

Autism in Northern Ireland



The Facts

This booklet is produced by Autism NI the local Autism Charity in N Ireland. Autism NI was formerly known as PAPA but we changed our name in 2006.

The booklet has 3 sections. The first section provides information on Autism and Asperger's Syndrome. The second section provides some advice for parents in N Ireland, the final section provides information on Autism NI and other information resources we produce. At the very back of the booklet there is a list of early signs of ASD in children between 18-24 months. Further information on early signs of ASD and what to do next is in our information for GPs booklet. If you need to discuss any of the issues in this booklet there are a variety of ways you can contact us:



Phone our Autism Helpline Monday, Wednesday, Friday 9.30am - 1pm 0845 0559010; Phone our Central Offices at any time and leave a message and someone will return your call 028 9040 1729; email us on help@autismni.org.

What is Autism?

Autism is a disability which disrupts the development of social and communication skills. The term Autism Spectrum Disorder (ASD) is used because Autism varies from person to person. Around 50% of people with ASD will have an accompanying learning disability. Some people with ASD will have average or above average intelligence, they are likely to be diagnosed with Asperger's Syndrome; this booklet has a section on Asperger's Syndrome starting on page 7. Regardless of an individual's level of functioning all individuals with an Autism Spectrum Disorder will have problems in the areas of Communication, Social Skills and Imagination. The section that follows will explain each of these in more detail.

Impaired Communication

Difficulties in using and understanding verbal and non-verbal communication are common in children with ASD. Impairments can be found in these areas:

- The development of spoken language – often no speech
- Responses to the communications of others – e.g. won't look
- Failure to initiate or sustain conversations – e.g. turn taking
- Pronoun confusion – e.g. "I" vs. "You"
- Stereotypical and repetitive use of language – e.g. using lines from a favourite cartoon or film to communicate
- Unusual highly personalised use of words and phrases – e.g. a child always salutes when given a direction while saying "yes sir"
- Abnormalities in pitch, stress, rate, rhythm and tone of speech

Communication involves both understanding language – receptive skills and providing information – expressive skills. The abilities of individuals with ASD vary widely in that some children will have a good grasp on comprehension – e.g. sit down but lack expressive skills e.g. my tummy hurts and vice versa. Many children with ASD experience difficulty with non-verbal communication – such as, eye contact, facial expressions and smiling. Children with ASD often fail to understand words or phrases that are abstract – e.g. we'll go swimming later" or "I love you" or that have a double meaning – for example, the teacher says to a child with ASD, "clear the table" and he goes over and pushes everything off it. Or the person may interpret things very literally – e.g. "give yourself a hand".

Some children have Echolalia, which is the repetition of words, signs, phrases or sentences spoken by other people. Some children use this as a communication device – for example, the adult says “do you want a car?” and the child might say “want a car” to mean yes. A child may repeat the same phrase over and over again as a means of regulating their own behaviour – such as, a child repeats aloud “time to clean up” while cleaning.

Impaired Social Skills

ASD is characterised by an impaired ability to engage in social relationships and can result in serious deficits in the ability to make friends. In fact, children with ASD often behave as if other people do not exist. This is demonstrated in various ways including failure to respond to their name when called, appearing not to listen when spoken to, unusual or inappropriate facial expressions, avoidance of eye contact, failure to respond to affection and sometimes treating people as if they were objects. Often children will acknowledge an adult only for the purpose of getting a need gratified and will return to ignoring the adult thereafter.

If a child with ASD has any social skills, they are characteristically learned and awkward in nature. Individuals with ASD also experience problems maintaining reciprocal relationships. Additional difficulties include the inability to take on another’s perspective, feelings and emotions, or provide or seek comfort, in conventional ways – for example, a child with ASD hurts another child and cannot understand why he is crying. Individuals with ASD tend to crave predictability and function best in highly structured situations. They are likely to become extremely dependant on elements of sameness in their lives, to the extent that they can have difficulty coping with changes in their environment or routine.

Impairments in Imagination

Children with ASD may have problems with imaginative play. They may not see a toy car as a car but rather as an object that rattles and makes funny patterns when the wheels are spun. This may account for part of the reason why such children have difficulty interacting with peers and joining in games with others.

Children with ASD typically have a narrow range of interests. They also may engage in repetitive, stereotyped body movements such as hand flicking, spinning or rocking. They may insist upon carrying certain objects around with them to help them feel secure. Need for sameness might extend to food. An individual with Autism may have a preference or dislike certain colours, textures or temperatures of foods. Some individuals focus on certain topics of interest. The person might remain intrigued with one or two topics such as music or modes of transportation, and exhaust everyone who comes into contact with him about their knowledge in that area of interest.

Sensory Difficulties

More often than not, individuals with ASD have unusual reactions to sensory stimulation. Some individuals show a hypersensitivity to stimuli – e.g. can hear lights buzzing, cannot tolerate touch, fascinated with spinning objects, must smell everything while others display a hyposensitivity to stimuli – such as a high pain tolerance or acting as if deaf. A person with ASD may be fascinated with a piece of shiny paper or may spend hours rocking or watching objects twirl. In general these types of reactions are providing some sort of sensory stimulation for the individual. An assessment by an Occupational Therapist will help your child if he/she is experiencing sensory problems.

Variability of Intellectual Functioning

A characteristic of people with ASD is the wide range of functioning within which they can fall. Individuals with ASD can be severely impaired to the extent that they are unable to talk or to perform independent living skills, or they may be functioning in the above-normal range of intelligence. Some people go to university, and have a career, many get married and have a family.

Uneven Development Profile

People with ASD have an uneven development profile. Being able to function in some areas at levels perhaps higher than their overall level of functioning. For example, a five year old with ASD may be reading books at a Primary 4 level while his self-help skills are at his own age level and his social skills are non-existent.

Difficulties in Sleeping

Some children with ASD have trouble falling asleep or require only a few hours of sleep each night to function. This can be extremely difficult for parents/carers who often sleep in shifts to prevent the child from getting into difficulties around the house.



What causes ASD?

Research suggests there is no single cause but that there is a physical problem affecting those parts of the brain that integrate language and information processed from the senses. ASD has a physical origin, not an emotional one.

Autism Information

ASD affects more males than females and it is estimated that one person in every hundred has an ASD. ASD can be diagnosed by the age of three, although some children are diagnosed earlier and some people may not receive diagnosis until their adult life. There is no known cure, but with appropriate education and support people with ASD can be helped to live their lives with as much dignity and independence as possible.

There are many different types of intervention for ASD; finding the right intervention for your child and your family can be a difficult decision to make; there are professionals who will advise you on this. The Autism NI booklet, *Journeys*, outlines the major intervention approaches for ASD and is available by contacting Autism NI.



Asperger's Syndrome

Some individuals may receive a diagnosis of Asperger's Syndrome; Asperger's Syndrome is an Autism Spectrum Disorder.

Features of an Asperger's Syndrome Diagnosis

- Individuals with Asperger's Syndrome may have average or above average intelligence
- Individuals with Asperger's Syndrome may not have experienced a delay in language development as children but may have had an unusual language development. Such as being very talkative from a young age and using language expected from much older people
- Individuals with Asperger's Syndrome may be very clumsy and poorly co-ordinated
- Individuals with Asperger's Syndrome may be very talented in a certain area

and excel in this, but have real problems with practical tasks and organisation

It is important to remember that Asperger's Syndrome is not "mild" Autism.

Lorna Wing (Burgoine & Wing, 1983) described the main clinical features of Asperger's Syndrome as:

- Lack of empathy
- Naive, inappropriate, one-sided interaction
- Little or no ability to form friendships
- Pedantic, repetitive speech
- Poor non-verbal communication
- Intense absorption in certain subjects
- Clumsy and ill-coordinated movements and odd postures

This list of features is not exhaustive, nor is it totally inclusive of all people with Asperger's Syndrome.

How does it feel?

Many people with an ASD have written about their experiences; some people who have been diagnosed find it helpful to read these experiences as it helps them to feel that they are not alone. A list of these accounts is available from Autism NI. The quotation below is from a book written by a young man called Marc Segal explaining how he felt. His book "Coping a Survival Guide" has been helpful to many young people with Asperger's Syndrome.

"As far back as I can remember, I had intricate thoughts and ideas which have made me unique. As a young child in early primary school I used to spend most of my time just doing my own thing and not really making

much sense to people. My ever intriguing thoughts and ideas were locked up in my head and I couldn't communicate them with others".

Local Wisdom

Here is some advice from local people who have children with ASD.

Rosemary, Bangor:

Diagnosis isn't the end of the world. It's the start of a fascinating, challenging journey for you and your child. No it isn't easy, but raising what child is? It's up to you (the parents) to make sure your wonderful individual achieves the most they can to fulfil their potential for a wonderful life."

Kathleen, Newry:

"Do I disclose my child has suspected ASD or has been diagnosed with ASD when applying for a place in a mainstream Nursery/pre-school?"





Some parents can be anxious that a Nursery or Pre-school will refuse to admit their child because of the diagnosis. Often mainstream Nurseries / Pre-schools obtain extra funding for a disabled child so a diagnosis of ASD should not hinder your child being accepted into your choice of placement for your child. Furthermore if a school has reached its enrolment figure and is full there is a possibility of

an extra placement being offered to a special needs child”.

Claire, Lisburn:

“My piece of advice would be to obtain a “buddy” card which allows the carer of a disabled person to gain free entry into the Lisburn Leisureplex and Island Arts Centre. When filling in the form put “Autism” as an explanation of the person’s disability and not Asperger’s as

some staff have not yet heard of Asperger's and this has resulted in delayed applications. The buddy card belongs to the person with Autism and may be used by a parent or any other carer. The Movie House Cinemas have a similar system of free entry for a carer that is worth investigating if your loved one enjoys the cinema. Other venues may have reduced or free entry for carers and my advice is always to ask. Lisburn Leisureplex also has priority queueing system, just show your Autism NI membership card".

Maire, Derry City:

"Many parents feel despair when their child is diagnosed, they feel helpless and want others to fix things for them. The reality is we each have to fix things ourselves by getting involved, organising, planning and pushing to get help. No-one can help us, we have to help ourselves, but by joining with other parents we can get the strength and courage to do this. We mustn't forget that parents who organise are parents

themselves, who are equally despairing and are doing their best. Getting involved by helping others helps me cope. Don't be too submissive with professionals - don't be put off, stick at it until you get a diagnosis. Don't take no for an answer - mobilise to get services, join with other parents and be a strong voice. It will not only help ultimately your child, it will help all the other children who need services. You will feel better if you feel you can do something".

Patricia, South Down:

"Being a member of a positive, supportive, informative Autism NI branch allows a parent/carers to understand and accept the reality of Autism as well as empowering and supporting them in their struggle to find and obtain whatever services are necessary to enable their child to reach their full potential".



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Desire for sameness



Loner



Socially inappropriate



Eccentric

Celina, Fermanagh:

I would say to any parent that they should not lose faith in their abilities as a parent and that they should celebrate their child's or family's achievements on a day to day basis, for example when Alex said mummy for the first time and was referring to me and not a Thomas the Tank engine, and the first time he pooped in the toilet were truly momentous days for both of us. Sometimes just making it through the day is an achievement for all of you but when something is done that you've been working really hard to instill in them then praise not only the child/ adult with ASD but look in the mirror and say well done you, you're not a useless parent after all.

Eilish, Belfast:

"Having someone in your household with ASD makes you a different family. I wish someone had told me that it's all a question of balance. Yes you must embrace the uniqueness but you must always seek normality".

About Autism NI (PAPA)

Autism NI (PAPA) is Northern Ireland's main Autism charity. Formed in 1989 by a group of parents and professionals concerned by the lack of ASD services in Northern Ireland, Autism NI (PAPA) now has over 800 individuals, family and agency members and a network of support groups that provide a range of educational talks and family based activities in local communities.

Our Mission Statement is:

"To ensure that people with Autistic Spectrum Disorder and their carers have access to appropriate services, enabling people with Autism to be valued members of their community".



The main areas of our work are:

- Raising awareness
- Research
- Branch support network
- Helpline
- Library and resources
- Training
- Responding to enquires
- Conferences and workshops
- Political lobbying
- Policy change/Strategic Planning



More about Autism NI

- We have 14 parent support branches throughout Northern Ireland and 2 support Groups
- We have Autism Ambassadors in each of the main Political Parties in Northern Ireland
- Our campaign for the Northern Ireland Autism Act has full cross party support
- We have a wide network of local, national and international partners both statutory and voluntary
- We were commissioned by the DHSSPS to be the Training agency for ASD in Northern Ireland



- All of our management and development staff are professionally qualified in areas related to ASD i.e. Social Work, Psychology, Counselling and Teaching
 - Our Autism NI Helpline is operated by professionally trained staff
 - Our Board of Directors is a balanced partnership of parents/professionals and individuals with ASD
 - Autism NI leads the way in ASD research in Northern Ireland
 - The Jigsaw of Early Intervention for ASD is being developed throughout N Ireland. This model takes the form of home intervention and specific resources and training for parents and professionals.
- We have produced an educational CD and DVD for parents and professionals
 - We are a pioneering force for policy/strategic development for ASD in Northern Ireland
 - We host conferences with worldwide experts on ASD in Northern Ireland
 - International Conference every 3 years
 - We are involved in ongoing research, training, parental support and political lobbying
 - We operate an on-line bookstore at www.autismni.org/bookstore.
- Autism NI provides a range of family support training.
- ACCESS parent discussion workshops
 - Grandparent workshops
 - Autism and You training for carers
 - Sibling Workshops
 - Social Skills workshops
- Contact Autism NI to find out what is available in your area

Autism Consultancy and Training (ACT)

Autism NI also provides a range of awareness and specialist training opportunities for professionals and carers. Please check out our website for further information.

www.autismni.org/training

Contact Autism NI to find out what is available in your areas.

Other resources produced by Autism NI

- Information leaflet for GPs
- Asperger's Syndrome and Mental Health
- Journeys: Choices not Solutions
- Autism PSNI and Emergency Services Fact booklet
- Keyhole® Rainbow Resource Kits and Training Manuals
- Autism NI Training Prospectus
- The Jigsaw of Early Intervention



Research we have been involved in

- Evaluation of the TEACCH Approach for children and adults in Northern Ireland (1996) Commissioned by the DHSSPS conducted by Autism NI (PAPA) and The University of Ulster
- NI Diagnostic Scoping Study (1998). Commissioned by the DHSSPS conducted by Autism NI (PAPA) and The University of Ulster
- The Task Group on Autism (2002) DENI. Autism NI (PAPA) was on the steering group of the Task Group which sought to develop and advise on good practice for Education in Northern Ireland
- The Keyhole Early Intervention Programme for children with ASD (2003) conducted by Autism NI and The University of Ulster. The Keyhole approach for Early Intervention is now being delivered in Northern Ireland and has been developed into an Autism NI training package
- Western Autism Support Project (WASP) (2004-2007) partnership between WHSSB and Autism NI to provide an early intervention therapist in the WHSSB area
- Evaluation of pre-school services for Autism in Northern Ireland (2006) Autism NI and The University of Ulster. Commissioned by DENI
- Connecting with Autism (2006) project to work with families to improve social communication with children with ASD
- Political research published in the Government and Autism report (2006) by Autism NI and Autism Cymru. Investigates UK and Worldwide provision for ASD and sets out a case for a separate programme for ASD
- Partnering North and West and South and East Belfast Trusts. The Orchardville Society and the Now Project in an EU funded research project into supported employment and ASD

Appendix

Early Signs of ASD – a child may demonstrate none, some or all of these symptoms

- The child begins to develop language then loses it or doesn't acquire language
- The child may appear deaf because they respond unevenly or not at all to sounds
- The child may have difficulty during transitions
- The child may have difficulty sleeping
- The child does not "point and look"
- The child may experience failure to bond (e.g. child is indifferent to parents' presence)
- The child may have limited imaginative play
- The child may not be interested in playing with other children
- The child may have impairments in social relationships

All individuals with ASD demonstrate varying degrees of the following:

- Deficits in communication and language
- Intense interest in certain interests or activities
- Dependence on routine
- Sensory problems
- Behaviour problems
- Variability of intellectual functioning
- Uneven development profile
- Difficulties in sleeping, toileting and eating

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