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AUTISM SPECTRUM DISORDERS (ASD)

POST-ASSESSMENT INFORMATION PACK FOR PARENTS

ASD Assessment Clinic

**Child Development Service (CDS) and
Child and Family Consultation Service (CFCS)**



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Dear Parents,

Coming to terms with a diagnosis and understanding what this means for your child, your family, and those working with your child requires a significant adjustment. It can feel overwhelming and there is lots of information available so it can be difficult to find information that you can trust.

Many parents have told us that it has been helpful for them to have some key information given to them, and that this has been useful in making sense of what Autism Spectrum Disorder means. We have therefore created this pack which brings together important information regarding Autism Spectrum Disorder which we hope will be both informative and helpful to you.

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

We would positively encourage you to become a member of the National Autistic Society (NAS) (www.nas.org.uk, 0808 800 1050) which has a wealth of information available to parents and schools. The NAS also has a helpline for advice and support on 0808 800 4104.

We hope that you find this information helpful.

Kind Regards,

ASD Assessment Clinics

East London NHS Trust

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The National Autistic Society (NAS)

A UK charity for those people with autism and their families
There is a lot of information on their website www.nas.org.uk
Some of which is included this pack.



1. What is an Autism Spectrum Disorder?

An '**Autism Spectrum Disorder**' (ASD) is a developmental disability that affects how a person communicates with, and relates to others. It also affects how they make sense of the world around them. Having ASD does not affect someone's physical appearance; it affects how a person interacts and communicates with others. The child or young person's behaviours can sometimes be seen as 'odd' or 'strange' to people who do not understand ASD. It is a lifelong condition, however as young people develop into adults they often find ways to compensate for their difficulties. Many children and young people with ASD go on to live fulfilling lives (e.g. independence, have a family, get a job). Although the cause of ASD is still being studied, it is suggested to be a combination of factors, both genetic and environmental.

What is a 'Spectrum Disorder'?

Autism is defined as a '*spectrum disorder*' which is an umbrella term that captures different presentations of autism. Although there are differences between individuals, the core areas of difficulty that make up the diagnoses are the same. They consist of a range of difficulties in areas of language, communication, social interaction, emotion, flexibility and imagination. The use of the term 'spectrum' also highlights that it is likely that people in the general population also have autistic traits. However these traits are often not significant enough to meet the criteria used to make a diagnosis.

Who is affected?

ASD is more common than people think. There are over half a million people in the UK with ASD - that's around 1 in 100 people. It is more commonly diagnosed in males than in females; however this could be because it is often harder to detect in girls and may not be recognised until adolescence, where their difficulties with social demands become apparent.

Different presentations at home and school

Parents often report that their child with ASD behaves very differently at home than at school. Parents often report that "The problem is at school, they're fine at home". Sometimes the social and sensory demands of school can be difficult for a young person with ASD to manage and this makes the school environment stressful for them. At home, the child or young person can be more relaxed and comfortable and often able to do activities they enjoy.

On the other hand, some parents report "They behave OK at school, but at home they are very difficult". Parents in these cases often feel blamed or worried they are doing something wrong. This is also a common problem where the child may have developed a coping mechanism in which they hold their anxiety and fear in at school; 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 person with ASD to manage some of the uncertainty. When making a diagnosis, these differences are considered; however the core difficulties need to also be reported across settings.

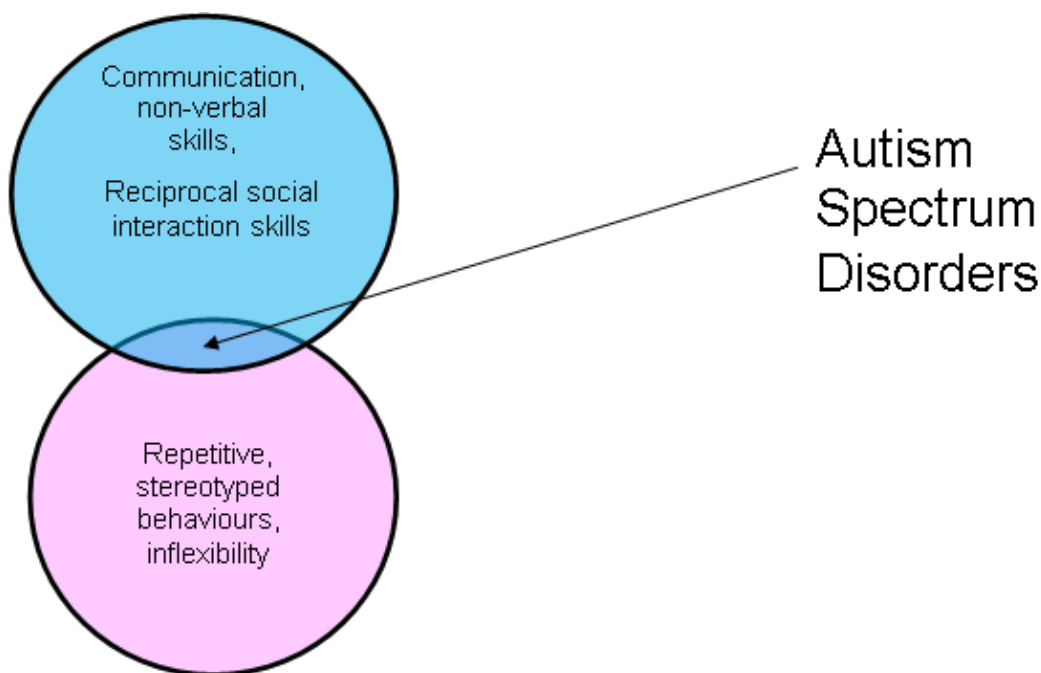
Characteristics of Autism Spectrum Disorder (ASD)

Dyad of Impairments

Autism Spectrum Disorders are characterised by subtle impairments which have been divided into two main areas of child development. The first area refers to differences in social communication. The second part of the dyad refers to restricted and repetitive behaviours. Within this there is an emphasis on sensory issues that were not included in the diagnostic criteria previously.

Language delay is no longer thought of as important as part of diagnosis. As this was the main reason for the different terms 'Autism' or 'Asperger syndrome' these are both now referred to as 'Autism Spectrum Disorder'.

The Dyad of Impairments



Difficulty with Social and Emotional Interaction

Those with ASD may:

- Prefer to spend time alone
- Not seek comfort from others
- Appear to be insensitive as they struggle to recognise others thoughts, feelings and actions
- Appear to behave inappropriately as it is not easy for them to express their feelings
- Have difficulty forming friendships

Difficulty with Language and Communication

Those with ASD may find it difficult to use or understand:

- Facial expressions
- Tone of voice
- Jokes and sarcasm
- Processing and retaining verbal information
- Common phrases

Restricted, Repetitive and Stereotyped Behaviour

Those with ASD find it hard to:

- Predict what will happen next
- Adjust to change of routine
- Cope in unfamiliar situations
- Enjoy imaginative play
- Plan for the future
- Have sensory sensitivity

Those with autism often have an intense special interest which can seem like an obsession.

Strengths

Although many people will concentrate on the difficulties that people with autism have, it is important to remember that children with ASD have *strengths* too. Children with ASD can:

- Be very honest and have a strong sense of social justice
- 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 problems and situations
- Have strong attention to detail

Other Conditions that can be associated with ASD

ASD can occur with other difficulties. It is a neurodevelopmental disorder which mean that the child's brain works in a different way. This may mean that other areas are also affected. Below are some other areas of difficulty that can be more likely to occur in children and young people with ASD.

| Disorder | Explanation |
|---|---|
| Attention Deficit Hyperactivity Disorder (ADHD) | ADHD relates to the child's ability to concentrate/stay focused and reduces 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) |
| Dyslexia or literacy difficulties | Dyslexia relates to difficulties in developing reading and/or spelling skills |
| Dyspraxia or Developmental Coordination Disorder (DCD) | DCD relates to motor coordination and planning |
| Obsessive Compulsive Disorder (OCD) | An anxiety-related condition where a person experiences frequent intrusive and unwelcome obsessional thoughts; followed by repetitive compulsions or urges |
| Epilepsy | Neurological condition which causes seizures or periods of loss of consciousness |
| Anxiety | Worries or feeling tense which can affect sleeping, appetite and ability to concentrate. It can be useful in short periods, however will become a problem long-term |
| Depression | Feelings of extreme sadness which interferes with someone's life, lasts for long periods of time, and can come back frequently |
| Feeding and Eating Disorders | Problems which include: refusing or avoiding food for a variety of reasons, feeding/eating aversions, extreme selectivity, tube dependency and lack of interest. |
| Gender Dysphoria | A condition that means that the person experiences discomfort related to their gender identity |

You may also hear about pathological demand avoidance (PDA). This is a description of a set of behaviours that can be seen in some children with ASD. It relates to high levels of anxiety and a need to be in control as a way of managing this. There is no separate formal assessment or diagnosis for PDA.

Interventions

There are a range of treatments and interventions that can help to support you and your child in managing Autism Spectrum Disorder (ASD). However, there is currently no 'cure' for ASD (although research into the causes of ASD help to increase our understanding and inform treatments and interventions). 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.

Commonly associated problems in ASD:

- Friendship difficulties
- Sleep difficulties
- Fears and anxiety
- Difficulties coping with changes in routine or unfamiliar situations
- Expressing emotions and feelings in a way that is helpful in the longer term

Whilst it is important to focus on the skills the child needs to develop, it is also essential for those around the child to develop their understanding of ASD and make changes to the way they communicate with the child. This is why we provide information (such as this pack) and invite you to group parent education sessions.

2. Parent section

Explaining Your Child's Diagnosis to Others

It is a personal choice with whom you share your child's diagnosis. In most cases, it is helpful to tell certain people, such as members of the family or key staff at your child's school.

Family Members: Other members of the family may have realised that your child is developing in a different way to other children, or has a different profile of strengths and difficulties. Try to include your child as much as possible in the decision-making and allow them to choose who will tell which people, and if they would like to be present. Many families choose to tell siblings, as they may have noticed some differences and can often help implement strategies at home. For strategies to work, it is best to have all family members acting consistently.

A short film, '[My Autism and Me](http://www.bbc.co.uk/newsround/15655232)' is a nice introduction to ASD for children and young people to watch <http://www.bbc.co.uk/newsround/15655232>

School: Your child may or may not be showing difficulties at school, but they will often benefit from the school having an understanding of their strengths and difficulties, and strategies being put into place to support them at school. The SENCO (Special Educational Needs Co-ordinator) at your child's school is the person who you will probably liaise with about your child's needs. Maintained schools are required to do their best to meet your child's SEN at school. If expected progress is not made in response to clearly planned intervention, you and the school may consider making an education health and care needs assessment. If agreed, a statutory assessment of your child's needs would take place and this may lead to additional funding to meet your child's needs at school.

Your friends: During your time of adjustment, and beginning to understand ASD, you may find this takes a lot of time and becomes your priority. However it is important to remember you also need support, and your friends can help you. Explain to your friends in a similar way to others, and try to discuss how you are feeling. A chat or an opportunity for you to leave the house, engage in a different activity or recharge your batteries can be essential.

Understanding your Child's Behaviour

There is usually a function underlying your child's behaviour, so think about what your child is trying to achieve by behaving in this way. Behaviour difficulties generally 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

Making Positive Changes

The following are some general strategies that can be helpful:

| | Strategies |
|------------------------------------|---|
| Setting and the environment | <ul style="list-style-type: none">- Keep the environment around the child as calm as possible with low amounts of stimulation- Organisation: set out expectations e.g. what you expect from your child/what they can expect- Creating a visual timetable or a list of house rules to reinforce written instructions |
| Improving communication | <ul style="list-style-type: none">- Provide a wide a range of communication/social opportunities appropriate for your child- Use words your child will understand - avoid sarcasm, metaphors, ambiguous phrases- Say things in the order in which they will happen – be clear and concise- Be patient, slow down communication for them to process the new information- Avoid arguing or raising your voice if they are angry/upset. Try to stay calm and give them helpful strategies for them to stay calm too. |
| Managing feelings | <ul style="list-style-type: none">- Relaxation – Deep breathing, thinking positively, redirection to pleasant, calming activities- Anger management –Identify the physical |

| | |
|--|---|
| | <p>sensations that show they are becoming agitated and develop a range of alternative activities to help them calm down e.g. breathing, counting</p> <ul style="list-style-type: none"> - Feelings thermometer – A visual prompt to help your child communicate how they feel |
| Increasing desirable behaviours | <ul style="list-style-type: none"> - Positive reinforcement is strengthening a particular behaviour by following 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. |
| Redirection/distraction | <ul style="list-style-type: none"> - 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 not effective with children with ASD 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).

Taking a Break

Dealing with difficult 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. Making sure that you have the energy to respond appropriately to and to support an individual with challenging behaviours is one of the most important aspects of any intervention.

Support from partners, family, friends or neighbours can be extremely important. However, help can sometimes also be requested from social services; it will vary according to the child and their particular needs, but can include respite, home help, funding for equipment or home modifications.

3. Sources of Support

For more detailed information regarding professionals who might be able to assist with behavioural difficulties in individuals with ASD, you can contact:

National Autistic Society (NAS)

393 City Road
London, EC1V1NG
Website: www.nas.org.uk
Autism Helpline: 0808 800 4104

Newham branch National Autistic Society (NAS)

Tel: 07795127787
Email: newham@nas.org.uk

Newham Parent Partnership Service

The Web building
49-51 Broadway
Stratford
E15 4BQ
Hours Monday-Friday 9.30-4.40
Tel: 0800 0131650
0203 3732869/0203 3732871

Newham Parents Forum

Tel: 07887382929
Facebook: Newham Parent Forum
www.newhamparentsforum.co.uk
Email: Newhamforum@gmail.com

Newham Carers Network

Tel: 0208 5190800
www.newhamcarers.org.uk

Barnado's Independent Support Service (BLISS)

This service helps with education, health and care plan process.
12 Church Hill
E17 3AG
Tel: 08088000037

Face 2 Face (parent befrienders)

Tel: 074368312115
www.Scope.org.uk/face2face

Newham Local Offer

Online directory of services.
www.newham.gov.uk/localoffer

Information about other common areas associated with ASD:

| Name | Website | Telephone/Helpline |
|---|--|--|
| Tourettes | www.tourettes-action.org.uk | 0300 777 8427 (Mon-Fri, 9-5) |
| Anxiety & Depression | www.mind.org.uk | 0300 123 3393 (Mon-Fri, 9-6) |
| Attention Deficit Hyperactivity Disorder (ADHD) | www.adders.org | |
| Obsessive Compulsive Disorder (OCD) | www.ocduk.org | 0845 120 3778 (Mon-Fri, 9-5) |
| Bullying | www.bullying.co.uk | 0808 800 2222 Mon- to Fri, 9-9 Sat-Sun 10-3 |

Recommended Books

There are many books available – please see the NAS website for the latest recommendations <http://www.autism.org.uk/shop/books/family-carers.aspx>

Attwood, T. (2006). *The complete guide to Asperger's syndrome*. London: Jessica Kingsley Publishers. Available from www.autism.org.uk/amazonshop

Higashida, N. (2014). *The reason I jump: one boys voice from the silence of autism*.

Mitchell, C. (2005). *Glass half empty, glass half full: how Asperger syndrome has changed my life*. London: Paul Chapman Publishing.

Caroline Hattersley (2013) *Autism: Understanding behavior*. The National Autistic Society. Available from <http://www.autism.org.uk/Products/Core-NAS-publications/Autism-understanding-behaviour.aspx>