

Children and Young People on the Autism Spectrum: What You Need to Know



RESEARCH AUTISM

IMPROVING THE QUALITY OF LIFE

IDENTIFICATION INTERVENTION INCLUSION

Introduction

This leaflet is for parents and carers of children and young people on the autism spectrum living in the UK. It provides the key facts about autism, explains how autism affects different people, and describes some of the issues they may face. It also provides information about different forms of support, rights and services, along with a list of useful organisations.

What is autism?

Autism is a lifelong condition that affects just over 1 in 100 children and young people. Autism affects how children and young people communicate with, and relate to, other people. It also affects how they make sense of the world around them.

Types of autism

Autism or autism spectrum disorder or ASD are all terms used to describe a very wide range of similar conditions including Asperger syndrome, autistic disorder and atypical autism.

Core features

Children and young people on the autism spectrum vary enormously from each other but they all share the two 'core' features of autism:

- difficulties with social communication and social interaction. For example, they may not be able to talk, may find it hard to hold a conversation, may not understand social rules such as how far to stand from somebody else, or may find it difficult to make friends
- restricted, repetitive patterns of behaviour, interests, or activities. For example, they may develop an overwhelming interest in something, may follow inflexible routines or rituals, may make repetitive body movements, or may be hypersensitive to certain sounds or smells.

Many children and young people on the autism spectrum will also experience high levels of anxiety thought to be made worse by the stress of living in a 'neurotypical' world.

Some children and young people on the autism spectrum also have significant strengths. These often include a good eye for detail, an excellent memory for facts and figures, and the ability to thrive in a structured, well-organised environment.

Level of functioning

Some children and young people on the autism spectrum are highly intelligent while others may have a significant learning disability. Some may also be non-verbal or have very limited speech. However the fact that someone doesn't speak does not necessarily mean that they have limited intelligence. Some children classified as having 'severe' autism can function very well with the right kind of support. Some children classified as having less severe autism, on the other hand, may face considerable difficulties which are overlooked because they appear to be coping.

Uneven profile of abilities

Many children on the autism spectrum have an uneven profile of abilities. This means that they may be relatively good at certain things (for example, maths), but may not be so good at other things (for example, thinking flexibly). Or, even more confusingly, they may have different abilities in the same area (such as good long-term memory but poor short-term memory).

Causes of autism

Autism has a variety of causes, which are likely to be a complex mix of genetic and environmental factors. Other conditions which sometimes occur alongside autism include:

- genetic conditions — such as fragile X syndrome, PKU or tuberous sclerosis
- medical conditions — such as epilepsy or gastro-intestinal problems
- developmental conditions — such as attention deficit hyperactivity disorder

Diagnosis

Early signs of autism in children may include lack of speech, delayed speech, speech which is odd, not responding to other people, not interacting with other people, restricted behaviours and interests, repetitive body movements, or strong reactions to noises, smells or lights. If you suspect your child has autism you should contact your GP, health visitor or the special education needs coordinator (SENCO) in your child's school. You may then be referred onto a specialist diagnostic service which will make an assessment of your child. If your child receives a diagnosis of autism, the diagnostic team should share information from the assessment with your child's GP. If you agree, they will share this with other public services to help them offer you the support you need.

Issues

Children and young people on the autism spectrum face many issues on a day to day basis. Those issues are likely to change as the child grows older, develops new skills, comes into contact with more people and encounters new situations. For example, he or she may start to speak or make friends but also become more anxious or demanding. However it is important to remember that each child is a unique individual, with unique needs and abilities. Because of this, he or she will experience those issues in a different way or may not experience them at all.

Common issues include:

- cognitive problems - such as difficulties understanding other people, thinking flexibly or planning ahead
- sensory processing problems — such as an aversion to bright lights, loud noises or strong smells
- mental health problems — such as anxiety, depression and compulsions
- physical problems — such as chronic fatigue — or motor problems— such as finding it hard to hold a pencil between fingers and thumb
- functional difficulties — such as problems with sleep, eating or going to the toilet

In addition, many children and young people are mistreated by other people. This mistreatment may include being bullied or being denied access to education or community facilities.

Some children on the autism spectrum have behaviours that other people may find challenging (such as anger, refusal to follow instructions, self-injury etc.). Such behaviours may be caused by a range of factors including anxiety and stress, sensory processing differences, underlying medical conditions, and specific situations that the child finds distressing. For example a 'meltdown' may be caused by a child's inability to communicate his or her basic needs and/or by a sensory overload. Challenging behaviours can usually be prevented or reduced if the right kind of support is provided. All challenging behaviour happens for a reason and we should not rush to judge what that might be. It is very important to explore the possible causes with the child and family before providing any kind of intervention.

Interventions

There are many interventions (treatments, services and other forms of support) used to help children on the autism spectrum. Those interventions include health and social care services, behavioural techniques, assistive and adaptive technology, augmentative and alternative communication systems, medication, diets etc. However there is no one-size fits all solution. Each child on the autism spectrum is unique, with unique needs and abilities. So what works for one child may not work for another. The most effective interventions are personalised to meet the unique characteristics of each child.

There is still a lack of high quality research evidence to support most interventions, although that does not necessarily mean they do not work. With support and understanding it is possible for all children to develop new skills and better achieve their potential. However some interventions are scientifically unfeasible, potentially harmful or both. For these reasons we recommend that you only use reliable sources of information when considering interventions. Reliable sources include:

- National Institute for Health and Care Excellence (NICE) at www.nice.org.uk UK agency which provides national guidance and advice to improve health and social care.
- Research Autism at www.researchautism.net UK charity which is dedicated to high-quality research into autism treatments, therapies and other approaches.

Rights

As the parent or carer of a child on the autism spectrum you have certain rights, especially if your child has a formal diagnosis of autism. For example, in England, children with special educational needs are entitled to receive an Education, Health and Care (EHC) plan from the local council. This document provides an assessment of your child's needs and also sets out the education, health and social care services that he or she must receive. Parents and carers in the other countries in the UK have similar rights, although the details vary from one country to another.

Services

NICE has made recommendations about the delivery of care to children and young people on the autism spectrum. This includes a recommendation that local services should work with and support the families of children and young people on the autism spectrum. It also recommends that local services should be coordinated by a local autism multi-agency strategy group. For details of your local strategy group please contact your local council. In addition

- your primary health care trust may provide health and therapeutic services — such as speech and language therapy, occupational therapy, physiotherapy etc.
- your local education authority may provide a range of services — such as a placement in a specialist nursery or school or support from a Special Education Needs Coordinator (SENCO) in a mainstream nursery or school
- your local authority may offer home-based social services — such as home adaptations, access to recreational and educational facilities, respite care etc.
- central government may provide financial benefits — such as universal credit
- other organisations may provide a range of other services and forms of support — such as advocacy, legal advice, online support, parent training, residential care etc.

For more information about organisations which provide services and support (some of which may also be able to advise you on your rights) please see the next page of this leaflet).

Organisations

- ASD Info Wales at www.asdinfowales.co.uk The national site for autism in Wales providing information on autism and implementation of Welsh autism policies
- Autism Alliance at www.autism-alliance.org.uk The major UK network of specialist autism charities providing a range of services and expertise
- Autism NI at www.autismni.org Parent led organisation which promotes collaboration between parents, professionals and individuals on the autism spectrum in Northern Ireland
- Irish Society for Autism at <http://autism.ie> National charity for people on the autism spectrum, parents and carers in the Republic of Ireland
- National Autistic Society at www.autism.org.uk National UK charity for people on the autism spectrum and their families providing a range of services and expertise
- Scottish Autism at www.scottishautism.org Scottish charity that exists to help those diagnosed with autism to lead full and enriched lives.

Portals

- Autism and Asperger support at <http://tinyurl.com/j853r52> NHS directory which provides details about services, schools, support groups, training courses etc in the UK
- Autism Connect Service Providers at <http://autism-connect.org.uk/index.php/users/providers> Autism Alliance directory of autism-friendly service providers within the UK
- Autism Services Directory at www.autism.org.uk/directory.aspx National Autistic Society directory which lists thousands of organisations and other resources in the UK.

Forums

- ASD-Friendly at www.asdfriendly.org UK discussion forum which provides a support network of parents with autistic and Aspergers children
- Autism And Aspergers In The Family at <http://autismandaspergersinthefamily.freeforums.org> UK discussion form for parents, carers and professionals
- Autism Connect at <https://autism-connect.org.uk> Autism Alliance run social network for people on the autism spectrum and their families
- NAS Community at <http://community.autism.org.uk/discussions> National Autistic Society run forum where you'll find people talking about autism.

Further information

Additional information on children and young people on the autism spectrum, including links to more organisations and resources, at www.researchautism.net/children-and-young-people

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