

A Guide

On

Autistic

Spectrum Disorders



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About this Pack

The implications of having a child with an Autistic Spectrum Disorder (ASD) are diverse and long term. Autism Northern Ireland is dedicated to improving the quality of life for those with ASD and their families/carers. This pack can not provide all the answers but we hope it will be a useful initial resource for you.

In presenting this pack Autism NI hopes that:

- * You are provided with relevant information
- * You will take the opportunity of joining a branch of our regional support Network

This pack has been evaluated by professionals and parents of children with ASD. Their comments were very much appreciated.

Information Resource Pack

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About Autism NI

Mission Statement

'To ensure people with autism and their carers have access to appropriate services, enabling people with autism to be valued members of their community'

Autism NI was formed in 1989 by a group of concerned parents and professionals and is a registered charity in Northern Ireland specifically aimed at promoting the needs of people with an Autistic Spectrum Disorder and their carers.

Autism NI is based in Donard, Knockbracken Healthcare Park with an extensive suite of offices and training facilities.

Autism NI has:
~ 20 Branches/Support Groups
In Northern Ireland
~ E-Bulletin

Autism NI is involved within the areas of:
~ Liaison with Statutory Services
~ Lobbying
~ Advocacy
~ Training

~ Fundraising
~ Partnership
~ Ongoing Research
~ Supported Employment

Autism NI Board of Trustees

The PAPA Board membership consists of professionals, parents of children/ Adults with ASD and members with ASD.

Autism NI Council

Council members are nominated by and from the membership and Branch Network.

This body exercises considerable influence over the broad direction of the Charity, acts as a vital link between Branches and the Central Organisation.

Autism NI Staff

The Chief Executive is responsible for the overall management, direction and strategy of the charity. The Development Team are responsible for Branch activities, Project work, advocacy and support. Training is Coordinated By ACT (a division of Autism NI). The Administrative Team are responsible for all administrative work, book sales and conference coordination

The Autistic Spectrum

An autistic spectrum disorder is a complex developmental disability that affects the way a person communicates and relates to people around them.

“Why is the term autistic spectrum used?”

The autistic spectrum is vast with each child having an individual space upon it.

For example a person with Asperger's Syndrome may be at the 'more able' end of the spectrum where as Kanner's Syndrome (sometimes referred to as Classic Autism) may be at the less able end of the spectrum.

People with an Autistic Spectrum Disorder may be of above average, average or below average ability and their Autism can affect them to a greater or lesser extent. Everyone is different. How their autism affects them may also change with time. Generally all those affected have difficulties with social interaction, social communication and imagination.

This is known as the 'Triad of Impairments'

Triad of Impairments

The most common diagnostic criteria in ASD are based on the Triad of Impairments

Social Interaction

...may often appear aloof indifferent to others. May not initiate social contact nor make inappropriate social contact - little attention to responses of others.

People with Asperger's Syndrome, unlike those with 'Classic Autism', who may appear withdrawn and uninterested in the world about them, may try to be sociable and do not dislike human contact. However, they still have difficulty with social timing and non verbal communication, including facial expression.

Social Communication

...may not appreciate the social uses and pleasures of communication. May not understand that language is a useful tool. May have literal understanding and/or have difficulties in comprehending and processing verbally presented information. People with Asperger's Syndrome may speak very fluently but they may not take much notice of the reaction of others. May "talk at" others, particularly regarding subjects of interest to them.

Imagination

...may be unable to play imaginatively with objects, toys or other children. Tend to focus on minor or trivial things around them - may have a limited range of imaginative activities. May be rigid and resistant to change. People with Asperger's Syndrome often excel at learning facts and figures, people with AS find it hard to think in abstract ways. This can cause problems for children in school where they may have difficulty with certain subjects such as literature or religious studies.

Associated features which may or may not be present often include repetitive and stereotypical behaviours ~ e.g. body movements, preoccupation with certain objects or activities, etc. There may also be sensory issues such as over or under sensitivity of touch, taste, smell, hearing, sight or movement.

Diagnosis

Your child may already have a diagnosis of ASD

Or

You may only now be recognising the signs

Importance of Diagnosis – One Parent's Perspective

"When the school suggested getting outside help to try to find out the cause of his difficulties I gratefully agreed. I saw a multitude of professionals. Soon I

became completely saturated and my heart would sink as I went to the next appointment. In fact it took over a year to find out. Not knowing was torture, and the helplessness I felt was soul destroying. One can't fight the unknown.

When the diagnosis came I just felt intensely relieved. Finally I had something concrete to work on, ASD. I hadn't heard of it, but I quickly resolved to read up on it and become as knowledgeable as possible in order to help my son.

I don't recollect feeling the intense grief one is supposed to feel. I believe that grief is not something one works through, accepts and moves on. I believe that grief is an ongoing emotion. Most of the time it is dormant as we move through daily life, then suddenly it can stab us when we are least expecting it. When other children say derogatory things, when I see my child struggling to cope, when other parents talk about the future and marriage and I realise that my children may never achieve it.

No, grief is an emotion that parents of children with autism can never be totally free of.

To label or not to label? In my opinion diagnosis is not about labelling, it's about embarking on a journey, a journey to knowledge and the chance to make life that much easier for the child with autism. The autistic spectrum is vast with each child having an individual space upon it.

One must first learn the difficulties that autism presents before it is possible to understand the many varieties of behaviours and the meaning behind them. Again one cannot fight the unknown.

As Richard Exley (1995) a young man with Asperger's Syndrome points out **'Autism is not a label, it is a signpost'**.

I sometimes think of diagnosis as a gateway that one must work through. It's a password that opens up avenues of information. If one can access it, it brings knowledge, understanding, and compassion and gives tools to build a solid structure from which to work on. It is difficult to get a statement of special educational needs without a diagnosis, without a statement it can also be difficult to access services and support.

..... AS is not an apology, it's a unique condition that has given me a unique child. I feel unaccountably proud of my children's achievements that they are both doing remarkably well at school. With their teaching assistants help, they are on course to lead fruitful and independent lives. I am grateful that if it is the case that I have been chosen to share my life with two such remarkable kids.

Children with Autism can achieve. Don't write them off. Don't give up trying even when you feel you are getting nowhere. What may seem like small progress to you may be so much more precious to us. By being open minded and reflective in your practice you can make a difference.

As Marc Fleischer, an adult with Asperger's Syndrome says, '**Autism is like having heavy shoes on, but you can climb mountains in heavy shoes.**' (Fleischer 1994)

Sally Blackburn (Parent)

Recent thinking recognises that if ASD identified early in a child's life it enables more effective intervention. Early diagnosis and intervention also helps to ensure families and carers have access to appropriate support. If you suspect your child has problems in any of the areas outlined, the first step is to go to your local G.P. and request a referral to your local consultant community paediatrician.

Autism NI booklet.....

'Important facts about Autism and Asperger's Syndrome for GPs'

.....available from Our Website.

Who's Who?

General Practitioner (GP)

GP's are doctors who are often the first point of call for health services. GP's are responsible for the general health of people with ASD but do not usually make the diagnosis. They may refer you to a paediatrician.

Paediatrician

Community Paediatricians are doctors who are specialists in the health and development of children. They are experts in the examination of children and are often called upon to diagnose children with Autistic Spectrum Disorders.

Child Development Team

A group of medical and non-medical professionals often coordinated by a Community Paediatrician. Team members typically include psychologists, speech and language therapists, occupational therapists, advisory teachers and early intervention therapists. Their main goal is to produce a comprehensive assessment of development which helps to make a diagnosis and to plan a programme for the individual.

Psychiatrist

Psychiatrists are doctors who specialise in understanding how developmental disorders, such as Autistic Spectrum Disorder can affect children's or adults' behaviour, emotional adjustment and social relationships. They may also advise on the use of appropriate medication.

Clinical Psychologist

Clinical Psychologists specialise in the natural development of learning, behaviour, emotional adjustment and social relationships. They usually specialise in helping either children or adults and are understanding of the nature and impact of developmental disabilities such as Autistic Spectrum Disorder and may be involved in diagnosis.

Educational Psychologist

Educational Psychologists aim to promote the learning and development of children and young people, and are involved in the statementing and placement of those with special educational needs.

Special Educational Needs Coordinator SENCO

SENCOs are teachers who have responsibility for pupils with special educational needs. They operate the "Code of Practice" which is a five stage legal framework of support for children with special educational needs.

Special Educational Needs

Each Education and Library Board has a Special Educational Needs Dept. which is responsible for children with Special Educational Needs.

Advisor/Field Officer for Autistic Spectrum Disorders

Referrals are made to the Support Teachers by Special Education. To ensure that the needs of each pupil are met in the most appropriate way, many factors will be considered when deciding on the best model of support.

Educational Welfare Service

The Educational Welfare Service is a specialist education support service which seeks to help young people and their families get the best out of the education system.

Speech and Language Therapist

Speech and Language Therapists can help to promote language and communication in people who have developmental disabilities including Autistic Spectrum Disorder. This can often be supported effectively through teaching techniques using visual schedules, visual instructions and individualised communication systems.

Health Visitor

Health Visitors are specially trained nurses responsible for the promotion of the health and development of pre-school children. Concerns about development may be first raised with or by a health visitor during routine developmental assessment in the home or clinic, leading to referral on to other professionals.

Social Worker

Social Workers can be accessed via the child development clinic and the Children with Disability social worker team. They provide an opportunity for parents to discuss, in confidence, their needs and access information on a range of Statutory Services and those provided by voluntary and private sectors. Assistance may be given in checking that families are receiving all their state benefit entitlements along with advice on applying for benefits. Information can be given on short breaks and respite services, support groups for young people and carers. Social Workers are critical in the carer's assessment process which can be a gateway to assessing support services.

Dietician

Dieticians provide advice, information and teaching on nutrition and diets. Your GP, paediatrician or hospital consultant can refer your child to the dietician.

Occupational Therapist

Occupational Therapists understand how developmental disorders can affect activities of daily living. Occupational Therapists give practical advice to parents and carers about how to reduce everyday practical problems faced by people with Autistic Spectrum Disorder. Sensory integration therapy is used by Occupational Therapists to treat the sensory issues and motor problems commonly seen in individuals with Autism.

Early Intervention

In Northern Ireland increasing numbers of preschool children are being identified as having an Autistic Spectrum Disorder (ASD) Recent research conducted by the University of Ulster and coordinated by Autism NI (Keyhole® Early Intervention Programme 2003/2006) clearly proves the effectiveness of early intervention. This involves the provision of a seamless service pathway from initial referral, through diagnosis to the development of an individual intervention plan. This incorporates home based teaching strategies, training and an ongoing support service in terms of enhancing provision for children with Autism in pre-school settings. (Details are available at www.autismni.org)

'The most effective programmes for students with Autism are those that incorporate a variety of best practices'
(Hefl in & Simpson, 1998)

In addition the following strategies have been shown to be beneficial (Task Group on Autism Report, Department of Education N.I. 2002)

- ~ One to one planning and work with the child
- ~ An emphasis on the promotion of communication
- ~ An emphasis on a visual approach
- ~ Developing the child's skills for independence

Various agencies, both voluntary and statutory, have responded to parents and children's needs by developing an early intervention service and there are examples of good practice in parts of Northern Ireland which Autism NI believes should be universally available for all those who have an early diagnosis of an Autistic Spectrum.

Model of Good Practice

- ~ the provision of multi-disciplinary assessment teams
- ~ home based early intervention programmes
- ~ support of pre-school facilities and personnel
- ~ training packages for parents and professionals

Education

The Education (N I) Order 1996

The Education (Northern Ireland) Order 1996 underpins a code of practice on the identification and assessment of Special Educational Needs. The code of practice addresses the identification, assessment and provision to be made for all children who may have special educational needs at some time in their school careers or even earlier.

For some children with autism, mainstream education is both appropriate and desirable. With the support and advice of professionals adaptations can be made to meet their individual and special needs. For others, however, the

mainstream environment can be overwhelming and confusing and high quality specialist education may be more appropriate.

Many children with an ASD will require a Statement of Educational Need which gives a legal entitlement of support. The timescale from assessment to proposed statement is 18 weeks.

For further information, contact:

Special Education Branch

Department of Education

Rathgael House

43 Balloo Road

Bangor BT19 7PR

Telephone: 02891279939

Ask for Special Educational Needs ~ A Guide for Parents

Special Educational Needs Advice Centre

SENAC is a registered charity which provides the following services:

A telephone advice line offering free and independent advice on Education and Library Boards' duties towards children with special educational needs.

Assistance for parents appealing Board decisions to the Special Educational Needs Tribunal. Where possible SENAC provides free representation for parents at Tribunal hearings.

Tel 028 90 705654

DARS is a service which is provided by the Education Authority.

Work – Adult Services

Many people with Autism go on to further education or employment. For others the transition from school to adult life can be a positive time but also can be an anxious time for all concerned. If the young person receives support from social services the responsibility for that supports will transfer from children's to adult services soon after they leave school. Social services must therefore carry out an assessment of their needs.

For others an option may be to attend a further education college post 16 years of age where they can access courses concentrating on personal development, work skills, vocational training, etc. We must, however, acknowledge the importance of these programmes being suitable for those with ASD. It is vital that there is appropriate training on awareness of autism for those that both

design and deliver such programmes. There are a number of community and disability organisations that provide vocational training for people with disabilities.

Orchardville Society & NOW Project (Belfast)

They provide a limited Job coach/employment support service for individuals on the Autistic Spectrum.

Orchardville Society: 02890 732326

NOW: 02890 436400

Autism Initiatives

Autism Initiatives is a registered charity recently established in Northern Ireland. It provides care and 'hands on' support for people with ASD in supported housing, through outreach services and in their registered residential facilities throughout the province.

Telephone: 02890791875

Strengths of Employees with an ASD

Willing to do repetitive tasks

Rarely absent

High tolerance of boredom

Consistent

Honest

Efficient, competent, reliable

Punctual

High level of accuracy

Autism NI Support Network

Branches

Autism NI has a network of branches across the North of Ireland which meets regularly to support parents, professionals and people with ASD. The branch contact is usually the branch chairperson and may be the parent of a child with an Autistic Spectrum Disorder.

South Belfast

East Antrim

Lisburn

Craigavon/Banbridge

North Down & Ards

North West

Newry & Mourne

North Coast

Fermanagh

Dungannon

Mid Ulster

Down

Omagh

West Belfast

Ballymena

Crumlin

South Down

For further information on Branch Meetings and Activities please see our website www.autismni.org/branches.

Various Approaches

TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children and adults)

Division Teacch began in North Carolina in 1966 as a research project. The project, led by Eric Schopler and colleagues, developed from clinical expertise at the University of North Carolina. Since its foundation Division TEACCH has developed in many parts of the world and is commonly used by Health and Education Services in Northern Ireland.

Central to TEACCH is a system of structured teaching, which maximises the visual presentation of information and also helps to physically structure the environment. This structure aims to make use of the strengths of people with Autism, their visual skills and adherence to routine, and use those strengths to help minimise their difficulties. Further principles of TEACCH include the importance of individualised assessment and close parent collaboration.

For further information, contact:

Division TEACCH

The University of North Carolina at Chapel Hill

Telephone 001 919 966 2174 Website: www.teacch.com

Son-Rise Program (Options approach)

This approach was developed in Massachusetts, USA by parents of a child with Autism over 20 years ago. The Son-Rise Program is a home based, child centred, parent directed programme involving the help of volunteers. The aim is to encourage the child to be self motivating via non confrontational and unconditional acceptance.

For further information, contact:

The Son-Rise Program at the Autism Treatment Centre of America

2080, South Under mountain Road

Shefield, Massachusetts 01257, USA

Telephone: 001 413 229 2100

Email: sonrise@option.org

Website: www.son-rise.org

Applied Behavioural Analysis (Lovaas)

This is a behavioural approach whose foundations are built on the premise that learning can be reduced to the repetition of responses, which increase with reward. In this way a task to be learned can be analysed into small steps which are then used as a teaching programme for the child. Each step can be shaped through positive reinforcement. It is an intensive intervention, which can take up to 40 hours per week.

For further information, contact:

PEAT (Parents Education as Autism Therapists)

Telephone: 028 90324882

E-mail: PEATNI@aol.com

SPEAC: www.speac-centre.org Tel: 02890 921270

CEAT: www.ceatni.net Tel: 02890 659678

Diet

Many parents report that their child has certain intolerances to a variety of foods while others have recorded how eating certain food has resulted in an increase in negative behaviours. Dr Shattock at the Autism Research Unit at the University of Sunderland has undertaken a study of the effects of diet on the population of people who have Autism.

For further details, contact:

The Autism Research Unit

The School of Health Sciences,

University of Sunderland, Sunderland SR2 7EE

Telephone: 01915108922 Website: <http://osiris.sunderland.ac.uk/autism>

Choosing an Approach

What's best? Consider.....and ask!

- ~ How long has this approach been in use?
- ~ What about research and evaluation?
- ~ Can it be used with other approaches?
- ~ How much does it cost?
- ~ How will this approach affect my family?
- ~ Beware of an approach which states it can cure ASD

While many approaches have been found to be effective no single approach has yet been found which is effective with all those who have ASD. An individual assessment is crucial and an approach that is flexible taking account of the individual is likely to be the most effective way forward.

Help

Your child may be eligible for DLA (Disability Living Allowance)

Disability Living Allowance is split into two components:

- * Care Component - Paid at three levels low, middle and high
- * Mobility Component - Paid at two levels low and high

Contact DLA Branch, Castle Court, Belfast 02890 336556

You may be entitled to ICA (Invalid Carers Allowance)

If you are earning less than a set weekly amount and unable to work full time because you are caring for someone receiving DLA you may be entitled to this allowance.

Contact ICA Branch, Castle Court, Belfast 02890336000

Child Tax Credit

Parents of children with a disabled child will receive a higher rate of Child Tax Credit.

Domestic Rates Reduction:

If you have a person in your household receiving DLA you may be entitled to a Domestic Rates Reduction:

You may be exempt for rateable value of a bath room, a "therapy" room and central heating.

Contact your local Rates Office

You are entitled to a Social Worker from the Children's Disability Team

Contact Social Services or ask your G.P. for a referral.

You may be Eligible for Respite Care

Talk to your Children's Disability Team Social Worker about respite care. This can be in different forms to suit your needs. Often there is a waiting list so get your name down early.

Zero Rating VAT

Certain goods and services for disabled people can be zero rated VAT.

Details can be found by calling 08450109000

or visiting: <http://www.hmce.gov.uk/forms/catalogue/catalogue.htm#700>

(Notice 701/7 VAT Relief for disabled people)

Family Fund

The family Fund makes available grants to families with disabled children.

Support from this charity is means tested.

Website www.familyfundtrust.org.uk Email info@familyfund.org.uk

Free and Reduced Admission and Fast Tracking

Many places in Northern Ireland offer free admission or reduced rates for disabled children and sometimes for their carer too. Also some establishments will allow disabled people to fast track queues. Your Autism NI membership card can be used as proof of disability.

e.g. Belfast Zoo

Ulster Folk & Transport Museum

Swimming Pools

Horse Riding

Free Nappies

Children who are not toilet trained because of a medical reason may be entitled to receive free nappies. Contact your Health Visitor

RADAR Key

Disabled children and Adults can purchase a Key for RADAR Disabled Toilets. Contact your Local Council Office

General Aids

For some people with autism the provision of equipment can enhance family life e.g. special car restraints for children. Ask your GP to refer you to Occupational Therapy.

Other Funding

Other funding bodies can be approached for specific needs. Contact you local Citizen's Advice Bureau for details of what might be available.

Useful Websites

Autism Support

Autism NI – www.autismni.org

Irish Society for Autism (ISA) – www.iol.ie/~isa1/

ASPIRE (The Asperger's Syndrome Association of Ireland) – www.aspire-irl.com

Asperger's Syndrome Info & Support – www.udel.edu/bkirby/asperger/

National Autistic Society – www.nas.org.uk

Government Websites

Department of Education Northern Ireland – www.deni.gov.uk

Department of Education and Science, Republic of Ireland www.education.ie

Personal Pages

Ben's Asperger Room – www.asperger-syndrome.com

Wendy Lawson – www.mugsy.org/wendy

Further Reading, Links & Resources

Autism Resources – www.autism-resources.com

Autism Connect – www.autismconnect.org

Tony Attwood – www.tonyattwood.com/

The Gray Centre – www.TheGrayCenter.org

Associated Conditions

Autism and Pervasive Developmental Disorder - www.autism-pdd.net

Attention Deficit Hyperactivity Disorder - www.addiss.co.uk

Hyperlexia - www.hyperlexia.org

Tourette Syndrome - www.tsa.org.uk

Irish Fragile X Society - www.fragilex-ireland.org

UK Fragile X Research Foundation - www.fraxa.org

Sotos Syndrome - www.well.com/user/ssa/whatisit.htm

Semantic Pragmatic Disorder - www.mugsy.org/spd5.htm

Practical Activities & Resources

IconTalk - www.icontalk.com

Do To Learn - www.dotolearn.com/

Preschool Zone - www.mcps.k12.md.us/curriculum/pep/pz.html

Specific Interventions

DIET – www.osiris.sunderland.ac.uk/autism

PEAT (Parents Education as Autism Therapists) - www.peatni.org

TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children and adults) - www.teacch.com



**FUNDAMENTALS
OF ASD**

**ASD SPECIFIC
TRAINING
PROSPECTUS**

PEP-R

**AUTISM NI
(PAPA)
AUTISM**