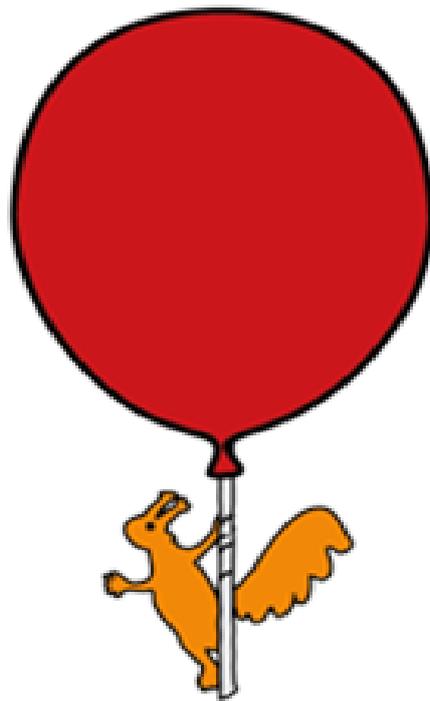


# **Alder Hey**

## **Autism Spectrum Disorder Pathway**

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



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### Information about ASD

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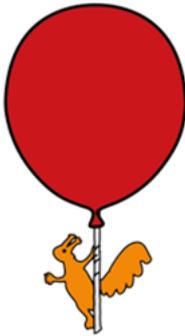
### Information and contact details

### A little Extra

### Final Thoughts

*A note on language:* There is ongoing discussion about the correct language to use when talking about ASD and there is still no agreement. What we know is that there is a shift towards 'Identity First' language. For example, an adult might say they are an 'autistic adult' rather than an 'adult with autism'. Following discussion with a local parent group, reading about autistic people's views and from looking at the language used by leaders such as the National Autistic Society, this leaflet aims to use 'Identity First' language.





## What is Autism Spectrum Disorder? (ASD)

Anyone can be born with ASD; it is part of what makes them who they are. If a child or young person gets a diagnosis of ASD it means they are autistic and they will always be autistic, but this is OK!

If we did not have autistic people, our world would miss the chance to know kind friends, committed workers, great teachers, funny comedians and great thinkers!

There is a mixture of reasons why some people are born autistic. It will be different for each person. Most autistic people share these experiences:

- They communicate differently
- They like restricted, repetitive patterns of behaviour, interests or activities
- They may have more specific likes and dislikes to sensory aspects of life

Being autistic means that life might be different in some respect. The world is getting better at understanding ASD and what helps autistic people. Getting a diagnosis of ASD is not always expected. All feelings about it are normal but remember ASD is very common! Being autistic will have positives and negatives (like most of life).

Every autistic person has their own needs, personality and strengths. With the right support, being autistic does not stop a person being the best they can be.





## What does ASD look like?



You may hear people say, "Once you've met one autistic person, you've met one autistic person". This is true, but there are some shared experiences which can help you see the way ASD presents. It can help to think of ASD like a coin with two sides. Each side gives some examples of experiences many autistic people have:

- Objects & ideas can be more interesting than people
- Talking too much or too little is common
- Chatting can be tiring
- People don't say what they mean so talking is confusing
- What you laugh at is sometimes different
- Talking & showing feelings can be tricky
- Using facial expressions & gestures does not come naturally & understanding other people's can be hard work
- Specific people are important, lots of friends less so
- Keeping up with friends is hard
- Following play & games is tricky
- Different social interests to friends
- Having alone time can be more important



- Changes are hard to experience
- You might move your body in a different way
- Playing with the same things, eating or watching the same things feels nice
- Seeing another person's point of view takes more effort
- Doing things 'your way' feels better
- You get more involved & passionate about things you love than others
- You like to collect and organise in 'your way'
- Interesting things take up lots of your time
- Busy or bright places can be draining
- More overwhelmed by daily sounds
- Smells & tastes can be more intense or you might like to smell or taste certain things more than others
- Textures and how things feel often cause more intense reactions





Sometimes we forget the positives that come along with being told your child thinks and sees the world differently. Here is our list of the wonderful traits we have seen in the young autistic people we work with:

**Interesting**

**Creative**

**Unique**

**Funny**

**Clever**

**Honest**

**Leaders**

**Logical**

**Detailed**

**Inspiring**

**Driven**

**Passionate**

**Sensitive**





## Local support – information and contact details

### Local Offers

A Local Offer shows what is available in your area.

- Liverpool's Local Offer: [www.liverpool.gov.uk/localoffer/SEND](http://www.liverpool.gov.uk/localoffer/SEND)
- Sefton's Local Offer: [www.seftondirectory.com/localoffer](http://www.seftondirectory.com/localoffer)

### Liverpool Services

#### The Liverpool Autism Training Team

Free training on ASD for parents of children with & without a diagnosis. Contact the team to find out which training is best for you. They also run free drop-in sessions at Children's Centre's throughout Liverpool.

Tel: Tracey Williamson on 0151 233 5946

Email: [asdtrainingteam@liverpool.gov.uk](mailto:asdtrainingteam@liverpool.gov.uk)



## Liverpool Parent and Carers Forum (LivPaC)

LivPaC is a group of parents, carers of children and young people with special additional needs and/or disabilities (SEND). They give parents and carers a voice. They use their experience and feedback from families to help others plan and make services. All parents & carers can go to LivPaC coffee mornings to meet other parents and share experiences.

E-mail: [livpac@hotmail.co.uk](mailto:livpac@hotmail.co.uk)

Web: [www.livpac.org.uk](http://www.livpac.org.uk)

## SEND IASS

SEND IASS services provide free & confidential, impartial advice & 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 people in Liverpool and Knowsley.

Topics covered include: Advice and Support relating to School Admissions & Appeals, Education, Health and Care plans (EHCP), Tribunals, Disability Discrimination, SEN Support, Transport, Exclusions and Post-16 work.

Tel: 0800 012 9066

E-mail: [liverpoolandknowsleysend@wired.me.uk](mailto:liverpoolandknowsleysend@wired.me.uk)

Web: [www.liverpoolandknowsleysend.com](http://www.liverpoolandknowsleysend.com)



## Liverpool Parents' Interest Group

The group is for Parents, Grandparents & Carers of children with ASD, ADHD & related conditions. They meet once a month and all are welcome. They sometimes they ask professionals to do talks.

Contact: Babbs Blueet-Duncan

Email: [babs.bd100@gmail.com](mailto:babs.bd100@gmail.com)

## Young Person's Advisory Service (YPAS)

YPAS support the mental health and emotional wellbeing of children & young people aged between 5 – 25 years & their families. They provide support and therapeutic services such a counselling, psychotherapy & family work.

Tel: 0151 707 1025

Email: [support@ypas.org.uk](mailto:support@ypas.org.uk)

Web: [www.ypas.org.uk](http://www.ypas.org.uk)

## Fusion Project

Fusion Project helps children & parents/ carers access a variety of 'breaks' such as leisure & play breaks, friendship groups & holiday breaks.

Tel: 0151 233 3620

E-mail: [fusion.project@liverpool.gov.uk](mailto:fusion.project@liverpool.gov.uk)



## Sefton Services

### **Sefton Carers Centre**

If you care for someone under 18 years old who has a physical disability, learning disability or emotional/behavioural condition (diagnosed or undiagnosed) then Sefton carers provide a variety of parent advice and support.

Tel: 0151 288 6060

Web: [www.sefton-carers.org.uk](http://www.sefton-carers.org.uk)

### **Sefton Parent Carer Forum**

A community of families who have children with disabilities or additional needs. They offer support to each other and work with service providers to create quality services that meet the needs of all parent carers & their children.

Web: [www.seftonpcf.org](http://www.seftonpcf.org)

Email: [info@seftonpcf.org](mailto:info@seftonpcf.org)

### **Jakes Sensory World & Garden**

Held at Netherton Activity Centre, this is a place for children to access soft play, stay & play and sensory experiences. They also help organise birthday parties.

Tel: 0151 525 5106

Web: [www.sefton.gov.uk](http://www.sefton.gov.uk)



## Aiming High

This group provide sessions during term-time and holidays for young people with needs. They give support when young people reach key 'transition points', such as moving from school into work.

Email: [aiminghigh@sefton.gov.uk](mailto:aiminghigh@sefton.gov.uk)

Web: <https://www.sefton.gov.uk/aiminghigh>

## Autism & Social Communication Team

A team run within the Sefton Inclusion Service. They provide support, advice & coffee mornings. Get the chance to talk with a professional involved in the area of social communication difficulties.

Email: [socialcom@sefton.gov.uk](mailto:socialcom@sefton.gov.uk)

Tel: 0151 934 2347

## Sefton Council for Voluntary Service (CVS)

A charity that provides a project called 'Buddy Up'. This is a mentoring & befriending project for young people aged between 13 and 18 who have additional needs & are at risk of social isolation.

Tel: 0151 920 0726

Web: [www.seftoncv.org.uk](http://www.seftoncv.org.uk)



## **SEND IASS**

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

Tel: 0151 943 3334

E-mail: [seftonsendiass@sefton.gov.uk](mailto:seftonsendiass@sefton.gov.uk)

## **Parenting 2000**

They provide information about a range of topics, therapeutic services & counselling to children, young people, families, adults & groups. They run Alchemy Youth Club for young people to meet friends and increase their confidence.

Tel: 0151 920 7137 / 0151 932 1163 (Crosby) & 01704 380047 Southport

Web: [www.parenting2000.org.uk](http://www.parenting2000.org.uk)

## **Liverpool & Sefton Services**

### **ADDvanced Solutions Community Network**

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

Tel: 0151 486 1788

Email: [info@advancedsolutions.co.uk](mailto:info@advancedsolutions.co.uk)

Web: [www.advancedsolutions.co.uk](http://www.advancedsolutions.co.uk)



## The Isabella Trust

They provide information, support & training to parents of autistic children and children with sensory processing difficulties.

Tel: 07956 749 774

Email: [info@theisabellatrust.org](mailto:info@theisabellatrust.org)

Web: [www.theisabellatrust.org](http://www.theisabellatrust.org)

## 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 & Sefton (up to the age of 18) who are experiencing mental health difficulties.

Tel: 0151 293 3662

Email: [camhs.referrals@alderhey.nhs.uk](mailto:camhs.referrals@alderhey.nhs.uk)

Web: [www.freshcamhs.org](http://www.freshcamhs.org)

## Merseyside Youth Association (MYA)

Merseyside Youth Association (MYA) provides support services to children & young people. They have different creative & educational projects for children & young people.

Tel: 0151 702 0700

Web: [www.mya.org.uk](http://www.mya.org.uk)



## National services support – information and contact details

### **The National Autistic Society (NAS)**

The National Autistic Society has lots of information about ASD. It can be used by young people, families and schools. They also offer access to training.

Tel: 0808 800 4104  
Email: [nas@nas.org.uk](mailto:nas@nas.org.uk)  
Web: [www.autism.org.uk](http://www.autism.org.uk)

### **Cerebra**

They know how hard it can be to get a good night's sleep. They have online sleep guides and a sleep advice service.

Tel: 0800 328 1159  
Email: [enquiries@cerebra.org.uk](mailto:enquiries@cerebra.org.uk)  
Web: [www.cerebra.org.uk](http://www.cerebra.org.uk)

### **Bladder & Bowel UK**

The Bladder & Bowel UK website has a range of resource leaflets you can download for free in relation to toilet training. They have articles and resources about ASD & toilet training too.

Tel: 0161 607 8219  
Web: [www.bbuk.org.uk](http://www.bbuk.org.uk)  
Email: [bbuk@disabledliving.co.uk](mailto:bbuk@disabledliving.co.uk)



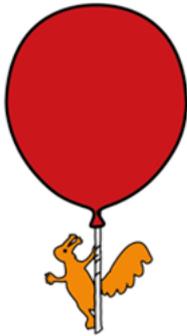
## Newlife

A charity that helps families to get equipment they may need to improve their child's quality of life.

Tel: 01543 462 777

Web: [www.newlifecharity.co.uk](http://www.newlifecharity.co.uk)





## A Little Extra...

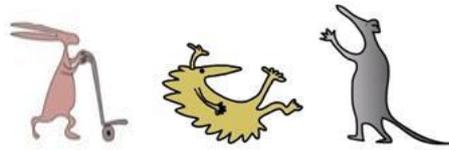
These books have been recommended by parents & professionals to help you develop your knowledge about ASD:

1. 'NeuroTribes', Steve Silberman
2. 'Uniquely Human: A different way of seeing autism', Barry Prizant
3. 'Autism: talking about a diagnosis', Rachel Pike
4. 'The Superhero Brain, Explaining Autism to Empower kids', Christel Land
5. 'The Children's guide to autism', Fiona Reeves
6. 'Aspergirls', Rudy Simone
7. 'The Spectrum Girl's Survival Guide, How to grow up awesome and autistic', Siena Castellon
8. 'The Asperkid's Secret Book of Social Rules', Jennifer Cook O'Toole
9. 'Nerdy, Shy and Socially Inappropriate, a user guide to Asperger life', Cynthia Kim
10. 'It's an autism thing...I'll help you understand it', Emma Dalmayne

There is an animation on You Tube called: '**Amazing Things Happen**' by **Alexander Amelines**. It is a great explanation of ASD and how all brains work differently.



## Final thoughts...



***“I see people with ASD as a bright thread in the rich tapestry of life”***

Tony Attwood, Clinical Psychologist, leading speaker on Asperger's Syndrome

***“Just because a computer is not running Windows, does not mean it's broken”***

Steve Silberman, author of 'Neurotribes'

***“I am different, not less”***

***“The most interesting people you'll find are the ones that don't fit into your average cardboard box. They'll make what they need; they'll make their own boxes”.***

Temple Grandin, Professor of Animal Science, author, speaker and autism spokesperson

***“Sometimes it is the people no one can imagine anything of who do the things no one can imagine”***

Alan Turing, creator of first computer



**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.

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