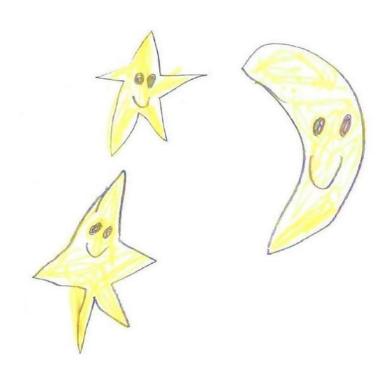
# Autism Spectrum Conditions (Autism)

# Post-Assessment Information Pack For Parents

Created by: The CHildren with Autism in Newham Diagnosis (CHAND) Service, East London NHS Foundation Trust.



Disclaimer: the information contained in this booklet was accurate at the time of publication, but may be subject to change. Last review: September 2023. The CHildren with Autism in Newham Diagnosis Service (CHAND)

Lord Lister Health Centre 121 Woodgrange Road London E7 0EP

Telephone: 020 8586 6250

Dear Parents and Carers.

Coming to terms with a diagnosis of autism and understanding what this means for your child, your family, and those working with your child, can require significant adjustments. It can feel overwhelming as there is so much information available about autism, making it hard to find trustworthy sources.

We have received feedback from many parents who found it helpful to read key information about autism. With this in mind, we have developed this pack of important information about autism. Our aim is for this pack to help you better understand autism, and to give you information about support available for you and your child.

The pack includes information from The National Autistic Society and information on diagnosis, causes, interventions, parenting, and valuable resources for support.

We positively encourage you to join the National Autistic Society (NAS) (www.nas.org.uk, 0808 800 1050), an organisation that offers a wealth of information and support for parents and schools. The NAS also has a helpline for advice and support on 0808 800 4104.

Please do not hesitate to contact us if you have any questions or concerns regarding your assessment or the recommendations provided during your feedback appointment.

Kind Regards,

**CHAND** team

**East London NHS Foundation Trust** 

# **Contents**

1.	W	hat is Autism Spectrum Condition (ASC)4
	-	Characteristics of autism
	-	Strengths of autism
	-	Different presentations at home and school
	-	Conditions associated with autism
	-	Language around autism
2.	Su	pporting your child9
	-	Explaining your child's diagnosis
	-	Understanding and supporting your child's behaviour
	-	Interventions: making positive changes
	-	Seeking professional help
3.	Yo	our child's rights14
	-	The Equalities Act and Reasonable Adjustments
	-	The Autism Act
4.	Fir	nancial support15
	-	Benefits
	-	Charity funding
5.	Su	pport for parents/carer's15
	-	Taking a break
	-	Carer's assessment
	-	Support groups
6.	Us	seful resources16
	-	Contacts
	-	Apps
	-	Recommended books
7.	Gl	ossary

# The National Autistic Society (NAS)

A UK charity for autistic people and their families. There is a lot of information on their website "http://www.nas.org.uk" <a href="www.nas.org.uk">www.nas.org.uk</a> (some of which is included this pack).



#### 1. What is Autism?

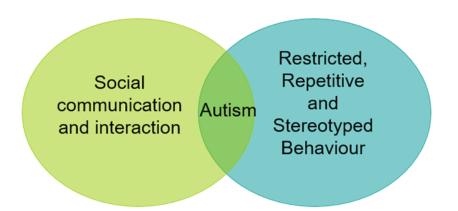
Autism is a neurodevelopmental condition, which means that there is a difference in the way that autistic people's brains are 'wired' to process information. Autism affects how a person communicates with and relates to others, and how they make sense of the world around them. This unique wiring means that people who are autistic may process information and interpret the social world differently to what is expected of them. It is important to note that autism does not affect a person's physical appearance. Rather, it influences their social interactions and how a person connects with others.

Autism is a lifelong difference in thinking, however, as young people develop into adults, they often find ways to compensate for their challenges, allowing them to reach their full potential. With the right support in place, many autistic children and young people go on to lead fulfilling lives, achieving independence, starting families, and pursuing careers.

While the exact cause of autism is still under study, research suggests that it results from a combination of genetic and environmental factors. Autism is more common than people think, with recent research finding that approximately 1 in 36 children are autistic (US, 2020). Notably, autism is more commonly diagnosed in males than in females. Researchers now think this discrepancy may be because the features of autism show up in a different way for women and girls, which has not been as well recognised in the past. Also, their differences may not become apparent until adolescence, when social demands become more challenging.

#### **Characteristics of Autism Spectrum Conditions**

Autism is differences in:



Autism Spectrum Conditions are characterised by difference in two areas of development: social communication and interaction, and restricted and repetitive behaviours (which also includes sensory differences). Autistic individuals display multiple differences in each of these areas. Most people in the general population will experience some difficulties in one or both of these areas - Autism is diagnosed when there is a strong pattern of difference across both areas.

Social communication and interaction	Restricted, Repetitive and Stereotyped	
	<u>Behaviour</u>	
Autistic people may:  o Prefer to spend time alone o Not seek comfort from others o Appear to be insensitive as they struggle to recognise others thoughts, feelings and actions o Behave in a way that surprises people as it is not easy for them to express their feelings o Have trouble understanding unwritten social rules e.g. stand too close	Autistic people may:  o Struggle with unstructured time  o Not enjoy imaginative play o Have sensory sensitivities o Have an intense, special interest which may seem like an obsession  o Move their hands or bodies in a repetitive way, such a jumping, rocking or hand flapping	
Difficulties may include understanding:	Difficulties may include:	
o Facial expressions o Tone of voice	o Predicting what will happen next	
o Jokes and sarcasm	o Adjusting to change of routine	
<ul> <li>Processing and retaining verbal information</li> </ul>	o Coping in unfamiliar situations	
o Common phrases	o Planning for the future	

In the past, language delay was considered a significant factor in autism diagnosis. This is no longer the case.

#### Strengths of autism

While an autism diagnosis often emphasises the challenges autistic people may face, it is important to remember that autism is associated with a range of remarkable qualities and strengths too.

People who are autistic may:

- ✔ Be very honest and loyal
- ✔ Have a strong sense of social justice and moral code
- ✔ Be very focused on school work and good at following rules
- ✓ Have special interests that involve developing deep levels of knowledge and skills in a particular area
- ✓ Be very determined
- ✓ See things differently and bring novel ideas and approaches to situations
- ✓ Have strong attention to detail

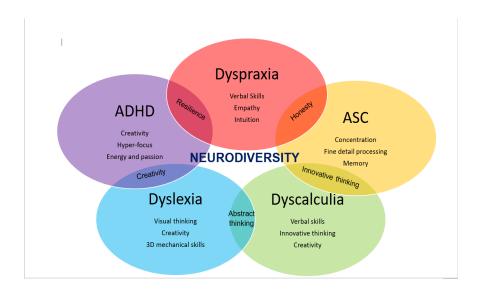
#### Different presentations at home and school

Parents often notice that their autistic child's behaviour varies significantly between home and school. Parents often report that "The problem seems to be at school, they're fine at home". Sometimes the social and sensory demands of school can be difficult for a young autistic person to manage, and this makes the school environment stressful for them. At home, the child or young person tends to feel more relaxed and comfortable and they can do activities they enjoy in a safe and familiar space.

On the other hand, some parents may express concerns such as "They behave OK at school, but at home they are very difficult". In these cases, parents often feel blamed or worried they are doing something wrong. This is also common, where the child may have developed a coping mechanism in which they hold in their anxiety and fear at school, then at home they vent their frustration in safety. It may also be because school has a predictable, consistent and strict routine which helps the young autistic person to manage some of the uncertainty they experience.

Autism diagnosis relies on observing the core features of the condition across various settings. However, we know that autistic children often have very different experiences at home and school.

#### Other Conditions that can be associated with Autism



Autism is a difference in a person's brain wiring, which means that the child's brain works in a different way. These differences can sometimes extend to other areas. Above are some differences that can be more likely to occur in children and young people who are autistic. These conditions share similar characteristics, which may mean that your child's needs may not be fully explained by autism alone.

Autistic individuals may also experience mental health needs, such as anxiety or depression, or have neurological conditions like epilepsy. These physical and mental health conditions are distinct from autism and may be hard to see, so it is important to give your child appropriate support according to their individual needs. Please see the glossary on page 20 for further information about different mental health conditions.

If you suspect that your child is facing challenges that do not appear to be directly related to their autism, we encourage you to have a conversation with your child's school teacher or consult your GP (General Practitioner) to discuss your concerns.

Please see the glossary on page 20 for more information on neurodiversity.

#### Language around Autism

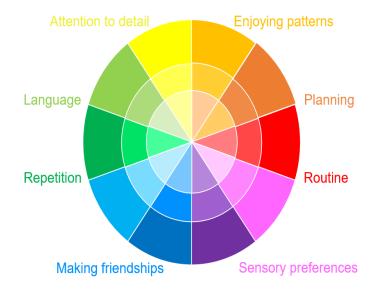
You may notice that Autism has had many names in the past, such as:

- Autism
- Autism spectrum disorder (ASD)
- Autism spectrum condition (ASC)
- Atypical autism
- Classic autism

- Kanner's autism
- Pervasive developmental disorder (PDD)
- High functioning autism (HFA)
- Asperger's syndrome
- Pathological demand avoidance (PDA)

Currently, autistic people are diagnosed with Autism Spectrum Condition (ASC). This diagnosis used to be known as Autism Spectrum Disorder (ASD) and that term may still be heard in some places - there is no difference in meaning. The terms 'ASC' and 'autism' are preferred because ASC acknowledges both characteristic strengths and difficulties, framing it as a difference rather than a disorder. Throughout this booklet we refer to ASC as autism for clarity.

The 'spectrum' is an umbrella term that captures different presentations of autism which have been separated in the past. The use of the term 'spectrum' also highlights that it is likely that people in the general population may have some 'autistic' traits, even when these traits do not form a pattern to meet the criteria for an autism diagnosis. It is crucial to recognise that each autistic person is unique, though they may share differences in areas of language, communication, social interaction, emotion, flexibility and imagination.



### 2. Supporting your child

Autism is characterised as a difference in thinking and behaving, not a condition to be 'cured'. Nevertheless, there are various interventions available to help support you and your child in managing difficulties that may be associated with autism.

#### Common challenges in autism:

- Making and keeping friendships
- Sleep difficulties
- Fears and anxiety
- Coping with changes in routine or unfamiliar situations
- Expressing emotions and feelings in a safe manner

Currently, the interventions for children and young people on the autism spectrum aim to improve language and communication skills, enhance social functioning, emotional regulation skills and meet their sensory needs.

Whilst it is important to focus on developing your child's skills, it is also essential for those around the child to enhance their understanding of autism and make changes to the way that they communicate with your child. To help with this, we provide information, such as this pack, and invite you to participate in group parent education sessions. Please contact the CHAND team for information regarding the next parent workshop (contact details on page 2).

We also encourage you to look out for support and information from other sources, for example your child's school or the Newham Local Offer website (details on page 18).

#### **Explaining Your Child's Diagnosis to Others**

Sharing your child's diagnosis is a personal choice. In most cases, it can be helpful to tell people who spend significant time with your child, such as family members and teachers at your child's school.

**Family:** Other members of the family may have realised that your child's development differs from that of other children, or that they possess a unique set of strengths and challenges. Whenever possible, involve your child in decision-making and allow them to choose who will be informed and whether they want to be present during discussions.

Many families choose to tell siblings, as they may have noticed some differences and can often help implement strategies at home. Consistency among all family members is essential for strategies to work effectively.

**School:** Your child may or may not be showing differences at school, but it can often be beneficial for the school to understand their strengths and challenges and to implement strategies to support them effectively. The SENCO (Special Educational Needs Co-ordinator) at your child's school is the person who you will likely liaise with about your child's needs. Mainstream schools are required to do their best to meet your child's Special Educational Needs (SEN). If, despite well-planned interventions, the expected progress isn't achieved, you and the school may consider initiating an Education, Health, and Care Needs Assessment. If approved, a statutory assessment of your child's needs will be conducted, potentially resulting in additional funding to support your child's needs at school. This funding will be outlined in an Education Health Care Plan (EHCP), which is reviewed annually.

**Friends:** During your time of adjustment, and beginning to understand autism, it is natural for this to become a significant focus in your life. However, it is important to remember that you may also need support, and your friends can be a valuable source of help. Consider discussing your feelings with friends as you explain your child's needs. Making time for conversations with a friend and taking breaks outside the house to recharge your batteries are essential steps to prioritise your well-being.

#### Understanding and supporting your Child's Behaviour

Behaviours that are sometimes labelled as 'difficult' or 'challenging' often serve a purpose, such as communicating when something is wrong. Try to think about what your child is trying to achieve by behaving in this way, using the chart below to break down and reflect on each event.

Behaviour difficulties may arise due to:

- Confusion or fear produced by unfamiliar events and situations
- Changes in routine
- Difficulty understanding instructions or what is expected
- Not understanding social rules
- Finding it difficult to understand and express feelings
- Over-sensitivities to different sensory sensations e.g. noise, light, touch
- Specific fears of situations or objects
- Pressure to do tasks that are too difficult

Before	During	After

# **Interventions: Making positive changes**

The following are some general strategies that can be helpful:

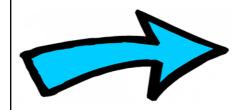
	Strategies
Setting and the environment  Improving communication	<ul> <li>Keep the environment around the child as calm as possible with minimal stimulation</li> <li>Organisation: set out expectations e.g. what you expect from your child/what they can expect from you/others</li> <li>Consider using visual aids such as a visual timetable or a list of written expectations, to provide visual cues for your child</li> <li>Provide a wide a range of communication/social opportunities appropriate for your child</li> <li>Use words and language that your child will understand - avoid sarcasm, metaphors, ambiguous phrases</li> <li>Think about what your child can see to help them understand – for example, show them a photo of what you are talking about</li> <li>Present information in the order in which they will happen - be clear and concise</li> <li>Be patient, slow down communication to allow them to process the new information</li> <li>Avoid arguing or raising your voice if they are angry or upset. They are not likely to fully understand you in this state, so if possible, wait to talk to them later. Try to stay calm and offer helpful strategies for them, such as taking some deep breaths together.</li> </ul>
Managing feelings	<ul> <li>Relaxation – Deep breathing, thinking positively, redirection to pleasant, calming activities</li> <li>Anger management –Identify the physical sensations that signal agitation and develop a range of alternative activities to help them calm down e.g. breathing, counting</li> <li>Zones of regulation- A visual prompt to help your child express and communicate how they feel</li> </ul>

#### Increasing desirable behaviours



- Positive reinforcement involves strengthening a particular behaviour by rewarding it with something desirable such as favourite food, toy, activity or verbal praise.
- Token systems can also be used in which your child collects points, ticks, stars, stickers for desired behaviour.
- Be clear Specify exactly what you want when giving an instruction. For example, 'can you stop that right now' is clearer than 'can you stop that'. This clarity helps your child understand your expectations and gives them a better chance of success.

#### Redirection/distraction



 Redirecting your child's attention to a preferred topic of conversation or activity can be an effective way of preventing a situation getting worse or diffusing a difficult situation.

#### **Punishment/negative reinforcement:**

This strategy is generally <u>not effective</u> with autistic children as it does not address the root cause of the behaviour. It can lead to the child feeling bad about themselves which can worsen their behaviour.

If difficulties persist, seek professional help to discuss specific strategies for you and your family.

#### Seeking professional help

You should always think about getting professional help if your child has:

- Difficult behaviour which is putting themselves/others at risk e.g. self-injury/aggression.
- Difficult behaviour is happening in several situations and behavioural strategies are not working after trying them for a number of months.
- If you are finding it difficult to cope with your child's behaviour.

The first point of contact should be your **GP**. You will need to describe your difficulties and then ask to be referred to your local Child and Adolescent Mental Health Service (**CAMHS**).

CAMHS will prioritise referrals and not all referrals can be accepted, even when children do have emotional and behavioural needs.

You can also speak with your child's **school** and ask what support they can offer, or whether they know of any groups that can help you. We recommend asking the school whether they can provide any therapy in school from a counsellor, which is sometimes possible.

# 3. Your child's rights

Your child has rights and protection by law in the UK due to their autism diagnosis. **The Equality Act (2010)** recognises autism as a disability, so that your child is entitled to "**reasonable adjustments**" in accessing and using services if you choose to share your child's diagnosis, including places like: schools, shops, cinemas, hospitals, leisure centres.

#### Website:

https://www.citizensadvice.org.uk/law-and-courts/discrimination/check-what-type-of-discrimination-youve-experienced/duty-to-make-reasonable-adjustments-for-disabled-people/

**The Autism Act (2009)** provides further guidance that Councils and Health Services must follow to support the needs of people with autism.

Website: <a href="https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act">https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act</a> <a href="https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act">https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act</a> <a href="https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act">https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act</a> <a href="https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act">https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act</a> <a href="https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act">https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act</a> <a href="https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act">https://www.autism-act</a> <a href="https://www.autism-act">https://www.autism-act</a> <a href="https://www.autism-act">https://www.autism-

## 4. Financial support

Your child may be eligible for some financial support from the government. You can apply for Disability Living Allowance to help with the extra costs of looking after your child.

Website: www.gov.uk/disability-living-allowance-children

Telephone: 0345 712 3456

**Family Fund** is a grant-making charity for families raising a disabled or seriously ill child, on a low income.

Website: www.familyfund.org.uk

**Our Newham Money** is a service providing financial advice and support to Newham residents who may be struggling with debt or the everyday cost of living.

Website: <a href="https://www.ournewhammoney.co.uk/">https://www.ournewhammoney.co.uk/</a>

Telephone: 020 8430 2041

Email: <a href="mailto:ournewhammoney@newham.gov.uk">ournewhammoney@newham.gov.uk</a>

Address: Our Newham Money, 112-118 The Grove, London, E15 1NS

# 5. Support for parents/carers

#### Taking a Break

Dealing with challenging behaviours can be highly demanding for parents and carers. All parents need a break from caring for their children from time to time- this is normal and healthy. Ensuring that you have the energy to respond effectively and support an individual with challenging behaviours is one of the most critical aspects of any intervention.

Support from partners, family, friends or neighbours can be invaluable. Additionally, you can seek assistance from social services. This will vary based on the child's specific needs and can include services like respite care, home help, and funding for equipment or home modifications. Read below for more information.

For more information and support, **Mencap** is an organisation that assists parents. Local groups can connect you with other parents facing similar situations and provide support with various applications.

Telephone: 0781 407 8247

Email: <a href="mailto:ieva.jupe@mencap.org.uk">ieva.jupe@mencap.org.uk</a>

If you are going through something difficult and need some support with your mental health, you can sign up to **Newham Talking Therapies (NHS)** and they will call you to discuss how they can support you.

Website: https://newhamtalkingtherapies.nhs.uk

You can also contact the **Samaritans** for free at any time for someone to talk to when you are feeling low.

Telephone: 116 123

Email: jo@samaritans.org

#### Carer's assessment

As the carer of your autistic child you may be entitled to a carer's assessment by Adult Social Care in Newham to discuss your needs and how you may be supported as a carer. Assessments can be completed face to face, over the phone, online or via self-assessment.

Website: <a href="https://www.newham.gov.uk/health-adult-social-care/carers-assessments">https://www.newham.gov.uk/health-adult-social-care/carers-assessments</a>

#### 6. Useful Resources

#### Contacts

**Ambitious about Autism** is a charity which provides information and practical support for autistic young people and their families. They have a wealth of resources about autism on their website.

Website: https://www.ambitiousaboutautism.org.uk/

Ambition Aspire Achieve runs Terence Brown Arc in the Park, which is an adventure play, sports and youth hub for young people with disabilities and/or additional needs and their families.

Website: <a href="https://www.theaaazone.com/arc-in-the-park.html">https://www.theaaazone.com/arc-in-the-park.html</a>

Address: Terence Brown Arc in the Park, Hermit Road Park, Bethell Avenue, Canning Town, E16 4JT

The National Autistic Society (NAS) **Autism Helpline** provides impartial, confidential information, advice and support for autistic people and those who support them. They also

offer an interpreting service in over 120 different languages to callers using landline telephones in the UK.

Telephone: 0808 800 4104

**Barnardo's Independent Support Service (BLISS)** is a service which helps with the Education, Health and Care Plan process.

Telephone: 0808 800 0037

Email: ISNewham@barnardos.org.uk

**Carer's First Newham** provides help with online help and advice, as well as 1-2-1 practical and emotional support, for carers in Newham.

Website: https://www.carersfirst.org.uk/newham/welcome/

Telephone: 0300 303 1555

Email: hello@carersfirst.org.uk

Address: Resource Hub, 1 Russell Road, Leyton, London, E10 7ES

The **Discover Children's Story Centre** provides '**Mighty Mega'**, a free Saturday morning club for disabled children and children with SEN aged 5-11, their families or carers. Sessions can include art, storytelling, photography, music, dance, theatre and animation.

Website: <a href="https://discover.org.uk/event/mighty-mega/">https://discover.org.uk/event/mighty-mega/</a>

Telephone: 020 8536 5555

Email: bookings@discover.org.uk

Address: Discover Children's Story Centre, 383-387 High Street, Stratford, London, E15

4QZ

The **National Autistic Society (NAS)** is a charity which provides services, advice and guidance to autistic people and their families.

Website: www.nas.org.uk

**The Newham Parents Forum** (NPF) is a voluntary group of parents and carers of children and young people (0-25) with special/additional needs and disabilities (SEND) living in Newham. They provide an opportunity for parents and carers to express their views and input into the planning and delivery of SEND services.

Website: www.newhamparentsforum.co.uk

Telephone: 0749 502 1062

Email: info@newhamparentforum.co.uk

The **Newham Carers Network** provides information, advice and support for carers from all communities, including young carers.

Telephone: 020 8519 0800

Email: info@newhamcarers.org.uk

Address: Stratford Advice Arcade, 107-109 The Grove, Stratford, E15 1HP

The **Newham Local Offer** provides an online directory of services available to families with a child or children who have a disability or additional need.

Website:

https://families.newham.gov.uk/kb5/newham/directory/localoffer.page?localofferchannel=0

The **NHS Autism** website has lots of information covering a range of aspects including autism in everyday life, where to get support, and links to videos easy read information about autism.

Website: <a href="https://www.nhs.uk/conditions/autism/">https://www.nhs.uk/conditions/autism/</a>

**Scottish Autism** provides free online courses called **Right Click** courses for parents of autistic people. Courses cover a range of topics, such as toileting and relationships, for autistic people of all ages. The courses are mostly videos but there are some downloadable documents, and you contact an autism advisor to answer questions or give more specific advice for your family.

Website:

https://www.scottishautism.org/services-support/family-support/right-click-online-support/right-click-programmes

Special Educational Needs and Disability Information Advice and support Service (SENDIASS) Newham is a statutory service designed to support parent/carers, children and young people 0-25, with issues relating to their special educational needs and disability (SEND) rights and provision.

Website:

https://families.newham.gov.uk/kb5/newham/directory/localoffer.page?localofferchannel=8

Telephone: 0203 373 0707

Email: sendiass@newham.gov.uk

The **Sleep Right Service** is a free support service that helps parents and carers of disabled children to improve their child's sleep. They offer sessions face-to-face, over the phone and online.

Website: www.scope.org.uk/family-services/sleep-right

Telephone: 0808 800 3333

Email: helpline@scope.org.uk

#### Apps

**Kooth** is a free online counselling and emotion well-being platform for children aged 10-16.

Website: www.kooth.com

**Lumi Nova** is an app for children aged 7-12 to provide digital therapy targeting fears, phobias, anxiety and stress.

Website: https://www.bfb-labs.com/ln-elft

#### **Recommended Books**

There are many books about autism available – please see the **NAS website** for the latest recommendations.

Website: <a href="http://www.autism.org.uk/shop/books/family-carers.aspx">http://www.autism.org.uk/shop/books/family-carers.aspx</a>

**Autism: Understanding Behaviour** - Hattersley, C. (2013). The National Autistic Society.

Available from:

http://www.autism.org.uk/Products/Core-NAS-publications/Autism-understanding-behaviour.aspx

Glass half empty, glass half full: how Asperger syndrome has changed my life-Mitchell, C. (2005).

**M is for Autism/M in the Middle** – Students of Limpsfield Grange School. Fictionalised description created by a group of autistic young women.

**The Awesome Autistic Go-To Guide** – Masterman, T., & Purkis, Y. (2020). A book which supports young people to take pride in their Autistic brain and identify their own strengths.

The complete guide to Asperger's syndrome - Attwood, T. (2006).

Available from: www.autism.org.uk/amazonshop

**The Ice-Cream Sundae Guide to Autism** - Elley, D., & Houghton, T. (2020). A book to support young people to understand what makes them different in a positive frame.

The reason I jump: one boy's voice from the silence of autism - Higashida, N. (2014).

**Uniquely Human** - Prizant, B & Fields, T. (2015) Practical guide to autism by an experienced specialist.

# 7. Glossary

**Attention Deficit Hyperactivity Disorder (ADHD):** relates to the child's ability to concentrate/stay focused and reduces their ability to maintain attention without being distracted, to control what behaviour (because of impulsivity) and to control the amount of physical activity appropriate to the situation (restless and fidgety).

Website: https://www.adhdfoundation.org.uk/

**Anxiety**: worries or feeling tense which can affect sleeping, appetite and ability to concentrate. It can be useful in short periods, however can become a problem long-term.

Website: www.mind.org.uk

Telephone: 0300 123 3393

**Depression**: Feelings of extreme sadness which interfere with someone's life, lasts for long periods of time, and can come back frequently.

Website: www.mind.org.uk

Telephone: 0300 123 3393

**Dyslexia:** relates to difficulties in developing reading and/or spelling skills.

Website: https://www.bdadyslexia.org.uk/

**Dyspraxia** or **Developmental Coordination Disorder (DCD)**: relates to motor coordination and planning.

Website: https://dyspraxiafoundation.org.uk/

**Eating and Feeding Disorders**: problems including refusing or avoiding food for a variety of reasons, feeding/eating aversions, extreme selectivity, tube dependency and lack of interest.

Website:

https://www.nhs.uk/mental-health/feelings-symptoms-behaviours/behaviours/eating-disorders/overview/

If your child is fussy about eating then there are lots of helpful resources on the SCYPS fussy eater's page.

Website: <a href="https://www.elft.nhs.uk/scyps/fussy-eaters">https://www.elft.nhs.uk/scyps/fussy-eaters</a>

**Epilepsy**: Neurological condition which causes seizures or periods of loss of consciousness.

Website: https://www.nhs.uk/conditions/epilepsy/

**Gender Dysphoria**: a condition involving experiencing discomfort related to gender identity.

Website: <a href="https://www.nhs.uk/conditions/gender-dysphoria/">https://www.nhs.uk/conditions/gender-dysphoria/</a>

**Neurotypical** and **Neurodiverse**: 'neurodivergence' is the concept that certain developmental conditions are normal variations in the brain, and that people who have these features share certain strengths. Neurodiverse people experience, interact with, and interpret the world in unique ways. Often, people diagnosed with ADHD, autism and

learning difficulties identify as neurodiverse, which can help reduce stigma around differences in learning and thinking.

**Obsessive Compulsive Disorder (OCD)**: An anxiety-related condition where a person experiences frequent intrusive and unwelcome obsessional thoughts; followed by repetitive compulsions or urges.

Website: www.ocduk.org

Telephone: 0845 120 3778

**Pathological Demand Avoidance (PDA)**: A set of behaviours that can be seen in some autistic children. It relates to high levels of anxiety and a need to be in control as a way of managing the anxiety. There is no separate formal assessment or diagnosis for PDA.

Website: https://www.pdasociety.org.uk/

**Social stories**: short stories that you can write to support your child with a change. They can read them back and it helps make the change more manageable

#### Website:

https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-coversations

**Tourette's**: A condition that causes a person to make involuntary sounds and movements called tics.

Website: www.tourettes-action.org.uk

Telephone: 0300 777 8427

Thank you for taking the time to read this booklet, we hope that you found some useful information about autism and ways to support your autistic child.

Please contact the CHAND team if you have any queries about this booklet (contact details on page 2).

This booklet was designed by staff from the CHAND team including Paige Frankson (Assistant Psychologist), Laurie Nettle (Highly Specialist Speech and Language Therapist), and Florence Cobb (Neurodevelopmental Specialist Nurse). We used parents' feedback to adjust the pack to families' needs.