Autism Spectrum Disorder

For any parent hearing or suspecting that their child might have Autism Spectrum Disorder (ASD) can be very distressing. Parents have told me about their need for information about ASD and the diagnostic process. It can be a long and confusing journey to a diagnosis.

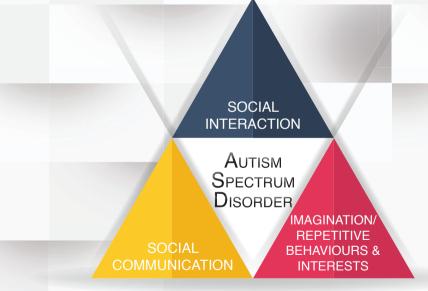
This booklet was designed as an introduction to ASD and the diagnostic process for parents and carers.



→ WHAT IS AUTISM SPECTRUM DISORDER?

Autism Spectrum Disorder (ASD) is a complex condition affecting different people in different ways. It is described as a triad of impairments because it affects three main areas in an individual's presentation. These are social interaction, social

communication and social imagination. A person may also present with repetitive and stereotypical behaviours and interests. Some individuals may also have intellectual disability or specific learning disabilities in addition to their ASD.

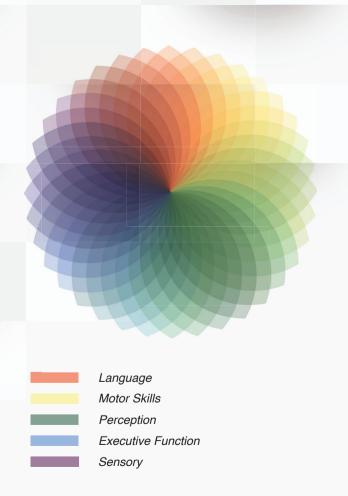


People with ASD can also present with strengths in many areas including maths, art, music, science and history, to name a few. They can have unique ways of looking at the world and can often think 'outside the box'.

Research suggests that Autism Spectrum Disorder affects up to one person per hundred, or more, in the population. It can be diagnosed in children from as young as two years right through to adulthood. ASD is an 'umbrella term' that includes the following disorders: Childhood Autism, Asperger's Syndrome and Atypical Autism.

ASD is a lifelong condition, the symptoms of which can change as the individual gets older. Children grow and develop in the same ways as their peers but difficulties in the three core areas may persist as they grow. It is envisaged that, with support, most people can learn to manage their difficulties and live a regular life. Temple Grandin, a woman with Asperger's Syndrome, says she feels she had a very long childhood and that she only became an adult when she was thirty years of age.

ASD is described as a spectrum because of the great variation in how it presents:



SOCIAL INTERACTION

One person may be very aloof while another may be very sociable but may interact in an unusual way.

SENSORY ISSUES

People with ASD can be over or undersensitive to sensory input. They may need more stimulation from their environment than peers, for example, they may seek movement or visual stimulation. Other people can be overstimulated by things in the environment and may find certain noises or sensations distressing.

REPETITIVE & STEREOTYPICAL BEHAVIOURS

People may present with unusual and repetitive mannerisms and behaviours. Some people have poor imaginative and play skills.

SOCIAL COMMUNICATION

One person may be very talkative while another may have limited language and communication skills.

EARLY INDICATORS OF AUTISM SPECTRUM DISORDER

Many people can identify with the features of ASD. We all have personal habits or characteristics that add to our uniqueness as individuals. Every child is unique and distinct and all children present with their own characteristic behaviours and preferences. Children with ASD present with additional characteristics which, in combination, indicate the presence of the disorder.

These include features such as those described below:

SOCIAL INTERACTION

Shows minimal expressed pleasure when interacting with others.

Limited reciprocal social communication.

Poor eye contact.

Limited interest in peers.

Preference for playing alone.

Limited understanding of other people's feelings.

SOCIAL COMMUNICATION

Delay in language skills.

Poor use of gestures such as not pointing to request things or not pointing to show things of interest.

Repeating words or phrases out of context.

Poor understanding of language.

Not answering to their name.

Literal interpretation of language.

Has difficulty understanding when someone is teasing.

IMAGINATION/REPETITIVE BEHAVIOURS & INTERESTS

Arranges objects in patterns.

Preference for sameness and routine.

Need for preperation around change.

Unusual movements of hands and body.

Delayed pretend play skills.

Repetitive and copied quality to play.

Preference for factual information.

Repeats unintelligible sounds.

PREPARING FOR THE ASSESSMENT

The diagnostic assessment attempts to be as comprehensive as possible. Nevertheless, it still only provides a snapshot of a child at a particular time in their life. Try not to worry about how your child will perform during the assessment. I will try to take all factors into account. You will be asked for your valuable information and thoughts during a Parent/ Carer interview. Parents who have been through the assessment process suggest that you write down your concerns about your child before attending the Parent/Carer interview.



WHAT HAPPENS IF MY CHILD RECEIVES A DIAGNOSIS OF ASD?

The Department of Education has responsibility for providing appropriate educational provision to all children. A range of educational provision is available to meet the diverse needs of children with ASD. This includes:

- Early preschool attendance with support or a specialist preschool for children with ASD or a home tutor.
- The child attending a special class, for children with ASD, attached to a mainstream school with such a facility.
- The child attending a special school for children with ASD and intellectual disability.

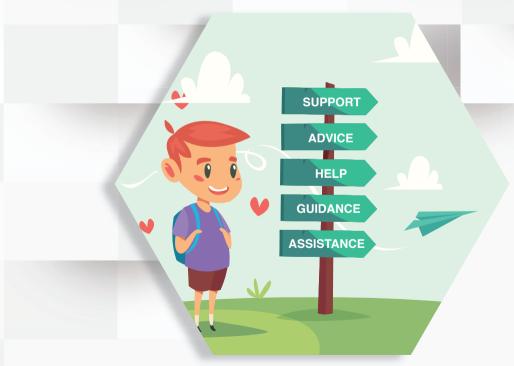
Information on educational options can be obtained from your local Special Educational Needs Officer (SENO). Their contact details are available on the National Council for Special Education website: www.ncse.ie

Whatever the outcome of the assessment, it is important to remember that your child is the same person after the assessment as they were before. They have their own unique personality and strengths which make them the person they are.



ASD is only a part of who an individual is . A diagnosis of Autism Spectrum Disorder is a framework for understanding the needs with which your child presents. A diagnosis can be a signpost towards the kinds of supports that will help your child fulfil their potential. There are

many things that can help make life easier and more fulfilling for a child with Autism Spectrum Disorder and many of these you will be doing already. I will make recommendations about other supports and strategies that will help you and your child going forward.



SOME RECOMMENDED WEBSITES & RESOURCES

- www.do2learn.com The National Autistic Society UK produces an excellent Publications Booklet/Website through which books can be ordered.
- 2. www.thegreycenter.org Carol Grey's Social Stories and Comic Strip Conversations help children with social communication difficulties to understand what's happening and how to behave in different situations.
- 3. www.middletownautism.com is an organisation that provides information and training for parents and professionals.
- 4. www.zonesofregulation.com Leah Kupyer's Zones of Regulation programme which aims to help chidren understand their feelings and regulate themselves.
- 5. www.shineireland.com Cork based ASD charity.
- 6. www.autism.org.uk National Autistic Society (UK): a very useful website.
- 7. www.brothersofcharity.ie/southernservices Brothers of Charity website.
- 8. www.pecs-unitedkingdom.com Information on Picture Exchange Communication System and strategies to help develop social communication skills.
- 9. www.tonyattwood.com Tony Attwood.com
- 10. www.teacch.com TEACCH website with information on ASD and strategies to support people with ASD.
- 11. www.sensorysmarts.com Information on helping a child with sensory issues.
- 12. www.winslow-cat.com Resources for Visual Teaching Methods/Books/Computer Programmes etc.

The following texts might provide some useful resource materials for those working with Freya: Gerland, G (1997). A real person: life on the outside. London: Souvenir Press

Hannah, L (2001). Teaching young children with autistic spectrum disorders: a practical guide for parents and staff in mainstream schools and nurseries. London: The National Autistic Society UK.

Jordan, R and Powell, S (1995). Understanding and Teaching Pupils with Autism. New York: John Wiley & Sons Limited.

Lawson, W (2001). Understanding and working with the spectrum of autism: an insider's view. London: Jessica Kingsley Publishers.

Leicester City Council & Fosse Health Trust (1998). Autism: how to help your young child. London: The National Autistic Society.

Wing, L (1996). The Autistic Spectrum: A Guide for Parents and Professionals. London: Constable.

Winslow Press Catalogue (Resources for Visual Teaching Methods / Books / Computer Programmes etc.)

Tel: 0845 2302777 / www.winslow-cat.com for a brochure.

Based on the book Playing Laughing and Learning with Children on the Autistic Spectrum – A Practical Resource for parents and carers by Julia Moor; available through Amazon.co.uk.

Hanen – More Than Words Programme Hanen 'More than Words Programme; Helping Parents Promote Communication and Social Skills in Children with Autistic Spectrum Disorder'

Giggle Time – Establishing the Social Connection; A Programme to Develop the Communication Skills of

Children with Autism – Susan Sonders ISBN 1 84310 7163. It is available through amazon.co.uk.

Building Bridges through Sensory Integration by Ellen Yack(Author), Paula Aquilla(Author), Shirley Sutton(Author)

The Out-of-Sync Child, by Carol Stock Kranowitz

WHAT SUPPORTS ARE THERE FOR PARENTS TO USE?

CHOICE BOARD - A choice board may be placed on the fridge with empty objects representing food in the fridge (or laminated packets, photos or representational pictures (i.e. Boardmaker). A choice board may also be placed beside the TV, so the child can communicate what he/she wants to watch. If the child will not bring the pictures of what he/she wants to watch then empty the DVD cases and make a choice board. Using the DVD cases may make more sense for the child. Categorising and storing his/her toys in sets is useful and putting them out of reach on a playroom shelf will create the need for him/her to ask for them. Take photos of each set i.e. fireman Sam toys, animals etc, and have these on a choice board so that the child can bring the pictures to you. Tidying away the toys into sets will help him/her categorise words for language.

USING VISUAL AIDS - It is imperative for you to use pictures or objects to communicate with your child. E.g. when the child sees the keys he/she knows you are going in the car. Use pictures to encourage him/her to 'sit', 'go to bed', 'go outside', 'open door', 'trampoline', 'make buns', 'feed fish'.

A 'No card' (available through Pyramid Education) can be placed around the house for places your child is not allowed into or to communicate to that they cannot have an item. A see through 'no card' placed over a picture of a requested item can aid understanding. Labelling the house with pictures may also help the child interact with you. If you put a 'feed the fish' picture beside the fish bowl within eye level he/she may bring that to you to indicate she wants to feed the fish. This is initiating communication. The same can be done with a locked door. Put a picture of the trampoline on the back door or pictures of his/her favourite outdoor toys may help him/her communicate with you that he/she wants to go outside.

The following programmes will help develop expressive communication:

- Floor Time Approach by Greenspan (1998).
- Hanen Programme More Than Words Helping Parents Promote Communication and Social Skills in Children with Autistic Spectrum Disorder.
- Go Games.
- Music Therapy.
- Intensive Interaction.
- Videoing your child doing actions i.e. sleeping and playing them back showing him/her a picture to match the action.
- Requesting 'help' using a Pecs card.

THE PICTURE EXCHANGE COMMUNICATION SYSTEM (PECS) -

Expanding the variety of the child's communication intentions is the next step. This can be achieved through use of the Picture Exchange Communication System (PECS) which was developed as a means to teach children with autism a rapidly acquired, self initiating, functional communication system. Its theoretical roots combine the principals from applied behaviour analysis, typical speech and language development, and guidelines established within the field of alternative and augmentative communication. Training involves:

Phase One: Initiating an interaction by requesting – by handing a picture or object to a communicative partner.

Phase Two: Initiating a request by repeating the above except this time distance is involved.

Phase Three: Picture discrimination – selecting a picture from a choice in order to request an item.

Phase Four: Sentence Structure – The child will use a sentence strip with the 'I want' icon and select a picture of the requested item.

Phase Five and Six: Attributes and additional vocabulary - the child will sequence sentences with pictures and

a sentence strip and say the sentence.

Once the child is able to use pictures to request items functionally within the class/home a PECS folder can be provided to keep all her functional pictures in. He/she can learn to go to this book and give a sentence strip to an adult when he/she wants to comment/ ask a question/ describe.

The PECS book is important for the child so as he/she can learn to continue developing his/her functional communication skills despite having an expressive language disorder. The emphasis is on independent use... PECS provides the training ground for expressive language development within a social communication framework. Comments are formulated by sequencing pictures onto a sentence strip, and the act of communication is giving that sentence strip to another person. The child will be encouraged to read the phrase i.e. 'I want ice-cream'.

The home will require re-structuring to ensure that all 'motivating' activities and toys/foods are not in the child's reach. The child will have to communicate with the adult to request items. They cannot be freely accessed particularly for him/her.

The PECS manual and equipment is available @ Tel: (01) 273609; Email: pyramid@pecs.org.uk

The Boardmaker is a DVD rom containg thousands of pictures for printing and laminating to make pecs cards. It is available through www.inclusivetechnology.org.

It may be useful to start exchanging real life items with photographs of the real item attached. This is for purposes of consolidating an understanding that the real item can be represented by a picture.

It is imperative that you get down to the child's level when communicating especially with pecs. When you

show him/her a picture, bring it up to your mouth and model the word for him/her. Each time you model the word with the picture by your mouth you are helping him/her attach meaning to that picture.

THE FLOOR TIME MODEL BY GREENSPAN - This involves sitting down with the child in a quiet place with toys that will lend itself to interaction. This model is based on the belief that children can learn interactive spontaneous communication; social emotional and cognitive learning through interactive play. The adult allows the child to take the lead. The adult will comment on actions, emotions, labels as the child plays. Words are more meaningful when the language being taught is being directly experienced by the child. The adult will sit face to face with the child and interpret emotions, label toys or actions as the child plays.categorise words for language.

HANEN - 'MORE THAN WORDS PROGRAMME': HELPING PARENTS PROMOTE COMMUNICATION AND SOCIAL SKILLS IN CHILDREN WITH AUTISTIC SPECTRUM DISORDER

This is an excellent resource in the development of communication. The programme is comprehensive and individually tailored to each child's stage of communicative development. The programme incorporates Freya's strong interests. There are specific structured tasks to complete for each stage of the child's development. The book is not complicated and specifically written for parents. Parents can make enquiries from their speech and language therapists about programmes running in their area.

GO GAMES - The aim of go-games is for the adult to produce an action in response to the child saying, 'go'. He/she will learn that communication 'pays off' and that he/she can produce a strong reaction in people by talking. Other 'go' games could be simply throwing a ball, knocking down a stack of pillows, letting go a friction car, blowing a bubble, letting go of a blown up balloon. Sound sensitive toys are also very valuable to link

sound to an affect i.e. plasma globe (Argos) lights up when you talk. Other sound sensitive toys are available in local toy shops.

MUSIC THERAPY -

Music therapy is excellent in building social communication interactions with children on the spectrum. A music therapist can engage a child in a turn taking interaction or a mini 'conversation' using music. (Cochrane, 2010)

INTENSIVE INTERACTION - (www.intensiveinteraction.co.uk)

Intensive interaction has been successful in increasing the expressive language and social interaction of children and adults with a diagnosis of autism. The basic skill is imitating the child, their actions and their words. This creates a greater self-awareness.

SOCIAL INTERACTION SKILLS

The difficulty in developing fluent interpersonal skills is probably the most noticeable feature of children with autistic spectrum disorder. These children are not anti-social. Rather, they are asocial – at times wanting to be part of the social world, but not knowing how to enter it. But children with autistic spectrum disorder do not pick up social skills incidentally; these need to be specifically taught.

Other people need to understand the difficulties posed by the child with autistic spectrum disorder and the reason why the child behaves the way he/she does. These children often appear to find it easier to relate to adults or younger children than to others their own age. This may be because adults make more allowances, and modify their own behaviour towards the child. Others find it easier to interact with younger children, with whom they can take the lead without feeling intimidated.



DEVELOPING SOCIAL SKILLS AND SOCIAL UNDERSTANDING

SENSE OF SELF - It is often said that children with autistic spectrum disorder have a high level of egocentricity. This may make it sound as if they choose to act in this way – they don't! They often don't even understand their own feelings and behaviour. The aim of intervention is to increase the child's confidence in himself/herself as an individual, since increased self-esteem reduces anxiety. There is a need to strive to give the child a positive image of himself/herself. The child may need to be taught to develop a "sense of self". Encourage the child to reflect on his/her own role in events and activities, using photographs of daily activities to make up little books or video accounts.

INTERACTIONS WITH OTHERS - Children with autistic spectrum disorder lack an awareness of the needs of others in relation to themselves. Intervention should aim to increase the desire to interact with others. It may start with increasing awareness of the ways in which other people behave, and then work to equip the child to interact with others. To do this, it is necessary to teach specific social skills, preferably in realistic, functional settings:

Make the most of activities, which lend themselves to working with a partner e.g. looking at books, before simple co-operative games and activities. Developing interaction with adults should be a first step before focusing on peer interaction.

PERSONILIZED READING BOOKS - Children with ASD are very visual and it may be that she has the ability to learn to read much easier than he/she has for communication in a verbal way. This needs to be explored. The child requires appropriate structure and flexibility to help him/her make connections in his/her learning.

For example, in development of the child's reading skills, he/she may benefit from "personal" vocabulary / reading books focusing on real people and places he/she knows. This will help to motivate the child. If it is an animal book the pictures can be scanned and laminated separately. Velcro can be added to the book and separate pictures. He/she could match the laminated pictures to the pictures in the book by sticking them in. Make up stories that are directly related to the child, his/her experience and interests. All the pictures/symbols that feature in the child's books should be relevant to him/her e.g. people and places he/she knows. Teaching should include a photograph, symbol and the written words (with the use of symbols above new words as they are introduced to reinforce recognition and meaning). In teaching reading skills in a systematic way, the symbol gives a stepping-stone from the photograph to the abstract word. As he/she gets older, symbols should also be used on work sheets and to add meaning to the child's written work e.g. "writing" shopping lists, news, daily diary of activities etc. See www.do2learn.com for downloadable symbols. Some children with autism who are very visual make quicker progress in learning to 'read' than in using speech.

A personalized photograph album: This book has a recording facility on each leaf so that a short message can be recorded. This benefits the child in that phrases are recorded in response to motivating pictures. Making his/her own DVD's: of familiar people saying phrases that the child is being encouraged to learn in different contexts.





MATCHING OBJECTS TO PICTURES AND SORTING -

As a sorting skill you could get two clear Fanta bottles, cut the top off and fill with water and/or food colouring/ bubbles. On each bottle front put a picture of a different animal and encourage the child to sort his/her toy animals i.e. little cows and ducks. (At the child's development stage all four legged animals will be dogs or cows). This can be done to sort balls from bricks or any item.

COMPUTER BASED TECHNOLOGY -

Choose It Maker Two - is an excellent programme to help develop concentration, listening, comprehension and reading. The child is required to make a choice on verbal command. The teacher or therapist records their own voice. The number of picture choices can be decreased or increased in accordance to ability. Once the child has touched the correct picture (touch screen) or clicked on it (if he/she has mouse skills) the picture enlarges and the child is immediately rewarded through visual images and song. The child's own pictures of familiar people and toys can be transferred easily to this activity and motivating picture choices can be employed.

Flash Pro 2: - This programme is an excellent resource it has over 8,000 real photographs arranged in categories for instant printing and use. There is also a sound category in which once clicked on the picture it makes a sound.

Available from Inclusive Technology Limited,

Tel: (01)457819790,

Email: inclusive@inclusive.co.uk.

Website: www.inclusive.co.uk

An advisor is available for individual advice.