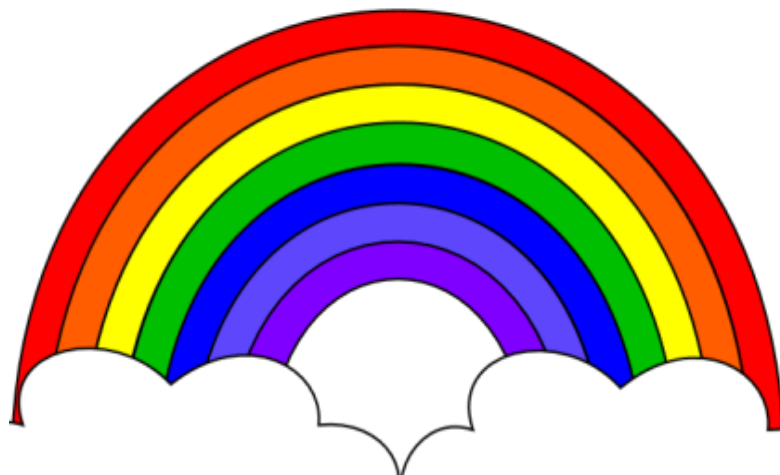




Alder Hey Children's
NHS Foundation Trust

Alder Hey Autism Spectrum Pathway

**Information & Additional Support for
Parents & Carers**



What is Autism Spectrum Disorder (ASD)?

ASD is a lifelong neurodevelopmental condition that affects the way a person communicates and relates to people around them. Children with ASD can find the world a confusing place and may have high levels of anxiety, despite their intelligence. ASD may impact on other aspects of behaviour too for example, they may find it hard to be flexible or accept change.

ASD is not an illness and children will not 'grow out of it'. They may always find some things harder than others. Each child with ASD has their own personality, strengths and needs just like anyone else and with the right help and support they will develop and grow.

What causes ASD?

ASD can affect anyone, no matter what their ability or background. More boys than girls are affected, a ratio of 4:1. After 50 years of research, there is still no agreed explanation for ASD but it is unlikely there is one single cause for ASD.

What does ASD look like?

People with ASD will have:

- Persistent difficulties in social communication
- Restricted, repetitive patterns of behaviour, interest or activities

This is called the 'Dyad of Impairments'

Persistent difficulties in Social Communication

Communication can be verbal (e.g. words) and non-verbal (e.g. expressions & gestures). We naturally use and make sense of this communication all the time. A child with ASD can sometimes find it hard to do that.

A child with ASD may:

- Appear aloof / in their own world
- Struggle with 'chit-chat' & conversation
- Not respond to their name
- Avoid / have impaired eye contact
- Not join in others' games
- Have difficulty knowing what people are thinking / feeling
- Have little / no sense of danger
- Not show / recognise emotion
- Not respond as expected to physical affection

Restricted, repetitive patterns of behaviour, interest or activities

Repetitive behaviour patterns and resistance to change are features of ASD. They can be a comfort and way to relieve stress, which for a person with ASD could be important. Sometimes the routines are inappropriate or stop the person doing other things.

A child with ASD may:

- Use toys in a repetitive way e.g. lining them up
- Show complex play copied from videos, repeated over and over again
- Engage in repetitive activities such as watching the same TV clip
- Have difficulty playing imaginatively with parents / children
- Hand flap, body spin, finger tap
- Twisting or turn objects close to the eyes, looking at it from different angles
- Need repetitive routines in everyday life e.g. using the same route
- Have obsessional interests e.g. Thomas the Tank engine
- Have special interests & collect facts / talk obsessively about it

A child with ASD may underreact or overreact to sensory experiences and this can include one or more of the senses:

- ✓ **Vision** – Bright lights, sunlight, bright colours could be painful to look at.

- ✓ **Smell** – Certain smells could be overpowering (e.g. perfume, fabric conditioner).

- ✓ **Touch** – Sensitivity to touch. This may affect hair brushing or the types of clothes they wear.

- ✓ **Taste** – Food may need to be smelled or touched before eating. Textures and/or food touching may be difficult to tolerate.

- ✓ **Hearing** – Sounds could be intense, sudden unexpected noises could be upsetting, complex multiple sounds could be confusing.

- ✓ **Pain** – Response to levels of pain that other people would find unbearable may be minimal or being more sensitive to pain than others will be noticeable.

All of these sensory experiences can be sought out for stimulation as well as avoided

There are lots of [Psychological theories](#) that have been shared to aid our understanding of ASD. One of them you may have heard of is:

Theory of Mind

A child with a diagnosis of ASD may find it hard to see that people have different thoughts and feelings to themselves. They may also have difficulty understanding their own feelings and emotions.

This can result in finding it hard to:

- Predict others' behaviour
- Know the intentions of others
- Understand rules of conversation
- Negotiate friendships
- Understand deception
- Sort fact from fiction

[There are some important things to remember:](#)

- ✓ A diagnosis of ASD is not your fault! ASD has nothing to do with parenting style.
- ✓ You may have been told that your child was 'naughty'. The diagnosis can help you to explain to people why your child is behaving a certain way.
- ✓ You may have a range of feelings about the diagnosis. Your feelings are normal; so don't feel too guilty about this. You have been given news which will affect you forever. It may help you to speak to someone you trust about how you are feeling.
- ✓ Try not to worry too much about the future. Just like any other child, your child will change and develop. With the right help and support they will learn to manage some of their difficulties. Many adults with ASD lead happy lives.
- ✓ Be wary! There is a lot of poor information about ASD on the internet. If you want to research, start with the websites in this pack.

Common words & terms you may have heard:

Asperger Syndrome *It is worth noting that Asperger's is no longer used as a separate diagnosis according to NICE guidelines, but may still be used as a descriptive term.* It describes children at the more 'able' end of the spectrum with average/above average intelligence. They often wish to be or appear sociable but find it difficult. Their language can sound formal or stilted and they may fail to adjust their language to different situations or the need of their listeners. Remember that although children described as having Asperger's Syndrome may appear quite able, they still have difficulties underpinned by the dyad of impairments.

Autistic Savant is used for someone with ASD who has a special talent, for example, drawing, memory, maths or playing an instrument. Only about 4 – 9% of individuals with ASD will have this. We think it could occur due to the single minded concentration some children with ASD can give to one subject.

Echolalia – Some children with ASD may directly copy another person's words or phrases (including from TV & radio etc...) This may lead adults to have a false impression of a child's language ability. Echolalia can often hide a problem with understanding language.

Receptive Language - this is the information we hear that leads to us develop understanding. Children with ASD may have difficulty understanding what is being said to them, especially if the language is too difficult or hard to follow.

Expressive Language - this is the words and actions we use to communicate information to others.

Additional Support Information

Autism Initiatives 0151 330 9500
www.autisminitiatives.org (9am – 5pm)

The National Autistic Society 020 7833 2299
www.autism.org.uk Helpline 0808 8004104

Useful reading material and DVDs

Books and resources can be found on the National Autistic Society
www.autism.org.uk/pubs

Jessica Kingsley Publishers has reading material
www.jkp.com/uk/autism-and-related-conditions.html

Websites

National Autistic Society

www.autism.org.uk

The National Autistic Society web site has information for teachers and families. This is one of the most up to date reliable resources.

There is also an online forum under the “Community” tab. Individuals with and without ASD can register to share thoughts, experiences and give advice / support.

Autism Training Team

www.livewellliverpool.info

Training, support and drop in advisory sessions for families whose child has been diagnosed with Autistic Spectrum Disorder (ASD).

[Embrace Group](#)

www.embracegroup.co.uk

Services Directory to search for support for Young People.

[Autism Initiatives](#)

www.autisminitiatives.org

Autism Initiatives mission is to meet the needs of people with autism, their families and carers with a range of services which are personal, professional and innovative.

[Autism Education Trust](#)

www.autismeducationtrust.org.uk

The AET website gives advice and resources for professionals, parents, carers, children and young people with autism. The AET manages online resources for children and young people: the 'Kids Zone' provides young children with information, advice & games.

[Liverpool Early Help Directory](#)

www.ehd.liverpool.gov.uk

This is for all families, the Local Offer section is specifically for families with children or young people with SEND from 0-25, including post 16 services.

[TEACCH](#)

www.teacch.com

TEACCH is all about structure and understanding for individuals with ASD. The TEACCH approach tries to respond to the needs of autistic people using the best available approaches and methods known so far, for educating and teaching autonomy.

Aspergernauts

www.aspergernauts.co.uk

The Aspergernauts community is the place to be to make new friends, discuss topics and find more information and is designed for everyone including people with Asperger's, their parents/carers, teachers and professionals.

Government Information

www.gov.uk/browse/disabilities/benefits

www.gov.uk/carers-allowance

These GOV.UK sites have information about disability living allowance and attendance allowance.

The Liverpool Autism Training Team

Training to cover the following age groups: 4-7yrs, 8-11yrs & 11-19yrs

Aims: After this training Parents/Carers will be able to:

- Understand Autistic Spectrum Disorders (ASD)
- Understand how ASD affects the individual child
- Recognise the difficulties associated with theory of mind
- Identify areas of sensory difficulty
- Confidently begin work with their child
- Adapt their own communication
- Understand and begin using visual aids
- Identify and define difficult behaviour
- Begin to view situations from the child's perspective
- Use structure within the child's setting
- Apply a range of behaviour strategies
- Recognise social difficulties and apply a number of strategies
- Develop self-help strategies for their child

Dates: Courses are run throughout the year

Contact: Tracey Williamson on 0151 233 5988
asdtrainingteam@liverpool.gov.uk

Cost: Free

Target audience: Parents and Carers who support a child with ASD.

The Liverpool Autism Training Team: Drop-in Advisory Sessions

Taking place at different Liverpool Children's Centre's, they are for anyone working in a Liverpool setting as well as for families who have children they are concerned about in relation to ASD.

Please call Tracey Williamson (Parent Trainer) for details of the dates and venues on: 0151 233 5988

The Isabella Trust

They aim to improve the quality of life of children with Autistic Spectrum Disorder and Sensory Processing Difficulties by supporting families and carers.

Tel: 07956 749 774

Email: info@theisabellatrust.org

ADDvanced Solutions Community Network

They offer training, support and social activities for families with children with neurodevelopmental difficulties.

Tel: 0151 486 1788

Email: info@advancedsolutions.co.uk

Web: www.advancedsolutions.co.uk

PSS: Person Shaped Support

They can give help and support around Educational Health Care Plans.

Tel: 0151 702 5555

Email: info@pss.org.uk

SEND IASS

SEND IASS services provide free and confidential, impartial information, advice and support to children/young people 0 – 25yrs, with special educational needs and/or disabilities (SEND), and their parents/carers.

Liverpool and Knowsley SEND IASS is a combined service for residents of Liverpool and Knowsley. It is delivered by WIRED. WIRED has an excellent record of high quality services for children, young people, parents and carers in Wirral, Warrington and other areas. Liverpool and Knowsley SEND IASS offer:

- Telephone and Email Service
- Information, Advice and Support for parents/carers, and young people with SEND.
- Written information about Special Educational Needs (SEN)
- Information sessions for parents and carers
- Information, Advice and Support relating to School Admissions & Appeals, Education, Health and Care plans (EHCP), Tribunals, Disability Discrimination, SEN Support, Transport, Exclusions and Post-16.

For further information about SEND IASS:

Tel: 0800 012 9066

E-mail: liverpoolandknowsleysend@wired.me.uk

Web: www.liverpoolandknowsleysend.com

Face2Face Befriending Service

Face2Face is a joint project between 'Scope' and Alder Hey. Trained parent volunteers called 'Befrienders' (who are all parents of disabled/complex needs children) offer emotional support to any parent or carer of a disabled/complex needs child accessing an Alder Hey service.

For further information about Face 2 Face:

Tel: 0808 800 3333 (open 9-5 weekdays closed bank holidays)

E-mail: response@scope.org.uk

Contact: Vicky Harris 07843 467 588

Email: vicky.harris@scope.org.uk

Web: www.scope.org.uk/face2face

Liverpool Parents' Interest Group

The group is run for Parents, Grandparents & Carers of children with Autism, ASD, Asperger's Syndrome and other social and communications difficulties.

They meet once a month and everyone is welcome. They sometimes they ask professionals like Speech and Language Therapists, Mencap & Dental nurses to do a talk.

Free refreshments & play facilities for younger children are provided.

They ask that you ring to check details are up to date.

Contact: June Ardrey 07837 098 625 (text only)

Email: emlousib@gmail.com

Email: babs.bd100@gmail.com

Liverpool Parent and Carers Forum (LivPaC)

LivPac aims to support and train parents/carers, so that they feel empowered and informed from services and professionals.

E-mail: livpac@hotmail.co.uk

Web: www.livpac.co.uk

Young Person's Advisory Service (YPAS)

Young Person's Advisory Service (YPAS) provides support and therapeutic services in Liverpool for children aged 5 -15 years, young people aged 16-25 years and their families.

YPAS is a charity that supports children, young people and families with their mental health and emotional wellbeing difficulties. They provide services that include: Counselling, Psychotherapy, Information/ Advice/ Guidance, Family work, Parent/ Carer support, Group work programmes, drop-ins (general/ LGBTQ+/ transgender)

Web: www.ypas.org.uk
Tel: 0151 707 1025
Email: support@ypas.org.uk

FRESH CAMHS

Alder Hey FRESH CAMHS is part of the Liverpool CAMHS Partnership. They offer specialist services to support children and young people in Liverpool and Sefton (up to the age of 18) who are experiencing mental health difficulties.

They consult, advise, train other agencies and accept referrals from a range of professionals. In the team, clinicians come from a range of clinical and professional backgrounds.

The service works with young people, parents, carers and partner agencies to make sure the right care is given to each person depending on their needs.

Web: www.freshcamhs.org
Tel: 0151 293 3662
Email: camhs.referrals@alderhey.nhs.uk

Merseyside Youth Association (MYA)

Merseyside Youth Association (MYA) provides support services to children and young people.

Working with 5000 young people a year, they provide projects to help young people:

Be healthy, active, creative, included & ready

Web: www.mya.org.uk

Tel: 0151 702 0700

Cerebra Sleep Service

They know how hard it can be to get a good night's sleep and have a team who can give advice and guidance.

How they can help you get a better night's sleep:

They can help with: refusing to go to bed, difficulty going to sleep, not wanting to sleep alone, waking up at night & waking up early. They can offer one-to one support, workshops (good for parent groups) and information resources.

Tel: 01267 244210

E-mail: sleep@cerebra.org.uk

Sleep Solutions

Sleep Solutions provides support for families of disabled children and those with additional needs aged 2-19, with severe sleep problems. All their staff specialise in working with disabled children and children with additional needs.

They offer a sleep service that includes workshops, clinic appointments and home visits (where appropriate) as well as phone & email support. Tel: 0743 5964 605

E-mail: jean.brown@scope.org.uk

Social & Leisure Support

There are two youth clubs for young people with social and communication difficulties in the city. Please contact each club directly to make sure there are places available or to arrange a visit.

Central Youth Club (Central Plus)

62 Walker Street

Liverpool

L6 1EJ

Tel: 0151 263 3856 (Marie Wallensang)

Web: www.localgiving.org/charity/centralyouthclub

Childwall Youth Club (Splice)

Lyndene Road

Childwall

L25 1NG

Tel: 0151 737 2491 (Lee McLoughlin)

Fusion Project

Fusion Project directs children and young people into play and leisure provision in their community.

Tel: 0151 233 3621

E-mail: fusion.project@liverpool.gov.uk

Transition to Adult Services

Liverpool Asperger Team (Adult Service)

The Liverpool Asperger team provides assessment and support to working age adults within Liverpool. The team consists of nurses, social work colleagues and medical colleagues from the Liverpool community learning disability team

Address:

Mersey Care NHS Foundation Trust Community Hub
Falklands Approach
Norris Green
Liverpool
L11 5BS

Telephone: 0151 737 4800

Useful Reading

For younger brothers and sisters:

Bleach, F. (2001). *Everybody is different: a book for young people who have brothers or sisters with autism*. London. The National Autistic Society

This book is different! Written and illustrated by an accomplished artist who has worked in a National Autistic Society school, it explores the characteristics of autism, and what it feels like to be a brother or sister of someone with autism.

Davis, J. (1994). *Able autistic children with Asperger syndrome: a booklet for brothers and sisters*. The Early Years Diagnostic Centre

Designed for siblings of children with able autism or Asperger syndrome from the age of seven, this booklet focuses on Asperger syndrome and the sibling experience.

Fairfoot, E. and Mayne, J. (2004). *My special brother Rory*. London: The National Autistic Society

A sister's view of the pleasures and pitfalls of having a brother with autism. A cheerful and positive book.

Gorrod, L. (1997). *My brother is different*. London: The National Autistic Society
Written by a mother of a child with autism and beautifully illustrated in full colour, this book explains the behaviour of a child with autism in terms that young siblings will understand. This book is aimed at younger siblings aged 4-7.

Hunter T. H. (2006). *My sister is different*. London: The National Autistic Society
The ups and downs of life with a sister who has autism, written and illustrated by ten-year-old whose sister has autism.

For adolescent brothers and sisters:

Hoopman, K. (2000). *Blue bottle mystery*. London: Jessica Kingsley Publishers
Aimed at 8-13 year olds, this warm, fun-filled fantasy story has a hero with Asperger syndrome. Tied up with the exciting mystery is the story of how Ben is diagnosed with Asperger syndrome and how he and his family deal with the problems and the joys that come with this. This book is a delight to read and also a valuable teaching tool that demystifies Asperger syndrome.

Haddon, M. (2003). *The curious incident of the dog in the night-time*. London: David Fickling Books.
Winner of the 2003 Guardian Children's Fiction Award and Whitbread Book of the Year. A really good read for readers old and young. The hero, Christopher Boone, is a teenager with Asperger syndrome. Contains some strong language.

Jackson, L. (2002). *Freaks, geeks and Asperger syndrome*. London: Jessica Kingsley Publishers

Luke, who has Asperger syndrome, was 13 when he wrote this book. He talks about a host of tricky teenage topics, including bullying and dating.

For adult brothers and sisters:

Attwood, T. (1998). *Asperger's syndrome: a guide for parents and professionals*.

London: Jessica Kingsley Publishers

Attwood, T. (1993). *Why does Chris do that?* London: The National Autistic Society

The strength of Tony Attwood's writing is that he has made the essential imaginative leap into the world of ASD. He has real empathy with the children and adults he writes about and his sympathy, knowledge and common sense come through on every page.

Please note: This booklet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this booklet alone for information about your child's treatment.

Alder Hey Children's NHS Foundation Trust is neither liable for the contents of any external internet site listed, nor does it endorse any commercial product or service mentioned or advised on any of the sites.

This information can be made available in other languages and formats if requested.

[Alder Hey Children's NHS Foundation Trust](#)

Alder Road

Liverpool

L12 2AP

Tel: 0151 252 5252

Email: asdqueries@alderhey.nhs.uk

© Alder Hey

SDP/B/2/18

Review Date: October 2021

PIAG: 061

