Temple Street
CHILDREN'S UNIVERSITY HOSPITAL

Information on Autism Spectrum Disorders

For Parents and Carers

This booklet was designed to increase awareness and knowledge of Autism Spectrum Disorder (ASD) for parents and carers.

This booklet explains the main features of ASD. We have included some tips that you may find useful in helping you to access services and support your child's development.

If you are a parent of a child who does not have a diagnosis of ASD but you are concerned that your child has some of the difficulties described in this booklet we recommend that you discuss it further with your GP.

At the back of this booklet you will find a glossary of words used in this booklet. We hope you find this booklet helpful.

Definition

Autism Spectrum Disorder (ASD) is an umbrella term used to describe a range of disorders from autism to Asperger's Syndrome.

Autism is a developmental disorder of social interaction. Autism is more common in males than females (approximately 4:1).

Children with autism have difficulties in 3 main areas:

- Social impairment
- Communication impairment (verbal & non-verbal e.g. poor eye contact)
- Narrow interests and repetitive routines

To be diagnosed with autism, children must have difficulties in all 3 areas, and some of these difficulties must be present before the age of three.

Each child's symptoms and the way they are affected can vary. The first signs of autism usually appear as delays in development before the age of three.

Although a diagnosis of autism may not be made until a child is 3-4 years old, parents often report that they knew something was not right at a younger age e.g. their baby did not like being cuddled or did not play with children of their own age . Their child may have only allowed contact to get a need met e.g. food.

This lack of desire for communication and physical contact is very difficult and frustrating for the parent trying to bond with their child.

Asperger's Syndrome is an autistic spectrum disorder with difficulties with social interaction and narrow interests. There is no general delay in speech and language or intellectual development.

Asperger's Syndrome shares many of the symptoms of autism. Although the speech of those with Asperger's Syndrome usually begins to develop normally they can present with specific problems e.g. understanding more abstract language and they may interpret language in very literal ways. For these children the term " fit to burst" could be understood as literally meaning that a person will burst.

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

Children with PDD-NOS may have similar difficulties as children with autism. A diagnosis of PDD-NOS is given when the child's symptoms do not meet all 3 diagnostic criteria for autism. They must have difficulties with social interaction and either difficulties with communication or restricted interests. The age of onset may also be different to that which is normally expected.

The term ASD will be used through out this booklet to describe the range of difficulties from children with autism to Aspergers Syndrome.

Please note:
A diagnosis of any Autistic Spectrum Disorder can also occur with other disorders such as a learning disability or Attention Deficit Hyperactivity Disorder (ADHD).

The 3 main areas of difficulty for children with ASD will be outlined below.

Social Impairment Difficulties in Social Understanding and Social Interactions

Most children are ready to become sociable and develop communication skills from birth. They know that other people are important for comfort, to share pleasure with, to ask for help and to learn from.

Children with ASD may find all this very difficult. They may not be interested in people and find it hard to see things from another person's point of view. They are often described as being in a "**world of their own**".

A young child with ASD may have difficulty making sense of people, and may find mixing with others frightening and unpredictable. They may:

- May not use eye contact when they are talking
- Have difficulty understanding or using gestures
- May find it difficult to something from another persons point of view
- Relate better to objects and ignore people
- Be happy with approaches from people they know well
- Be unaware of social rules e.g. sharing and taking turns

Communication Impairment

Children with ASD do not usually communicate like other children of their age. They find it very hard to make sense of the things that happen around them. Words may mean very little to them and they may be unable to link what they see with what is being said to them.

Young children with ASD not only have difficulty making sense of words but also have difficulty with reading non-verbal cues e.g. facial expressions and gestures. This makes it difficult for them to learn what is expected of them. They may not recognise when someone is happy or upset and what that means.

A young child with ASD may:

- Use words and then “lose” them, or may not use them regularly
- Have difficulty understanding language out of context e.g. he/she may not understand the words “dinner is ready” unless the words are associated with cues e.g. they can smell their dinner and see it on the table
- Develop language that does not follow the normal pattern or may not speak at all
- Often use words out of context
- Repeat words and phrases that other people say, either immediately (immediate echolalia) or later (delayed echolalia)
- Develop language that appears advanced for their age but they may not understand what it means
- Learn to talk easily, but find it hard to understand communication that is not literal. Expressions like “if you eat any more you’ll burst”, can be very frightening for them.
- They may have difficulties understanding that a story is not real

Narrow Interests and Repetitive Routines

Imagination helps us to understand the world, to work out what will happen next and see other people's point of view. Children with ASD often have difficulty doing this. One of the first signs of the development of imagination is pretend play e.g. brushing dolly's hair. In children with ASD imagination may develop very slowly, in unusual ways, or not at all.

Problems of imagination can show themselves in different ways. Some children may never seem interested in what a toy represents. They may focus on the features of the toy such as the wheels of the truck or the box the toy came in. Other children may run the toy truck in and out of a garage, but don't act out a story. Some children, who do act out stories or take on a particular character, may be only imitating a favorite video or book.

This does not mean that children with autistic spectrum disorders do not have an imagination. It just means they tend to have less ability in this area. They also tend to be less interested in sharing their imaginative ideas than other children.

Problems with imagination make the world a very uncertain place, so children with ASD find reassurance in routines and patterns that they can control. Repetitive behaviours and routines are a common feature of ASD e.g. the child:

- May become upset if a familiar routine changes, e.g. a different teacher in class
- Will often avoid new experiences, for example, trying different foods or wearing new clothes
- Will often pay close attention to unusual details and struggle to see the bigger picture e.g. spins car wheels rather than drive the toy car
- May be slow to develop pretend play (pretend a building block is a car)
- Develop stereotypical body movements (for example, some children will flap their hands, some may rock back and forth)

Sensory Integration

Sensory Integration (SI) is a theory and treatment approach developed by an American Occupational Therapist and Psychologist Dr Jean Ayres in the 1960's.

Sensory Processing Disorder is the current term used to refer to Sensory Integration difficulties which can present as part of a wider condition such as ASD or may be diagnosed as a Sensory Processing Disorder.

Signs of a Sensory Processing Disorder may include:

- Over or under sensitive to touch, movement, sight, sound or taste
- Activity level unusually high or low
- Clumsy, awkward movements
- Delay in speech, language, motor and academic skills
- Poor organisation of behaviour
- Sensory seeking behaviours e.g. hand flapping
- Poor self awareness

The basis of Sensory Integration is that learning is dependent on the ability of an individual to take in sensory information from the environment and movement of themselves into the central nervous system and use this information to plan and organise their behaviour. The sensory systems include the:

1) Tactile (Touch)
2) Auditory (Hearing)
3) Vestibular (Balance and Movement)
4) Proprioceptive (Body position in space)
5) Visual
6) Gustatory (Taste)
7) Smell

If a child has difficulty in processing information from the sensory systems it may affect their ability to plan, behave and co-ordinate their motor skills. A common feature of sensory processing disorder is fluctuation in how they present, some days they may react appropriately and some days they struggles with tasks they were able to do the day before.

The aim of Sensory Integration Therapy is to provide appropriate sensory input opportunities that will cause changes in how the body processes the information and help the child to process the sensory information appropriately.

As we grow we all learn from our experiences and develop our sensory systems, but some children need our help to learn how to manage the sensory information. Some children react very differently to what you would expect, e.g. over-react to a stimulus, being very upset by certain clothing textures or being given a hug, while some under react to a stimulus, by not reacting if they hurt themselves or may hurt you by hugging to hard.

Sensory processing difficulties may be seen as behavioural problems, inattention, co-ordination or emotional difficulties or vice versa. All behaviours serve a purpose we need to work out what that is! If we only deal with the behaviour and not the sensory difficulty the sensory issue still exists and may be acted out in a different way. It is important that you work with an Occupational Therapist who has Sensory Integration training to learn how to identify what is a sensory issue and what is behavioural, to support you and your child to address their needs.

Multidisciplinary Team

Ideally, assessment for children with ASD is carried out by a multidisciplinary team, which may include:

Speech & Language Therapist

The Speech and Language Therapist assesses, diagnoses and treats children with communication difficulties. Communication difficulties include problems with speech, with understanding and using language, fluency, voice and with the social use of language.

Occupational Therapist

The Occupational Therapist specialises in the assessment of the child's motor sensory and functional skills in relation to everyday activities e.g. play. The overall aim of paediatric occupational therapy is for each child to reach their optimum level of function and promote development.

Psychologist

The Psychologist assesses the overall developmental skills of the child, with particular emphasis on intellectual ability, adaptive behaviour (every day activities), learning style and social interaction with other children and makes recommendations about correct educational placement. e.g. mainstream class versus special school setting.

Social Worker

The Social Workers offers practical and emotional support during the period of assessment and diagnosis and supports parents in accessing appropriate supports for their child and family after the assessment period

Psychiatrist

The child psychiatrist carries out an assessment which involves interviewing the parents in relation to the child's difficulties and observing the child. The child psychiatrist makes a diagnosis of ASD and /or other conditions in collaboration with other members of the multi-disciplinary team.

Peadiatrician

A paediatrician is a doctor who specialises in working with babies and children.

Practical Ideas

Communication

Non-verbal children with ASD or those with very limited language can often benefit from other methods of communication such as Lamh and PECS (Picture Exchange Communication System).

Lamh is a manual sign system based on Irish Sign Language. It is used by individuals with communication difficulties to support communication.

PECS was developed by Andy Bondy and Lori Frost as an alternative communication system for young children with Autism. It involves the child communicating by exchanging pictures. Initially the pictures are used to make requests and later the child can build sentences to communicate for a variety of reasons. Using picture schedules / timetables of your child's day can help him/her predict what will happen next.

The following are some general guidelines to help develop your child's communication skills:

The child with Autism requires a strong incentive to communicate with others. They need to have a reason and something to communicate.

Give your child a reason to communicate and then wait:

- Place his/ her favourite things within his view but out of reach.
- Place his/ her favourite food on a high shelf or counter top where he can see but not reach it.
- Place his / her favourite toy or video on a shelf that is out of his reach but within his view.
- Place a favourite object, in a clear container that is hard to open or a plastic jar with a difficult screw-on top.
- You can also manipulate his environment in other ways, to encourage communication. e.g. give yoghurt without a spoon, or give an unopened bag of crisps.

Wait for your child to communicate in any way to indicate what is wanted. If your child does not yet have any words to indicate needs, they may cry, may reach, point or vocalise. Respond to his/ her communicative attempt and interpret the message by saying what should be said if he /she could, e.g. "biscuit".

If your child is using speech you may have to expand their single word to two words e.g. "biscuit", expanded to "want biscuit". If he is already saying "want biscuit" you say what your child should say, if he/she could "I want a biscuit".

Offer things bit by bit: If you give everything all at once, your child won't need to ask you for anything. By giving him /her small amounts, you provide more opportunities for him to communicate his needs to you. Some toys are easy to give out bit by bit because they have multiple pieces.

You can also use this strategy when giving food and drink. Give him/her a small amount of juice in his / her bottle to encourage them to look for more.

Encourage your child to make choices. You can initially offer a choice between something you know is liked and something he /she definitely dislike e.g. biscuit and broccoli.

Encourage him / her to make a choice by reaching/pointing/verbalising You can do this by waiting for a response. Once something is initiated hand the object straight away. If a choice is not made put your hand on his /hers and place it on the object you know he / she wants.

Always make sure you 'label' what he has chosen so he can learn to connect the word to the real object.

Joint attention; is important for the development of communication skills. It involves a child and adult looking at something together or playing with something together. Both share the enjoyment of the activity by looking from one object to another.

Playing with interesting toys; a ball, games with puppets or looking at books with lots of textures or lift the flap type books, provide opportunities for joint interaction.

Get down to your child's physical level and be face to face while playing with these toys. Exaggerate your facial expressions so your child learns to look at your face as well as the toy.

Talk about what is happening. Follow your child's lead and describe what he/ she does and label (give the word for) what he / she looks at. If possible try to have the toys near your face to encourage eye contact.

When looking at a book together, sit opposite him /her or hold the book up against your chest to encourage eye contact.

Help your child understand what you say by:

- Saying less e.g. "come over here and sit down" can be reduced to "sit down"
- Stressing key words
- Speaking slowly
- Show what you mean by using gestures, pictures and objects.

Using simple language during everyday routines is a great way of increasing a child's understanding of language as it is linked to what they are doing and gives them the words connected to it. Use simple language during routines such as dressing, bath-time, dinner time. While playing with high interest toys talk about what is happening, e.g. "bubbles popped", bubbles all gone".

During physical play, use the word for what you are doing, e.g. "tickle" as you tickle him, or "up" as you lift your child up in the air and "down" as you let him/ her down again.

Encourage the use of single words. Be specific! When you offer a drink, drop by drop, model the word "milk/juice". Stop in the middle of a fun game such as tickling or swinging and model the appropriate word, i.e. "tickle"/ "swing", during bubble blowing model the word "bubble".

Interpret his/ her message, e.g. when he/ she holds their arms up to be lifted, say the word "up". When he / she rejects an item, say "no". What you're doing really is saying it as he/ she would if they could.

Later you can leave a pause for your child to attempt the word, however don't wait too long. It is enough initially to show you expect a response but say the word if it is not being used as yet.

If your child is already using words and sentences to communicate his / her basic needs, it is important to encourage him to communicate for a variety of reasons. These include;

- To greet someone
- Relate information
- Ask and answer questions
- Talk about the recent past and near future.

The following are ideas to help develop some of these areas.

Use picture diaries and communication books to help your child talk about things he / she has done. This will help him / her to relate past experiences and comment on what he / she has done. For example after a trip to the zoo, present him with pictures of what was seen at the zoo. You can initially model the appropriate language while looking over the pictures with your child e.g. "I fed the ducks" "I saw lions".

"Wh" questions
These questions ask "what", "who", "where", "when", "how", "why". The easiest questions to answer are "what" questions, after these, come "who" and "where". Questions that ask "when", "how", "why" are more difficult.

The simplest "what" question to answer is "What is that?" Your child can learn to answer this question if you provide verbal models of possible answers. The next most common "what" question is "What do you want?". Initially, give visual cues (show him/her the object) to help him / her respond. You could use pictures or object choice and prompt him / her to say the word e.g. "is it a car or a doll you want ?"

Understanding of the questions “who” , “where” and “when” begins as you model these questions and their answers, over and over in routines, songs and games. At bath time you could ask “where is your nose?” before washing your child’s nose. To make sure your child gets practice answering questions that begin with “who” “where” and “when” work them into your conversation as often as you can. Accidentally drop your fork under the table and ask, “Where is my fork?”

You could also play hiding games. Hide items around the room and encourage him /her to find them asking each time, e.g. “Where is the car?”. Model the answer, e.g. “under the box”. Later encourage your child to ask you where the animals are. Someone else could prompt him by whispering the question to him.

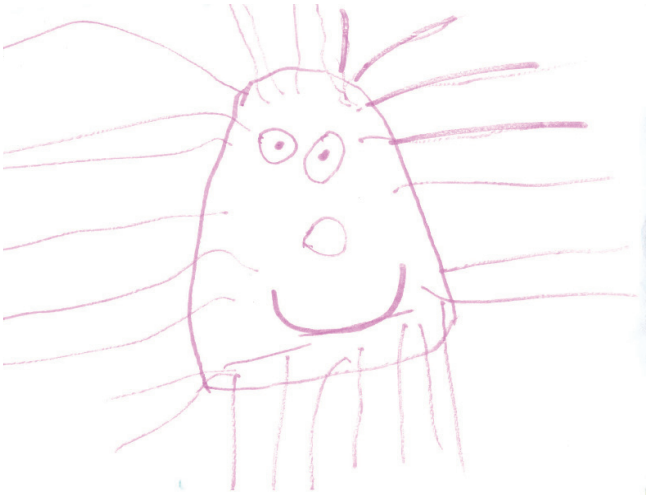
Conversational skills:
A successful conversation is a two way process. It involves questions, comments and responses related to a topic both people are interested in. Each partner should get an opportunity to both ask and answer questions. It is not always best to let your child lead the conversation. Always letting your child lead, will take you both into a conversational dead end. This can happen if they get stuck talking about one thing and can’t move on. If he / she is not tuned into you they may think that because they are passionate about a topic you must be too. It is important to learn good conversational skills particularly for interaction with peers.

If no matter what you try, your child persists on talking about their own interests, you will have to be more direct. You will have to insist on a change of topic. Warn that after a few moments you are planning to have a conversation about something else. Then switch topics. You can help reinforce the idea of a new topic by using a timer; or by using a visual cue, such as a card that shows him the number of things to say about something, e.g. “Let’s say two more things about Dora and then talk about something else”. You could also use a signal to warn him / her that it is time to change the topic, such as holding your hand up in the stop position.

Ideas adapted from:

Talk Ability by Fern Sussman

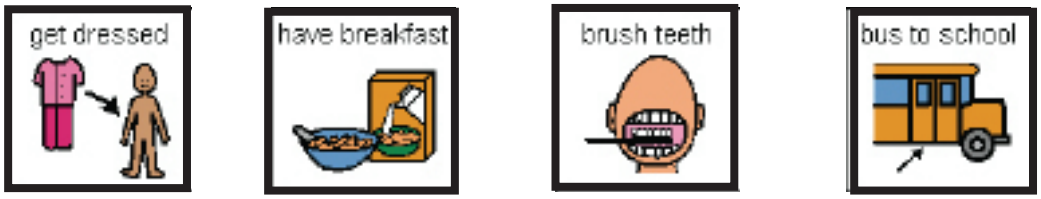
More Than Words by Fern Sussman



Visual Schedules

Visual schedules are an example of visual structure. You can use a visual schedule to help your child understand what is going to happen in the day or to help your child to follow the steps needed to complete a particular task like getting dressed or going to the toilet.

Here is an example of a simple visual schedule;



Photographs or actual objects can be used and it is always a good idea to write the name underneath the symbol, picture or object. These can also be used to explain to a child that first one thing will happen and then another. Below is an example of how you can use a visual sequence to explain this concept.

Visual schedules are widely used with children with ASD and were originally developed as part of the TEACCH approach. More information on this approach can be found in the interventions section of this booklet on page .

Behaviour Difficulties

Play

One of the ways you can help prevent problem behaviours is by making time each day to play with your child on a one to one basis. During this play you can follow your child's lead allowing them to be in charge of the play. This will help to enhance your relationship with your child and will give your child a chance to be in charge, feel in control and improve their self esteem. This positive time spent together will help your child to be able to follow direction from you, at other times and accept consequences for misbehaviour that you might put in place.

Understanding the behaviour

Difficult behaviour is almost always a means of communication. It is important to look for the causes of the behaviour or what your child is trying to communicate. For children with Autism there are additional underlying factors which could lead to difficult behaviour. These could include:

Sensory sensitivities

Difficulty with communication

Lack of social understanding

Need to keep things the same

Obsessions or special interests.

One of the ways that you can help prevent problem behaviours is to closely examine your child's behaviour. You can do this by thinking about and writing down what exactly happened just before an incident of difficult behaviour, what happened during the incident and then what happened immediately afterwards. This can help you to understand what caused that incident and how you responded. Sometimes this may shed some light on things that you can change so as to reduce or prevent that behaviour. This can also help you to look at how you responded to the behaviour.

These are some other things you can do to help prevent problem behaviour for your child with ASD:

- Reduce your language –using less words can help your child to understand and process more of what you say
- Use visual support
- Follow a daily routine
- Motivate your child and Reward good behaviour
- Prepare your child for change
- Use FIRST and THEN
- Be consistent
- Keep the environment organised, structured and uncluttered.

How do I manage Difficult Behaviour when it does happen?

How you respond to difficult behaviour is very important. It is important that children feel that the adult is in control, this will help your child to feel safe. Be careful not to accidentally reward difficult behaviour by giving too much attention (negative or positive) or giving in to demands. These responses will reinforce the behaviour leading to the child repeating the behaviour.

Active Ignoring

This involves turning your back on behaviour that you don't like and pretending that you don't see it, totally taking your attention away from the child. This strategy is particularly useful for dealing with temper tantrums. This can be used when you know that your child and others around them are safe. If the environment is not safe you can move your child to a safe place and then take your attention away from them until they calm down. Once your child has calmed down you can go to them redirect them by introducing a new activity to help them to move on from the tantrum.

Dealing with behaviour that can't be ignored?

If your child engages in dangerous behaviour, like hurting others or throwing things for example you may need to put in place consequences for this behaviour. The aim of putting consequences in place is to help stop the behaviour and prevent it reoccurring and to help your child to learn self control.

Time Out

"Time out" involves moving your child to a safe area where they need to sit for a period of time without getting any attention. The aim of "time out" is to take the child away from the situation, giving them time to calm down for attention to be taken away. The period of time a child spends in time out should be the same as their age. For example a three year old should be in time out for no longer than 3 minutes. You can use a visual cues like an egg timer and a coloured mat to help your child to understand time out. If your child refuses to stay in time out you should consistently place them back without speaking to them or giving a lot of eye contact. Once time out is over you should help your child to move on by directing them to another activity.

Other Tips

- Try to stay calm in the face of difficult behaviour. Shouting or getting angry will make the situation worse.
- If you are overwhelmed trying to walk away and get another adult to take over while you get some time out!
- Try to give logical consequences for behaviours eg. If two siblings are fighting over a toy put it up high out of reach.
- Be consistent – it is important to always respond in the same way to when managing behaviour, otherwise your child will get confused and won't be sure of the rules.
- Work together- It is important that everybody who cares for the child does the same thing. This means sitting down when the child is not around and deciding on a plan of action.

Ideas adapted from – EarlyBird Parenting Programm
Bringing up Responsible Children by John Sharry

Feeding

Children with ASD can often have difficulty with feeding, they may be:

- Selective, restricted or a faddy eater
- Refuse food
- Avoid new/ unfamiliar foods
- Be restricted on the visual appearance of food (packaging)
- Have a fear of contamination e.g. foods touching

Children with ASD commonly present with behavioural issues relating to food. For many children however, problems with food can stem from difficulty with sensory processing (touch & taste) or difficulty with oral motor control.

Children that avoid particular tastes and textures restrict their diet, avoid new foods (to limit unknown experiences) and can only handle familiar foods in their mouths.

It may be beneficial not to focus on trying to get them to eat foods you know they have difficulty with. Oral play activities can help the child develop oral processing and oral awareness to educate their systems in a non-threatening manner.

For 15 minutes before mealtimes engage your child at the table in oral activities to prepare his / her for food e.g.

- Blowing bubbles
- Ping pong football using straws
- Funny facial expressions using their mouths
- Cheek Massage – rub cheeks starting around the cheek bones, over the cheeks, chin and under the chin.
- Suck in cheeks, lips – making smacking noises
- Blow up cheeks and blow out – making mouth noises
- Blowing musical instruments or ping pong ball across the table

What may work?

Prioritise need– if calorie intake is needed increase preferred food but get advice from dietician

Exposure of new foods needs to be made at least 14 times to make it familiar - food may need to be placed on a separate plate on table and slowly moved closer until it can be left on your child's plate.

Make tiny changes, find things that are similar to increase variety, make one change at a time.

Work on sensory issues – under advice of Occupational Therapists (OT) i.e. use of chewy tubes

Provide opportunities for food play with their hands

Encourage involvement in food preparation

Make food scrap book – "Foods I like and foods I would like to try"

Social stories and visual cues

Consistent approach is needed at home and at school

Toileting

Try not to start toilet training too early ie: before you think that your child is ready as this will create stress for every one involved. You will know when your child is aware as there will be change in their behaviour.

It is important to **establish a routine** with your child, for example, taking them to sit on the toilet or the potty after every meal (approximately 20 minutes after the meal). Some parents find it useful to use picture/ visual cues to remind your child about what is about to happen, such as a visual schedule

It is helpful to **keep a record** of when your child goes to the toilet so you can determine whether trips to the toilet need to be more or less frequent; and to determine at what time of the day your child usually uses the toilet/potty

Some children may have a **fear of sitting on the toilet**. This may be because they are afraid of sitting on the toilet seat, feel unstable, are afraid of falling in and of touching the water etc. Some ideas that may be helpful if you encounter these difficulties are:

- It can be useful to build up positive experiences with being in the bathroom/ sitting on the toilet e.g. providing them with calming and pleasant activities such as listening to music, looking at a picture book.
- Using a foot rest or a clip-on tray may help your child feel more secure when sitting on the toilet.
- Rewards: showing your child that you are pleased with them when they sit on or use the toilet. Praising your child can be a very effective. Allowing your child to do a favourite activity afterwards can also be effective or using a star chart

Sleep Problems

It is a good idea to get your child into a **bedtime routine** and this in turn will help you get a full nights sleep. It is important to keep a consistent routine at bedtime and to stick to it no matter how hard it is.

It can be useful to have a favourite book or story for your child once they get into bed. You can also have some of their favourite toys, books pictures in the room.

Once you follow your child's bedtime routine you should leave the room! If the child comes out of their room, take them back calmly and with as little fuss as possible.

If your child is afraid of the dark or anxious about being left alone there are a few things you could try:

- Leave the bedroom door slightly open so that they can hear your voices/activity in the house
- Have a night light or leave the landing light on
- Play quiet calming music
- If possible have your child share with one of their brothers or sisters

Activity Levels

Some days we need things to hype us up or calm us down to help us work best. Think about what helps you to perform best at work or to relax before bedtime e.g. cups of coffee, exercise, reading a book. It is a very individual thing.

Physical activity effects our arousal levels. Running and jumping activities have a hyping affect on our sensory system. Activities that involve rhythmical and heavy work can have a calming affect.

Often children with ASD have difficulty with multi sensory processing. This refers to a child's ability to receive and respond to a lot of sensory information at the same time. A child needs to be able to filter the relevant information from all other sensations around them, so they respond correctly and aren't overwhelmed.

It is important to consider your child's environment. Is it over stimulating and cluttered with too many distractions? It is also important to consider how your own behaviour affects your child.

If you feel stressed your voice increases and you may react differently to situations. Your child can react to that. Try to stay calm and keep a low flat voice, as this will have a calming affect.

Getting the Hands Ready for Work

Sometimes it is helpful to draw attention to the arms and hands before starting work, games include:

- Clapping games
- Rub down or squeeze from shoulders down to their hands
- Banging a drum or a tambourine with their hands
- Warm up activities including shoulder shrugs, waving, pushing hands together, pulling hands apart. These can also be fun with a partner or in a game of "Simon Says"

WAIT- give them time to try and learn with each task

Educational Interventions for Children and Young People on the Autism Spectrum

There are a variety of interventions used for children with ASD. Different types of intervention are suited to different children at different times in their lives. Often, educational providers use parts of a number of different approaches to meet the child's unique needs. This is known as the Eclectic Approach.

The following are some of the most common and well researched educational interventions used for children with ASD:

TEACCH- Part of the TEACCH programme involves the use of visual support, structure and organisation of the environment. Each programme is individualised depending on the child's needs and parents should be partners in implementing programmes so that the programme can be used at home and in school. More information about TEACCH can be found at http:/teacch.com/

Applied Behaviour Analysis (ABA) This way of teaching for children with ASD which involves breaking down tasks into tiny parts. Each part is taught in an intense approach which positively reinforces the correct response to a command and ignores or redirects an incorrect response. This reinforcement is very technical and precise. How well a child progresses depends on their individual needs as well as how the programme is implemented. For more information on ABA go to www.autism.org.uk/

PECS – (Picture Exchange Communication System) an explanation of this can be found in the communication section of this booklet on page. More information about PECS can be found at http://www.pecs.com/ .

Social Stories- Social Stories were first developed by Carol Gray in 1991. Social Stories involve use of stories to help children to learn a routine, do an activity, ask for help, how to behave in certain situations or how to respond to feelings like anger and frustration. Using social stories with children with ASD can help them to better understand social situations and how to behave in different situations. For more information and examples of Social Stories go to http://www.thegraycenter.org/

Grants / Entitlements

A range of grants and entitlements are available to support children with ASD and their families. These are listed below

- Domiciliary Care Allowance
- Respite Care Grant
- Carers Benefit
- Carers Allowance
- Medical Cards
- Incapacitated Child Tax Allowance
- Home Tuition Grant
- July Education Programme
- Home Help

Domiciliary Care Allowance

This is a monthly allowance paid to the carer of a child under the age of 16 years with a severe disability who lives at home. The child must need constant care and supervision more than a child of the same age.

The income of the parents is not considered. Only the means of the child are taken into account e.g. compensation, inheritance. The medical section on the form should be signed by your GP. Sent the form to

Domiciliary Care Allowance Section
Social Welfare Services
Department of Social and Family Affairs
College Road
Sligo

It is important to include copies of your child's medical and /or developmental reports to support the application.

www.dohc.ie Department of Health and Children

Respite Care Grant

If you receive Domiciliary Care Allowance and are not receiving other carer's payments the HSE pay you the Respite Care Grant automatically each year during the month of June.

The Department of Social and Family Affairs also pays a Respite Care Grant automatically in June to those in receipt of Carer's Allowance or Carer's Benefit. For further information visit www.welfare.ie Department of Social Protection

Carer's Benefit

Carer's Benefit is a payment made to insured persons in Ireland who leave the workforce to care for a person in need of full-time care and attention.

You can get Carer's Benefit for a period. This may be claimed as a single continuous period or in any number of separate periods up to a total. However, if you claim Carer's Benefit for less than six consecutive weeks in any given period you must wait for a further six weeks before you can claim Carer's Benefit to care for the same person again.

If you are caring for more than one person, you may receive payment for each person. This may result in the care periods overlapping or running concurrently.

The application form for Carer's Benefit (CARB 1) can be got:

At your local social welfare office or Citizen Information Centre

By phoning lo-call 1890 202325

Online at www.welfare.ie

Carer's Allowance

Carer's allowance is a payment to people living in Ireland who are looking after someone who is in need of support because of age, physical or learning disability or illness, including mental illness.

The Carer's Allowance is means tested, it is mainly aimed at people who are not in work or with low incomes who live with and look after certain people who need full-time care and attention.

Working:

While receiving Carer allowance you can take up one of the following options

- Work outside the home for up to 15 hours a week.
- Attend an educational or training course or take up voluntary work for up to 15 hours a week
- Work part time as a home help for the HSE for up to 15 hours per week

Other benefits:

People getting carer's allowance are eligible in their own right for certain extra benefits. You will also qualify for Free Household Benefits such as;

- Free Electricity/Natural Gas/Bottled Gas Refill Allowance
- Free Television Licence
- Free Telephone Rental Allowance
- Free Travel Pass.

Carer's Allowance is not taken into account in the means assessment for a Medical Card.

For further information contact your local health centre or check with website below.

www.dohc.ie Department of Health and Children

Medical Card

Medical cards are given to people with low incomes and other qualifying people. They entitle you to a range of health services free of charge. These include GP services, certain prescribed drugs and public hospital services. Having a disability does not automatically entitle you to a medical card.

Most medical cards are granted on the basis of a means test and/or medical need. An application form can be downloaded from the Health Service Executive (HSE) website www.hse.ie or you can apply on line at www.medicalcard.ie

Incapacitated Child Tax Allowance

This tax credit can be claimed by the parents of a child with a permanent disability. The disability must have arisen before the child reached the age of 21, or while he or she was in full time education. Where there is more than one child the tax credit can be claimed for each child.

To apply you should write to your tax office with your child's details, quoting your PPS Number, along with a letter from your GP. This should be sent to your regional Revenue Office- addresses of which are listed on www.revenue.ie

Home Tuition Grant

The Home Tuition Programme provides funding to parents to provide education at home for children who are unable to attend school for a number of reasons such as chronic illness or while a child is awaiting a suitable school. You can apply for a maximum of 20 hours a week home tuition for your child. If your child is approved for a home tuition the cost of the tuition is paid by the department of Education and Science.

The application Form can be downloaded from Department of Education and Science website www.education.ie

Home Tuition Information

Dial (090) 648 followed by the Extension Number 3858

Dial (057) 932 followed by the Extension Number 5419

The Home Tuition Grant is only provided to children with a diagnosis of Autism in situations where no Autism specific Educational placement is available with the Department of Education School for the child.

The Special Education Needs Organiser for your area must sign the Home Tuition Application to confirm that there is currently no educational placement available for your child before you submit your application to the Department of Education.

The Special Educational Needs Organiser (SENOS) are appointed by the National Council for Special Education. They provide children with a direct local service to parents of children with special educational needs and to schools . A list of SENOS and their contact details is available on the National Council for Special Education website; www.ncse.ie

How Do I Access a Tutor For My Child?

It is up to each parent or carer to find a tutor for home tuition. Below are listed some ways to do this.

- Jonix Educational Services is a service that provides tutors within a preschool setting. Contact Sarah Dunne Coordinator (086 7753795) www.jonix.ie
- It is also possible to advertise for a home tutor on www.rollercoaster.ie under their special needs discussion board or in local / national newspapers.
- Advertise in schools

July Education Programme

The July Education Programme is a funding arrangement for schools to provide further special needs education in the month of July. If schools are not participating in the July Education Programme, Home tuition is offered as an alternative for the pupils.

Children with autistic spectrum disorders or with severe learning disabilities may also be qualify for home tuition during July. Department of Education and Science website www.education.ie

Special Needs Assistants

Special Needs Assistants (SNAs) work with children who need extra non-teaching support perhaps because of a physical disability or behavioural difficulties. This might include a significant impairment of physical or sensory function, or where their behaviour makes them a danger to themselves or other pupils. Children's needs range from needing an assistant for a short period each day (for example, to help feed or bring them to the toilet), to requiring a full-time assistant in their classroom.

SNA's may work with more than one child and can also work on a part-time basis depending on the needs of the school.

Applications for a preschool Special Needs Assistant(SNA) are made to the Disability Manager in your local HSE area. You can contact the Disability Manager in your local HSE area. Applications for school age children are made to the Department of Education by the individual schools.

Home Support / Home Help

An application can be made to your Public Health Nurse (PHN) for Home Help. Home Helpers may be employed directly by the HSE or by voluntary organisations on behalf of the HSE. They assist with normal household tasks such as shopping and cleaning and are assigned to people that are unable to carry out these tasks themselves. Access to home help varies greatly throughout the country.

Assessing your child's needs Disability Act 2005- HSE Publications

Assessment of need for children under 5 years of age:

Under Part two of the Disability Act 2005, children under 5 years of age with disabilities have a right to:

- An independent assessment of their health and educational needs arising from their disability
- An assessment report
- A statement of the services they will receive
- Make a complaint if they are not happy with any part of the process

What is an Assessment of need?

As a parent you can make an application to your local assessment officer for an assessment of need on your child. The assessment reports on a full range of your child's needs associated with his or her disability.

After this you will receive a report detailing your child's health and educational needs and the services required to meet those needs e.g. speech and language therapy, occupational therapy.

Who will carry out the assessment?

Your first point of contact is your local Assessment Officer who is responsible for arranging your child's assessment.

The assessment is carried out independently by identified professionals and is based solely on your child's disability needs. It is carried out regardless of the cost or availability of the services.

Where do I apply?

Application forms are available from your local health office. Call the HSE information line on 1850241850 or check out www.hse.ie for a list of local health offices in your area.

How long will it take?

Your child's assessment must start within 3 months from when the application form is accepted by the HSE. It must be completed within a further 3 months from the date on which the assessment commenced. In exceptional circumstances the assessment may take longer than 3 months, but it must be completed as soon as possible.

What happens next?

When the assessment is completed a HSE Assessment Officer will prepare a service statement for you. This service statement will say what services and supports need to be provided to your child and will be prepared within 1 month of the assessment being completed.

Books

- Autism: how to help your young child - Leicestershire Health Trust available on www.autism.org.uk
- Aspergers Syndrome: a guide for parents and professionals - Tony Attwood
- The out of sync child - Carol Stock -Kranowitz
- Social Stories - Carol Gray
- Sensory Integration Information Booklet. Resource for parents and therapists available from. www.sensoryintegration.org.uk
- The out of sync child has fun - Carol Stock -Kranowitz
- Toilet training for your child with Autism

Websites

AUTISM ASD

www.autismireland.ie/ - Irish Autism site

www.autism.org.uk - UK Autism site

www.aspire-irl.org/ - Asperger's site

www.sensoryintegration.org.uk -Sensory integration site- information on Autism / Asbergers

www.tonyattwood.com.au/ - Tony Attwood site information on Autism / Asbergers

Organisations

www.iaslt.com/ - The Irish Association of Speech and Language Therapists

www.aoti.ie - The Irish Association of Occupational Therapists

www.psihq.ie - The Psychological Society of Ireland

www.autismni.org/ - Autism Northern Ireland

www.nas.org.uk - The national autistic society UK, Helpful information on all aspects of autism including behaviour, toileting and feeding difficulties.

www.autismspeaks.org.uk/ - research charity for autism

Glossary

This glossary is a list of words used in this booklet and words that may be used in your child's assessment or report.

Abstract Language:

Time concepts such as yesterday, tomorrow or position words such as behind or beside.

Assessment:

Informal assessment uses observation of children playing, interacting with adults and other children and reported information from parents and teachers about the child's development.

Formal assessment uses standardised tests to compare a child's development with established norms.

Adaptive Behaviour

Adaptive behaviour is defined as the skills necessary to take care of oneself and get along with others in real life situations

ADHD – Attention Deficit Hyperactivity Disorder:

ADHD is a well defined and widely accepted condition. The core features include inattention hyperactivity and impulsivity. They cause significant problems at home and at school. These behaviours need to be present over and above the levels expected for their mental and chronological age.

Autism Spectrum Disorder:

This is a lifelong developmental disability that affects the way a person is able to communicate and relate to people around them. The diagnosis of autism spectrum disorder is given when children have difficulty in three main areas. These are known as the triad of impairment and include difficulties in

- Social understanding and mixing with others
- Social communication (verbal and non verbal)
- Rigidity of Thinking and difficulties with social imagination

Babble:

Repetitive strings of sounds produced by infants

Cognitive Functioning:

A term used to define the intellectual capacity of an individual based upon the assessment of a wide range of areas e.g. verbal, non verbal, reasoning, memory, speed of processing, concept formation and ability to make sense of the world around them

Communication:

The sending and receiving of messages using spoken or written language, non verbal sounds, gestures or body language, symbols etc…

Comprehension:

Understanding; in the context of speech and language. It can be broken down into verbal comprehension (understanding of words and their meaning and non verbal comprehension (understanding of gestures, context and situation).

Delayed Language Development:

Usually used to describe a situation where the child has a delay in talking and understanding words, but skills are developing within the normal developmental sequence.

Diagnosis:

The name given to a particular condition that a person has, or the process of identifying it.

Dyspraxia:

A disorder of co-ordination affecting the ideation, planning and execution of motor and sensory movements. The term can often be referred to as 'Clumsy Child Syndrome' or 'Developmental Co-ordination Disorder, DCD'. The child can have varying degrees of difficulty with things such as, balance, gross and fine motor co-ordination, posture, organising and impacts functional tasks such as dressing, eating, and writing etc. It can also affect co-ordination of speech organs and impact on language development.

Echolalia:

This refers to when a child copies what has been said; sometimes with the same intonation and/or accent, rather than responding in an appropriate way in their own voice. It demonstrates a lack of comprehension of what has been said and of communicative intent on their part.

EEG:

A graphic record of the electrical activity of the brain as recorded by an electroencephalograph

ENT Consultant:

A doctor who specialises in the diagnosis and treatment of Ear, Nose and Throat conditions.

Expressive language:

The use of language to communicate to others ones needs and emotions and to share experience and information.

Fragile X:

The most common identifiable form of inherited learning disability. The cause is an abnormality just above the tip of the X chromosome's long arm, which may be passed from one generation to the next.

Global Delay:

This is a significant delay in development in two or more key development and all areas of communication, motor skills and ability to mix with others.

Learning Difficulties:

A general term used to describe a wide range of problems experienced by children who find it significantly harder to learn than other children of the same age.

Multi Disciplinary Assessment:

Assessment carried out by professionals of different disciplines to give an 'all round' picture of the child's development. Members may include professionals from Psychiatry, Social Work, Speech and Language Therapy, Psychology, Occupational Therapy and Nursing.

Non Verbal Communication:

Communication that does not use spoken language, e.g. the use of gestures, facial expressions, body language

Paediatrician:

A doctor who specialises in working with babies and children.

Phonology:

The range of sounds that are used for speech in a particular language.

Phonological Difficulties:

Difficulties selecting and using the correct speech sounds when speaking

Pragmatic Difficulties:

Difficulty using language and understanding meaning in context. A child with pragmatic difficulties may not understand someone else's language and behaviour.

Receptive language:

The ability to understand language and to follow verbal instruction

Special Education Needs:

Special education needs describe the support that a child with learning difficulties needs at preschool or school. Children with special education needs require extra or different help than that given to other children of the same age

Specific Language Impairment:

A term used to describe language difficulties with comprehension and/or expression. Usually used when a child's language falls well behind children of the same age or when language development is unusual or disordered.

Specific Learning Difficulties (Dyslexia):

A specific learning difficulty that leads to problems around learning basic skills of reading, writing and / or spelling, such difficulties being unexpected in relation to a persons other abilities.

Standardised Tests:

Assessment tests which have been developed using data from large numbers of children to compare them with other children of the same age in similar conditions.

Social Interactions:

How one person relates to another verbally or non verbally.

Notes

Authors: Sinead Crowley - Senior Social Worker
Clare Donoghue - Senior Occupational Therapist
Colette Slevin - Senior Occupational Therapist
Sharon Keogh - Senior Speech and Language Therapist
Myra Barry - Senior Clinical Psychologist
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