

Helping Hands

Autistic Spectrum Disorders (ASDs) and Related Conditions



Drawing by Aine, aged 9

***A guide for parents of children
recently diagnosed with an
Autistic Spectrum Disorder, or who are
in the process of getting a diagnosis.***

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Autistic Spectrum Disorders



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About this Programme

This programme was developed by team members of Enable Ireland who had a keen interest in providing information for parents whose children had received a diagnosis of ASD or who are currently going through the assessment and diagnosis process. This group was made up of:

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This booklet draws upon the work of the [Early Support](#) programme developed by the National Autistic Society and TreeHouse to provide information for parents who have children with an Autistic Spectrum Disorder. We extend our thanks to all those involved as this publication provided information that was invaluable to the work involved in developing our booklet. We would also like to thank Clodagh Sheehan, administrator, Enable Ireland for her support.

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Introduction –

Where you are now

There are two very important things for you to remember:

It's not your fault

The fact that your child has an ASD, or may have an ASD, has nothing to do with the way that you have been looking after him or her. The cause of Autistic Spectrum Disorder is not yet known, but we do know for certain that Autistic Spectrum Disorder is not caused by parenting. Parents of young children with ASD are just like everyone else. Autistic Spectrum Disorder affects children from all walks of life and in all countries and cultures.

You're Not Alone

Many parents are going through what you are going through and there are many others that are further on in the journey.

Even if you don't feel like taking any other steps right now, we recommend that you make contact with other parents of children through a local support group as soon as possible. They can help you make sense of the things you read and can be a valuable source of information on advice and how things work in your area.

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Coming to Terms with the Diagnosis of Autistic Spectrum Disorder or a Related Condition

If your child has not yet had a diagnosis, uncertainty about his/her situation may be very stressful for you. Sometimes the process of reaching a diagnosis seems to take a long time and for some parents this time is harder than the period after the diagnosis.

If the process of diagnosis is taking a long time, it may be that professionals suspect your child has an Autistic Spectrum Disorder or a related condition, but want to be certain their diagnosis is correct. This is important because it affects the type of help that will most effectively address your child's needs. Unfortunately, there are delays sometimes simply because of the high demand on services for children with disabilities.

There is general agreement that getting the appropriate education and/or therapy at the earliest possible stage maximises the chance that a child with Autistic Spectrum Disorder will develop their abilities. However, in Enable Ireland you do not have to have a diagnosis in order to access services for your family.

If you have received a diagnosis, even though you may have thought you wanted definite information, it may come as a big shock. Many families experience diagnosis as a time of great emotional upheaval.

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'this was a day we were dreading but yet couldn't wait for. I think we told ourselves that it didn't matter to us to hear the words that our son has Autistic Spectrum Disorder it is just that we felt he needed the 'label' to progress and get the help he deserves.'

Some families feel that they need to grieve the loss of the child they thought they had. Feeling angry or feeling that you must be at fault are normal and common reactions. This process is an important part of accepting your child's diagnosis, and it can take time.

When some family members find it easier than others to adapt to the family's new situation, this can add to the strain.

Some families go through a process that starts with shock and an inability to do anything, and then moves through anger to some sort of acceptance. Different family members are likely to take a different amount of time to go through this process. But parents of children with Autistic Spectrum Disorder emphasize that it really helps when you reach a point at which you can begin to accept the situation.

'I think the most important thing is for someone to tell you to accept he's got this thing. Once you accept, you can help. I think what we tend to do is feel sorry for our children, and then you can't do anything.'

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Some parents say it is helpful to think in terms of setting out on a journey. It won't be the journey you expected or wanted to go on and it will have low points, but it will also at times bring rewarding experiences.

However, it is important not to deny how stressful it can be to have a child with an ASD.

'Sometimes you have negative thoughts about your child, but when you talk to other parents you realise it's quite common, and that it doesn't mean you're a dreadful person, or a bad parent'

Some parents feel very alone and unsure of how to cope with social situations.

It can also be particularly difficult to handle other people's lack of understanding. Over time, you will develop skill in handling other people's reactions.

'don't apologise for your child's behaviour, they have the right just like you and me to be accepted for who they are'

All parents say that what really helps is talking to other parents of children with Autistic Spectrum Disorder.

This guide aims to help you to find the information and support you need so that you can move forward and feel more in control.

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What is an Autistic Spectrum Disorder (ASD)?

Autistic Spectrum Disorders (ASDs) are lifelong, developmental disabilities that affect the way a person communicates and relates to people around them.

Children with ASDs are affected in a huge variety of ways and to very different degrees. This is why it is called 'the autistic spectrum'. Autistic Spectrum Disorder can affect children with any level of learning ability. So, having an ASD doesn't necessarily mean that you have learning difficulties.

Some children have other difficulties which are not directly related to their ASD, such as [dyspraxia](#), dyslexia or [attention deficit hyperactivity disorder \(ADHD\)](#). It is important to seek an assessment of any other conditions, as this affects the sort of support that will best meet your child's needs.

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What are the Signs and Characteristics of Autistic Spectrum Disorders?

Children with ASDs have significant difficulties relating to other people in a meaningful way. Their ability to develop relationships is impaired, as is their capacity to understand other people's feelings and the social rules of communication.

Everyone with an ASD has difficulties in three main areas. These are known as 'the triad of impairments', or 'the three impairments':

- **Social Interaction**
difficulty understanding social 'rules', behaviour and relationships, for example, appearing indifferent to other people or not understanding how to take turns.
- **Social Communication**
difficulty with verbal and non-verbal communication, for example, not fully understanding the meaning of common gestures, facial expressions and tone of voice.
- **Rigidity of Thinking and Difficulties with Social Imagination**
difficulty in the development of interpersonal play and imagination, for example, having a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively.

All children with Autistic Spectrum Disorder have impairments in all three areas. However, the ways in which the three impairments manifest themselves vary enormously. They are described in more detail in the following pages.

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Social understanding and social behaviour

When they are born, most babies seem ready to become sociable and develop communication skills. Young children just seem to know that other people are important to turn to for comfort, to share moments of pleasure with, to look to for guidance and to learn from.

Children with ASDs find this all very difficult. They may seem less interested in people. They find it hard to see things from another person's point of view. They often seem trapped in a world of their own. Some may like being sociable and tactile but don't seem to understand how to do these things. A young child with an ASD can't make sense of people, and may find them frighteningly unpredictable. They may:

- seem to relate better to objects than people
- only tolerate approaches from very familiar people
- only be receptive to approaches from people they know well
- not want to be comforted in distress
- seem to use people as a means to an end – for example, by taking someone's hand to obtain something out of their own reach
- seem to be unaware of social rules and conventions.

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Social Communication (Verbal and Non Verbal Communication)

Children with ASDs may not be eager to communicate. They may not be ready to learn things that other children learn naturally and therefore don't have a chance to tune into language in the same way. They find it hard to make sense of what is happening around them. Words may mean very little to them and they may be unable to link what they see with the things being said to them.

Young children with ASDs not only have difficulty making sense of words, but also with reading non-verbal messages in facial expressions and gestures. This makes it difficult for them to learn what is expected of them, and to recognise when someone is happy or upset or what that means. A young person with an ASD may:

- develop speech in a way that is slow, disrupted or disordered – or may not develop speech at all
- often use words out of context and without trying to communicate
- not respond when spoken to
- use language correctly, but not really understand what they are saying
- echo words other people say – straight away, or later (this is sometimes called **echolalia**)
- use words and then 'lose' them (not use them again)
- not use eye contact as a natural part of communication
- rarely understand or use gesture
- develop a pointing gesture, but use it to indicate need rather than share an experience.

'my son enjoys his life, even if communication is frustrating, and I would not have him any other way'

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Rigidity of Thinking and Difficulties with Social Imagination

Imagination helps us to understand the world around us and to predict and see the perspectives of other people. Children with an ASD are unable to do this to any great extent. When pretend play begins to appear in children who don't have an ASD, it is a sign that imagination is beginning to develop. In children with ASDs, this process occurs very slowly, in unusual ways, or not at all.

Problems of imagination show themselves in different ways. Some children never seem interested in what a toy is or what it represents. They may focus on the features of the toy such as the wheels of the car or the box the toy came in. Some children seem to act out stories or take on particular characters, but the story turns out to be an imitation of a video or a book. This doesn't mean that children with Autistic Spectrum Disorders don't have any imagination; it means they tend to have less ability in this area and they tend to be less interested in sharing their imaginative ideas than other children.

Some children with ASDs learn to talk easily, but find it hard to understand communication that is not literal. Expressions like 'I laughed so much I nearly died', or 'If you eat anymore you'll burst', can be very frightening for them. They may have difficulties understanding that a phrase or story is not real.

Problems with imagination make the world a very uncertain place, so children with ASDs find reassurance in setting up routines and patterns that they can control. Repetitive behaviours and routines are a common feature of ASDs.

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A young child with an ASD:

- cannot easily make sense of sequences and events
- may become distressed if a familiar routine changes
- may impose routines on others
- will often engage in stereotypical body movements (for example, some children will flap their hands, some may rock back and forth)
- will often resist new experiences, for example, trying different foods or wearing new clothes
- may find it hard to work out what other people are going to do, and cannot make sense of why other people do what they do – they are unable to take someone else's perspective or point of view
- will only develop symbolic play slowly – if at all (symbolic play is play which involves pretending and using imagination)
- will often pay particular attention to unusual details and struggle to see the bigger picture

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Other Common Challenges for Children who have an ASD

This section may be daunting, so it is important to remember that strengths and challenges change over time and that not all the following will be relevant to your child.

- **Sensory Difficulties**

A significant number of children with an ASD are very sensitive (hypersensitive) or under-sensitive (hyposensitive) in one or more of their senses. They may have heightened sensitivity to certain types of sound, touch, texture, taste of food, light, colour or smell. Something like a clothes label, for example, may cause the child extreme discomfort. Some children lack sensory discomfort. Other children lack sensory awareness of temperature or pain. Some children shift between hypersensitivity and hyposensitivity. Sensory difficulties can have a significant impact on behaviour and communication.

'My child can't cope with music sometimes, maybe it's because they are not comfortable, for whatever reason this can lead to shouting, crying'

- **Sleeping Difficulties**

Children may have problems getting to sleep or may wake periodically throughout the night. The child may catch up on sleep during the day or may seem to require much less sleep than the rest of the family.

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- **Eating Difficulties**

Some children only eat certain foods, or foods of one consistency or one colour. Others have rituals, such as insisting different foods never touch on the same plate.

- **Difficulties with Toileting**

As with eating difficulties, it may be advisable to look into whether there are other medical reasons for your child's difficulty, such as constipation.

- **Bowel Problems, which may cause pain**

Some children may be prone to constipation or diarrhoea and some benefit from a specific diet; they may experience both, at different times, or at the same time (if the bowel is blocked, then only liquid matter can pass through the blockage).

- **Difficulties developing Independence and Personal Care Skills**

- **Difficulties with Motor Skills**

For instance, some children with ASD may have unusual difficulty holding a pencil (a fine motor skill). Some children may be clumsy or may have an odd way of standing or walking (gross motor skills).

- **Obsessions**

Thomas the Tank Engine and dinosaurs are common obsessions, as well as various types of electrical equipment. Some children with an ASD insist on certain rituals.

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- **Fears and Phobias**

These can include everyday things such as certain advertisements, pictures in books, specific songs, buttons or clocks.

- **Poor Spatial Awareness**

Spatial awareness is a sense of knowing where you are in relation to other objects around you.

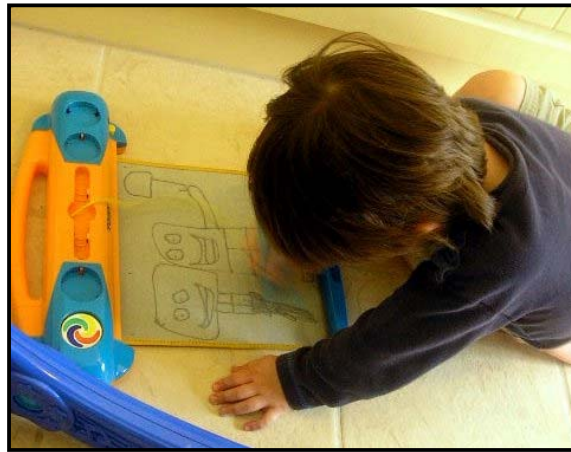
- **An Unusual Focus on Detail**

Focusing on minor details and ignoring the main picture – for example, a child with ASD may look at a spot of dirt on the floor when they are in the middle of a chasing game.

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What are the Strengths of Children with an ASD?



Every child is unique, but there are particular strengths and skills that children with an ASD seem more likely to develop than other children. These may include:

- An ability to focus on detail and to concentrate for long periods of time on a single activity. Some children can give their sole attention to a task and therefore achieve a high level of skill and continue to work on tasks way beyond the point at which other children of the same age would tire of them.
- A talent for learning facts and skills they want to, and when they are presented in a way particularly suited to their learning style, for example using lots of visual materials.
- A very individual way of looking at the world and figuring out how the world works.

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Getting Exact Information about your Child's Diagnosis

The term **Autistic Spectrum Disorder (ASD)** is an umbrella term that encompasses the terms **Autistic Spectrum Disorder**, **Asperger Syndrome**, **Autistic Disorder**, **classic Autistic Spectrum Disorder** or **Kanner's Autistic Spectrum Disorder**. The information in this pack is relevant for children with ASDs and related conditions, which include:

- **pervasive developmental disorder (PDD)**
- **pervasive developmental disorder not otherwise specified (PDD-NOS)**
(also known as **atypical Autistic Spectrum Disorder**)
- **semantic pragmatic disorder (SPD)**

The behaviours described in the 'three impairments' discussed on pages 10 to 13 might be seen individually in a non-autistic child from time to time, but an **Autistic Spectrum Disorder** is diagnosed when a child has behaviour indicating all three impairments. The underlying causes of **Autistic Spectrum Disorder** are unknown in the majority of cases (and may well be different for different individuals with ASD).

In recent years, there has been a marked increase in the number of children diagnosed with **Autistic Spectrum Disorder**. It is not clear why this is the case. Some people believe it is the result of better diagnosis, others believe there has been an increase in the incidence of ASD. If you would like more

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information on this subject, contact the [NAS Helpline](#). Contact details are given at the end of this booklet.

When you get a diagnosis for your child, it is important that the person making the diagnosis also gives you an indication of how your child, as an individual, is affected. This will give you more of an idea of their skills and needs, and the support you might want to ask for now, and in the future.

Ask the [paediatrician](#) and other professionals you are talking with to write down information about your child's diagnosis for you, so that you have a written record of your child's difficulties. This helps because you have information to read through in your own time and to refer to again as time goes by. Written information about your child and their needs and difficulties can be important when you are asking for services to help your family – but don't forget you may be able to access services without a diagnosis.

As with all children, the full picture of your child's abilities and difficulties will only become apparent over time, and it is important that you review their progress regularly with all the professionals involved.

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Therapies and Interventions

How are therapies and interventions helpful?

All parents want to ensure that their children are being given the best chance to make progress. Effective early intervention can help your child:

- communicate with you and with other people
- understand more about the world around them

Effective intervention can also help you:

- interact with your child better
- understand and respond to your child's behaviour.

Many children with the kind of difficulties described in this booklet are helped by having structure and routine built into their daily lives. Making the world predictable reduces anxiety and associated difficult behaviour. Structure needs to be communicated to the child in a way they can understand. For example visual cues and schedules are helpful because children with an ASD are often better at understanding information that is presented visually, in the form of pictures or photographs.

What kind of intervention might help?

There are several teaching and therapeutic approaches which have been developed specifically for children with Autistic Spectrum Disorders. Some were developed for all ages, and in all settings, while others are specifically for pre-school children in a home setting. The professionals working with you may use some of these approaches as part of the intervention programme being developed for your child at home or in a pre-school or school setting.

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Choosing an intervention method for your child

There's a lot of debate about different types of intervention and therapies and some parents or professionals hold strong views about 'what works' and 'what doesn't'. Some families feel a particular therapy or intervention has really helped their child and so are keen to recommend it. Other parents, who have not experienced such good results, feel families should be warned that there are no easy solutions or magic cures for Autistic Spectrum Disorder. It is important to remember that each child is different, and that what helps one child might not help another, and also that children can benefit from different interventions at different stages of their progress.

There are many interventions, with varying levels of research evidence about how effective they are. This booklet can give some basic information about some of the options available, but it cannot recommend any particular methodology.

However, you will be in a better position to discuss possibilities and make a plan for your child if:

- you're aware of all the options available
- you've talked to other parents about their choices
- you've had a chance to observe the interventions/therapies in practice
- the information you have about the effectiveness of different approaches comes from more than one source

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As you consider different alternatives you may want to ask some of these questions:

- Does this approach have a track record?
- How does it work?
- Is there evidence about how many children with Autistic Spectrum Disorder have undergone this therapy and what the outcomes are?
- Is there any evidence about whether children who have strengths and difficulties similar to my child are particularly likely to benefit from this approach?
- Is the therapy unsuitable for certain people? Who? Why?
- Are there any side effects? If yes, what are they?
- On what basis will professionals decide whether a particular approach is appropriate for my child?
- How will we judge whether the therapy is successful for my child?

Don't forget to ask questions about the therapist's training and experience (including experience of working with clients with your child's difficulties), and about the arrangements for therapy including cost, payment arrangements, transport and accommodation and whether you will have a written agreement with the therapist.

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Specific Programmes offered by Enable Ireland

AT (Assistive Technology)

Assistive technology is any item, whether purchased off the shelf, or customised, which enhances an individual's independence. Assistive technology may be as simple as changing the text size on a PC or more complex such as screen reading software which reads text and websites aloud. Assistive technology is not exclusive for people with disabilities as everyone can benefit from AT. For example, the settings can be adjusted on your computer to reduce eye strain or you can be provided with a wrist rest to avoid repetitive strain injury. Some of the common types of assistive technology devices used in special needs are alternative mice, switches, touch screens and alternative and augmentative communication devices.

The DIR®/Floortime Model

This model is based on new insights into the development of the mind which have made it possible to help children and families with special needs to build healthy foundations for social, emotional, and intellectual capacities rather than focusing on isolated behaviours. Central to the DIR®/Floortime™ Model is the role of the child's natural emotions and interests which has been shown to be essential for learning interactions that enable the different parts of the mind and brain to work together and to build successively higher levels of social, emotional, and intellectual capacities. Floortime™ is a specific technique to both follow the child's natural emotional interests and, at the same time, challenge the child toward greater mastery. The DIR®/Floortime™ Model, however, is a comprehensive framework which enables clinicians and

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parents to construct a program tailored to the child's unique challenges and strengths. It often includes, in addition to Floortime™, various problem-solving exercises and typically involves a team approach with speech therapy, occupational therapy, educational programs, and, where appropriate, biomedical intervention. The DIR®/Floortime™ Model also emphasizes the critical role of parents and other family members because of the importance of their emotional relationships with the child.

Earlybird

The National Autistic Society developed the Earlybird programme. It is a three month programme for parents of a preschool child who has a diagnosis of Autistic Spectrum Disorder. Six families can attend the programme together. This involves eight group sessions and three individual home visits where the parent is videoed working on specific goals with their child. The programme offers parents the opportunity to understand their child's Autistic Spectrum Disorder. They explore strategies to develop social communication and learn how to prevent problems and encourage appropriate behaviour. Parents can share experiences and ideas with others in similar situations.

PECS (Picture Exchange Communication)

PECS is an alternative method of communication. It relieves the pressure created by the inability to converse verbally, as it replaces the verbal element with the use of a picture or symbol. When using the PECS system, the child must initiate the communication, a skill that is often challenging for children with Autistic Spectrum Disorder. As an example, if a child wants to have a drink he or she will select the picture symbol for the preferred drink and give it to the adult in exchange for the drink. The adult would then praise the child

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and repeat the request verbally to model appropriate language. PECS is not intended to replace verbal communication, rather that it should reduce the frustration of being unable to communicate and give the child a greater sense of independence. Initially, two adults are needed when starting PECS with a child. One person is the communicative partner and will have the object that the child desires. The second person is the physical prompter and will physically prompt the child to exchange the picture for the desired object. The physical prompter can be faded over time as the child moves through the phases of PECS. PECS can be used in a variety of settings and as the child becomes a more competent PECS user more and more pictures can be introduced building to sentence formation.

Parents Plus

The Parents Plus Early Years Programme is a video based parenting course to promote development and manage behaviour problems in young children aged one to six. The focus of the Parents Plus Programme is positive, aiming to build on parents' strengths and help them to solve discipline problems and to have more enjoyable and satisfying relationships with their children. The course normally runs for six to eight weeks and relies heavily on group discussion and video footage. The programme is divided into two sections. The first section looks at building a positive relationship with your child and includes topics such as child centred play and communication and encouraging and supporting your child. The second section focuses on building cooperation and responding to misbehaviour and deals with topics such as understanding misbehaviour and the praise ignore principle.

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Sensory Issues

Many children with an Autistic Spectrum Disorder can experience sensory and motor problems during their early development. Unlike the diagnostic process for Autistic Spectrum Disorders there is (as yet) no set pattern of sensory or motor behaviours which are specific to children with autism. There is however a growing bank of information being reported by parents of children with an Autistic Spectrum Disorder regarding the occurrences of sensory and motor problems (Baranek 2002). These difficulties can interfere with your child's ability to interact with you, other people, or to complete everyday tasks such as brushing their teeth, washing their hair or going shopping. You may already have discussed some of these issues with your Occupational Therapist during the diagnostic process. The occupational therapist many have completed the Sensory Profile, or have taken a detailed sensory motor history with you.

The theory of sensory integration can be used to understand why children behave the way they do. With the information your Occupational Therapist has collected they may be able to provide you with ideas on how to slightly alter everyday activities to take into account your child's sensory needs. Each child will have individual sensory and motor needs. Therapy programmes will be aimed at meeting these needs in a variety of ways. The therapist may see your child for a block of therapy in individual or group sessions focusing on motor and sensory activities that are challenging for your child. Some of these sessions will take place in the centre using some sensory equipment such as swings, therapy balls, crawling through tunnels or diving into a ball pool. The idea is that your child has fun, is challenged to just the right level

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and grows in confidence with their abilities. Your therapist may also be able to advise you on sensory diet ideas for your child or may be able to make suggestions on activities to help in the preschool/ school environment and maybe able to make suggestions on useful pieces of equipment.

Sign Language

Signing can be used with other communication systems like PECS, and with other interventions. [Makaton](#) and [Signalong](#) are two examples of signing. Signing is not usually taught as a replacement for speech, but to assist in the development of spoken language and communication of intentions. Signing may be a more accessible and interactive communication tool for children who have difficulty discriminating between visual symbols presented to them in pictures, or for those who do not have the fine motor skills or motivation to manipulate picture cards.

Talk Tools

Talk tools is an approach devised by Sara Rosenfeld-Johnson. It is a tactile teaching technique which supplements traditional therapy. Children who have difficulty with oral sensory awareness, muscle tone/strength in the jaw, lips, cheek and tongue may benefit from this approach. The Speech and Language Therapist working with your child may complete an assessment to determine if this approach is required for your child.

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Therapeutic Listening

Therapeutic listening is a therapy tool that combines sound based intervention with sensory integration activities, which have been designed to produce specific effects on listening. It is a structured program that involves the child listening to specifically designed music that has been individually selected. The child listens to the music through headphones, usually for duration of eight to twelve weeks. The goals of therapeutic listening can include improving sensory modulation, attention, behaviour, postural organization and speech and language difficulties.

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

TEACCH is a whole life approach which aims to support children and adults with ASD by using visual information, support and predictability. The priorities of TEACCH include the development of structured teaching as well as maximising on the strengths and interests of children and adults with ASD.

Key components in the use of the TEACCH strategy include structuring the physical environment, using visual schedules to help children structure and plan their day, the use of a work system (if appropriate) and ensuring that expectations are clear and explicit. A large emphasis lies on the use of visual support and material. TEACCH strategies are often used during intervention sessions with Enable Ireland. They can also be incorporated into the preschool and school environment.

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What education provision is available for children and at what age?

Understanding of the nature and impact of ASD is still developing. Provision for young children is further complicated by the fact that the challenges that a child is facing may only be recognised slowly as their development begins to look different from that of other children. Diagnosis is sometimes difficult or ambiguous.

For children with an ASD, education may mean learning some things that other children develop naturally. For example, specific teaching may be needed to help children learn to tolerate or interact with other children or to understand the rules and routines of situations that other children take for granted.

The education of children who have an ASD is often the main concern of parents following diagnosis. Support for children with ASD is organised by the Department of Education as part of their provision for children with special **educational needs**. Extra help or support in the pre-school years is provided at different levels, depending on a child's need for extra help. This support is sourced by the Department of Education or Health Service Executive depending on the setting.

It can be time consuming and tiring to work out what is the best early years setting or school for your child. Some services / educational facilities are further ahead in responding to the rising number of children with identified

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ASD than others. The best provide good early support for young children with Autistic Spectrum Disorder. Others are not so good.

What should you look for?

It can be helpful to ask yourself:

- What kind of education does my child really need?
- What education provision is available in my area and at what age?
- What level of education and additional support is my child legally entitled to?

What education does your child need?

Although each child with ASD is unique and the Autistic Spectrum Disorder spectrum is very broad, there are some features that are common to all good Autistic Spectrum Disorder education provision. These include:

- access to professionals who understand ASD
- willingness and ability to present information in a way that addresses a child's communication difficulties.
- willingness and ability to adapt some 'normal' routines for a child with ASD, in line with their individual needs.

For the very youngest children, parents and carers normally play the most important role in deciding and funding the provision that is right for their child.

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Questions to ask about services for very young children

- How much one-to-one attention from an adult will my child have?
- Will the adult(s) have the skills to build up my child's desire and ability to interact and communicate?
- How will my child's time be structured?

Questions to ask about early years settings

- Are activities adapted to meet the particular needs of my child?
- How will the setting provide structure and consistency?
- How much one-to-one attention from an adult will my child have?
- Do the adult(s) have the skills to address my child's specific communication, social, behavioural and sensory needs?

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Looking for the right school

In Ireland, children are required to attend school at the start of the term at the age of 6.

There is no straightforward answer to the question 'What's the 'right' type of education?' because Autistic Spectrum Disorders are so complex and individual. The 'right' kind of provision is the one that meets your child's individual needs.

Talk with other parents, support groups and ask questions of any schools and early years settings that you visit. It is important that you get to know the choices available and get a sense of the training, expertise, environment and ethos which is on offer to meet the needs of your child.

As different children with Autistic Spectrum Disorder needs very different types of provisions, it is a good idea to start looking at a range of schools available in your area as early as possible. It may take some time to find the place that you feel will best meet your child's needs.

Questions to ask about schools

- Is the curriculum adapted to meet the particular needs of my child?
- Will they be able to provide an appropriate environment for my child – for example, structure, consistency, specific communication approaches?
- Will my child get the level of one-to-one support from an appropriately skilled adult that they need?
- How willing is the school to work with parents and discuss things with us?

Information for Parents *Autistic Spectrum Disorders*



What level of education is your child entitled to?

Children with **special educational needs** enjoy the same rights as any other child to receive educational provision that meets their individual needs. It is unlawful for education settings to discriminate against children with a disability and prospective children who may have a disability, and they must make reasonable adjustments to accommodate children's disabilities.

In certain circumstances schools can provide additional support for your child. Applications are made by the school principal that may be accompanied by reports from the professionals working with your child.

Education – Primary

Applications for **Resource, Learning Support and Special Needs Assistant resources** are made by the School Principal to the Department of Education & Science / Special Education Support Service. The Department's websites, www.education.ie and www.sess.ie, outline the roles of a special needs assistant, resource teacher & learning support teacher or you can contact the Special Education Section, Department of Education & Science, Cornamaddy, Athlone, Co. Westmeath (0902) 74621.

School transport information is available from the School Transport Section, Department of Education & Science, Portlaoise Road, Tullamore, Co. Offaly (0506) 21263

Home Tuition hours may be available to children if they are unable to attend school due to a medical condition or while waiting for an appropriate school placement. Information is available from the Home Tuition Section, Dept of Education & Science, Athlone (090) 6474621 and application forms are available on www.education.ie. Click on Children with Special Needs.

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Helping your Child at Home – Behaviour

Some children have behaviours that parents find very difficult to manage, and that cause considerable stress for the whole family. Before you try to tackle behaviour, decide whether it really is a problem rather than just inconvenient or embarrassing. It is always useful to start by trying to identify the reason for the behaviour from the child's perspective, and considering what the child is trying to communicate through their behaviour. Some behaviours are directly linked to difficulties the child has communicating because of their Autistic Spectrum Disorder. Other triggers might be social situations which they find stressful, unstructured time, sensory difficulties, medical reasons, and change which your child finds stressful. You may find it helpful to track your child's behaviour in a diary so you can begin to see patterns in behaviour and notice small, positive changes as you develop strategies. Understanding your child's particular difficulties will help you develop strategies to help with behaviour problems. Try to be consistent when dealing with difficult behaviour, and don't expect it to change overnight.

Exercise, such as trampolining or swimming, can be a really good way of relieving stress and working off frustration.

Sometimes a member of our team can give practical advice, or it may help to talk to other parents who have experienced similar problems and who have developed creative solutions to help their child. There are several helpful books giving advice on strategies for difficult behaviours. Details are given at the end of this booklet.

Information for Parents *Autistic Spectrum Disorders*



Brothers and Sisters of a child with Autistic Spectrum Disorder

When a child is diagnosed with ASD it affects the whole family and it is important to consider the feelings of siblings and to recognise that they have a need for information about their brother or sister and what ASD means for them. They need information for reassurance, to answer their own questions and questions posed by others, and to plan for their future. This need is lifelong and the topics are ever-changing. Throughout their lives, the types of information siblings need – as well as how it is best presented – will vary with the sibling's age.

Brothers and sisters may have feelings that are difficult to express, even to a friend; sadness that a sister can't learn things that others take for granted, anger when a brother's behaviour problems prevent the family from doing things other families do, or the special pride when a sibling with a disability learns a basic but important life skill after months or years of practice.

Members of your team and other parents can help you work out the type of information your other child or children need as well as how best to give them that information. 'Sibshops' may be available – these are fun workshops where siblings can meet with others in a similar position in a positive environment to learn about ASD and other disabilities, share experiences and feel that others understand them. A member of the team can also work with siblings individually if appropriate.

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Being a Parent

Parents of children with ASDs often feel they have to take on the vital role of ensuring that their child gets what they need. This may seem daunting as you think about the journey ahead but many parents find that later they become impressed by their own determination, level of knowledge and sheer ability to cope. But you don't have to become a 'super mum' or 'super dad'. It is important to look after yourself too.

In order to get support for your child, you may have to read about the subject, ring people or follow up when things don't happen.

If you understand what you are entitled to and how statutory services operate, you will find it easier to ask professionals the right questions at the right time.

Other parents emphasise that it is important to develop good working relationships with professionals who are supporting your child and to recognise the constraints that they work under. It also helps to work closely with the people who are supporting your child on communication, behaviour management and daily structure. If your child is treated consistently, the better the results will be and the less isolated you will feel.

In the past, understanding of Autistic Spectrum Disorder was often inadequate. There is more knowledge and understanding than there used to be, partly because of the efforts of parents and Autistic Spectrum Disorder charities to educate professionals about the condition. At times, however, you can still come across gaps in professionals' understanding.

Information for Parents Autistic Spectrum Disorders



Benefits and Financial Help

Applying for benefits can be difficult for parents as it often means describing your child's difficulties rather than his or her strengths. The language used on many forms can be upsetting and outdated. It can also be a time when you realise how much help and support your child actually needs. Many families also question whether they are entitled to claim certain benefits, believing they are for needier families. It's important to remember that your child has a right to claim.

You may find that your child's Autistic Spectrum Disorder is difficult to describe within the sections of standard benefit forms. This does not mean that you are not **entitled to** support, so don't be put off from applying. It's worth talking this through with someone who has had experience of describing a child with ASD on application forms before. This could be another parent or a team member.

Below are the main benefits and entitlements that should be considered if your child receives a diagnosis of ASD. Current rates for the benefits listed below as well as other benefits available are detailed in the booklet 'Benefits & Entitlements' available in the Enable Ireland Centre. A team member will be able to advise you further.

Carers Allowance (means tested)

For parents looking after their child full time.

Recipients may be entitled to a Free Travel Companion Pass, Telephone Rental, TV Licence and Gas or Electricity allowance. Apply to Dept of Social, Community & Family Affairs, Carers Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford 043-45211.

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The number of hours that the recipient can work has remained at 15 hours per week but this must be cleared with this department as most incomes will be assessed as means.

Carers Benefit

Insurance based benefit for people who need to leave employment to look after a child in need of full time care.

The duration has remained at 24 months. Carer may work up to 15 hours per week. There is a limit on this income. Carers Leave legislation has been introduced to protect employment rights. A separate application must be made to your employer.

Apply to Dept. of Social, Community & Family Affairs, Carers Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford (043) 45211.

Domiciliary Care Allowance

You must be the carer of a child between 0 and 16 years who “lives at home and who has a disability so severe that they need constant care and supervision, substantially more than an able-bodied child of the same age would require”.

There is a means test of your child’s means only.

Application form from HSE, Local Health Care Unit, Rooskey, Monaghan (047) 30400.

H.S.E. Community Care, County Clinic, Navan (046 9021595).

Child’s birth certificate must be included with application.

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Employed Person taking care of an Incapacitated Individual Leaflet IT47 (August 2006)

There is a tax free allowance if you employ someone to care for a family member who is incapacitated. This is not a tax credit, allowance is granted at marginal tax rate - the amount of the allowance is deducted from income before tax is applied. Check leaflet as there are many conditions attached to this allowance. The ceiling on the amount that can be claimed remains at €50,000 per year.

Home Support Services Applications to HSE, Cavan/Monaghan Disability Services, Rooskey, Monaghan / HSE, Community Care, County Clinic, Navan (046) 9021595.

Please discuss with team for further details or see Preschool & Home Support Information Leaflet.

Incapacitated Child Tax Credit Leaflet IT18 (Aug. 2006)

If you are the parent of a child who is “permanently incapacitated” you can claim an additional tax allowance. Contact your tax office - forward a letter outlining your child’s details, accompanied by your PPS number and a letter from your GP stating that your child has ASD.

Medical Card holders are entitled to GP services, community services, dental services, prescription medicine costs, hospital care and a range of other benefits free of charge.

GP Visit Card holders are entitled to the services of a GP free of charge. You qualify in much the same way as qualifying for a medical card except that the income guidelines are higher.

Information for Parents Autistic Spectrum Disorders



In 2005 changes were made to the assessment process for Medical & GP Visit Card applications, which mean that the HSE now assesses income after tax and PRSI is deducted, rather than gross income.

Nappies / Incontinence Supplies Children over 3 years who are not toilet trained due to a disability or medical condition are entitled to a supply of nappies or pull-ups. Contact your Public Health Nurse at your local Health Centre who will organise this for you.

Preschool Fees Applications can be made to the Family Support Panel **Cavan/Monaghan** via the Early Services Team or Public Health Nurse for support with payment of preschool fees in some situations. In **Meath** applications to the Family Support service, Family Resource Centre, Commons Road, Navan. Parents who are on Back to Education programmes may be able to access childcare funding via Monaghan Partnership. FAS also sometimes contribute to childcare funding when on their training courses.

Preschool Support Worker Applications to HSE. Please discuss with team for further details or see Preschool & Home Support Information Leaflet.

Respite Care Grant The payment is made regardless of the carer's means but is subject to certain conditions. It is automatically paid if you are already in receipt of Carers Allowance, Carers Benefit, Domiciliary Allowance or Prescribed Relative Allowance. This scheme was extended in 2005 to all carers regardless of the carer's means. However the carer must not be working outside the home for more than 15 hours per week or be in receipt of an unemployment payment.

Information for Parents Autistic Spectrum Disorders



A Final Word

With all the challenges facing parents who have a child with an Autistic Spectrum Disorder (ASD), it is a common experience to start to focus on meeting their child's needs at the expense of their own. When a child depends so much on the understanding of someone who can tune into their complex needs, it is hard for parents both to persuade others to give them a break from care and to develop confidence that others can do it.

Brothers and sisters of a child with an ASD may need their own support, or they may just benefit from being with other children who share his experience. They may have this opportunity if their parents join a local group. There are a number of books for siblings that explain ASDs in a child-friendly way which you can find out about at the end of the booklet.

Finally, parents stress that by taking one step at a time they have been able to overcome what they felt were huge challenges. You may never be able to answer all the questions, but the ratio of questions to answers will change and you will be more able to see the bigger picture.

'After the tears (and there were lots) the reality kicks in. Would we change our son for someone without Autistic Spectrum Disorder? Absolutely not. Our son is a healthy loving happy little chap and we are the luckiest parents in the world'.

Information for Parents Autistic Spectrum Disorders



Getting Help

Parent groups and voluntary organisations

Voluntary organisations, charities and parent support groups provide a broad range of support, and can help you to find out how services work in your area. They can also help with practical things like applying for financial help and benefits.

Many families stress how important parent support groups have been to them. These groups provide early support, advice, information, and to some extent, a social life.

You can find out about local groups by talking to other parents or asking your library for a list of local voluntary organisation.

The following support groups are available in the Cavan/Monaghan/Meath area:

North East Autism Support Group

Jennie Farrelly (042) 9668167
(087) 6749980
Ann Sheridan (047) 55188

Special Needs Active Parents (SNAP) - Monaghan

Kellie Ann (042) 9749241
Annette (047) 57983

Meath Autism Network

Contact: (087)2532571

Louth Autism Network

Jacinta Walsh (087) 2467431

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Internet and email Networks

Some parent support groups operate on the internet. Email networks and chat rooms can be valuable sources of information. There are discussion groups and chat facilities for parents, siblings, people with Autistic Spectrum Disorder, and general groups for anyone with an interest in Autistic Spectrum Disorder.

Email discussion lists let you post questions and useful information to other members on the list, at a time that's convenient for you. Chat channels are for conversations in 'real time'.

There is an Irish based Special Needs discussion board called Rollercoaster. It can be accessed on the following site: www.rollercoaster.ie

The NAS website has links to a range of internet groups. To reach the list of links, go to www.nas.org.uk/external. A few of these links are included below for information.

As these are open internet groups, this publication cannot endorse their contents, but you might find it helpful to know about them.

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Useful Organisations

Autistic Spectrum Disorder NI (PAPA)

Donard House,
Knockbracken Healthcare Park,
Saintfield Road,
Belfast,
BT8 8BH

Registered Charity XR22944 in Northern Ireland

Phone: Helpline Mon/Wed/Fri 9.30-1pm 0845 055 9010, Switchboard 028 90 401729

Fax: 028 90 403467

Email: [info@Autistic Spectrum Disorderni.org](mailto:info@AutisticSpectrumDisorderni.org)

Irish Autism Action

Irish Autism Action is an organisation of parents for parents. Members all have first hand knowledge of discovering autism in their families and learning to cope with it.

Irish Autism Action
41 Newlands
Mullingar
Co Westmeath

Phone: 044 933 1609

Email: kevin@autismireland.ie

Web Address: www.autismireland.ie

Special Needs Discussion Board

www.rollercoaster.ie

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Contact a Family (CAF)

Helps families who care for children with a disability or special need. CAF is a main source of information about rare disorders and can assist affected adults as well as children.

209-211 City Road
London EC1V 1JN

Freephone Helpline: 0808 808 3555
Textphone Helpline: 0808 808 3556
Tel: 020 7608 8700
Minicom: 020 7608 8702
Fax: 020 7608 8701

Email: info@cafamily.org.uk
Web: www.cafamily.org.uk

National Autistic Society (NAS)

Formed in 1962, the [National Autistic Society \(NAS\)](#) is the UK's leading charity for people with Autistic Spectrum Disorder, including Asperger syndrome, their parents and carers. It has a membership of 15,000, a network of 60 branches and 90 partner organisations in the Autistic Spectrum Disorder field. The NAS exists to champion the rights and interests of all people with Autistic Spectrum Disorder and to ensure that they and their families receive quality services, appropriate to their needs.

The [National Autistic Society](#) has an [Autistic Spectrum Disorder Helpline](#) for anyone in the UK whose lives are affected by Autistic Spectrum Disorders. It answers enquiries on a wide range of topics and can direct you towards sources of help and support. The Helpline is accessible to callers whose first language is not English as it has access to interpreters and it also has a minicom number for deaf and hard of hearing callers. The Helpline is open 10am-4pm Monday to Friday. Helpline information sheets are also available online at www.Autistic Spectrum Disorder.org.uk/a-z.

Information for Parents Autistic Spectrum Disorders



Books and Other Sources of Information

Autistic Spectrum Disorder: How to help your young child

Leicestershire County Council & Fosse Health Trust
The National Autistic Society (1998)

Can't Eat, Won't Eat: Dietary Difficulties and Autistic Spectrum Disorders

Brenda Legge
Jessica Kingsley Publishers (2002)

Caring for a Child with Autistic Spectrum Disorder

Martine Ives and Nell Munro
Jessica Kingsley Publishers (2002)
A broad ranging book which aims to answer all the questions that parents of newly diagnosed children ask and with numerous useful contacts.

Challenging Behaviour and Autistic Spectrum Disorder: Making Sense – Making Progress

Philip Whitaker
The National Autistic Society (2001)
A step-by-step practical guide for parents, teachers and carers of youngsters with ASD looking at prevention and management of common behaviour difficulties.

Diagnosis: Reactions in Families

Brenda Nally
The National Autistic Society (1999)

Diet Intervention and Autistic Spectrum Disorder

Marilyn Le Breton
Jessica Kingsley Publishers (2001)

Everybody is Different: A Book for Young People who have Brothers and Sisters with Autistic Spectrum Disorder

Fiona Bleach
The National Autistic Society (2001)
Aimed at children aged 8 – 13.

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Freaks, Geeks & Asperger Syndrome

Luke Jackson
Jessica Kingsley Publishers (2002)

Guidelines for Working with Children with Autistic Spectrum Disorders at Foundation Stage and Key Stage 1

South Gloucestershire Council
National Autistic Society (2005)

It Can Get Better: Dealing with Common Behaviour Problems in Young Autistic Children

Paul Dickinson and Liz Hannah
The National Autistic Society (1998)

Life Behind Glass

Wendy Lawson
Jessica Kingsley Publishers (2000)

My Brother is Different: A Book for Young Children who have Brothers and Sisters with Autistic Spectrum Disorder

Louise Gorrod
The National Autistic Society (1997)
Aimed at children aged 4 – 7.

My Sister is Different

Sarah Hunter
National Autistic Society (2006)
Life of a sister who has Autistic Spectrum Disorder, written by a 10 year old
who also has an ASD.

My Social Stories Book

Carol Gray
Jessica Kingsley Publishers (2002)

Playing, Laughing and Learning with Children on the Autistic Spectrum

Julia Moor
Jessica Kingsley Publishers (2002)
A practical guide to play activities. Useful for toddlers and primary school
children who are struggling to learn how to play.

Nobody Nowhere

Donna Williams
Corgi (1993)

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The Out-of-Sync Child

Carol Stock Kranowitz
G P Putman's & Sons (1998)

Sleep Better! A Guide to improving Sleep for Children with Special Needs

V. Mark Durand
Paul H. Brookes (1998)

Specific Disorders and your Child's Behaviour: A Parent's Guide to Behavioural Phenotypes

Contact a Family (2004)

Teach Me Language?

Sabrina Freeman and Lorelei Dake
SKF Books (1996)

Teaching Young Children with Autistic Spectrum Disorders to Learn

Liz Hannah
The National Autistic Society (2001)
A very practical and straightforward book for parents and staff in mainstream schools and nurseries, for children from three to seven. It contains lots of ideas and exercises to address the particular needs of a child with Autistic Spectrum Disorder (ASD).

The Autistic Spectrum: A Guide for Parents and Professionals

Lorna Wing
Constable and Robinson (2002)
Explains how people with Autistic Spectrum Disorder see the world, the reasons behind their behaviours and why they need a more structured and routine environment.

The Autistic Spectrum: A Parent's Guide

National Autistic Society (2001)
The NAS 'parent's pack' also contains six leaflets for parents who have just received a diagnosis for their child.

Thinking in Pictures

Temple Grandin
Vintage Books (1996)

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Understanding and Working with the Spectrum of Autistic Spectrum Disorder

Wendy Lawson
Jessica Kingsley Publishers (2001)

Visual Strategies for Improving Communication

Linda Hodgdon
Quirk Roberts (2004)

We can do it! Helping children who have learning disabilities with bowel and bladder management: a guide for parents

Enuresis Resource and Information Centre (2002)

All of the books listed above can be ordered from:

NAS Publications
Central Books Ltd
99 Wallis Road
London E9 5LN
Tel: 0845 458 9911
Fax: 0845 458 9912
Email: nas@centralbooks.com

Useful Web addresses for Sensory development

www.thinkingtoys.ie

Irish based company sell a wide range of products that focus on stimulating sensory, motor and cognitive learning.

www.rompa.com

Ireland based company that specialise in sensory based products.

www.southpawenterprises.com

American based company focusing on selling sensory integration and developmental products.

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Glossary

Advocacy – support to help people who find it difficult to communicate their views, especially in relation to statutory and legal services.

Asperger Syndrome – a type of Autistic Spectrum Disorder. People with Asperger Syndrome usually have fewer difficulties with language than people with Autistic Spectrum Disorder and do not have accompanying learning disabilities that some people with Autistic Spectrum Disorder have. They are likely to be of average or above average intelligence.

ADHD – attention deficit hyperactivity disorder. A developmental disorder which can cause overactive behaviour (hyperactivity), impulsive behaviour and difficulties in concentrating.

ASD – Autistic Spectrum Disorder, a developmental disorder characterised by difficulties with social interaction, social communication and rigidity of thinking.

Carer's Allowance – a benefit available to people with care for someone with a disability.

Casein – protein found in milk and milk products.

Dyspraxia – a difficulty in co-ordinating movement.

Echolalia – repeating words or phrases spoken by someone else.

Gluten – protein found in wheat.

Makaton – a form of sign language often used with people who have learning disabilities.

Paediatrician – a doctor who specialises in treating children.

PDD – pervasive development disorder. A general term for disorders which affect communication and social skills and includes Autistic Spectrum Disorders.

PDD-NOS – pervasive development disorder not otherwise specified. Where someone has a pervasive development disorder, but there is not enough information to give a more specific diagnosis.

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PECS – a picture exchange communication system. A way of using pictures and symbols to help children who have difficulty communicating with speech.

TEACCH – an Autistic Spectrum Disorder-specific approach which helps children cope with and understand their environment.

Triad of Impairments – the three impairments which characterise Autistic Spectrum Disorder: social communication, social interaction and rigidity of thinking.