neurodiversity’ is an umbrella term which is used to describe people who have brains and thinking styles which work in a slightly different way to ‘neurotypical’ people.

It includes a wide range of differences, such as autism, ADHD, dyspraxia, OCD,Tourette’s Syndrome and literacy and numeracy difficulties.

We believe that being neurodiverse provides our children with strengths that should be nurtured, and challenges that should be effectively supported. Because no two children are the same, all neurodiverse children will experience the world differently and it is important to think about how approaching things in a different way may minimise challenges and benefit your child in a neurotypical world.

“If you are always trying to be normal, you will never know how amazing you can be.” Maya Angelou

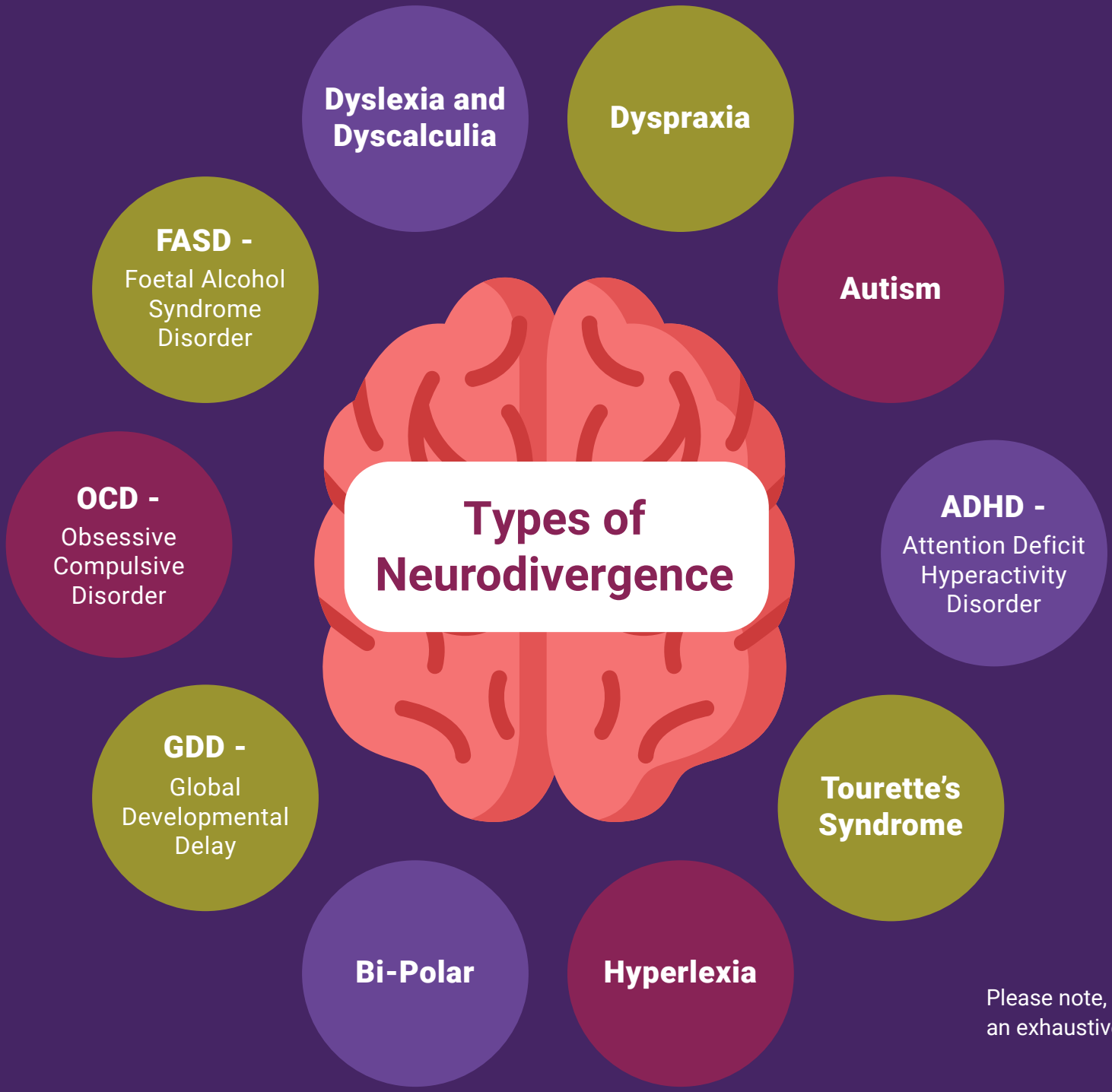
A Note on Terminology

The terminology used to describe neurodiversity is changing, driven largely by the research and writings of neurodiverse adults. As a parent of a neurodiverse child, discussions over the use of language are probably way down on your list of concerns, but as your experience and knowledge grows you may see how some of the words used to describe your child have subtly negative connotations. Within this pack we have chosen to use identity first language (autistic child) rather than person first (child with autism) as the majority of autistic adults prefer this.

We also understand that grammatically, it is correct to say that a person is neurodivergent, however, we received feedback from some families and service providers that this isn’t a term with which they can easily identify. In light of that feedback and the fact that the NHS and some other services still use the term, we have used ‘neurodiverse’ as the best- understood description at this time, recognising that terminology will continue to change.

If you are speaking to neurodiverse/neurodivergent individuals, be led by the terminology that they prefer – if in doubt, just ask them.

To understand more about the impact of the words used to describe disabilities please read this excellent blog article by Ann Memmott Ann’s Autism Blog: Appropriate Descriptions around Autistic People **(https://annsautism.blogspot.com/2021/07/appropriate-descriptions-around.html)**



Please note, this is not an exhaustive list.

What is Autism?

Autism is a lifelong neurological difference that affects how people communicate and interact with others.

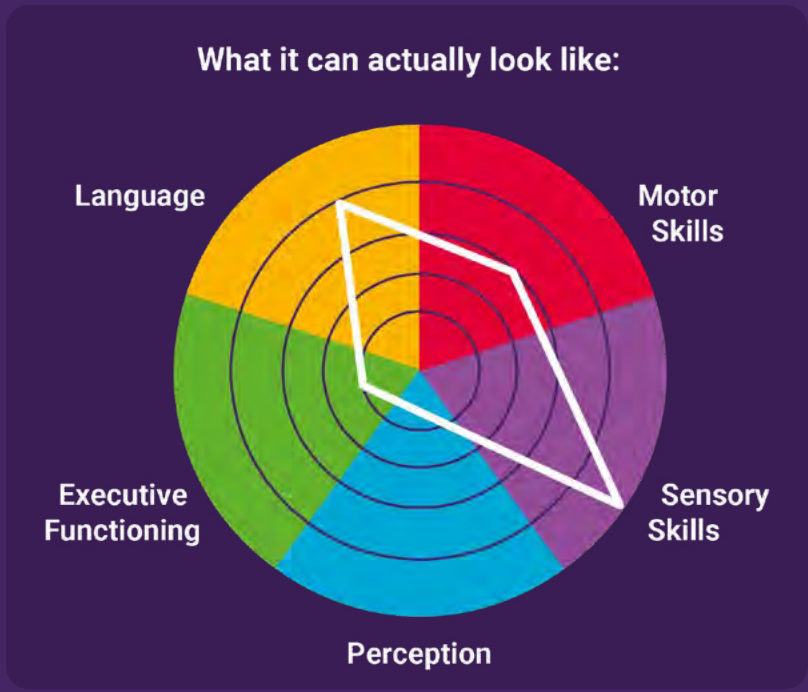
Most autistic people see, hear and experience the world differently from neurotypical people, but like neurotypical people, every autistic person is unique and complex.

Historically, there was a common misconception that the autistic spectrum is a straight line between low and high functioning, but as understanding has increased, it is clear that everyone is completely different and has different strengths and weaknesses - you might hear this referred to as a 'spiky profile' and it is a great way to explain the differences of ability that are associated with neurodiverse conditions. For example, one autistic person may be highly creative, but struggle to organise themselves. Another may excel at maths, but find it hard to join in two-way conversations.

"Sometimes I am very proud of who I am because I can prove people wrong who think I can't do things, but the other side is annoying because people can label me as just being 'autistic' and I am much more than that."

This graphic shows that when a person is on the autism spectrum they may demonstrate great strengths in some areas but be lacking in skills in another.

The Autism Spectrum



Autistic people will typically have challenges in some of the following areas:

1. Social Interaction

They may:

- Find it difficult to initiate and maintain friendships and relationships
- Prefer to have daily routines
- Demonstrate repetitive behaviours
- Like to strictly follow rules
- Have a strong sense of justice
- Speak in a way that is overly direct
- Prefer to interact with objects or animals to people
- Have difficulty reading facial expressions and body language cues correctly and use facial expressions themselves that can be misinterpreted
- Find it hard to understand and express their feelings
- Like to feel in control, and may have difficulty taking turns

"I often felt like I was my child's interpreter."

For further information about communication difficulties please see section on Communication, Speech and Language

2. Communication

They may:

- Need more time to process information
- Sometimes find it painful to make eye contact and therefore avoid doing it - or sometimes stare too much!
- Have a language delay or be non-verbal or selectively mute or situationally mute
- Appear very articulate but actually lack understanding
- Use repetitive language
- Mimic phrases they hear or tones of voice/ accents (this is called Echolalia)
- Take things literally – so may have difficulty understanding sarcasm or expressions like 'It's raining cats and dogs'
- Find it difficult to maintain focus, or engage in a conversation which does not spark their interest
- Will give their honest opinion, not realising that the other person was fishing for a compliment!

3. Sensory Processing Differences

Autistic children experience the world differently to neurotypical people and this can be across all of their senses. As Sensory Processing is a challenge for so many neurodiverse children, a specialist Occupational Therapist has provided a thorough overview of the difficulties, and suggested some hints and tips, and this information can be found in the **Sensory Needs Section**.

Sensory things that may be difficult

I can be overly sensitive to loud noises

New clothes can be itchy

I find it really hard to focus or concentrate

I find some foods scary

I get muddled and confused in keeping up with conversations

I am not keen on someone touching me to get my attention

I find being tickled or cuddled uncomfortable

I don't like the smell of cooking

I chew on everything

Hand dryers scare me

I hate fire alarms

I hate having my hair brushed or washed

4. Processing information

Autistic people often have a good eye for detail, although this may be at the expense of looking at the bigger picture and they may need more time to build up connections and associations. Psychologists call this having Central Coherence differences. There may be other differences related to their ASD, such as:

- They may benefit from support in learning sequences (in an early years child, that might be the steps involved in getting dressed/undressed or cleaning their teeth).
- They may benefit from multi-step instructions being broken down into smaller steps (both of these points may be due to what psychologists call Executive Function differences). The picture on the next page shows the Executive Functioning tasks that neurodiverse people may find challenging. There are many interventions that can be put in place to help with this. We discuss some of these on **pages 65** and **85**.
- Neurotypical people may find it hard to work out how an autistic person sees the world. In the same way it can sometimes be difficult for an autistic person to imagine something from the point of view of someone else. Psychologists call these Theory of Mind differences and you may also see it referred to as the Double Empathy Problem. You can read more about it here: **Milton's 'double empathy problem': A summary for non-academics | Reframing Autism (https://reframingautism.org.au/miltons-double-empathy-problem-a-summary-for-non-academics/)**
- **This video clip 'Amazing Things Happen' from the Amazing Things Project helps to show how an autistic person may see the world https://www.youtube.com/watch?v=Ezv85LMFx2E**

Executive Functioning
01
Impulse Control
Think before acting
02
Emotional Control
Keep feelings in check
03
Flexible Thinking
Adjust behaviour to unexpected changes
04
Working Memory
Keep key information in mind while using it
05
Self-Monitoring
Self-awareness to how one is doing in the moment
06
Planning and prioritising
To set and meet goals
07
Task Initiation
Take action to get started on tasks
08
Organisation
Keep track of things physically and mentally

5. Special Interests

Your child may have an interest in one subject to the exclusion of everything else.

Many autistic people find their interests hugely enjoyable, therapeutic and rewarding. This intense focus (hyper-focus) can be very useful, as it can be used to help solve problems or find new ways of looking at things, but they can be so absorbed in something that interests them that they forget to undertake self-care, such as remembering to eat or drink!

The special interest may be something like an interest in trains, dinosaurs, LOL dolls, make-up tutorials, or Minecraft; it may be a person, a pet or a cuddly toy, or it might be something more unusual like vacuum cleaners! Sometimes the interest can be in sorting items by colour or lining them up, rather than in role play activity. They may consider that anything which doesn't include their special interest is a waste of time and to some other people this may appear rude.

You may find that your child loves to talk about their special interest at length. If they do, try to remember how happy it is making them to share their interest with you (even if you don't find the subject interesting) and that they are likely to only "info dump" on people they feel safe with.

Top tip – If you, or your child's school, can find ways to work their current special interest into their education it will help your child to focus and learn.

Autistic Masking

It can be difficult to obtain a diagnosis of autism when a child appears sociable, but if you know them well enough you can see how much energy they are having to put into performing to appear "normal". This is called 'Masking'.

Some autistic people can socialise incredibly well, but this can be exhausting as it is often learnt behaviour rather than intuitive. Pretending to be something you are not can take up a lot of emotional and physical energy.

How this might affect your child?

Some autistic children learn to mask without even realising they are doing it. They are noticed for autistic behaviours (**stimming**, talking about their special interests, not maintaining eye contact etc.) and naturally try to suppress them to stop the criticism. Some autistic children and young people worry about being ostracised by their peer group, so learn to mimic how others might behave.

The problem is that the longer the child masks their natural autistic self, the more stressed they become. It is one of the reasons why teachers may not see a problem with some autistic children in school, but when that child gets home the stress from being the model student all day long becomes too much to bear and they end up mentally exhausted and overwhelmed; perhaps exploding with rage, tears, or withdrawing completely. It is even more likely to occur if they don't have a diagnosis, which helps them to understand why they may behave in a certain way, or why they may have specific needs that differ from their peers.

Masking may also make diagnosis more difficult as schools will be asked for their observations, and if a child is masking at school, the school may say that they see no signs of neurodiversity, even though a parent provides a long list of things that they are concerned about. We have provided links to information about masking, which you may wish to share with your school to help explain that this is a common problem.

Further information

- **www.reframingautism.org.au/self-reported-camouflaging-behaviours-used-by-autistic-adults-a-summary-for-non-academics**
- Autistic Masking resources from Kieran Rose, The Autistic Advocate **www.theautisticadvocate.com/autistic-masking**

What masking may look like

Copying gestures

Learning scripts

Ignoring sensory needs

Hiding stims

Excessive self-monitoring behaviour

Worrying or overthinking previous conversations to understand what you did wrong

Trying to disguise or contain meltdowns

Trying to behave 'normally'

Girls and Autism

The way that boys and girls are assessed for autism is the same, however, the areas in which they face challenges can be different. Please note that these are generalisations and that some girls will present with typically “male” autistic traits and some boys will present with the “female” traits and it is often the case that parents of these boys will also struggle to secure a diagnosis.

“It took 3 years for my daughter to be diagnosed and were initially told she didn’t have autism because she had an imagination! My son’s diagnosis took around a year. We were fortunate to have the support of their primary school who put many interventions in place while we were going through the long diagnostic processes. We were relieved when they were both diagnosed as it meant there were reasons behind their behaviours and proper structures and interventions could be put in place to limit their anxiety.”

For girls who have complex needs, autistic traits may be clear, but for many in a mainstream environment, the way that autism presents may differ significantly to the male presentation.

Historically, more boys than girls were diagnosed with autism, as the diagnostic criteria was biased towards boys. That is starting to change as understanding improves about the differences.

Girls are more likely to:

- Have special interests in the same way that many boys do, but are often in more culturally acceptable areas, for example, Harry Potter, Our Generation dolls, boy bands, make-up tutorials on YouTube etc.
- Seem better able to manage social relationships when they are young, but difficulties often occur in later primary years as they approach adolescence.
- Be more likely to become withdrawn than behave aggressively.
- Mask their differences. Many boys do this too, but it is a very common feature for girls.
- Have a group of friends who support them and guide them through difficult social situations. However, these relationships can change as girls grow up and interests change, and they may find it very difficult to lose not only friends but also their support network.

Further information

- Free mini guide - **Girls and Autism: Flying under the radar | Nasen (www.nasen.org.uk/resources/girls-and-autism-flying-under-radar)**
- Book - Women and Girls with Autism Spectrum Disorder – Sarah Hendrickx - **Girls and Women and Autism: What's the difference? - Sarah Hendrickx - YouTube** (https://www.youtube.com/watch?v=yKzWbDPisNk)
- You tube presentation by Tony Attwood: Autism in females (https://www.youtube.com/watch?v=wfOHnt4PMFo)

"If people just understood all our differences a little more, especially about girls, because a lot of girls mask like me and then this makes things very hard for us''

Demand Avoidance Behaviour (sometimes referred to as Pathological Demand Avoidance - PDA)

Demand Avoidance Behaviour is a characteristic whereby the child or young person avoids the demands of everyday activities due to fear, anxiety, reaction to sensory or communication difficulties etc. If these demands feel overwhelming there will be a desire for the person to try to control situations/environments.
It goes beyond simply not wanting to do something and can cause extreme anxiety and resistance. As a parent, it can be very challenging to support a child who is struggling to cope with the demands of everyday life, but it is important to understand that they are not deliberately being defiant, they are having difficulty adjusting and are trying to take control of their environment.
Not all professionals agree with the diagnosis of PDA or that it is something that should be diagnosed separately from ASD. This is why we are using the phrase Demand Avoidance Behaviour.

There are strategies that can help reduce pressures from demands and potential conflict and the most important thing is to show understanding. With the right support in place, the ability to cope and self-confidence will grow, which can help people better cope with day-to-day life.

Parent experiences of Demand Avoidance Behaviour

Parenting a child with this profile may need a different parenting approach and challenges can be different for every child. We asked families for their experiences and tips on what has helped them:

- 'Demands aren't bad per se but too many can cause problems and can result in a meltdown'
- The PDA Society have some helpful resources -**https://www.pdasociety.org.uk/resources/helpful-approaches-for-parents-carers/**

- ‘Try to have a joint decision-making process so that when a demand is made, your child may not respond as dramatically’.
- ‘Agree the non-negotiable rules and boundaries. If you can give clear reasons for these boundaries and agree them together then this can help. ‘
- ‘When a rule cannot be compromised, it can be helpful to remove the personal aspect and explain why it is needed. We use sentences like. ‘Sorry it is health and safety rules, that’s just how it is. I can’t do much about that‘
- ‘ We always have an exit strategy and so does the school. We support my child to know how to appropriately remove themselves from an anxiety provoking situation. Together with school and at home, we understand my child may need to avoid a stressful situation, but you need to agree an appropriate way to do this together. For instance, you might agree a quiet zone to which a young person can retreat. You can also provide reassurance that if something can’t be done today it can be tried again another time.’

Rewards can be challenging

- ‘My son does not like praise and rewards as it can be trigger point, particularly personal praise can be overwhelming, as it feels like an expectation and we handle it very sensitively.’
- ‘In fact, rewards can create a demand in themselves, as there is pressure to do well to get the reward. Surprise rewards work a lot better for us.’
- ‘We find that saying something like “you’ve put a lot of effort into that and I know you were a bit worried about it, why don’t you have a break/do something of the you are interested in now’ can be helpful.’

Sanctions and consequences

- ‘My child has difficulties with sanctions or consequences. This often leads to escalations as she feels out of control when the sanction is being given to them. When she calms down, we find it useful to talk through ways to avoid these situations arising in future. We will ask for her views on what she thinks she could have done differently, or what she would feel is a fair outcome.’

Read the experiences of adults with PDA:

- Kirsty Forbes is a highly qualified PDA support specialist and blogger. **Kristy Forbes - Autism & Neurodiversity Support Specialist (www.kristyforbes.com.au)**
- **Sally Cat PDA (www.sallycatpda.co.uk)**

Further information

- Understanding PDA (The priory): **(www.priorychildrensservices.co.uk/news-blogs/understanding-pathological-demand-avoidance-pda)**
- **www.pdasociety.org.uk/resources/understanding-pathological-demand-avoidance-syndrome-in-children-a-guide-for-parents-teachers-and-other-professionals-jkp-essentials/**
- **www.pdaparenting.com/2019/01/16/me-and-my-pda-a-guide-to-pathological-demand-avoidance-for-young-people/**

The Positives of Autism

Autism can be challenging, but many autistic adults can have successful relationships and families of their own and have discovered that combining their autistic ability to hyper-focus and their special interest has led to a fulfilling career.

There are numerous ways in which autistic individuals have contributed to both scientific and cultural advancements within society. These are just a few:

- Greta Thunberg
- Thomas Edison
- Elon Musk
- Albert Einstein
- Sir Isac Newton
- Thomas Jefferson
- Mark Twain
- Wolfgang Mozart
- Vincent Van Gogh
- Chris Packham
- Alan Turing
- Anthony Hopkins
- Darryl Hannah
- Satoshi Tajiri – Creator of Nintendo's Pokémon
- Eminem

Autistic Bloggers/Writers

A good way to find out more about autism is to follow the blogs of autistic adults.

- Emily@21andsensory who is an amazing autistic graphic designer, blogger and podcaster **www.instagram.com/21andsensory/**
- Dean Beadle - www.**deanbeadle.wordpress.com/**
- Pete Wharmby - **www.patreon.com/pwharmbyautism**
- Ann Memmott - **http://annsautism.blogspot.com/2019/01/autism-some-vital-research-links.html**
- Chris Bonnello – writer of the Underdogs children's novels, based on the adventures of a group of neurodiverse children. Blog Autistic Not Weird - Insights from an Autistic Teacher and Speaker **https://autisticnotweird.com/**

"The best thing about being autistic is being myself, in a unique way."

Further reading

- **The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism** - by Naoki Higashida – provides an insight into the mind of a non-verbal autistic child. The film adaptation of this book was released in cinemas in June 2021.
- The National Autistic Society website - What is autism **www.autism.org.uk/advice-and-guidance/what-is-autism**
- Tony Attwood lecture of the characteristics of Aspergers - Could It Be Aspergers? - **www.youtube.com/watch?v=LuZFThlOiJI**
- Autism Education Trust **www.autismeducationtrust.org.uk**

What is Attention Deficit Hyperactivity Disorder / Attention Deficit Disorder (ADHD/ADD)?

People with ADHD have difficulty regulating their attention because of poor neurotransmitter activity (the way chemicals are released and transferred within the brain) and differences in the structure of the brain. ADD is similar, but without the hyperactivity.

“My brain doesn’t sit still, ever!”

ADHD usually presents in three different ways, hyperactivity (which means the need to move around more), impulsivity and inattention. Children with ADHD may be labelled as disruptive, for behaviour which they cannot control.

These are the main features of ADHD but there are many more that have a significant impact on a child’s organisational skills and emotional well-being.

ADHD can present differently in females - we’ve included a book recommendation below that describes the differences and dispels some myths.

ADHD can occur with other neurodevelopmental conditions such as ASD, specific learning disorders, tics/Tourette's syndrome.

Signs of Inattention

- Makes careless mistakes in work, due to lack of attention to detail
- Often loses or misplaces things
- Avoids activities that require a lot of concentration
- Has difficulty organising themselves, tasks and activities
- Does not seem to listen, even when spoken to directly
- Cannot follow complex, multi-step instructions (especially verbal)
- Easily distracted

Signs of Hyperactivity

- Fidgets with anything to hand, taps feet, rocks on chair, wriggles in seat
- Gets up from the desk/table during lessons/mealtimes for no apparent reason
- Talks excessively and often at a louder volume than others
- Runs or climbs in situations where it is not appropriate
- Has trouble engaging in leisure activities quietly
- Always seems to be ‘on the go’
- Long term rewards, or delayed punishment do not work as disciplinary tools

Signs of Impulsivity

- Blurts out answers before the question has been read out in full
- Unable to consider long term consequences of actions
- Interrupts or speaks over other people
- Seems totally unaware of danger
- Accident prone
- Emotional outbursts
- Answers back – speaks before thinking

Hints and tips

School

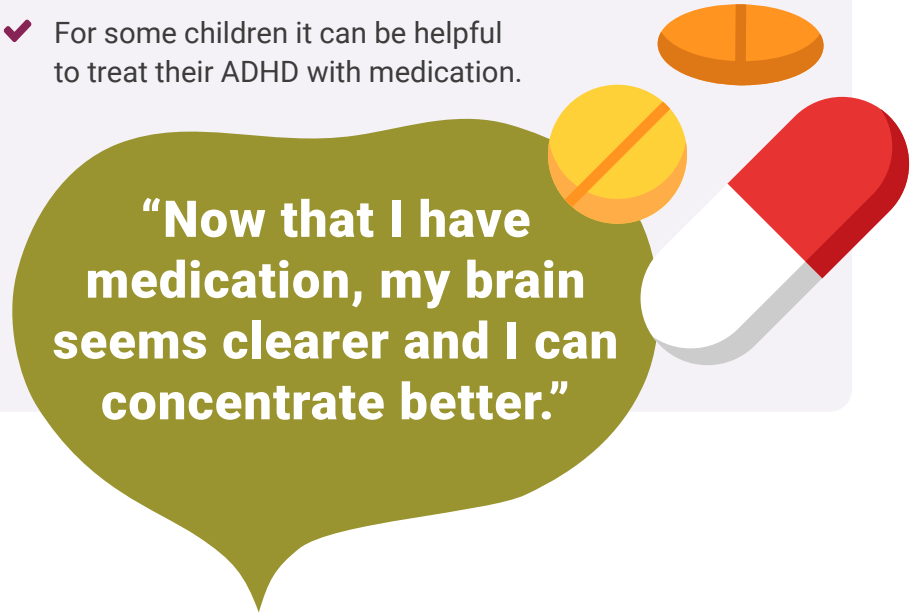
There are many strategies that can help. Ensuring the correct provision is in place at the child's educational setting will help them to thrive. Consider asking them to:

- Introduce brain/sensory breaks
- Think about desk placement - seat a child where they are less easily distracted, but near their friends so they don't feel that they are being punished
- Break down the work into small manageable steps. Use a whiteboard as a checklist to list these and allow the child to tick them off as achieved
- Use a timer to help manage tasks and activities
- Use visuals to help organisation.

Hints and tips

Home

- Don't mistake distraction for defiance. If you ask your child to put on their shoes, but instead you find them playing with a pet, it is likely that they were distracted from completing the task, rather than deliberately not doing as they were told.
- Use timers/apps and visual timetables.
- When undertaking a task help your child to visualise what the end result will look like. Children with ADHD often struggle to plan how to do something, because they don't know what they are aiming for. Working backwards from the end result can help them to start the task, as they can then see the path they need to take.
- For some children it can be helpful to treat their ADHD with medication.

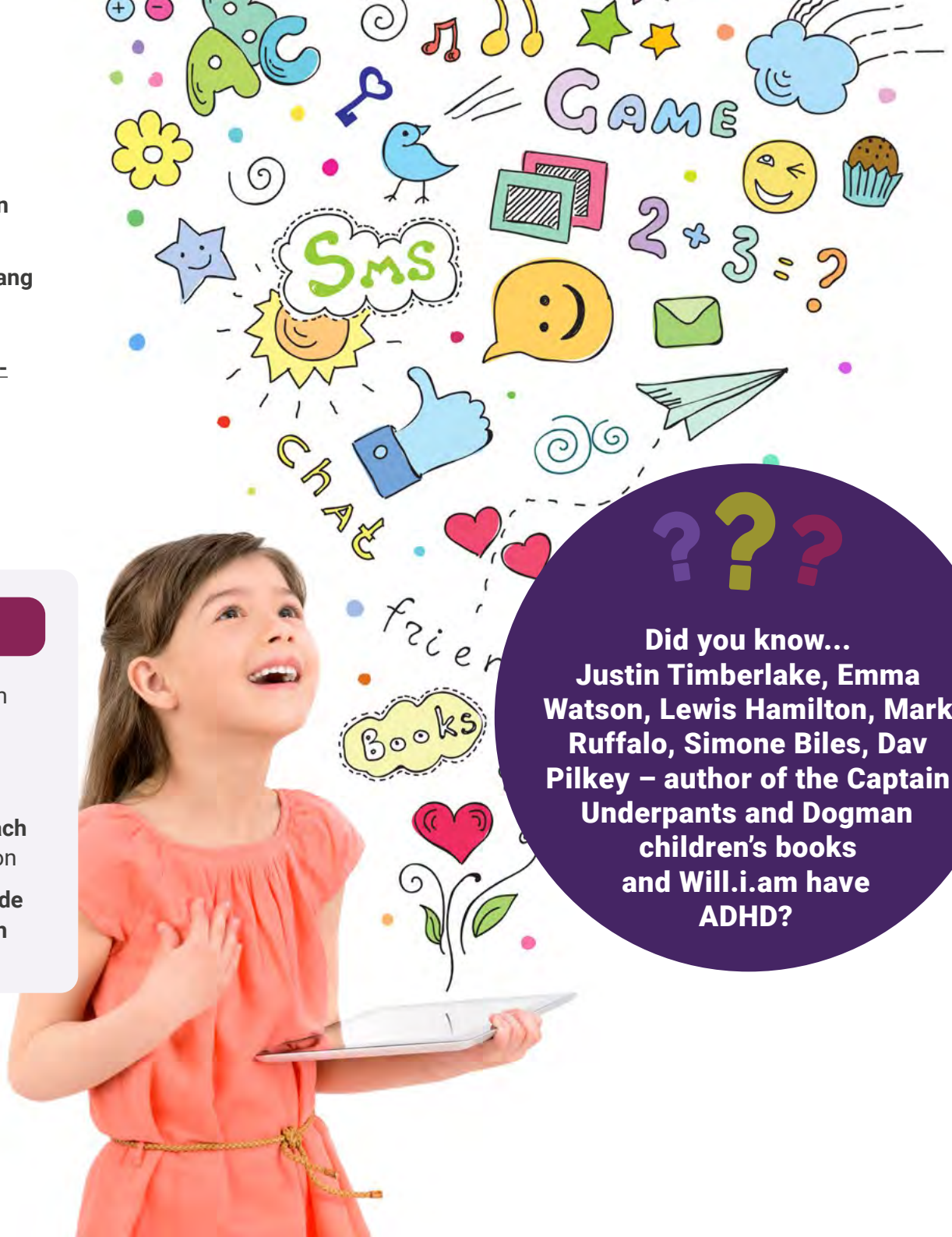


Writers/Bloggers with ADHD

- Rene Brooks - **Black Girl Lost Keys | Putting the Ayy in ADHD (https://blackgirllostkeys.com/)**
- Joshua Grenville-Wood (co-author of **The Umbrella Gang** comics and a professional golfer) **ADHD Foundation Comic Preview (www.adhdfoundation.org.uk/wp-content/uploads/2019/10/Hi-RES-ADHD-Foundation-Umbrella-Gang-comic.pdf)**
- **Dyskinesia: Love, Lunacy, and Life on the Spectrum: Life with ADD, Asperger's, autism, and a dog. (https://dyskinesia.wordpress.com/)**

Further information

- ADDitude - Inside the ADHD Brain: ADD Symptom Tests, Treatment, Support (**https://www.additudemag.com/**)
- **Book: Smart but Scattered: The Revolutionary "Executive Skills" Approach to Helping Kids Reach Their Potential** by Richard Guare and Peg Dawson
- **Book: Women With ADHD: A Life-Changing Guide to Overcome the Hidden Struggles of Living with ADHD** by Roberta Sanders



Did you know... Justin Timberlake, Emma Watson, Lewis Hamilton, Mark Ruffalo, Simone Biles, Dav Pilkey – author of the Captain Underpants and Dogman children's books and Will.i.am have ADHD?

What are Specific Learning Difficulties, like dyslexia?

Specific Learning Difficulties (SpLD) including Dyslexia, Dyscalculia and Dysgraphia: Literacy and Numeracy difficulties

A Specific Learning Difficulty is a neurodevelopmental condition which can occur across a range of intellectual abilities. Identifying Specific Learning Difficulties is not always easy - it can be complex. It is vitally important to understand children's learning differences. Literacy and numeracy difficulties are best thought of as being on a continuum, with dyslexia, dyscalculia and dysgraphia falling at one of the spectrum. Its common for people who are neurodiverse to have co-occurring conditions (more than one at the same time), for example children with ADHD or dyscalculia may also be dyslexic.

With the right help and support the majority of children do learn to read, write and do maths. It is important to understand why a child is struggling: in common with other neurodiverse children, dyslexic children may have problems with aspects of executive function such as working memory, organisation or time management. It is important to understand a child's strengths and how a child thinks. This needs a good assessment to ensure that the right approach is used. Playing to our strengths can help overcome the things we don't naturally find as easy. It will also help the child understand why they may not be able to do what their peers do and stop them from thinking they are stupid! The Educational Psychology Team can help schools with free assessment tools.

There is also a free screening checklists for neurodiversity on the British Dyslexia Association website**: https://www.bdadyslexia.org.uk/dyslexia/how-is-dyslexia-diagnosed**

If a specific learning difficulty is not identified and supported, the young person may be embarrassed and try to mask their difficulties, or exhibit distressed behaviour and may not meet their true potential. As a result, there is an increased risk of low self-esteem, poorer overall mental health, unemployment/under-employment and dropping out of school.

Different terms are used to describe the conditions:

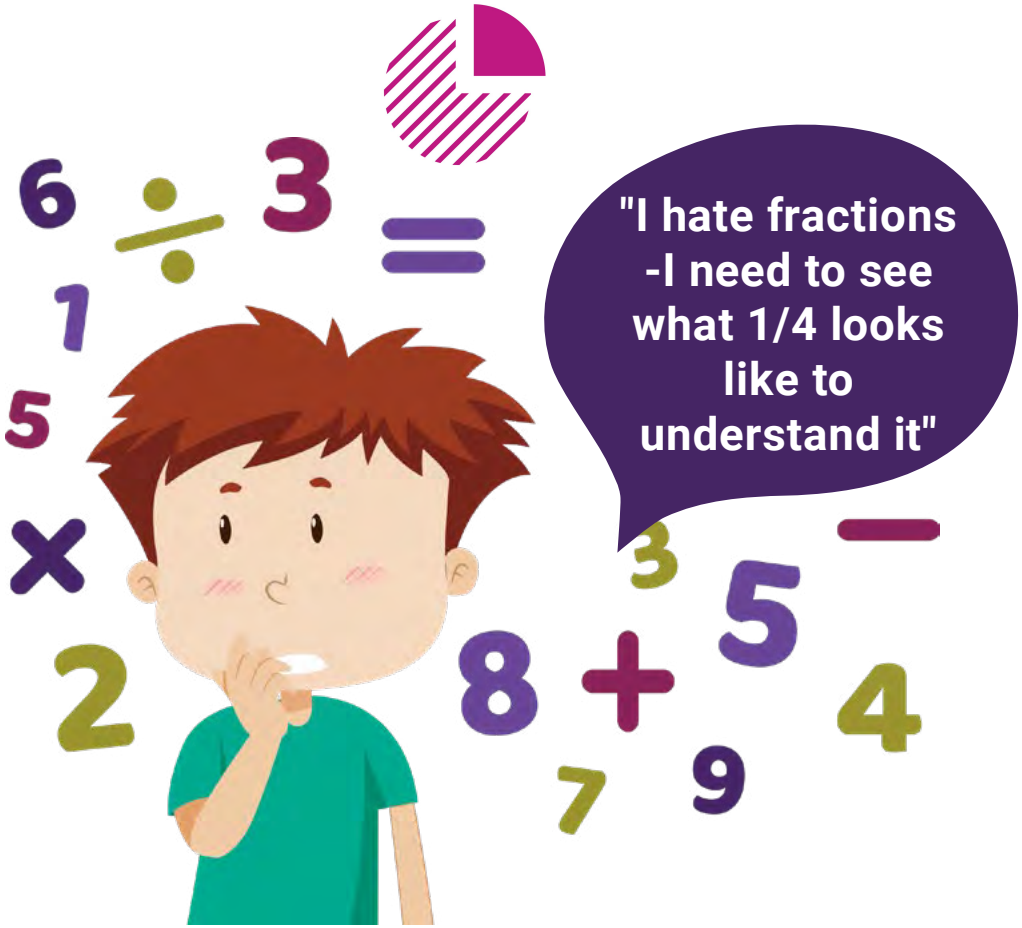
Dyslexia is a term for children who may have difficulty with reading, writing and spelling. As a result, these tasks may be slow, effortful, and not fluent processes for the child. Sometimes this shows later as the demands in school / college for reading and writing increase. It can also show in getting ideas down on paper for essays and exams.

Problems may begin even before learning to read, for example having difficulties with phonics and having trouble breaking down spoken words into syllables and recognising words that rhyme. Younger children may not be able to recognise and write letters as well as their peers. People with dyslexia have difficulty with accuracy and fluency in reading and with spelling. Children may find it difficult to complete the same amount of work as their peers. They may find it hard to read written instructions and so give verbal or written answers that seem inappropriate.

Children and adolescents with dyslexia often try to avoid activities involving reading. They may find it easier to understand pictures, video, or audio rather than written words.

Dysgraphia is a term used by some people for writing difficulties including difficulties with handwriting and fine motor skills - for example holding a pencil with sufficient control, forming letters and shapes, or spacing of words when writing.

Dyscalculia is a term used by some people to describe difficulties with learning number related concepts or using the symbols and functions to perform maths calculations. Problems can include difficulties with number sense, telling the time, memorising number patterns, calculations and maths reasoning. Whilst 25% of the population may have maths difficulties, only around 6% may have dyscalculia.



Within the UK, most neurodiverse conditions have agreed medical diagnostic criteria (e.g., ASD, ADHD, Dyspraxia, Tourette's); Dyslexia, Dysgraphia and Dyscalculia are educational diagnoses which means that these terms are not used by some organisations, but they are types of neurodiversity. A thorough assessment as part of the assess, plan , do, review cycle (https://www.pinpoint-cambs.org.uk/information-hub/education_school/sen-support-ehcps/), is very important to ensure that a child's needs are fully met through future teaching and the support the child gets, without needing a diagnosis!

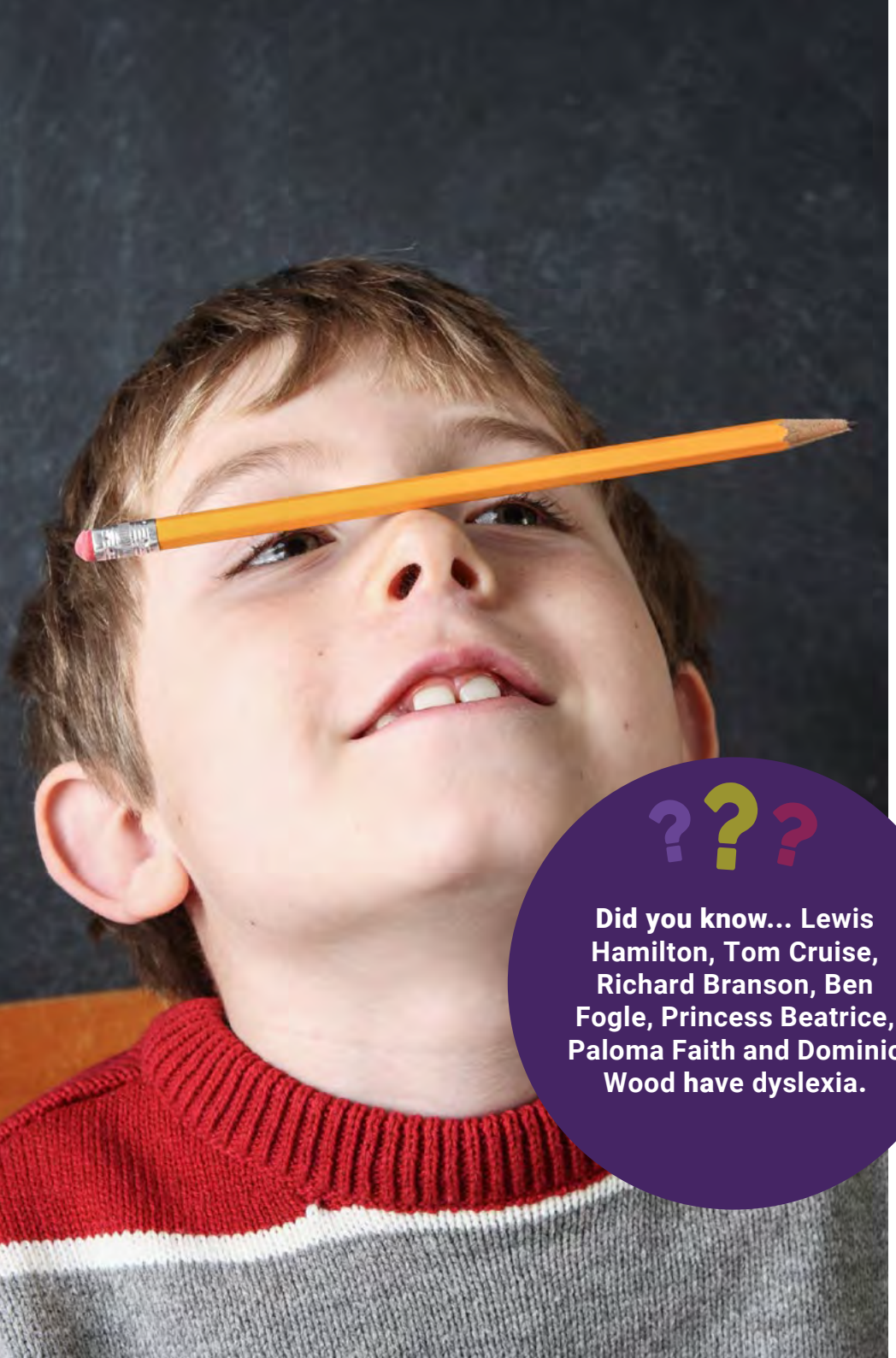
Assessments need to include recognising and celebrating a child's strengths as well as their difficulties to maintain their self-esteem and achieve their potential.

Cambridgeshire County Council want all children to get the help that they need, based on their literacy and maths needs, regardless of whether or not they have particular patterns of difficulties or whether the parents have paid for a particular assessment. You should not need a diagnosis of dyslexia or dyscalculia to access this support.**https://www.cambslearntogether.co.uk/cambridgeshire-send/cambridgeshire-send-oap-toolkits/primary-and-secondary-send-oap-toolkit/parent-information**

However, it should be recognised that children and families may want a diagnosis. Currently these are only available by paying for a private assessment. Formal assessments may also form part of an Education Health Care assessment. **https://www.bdadyslexia.org.uk/services/assessments**

Pinpoint Cambridgeshire have a range of 'handy guides', written by parents for parents like this one on Dyslexia: **https://www.pinpoint-cambs.org.uk/wp-content/uploads/2020/12/Dyslexia-1.pdf**
One on Dyscalculia: **https://www.pinpoint-cambs.org.uk/wp-content/uploads/2020/12/Dyscalculia-1.pdf**

The NHS provides a link to the British Dyslexia Association www.nhs.uk/conditions/dyslexia



Did you know... Lewis Hamilton, Tom Cruise, Richard Branson, Ben Fogle, Princess Beatrice, Paloma Faith and Dominic Wood have dyslexia.

“A laptop helps me get down what I want to write.”

“I love colour, I need visual resources. I don’t want to be made to feel stupid though.”

Help at school

If you have concerns, talk to your child’s school about how they identify and meet literacy and maths needs. There are various assessments that schools can use to analyse a pupil’s literacy and maths difficulties in detail. The results should be used to decide if extra help is required to make progress, and if so, what type of help.

These strategies should be used as early as possible, to help any child or young person with literacy or maths difficulties.

Training and resources are available from the Local Authoritiy to help schools and support your child and may include access to a literacy programme.

What you can do to help your child

The approach for supporting literacy and learning difficulties in Cambridgeshire schools is support based on need, without the requirement for a diagnosis. Cambridgeshire expects schools to make this 'ordinarily available' to every child that needs it - will call this Ordinarily Available Provision' (OAP). It may be helpful for you to understand what is available so that you are empowered to discuss the help you child needs with teachers and

Cambridgeshire Learn Together (where you will find the 'Ordinarily Available Provision' resources)

Cambridgeshire has a website, Learn Together, that provides lots of practical advice and support about helping children with their reading, writing and maths. Whilst this is written for professionals, it can be useful for parent carers. Specific Learning Difficulties are under the cognition and learning section. **https://send.cambridgeshire.gov.uk/kb5/cambridgeshire/directory/site.page?id=hP0gBxV7gM8**

Cambridgeshire Dyslexia Guidance

The Cambridgeshire Dyslexia Guidance has been co-produced with parents and carers of children with dyslexia, young people with dyslexia and professionals working in the field of dyslexia. **https://www.cambridgeshire.gov.uk/asset-library/imported-assets/CAMBRIDGESHIRE%20DYSLEXIA%20GUIDANCE%20FEBRUARY%202019.pdf**

Further information

- Cambugs 1, 2 and 3 (evidence-based app developed by Educational Psychologists, parents and Cambridge University): a fun way to teach children letter sounds, phonics and key words. You can watch a YouTube video on Cambugs letter sounds here **https://www.youtube.com/watch?v=zbltMVnEhWw**, and a video about Cambugs phonics here **https://www.youtube.com/watch?v=gLae3lJPXYY**
- **British Dyslexia Society - What is dyslexia?** - British Dyslexia Association **www.bdadyslexia.org.uk/dyslexia/about-dyslexia/what-is-dyslexia**
- Jobs for Dyslexics UK - Exceptional Individuals - **www.exceptionalindividuals.com/jobs-for-dyslexics/**
- What is Dyscalculia? - The British Dyslexia Association -**www.bdadyslexia.org.uk/dyscalculia**
- Dysgraphia - Psychology Today United Kingdom - **https://www.psychologytoday.com/gb/conditions/dysgraphia**

What is Dyspraxia?

Dyspraxia (sometimes known as developmental co-ordination disorder (DCD), affects physical co-ordination for both fine and gross motor skills.

This can make it hard to participate in everyday activities such as:

- Writing
- Self-care - getting dressed and toileting, tying shoelaces etc.
- Riding a bike, learning to drive and many elements of sport and play, and a child may appear clumsy.

Oral motor skills may be affected too which can affect eating, drinking and speech.

Not only is physical co-ordination affected, thought processes can be disorganised too and this can increase anxiety.

"Giving me time to think can help."

Hints and tips

- ✔ Talk to your school - strategies such as using a gym trail, wobble cushions, sensory breaks, using a laptop and pencil grips may help.
- ✔ Scooter boards and balance boards can help to teach a child to feel and understand their body movements and help spatial awareness.
- ✔ Sometimes just encouraging your child to slow down and think about what they are doing can help with their organisational skills.
- ✔ Chunky cutlery is easier to grip and control.
- ✔ Help strengthen hand dexterity by engaging in activities with play dough, rolling, cutting, slicing, picking up with a fork etc.

"Once my school understood I had dyspraxia, there were lots of things they could do to help me, like using a laptop in class."

???

Did you know... Daniel Radcliffe, actress/ model Cara Delevingne, singer Florence Welch (Florence & the Machine), photographer David Bailey and scientist/ presenter Maggie Aderin-Pocock are Dyspraxic.

Further information

- Cambridgeshire Community Health https://www.cambspborochildrenshealth.nhs.uk/services/cambridgeshire-childrens-occupational-therapy-service/online-learning-and-training/co-ordination-and-motor-skills/
- www.dyspraxiafoundation.org.uk

What is Tourette's Syndrome?

Tourette's Syndrome (TS) is when somebody makes movements and noises that they can't control. These noises and movements are called tics.

Tics are usually fast and happen again and again. Tics are preceeded by an internal sensation called a 'premonitory urge' that is typically reported as uncomfortable feeling (like an itch) that they need to get rid of, which is why they perform the tic (i.e. to relieve the uncomfortable sensation).

TS is a genetic condition, with onset typically at around 5 years of age but an increase in tics is often seen around the time of puberty. It is characterised by the presence of multiple motor tics and one or more vocal tic that are present for over a year. Some people only have motor tics and others only have vocal tics, these are referred to as Persistent (or Chronic) tic disorders. For people with tics that present for less than one year, this is referred to as Transient tic disorder.

A diagnosis of TS does not reference severity so some people may have just a few tics which do not interfere with daily life, whereas for others, tics can be more frequent and complex so it can have more of a significant impact.

Contrary to popular opinion, **only about 5-10% of people with TS have vocal tics which involve swear words** and these can be managed using therapies in the same way as other vocal tics.

Tics will naturally 'wax and wane', with periods where people will have more or less tics, with no apparent pattern to this increase/decrease in tic frequency. However, tics are also related to emotional expression and may be more evident at times of high emotion, anxiety, stress or tiredness – so there may be good days and bad days. Tics can be made worse when stressed, nervous, excited or anxious, so young people may find that they tic more than usual in these situations, such as standing up in front of people to give a talk, getting in from school, at Christmas or when going on holiday.

Some people can learn to control or suppress the tics, for example, in a social situation. For some people this may happen automatically and they may not realise they are controlling their tics, whilst for others it can be effortful and may be exhausting. In the majority of cases, the tics will improve and may go away completely by late adolescence/early adulthood. This is thought to reflect changes in the brain and ongoing development of inhibition networks.

TS is often associated with other neurodiverse conditions (co-morbidities) such as ADHD, anxiety, especially social anxiety, Obsessive Compulsive Disorder (OCD) and specific learning difficulties. It is often most helpful to support children and young people with tics in managing co-morbidities, as this can have a positive impact on the tics.

Getting a diagnosis for TS

The first step is to visit your GP who will ask about the tics, how often they occur and what kind of things your child does. They will then refer to a specialist who will ask you and your child lots of questions and base their decision on meeting your child. There are no medical tests like blood tests or scans to work out if you have TS.

Learning about tics and identifying how best to support your child will be the first treatment approach and behavioural therapies may be recommended.

There are two evidence-based therapies for tics, which are Habit Reversal Therapy and Exposure and Response Prevention.

Both therapies help your child to recognise premonitory urges and learn how to react differently to the signals, for example, if the brain sends a signal to the hand to punch the leg, then learning to recognise that signal and instead of punching the leg your child can learn how to resist the urge and just make a fist with the hand and clench the arm instead. This can be helpful if your child has tics that are interfering with daily life, causing harm to themself, or that may be socially embarrassing (e.g. shouting out).

For some children, medication may be suggested to manage TS and your doctor will discuss with you and your child if they think this may be helpful. You should talk to your doctor about all the options available for treating TS.

Hints and tips

- Be understanding – tics are involuntary and can't be controlled.
- Be sensitive that the person with tics may feel self-conscious or embarrassed.
- Practice mindfulness and breathing exercises to help to relax.
- Physical activity and intense concentration can help to lessen tics - encourage those activities.

Further information

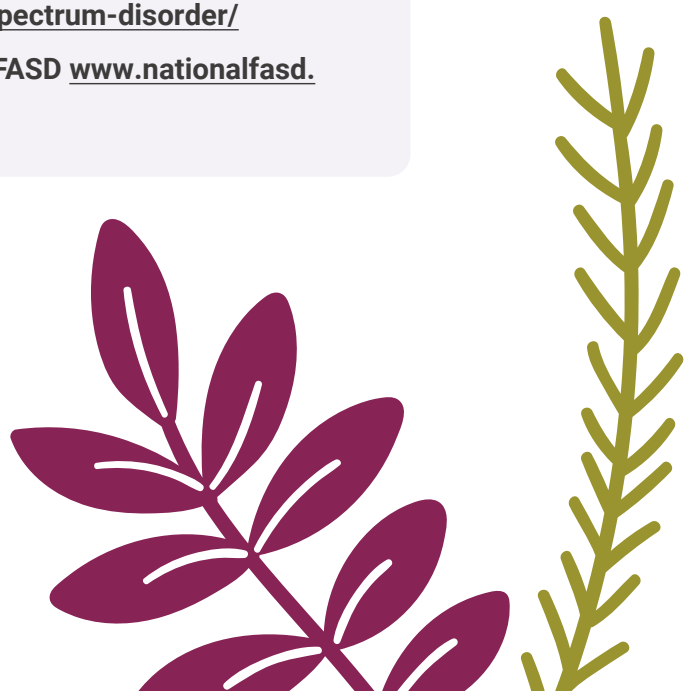
- www.nhs.uk/conditions/tourettes-syndrome
- www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/tourette-syndrome
- www.tourettes-action.org.uk
- www.tourettes-action.org.uk/storage/downloads/1487860486_TS--the-simple-truth---A-guide-to-TS-for-children-and-young-people.pdf

What is Foetal Alcohol Spectrum Disorder (FASD)

Little is known about the effects of alcohol in pregnancy, but research and awareness are increasing, which are helping to provide early support for children and help for affected parents in a non-judgemental way. We have a local group that can offer support to families: https://www.facebook.com/groups/1320037864718272

Further information

- www.nhs.uk/conditions/foetal-alcohol-spectrum-disorder/
- National FASD www.nationalfasd.org.uk



"What's interesting is that my child has so many diagnoses, yet a consultant thought that was preferable to giving the diagnosis of FASD. They experience difficulties in many areas and have deteriorated throughout their school life. I wonder whether it would have been worth having the more accurate label so that others could understand all the problems together? Currently, we feel like we're being pushed around many services where everyone focuses on only one aspect, then when they don't fit those criteria exactly, we're moved on. I just want someone to see my child as I do - a complete, lovely person!"

What is Obsessive Compulsive Disorder (OCD)?

OCD can be a debilitating condition and is often misunderstood; so much so that many people hide it for many years. The good news is that OCD is a treatable condition, with both therapy or medication available that can help with management and recovery. Children and adults with OCD experience intensely negative, repetitive, and intrusive thoughts, combined with a chronic feeling of doubt or danger (obsessions).

Common OCD themes include fear of germs, harm, symmetry, sexual thoughts, violence and thoughts of harm to self and others. These thoughts are known as 'ego dystonic' as they are completely against the suffers values and feel 'wrong' to them.To suppress the thought or lessen the anxiety, they will often repeat an action, again and again (compulsions).

1 Obsessive thoughts

These are thoughts, ideas and intrusions which occur repeatedly. These thoughts are likely to be unwelcome and frightening and they can make people feel scared, anxious, and out of control.

There are two aspects to OCD

2 Compulsive actions

These are activities which are repeated to try and take control over a situation to reduce the anxiety caused by obsessive thoughts. These can include:

- Physical actions such as washing hands
- Checking things, for example that doors are locked, or plugs switched off
- Repeating sequences in your mind – words, or numbers
- Constantly asking for reassurance

The main treatment is cognitive behavioral therapy (CBT). If this does not help, medication may be offered or a combination of both.

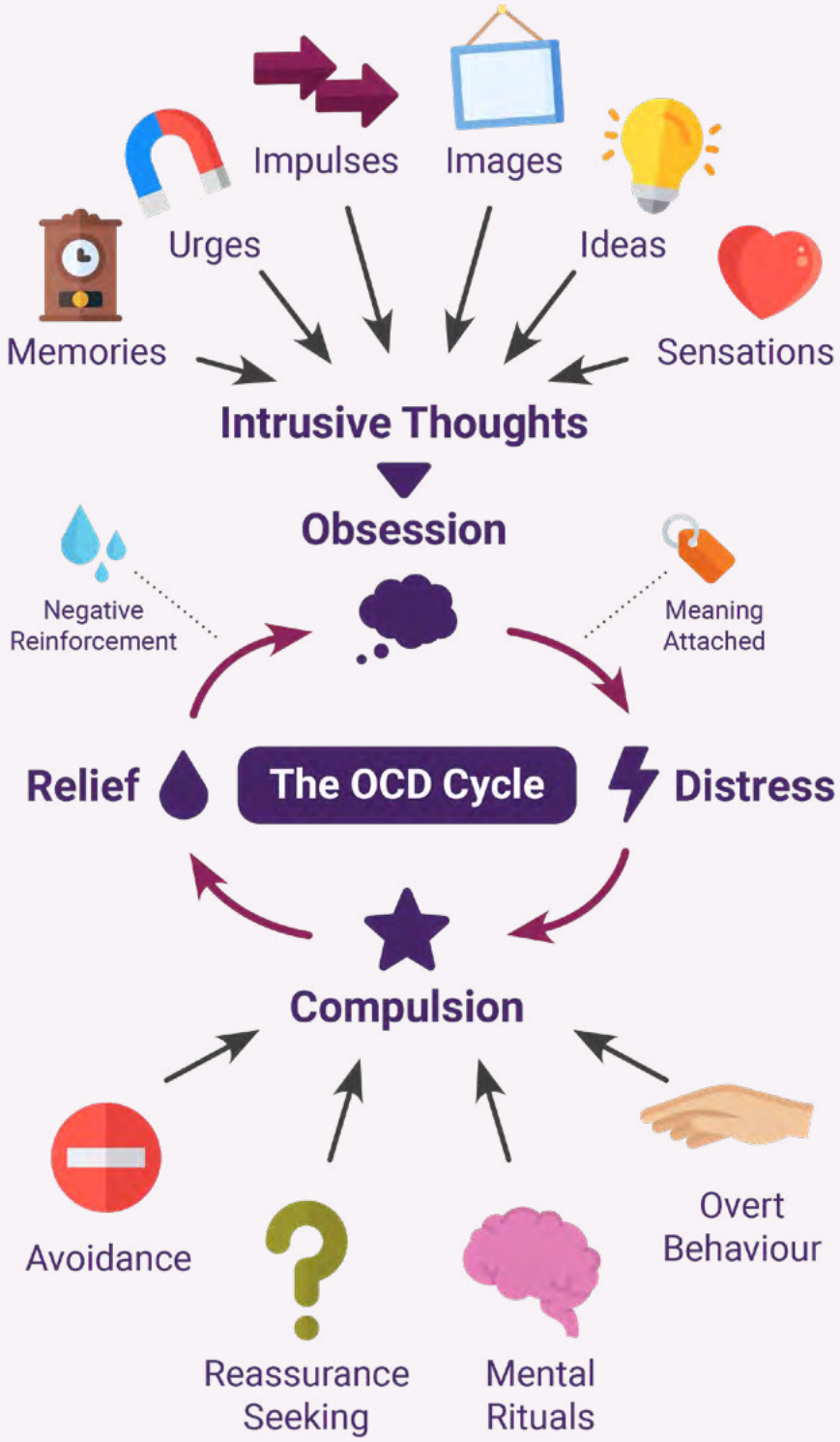
One of the greatest challenges if you have OCD, is to debunk the widely held belief that OCD is a mild or even “quirky” problem that is nothing more than hand washing. People might use the phrase “a bit OCD” without understanding what it really means.

There are also positives! People with OCD can have incredible attention to detail, and many are creative. By understanding the way they deal with their own difficulties, people with OCD often can be understanding of others who are dealing with things that they can’t control.

Further information

- www.nice.org.uk/guidance/CG31/chapter/1-Guidance#steps-35-treatment-options-for-people-with-ocd-or-bddP
- www.youngminds.org.uk
- www.mind.org.uk
- www.nhs.uk/mental-health/
- www.ocdaction.org.uk

Did you know... Leonardo Di Caprio, Charlize Theron and David Beckham have OCD?



Co-Occurring Conditions (Comorbidities)

'Co-morbid' is a scary word but it just means other conditions that are likely to exist along with the main diagnosis, or biggest area of need. These can be other neurodiverse conditions: for example, people with ADHD may also be dyslexic or have dysgraphia. People can also have medical conditions alongside neurodiverse conditions.

This list is not exhaustive, but some examples are:

- **Learning disabilities and learning difficulties** – which affect the way that a person learns new things, and they may have difficulty understanding complex information, or coping independently.
- **Hypermobility** - very flexible joints which may cause you pain. **https://www.hypermobility.org/**
- **Ehlers-Danlos syndromes (EDS)** are a group of rare inherited conditions that affect connective tissue. Connective tissue provides support in skin, tendons, ligaments, blood vessels, internal organs and bones. **www.ehlers-danlos.com/eds-types**
- **Scoliosis** - curvature of the spine which may result in back pain. **www.sauk.org.uk**
- **Irritable Bowel Syndrome (IBS)** - chronic tummy pain, cramps and diarrhoea. **www.nhs.uk/conditions/irritable-bowel-syndrome-ibs/further-help-and-support/**
- **Epilepsy** - a neurological disorder which can cause seizures or unusual sensations. **https://epilepsysociety.org.uk/**
- **Fragile X** – a genetic condition with traits including learning disabilities and some pronounced physical features. Some autistic children will be tested for Fragile X. **www.fragilex.org.uk/**
- **Prosopagnosia (Face blindness)** – people with this have great difficulty recognising faces that they have seen before, even many times, especially if they are not in their usual context i.e. you see a teacher at the shops. **www.faceblind.org**
- **Auditory Processing Disorder (APD)** – Anyone with this problem does not actually have an issue with their actual hearing, but rather the brain's ability to process and interpret the signals it is receiving from the ear. This can result in a delay in processing what someone is saying to you, difficulties in differentiating between similar sounding words and being unable to filter out background noise. **www.additudemag.com/what-is-auditory-processing-disorder**

Section 2

Early Intervention and Diagnosis Process

Pre-diagnosis - first steps

If you have any concerns about your child or young person then trust your instincts. You know them better than anyone else and are their greatest advocate.

You may have a sense that some of your child's reactions seem to be extreme or excessive, or don't follow similar development patterns of other children their age. Sometimes you might have support from those around you, but for some it can feel that staff at school/ pre-school, family members and friends may see things differently and dismiss your concerns or seem to be judgmental. If this happens, talk to another professional such as your GP, health visitor or a trusted member of staff from school/pre-school.

Not all families will want to seek a diagnosis and that is ok, it is an individual family choice.

Sometimes it can be that you are not the first to notice differences. Some parents will naturally make adjustments to their own communication and interaction with their child to compensate, without realising, especially if there is no sibling for comparison. If your child's difficulties are pointed out by other family members or staff at pre-school/school in the first instance it is not your fault for not seeing it.

For younger children, sometimes the first difference you or others become aware of is their delayed communication. You may be referred to Speech and Language Services.

"Originally, I didn't want to label my child as autistic because I was worried about what people would think. Now my child has been diagnosed, I am so glad that we did because it has really helped me to understand him."

"I felt no one understood my child. I didnt understand why my child was getting upset."

Recognising that you need help

When you realise that your child needs support, the first step is usually to speak to your GP, health visitor, teacher or special needs co-ordinator (Senco) at school. It can also help to increase your own understanding by reading books, looking at information available online (but make sure that it is a reputable site as there is lots of misinformation online), or talking to other parents in a similar situation. Pinpoint offers free information sessions and parent to parent support . If you don't know anyone, there are many support groups right across Cambridgeshire– check out the Council's 'Local Offer' which provides information for families of children with special educational needs and disabilities. You can also search on social media for terms like 'SEND', 'Autism', 'ADHD' etc., as well as Cambridgeshire/your town/geographical area to find details of local online groups. It can be a great relief to find other people dealing with the same emotions and challenges. It's important to note that you don't need a diagnosis to access help.

Further information

- **Cambridgeshire Local Offer SEND Information Hub offer: https://send.cambridgeshire.gov.uk/kb5/cambridgeshire/directory/home.page**

- **Pinpoint:https://www.pinpoint-cambs.org.uk/**
- **Cambridgeshire Early Help: www.cambridgeshire.gov.uk/residents/children-and-families/parenting-and-family-support/accessing-support-for-your-family**

"This doesn't mean your child is broken, just that their brain works differently. Give your child the tools to operate in a neurotypical world on their terms, without dimming who they are."

"Some days I wondered whether I was imagining her difficulties but when I started to keep a note of things that happened on difficult days a pattern started to emerge and it helped me understand the things that triggered her behaviour."

Keeping a record

It will help the medical professionals to understand your child if you keep a chronological record of behaviours that you find unusual or concerning, including dates and places. Also include any comments made by professionals, other family members, child-minders, former or present teachers, or friends as this helps to validate your concerns. These examples may include distressed behaviour, anxiety, sensory difficulties, unusual speech patterns, interactions with other children, or executive functioning issues.

“Try to detect when your child reacts poorly to certain smells, sounds or other sensory stimuli. Sometimes they don’t even realise what has triggered them. Sometimes it feels weird for them to say when a sensory thing is bothering them due to the public need to mask and not “act autistic”.”

Many neurodiverse children can have good days and bad days – it is helpful to understand the factors that lead to distressed behaviour and to have those examples to hand when you are talking to professionals.

GPs and health visitors do not have the expertise to diagnose neurodiverse conditions but most do have a lot of experience of them and can refer your child to a paediatrician or other clinician who is qualified to undertake an assessment. They can also provide details of other services that may help. You can ask them to include your observations when they make the referral, which will give the professional making the assessment an opportunity to read the information before your appointment.

As part of the health visitor contacts, you and your child will be invited to attend an Under 1 Year and a 2-3 Year Review. These reviews provide an opportunity for practitioners to assess the strengths and needs of your child and your family and to plan further care. During each review the practitioner will explain their role and what the review will entail and go through the Ages and Stages Parental Questionnaire with you and discuss any concerns you may have regarding your child's development. Following on from that, practitioners can provide further support, signpost to groups and other agencies and make referrals to other professionals such as a paediatrician if needed.

If the difficulties aren't immediately obvious, (which often they are not!), sometimes the GP or Health visitor may ask you to undertake further observations or may ask you to return to them in six months if you still have concerns.

Your GP may also refer you to a parenting course. This does not mean that you are a bad parent, it is simply to share different parenting techniques which may help your neurodiverse child.

Parent top tip

- Buy a big folder and start keeping a copy of everything, literally everything, to build a complete picture of your child. My son bit a child at school, and the teacher spoke to me on the school gate, at the time I was upset and couldn't really focus on what they were saying so I asked them to confirm in writing and this was actually really useful information when I spoke to my GP about my son's difficulties.

What if my GP does not refer my child?

If your child is not referred for a further assessment, ask for the reason why. If you don't agree with their decision, you can ask for a second opinion. Meanwhile, continue to add to your log of evidence.

"A friend recommended that I read Tony Attwood's book about Asperger's and I couldn't put it down. It was as though he was writing all about my son – everything started to make sense."

Overview of the diagnostic process and what to expect

The process, and amount of time that you need to wait to see a paediatrician, or diagnosing clinician varies depending where in Cambridgeshire you live.

The NHS guidance from the National Institute for Health and Care Excellence is currently being reviewed. You can view updates online at: **www.nice.org.uk/Guidance/CG128**.

The current recommended timescale from referral to appointment is 18 weeks although these timescales are often exceeded.

You can request an alternative provider to carry out the assessment (especially if you find an alternative with a shorter waiting list) and these rights are outlined in the nhs patient choice leaflet (**www.nhs.uk/NHSEngland/patient-choice/Documents/patient-choice-leaflet.pdf**) with more detailed information available here **www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs.** We suggest that you check with other families and your local support group to hear their recommendations.

What can I do whilst I am waiting?

Just because you are waiting for an assessment and your child does not have a diagnosis, it does not mean that you need to wait to access support. Many services, charities and support groups will be happy to help without a formal diagnosis. A diagnosis is not required to access support for your child at school or pre-school so you should talk to them to ask what they can do to help.

Look through the information in this guide to find information that may help you now and look for accessible talks and webinars that are available from local practitioners.

I've got an appointment, what can I expect to happen?

The diagnosing clinician may be a paediatrician, psychiatrist and speech and language therapist. Specialist nurses and occupational therapists may also provide input. Usually, the appointment is with one professional but sometimes there may be more than one person in attendance and this can be called a Multi-Disciplinary Team Meeting (MDT)

They may have received your observations with the referral but will also ask you to tell them about your concerns, so it useful to keep your own copy that you can refer to.

They may talk to your child and try to engage them in conversation or get them to participate in some simple games or activities to observe their responses. They will also consider reports and observations from school or other education settings.

Top tips

- Make sure you bring your list of the signs you see (chronological diary).
- Bring a pen and paper with you so you can take notes.
- Consider bringing your partner/a friend/family member – there's a lot to take in at these meetings so it helps to have an extra set of ears and some moral support.
- Take a drink and snack for your child as well as a favourite toy for whilst they are waiting.

Various diagnostic tools are used, depending on the specific condition, where you live and which specialist you see. The most commonly used are:

Autism Diagnosis

Autism Diagnostic Observation Schedule (ADOS)

The majority of NHS and private providers undertake initial assessments and then use an ADOS which is an observational tool used to assess children for ASD. It includes a variety of activities such as puzzles, books, role play, which may differ depending upon the age of the child. Most children enjoy these activities and don't find the assessment stressful.

- The ADOS assessment will be considered alongside a developmental history and general observations and is not a stand-alone tool. **www.nice.org.uk/guidance/cg128**
- The assessment usually takes 60-90 minutes. Parents of younger children are usually invited to stay for the duration of the assessment. Parents may be asked to leave the room for some of the assessment if the clinician feels this is appropriate.
- After the assessment, you will often receive a decision about a diagnosis straight away. A report is then produced which is usually shared with parents/carers at a follow-up appointment within 8 weeks of the assessment.

Brief Observation of Symptoms of Autism (BOSA)

The BOSA diagnostic assessment for autism was introduced in some areas when ADOS assessments could not be undertaken because of Covid-19. The assessments have been well received by families and clinicians, so are likely to continue.

Other diagnostic tools and evidence, in addition to BOSA are used in order to get the relevant information and compare with a standardised diagnostic criterion.

Overview of the BOSA assessment

- There are opportunities for a parent to engage in social interactions and activities with their child through games and conversation, creating an environment in which symptoms of autism can be observed by the clinician.
- To ensure that the assessment runs smoothly, the clinician will provide clear instructions in advance so parents can be well prepared. They will also be able to support parents with what to do during the assessment if needed.
- In most cases, there will be a screen in the room which will be blank so that the child is not aware they are being watched. Sometimes the observation could be from the next room with an observation window or in the room with observers wearing PPE and being socially distanced.
- The observation is planned to last 12 to 14 minutes – but often takes longer.
- The parent and child then leave the room and the professionals all discuss what has been observed. They also look at the history and any information from school, parents and other professionals. Then the parent is called in and a diagnosis is given if appropriate. Parents can ask for their child to be told but it is up to the parent if they want this to happen.
- The team involved in observing the BOSA are all ADOS trained and have experience in the ADOS assessment process.
- BOSA has been well received by families - children are calmer as their parents are there with them and it feels like they are just playing some games and chatting. Parents feel more involved and can better understand what is happening.

In the event that the BOSA observation did not provide evidence of the presence of autism, additional evidence should be sought through alternative methods (e.g. Autism Diagnostic Interview-Revised parent report) before it is concluded that it doesn't exist.

Developmental, Dimensional and Diagnostic Interview (3Di)

The clinician undertakes a 3Di interview to assess a person for autism; asking parents/carers multiple choice questions, although comments can be added. It covers areas such as:

- Family history and background
- Behaviour
- Eating habits
- Sleeping habits
- Communication
- Social interaction

The ADI-R (Autism Diagnostic Interview - Revised)

The clinician undertaking this assessment interviews the parent or carer who is familiar with the developmental history and current behaviour of the person being assessed.

The questions focus on behaviour in 3 areas:

1. **social interaction;**
2. **communication and language; and**
3. **restricted and repetitive, stereotyped interests and behaviours.**

It can be used with adults and children from the age of two.

As well as being used to give a formal diagnosis, the findings can be helpful to suggest appropriate support.

Other tools for autism diagnosis are available such as the DISCO assessment for autism - DISCO (**https://www.autism.org.uk/what-we-do/diagnosticservices/disco**), The use of a particular assessment tool often depends on which diagnostic tool the clinician is trained in - all are equally valid.

'The interview was very thorough and took over 2 hours. I was asked about my son's behaviour as a baby and toddler – he was 13 when the assessment took place so it was a lot to remember! We found it useful to look at old photos and videos, and to talk to family and friends before the interview to discuss any unusual behaviours.'

ADHD Diagnosis

Diagnosing ADHD in children depends on a set of strict criteria. To be diagnosed with ADHD, your child must have 6 or more symptoms of inattentiveness, or 6 or more symptoms of hyperactivity and impulsiveness.

To be diagnosed with ADHD, your child must have:

- been displaying symptoms continuously for a minimum of 6 months
- shown symptoms of ADHD before the age of 12
- Display symptoms in at least 2 different settings – for example, at home and at school
- symptoms that make their lives considerably more difficult on a social or educational level

The specialist can make an accurate diagnosis after a detailed assessment. The assessment may include:

- a physical examination, which can help rule out other possible causes for the symptoms;
- a Qb test
- a series of interviews with you or your child and the completion of a Conners Questionnaire (for ages 6 and over);
- reports from other significant people, such as teachers. Your child's school will usually be sent a Conners Questionnaire to fill in too.

What is a QbTest?

A Qb Test is a computer-based test which measures attention, ability to concentrate, impulsivity and motor activity, to assess for ADHD.

The test results are analysed straight away and presented in a report that compares the young person's results with a group of people of the same age and gender who do not have ADHD.

The Qb test is not a stand-alone test and does not replace clinical judgement but will be used alongside other assessment tools detailed above.

The test:

1. Provides unbiased information
2. Standardises decisions
3. Reduces appointment times and delays in the diagnostic process
4. Can monitor how your child responds to treatment.
5. Is improving confidence in diagnosing or excluding ADHD.

The test is performed on a computer and takes 15 or 20 minutes. The test equipment consists of an infra-red camera, a head band with a reflective marker and a response button. During the test a number of symbols are shown on the computer screen and the task is to push the button when a certain symbol appears on the screen. The test is easy to perform and your child will receive instructions during the appointment.

Further information

- What is the Conners rating scale for ADHD? (**www.healthline.com/health/adhd/conners-scale#Short-and-Long-Versions**).
- For more information about the Qb test visit **www.qbtech.com**

Dyspraxia (Developmental Coordination Disorder)

The diagnosis of DCD is usually made by a paediatrician and/or occupational therapist.

Standardised assessments such as Motor Assessment Battery for Children (M-ABC) and the Beery Buktenica Development Test of Visual-Motor Integretion (Beery VMI) ABC Assessment are usually used to ascertain whether a child has DCD. It involves:

- gross motor skills tests – which measure the ability to use large muscles to walk, jump, catch/throw a ball and balance;
- fine motor skills – which measure the ability to use small muscles for accurate co-ordinated movements, such as drawing, writing and placing small pegs in holes;
- In older children they may also test to see if the child can produce significantly more work using a laptop than when writing.

Your child's performance in the assessment is scored and compared with the normal range of scores for a child of their age. The assessment may also involve discussions of family health history and any particular difficulties the child is experiencing in day-to-day life.

Once the diagnosis is confirmed, the paediatrician/OT involved will produce a report detailing the particular issues affecting your child and will suggest tools and exercises to help your child improve their fine/gross motor skills.

What next?

What to do if your child does not receive a diagnosis

You might be relieved to hear that the specialist does not consider your child's differences significant enough that a formal diagnosis is required. As with all spectrum conditions, many children with some neurodiverse traits can manage their differences very well. However, if you were concerned enough to make a referral, you may still have questions.

"We were referred to the paediatrician by my son's infant school. Looking back, we didn't really know anything about autism, other than Rainman and the other stereotypical idea of autism (which we now realise is hugely inaccurate). We didn't believe our son was autistic, he made eye contact with us, we communicated well with each other and didn't think his behaviour was particularly odd. We should have researched it, but just totally rejected the idea and carried on parenting. A couple of years later my friend was getting her daughter assessed for autism and I read a few articles she had shared about it. There were lots of traits mentioned that I didn't even realise were signs of autism and the more I read, the more I realised that my son is autistic and so am I."

As a first step, you might find the information in this support pack will give you enough knowledge to be able to help your child and suggest things that will help at school/pre-school. You can also discuss with your Health Visitor, School Nurse, School Senco or Therapist. A lack of diagnosis should not mean that your child's needs, whatever they may be, are not supported by their school or setting.

Sometimes difficulties can become more evident as children get older, especially for children with what used to be called Asperger's or High Functioning Autism* who learn to mask their differences. In these cases, continue to keep evidence and if you believe it is needed, return to your GP to ask for a re-referral for a second opinion and this may be outside of the geographical area. Or call **Contact - for families with disabled children** **www.contact.org.uk** who may be able to give you advice about your options, including private assessments.

You can access all of Pinpoint's help and support free and without a diagnosis: **www.pinpoint-cambs.org.uk**

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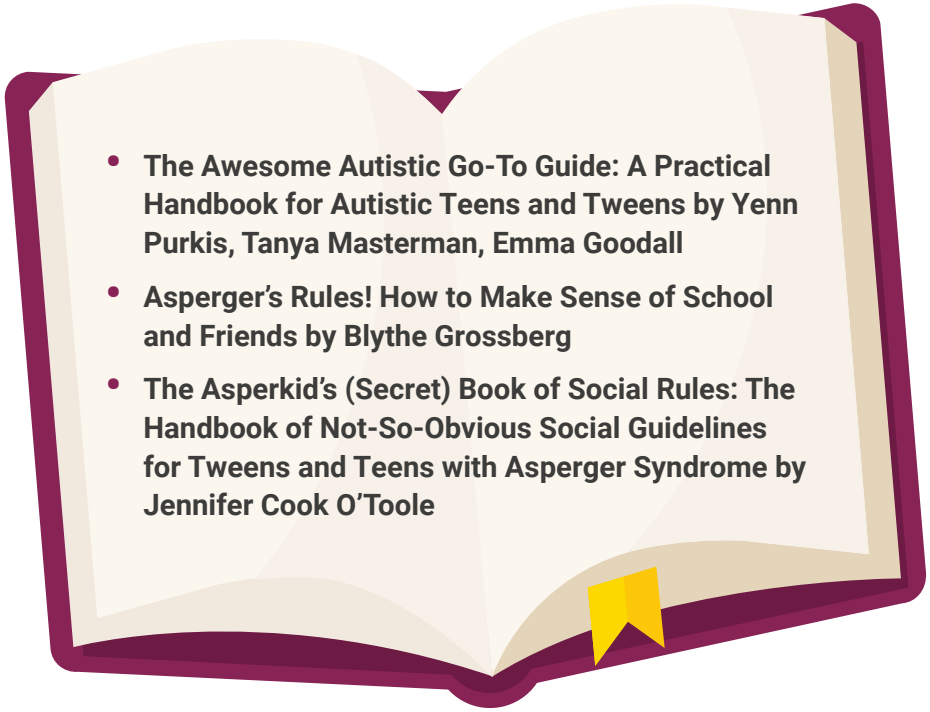
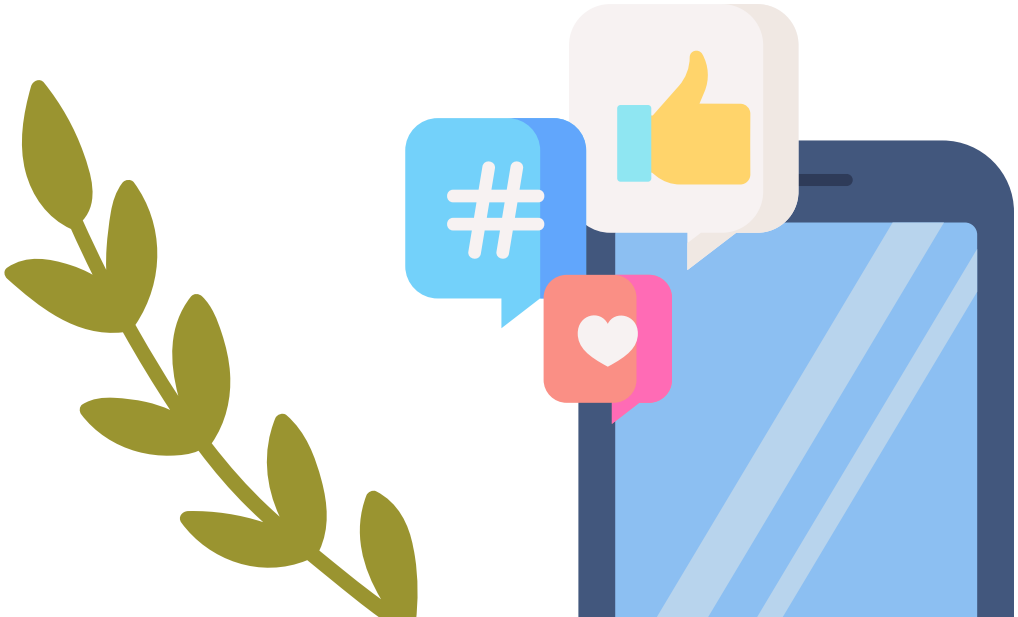
* Asperger's and high/low functioning labels are no longer used, and where appropriate, a diagnosis of Autism Spectrum Condition (ASC) will be given. However, it can be useful to access resources using these terms, although the terminology has now been superceded.

Books for Tweens/Teens to Read Themselves



- **The Awesome Autistic Go-To Guide: A Practical Handbook for Autistic Teens and Tweens by Yenn Purkis, Tanya Masterman, Emma Goodall**
- **Asperger's Rules! How to Make Sense of School and Friends by Blythe Grossberg**
- **The Asperkid's (Secret) Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome by Jennifer Cook O'Toole**



Neurodivergent Social Media - please note some of these may not be suitable for under 15's

(there is a more comprehensive list in the **Useful Information Section** at the end of this pack)

- **Emily@21andsensory** (**www.21andsensory.wordpress.com**) – autistic blogger/graphic designer who also has sensory processing disorder
- **Dean Beadle** (**www.facebook.com/dean.beadlespeaker**) - Autism Advocate, highly entertaining public speaker, LGBTQIA+, singer, Dr Who fan.
- **Rene Brooks** (**www.blackgirllostkeys.com/rene-brooks/**) – ADHD Blogger and Advocate
- **Lauren Melissa** (**www.instagram.com/autienelle/**) - Lauren chronicles her life as a woman on the autism spectrum, on Instagram, providing #Autietips along the way.
- **Paige Layle** (**www.instagram.com/paigelayle/**) – an autistic advocate who posts on Tik Tok and Instagram. Layle offers a lot of insight into neurodiversity and can help anyone gain more awareness of the misconceptions they might have about the autism spectrum.

16 and Beyond

Your child's school should begin helping them with careers advice from Year 8 onwards and for those with an EHCP from Year 9 onwards their annual reviews should include plans for transitioning to adulthood.

In the SEND Code of Practice, it states that support should continue after the age of 16 for those with an EHCP and this continues until they are 25, provided they stay within education/ training (this does not include higher education – so if they go to university from 18 their EHCP will end).

If your child has never had an EHCP but you think that they may now need one to provide extra support into adulthood, you (or your child) can ask the LA for an EHCP Needs Assessment.

What help is available?

If your child has an EHCP, in Year 9 a Preparing for Adulthood Advisor will contact your child and may attend their Annual Review meeting. They will assist your child by providing up to date information about:

Living independently

Contributing to society and the local community

Higher education

Friendships and social life

Employment

Physical and Mental Health inc. diet and exercise

Further information

- Pinpoint has a section on Preparing for Adulthood https://www.pinpoint-cambs.org.uk/information-hub/preparing-for-adulthood/

- NCS National Citizens Service https://www.cambridgeshire.gov.uk/council/communities/communities-service/national-citizen-service-ncs

Further information

- www.contact.org.uk/help-for-families/information-advice-services/education-learning/education-beyond-16/
- www.nationalcareers.service.gov.uk

Cambridgeshire's PfA Booklets for Parent Carers
www.cambridgeshire.gov.uk/asset-library/Preparation-for-Adulthood-Parents-Guide-February-2022.pdf

https://www.cambridgeshire.gov.uk/asset-library/Moving-On-Booklet.pdf

Considering University? – Bukky's story

Bukky Owoaje is an incredible young man who was diagnosed with Kabuki when he was a baby and dyslexia/dyspraxia in his teens.

After having difficulties at school, he successfully managed the move to university and has shared his story along the way.

Check out his blog at: **www.lifeentertainment1993.wordpress.com**

Bukky's learnings

1. Normal stands for 'Nothing Original Round My Actual Life':

N Nothing

O Original

R Round

M My

A Actual

L Life

It's my description of normal for people who have been considered not 'normal'.

2. Uni was incredible it's like a roller coaster of emotions - you meet new people, you learn new things and you find out more about yourself.

3. I found out I had dyspraxia and dyslexia in my first year at uni for which I received a massive amount of learning support from my student wellbeing officer.

4. I would tell myself it's ok to stand out from the crowd and be not the same as everyone else and I should just be me and not someone I shouldn't be. People would love me for me and others who don't that's life.

5. I struggled massively when I was at school but when I left school and got into college and uni I found out what I was good at and it's the case for many.

6. If you are struggling at uni with your mental health, the best thing to do is to talk to people - a friend, the wellbeing team, a mentor, family, halls staff or a lecturer. I learnt if I keep all my struggles to myself it wouldn't go away.

The support I got from uni was :

- Mentor,
- Notetaker,
- One to one support worker.

Further information

- Bukky's story: **www.kabukiuk.org.uk/bukky**

Huge thanks to Bukky for sharing his experiences with us.

Section 10

Useful information

The ‘Local Offer’ contains information relating to SEND services from your local authority

Cambridgeshire County Council is our Local Authority. Each Local Authority must have a 'Local Offer' for children with SEND. In Cambridgeshire this is being re branded under the title the Cambridgeshire SEND Information Hub

https://send.cambridgeshire.gov.uk/kb5/cambridgeshire/directory/advice.page?id=bPe2xezmLJc

Special Education Needs and Disabilities Information and Support Service (SENDIASS)

Provides free confidential and independent advice on all things SENDSEND Information, Advice and Support (SENDIASS)

Cambridgeshire County Council, ALC2630, New Shire Hall, Emery Crescent, Enterprise Campus, Alconbury Weald, Huntingdon, PE28 4YE

https://info.cambridgeshire.gov.uk/kb5/cambridgeshire/directory/site.page?id=MR9QIFVa_9Q

Email - sendiass@cambridgeshire.gov.uk

Confidential helpline open during term times: 0300 365 1020

Outside of term time please leave a message as a small number of staff are available to answer queries but it will take time for them to respond to your enquiry.

All areas

- IPSEA – Independent Provider of Special Education Advice **https://www.ipsea.org.uk**
- SOS SEN **https://www.sossen.org.uk**
- Contact A Family **www. contact.org.uk/**

SEND Children (see also the Local Offer – links above)

- Cambridgeshire's Short Breaks Offer **https://send.cambridgeshire.gov.uk/kb5/cambridgeshire/directory/site.page?id=e1fmGm1lH3g**
- Pinpoint's Information Section on Everyday Living **www.pinpoint-cambs.org.uk/information-hub/everyday-living/**
- Cambridgeshire Special Needs Community Informtion (SCIP) **www.cambridgeshire-self.achieveservice.com/service/SCIP**
- **Max Card in Cambridgeshire** **www.spectrum.org.uk/max-card/**

Educational Psychology Services

- Educational Psychology Service **www.cambridgeshire.gov.uk/residents/children-and-families/local-offer/local-offer-identifying-special-educational-needs-and-disabilities-0-25/send-service-0-25**

Elective Home Education

- **www.cambridgeshire.gov.uk/residents/children-and-families/schools-learning/education-your-rights-and-responsibilities/elective-home-education-ehe**

Children's Learning Disability Service (EPUT)

- **www.cambridgeshire.gov.uk/residents/children-and-families/children-s-social-care/disability-social-care-0-25**
  Disabled Children's Referral & Access Team
  01480 372767
  DisabledChildrenReferral&AccessTeam@cambridgeshire.gov.uk

Children's Mental Health Services

- Cambridgeshire Children's Mental Health Service: **www.cpft.nhs.uk/service-detail/service/child-and-adolescent-mental-health-services-camhs-63/**
- Keep Your Head **www.keep-your-head.com/**
- Kooth **www.kooth.com**
- Centre 33 **www.centre33.org.uk/**
- Pinpoint **www.pinpoint-cambs.org.uk/information-hub/health-and-mental-health/mental-health-and-wellbeing/**

Occupational Therapy Services

- Cambridgeshire Children's Occupational Health
  www.cambscommunityservices.nhs.uk/cambridgeshire-children's-occupational-therapy
  Families and professionals can continue to access up to date advice, support and services by calling us Monday to Friday 9am - 5pm via:
  0300 029 50 50

- TEC Technology Enabled Care Team
  https://www.cambridgeshire.gov.uk/residents/adults/staying-independent/equipment-and-technology/technology-enabled-care

  Phone: 01480 378 160 (9am to 5pm, Monday to Friday, answerphone when staff are not available).
  Email: TECS@cambridgeshire.gov.uk

Preparing for Adulthood

Cambridgeshire's Local Offer
www.cambridgeshire.gov.uk/residents/children-and-families/local-offer/local-offer-preparing-for-adulthood-14-25

Pinpoint Preparing for Adulthood
https://www.pinpoint-cambs.org.uk/information-hub/preparing-for-adulthood/

Contact A Family - Education beyond 16
https://contact.org.uk/help-for-families/information-advice-services/education-learning/education-beyond-16/

Thera Trust
https://www.thera.co.uk/

Information on The Mental Capacity Act and 16+yrs of age:
www.ipsea.org.uk/mental-capacity-and-decision-making

www.youngminds.org.uk/parent/z-guide/mental-capacity-act-2005

- Mencap
  https://www.mencap.org.uk/advice-and-support/children-and-young-people/transition-adult-services

- Social Care Institute for Excellence
  https://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/

- NICE
  https://www.nice.org.uk/guidance/qs140

- National Careers Service
  https://nationalcareers.service.gov.uk/

Schools

- All schools
  www.cambridgeshire.gov.uk/directory/?f.Classification%257Cclassification=Schools

- Special Schools
  https://send.cambridgeshire.gov.uk/kb5/cambridgeshire/directory/results.page?qt=special+schools&term=&sorttype=relevance

- Statutory Assessment and Resources Team
  Box SCO2209
  Scott House
  Huntingdon
  PE29 3AD
  01480 372 600
  If the number is engaged, please leave a message and we will return your call as soon as possible.
  Email: start@cambridgeshire.gov.uk

School Transport

- Cambridgeshire School Transport
  www.cambridgeshire.gov.uk/residents/children-and-families/schools-learning/school-transport

- Special Educational Needs Transport Advocacy Service
  https://sentas.co.uk/

Social Care

- Cambridgeshire's Local Offer
  https://send.cambridgeshire.gov.uk/kb5/cambridgeshire/directory/advice.page?id=bPe2xezmLJc

- Cambridgeshire safeguarding and child protection
  https://www.cambridgeshire.gov.uk/residents/children-and-families/children-s-social-care/safeguarding-children-and-child-protection

- Cambridgeshire Disability Social Care
  https://www.cambridgeshire.gov.uk/residents/children-and-families/children-s-social-care/disability-social-care-0-25

- Parenting and family Support Local Offer
  www.cambridgeshire.gov.uk/residents/children-and-families/parenting-and-family-support

- NHS Social Care Information
  www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment/

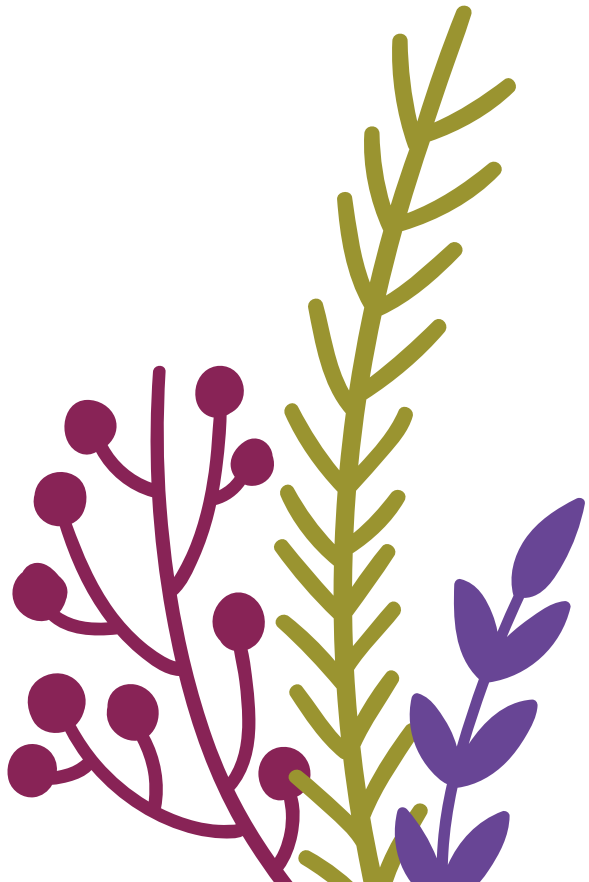
- Contact – How to Access Social Care Guide
  https://contact.org.uk/help-for-families/information-advice-services/

Speech and Language Services

- Cambridgeshire Speech and Language **www.cambscommunityservices.nhs.uk/what-we-do/children-young-people-health-services-cambridgeshire/specialist-services/childrens-speech-and-language-therapy**
- Speech and Language Uk **www.speechandlanguage.org.uk/information-and-support/**

Support for Family Carers/ Siblings

- Cambridgeshire Local Offer **https://www.cambridgeshire.gov.uk/residents/children-and-families/parenting-and-family-support/supporting-young-carers**
- Centre 33 Young Carers Support **https://centre33.org.uk/**
- Caring Together **www.caringtogether.org/**
- NHS Young Carers **www.cpft.nhs.uk/young-carers/**
- Sibs (Sibling Support) **www.sibs.org.uk/**
- Carers UK **https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment**
- Shout **https://www.cpics.org.uk/hear-text-line**



Useful Websites

General Help

- Pinpoint
  www.pinpoint-cambs,org,uk
- Special Needs Jungle
  https://www.specialneedsjungle.com
- Cerebra
  https://cerebra.org.uk
- Contact
  https://contact.org.uk/help-for-families/information-advice-services/get-in-touch/our-helpline/

Visual Resources and Social Stories

- Social Stories by Carol Gray
  https://carolgraysocialstories.com/social-stories/
- **https://www.thepathway2success.com/parent-support-executive-functioning/**
- Social Stories – Siobhan Timmins
  https://siobhantimmins.uk/
- Ultimate List of Free Visual Supports for Autism and Why They Work - The Sensory Toolbox
  https://thesensorytoolbox.com/visual-supports-for-autism/
- Zones of Regulation
  https://www.zonesofregulation.com/index.html
- BSP, speech & language resources for schools, therapists & parents
  https://www.blacksheeppress.co.uk/

Condition Specific Sites

- National Autistic Society
  https://www.autism.org.uk/
- Autism Education Trust
  https://www.autismeducationtrust.org.uk/
- Autism in Girls - Girls and Women and Autism: What's the difference? - Sarah Hendrickx
  https://www.youtube.com/watch?v=yKzWbDPisNk
- Tony Attwood - Aspergers in Girls
  https://www.youtube.com/watch?v=wfOHnt4PMFo

- ADHD
  https://www.adhdfoundation.org.uk
- ADHD UK
  https://adhduk.co.uk/
- ADHD in Girls
  https://www.verywellmind.com/adhd-in-girls-symptoms-of-adhd-in-girls-20547
- OCD-UK | A national OCD charity, run by, and for people with lived experience of OCD
  https://www.ocduk.org/
- Dyspraxia Foundation
  https://dyspraxiafoundation.org.uk/
- British Dyslexia Association
  https://www.bdadyslexia.org.uk/
- PDA Society
  https://www.pdasociety.org.uk
- Tourette's Syndrome
  https://www.tourettes-action.org.uk
- Avoidant/Restrictive Food Intake Disorder - ARFID
  https://www.arfidawarenessuk.org/
- Hypermobility Syndromes Association
  https://www.hypermobility.org

Neurodiverse Websites/ Facebook/Instagram/ Youtube Pages

- Autistic Not Weird - Insights from an Autistic Teacher and Speaker
  https://autisticnotweird.com/
- The Autistic Advocate
  https://theautisticadvocate.com/
- Pete Wharmby
  https://www.patreon.com/pwharmbyautism
- Sara-Jane Harvey, Agony Autie **https://www.youtube.com/channel/UCN9fwImPnx16e8-eThlKCWQ**
- Dean Beadle
  https://www.facebook.com/dean.beadlespeaker
- Emily@21andsensory
  https://www.instagram.com/21andsensory/
- How To ADHD
  https://www.facebook.com/howtoadhd
- Neurodivergent Rebel
  https://neurodivergentrebel.com/
- Rene Brooks ADHD
  https://blackgirllostkeys.com/rene-brooks/
- Lauren Melissa -
  https://www.instagram.com/autienelle/
- Kristy Forbes - Autism & Neurodiversity Support Specialist
  https://www.kristyforbes.com.au/
- Ann Memmott - Ann's Autism Blog
  http://annsautism.blogspot.co.uk/
- Autistic Inclusive Meets (AIM)
  https://autisticinclusivemeets.org/
- NeuroClastic
  www.neuroclastic.com
- Harry Thompson PDA
  https://www.youtube.com/channel/UCUOrWY2lW8NL4vfYslkGgLg
- Stories About Autism
  https://www.facebook.com/storiesaboutautism/
- Sally Cat PDA
  http://www.sallycatpda.co.uk/
- Non-Speaking Autistic Speaking
  http://nonspeakingautisticspeaking.blogspot.co.uk
- Yo Samdy Sam
  https://yosamdysam.com/

Useful Books

General

- **10 Rules** by Damian Milton
- **The reason I Jump** by Naoki Higashida
- **An Insider's guide to Asperger Syndrome** by Ian Hale
- **Nerdy, Shy and Socially Inappropriate: A User Guide to an Asperger Life** by Cynthia Kim
- **It's an Autism thing** by Emma Dalmayne
- **Fall Down Seven Times Get Up Eight: A young man's voice from the silence of autism** by Naoki Higashida
- **Pretending to be Normal: Living with Asperger's Syndrome (Autism Spectrum Disorder)** by Lianne Holliday Willey
- **I Think I Might Be Autistic: A Guide to Autism Spectrum Disorder Diagnosis and Self-Discovery for Adults** by Cynthia Kim
- **Neurotribes** by Steve Silberman
- **Fingers in the Sparkle Jar** by Chris Packham
- **Can You See Me?: A powerful story of autism, empathy and kindness** by Libby Scott and Rebecca Westcott
- **Asperger's Syndrome: A Guide for Parents and Professionals** by Tony Attwood

Education

- **Inclusive Education for Autistic Children: Helping Children and Young People to Learn and Flourish in the Classroom** by Dr. Rebecca Wood
- **Lost and Found: Helping Behaviorally Challenging Students (and, While You're At It, All the Others) (J-B Ed: Reach and Teach) 1st Edition** by Ross W. Greene, PhD
- **More Than Words - A guide to helping parents promote communication and social skills in Children with ASD** by Fern Sussman

Girls/Women

- **Women and Girls with Autism Spectrum Disorder: Understanding Life Experiences from Early Childhood to Old Age** by Sarah Hendrickx
- **Girls and Autism** by Barry Carpenter
- **Camouflage: The Hidden Lives of Autistic Women** by Dr. Sarah Bargiela
- **Autism and Girls** by Tony Attwood, Temple Grandon, et al
- **Nobody Nowhere: The Remarkable Autobiography of an Autistic Girl** by Donna Williams

- **Understanding Girls with ADHD: How they feel and why they do what they do** by Patricia O. Quinn and Stephen Hinshaw

Mental Health

- **The Guide to Good Mental Health on the Autism Spectrum** by Contributions
- **Trauma, Stigma and Autism: Developing Resilience and Loosening the Grip of Shame** by Gordon Gates
- **Avoiding Anxiety in Autistic Children: A Guide for Autistic Wellbeing** by Luke Beardon

Parenting

- **The Explosive Child: A New Approach For Understanding And Parenting Easily Frustrated, Chronically Inflexible Children** by Ross W. Greene, PhD
- **Raising Human Beings: Creating a Collaborative Partnership with Your Child** by Ross W. Greene, PhD
- **Treating Explosive Kids: The Collaborative Problem-Solving Approach 1st Edition** by Ross W. Greene, PhD
- **Unconditional Parenting: Moving from Rewards and Punishments to Love and Reason** by Alfie Kohn
- **Punished by Rewards: The Trouble with Gold Stars, Incentive Plans, A's, Praise, and Other Bribes** by Alfie Kohn
- **The Parents' Practical Guide to Resilience for Children aged 2-10 on the Autism Spectrum** by Jeanette Purkiss and Emma Goodall

Teens

- **The Parents' Practical Guide to Resilience for Preteens and Teenagers on the Autism Spectrum** by Dr. Emma Goodall and Jeanette Purkiss
- **The Asperkid's (Secret) Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome** Jennifer Cook O'Toole
- **The Anxiety Workbook** by Clare Ward and James Galpin
- **Asperger's Rules!: How To Make Sense of School and Friends** by Blythe Grossberg
- **The Awesome Autistic Go-To Guide: A Practical Handbook for Autistic Teens and Tweens** by Yenn Purkis, Tanya Masterman, Emma Goodall
- **Thriving with ADHD Workbook for Teens: Improve Focus, Get Organized, and Succeed** by Allison Tyler

Books for Children

- **The Disappointment Dragon: Learning to cope with disappointment**
- **The Red Beast: Controlling Anger in Children with Asperger's Syndrome**
- **The Panicosaurus: Managing Anxiety in Children Including Those with Asperger Syndrome** all by K.I. Al-Ghani
- **All Cats Are On The Autism Spectrum**
- **All Birds Have Anxiety**
- **All Dogs Have ADHD** all by Kathy Hoopmann
- **What to Do When Your Brain Gets Stuck: A Kid's Guide to Overcoming OCD** by Dawn Huebner and Bonnie Matthews
- **Underdogs** by Chris Bonnello (Autistic writer) - stories are about a group of neurodiverse children
- **The Dog Man and Captain Underpants Books** by Dav Pilkey (who has ADHD)
- **The Tourettes Survival Kit: Tools for Young Adults with Tics** by Tara Murphy and Damon Millar

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www.pinpoint-cambs.org.uk

https://www.facebook.com/pinpointcambs

Pinpoint is the Parent Carer Forum for Cambridgeshire. We support parent carers of children and young people aged 0 -25 years with additional needs or disabilities. As a parent carer forum, we enable the Local Authority to fulfil its statutory requirement to listen, engage and work together with parent carers for the benefit of children with Special Educational Needs and Disabilities (SEND) and their families.

Pinpoint:

Provides information and signposts parents and carers to the services best suited to help them with their child's needs.

Engages and empowers parent carers by running free events, workshops and training, including an annual conference, and uses these to gather feedback.

Works with statutory services as both a partner and critical friend; they both fund and provide support and services and Pinpoint ensures parents' voices are heard and that parents help to shape services.

We provide free information sessions and weekly Tii Hubs (parent to parent support). Our website has lots of help for day to day life and signposts to the services parent carers need: http://www.pinpoint-cambs.org.uk

We saw this booklet, that was developed in Essex , and wanted you to have it here in Cambridgeshire. Our partners in Cambridgeshire and Peterborough's Integrated Care Partnership agreed and provided the resources. We have edited it to make it work for Cambridgeshire families. You can find more help and support on our website including how to join our free sessions and events.

https://www.instagram.com/pinpointcambs/?hl=en

https://twitter.com/pinpointcambs

The Essex Family Forum

We wanted to record our thanks again to the Essex Alliance who created and shared this booklet. The power of parent carers working together to support other parent carers cannot be underestimated.

We are greater by working together and together we can achieve more. Thank you.

SEND the Right Message Charity (STRM)

MyOTAS – My Own Time And Space

Cambridgeshire County Council

NHS Cambridgeshire Community Services

Cambridgeshire & Peterborough Integrated Care System

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