Autism: A Guide for Parents and Carers Following Diagnosis

Foreword

You received this handbook because your child has just been diagnosed with Autism Spectrum Disorder (ASD).

We would like to welcome you as a member of the Autism Parents Association (APA). APA was founded in 2008 by parents, to help parents, and their children with ASD throughout the years ahead. We are here to guide you through the process, whilst also actively working towards improving services available in Malta.

Every child with ASD has the right to education, to meet his/her needs and to integrate into the community whether for leisure, work or future living at the same level as other members of our society.

The aim of the handbook is to provide parents with an overview of autism, guidance on how to cope in the early years, the services offered locally and the benefits to be gained from them.

The handbook was developed by parents for parents; information was sought from reputable websites and material published by well-known sources. The handbook is also available on our website.

15 years ago, when we were going through those confusing thoughts like 'where shall we start?', little to no help was available and a handbook like this would have facilitated our journey by far. I do hope this handbook helps your journey and gives you an insight into how you can be the manager of your child's condition... the beginning is a bumpy road but very soon you will get to grips with the situation and will realise that knowledge is the road to success. I am proud to be part of the creation of this handbook.

We are here to help so feel free to get in touch.

Sandra

Sandra Borg
Parent and Founder of Autism Parents Association

Autism Parents Association

Welcome to APA!

Our members are mums, dads and people on the autism spectrum. But our support does not stop there, as we welcome their sisters, brothers, grannies, cousins – the whole family and your friends.

When Sandra Borg and I set up APA our children were just 5 and 3 years old. Now they have grown up and become teenagers; at the same time APA has grown to 11 board members, including a member in Gozo. We all have children with ASD and volunteer our time to provide those with ASD the same opportunities as everyone else.

Today, APA is a registered NGO with over 200 family members and a proud member of Autism Europe. We have been in the press, on TV and in social media. Behind the scenes, we attend international and national conferences and events, meet with government, education, public bodies, NGOs and decision-makers on all aspects concerning the rights of people with autism to raise public awareness, acceptance and inclusion.

Our website keeps the public up to date with who we are, what we do, activities and other information. APA members are invited to a 'closed' private facebook group where APA shares news and parents post questions, experiences and tips. We circulate newsletters, organise a yearly fun day, social events and hold an annual General Meeting. We have active parent support agents and, for when your children are older, youth groups.

We are here for you.

Omar Farrugia
Parent and President of Autism Parents Association

> *As parents-to-be, we dreamt of things for our new born babies like everyone else would. Just because our children are different and might not reach the dreams that you have originally set... does not mean that we cannot dream. Today I dream and pray that my son is happy, healthy, understood, appreciated, not judged, loved, independent, and always seen as the uniquely beautiful human being that I was gifted with.*
> **Valerie Brincat - Parent and APA board member**

Important Telephone Numbers

Use this page to record frequently used numbers or contact details

CDAU, St Luke’s Hospital	2595 1803	
Child Guidance Unit, St Luke’s Hospital	2595 1800	
Student Services Department	2122 8349	2122 8350
Mater Dei	2545 0000	
Ambulance, Police & Fire Services	112	
Our Doctor		
Our Dentist		

Emergency Communication Passport

In the case of an emergency it is important that you inform the individual intervening that your child has ASD and provide them with a communication passport. This will ensure a smooth intervention. It details your child’s particulars such as name, date of birth, address, next of kin, special needs, medical information, how to communicate with the child and what to do if they are anxious, or have likes and dislikes.

Fill one out online:
https://www.pdffiller.com/27558159--Communication-Passport-Accident-and-Emergency-PDF-

Acknowledgements

APA would first like to show our great appreciation to ASD Info Wales for allowing us to reproduce the core information from their handbook. We cannot thank you enough.

As in so many other projects, Sandra Borg was the catalyst in the creation of this handbook in Malta. Sandra's drive, energy and actually achieving our wishes is inspirational. Committee members Emma McEwen and Maruska Dimech produced the local information. Emma also headed the management of the project. We thank Giselle Pisani (consultant for APA) for her valuable contribution.

Thank you to everyone who was involved in securing the funds, producing, contributing and reviewing this handbook. A special "thank you" goes to our children for their beautiful artwork.

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Contents

Introduction

If you have recently learned that your child is on the autistic spectrum, this guide is for you. It has been developed with the help of parents of children with autism, to:

- help you understand what autism is
- give you a picture of what you and others can do to help your child
- tell you about the support that is available
- answer the questions that many parents have at this time.

You may not want to read it all at once - you may find it more helpful to refer to different sections over time.

Throughout this booklet the terms autism, autistic spectrum disorder and the abbreviation ASD are used to cover a range of developmental disorders and terms, which include Kanner's autism, autistic spectrum conditions (ASC) and Asperger syndrome. In places, we refer specifically to Asperger syndrome.

Being a parent/carer or family member can be both very rewarding and very stressful. Dealing with the everyday ups and downs of family life and the world around us is hard enough, but doing it as a parent of a child with autism can at times seem near impossible.

We hope that this document gives you some useful information and points you to how and where you can access further information and help.

It has been written with and for parents / carers. We wanted this booklet to acknowledge that you are an important person in your child's life and often spend more time with your child than any other person, and therefore we hope the information enclosed will go some way to helping you. In it we have laid out sections with some hints and tips to help you to help your children fulfil their full potential. Your life may indeed feel or be very different after your child's diagnosis, but different doesn't necessarily mean 'bad' or 'wrong', it may just mean different.

With all good wishes...

What is Autistic Spectrum Disorder (ASD)?

An autistic spectrum disorder (ASD) is a developmental disorder which affects the way a person communicates with and relates to other people and the world around them. The way in which people are affected varies from one individual to another and by age and intellectual functioning.

Children with ASD are affected in a variety of ways and to very different degrees. This is why it's called 'the autistic spectrum'. Autism can affect children with any level of intellectual ability, from those who are profoundly learning disabled, to those with average or high intelligence. So, having ASD doesn't necessarily mean that you have learning difficulties. The more seriously affected children at one end of the spectrum have learning difficulties as well and require high levels of support. At the other end of the spectrum, some people with Asperger syndrome or 'high-functioning autism' are very intelligent academically. They may go on to be successful in their chosen field. However, they still experience significant social and communication difficulties.

> *'It's as if your child's brain has been wired up in a different way to usual. This doesn't change, but the ways in which it shows itself, and the extent to which it shows itself, do change.' Early Support Service*
>
> *'It's nothing that you've done. A child doesn't become autistic. It's in them already. They don't learn to be autistic.' Early Support Service*

What are the signs and characteristics of Autistic Spectrum Disorder?

Children with ASD have significant difficulties relating to other people in a meaningful way. It is very common for ASD children to have profound sensory issues. This, combined with the triad of impairments, means that children with autism experience the world very differently. The 'triad of impairments', or 'the three impairments' are issues with:

- 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 or tone of voice

- ridigity 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.

It is usual that all children with a diagnosis of autism have difficulties in all three of these areas. However, the ways in which they manifest themselves vary enormously. This can make children with ASD very anxious. In this guide, we will aim to help you understand the characteristics of autistic spectrum disorder in more detail.

Under the DSM-5 criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognised until later.

Coming to Terms with a Diagnosis of Autism or a Related Condition

First, there are two very important things to remember:

1. It's not your fault

The fact that your child has ASD has nothing whatsoever to do with the way that you have been looking after them. The causes of autism are as yet unknown, but we do know for certain that autism is not caused by parenting. Parents of young children with ASD are just like everyone else. Autism affects children from all walks of life and in all countries and cultures.

2. You aren't alone

In Malta, whilst there aren't any statistics about the prevalence of autism, research indicates that ASD affects one in every hundred children*. The Autism Parents Association in Malta consists of over 200 families, all of whom have children who are on the spectrum. Many other parents are going through what you're going through and there are many who are further on in their journey.

The way in which a diagnosis has been made will vary from one person to another. For some it would have been a relatively straightforward process but for others it may have taken months or even years.

For some parents, receiving a diagnosis is a shock as they may not have realised that their child had ASD. For others, there may be feelings of relief following a long time of knowing that there was something different about their child.

> *"Getting a diagnosis meant I could start to live and get the best out of life for my son."*
> *Parent*
>
> *"..we finally held the missing puzzle piece. This helped as we could now justify typical autistic behaviour and learn how to tackle and resolve arising situations." Sibling*

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*Elsabbagh et al. 2012; Fombonne, 2011; ADDM 2012; Mattila et al. 2011; Saemundsen et al. 2013; Baird et al. 2011.

There is no right or wrong way to feel about your child being diagnosed with ASD. Parents experience a variety of emotions around this, and these can often change on a daily basis. It is quite normal to experience feelings such as:

Sadness
Anger
Relief
Denial

Guilt
Frustration
Fear
Grief

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 autism emphasise that it really helps when you reach a point at which you can begin to accept the situation.

Within the family, other people will also be coming to terms with the diagnosis and this may take some time with some taking longer than others to do so. Difficulties may arise when people are not experiencing the same feelings, or not experiencing the same feelings at the same time. It is important to realise that individuals will feel differently, and to try and have some understanding about this. Talking about problems will often help with family understanding, but is usually only a good idea when all those involved are ready to do so.

> *“My mum has become involved and founded a support group for parents of children with ASD. As a result of this I am fortunate enough to have had multiple opportunities to attend group meetings and various seminars that have offered a lot of help, advice and information on how people with ASD think, act and function.” Sibling*
>
> *“If you can, find a parent support group so that you are supported and don’t feel so alone.” Parent*

Having a child with ASD can provide a lot of stress within the family due to the needs or behaviours of the child. This will more than likely have been the case for a long time before the diagnosis is received. This can cause tension for individuals and tension within relationships in the family. Disagreements about the way to manage behaviours or the way to move forward can occur.

However, it is important to remember that your child is still the same child they were before they received their diagnosis; they have not changed. The only change is that now you have a diagnosis you will be better able to understand your child and their needs.

> *"I am a very lucky lady to have the honour of having my son. Autism in our house stands for Always Unique, Thoughtful, Intelligent, Smart Mum's boy. I did not know so many qualities could be in one person. Autism found him; he has made me a better person."* - Parent

A	Always
U	Unique
T	Thoughtful
I	Intelligent
S	Smart
M	My Child

> *“Helping your child is a marathon, not a sprint. Pick your battles and take it one day at a time.”* Parent, Mellieha
>
> *“Accept help when it is offered to you. Be aware of signs of exhaustion and do not feel guilty about taking a break without the child. Plan well ahead and take your deserved rest. Ask for help if you feel you cannot cope. There is help available in Malta for us parents. Your child needs you in good health!”* Parent, Ghaxaq

Some top tips following diagnosis:

- **When you feel ready, consider contacting/joining a support group**
- **Talk to someone you trust and feel comfortable with about how you are feeling**
- **Don’t forget that extended family can be affected too and may need help/support**
- **Remember you are a very important person in your child’s life and you have needs too!**
- **Write down any questions you may have so that you can take them with you to future appointments - there is a notes page for you to use at the end of this section**
- **Learn about autism - there are some books and websites recommended in this booklet**
- **Just remember, you are not alone**

Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this…

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "welcome to Holland".

"Holland?!" you say, "What do you mean, Holland?" I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.
But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to some horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.
So you must go out and buy a new guidebook. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."
The pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Celebrating Holland - I’m Home!

By Cathy Anthony

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I’d planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger - the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travellers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn’t so bad.

I think that Holland is used to wayward travellers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I’ve wondered what life would have been like if I’d landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

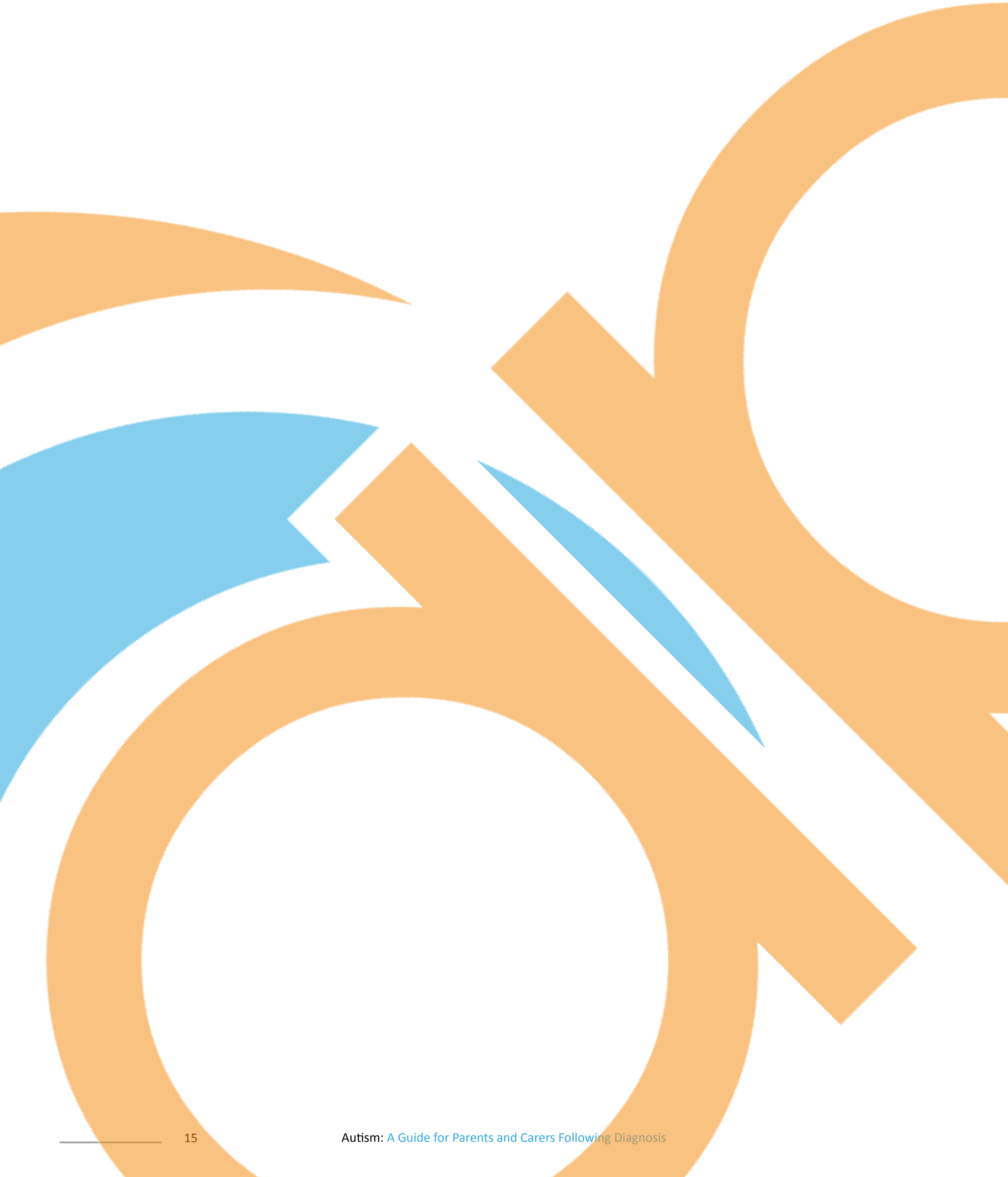
Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveller and discovered that it doesn’t matter where you land. What’s more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that are Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn’t planned. Yet I am thankful, for this destination has been richer than I could have imagined!

Notes




APA
WALK NOW FOR AUTISM
ARTECH
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Characteristics of ASD

This section will try to explain the characteristics of autism in more detail:

- Social understanding and social behaviour
- Social communication
- Rigidity of thinking
- Anxiety
- Repetitive Behaviours/Stimming
- Special Interests/OCD
- Sensory issues

As we mentioned earlier in this book, children with ASD are affected in a variety of ways and to very different degrees, and this is why it is called a spectrum. It is important to remember that the autism spectrum is broad and therefore different individuals with ASD may display all or only some of the characteristics described in the following sections.

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 ASD 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 ASD can't make sense of people, and may find them frighteningly unpredictable. They may:

- seem to relate better to objects than people
- show preference for individual activity
- only tolerate approaches from very familiar people
- are more adult orientated than peer orientated
- 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
- have a poor understanding of social rules and conventions

Social Communication (Verbal and Non-Verbal Communication)

Children with ASD may not be eager to communicate. They may not be ready to learn things that other children learn naturally and therefore don’t have the chance to tune into language in the same way. 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 the things being said to them.

Young children with ASD 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 and what that means.

A young child with 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
- show little desire to communicate socially
- not respond when spoken to
- develop expression before understanding
- talk at, rather than to
- 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
- not appreciate the need to communicate information
- have poor grasp of abstract concepts and feelings
- rarely understand or use gesture
- develop a pointing gesture, but use it to indicate need rather than to share an experience.

“The concepts of physical and mental impairment are fairly easy for people to grasp, but the idea of social impairment is much more difficult to understand (and to explain).” Early Support Service

“Don’t teach a child with autism something which is ok when they are a child but isn’t appropriate in adulthood.” Parent, Mosta

Rigidity of Thinking and Difficulties with Social Imagination

Imagination helps us understand the world and predict and see the perspective of other people. Children with ASD are unable to do this to any great extent. When pretend play begins to appear in children who don't have ASD, it's a sign that imagination is beginning to develop. In children with ASD 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. Other children may run the toy car in and out of a garage, but don't act out more complex stories. 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 book. This doesn't mean that children with autistic spectrum disorder don't have any imagination; it just 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.

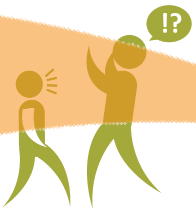
Some children with ASD learn to talk easily, but find it hard to understand communication that is not literal. Expressions like 'I laughed so much I nearly died', or 'If you eat any more you'll burst', can be very frightening for them. They may have difficulties understanding that a phrase or story is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

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

A young child with 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
- cannot deviate from one way of doing things
- may be tolerant of situations and then over-react to something minor
- may find it hard to work out what other people are going to 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 attention to unusual details and struggle to see the bigger picture
- can develop extreme behaviours to avoid some things/experiences.

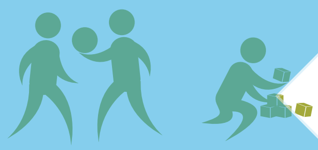
These pin people illustrate some of the ways in which autism is displayed



One-sided interaction

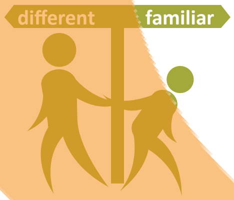
Echolalic – copies words like parrot

Inappropriate laughing or giggling



Does not play with other children

Talks incessantly about only one topic



Variety is not the spice of life

No eye contact

Lack of creative, pretend play

Bizarre behaviour

Handles or spins objects

But some can do some things very well, very quickly, but not tasks involving social understanding

A World of My Own

By Sandra Borg

Jesus sent me to a young Mum and Dad
And a lovely little girl
My shiny eyes and cheerful smile
Stole the hearts of those around

When I was born all looked strange
And I loved to gaze around
I kept looking but I couldn't understand
Why I was on this ground
I hated changes so I'd scream
And this showed Mum and Dad what I was feeling
Until one day I started walking
Then I could run and reach the things I wanted

Mum would raise her voice and cry
And this made me laugh
Sometimes I was put into bed
Even though the sun was still shining

I love seeing things that are shiny
With lots of colours and animals
But I'd ask why would Mum put them ever so high?

I loved to run after cats in the street
And try to fly like birds in the sky
I loved to watch TV
And line my toys side by side

I hate the feel of clothes on my body
It seems there is a hedgehog stuck to my body
I hate to go to crowded places
And lots of noise makes my head go crazy
I started school and that was fun!
I loved to see my teacher chase me
When I'd be looking for my animal friends
Up and down the stairs

My teacher praised me
When I knew my things
or when we had time to paint or draw

I would not sit for long
But when she kept me by her side
I felt safe and loved
And her firm and high toned voice
Made me feel just right

One fine day all things changed
Lots of pictures came my way
Mum and Dad and many people
All started to speak my way

Now things are ever so clear
I've learnt some rules of this new world
I've learnt that my mouth is there to speak
I've learnt to play with toys
I've learnt to join in games
I've learnt to wait
My what's next board helps me keep calm
And content during my busy day

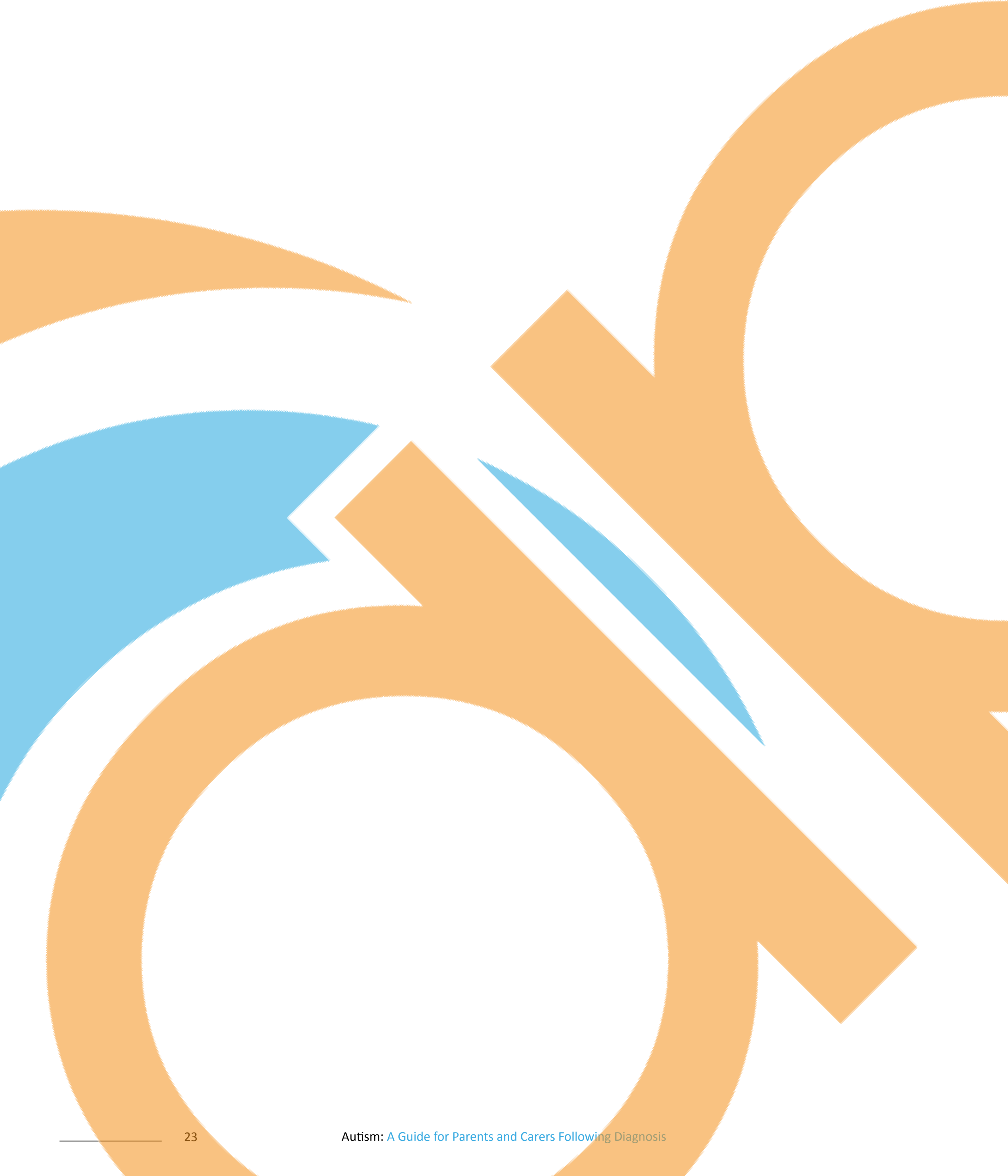
Mum says there is still lots to learn
she reads me lots of funny stories
And helps me colour and write
Even though I don't know why

Every day is ever so different
Here and there and everywhere

But now I'm ever so happy
And my sparkly eyes and cheerful smile
Will remain with all the people
Which were and are by my side.....

I'm "different" I'm Nigel.

Notes



Anxiety

One of the things that many parents talk about is how anxious their child seems to be.

High levels of anxiety in children with ASD are often a common feature and it is this feeling of anxiety that might be causing some of the behaviours that you may see in your child.

Your child might be feeling anxious about something but is not able to tell you. In fact the way of communicating their anxiety is often through behaviour. Some of the behaviours you might see are:
- Tantrums and aggressive behaviour
- Becoming withdrawn and resisting any interaction with others
- Experiencing pain
- Become distressed

The reason anxiety is mentioned at this point in this booklet is because anxiety is not always talked about when your child is diagnosed. But being aware that your child might be anxious about something is such an important part of helping your child.

Anxiety and autism go hand in hand and it is more prevalent in children with autism because they have difficulty making sense of the world around them and understanding social rules. Causes of anxiety are numerous, which makes it very difficult for parents to know what to do or how to react.

We all experience anxiety; it is part of our everyday life and we all react to stressful situations in a way which is personal to us, but the symptoms of anxiety are often similar. Think of a time when you have felt anxious; you may have experienced feelings such as being scared, panic, increased heart rate, sweating, sickness, not knowing where to turn or what to do next, loss of confidence etc. These are unpleasant feelings and can impact our mood, energy levels and behaviour; so imagine what it must be like to feel anxious every day of your life but not understand why.

> *“My child needs deep pressure to calm down. We showed him that carrying heavy bags and books helps him to feel better. He often asked for a hug. Now we have taught him that if he wants pressure to ask for pressure and not a hug as it is more appriopriate now that he is older.”* Parent, Hamrun

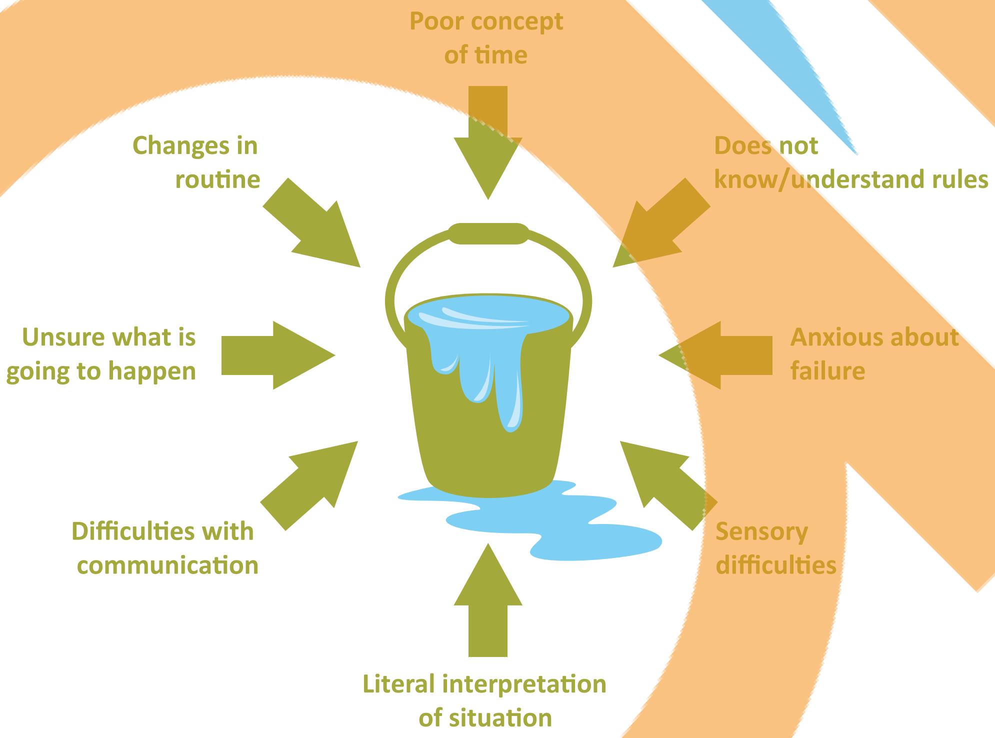
Children with ASD experience anxiety for a variety of reasons, which can include:

- meeting strangers
- being given too many choices
- not being able to communicate their needs
- changes in routine
- new activities or places
- experiencing unpleasant sensations, eg dog barking, flashing lights, crowded and noisy environments, overpowering smells
- transition from one activity to another - even small transitions
- trauma - remembering unpleasant events eg having a haircut, seeing the dentist or doctor, which when being asked to repeat makes them anxious

‘Reality to a person on the autism spectrum is a confusing, interacting mass of events, people, places, sounds and sights. There seem to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything. Set routines, times, particular routes, and rituals all help to get order into an unbearably chaotic life.’ (Joliffe, 1992, p16)

Sometimes, children with ASD can be anxious about more than one thing at a time causing overload, which could then lead to extreme anxiety behaviours (meltdown).

Below is the analogy of a bucket overflowing. When levels of anxiety get too high it can result in the extreme anxiety and inappropriate behaviour.



For all of these reasons and more, it is no wonder that children with ASD experience anxiety. Their quest in life can become one of routine and predictability. Some children may want to control situations or take part in things only on their terms. This might be because being in control reduces their anxiety levels.

Some top tips for managing your child's anxiety:

- Always consider anxiety levels when deciding how to manage your child's behaviour or when introducing them to change or new activities.
- Be empathetic - remember how it feels when you are anxious
- Allow for the autism - be patient and tolerant
- Maintain a neutral and calm tone of voice - your own anxiety, anger or frustration can make a child more anxious
- Keep a diary of your child's behaviour and you may be able to identify a trigger for their anxiety
- Establish routines and stick to them. If you do need to change a routine, provide your child with as much notice as is possible. Explain what is going to happen instead
- Small transitions can be a big deal to a child with ASD eg taking a bath and then cleaning teeth straight away might cause anxiety. Allow time between activities wherever you can
- Give one instruction at a time
- Give your child time to process information
- 'Fiddle toys' such as stress balls, play dough, etc may help a child to lower their anxiety levels
- If your child is upset, distressed or behaving in a challenging way, consider whether this is being caused by sensory issues. Sometimes it may be the fear of what might happen which will make them anxious
- Identify a 'safe place' that your child can go to when they are feeling anxious, for example their bedroom. Provide your child with a time out mechanism for when things are getting too much. Use of a 'time out' or 'break' card can be useful or even coloured cards to relay how they feel; eg 'red' might mean "Time out now", 'green' might mean "Okay for now". Alternatively, you could have a verbal code or hand gesture. If your child is older you could try teaching them an anxiety scale using numbers eg 1= calm 2= very happy 3= feeling worried 4= very anxious 5= extreme anxiety
- If your child has a way of calming themselves which you find difficult or annoying, be tolerant as your child is doing this to reduce the unpleasant feelings they are experiencing
- Help your child to understand social rules. Social stories or visual structures can be helpful
- Learn as much as you can about autism

Repetitive Behaviours/Stimming

The term “repetitive behaviour” is used to describe specific types of unusual or seemingly odd behaviours that are often seen in children with autism.

Repetitive behaviour is sometimes referred to as self-stimulating behaviour or stimming. This behaviour may involve any or all the senses in various degrees in different individuals. Several examples are listed below:

- Visual - staring at lights, blinking, gazing at fingers, lining up objects
- Auditory - tapping fingers, snapping fingers, grunting, humming
- Smell - smelling objects, sniffing people
- Taste - licking objects, placing objects in mouth
- Tactile - scratching, clapping, feeling objects, nail biting, hair twisting, toe-walking
- Vestibular - rocking, spinning, jumping, pacing
- Proprioception - teeth grinding, pacing, jumping

Some repetitive behaviours are very obvious while others are more subtle and hard to detect such as blinking or eye rolling, tapping fingers and mild hair twisting.

We all engage in some of these behaviours occasionally, especially when we are stressed. However, your child may engage in these activities excessively to the point that they interfere with learning or daily living activities.

Why Repetitive Behaviour?

It’s not completely clear why repetitive behaviour almost always goes with autism, but it is the case that children with ASD experience a lot of chaos in their world and repetitive behaviour is a way of bringing predictability to an otherwise unpredictable and frightening world. Some of the reasons children adopt repetitive behaviour are outlined below:

- Self regulation, which helps the child become calm and overcome situations of stress or upset
- Demonstrates excitement
- Provides the child with an escape route when they are overworked or wound up
- Makes the child happy. Some children find the behaviour pleasurable even if causing injury to themselves
- Provokes a reaction from others, which reinforces the behaviour
- A way of avoiding a task or activity

Some children learn to monitor their behaviours so they can engage in them in 'safe' environments (at home rather than at school or out in the community).

No matter what repetitive behaviour your child engages in, you need to understand this is something that they need to do in order to find peace in their autistic world.

> *"My son taps repetitively on every surface. On the basis of 'if you can't beat them, join them' we got him a drum kit. If he gets cross, angry or frustrated he goes and plays drums which helps him calm down and he is a grade six drummer now which gives him something to be proud of."* *Parent*

Some top tips for managing your child's repetitive behaviours / stimming:

- Be patient and tolerant - allow for the autism
- If the behaviour is causing or likely to cause your child harm, ask to be referred to an Occupational Therapist who might be able to help reduce or change these behaviours
- Become a detective - observe your child and try to understand the underlying causes of the behaviour, what has happened that day, what is due to happen, has anything been different, are you wearing a new perfume, etc
- Keep a behaviour diary
- Don't reprimand your child for their behaviour - ignore the bad but always give lots of praise for good behaviour
- Read the section in this booklet about supporting your child with different behaviour
- Remember there will be a reason that the behaviour is happening. As well as the autism look out for signs of sensory or medical problems
- Learn about autism - there are some books and websites recommended in this booklet

Special Interests/ Obsessive Compulsive Disorder

> *"My son is obsessed with dinosaurs. We draw them, paint them, use plasticine and clay to sculpt them. At school his friends draw and cut of different dinosaurs and hide them around the playground for my son to find them which provides great social interaction."* Parent, Ta' Xbiex

All children have favourite things, games, films, toys but most children can be distracted or engaged in another activity without too much fuss. Also, most children like interaction with other people in order to get the most enjoyment from their activities.

However, some children with ASD seem to develop interests in a way that makes it seem as though they are obsessed. These interests are usually referred to as 'special interests' and to a child with ASD they might be the most important thing in their life. Children with ASD normally develop interests that do not involve anyone else, where they can retreat into their own little world for hours and hours, whereas other children might want to talk non-stop about their interest, which in turn makes it difficult for them to develop friendships.

These interests are different to repetitive behaviours but some of the reasons for the special interest can overlap, such as

- Reducing anxiety
- Maintaining a sense of calm
- Makes them happy
- A way of avoiding another task or activity

To others some of the interests of children with ASD may appear utterly pointless or mind numbingly boring but the child will be experiencing something completely unique to them. For some children their ability to focus on detail will mean that they are experiencing something completely beyond your imagination.

> *"Teaching a child with Autism can be a challenge...use their area of interest in any task and you will succeed!"* Parent, Mosta

All special interests can be anything from weird to wonderful. Some of the more common examples of special interests in children might include:

- Lining up toys eg cars, trains etc
- Drawing
- Counting
- Watching things spin
- Dinosaurs
- Cartoon characters
- Thomas the Tank Engine
- Types of cars

As with repetitive behaviours children can become engaged in their special interest if they are feeling anxious or scared, but the reality is that they have an uncontrollable desire to involve themselves in these things because their interest is real and their enjoyment and satisfaction is real.

Children with ASD will normally have one special interest at a time, but they often change as the child develops and experiences more things.

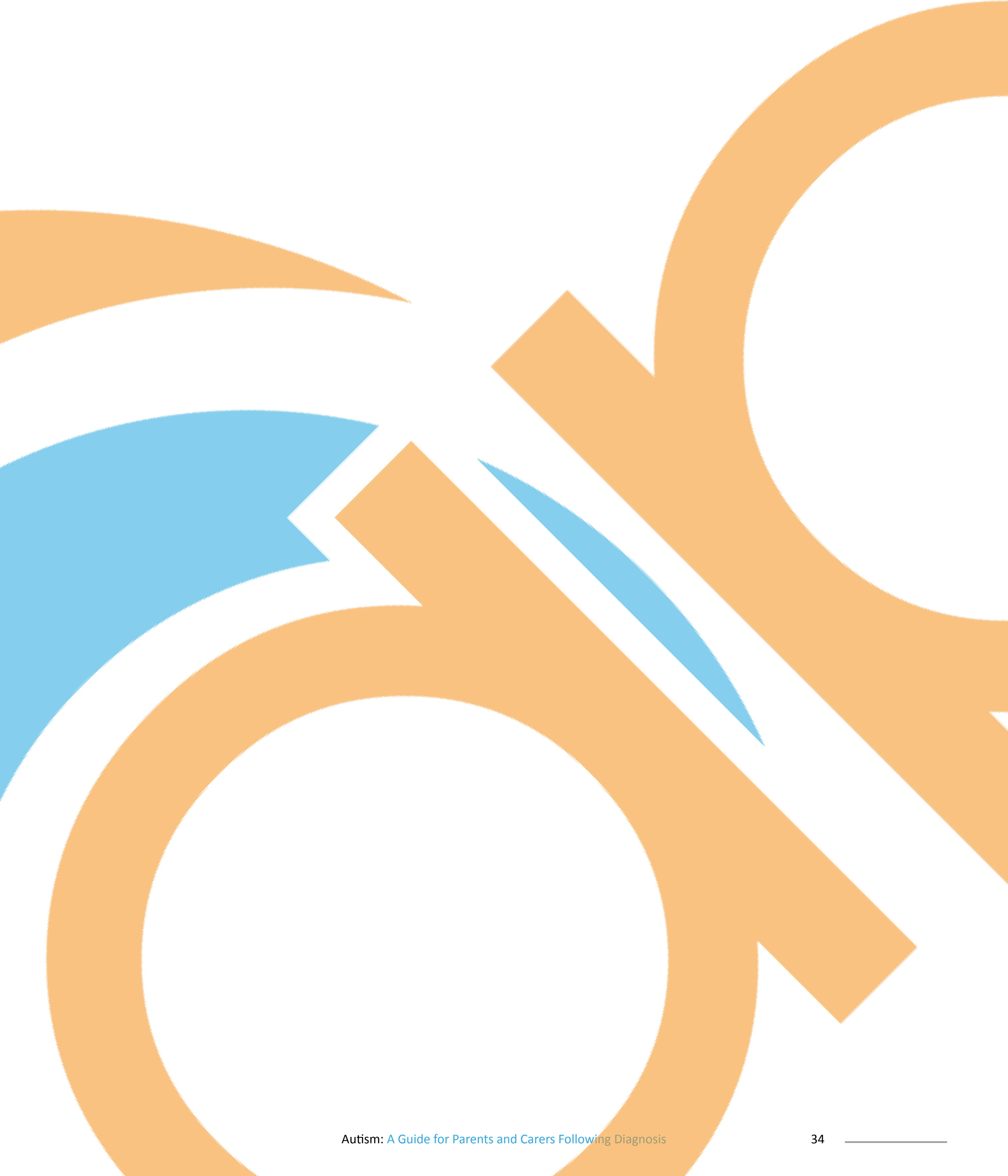
Special interests can interfere with learning or daily living activities but they can also be used to motivate and engage with your child. Some of the most famous people with ASD have developed successful careers from their special interest.

> *"Even though my son had great difficulties working in a group and turn taking, his keen interest in music allowed him to overcome his difficulties. We encouraged him to join in workshops and group music sessions, and this helped him to work on his social skills and team work, with like-minded people. He is now a valid member of a rock group and enjoys performing in gigs throughout the area."* *Parent*

Some top tips for managing your child's special interests:

- Be patient and tolerant - allow for the autism
- Empathise with your child, show them that you know how important their interest is to them
- Don't tease the child about (or criticise) their interest
- If the interest is interfering with learning or daily activities, try offering specific times for them to spend on their special interests and once agreed don't waiver on this unless you have given advanced warning
- Look for ways to expand your child's special interest
- Learn more about what they are doing and talk to your child about their interest; this might help you to engage more with your child
- If you are travelling, try to take their special interest with you so that they have an instant comforter if they are feeling anxious or to stop them from becoming bored
- Remember, to you the special interest may seem pointless or silly, but to your child it might be the most precious thing in the world
- Learn about autism: There are some books and websites recommended in this booklet.

Notes



Sensory Issues

The seven senses are **sight, hearing, touch, smell, taste, balance** (vestibular) and **body awareness** (proprioception). In individuals with ASD, the brain sometimes processes sensory information differently to those without ASD. Everybody is different and therefore individuals will experience things differently and respond in different ways.

Sometimes these different sensory perceptions can cause pain, distress, anxiety, fear or confusion and result in 'challenging' behaviour as the individual tries to block out what is causing the problem.

In some cases, the senses may work too well and the brain receives too much information (hypersensitive) or not well enough where the brain doesn't get enough information (hyposensitive). When the senses are hyper you may find that individuals with ASD rock, flap, spin, hit their ears, etc as a way of trying to block out the overload that they can't tolerate and to help them to calm down or relieve the pain. In cases where the senses are hypo, individuals may make or seek out noises, bang objects, etc as a way of causing more sensations and getting the senses to work better.

Things to look our for:

Hypersensitive

Dislikes dark and bright lights
Looks at minute particles, picks up smallest pieces of dust
Covers ears
Dislikes having their hair cut
Resists touch
Avoids people
Runs from smells
Moves away from people
Craves certain foods
Uses tip of tongue for tasting
Places body in strange positions
Turns whole body to look at something
Difficulty walking on uneven surfaces
Becomes anxious or distressed when feet leave the ground

Hyposensitive

Moves fingers or objects in front of the eyes
Fascinated with reflections, brightly coloured objects
Makes loud rhythmic noises
Likes vibration
Likes pressure, tight clothes
Enjoys rough and tumble play
Smells self, people and objects
Seeks strong odours
Mouths and licks objects
Eats anything
Rocks back and forth
Lack of awareness of body position in space
Spins, runs round and round
Bumps into objects and people

Taken from 'Sensory Issues in Autism' by the Autism and Practice Group, East Sussex County Council

Examples of sensory issues that your child may experience include:

- The brain tries to process everything at once without filtering out unimportant things like background noise, wallpaper, people moving about, the feel of clothes on their skin, etc resulting in sensory overload.
- Sometimes there is an inability to separate foreground and background information so that everything is seen as 'a whole'. For example, when they look at a room they will see everything at once and so even when something small is changed they will notice. This will make the room look 'wrong' and can cause fear, stress and frustration.
- When there is too much information to be processed at the same time it may be difficult for children with autism to break a whole picture down into meaningful units. For example, when talking to someone we will see their whole face but some people with autism may see eyes, nose, mouth, etc as individual things which all need to be processed separately. This makes it more complicated to process information and can lead to the child focussing on only one aspect or not having enough memory to process everything.
- Sometimes it can take time to process information, particularly if there are distractions (eg background noise, scratchy clothing, etc), if there is a lot of information to process or if the context changes (eg they may learn to make a cup of tea in the kitchen but be unable to transfer that skill to a different kitchen).
- In some cases senses become distorted which may mean that the child sees, hears, smells, tastes or feels something different to everyone else.

> *"When my son was older he explained to me 'When I was a baby I remember having a strange object thrust into my mouth which I found quite annoying. It had a very strange taste and an even stranger texture. Also, when I sucked on it, it made the most awful squeaking noise.' I now realise the reason why my son got so distressed when a rubber teat on a bottle or dummy was put into his mouth!!"* Parent

- At times one of the senses may appear 'shut down' as a way of the child coping with sensory overload. For example, when noises become unbearable the child may appear to be deaf because this enables them to cope and to allow their other senses to work better.
- Due to the difficulties outlined above, some children will use some senses to compensate for others. For example, they may smell, lick or touch objects, or watch their feet whilst walking, etc.

It is important to remember that when people are tired, unwell or stressed their tolerance levels are affected and this is also true of a child with ASD ability to tolerate sensory stimuli. Therefore, try to learn what sensory issues your child may have and the ways in which they cope with these so that you can understand and support them. Below is a list of things that may be helpful and things that may challenge your child. Through observation you may be able to tell if suggestions on the list, or something similar, are relevant to your child.

These things might help me	These things might challenge
Look to the side of my face or over my shoulder when you are interacting with me	Direct eye contact
Address what you are saying to the wall	Direct communication
One person talking to me at a time	More than one person talking to me, other people's conversations
Neutral odours	Perfume, aftershave or other scents
Plain clothes	Patterned clothing
Dull coloured clothing	Bright coloured clothing
Uplighters	Strip lights
Red or green bulbs	Bright or white light, bright sunshine
A quiet environment	Kettles, engines, traffic sounds, phones
Quiet personal care	The toilet flushing, running water, fans
Consistency	Different people responding to me in different ways
One thing at a time	Being bombarded by a lot of information
Knowing what is happening next	Unpredictability and chaos

Taken from 'Sensory issues in Autism' by the Autism and Practice Group, East Sussex County Council

Some top tips relating to sensory issues:

- Observe your child and try to learn which sensory issues they may have - the more you can learn and understand, the easier he/she will be to support
- If your child is upset, distressed or behaving in a challenging way, consider whether this is being caused by sensory issues. Sometimes it may be the fear of what might happen which will stress them
- Be aware that your child may only be able to utilise one sense at a time. For example, when they are looking at something they may not hear you
- When you've identified issues, which trigger sensory problems, try to avoid these where possible
- Follow a routine, where possible, to try and avoid sensory overload and stressful situations
- Have a quiet time/space so your child can relax and regain their composure
- An Occupational therapist can help you identify your child's sensory issues

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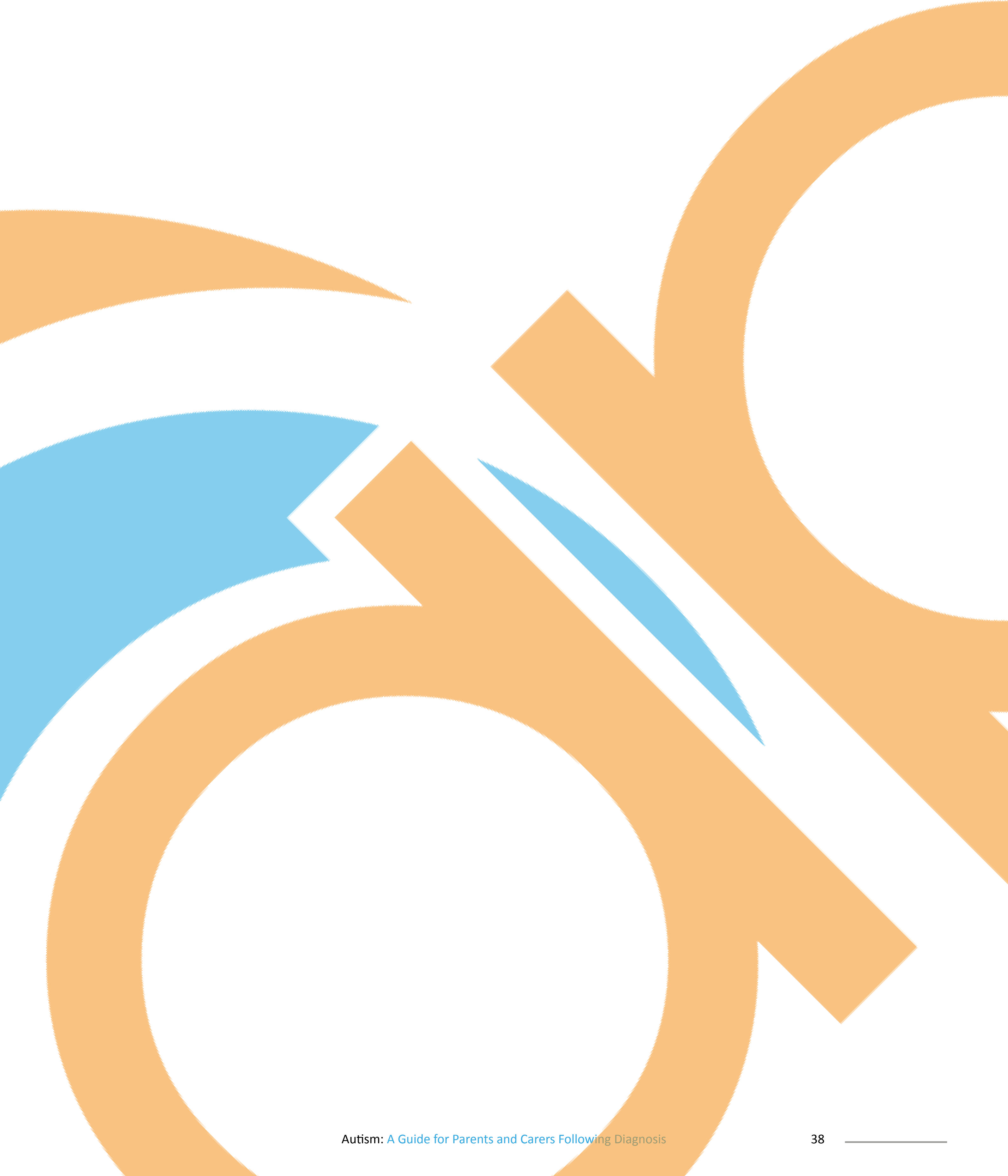

ASD and Other Disorder

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

Sometimes individuals with ASD have another disorder as well. Some conditions appear to affect individuals with ASD more frequently, although it is sometimes difficult for professionals to ascertain whether symptoms are part of the ASD or another condition. Some of these disorders are:

- Dyspraxia
- Dyslexia
- Hyperlexia
- Depression
- Anxiety
- Epilepsy
- Obsessive Compulsive Disorder (OCD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Tourette's Syndrome

It is important to recognise that individuals with ASD are not excluded from other mental health and physiological conditions.

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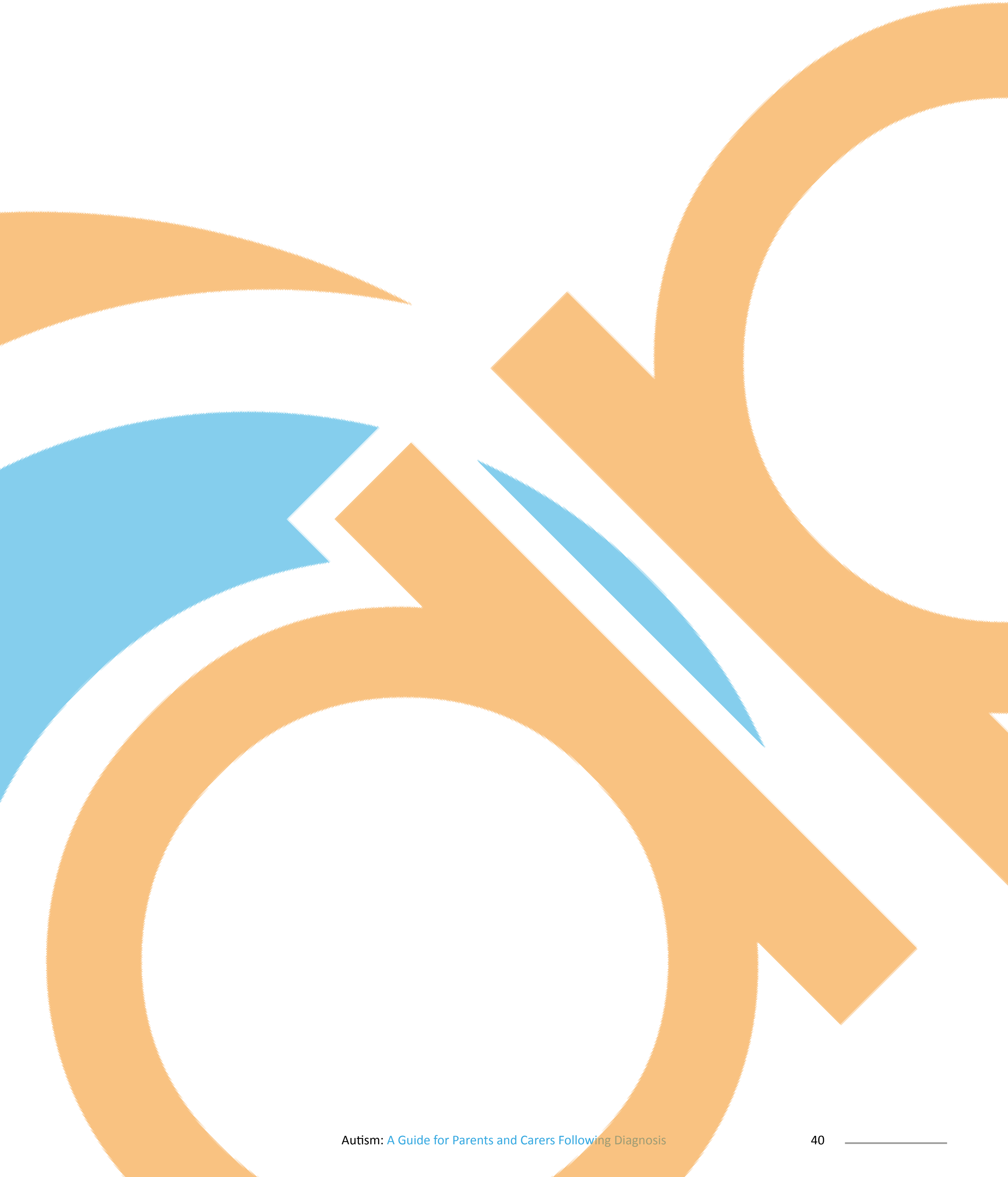

Communication

Individuals with ASD have difficulties with both social communication and social interaction, and this can cause problems in giving information to and gaining information from your child.

Being aware of these difficulties and adapting your own communication style will go some way to ensuring that your child understands what you are asking them and ensuring you get the most accurate response.

Long questions and explanations can cause confusion for someone with ASD, so try to avoid using them.

People with ASD will often have a very literal understanding of language. Idioms, metaphors and similes may be very confusing or create misunderstandings. Here are some examples of everyday sayings that can cause confusion for an individual with ASD:

Idioms:

Make up your mind
You're barking up the wrong tree
Pull your socks up
Don't make a mountain out of a molehill
That's the pot calling the kettle black

Metaphors:

She's an old flame
Dad is a rock
You are an angel
Bill is a snake
My head was spinning

Similes:

He is as rich as a king
She is as cool as a cucumber
You are as cold as ice
As bright as a button

When interpreted literally, these phrases are very strange and can have a totally different meaning so avoid using them. Don't be misled by the individual using metaphors; it does not necessarily mean they will understand yours, especially if they are not familiar with them.

People with ASD often have an unusual way with eye contact and some describe feeling uncomfortable with maintaining eye contact. Just because your child is not maintaining eye contact does not mean that they are not paying attention to you.

Because people with ASD may have problems interpreting social cues such as eye contact and body language, they may not realise that you are addressing them. Start by saying their name and making sure you are in their view before speaking.

If your child has sensory problems, it may be difficult for them to focus on what you are saying if the area around them is busy. Try and reduce noise, smells and bright lights before talking to them.

“Following Diagnosis I discovered that we could have longer and deeper conversations over a cup of hot chocolate by candle light or with the dimmer switch turned down, and also by speaking through glove puppets in his toy puppet theatre.” Parent

“Loud noises, including shouting, make my son just shut down and then you can’t reach him. My son is always better being shown things rather than told (where possible).” Parent

We often use analogies to try and explain things to children in simpler terms. For example, if we are trying to explain why a child needs to eat his dinner, we might talk about it being like putting fuel in a car and explain that if the car doesn’ t have enough fuel it will break down. It is difficult for a child with ASD to link this sort of an explanation with the original problem you are trying to explain. Try and use facts to explain things instead of analogies. Someone with ASD may need more time to process and understand what you are saying. Pausing frequently and allowing them to think, and allowing a longer time for a response can help.

“One voice - only one person should speak to the child at one point in time” Parent, Naxxar

Try not to rely on your tone of voice, facial expression or eye contact to convey a message as the individual with ASD may not be able to understand these subtle ways of communicating. Sarcasm is even more confusing and often relies on somebody reading tone of voice, facial expression and then contrasting them with the words being used. Individuals with ASD will often be unable to do this, and will assume the words used are accurate. So if your child’s hair is looking messy, say this rather than saying it looks lovely and making a funny face.

“When our son was 17, about six months after his Aspergers diagnosis, he was just beginning to make sense of what it meant for his past experiences. He told me that he’d always thought I’d been angry with him a lot of the time. Unless I was laughing, smiling or obviously happy then he’d thought that actually I was angry. I felt sad but I started to do two things: I gave clearer facial signals, including smiling much more; and if we were having a conversation about something important or difficult we agreed to tell each other this is how I’m feeling now...’ including, if necessary, saying “I am upset” and “I feel angry”...” Parent

In a similar way, a child with ASD may not support their verbal communication with body language, facial expression or changes in tone of voice. If they do use these forms of communication, they may not accurately reflect how the person is feeling so be careful not to make assumptions.

Using generalised questions may produce misleading answers, eg "How are you feeling?" may get a learned response of "very well, thank you", but asking "have you got a sore tummy?" may get a "yes", because it is a specific question.

People with ASD often do not offer any more information than they are asked for. For example, if asked "can you reach the milk out of the fridge?" they may answer "yes", but may not offer additional information such as "but only if I stand on tip toes on top of a box".

When giving information, or teaching someone with ASD, it is often helpful to use pictures or photographs. Always check that the child has understood what you have told them by asking them to explain it to you.

> *"My son was nonverbal until the age of 7. At age 4, I introduced him to the PECS system. We started with his favourite foods and drinks, those items that motivated him to communicate. Consistency and support are crucial. His first words were all the pictures we used in his communication book. I made a portable visual schedule and took it everywhere with me."* Parent

Some top tips relating to communication:

- Ensure you have their attention; say their name before beginning
- Minimise sensory distractions such as noise, bright lights and busy rooms
- Use a clear, calm voice
- Keep things short and simple
- Allow your child some time to process information and check that they've understood
- Beware of using idioms, metaphors and similes - ensure they know what you mean
- Use facts to explain things, avoid analogies and never use sarcasm
- Don't rely on body language, gestures and tone of voice
- Ask specific questions
- Use pictures to help explain things
- Always check you have been understood

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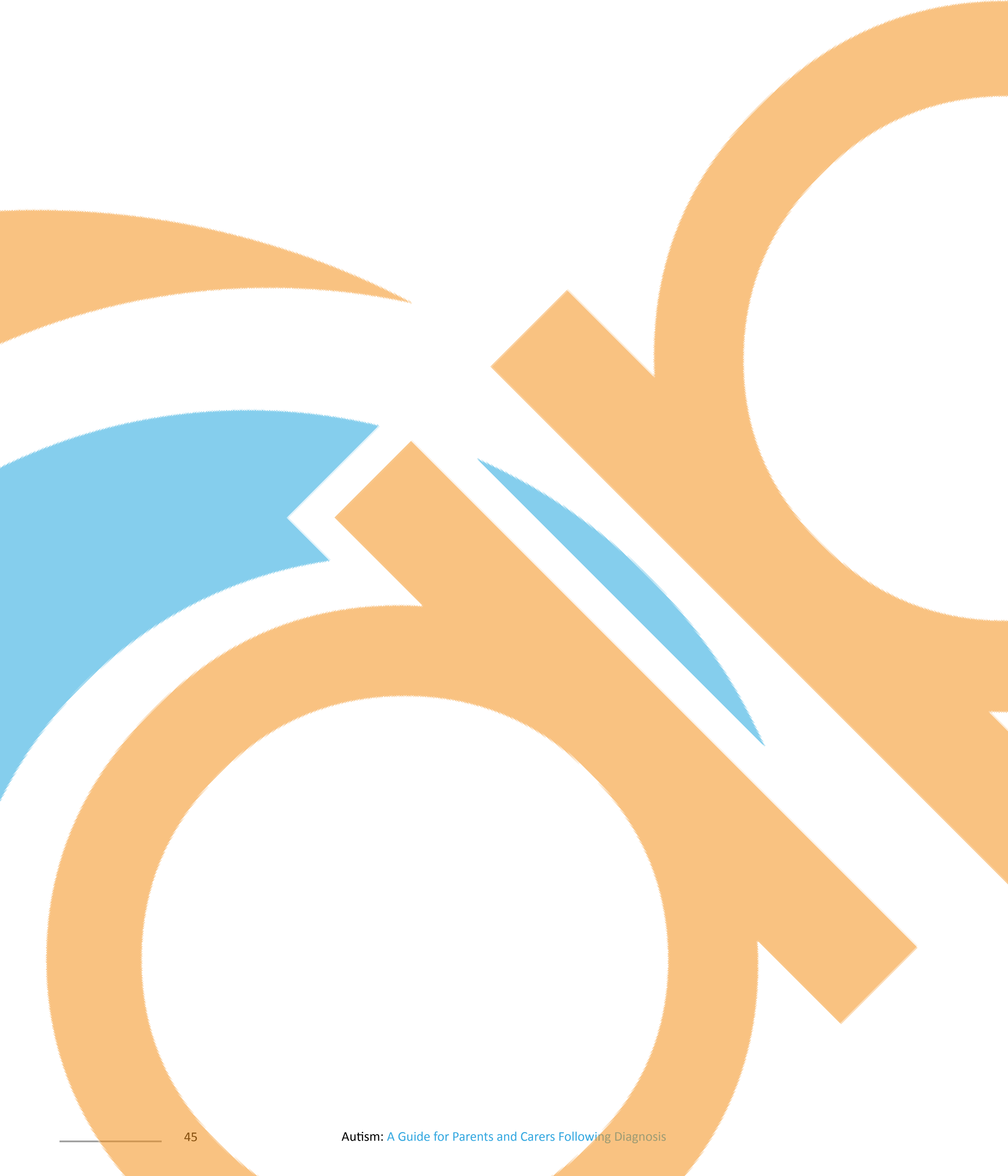
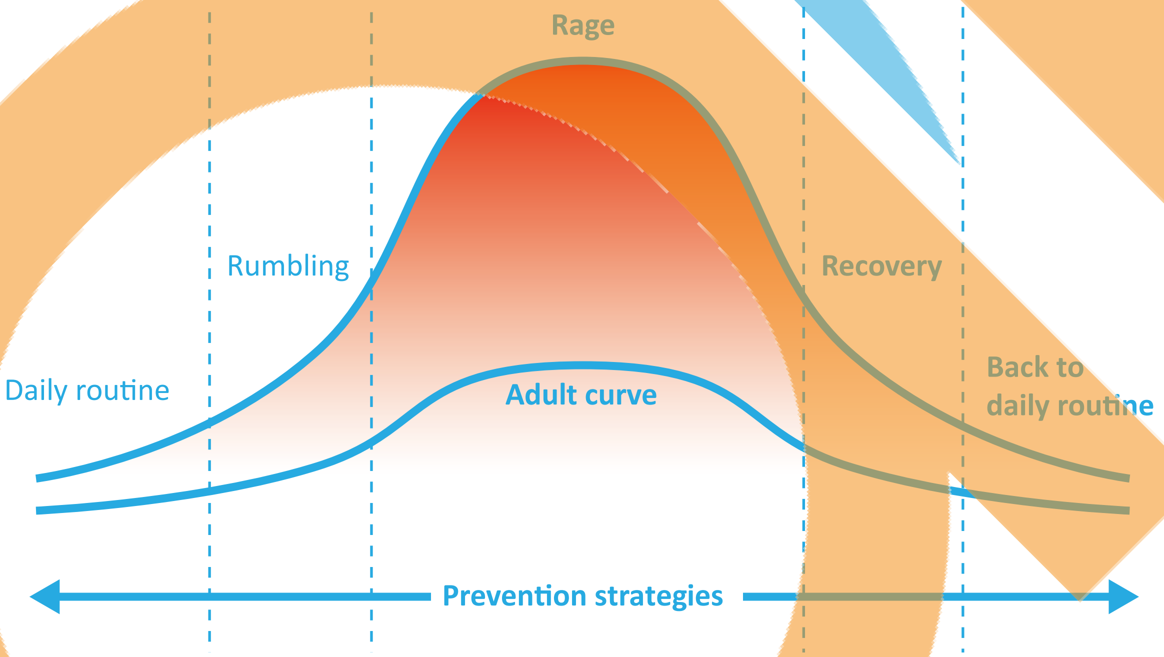


Supporting Your Child with Different Behaviour

Everyone displays ‘behaviour difficulties’ at some time because it is a way of communicating what they are thinking or feeling. Those with autism may seem to display challenging behaviour more frequently than other children but this is because they see the world differently.

They do not always understand social rules, may have difficulty expressing themselves and may struggle to cope with changes in routine and understanding how other people may be feeling, all of which can lead to very stressful situations for them. This, together with any sensory issues they may have, can be overwhelming for them to deal with and their only way to cope and to let you know that they are struggling is through inappropriate or ‘challenging’ behaviour (sometimes described as tantrums, rage and meltdowns).

Tantrums, rage and meltdowns can mean different things for different individuals but they usually occur in three stages which are rumble, rage and recovery (diagram below). The rumble phase is the start of the behaviour, also known as the trigger or antecedent. It is the most important phase because this is the point where the child is building up to the rage phase and there are usually opportunities to defuse the situation. Every child is different but you may notice certain ‘rumbling’ behaviours such as fidgeting, making noises, foot tapping, pulling faces / grimacing, etc.



Adapted from Curtis and Dunn 2000

These behaviours may initially appear to be minor and unrelated to the ensuing meltdown or they may be more obvious but over time you will be able to more easily identify what your child's rumbling behaviour is. Later in this section we will describe the 'cause, behaviour, function' chart and how to use it to identify the triggers, the rumbling behaviours and the reasons behind these. This in turn will help you to identify the best way to intervene at the rumbling stage and to develop some prevention strategies to stop your child reaching the rage phase.

The rage phase is the 'acting out' behaviour or meltdown. Again, this will be individual to your child but may include externalised behaviour (eg screaming, hitting, biting, destroying property, etc) or internalised behaviour (eg becoming withdrawn). If your child reaches this stage, the main thing to do is to try to remain calm and to ensure the safety of the child and those around them.

The recovery phase is when the behaviour has passed. The child may be tired/sleepy or may apologise whilst others may deny the behaviour or even not remember what happened.

When your child misbehaves, it is important to think about what may be causing the behaviour and what they are trying to communicate. The iceberg is a useful way to help people analyse and understand what is causing a certain behaviour in a child with ASD. When you see an iceberg you are only seeing a very small part of it - the 'tip of the iceberg'. The largest part of the iceberg is unseen as it lies beneath the surface of the water. The iceberg diagram helps you to think about the characteristics of ASD and how they may affect your child in a certain situation (there is a blank diagram for you to use at the end of this section).

A Typical Situation

What we can see:

The Specific Behaviour:

Shouting and screaming in a supermarket

What we can't see:

The possible reasons / underlying difficulties:

Interaction

Doesn't understand how to behave - why are people lining up? What are people doing, wandering up and down, looking at things? Why do I have to wait? Ohh, lots of nice sweets - I want one - why can't I have one?

Communication

Do not know how to express what they want.

Trying to communicate that they are frustrated at not being allowed to eat the sweets/they are bored/cold, etc.

Flexibility of thought

This is a different shop to the one we normally go to - everything is different I don't know what to expect.

Sensory

Lots of bright lights, very noisy, unpredictable noises, horrible smell of fish, some areas are really cold (freezer department).

Also, think about the **function** of the behaviour - what do they get from doing the behaviour?

I scream and shout → Mum / Dad gives me the sweets or they take me out of the shop.

To try and find out what is causing or triggering the behaviour it can be useful to look at the cause, behaviour and function (purpose) of the behaviour.

Cause - This is the trigger for the behaviour. This can sometimes be clear-cut such as somebody saying 'no' to a request but in individuals with ASD it can be more difficult to identify because the cause may be related to sensory issues such as loud noises or specific sounds or related to the need for predictable routines.

Behaviour - It is important not to jump to conclusions about behaviour as many individuals with ASD have difficulties in expressing their feelings in an appropriate way. For example, anxiety may present as worry but could also present in repetitive behaviours or aggression.

Function - This is the purpose of the behaviour which may be to gain something they wanted, to avoid something or simply to communicate feelings to others.

The best way to look at this would be to monitor and record behaviours over a period of one to two weeks. Each time an undesirable behaviour occurs, write it down on a chart such as the example below (there is a blank chart for you to copy/ use at the end of this section):

Date and time	What happened before?	What happened during?	What happened after?
You might see a pattern emerging when behaviour occurs eg around 11am every day; this might lead you to think that they are hungry.	Where is the young person? Who is there? What is the young person doing? What are the adults doing?	What exactly does the behaviour look like? How does it start? How does it escalate?	What happened immediately after the behaviour? What did the young person do? What did the adult do? How did the young person feel? What did other people do?
Example			
Friday afternoon (3.30pm) after school	**Where:** In supermarket in vegetable aisle. **Who:** John (young person with ASD), mother and two year old sister, crowded supermarket – lots of children as after school. **What are people doing?** John – walking ahead, mother looking at carrots with two year old in trolley.	John starts looking around. John starts counting the carrots (handling them). Mum tells John not to touch the carrots. John starts pacing and then running across the aisles. Mum shouts at John to come back and then goes after him. John reaches the magazine aisle and grabs his favourite magazine. Mum takes the magazine off him telling him that he can't have it and to go back to the vegetable aisle. John starts screaming and lies on the floor. Mum gives him the magazine or mum takes him home.	John is beginning to feel anxious or bored. Counting carrots helps to calm him / or keep him occupied. Mum is worried that other people watching will be critical of John touching the carrots. John goes back to feeling anxious / bored so seeks another way to entertain himself. Mum is worried she will lose John in the crowd. John has found something to make him feel better. Mum feels cross. John feels distressed as he cannot have what he wants. John has something to help him manage his anxiety / boredom. John's anxiety is relieved as he gets to go home and mum feels distressed and upset.

In the example we can see that John does not like supermarket shopping; he might find it boring or he might be anxious because of the busy environment. John's initial behaviour of counting carrots was because he was either bored or he was anxious. If mum knew this she could have averted the behaviour escalating by asking John to put five carrots in the bag and this would have kept him occupied, helping him to manage either his boredom or anxiety. However, because mum did not let him continue his behaviour John had to find another way to relieve his boredom and anxiety. Eventually John got what he wanted, either he got to go home earlier or he got his favourite comic.

At the end of the time spent monitoring, look through the chart and try and find common patterns. The 'what happened before?' sections will give clues as to the cause or trigger. The 'what happened after?' will give clues as to the function the behaviour services.

It is always better to try and manage an individual's behaviour by avoiding it, and avoiding the trigger point, and this is particularly true when the person has ASD.

When you have the information you need and can identify a clear pattern of behaviour, you can begin to work on it. There are two ways in which you can try to address the behaviour, either:

- Alter the environment or
- Work on the behaviour directly

If the child's behaviour is appropriate even if it is undesirable (for example becoming anxious around a change in routine) you should not try to change the behaviour, but rather change the environment. If sensory issues are the cause of the unwanted behaviour, altering the environment will also be the way to move forward.

> *"Making sure my son is not hungry stopped his challenging behaviour. It took a friend to notice and point it out to me. That was a few years ago. I did not feel bad, I just did not know, regular healthy meals solved the problem."* Parent

If, however the behaviour is not appropriate or desirable you may need to start some work around changing the behaviour.

Altering the Environment

Behaviour triggered by sensory stimuli such as noise, temperature changes	Reduce sensory stimuli, make a quiet space, avoid supermarkets at busy times etc.
Behaviour occurs around other people	Educate key people as to the needs of the individual with ASD, how to communicate, note sensitivities they may have
The response to behaviour varies from one to another	Have a clear plan around how to respond to the behaviour and ensure all key people follow the same plan
The environment is chaotic with lots of unpredictable changes	Try to develop a routine that is consistent and predictable

Working Directly on Behaviour

If you want to change a behaviour, try working using these two behavioural principles:

- If you reward a behaviour you will see more of it
- If you ignore a behaviour you will see less of it

When trying to decrease an unwanted behaviour, it is important that you teach a new way of behaving appropriately at the same time. This will prevent other negative behaviours developing. To do this you will need to remove all rewards from the unwanted behaviour and look for ways to reward a behaviour that is wanted.

For example, ignore the individual when they interrupt you talking by asking for something, but respond immediately if they say ‘excuse me’. In this situation the individual will learn that they will only get the response they are seeking by saying ‘excuse me’ first.

In order to help the learning of new behaviours it is important that your response is clear and consistent, you must respond in the same way each time.

Sometimes, the ‘reward’ for a behaviour is the attention you give to it. We can give attention to a behaviour in a number of ways including praising, giving rewards such as stickers / money, shouting, asking for explanations etc. Sometimes we do not even realise we are rewarding a behaviour because we are shouting or being negative to try and stop it.

In an individual with ASD the picture can be even more confusing; for example if the individual prefers to spend time alone, using ‘timeout’ as a punishment could be rewarding. It is therefore important that you take the individual into consideration when deciding on how to give or remove rewards for a behaviour. When managing an individual with ASD behaviour, it is important that you adapt your communication and this was discussed in an earlier section.

> *“Focus on one behaviour at a time. Repetition and reinforcement will eventually reduce the unwanted behaviour.” Parent*
>
> *“...the most valuable piece of advice I have gathered is to have patience, and to try and see things from their point of view.” Sibling*

Some top tips for supporting your child with different behaviour:

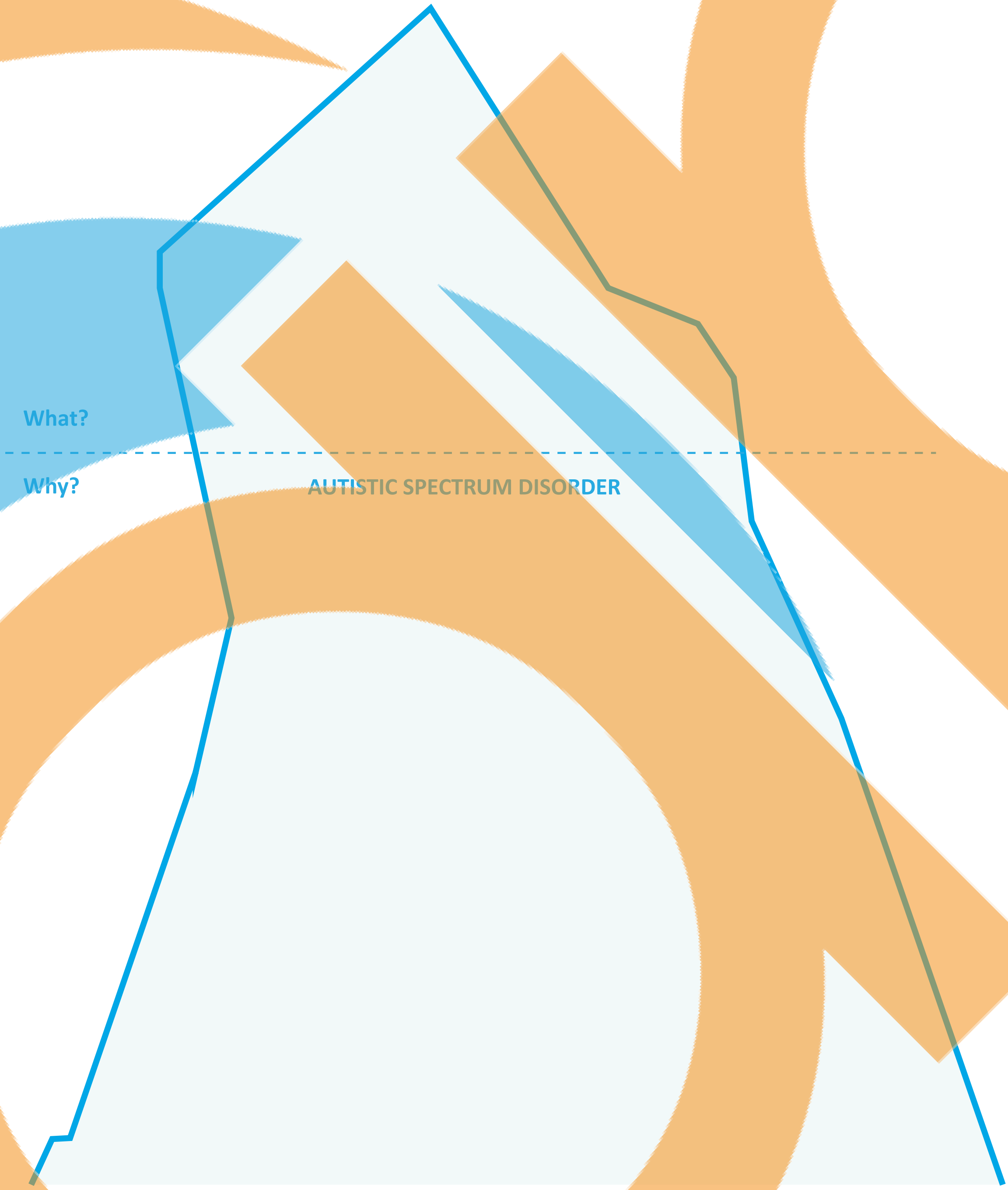
- Be positive and praise good behaviour. Make sure praise is given instantly and clearly so that your child knows what you are praising them for
- Don’t try to change too much too soon. Tackle one or two things at a time and perhaps try to choose something which will be easier to change first
- Improve the way you communicate with your child (see section on Communication)
- Help your child to understand and change their behaviours through, for example, social stories and explaining about other people’s thoughts and feelings
- Use calendars and other visual information to help your child understand the concept of time
- Plan ahead for activities and changes to routines (see section on managing change)
- Find out what relaxes your child so that you can help them calm down

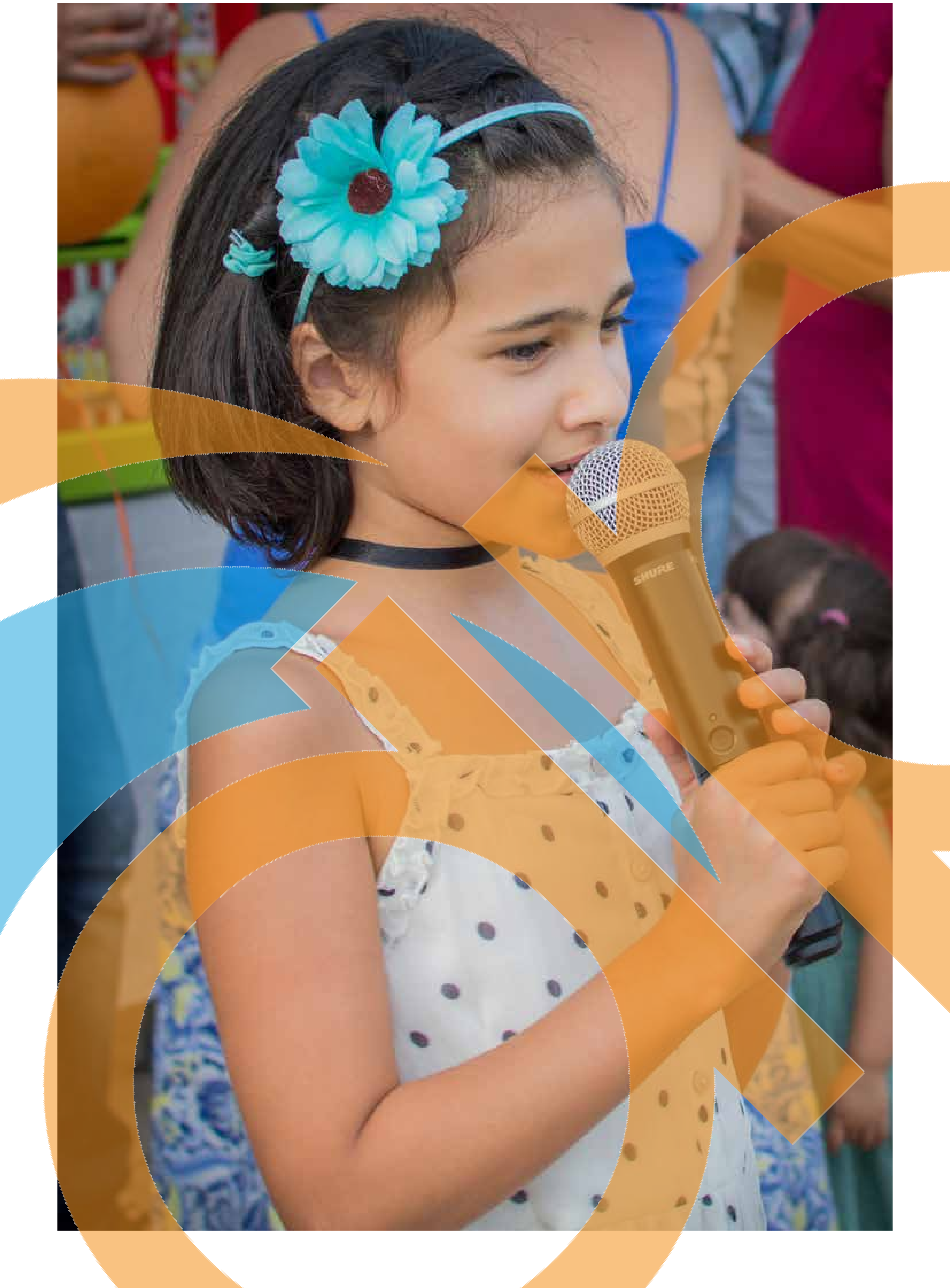
Date and time	What happened?	What happened during?	What happened after?
You might see a pattern emerging when behaviour occurs eg around 11am every day; this might lead you to think that they are hungry.	Where is the young person? Who is there? What is the young person doing? What are the adults doing?	What exactly does the behaviour look like? How does it start? How does it escalate?	What happened immediately after the behaviour? What did the young person do? What did the adult do? How did the young person feel? What did other people do?

The Iceberg Metaphor Worksheet

Write down your child's behaviour in the 'tip' of the iceberg

In the bottom part of the iceberg write down what happened before the episode, an outline of your child's sensory issues, and then what happened afterwards. This should help you analyse why your child behaved the way they did.

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Top Tips for Common Issues

Many parents report they need help with:

- Diet
- Sleep
- Toileting
- Play
- Body awareness

In this section we will briefly look at these and give you some top tips which may help.

Diet

What children with ASD eat can be an area of concern for some parents. In this section we will discuss two common diet issues:

- Extreme Fussy Eating
- Using diet as a treatment for ASD

Extreme fussy eating

It can be very exhausting when you are a parent/carer, to watch your child refusing to eat or to try new foods. It is not uncommon for children with ASD to be 'extreme' fussy eaters, ie only choosing to eat very specific foods, colours or textures. This is a highly complex problem to unravel and often you may need to seek expert help. What we do know is that when an individual is anxious, one of the first things that happens is their digestive system slows down (butterflies in your stomach-fight or flight). If your child is an extreme fussy eater, as well as numerous strategies you may be given, the aim is to work towards creating a calm, happy setting so they will be more willing to try new foods. You should not force them to eat.

Why ASD children are extreme fussy eaters is not clearly understood:

- Is it that they have sensory issues?
- Is it that they are using food as part of their repetitive behaviour?
- Is there some other factor that we don't understand?
- Children with ASD often have profound sensory issues and so food may not smell, taste or feel the same as it does to us. These issues may extend to memory anxiety – eg remembering an event/person when a particular food was eaten and that thought being so strong that it interferes with eating that food. Sometimes children with ASD eat 'non-food' ie paper, fluff, etc. This is called PICA. If your child does this talk to your doctor who should be able to refer you for more specialist help.

> *“Every time you ask me to try an apple I remember back to when I had a bad tummy, and I had an apple and was sick. When I have the fruit in my mouth my memory is so strong I can taste, feel, and smell the memory of the sick, and I can’t taste the apple... that’s why I won’t try it.”* Individual with ASD

- **What about the environment?** Is the environment putting them off eating? Bright lights, noisy children, sitting opposite messy eaters could be some of the reasons they are finding eating new foods difficult. The normal approaches to fussy eating may not work or apply to these kids. If you think your child is an extreme fussy eater ask your doctor for help and advice. They may be able to refer you to a dietician who can assess your child’s diet, check that it is nutritionally balanced and give you practical hints, tips and support.

> *“I need to eat on my own because I can’t block out the way other children eat, they eat with their mouths open, the food is falling out, they are picking their noses and it puts me off eating.”* Individual with ASD

- **Is something else going on?** Sometimes children refuse to eat because of an underlying medical problem that maybe making eating hard-sore mouth, painful teeth, constipation, etc. Speak to your doctor about this. They may be able to refer you to the appropriate health professional. Is your child eating a limited diet because of their strong desire for sameness giving them a sense of safety and calm?

Some top tips to try around diet:

- Spend some time monitoring your child. Keep a food diary to see how many different foods your child is eating. You may find that they are in fact eating a wider variety of foods than you thought
- Be a ‘detective’ and try and guess why they are eating in a certain way. If they have language, ask them why they can’t eat or if they can write, ask them to try and write it down, or draw what’s wrong
- A placemat which is ‘their area’ to eat from can help
- If your child finds eating with others difficult, make sure they are not sitting directly opposite another person
- If eating at school is difficult, ask what the environment is like at school or even visit the school during a mealtime
- Try and make meal times predictable. Serve three meals and planned snacks and try and establish a routine
- Visual prompts/timetables (pictures and or words, PECS) can be helpful
- Choice boards / choice books - These can have the foods your child eats in the front and foods they may like to try at the back, the aim being to bring the ‘Today I will try’ picture forward
- Try writing a Social Story (see glossary) these can be used to help your child try new foods or to explain why eating a varied diet is important (your ASD professional may be able to help you with this)
- Expose your fussy eater to food at every opportunity; get them to handle food, play with food, and help in the kitchen, so food and eating becomes relaxed and fun
- Always introduce ingredients one at a time. Eg carrots, potatoes, meat, chicken, not to confuse taste
- Use your child’s interest as motivators, eg make the food into a train, line up peas, maybe their favourite character could come to ‘tea’
- Try and make eating and being around food a pleasure not a chore!
- Remember, you need to persevere. You often have to expose your child to a new food a lot (15 or more times!) before they accept it as new food and will try it
- If your child has PICA look at what they are eating. Can you offer them something ‘safer’ or more acceptable to give them the sensation they are seeking but in a more acceptable form?
- Ask for help if you think you need it

Diet as a treatment for ASD

At present there is a lack of clear consistent evidence to recommend any particular kind of therapeutic diet for kids with ASD. Some parents report very strongly that their child has dramatically improved after following a special diet. Experts are trying to find out which of these therapeutic diets (of which there are hundreds!) may be useful, safe and have good evidence to say they help.

If you decide you want to try a special diet or supplements, there is more information on these via the UK National Autistic Society. It is strongly recommended that you seek impartial advice about this before embarking on this road. Many of the diets are expensive, a few can be harmful, and for children who seek routine a drastic change in what they are given to eat can be very distressing. This is especially true if your child is an extreme fussy eater. Here are two of the most popular diets and supplements:

- **Gluten and Casein Free diet (GFCF diet)**

This diet involves removing all gluten (a protein found primarily in wheat, barley, rye and oats) from the individual's diet, ie avoiding ordinary bread, pasta, crackers, many cereals, etc. It also removes Casein (a milk protein) so no cow's milk, ordinary cheese, yogurt, etc in the child's diet. It is based on the theory that individuals with ASD have a 'leaky gut' which affects their mental function and behaviour.

- **Fish oils and supplements high in Omega 3 supplements**

Omega 3 is a type of fat which is found in several foods (including oily fish-salmon, sardine, mackerel, herring, etc) which is important for brain function. Taking a supplement high in Omega 3 has been reported to help individuals with ASD attend and concentrate better. The amount of Omega 3 a child should take is not clear; however encouraging your child to eat more oily fish is not a bad thing.

There are many, many other dietary interventions around for ASD. If you think you may like to try one of these with your child, it is highly recommended that you speak to your doctor who may then be able to refer you to a dietitian. The dietitian will be able to discuss the pros and cons with you and support you during the period of 'trying the diet'. Most importantly they can make sure your child's diet is nutritionally balanced so they are not missing essential nutrients which could affect the overall health and growth of your child, eg a Casein free diet can make a child's diet low in calcium so can affect bone growth and thickness.

Where else can you get information?

Books:	***How to Get Your Kid to Eat But not too Much*** by Ellyn Satter
	Can't Eat Won't Eat by Brenda Legg
Websites:	www.autism.org.uk
	www.thegraycenter.org

Sleep

Many children with ASD will experience difficulties with sleep at some point. When a child has difficulty sleeping, it means the whole household has difficulty sleeping which can lead to a tired, irritable family. 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.

Many children display behavioural problems during the day purely because of tiredness and a lack of sleep during the night.

Often sleep problems can be rectified with behavioural interventions; sometimes even a small change can make a big difference. It is easy to 'give in' to behaviours in the night in order to settle the child for the whole house to get some sleep.

Individuals with ASD often prefer to have predictable routines. Ad hoc times and routines of going to bed can cause anxiety which will in turn cause the individual to have difficulty in sleeping. Busy environments can also cause difficulties in settling to sleep, especially if the child has sensory issues.

Children who need external pacifiers such as a dummy, TV or cuddles from a parent will be likely to wake in the night. On moving into light sleep they won't be able to re-settle without such pacifiers.

Many children become excitable during the late evening because they are overtired; if a child is not in bed early enough they will have more problems settling to sleep.

Below are some tips for managing sleep difficulties for you to try. However, if problems persist it may be a good idea to get some professional input to rule out other causes and to offer you some alternative strategies to those listed here.

Some top tips for managing sleep difficulties:

- Set up a regular night time routine and stick to it. Try to start ‘winding down’ at least an hour before bedtime. Baths, stories and a warm drink will all help your child to relax before bed. Avoid stimulating activities such as exciting TV, computer games and physical play.
- Create a non-stimulating bedroom where possible. Switch TV off, switch off or dim lights and try to control noise.
- Encourage your child to settle alone in their own bed. If you usually cuddle your child to sleep, gradually change this. Each night withdraw yourself a little more; sit next to the bed, away from the bed, in the doorway, on the landing etc until your child can settle alone.
- Repeat these steps if your child wakes in the night
- Have clear rules and explain them to your child eg ‘you must stay in your own bed’, ‘you are not allowed to watch TV in your room after 7pm’
- Do not allow your child to sleep in your bed because it is easier; it will only make more problems in the long term
- Encourage your child to stay in their own bed by using a reward chart
- If problems persist, speak to your doctor, occupational therapist, etc for more help

Toileting

Toilet training can be a difficult task whether your child has autism or not, but the process for children with ASD may take a little longer.

There are many good sources of information for toilet training such as the National Autistic Society (NAS), Education and Resources for Improving Childhood Continence (ERIC) (these are based in the UK but have websites and the contact details are listed below) or speak with an occupational therapist. We have listed some top tips relating to toilet training for you to consider.

Some children with ASD may be prone to constipation or diarrhoea and some benefit from a special diet. They may experience both, at different times, or at the same time (if the bowel is blocked, then only liquid matter can pass the blockage). If difficulties persist, or you are concerned in any way, contact your doctor to provide advice and, where necessary, to consider possible medical reasons for their difficulties.

> *“Protect your sofa by putting on a waterproof bed sheet.” Parent, Naxxar*

Some top tips for toileting:

- Ensure that everyone involved with your child is aware of the approach that you have decided to follow so that you are all consistent
- Use your child’s preference for routine to support the learning process
- Be aware that your child may not like change and therefore it may be easier not to toilet train using a potty as this will involve a further change from potty to toilet
- Observe your child to try and establish when they pee and poo so that you can try and establish when you are likely to need to take them to the toilet
- Have a visual sequence beside the toilet to help your child understand what to do
- Some children may find bowel movements frightening so it may be useful to explain the digestion process
- Some children may prefer the feel of a full nappy and be reluctant to change
- Consider the toilet/bathroom environment and how this will affect your child’s sensory issues
- Some children enjoy the feel of smearing and therefore alternative acceptable activities need to be provided instead
- Consider what alternatives are available if your child does not like the texture of toilet paper (eg, wet wipes, etc)
- Avoid childlike terminology as it may be difficult to change language later in life
- Use the same toileting routine in the community and when visiting new places as you do at home
- If difficulties persist, contact your doctor or other health professionals involved in the care of your child to provide advice and, where necessary, to consider possible medical reasons for their difficulties

Where else can you get information?

ERIC (Education and Resources for Improving Childhood Continence)
www.ericshop.org.uk *or* www.enuresis.org.uk
National Autistic Society
www.autism.org.uk

Play

Children with ASD often do not develop play in the same way as other children of their age and can appear to find play difficult.

Teaching and encouraging a child to play has a number of benefits. It helps a child develop language and to understand social situations through role play and aids interaction. It can encourage questioning and answering and develops a better understanding of how others play.

Rewarding the child during and following a play session is often a good incentive to take part next time; this can be as simple as a smile or a cheer or a ‘thank you so much for playing with me; I’ve had such fun’.

It can be useful to involve other family members in play so that the child has an opportunity to interact with other people but sometimes at first one to one is a first step.

- **Create a person friendly space**

Children with ASD find being with and interacting with others difficult so playing in a space with lots of distractions can make play more difficult. Ringing phones, blaring televisions, and electronic games can make engaging with our children much more challenging.

Only play with your child if you really want to. Five minutes of ‘I want to play’ will be much more useful than an hour of ‘I have to play’ and somehow our children just know if you are just going through the motions. If you are tired, stressed and anxious, don’t play; do it at a time when you feel more focused and positive. Play should be fun and easy, not a struggle.

- **Should I join in their chosen activity?**

Children with ASD often play in a way which seems strange to us. One type of play encourages joining in their chosen activity or engaging with what they like to do.

When your child does a repetitive behaviour, you could try doing it with them. It’s a way of saying ‘I want to be with you so much I want to do what you are doing more than what I am doing.’

After joining your child, you can then slowly start to expand on their play aiming to make solitary play into two way play.

Note: Be prepared that initially your child may not want to play with you and may very strongly indicate that they want to play by themselves. This is fine. Play is difficult for our kids and you may need to persevere before you get something back and your child learns this is fun!

> *"Dedicate quality time with your son or daughter with autism …role play and interactive games are crucial in the early days. If you see that your child is not interested, keep insisting and in the future you will be surprised to note that your child was not ignoring you after all."* Parent

Some top tips for play:

- Questioning children during play can be stressful. Try commenting or making statements about the child, the play or even how you are feeling eg 'that's a great tower you are making, I'm going to make one too'
- Turn off your phone / TV etc when playing to keep the focus on being with you
- Make yourself irresistible and get down to your child's level
- Try joining in their chosen activity. Really try and experience what they are doing.
- Focus on their chosen activity and if you feel your mind or your resolve dipping, stop and try again later
- Remember play is hard for our kids so do praise them at regular intervals for their efforts
- Play should be energetic and fun; if it feels laboured stop and try again another day
- Start with what your child likes to do, then free your imagination. Can you put a twist on what they like to do?
- Play with toys that use your imagination. Often simple items are best ie boxes, paper, feathers, bubbles, blocks, wigs, stickers, musical instruments, mini trampolines, scarves
- Don't overload your child's play space with toys. A few toys on a high shelf (to help initiate a request) are often better than a hundred easily accessible

Body Awareness (Behaviour and Boundaries)

Talking to your child about body awareness, sexual issues and relationships can seem quite daunting but it is important that all children and young people, including those with autism, are taught clearly and calmly in a way which they will understand.

People with ASD can have difficulty understanding body language, facial expression and tone of voice. They often have difficulties in reading social situations and are sometimes unaware that their behaviour is inappropriate. This can lead to confusion, misunderstandings and upset. They may also be confused or worried about changes that are happening to their bodies and their feelings.

There are many good sources of information and we have listed the relevant contact details below. We have also listed some tips for you to consider.

Earlier sections of this book about communication and behaviour may also be helpful to you.

> *"It can also be hard for people with autism to express themselves, especially emotions. [My brother] doesn't like people invading his personal space. This can mean that affection (hugs) is only offered when [he] feels comfortable. However, this doesn't stand as a rule for children with autism; you may find that your sibling may be over-affectionate. At this point they need to be informed of boundaries they must abide."* Sibling

Some top tips for supporting your child with body awareness:

- Socially appropriate behaviour needs to be adopted long before puberty begins. However, if your child displays 'inappropriate' behaviour make sure that you determine the purpose of the behaviour as it may be different to your assumption!
- Comment on inappropriate behaviour when it occurs but explain what is inappropriate about it and how the matter / situation could have been handled
- Be calm, clear and consistent - repetitive messages support learning
- Ensure your child has understood - ask them to tell you in their own words
- Talk to your child's school to find out what will be covered during PSD lessons, etc - to make sure that you are happy with what is being taught to your child and to try to ensure that you are working together
- Monitor television and film viewing - you may need to check their understanding of any sexual content

Where else can you get information?

Websites

The UK's Family Planning Association website includes information about sexual health, sex and relationships
www.fpa.org.uk

The UK's National Autistic Society has a section on their website about sex education for children and young people with ASD
www.autism.org.uk/living-with-autism/communicating-and-interacting/sex-education

The UK's National Health Service's Livewell website has information for young people about sexual health, sex and relationships
www.nhs.uk/Livewell/Sexandyoungpeople/Pages/Sex-and-young-people-hub.aspx

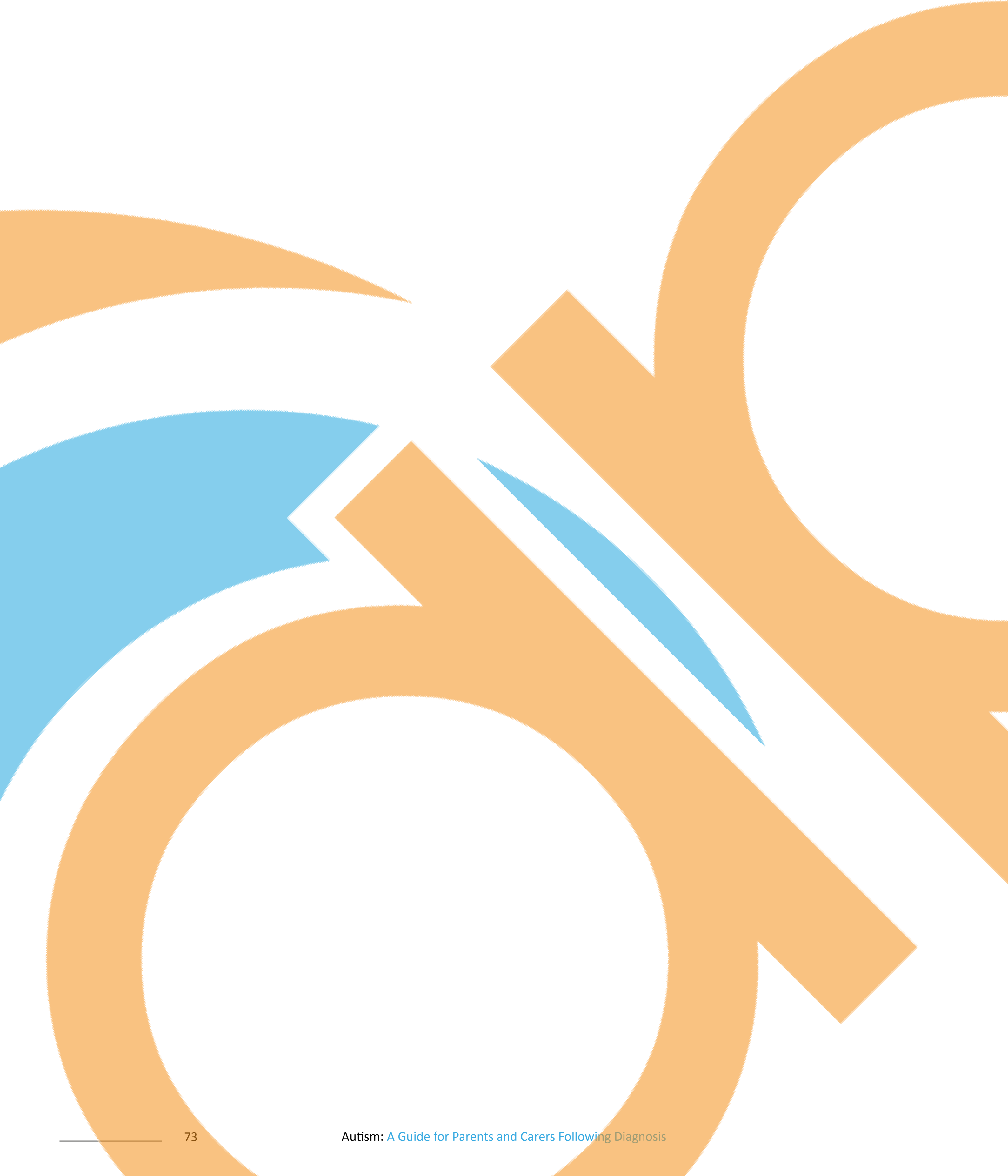
The BBC's website includes a useful section on the human body and contains information about puberty which may be helpful
www.bbc.co.uk/science/humanbody/body

Books

The Family Planning Association has three books (which are not autism-specific but for children with learning disabilities) and information relating to these can be found on their website.
These include:
Talking Together About Growing Up - Lorna Scott and Lesley Kerr-Edwards
Talking Together About Sex and Relationships - Lorna Scott and Lesley Kerr-Edwards
Talking Together About Contraception - Lorna Scott and Lesley Kerr-Edwards

Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger Syndrome - Sarah Attwood

Notes



What about Family, Friends and the Child Themselves?

Once you have come to terms with your child's diagnosis, you will also want to consider how you tell your other children, members of your family, your friends and the child with ASD themselves. In this section we provide some information and top tips about:

- Siblings
- Extended Family and Friends
- How do we tell our child they have ASD?

Siblings

> *"Understandably, when a child is diagnosed the thoughts and advice flow to the parents, but people do have a tendency to forget about the siblings and how it can impact upon them too. There are many difficulties that can be encountered; however these are equally measured with the good times and memories that can be created."* Sibling

Other children will often find things difficult too. They may find it difficult to understand the behaviours of their brother or sister with ASD. They may feel rejected if their sibling does not want to play with them, or does not respond to their social advances in the way they would like.

Sometimes other children can feel as if you are not giving them as much attention, or even as if you do not love them as much. Children, especially younger ones can find this difficult to explain to parents. Their feelings may be displayed in the way they behave which may not be how they would usually behave or how parents / family like. Sometimes other children start to behave differently as a means of securing parents' attention.

Providing siblings with information about autism will depend on their age and level of understanding. There are different ways to give information and this will depend on the needs of the individual child. For example, some will prefer to read a book; others would rather watch a DVD, whilst others will be happy to discuss it face-to-face with you or someone else. It may be helpful to provide them with a basic overview and then answer questions as and when they arise, giving simple and specific information.

> *“Aside from what can seem as the bad part of living with a sibling with autism there can also be good times, just like living with any other person.”* Sibling

Some top tips to support siblings:

- Talk about their feelings, tell them that it is okay for them to feel angry, sad, etc and that they may need some support themselves to deal with this
- Give them the opportunity to discuss their feelings with someone else they trust / feel comfortable with - sometimes young people would like to talk to someone else because they don't want to worry you
- Reassure your child(ren) that having to spend more time helping their brother or sister does not mean you love them any less
- Encourage them to interact with their sibling
- Help them to understand their sibling's behaviours and difficulties, but also explain their strengths and the things they are good at
- Acknowledge their role in the family - they are an important part of the family and whilst they are not their sibling's carers, they may want to be involved in helping and supporting you and their sibling
- Give your child(ren) the opportunity to have their own space - older siblings may appreciate privacy to do homework, have friends round, etc without interruptions.
- Allow them to have a safe place to keep important items, particularly if their sibling is prone to breaking things
- Make individual time with your child(ren); just 10 minutes a day can make a difference explain that this is their time rather than simply excluding their sibling with ASD
- Think together about activities which can be done as a family and what you can do with them on their own
- Remember to praise your other child(ren)'s positive behaviour. Look for things to praise such as sitting quietly, sharing, getting dressed without help. This will give attention and stop them seeking it in other ways
- Explain to siblings that other people may not understand what ASD is or know their brother / sister has autism so may react differently towards them

Where else can you get information?

www.autism.org.uk/16720
www.sibs.org.uk

Extended Family and Friends

Members of your family and friends may have noticed that your child sometimes behaves differently from other children. It is important that family and others understand what an autistic disorder is so that they can help to support your child and you appropriately.

Initially you may decide to only tell those closest to you but the decision to tell family and friends will be individual to you and your personal circumstances. Provide them with some basic information about autism and explain how it specifically affects your child and their behaviour. Let them know how best they can help and support you and your child.

Different people will react in different ways to the news. When there is denial about the diagnosis, especially from wider family members who may not know the child as well, it may be an idea to provide some information about ASD. They may offer unhelpful or well-meaning but misguided comments but providing them with appropriate information may help. Reading about typical signs/behaviours can often help others to understand, as people often do not realise what ASD is.

> *“No one believed me. I just knew from an early age that he was different but the family wouldn’t have it. Even after the diagnosis it took one or two people several years to get on board. I just kept leaving books and pamphlets about autism lying around and I know that some of them were reading them in secret. Everybody ‘got it’ in the end and we could all pull together.”* Parent

Family and friends may be unsure about ASD or specific aspects of your child’s behaviour so encourage them to talk to you if they want to know more or there’s something they don’t understand.

Accept help and support from family and friends when it’s offered. Sometimes people feel reluctant to offer help because they are unsure how they can help so think of some practical ways that they could help.

> *“Being a parent of a child with autism is a rollercoaster for the family as a whole. Allow time for yourselves, your partner and your other children. A strong united family is vital for the future of our children.”* Parent

Some top tips about extended family and friends:

- Explain to them about your child's diagnosis and provide them with information about autism
- Encourage them to ask if there is something they don't understand or want to know more about
- Explain how ASD impacts on your child and your child's behaviour
- Tell them how best to connect with your child, ie talk about their likes and dislikes and the best way of communicating with your child
- Acknowledge that they may struggle to come to terms with the diagnosis and may need support
- If someone makes unhelpful comments or is reluctant to accept the diagnosis, try not to take it to heart
- If family / friends offer to help, accept! If they don't offer it may be because they're not sure how they could help so ask, even if it's just to chat and listen

When do we tell our child they have ASD?

There is no hard and fast rule about when to tell your child and this will depend on personal circumstances. Their diagnosis may mean that their level of understanding or ability to process language is different to other children their age so the right time or age to discuss the diagnosis will depend on their individual abilities, needs and emotional strength and these are all factors you will want to consider. However, you are their parent and you know them best.

> *"I feel that revealing a diagnosis to a child is a very sensitive issue which ideally needs to happen in therapy. Every situation is different and every child will react differently. One needs to ensure that the child is supported when this process is done."* *Parent, Birkirkara*

Some parents decide to tell their child when they are young so that they gradually become aware of their differences whilst others prefer to wait until their child is a little older so that they will understand better. If children are told about their condition and provided with the support they need it is suggested that the likelihood of problems occurring decreases. Some children may begin to ask questions and this may be a good time to talk to them. However, be aware that some children may have questions but not know how to express them.

When talking to your child about their diagnosis try and be as positive as possible. Use language and information according to their age and level of understanding. It may be a good idea to provide minimal information to begin with and add more over time. Your child may need some time to process the information and may have mixed emotions about their diagnosis. It is important to let them know that they can talk to you about how they are feeling or any questions they may have.

> *"My Son is 13. I always told him that he's special. [I decided that] it's time to tell him that he has autism. I did and he started asking questions and I explained as clearly as I could say. He is in a special school I think that helped him to understand. He was quite positive. I explained that his best friend has autism too and he was quite happy to hear that he's not the only one."* *Parent, Santa Venera*

There is a range of books and online videos that may be useful for you to use and you could speak to your doctor, other professionals or indeed other parents to help you with this.

> *"It's not as if I was born with legs and then I had them taken away from me in an accident. I was born with Asperger's and I don't know any different...Maybe I'm one of the normal ones and you lot have the problem!"* *Individual with ASD*

Some top tips for talking to your child about their diagnosis:

- Use language and information appropriate to their level of understanding
- Try and be as positive as possible
- Give them time to process the information and encourage them to ask questions
- Reassure them
- Provide information in the most suitable way - books, websites, online videos, etc
- Have a question box, email or diary system if they find talking face-to-face difficult
- Ask for help from professionals and other parents

Where else can you get information?

Age 4 - 9 years

Doherty, K., McNally, O. and Sherrard, E. (2000) ***I have Autism. What's that?*** Down Lisburn Trust

Larson, EM (2006) ***I am Utterly Unique: celebrating the strengths of children with Asperger's syndrome and high functioning autism*** Autism Asperger's Publishing Company

Eye Television (2006) ***A Different Life: Rosie's Story*** (DVD)

Age 8 - 12 years

Elder, J. (2006) ***Different Like Me: My Book of Autism Heroes*** London: Jessica Kingsley Publishers

Autism Helpline (1999) ***What is Asperger's Syndrome and How Will it Affect Me?***

Vermeulen, P. (2000) ***I am Special: Introducing Children and Young People to their Autistic Spectrum*** London: Jessica Kingsley Publishers

Doherty, K., McNally, P. and Sherrard, E. (2000) I have Autism. What's that? Down Lisburn Trust

Gerland, G. (2000) Finding out about ***Asperger's Syndrome, High-Functioning Autism and PDD*** London: Jessica Kingsley Publishers

Jackson, L. (2002) ***Freaks, Geeks and Asperger's Syndrome*** London: Jessica Kingsley Publishers

Age 12 years+

National Autistic Society (2008) ***Being Me*** London: The National Autistic Society (CD- ROM and DVD set)

Autism Helpline (1999) ***What is Asperger's Syndrome and How Will it Affect Me?***

Services and Support

In this section we consider therapies and interventions which may be available for children and families with autism, information about services and the education system and claiming benefits.

Therapies/Interventions

Autism is a life-long condition and the causes are not yet known. Whilst it is important to recognise that autism is no-one's fault and as yet there is no known cure, we do know that there are approaches that can be helpful.

From talking to professionals and other parents or by looking at the internet you may come across a number of programmes, therapies and interventions.

However, it is important to remember that what works well for one individual may not necessarily work well for another. It may be advisable to discuss these, and / or others you may be aware of, with the professionals involved in the care of your child to find out which therapies / interventions are available and whether they think they may be of benefit. Please be aware that you may have to pay for the interventions listed below.

Examining existing research and findings for families for whom it has worked is probably the best ways to evaluate how effective an approach may be. Speak to other families who have tried the approach because, even if an approach has shown spectacular results, it may not be right for your child if you do not have the time and money to implement it in the same way. The families it has worked for may have plenty of money, large amounts of support from extended family and friends and live in an area where the service is easily accessible. If these things don't apply to you, then it's possible that the approach won't work either. Don't despair; there is plenty you can do to help your child, even if you don't plan on taking a bank loan to pay for therapies!

We have provided an overview of some of the most common therapies/interventions below.

Some of the therapies may not be available in Malta but a summary is included here in case you want to investigate the approach further. It is recommended that you ask your service provider or therapist which approach they adopt.

SPELL

SPELL stands for Structure, Positive (approaches and expectations), Empathy, Low arousal and Links. The SPELL framework has been developed by the National Autistic Society in the UK to understand and respond to the needs of children and adults on the autistic spectrum. The framework is also useful in identifying underlying issues; in reducing the disabling effects of the condition; and in providing a cornerstone for communication. It also forms the basis of all autism specific staff training and an ethical basis for intervention.

The SPELL framework recognises the individual and unique needs of each child and adult and emphasises that planning and intervention be organised on this basis. A number of interlinking themes are known to be of benefit to children and adults on the autism spectrum and by building on strengths and reducing the disabling effects of the condition progress can be made in personal growth and development, the promotion of opportunity and as full a life as possible.

TEACCH

TEACCH stands for the Treatment and Education of Autistic and Communication- Handicapped Children.

The long-term goals of the TEACCH approach are both skill development and fulfilment of fundamental human need. 'Structured Teaching' was developed to achieve these goals.

The key elements of Structured Teaching include:
- Developing an individualised person- and family-centred plan for each client or student, rather than using a standard curriculum.
- Structuring the physical environment.
- Using visual supports to make the sequence of daily activities predictable and understandable.
- Using visual supports to make individual tasks understandable.

PECS

The Picture Exchange Communication System (PECS) aims to improve word learning and overall communication through picture-word association, ie pictures are used instead of words to help children communicate. It uses the behavioural principle of reinforcement, where acting in a certain way (communicating with PECS) provides something the child wants thus reinforcing the required behaviour relating to that particular picture.

For further information:

Speech and Language Department
Tel: 21230822
Webiste: www.speechlanguage.gov.mt

ACTU: Access to Communication and Technology Unit
Tel: 21255876
E-mail: actu.mede@ilearn.edu.mt

Pyramid Educational Consultants UK Limited
Webiste: www.pecs.org.uk

PECS resources available from: Wwww.do2learn.com
Webiste: www.pecs.com
Webiste: www.childrenwithspecialneeds.com (click on '*downloads*')

Cognitive Behavioural Therapy (CBT)

Cognitive Behavioural Therapy (CBT) is based on the idea that how we think, how we feel, and how we act, affect each other.
CBT uses techniques to help people become more aware of how they reason, so that they can change how they think and therefore how they behave.

CBT is likely to work only for those individuals who have both the capacity and the preference for monitoring and managing their own behaviour. It is therefore more likely to work for high-functioning individuals with autism or Aspergers syndrome who are more than 8 years old.

Early Intensive Behavioural Intervention

Early Intensive Behavioural Intervention is a highly structured and intense intervention in which a child is taught a range of skills by a team of therapists.

The therapists breakdown the skills into small tasks that are considered to be achievable and which are taught in a very structured manner.

Desired behaviour, such as use of language or socialisation, is positively reinforced and accompanied by lots of praise. Negative behaviour, such as self-harm or aggression towards others, is not reinforced. For example, a child who hurts himself in order to gain attention would be prevented from hurting himself and the therapists might stop talking to the child until he showed a more desirable behaviour.

There is also a wide range of other therapies that you may come across. Again, our suggestions would be that you discuss them with the professionals involved in the care of your child and with parents / families who may have used those therapies and can give you feedback to try and help you decide if they would be suitable for you and your child.

Music Therapy

Music therapy uses live music making and composition techniques to encourage children, adolescents and adults with autism spectrum disorder to engage in spontaneous and creative musical activities.

The therapist and client use a variety of percussion or tuned instruments, or voice, to develop shared and interactive musical activities.

The individual with autism does not need musical skills to benefit from music therapy but the music therapist does need a high level of musical and therapeutic skill.

Supporters of music therapy believe that it can be used to develop social engagement, joint attention, communication abilities, while also addressing emotional needs and quality of life.

Social Groups

Social groups provide an opportunity for individuals with autism to meet each other and to improve their social skills in a safe, supportive environment.

Social Groups cont.

The groups are usually facilitated by professionals or volunteers but offer flexibility in the leisure activities they provide. For example, some may focus on one activity, such as drama, whilst others may offer a wider range of activities.
Social groups differ from social skills groups in that they are less focused on the attainment of skills and more focussed on providing opportunities for people to participate in mainstream leisure activities.

Social Skills Groups

Social skills groups provide an opportunity for individuals with autism to practice and improve their social skills in a safe, supportive environment.

Some groups include people with and without autism, although some groups consist only of people with autism. The groups are usually facilitated by professionals.

Social skills groups differ from social groups in that they are more focussed on the attainment of skills and are therefore likely to be more structured.

Developmental, Individual-difference, Relationship-based (DIR) / Floortime

The emphasis of this approach, developed by Greenspan and Weider (1999), is about following and imitating the child's actions, using sensorimotor techniques such as swinging the child or applying physical pressure if this increases attention to the adult. Adults also present problem-solving activities to the children and playfully obstruct any repetitive routines and attempt to elicit communication by not responding to non-communicative actions.

Relationship Development Intervention (RDI) Programme

RDI trains parents to foster the social communication skills of their children with autism. Parents are trained to target deficits in their child's interpersonal interaction skills (such as joint attention, gaze direction and use of facial expression) through stimulating and fun activities. Parents are trained to use indirect prompts and 'invitations' rather than directive ways of interacting. The idea is that once children with autism have discovered the value of relationships through repeated positive experience of interpersonal activity, they will be motivated to learn the verbal and non-verbal skills required to sustain these relationships.

Social Stories

A Social Story is a description of a social situation written in the first person (as if from the perspective of the child) and in a concrete style and format. The story includes sufficient detail for the child to recognise the situation when it actually occurs and examples of the appropriate kind of response to make. Other information might include details of how the child might feel in the situation, and how his / her response might affect others. The idea is that the child rehearses the story ahead of time with an adult. When a comparable situation occurs the child can then use the story to help guide his or her behaviour.

An example of a Social Story is included at the end of the Glossary section.

For more information relating to Social Stories try the following websites:
Website: www.autism.org.uk/16261
Website: www.thegraycenter.org/Social_Stories.htm

Applied Behavioural Analysis (ABA)

ABA involves teaching linguistic, cognitive, social and self-help skills across all settings and breaking down these skills into small tasks which are taught in a highly structured and hierarchical manner. There is a focus on rewarding, or reinforcing desired behaviours and ignoring, re-directing or otherwise discouraging inappropriate behaviours.

How a person progresses on an ABA programme will depend on a range of factors including their particular needs and abilities and the way in which the programme is implemented.

Lovaas

The Lovaas method is an early intensive behaviour therapy approach for children with autism and other related disorders. It is also known as:

- Applied Behavioural Analysis (Lovaas method)
- Early Intensive Behavioural Intervention
- Home Based Behavioural Intervention
- University of California LosAngeles (UCLA) Programme by Dr Lovaas
- UCLA Model of Applied Behavioural Analysis (ABA) (as developed in the Lovaas Institute for Early Intervention)

Behaviour modification is based on the fact that pleasant consequences can promote good behaviour and unpleasant consequences, such as punishments, can reduce unacceptable behaviours.

The therapy is on a one-to-one basis for six to eight hours per day, five to seven days per week for two or more years. Teaching sessions usually last two to three hours with breaks. As part of the sessions, all skills are broken down into small tasks that are achievable and taught in a very structured manner and accompanied by lots of praise and reinforcement. Examples of reinforcers are: play with a favourite toy, social rewards such as verbal praise and hugs and tickles. Gradually artificial reinforcers are replaced, if possible, by more social and everyday reinforcers. Aggressive or self-stimulatory behaviours are reduced or replaced by ignoring them or by introducing more socially acceptable forms of behaviour.

Rebound Therapy

This therapy uses trampolines in providing therapeutic exercise and recreation for people with a wide range of special needs. Participants range from mild to severe physical disabilities and from mild to profound and multiple learning disabilities, including dual sensory impairment and autistic spectrum disorder.

Rebound Therapy is used to facilitate movement, promote balance, promote an increase or decrease in muscle tone, promote relaxation, promote sensory integration, improve fitness and exercise tolerance, and to improve communication skills.

Drama Therapy

Drama therapy offers the opportunity for children with autism to build on their imitative strengths by learning, practising and perfecting 'lines' in a fun, supportive setting. It allows participants to work on social improvisation, practise social skills learned in other settings, work on reading and body language and develop speaking skills.

Touch / Massage Therapy

Massage is the practice of applying pressure, tension, motion or vibration to the skin, muscles and other soft tissues of the body and is used to obtain therapeutic effects. There are many different massage techniques and practices.

Massage or 'touch' therapy may have physical and emotional benefits for children with ASD and may improve their language and social skills or help with anxiety and sleep issues.

If you are interested in the therapy, there should be no potential risks of massage for children with autism. However, the evidence base for the effectiveness of this therapy is limited and more research needs to be undertaken.

Autism Assistance Dog

An autism assistance dog can give parents and children independence and provide a safer environment for the child making them feel more secure. An autism assistance dog is highly trained and socialised to meet the needs of the child and their family and can help change behaviour by introducing routines, reducing bolting behaviour, interrupting repetitive behaviour and helping a child with autism cope with unfamiliar surroundings. In addition, the dog can be trained to provide therapeutic support to a child.

It has been found that there can be a special chemistry between the dog and the child and in some cases the dog can have a calming effect when a child with autism is angry, anxious or distressed. They can distract a child away from disruptive or dangerous behaviour and create a space for the parent/carer to take control of a situation.

The Hanen programme

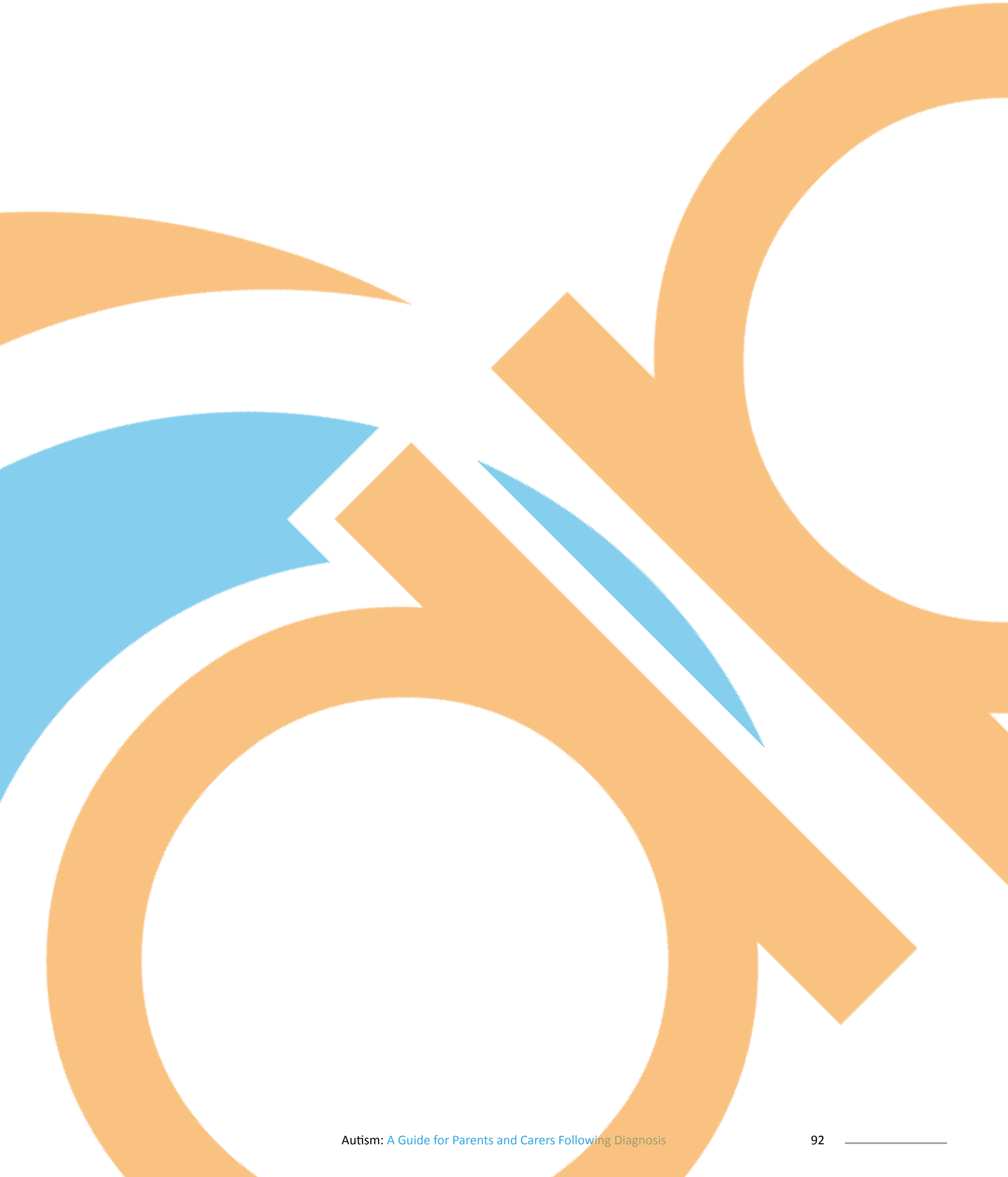
A family-based training programme that helps parents facilitate their child's language development and social interaction. Speech and language therapists trained in the Hanen approach use group sessions, individual consultations and evaluation to help parents learn strategies that will encourage language development.

Son-Rise

Son-Rise is a home-based programme for children with autistic spectrum disorder and other developmental disabilities. The programme emphasises eye contact, accepting the child without judgment, and engaging the child in a non-coercive way, and it hypothesizes that treated children will decide to become non-autistic.

However, no published independent study has tested the efficacy of the programme. A 2003 study found that involvement with the programme led to more draw backs than benefits for the families involved over time, and a 2006 study found that the programme is not always implemented as it is described in the literature, which means it will be difficult to evaluate its success/failure rate.

Notes



Education

The education of children who have ASD is often the main concern of parents following diagnosis. Educational support for children with ASD in Malta is organised by the Student Services Department (Directorate for Educational Services) as part of their provision for children with special educational needs. Extra help or support in the early years is provided at different levels, depending on how severe a child's needs are.

What education does your child need?

Children from birth to 3 years

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.

From birth to three years old, children may be cared for at home by family members or attend a childcare centre. Parents, carers and the person responsible for the childcare centre, normally play the most important role in observing developmental delays. Identifying special educational needs early is important so that children can be helped as quickly as possible. Once it is clear that your child has special educational needs, your child's school will provide different levels of additional educational support and intervention. This approach recognises that children learn in different ways and can have different kinds or levels of special educational needs.

When developmental delays are observed at home or at a childcare centre, concerns should be shared with professionals such as doctors (in government Health Care Centres, private GP's or paediatricians) or Speech and Language Pathologists working in Governmental services, who are in a position to recommend a child for an assessment. An assessment to determine the strengths and difficulties of a child, and a recommendation as to the level of support that a child may need in school, may be obtained from the Child Development and Assessment Unit (CDAU) or by a private psychologist.

> *"You will get a lot of reports, recommendations and goals. Keep all your child's reports from school, the various doctors and therapists in one lever arch folder chronologically. This made my life so much easier, especially for IEPS and follow up meetings."* *Parent, Naxxar*

Child Development and Assessment Unit (CDAU)

The CDAU within St. Luke's Hospital, offers a multidisciplinary assessment of children who have developmental challenges, including those within the autism spectrum. The Consultant Paediatrician within CDAU first assesses the challenges and strengths of the child, and then refers to the appropriate members of the CDAU multidisciplinary team: clinical psychologists, speech and language pathologists, occupational therapists, physiotherapists, early educational intervention teachers, audiologists and eye specialists. Families are also advised about and supported in applying for social and educational support services. Children and their families may need a variable duration of follow-up at CDAU and on-going therapy in the respective departments relevant to their needs.

A report from the child care centre or school about the child would be ideally made available on first referral to CDAU and assessment by the Consultant Paediatrician.

Children from 3 to 5 years

All children in Malta are entitled by law to attend mainstream kindergarten education. At the age of 5 children are obliged to attend school. Parents may opt to send their child to a state, church or independent school. It is a good idea to start looking at a range of schools available 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 when looking for the right school for your child
- 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?

Talk with other parents, support groups and ask questions on any schools and early years settings that you visit. It's important that you get to know the choices available and get a sense of the training, expertise, environment and ethos.

Once you have chosen a school for your child it is important to:

- Make an appointment to visit, talk to staff and familiarise yourself with the place so you can feel confident in placing your child there
- Ask as many question as you like and whenever you like
- Take time to explain your child’s likes and dislikes – a communication passport would be ideal
- Ask if it is possible for you and the child to have an orientation visit prior to the start of the school

Additional support for your child

The Statementing Moderating Panel

Whether following the assessment procedure at the CDAU or if taking a private route, a psychologist will assess and recommend the level of support that your child will need at school. For a student to receive the support of a Learning Support Assistant (LSA) the psychological assessment and a school based assessment (where applicable) of the child’s needs has to be passed to the Statementing Moderating Panel. The Statementing Moderating Panel has the role of identifying the needs of the students and issuing a ‘Statement’ according to the child’s needs, specifying the level of support that will be provided. The different levels of support are: one-to-one support, shared in-class support (the LSA supports two or more students in the same class) or shared support (the LSA supports the child for 2 and a half hours per day).

Learning Support Assistant (LSA)

The LSA will, in collaboration with the class teacher, parents and other professionals, co-ordinate the implementation of the student’s Individual Education Plan. However, wherever possible, the LSA shall also support other students in school as well as the teacher with the whole class. Children with a statement of needs are entitled to the free support of an LSA in state schools, church schools and independent schools.

Inclusion Coordinator (INCO)

Mainstream schools are supported by the services of an INCO, whose role is to support the teachers, parents, LSAs and School Management Team in catering for the needs of the learners who have received a certificate from the Statementing Moderating Panel. Furthermore, the INCO is responsible for coordinating support for these students, and coordinating the LSAs that work with them in class.

Individual Educational Programme (IEP)

The IEP directs and monitors the delivery of services to be provided for a student who is receiving special education services, including educational needs, goals and objectives, placement, evaluation criteria, and educational performance. The INCO is responsible for organising the IEP conference in Maltese schools.

An IEP conference is held at the beginning of the school year involving the parents, the teacher, LSA, INCO and other professionals who work with the student. Goals for the coming academic year are suggested by all stakeholders and discussed, and a final programme is drafted. The goals in an IEP focus on the acquisition of developmental, social and academic outcomes; for example, they may include improvement in communication, cognitive, gross motor and self-help skills. Throughout the year, the stakeholders work towards identified targets with the learner, and at the end of the school year, a review of the IEP is held and plans for the following year are discussed.

What level of education is your child entitled to?

Children with special education 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 they must make reasonable adjustments to accommodate children’s needs.

If you are experiencing any problems in accessing the support you feel your child needs, contact the Autism Parents Association (APA) in Malta.

Get more information on Inclusive, Special Education and the Statementing Moderating Panel.
Education, Student Services
Telephone 2122 8349 / 2122 8350
E-mail: studentservices.mede@gov.mt
Website: https://education.gov.mt
Address: Triq Fra Gaetano Pace Forno | Il-Ħamrun | HMR 1100

Benefits

You may be entitled to claim certain benefits and/or apply for reduced rates with some entities.

Disabled Child Allowance

The Disabled Child Allowance is given over and above the Children's Allowance. For up-to-date information about benefits, eligibility and how to apply visit www.socialsecurity.com.mt or alternatively go to your local Social Services offices.

Special ID Card

Commission for the Rights of Persons with Disability (CRPD),previously known as KNPD, provides several services for people with disability, and their families, including the provision of a Special ID card.

Some places give priority waiting, according to need, to Special ID card holders, for example at the airport and banks. Other places offer free or reduced prices on membership, activities and entrance fees. Card holders can benefit from free transport to state hospital appointments and ferry trips on the Gozo Channel Ferry. For how to apply for the Special ID card and the full list of card holder benefits visit **www.crpd.org.mt.**

Free Nappies

Holders of the Special ID card may be entitled to free nappies. Contact CentruServizzAnzjan, **csa@gov.mt, www.health.gov.mt.**

VAT Compensation

CRPD may provide compensation equivalent to the amount of VAT paid on items specifically intended for use by people with disability. Visit **www.crpd.org.mt.** for the list of items that qualify.

Income Tax Reduction

You may also be entitled to claim for a reduction in income tax for fees paid for services for a facilitator in respect of a child with special needs under Article 14B of the Income Tax Act. Contact Inland Revenue for more information **www.ird.gov.mt.**

Useful Contacts

Here is a list of services for child up to the age of 5 years old. Many of these organisations also offer services for older children. Some services are offered by the state or NGO's at no cost, however others are subject to a fee. Therefore make sure to ask for the cost of the service before enrolment.

Access to Communication and Technology Unit (ACTU)

The Access to Communication and Technology Unit (ACTU) provides Assistive Technology and Augmentative and Alternative Communication assessment and intervention service for people/students with physical, sensory, cognitive and/or communication difficulties and those who support them. It consists of an educational based trans-disciplinary team which brings experience from a variety of backgrounds including occupational therapy and speech and language therapy. Through these services ACTU aims to enable the student to communicate, learn and participate in society.

Application process

ACTU has an open referral system so parents, carers, educators and professionals can make a referral. Once the referral reaches our office it will be processed and then put on our waiting list. The referral needs to be signed by the parents.

21255876
actu.mede@ilearn.edu.mt
ACTU - Student Services Department
Fra Geatano Pace Forno Road
Hamrun

Winter: 8:00am - 4:00pm
Summer: 8:00am -1:00pm

Aġenzija Sapport

Aġenzija Sapport is committed to enhance the quality of life of persons with disability through personalised support and advocacy. It works with persons with disability and their families to secure the means, opportunities and services whereby they can execute their right to fully participate in community life. Services offered include: Social Work Services, Community Services, Independent Community Living, Residential Services, Day Centre Sign Language Interpretation, Occupational Therapy, Empowerment Scheme, Support groups and Workshops for parents and carers of children with disability, Support groups for Adult Siblings of persons with disability.

Aġenzija Sapport cont.

How can my child benefit from this service?

- A social worker meets the family at their home and an initial assessment is carried out. The social worker assesses the needs of the family.
- A care plan is formulated and the social worker keeps regular contact with the family to ensure the care plan is being implemented.
- If the child requires Community Services or Independent Community Living, the social worker formulates a report together with the family, and presents the case to the Services Allocation Committee.
- The Social worker also liaises with professionals involved in the case and if no professionals are involved, the role of the social worker is to act as a bridge between the family and the services offered for persons with a disability.

Application process

Application for such services is done through a referral process, either by third parties or also by self-referral. The parents must be aware of the referral since they work only when they have consent from the parents. The social workers can send the referral to any professionals who want to refer a case and one can also visit the offices and speak with a social worker.

Hours of service

An assessment is done during a home visit to establish the number of hours needed by the client to be used for Community Services up to 12 hours a week or Independent Community Living, exceeding 12 hours a week.

22568000/ 79442121
sapport@gov.mt
www.sapport.gov.mt
Facebook: Agenzija Sapport

ADHD Malta

ADHD Malta support individuals with ADHD and their families while creating awareness about ADHD in the Maltese community. Monthly meetings are organised, social media promotion, community service, website, videos, library, parenting skills courses, social skills courses, anger management, ADHD coaching course are offered and more.

How can my child benefit from this service?

There are courses which are specified for the children which may help them to overcome certain issues. Meetings and parenting skills seminars train the parents to help their child.

Application process

Send an email to adhdmalta@gmail.com to find out when courses take place.

79706364 President
21233749 answering machine
adhdmalta@gmail.com

www.adhdmalta.com
ADHD, P.O. Box 2
St Julians STJ 1001

Autism Parents Association (APA)

APA is an official non-profit voluntary organisation designed to help and facilitate families with children on the autism spectrum. APA is run by volunteers whose children are on the spectrum.

The aim of the Association is to create awareness, inclusion and tolerance in every aspect of society. APA organises seminars, social events, provides a private forum for parents to post questions, has active parent support agents and influences decision makers on all issues related to the rights of people with autism.

Application process
Membership forms may be downloaded from the website. Membership is renewed annually.

autismparentsassociation@gmail.com
www.autismparentsassociation.com
facebook - AutismParentsAssociation
twitter - APAMalta
Autism Parents Association
P.O. Box 30
Marsa MTP 1001

Autism Spectrum Support Team

The Autism Spectrum Support Team recognises that each student is an individual, and seeks to maximise the student's potential. It aims to empower educators and parents to meet the individual educational needs of the child with autism, facilitating learning, supporting behavioural and social development and maximising on students' abilities in mainstream and resource environment.

How can my child benefit from this service?
Once the referral is received by the team, contact is made with the school and the school INCO. A meeting is scheduled to understand the needs of the child and the school and act accordingly.

Curricular hours and three observation sessions are used to meet all staff in school and observe those students who need some extra help. Normally staff for each year group are given three informative sessions related to autism.

Photocopied information is passed to the school staff, whilst at the same time, they are exposed to resources and other related material which will help them to differentiate work for their respective child.

A plan of action is given to the school and the INCO detailing how to facilitate the referred child and the other children in general.

The team also helps the school to organise an informative meeting about autism (school based) for parents.

Autism Spectrum Support Team cont.

Application process

Referral through parents or Head of School (with parental consent) to the Service Manager Special Education/ Resource Centres. This is passed on to the Team who will make the initial contact with the school.

2122 8349 / 2122 8350
studentservices.mede@gov.mt

Service Manager
Special Education/Resource Centres
Triq Fra Gaetano Pace Forno
Il-Ħamrun HMR 1100

Child Development and Assessment Unit (CDAU)

The Child Development Assessment Unit (CDAU) within St. Luke's Hospital, offers a multidisciplinary assessment of children presenting with special/additional needs, disability and developmental challenges, including those within the Autism Spectrum. It also closely liaises with various related departments to provide Occupational, Physio and Speech Therapy as well as Early Intervention Teacher services from the Education Department.

How can my child benefit from this service?

Children benefit from a holistic multidisciplinary assessment as well as the therapy and support he/she may require. The Consultant Paediatrician assesses challenges and strengths of the child, and refers the child to the appropriate members of the CDAU multidisciplinary team. The team includes clinical psychologists, speech and language pathologists, occupational therapists, physiotherapists, early educational intervention teachers (from the Department of Education), audiologists and eye specialists (within Mater Dei Hospital). Children may also be referred to the Childen and Young Persons Services (formerly referred to as 'Child Guidance Clinic') at St. Luke's Hospital for behavioural difficulties, and other appropriate services within Mater Dei Hospital Outpatients Department including genetics, paediatrics, paediatric neurology, endocrinology, surgery, radiology and orthopaedic services. Families are also advised about and supported in applying for social and educational support services. Children and their families may need a variable duration of follow-up at CDAU and on-going therapy in the respective departments relevant to their needs.

Application process

Children are referred to CDAU by doctors (in governmental Health centres, private GP's or paediatricians etc) or those Speech Therapists working in Governmental services. The referral may be left open to 'CDAU' or may specify a Consultant Paediatrician. A report from the child care centre or school of the child would be ideally made available on first referral to CDAU and assessment by the Consultant Paediatrician.

Child Development and Assessment Unit (CDAU) cont.

25951803
CDAU
St. Luke's Hospital,
G.mangia
Main reception - ground floor level 0
Monday to Friday: 8:00am – 2:00pm
Saturday: 8:00am -12:00 noon

Early Intervention Service

The Early Intervention Service aims to provide a family centred and comprehensive support system for children with developmental disabilities or delays in the first five years (0-5) of life. The principle is to minimise the delays and maximize the chances of reaching typical milestones in development. It also supports and implements screening procedures to increase the early identification of difficulties and provide the family support as early as possible.

How can my child benefit from this service?
Assessment and Intervention in the child's natural environment e.g. home or school. The programme, 'Early Beginnings' focuses on four main areas of development including Physical development – Gross and Fine motor; Communication, Language and Literacy; Personal, Social and Emotional; Cognitive and Numeracy.

- The Early Intervention team helps parents and educators in the planning and application of an educational programme tailored to the child's needs.
- Support groups and workshops for parents supporting children with various needs.
- Group therapy in different areas involving both children and parents/carers.
- Support of Early Intervention Team in IEPs and transitions.
- Whole school approach targeting a school inclusion programme.
- Support and training provision to early years educators as continuous professional development.
- Screening assessment.
- Attendance in case conferences of children undergoing assessment at the CDAU and providing an educational report.

Application process
A referral form needs to be filled in to apply for the Early Intervention Service. Children undergoing assessment at the CDAU are also assigned an Early Intervention team member on parent approval.

Once a referral form has been filled in, a family Interview is carried out to establish rapport with the family, provide information on the services available, gather developmental information through assessments, obtain consent from parents as well as inform parents on the conditions of the service.

Early Intervention Service cont.

A member of the early intervention team will contact the family by telephone or in person to plan the meeting time and place which is convenient for the family. This applies for both home visits and school visits. In case of school visits the first meeting needs to take place with the parent/s or carer/s to establish the initial contact with family members.

2122 8349 / 2122 8350
studentservices.mede@gov.mt

Service Manager
Spec. Education/Resource Centres
Triq Fra Gaetano Pace Forno
Il-Ħamrun HMR 1100

Equal Partners

Our Foundation provides a range of services and due to our belief in the social model towards disability, all of our support programmes and services are individualised and are delivered in the community, in the natural environment where the individual requires support, including in homes, schools, places of work and recreation and the community at large.

Our core services:
- Psychological Consultation and Assessment
- Early Intervention
- Home Education
- Stepping Out Programme
- Tempo Libero

How can my child benefit from this service?
Equal Partners seeks to support people with disabilities and learning difficulties toward a more independent and meaningful life within an inclusive society. Support is given according to the particular needs of each individual.

Application process
Contact Equal Partners for membership and application.

Hours of service
Hours are flexible and usually after school.

21250400
info@equalpartners.org.mt
www.equalpartners.org.m
Facebook: We Empower – Equal Partners Foundation

Equal Partners Foundation
7, Market Street
Floriana FRN 1083

The Foundation for Educational Services (FES)

The Foundation for Educational Services (FES) is a public entity within the Ministry for Education and Employment. It was created as a mechanism that works hand-in hand with the Education Directorates to provide a range of innovative educational initiatives. Our goals are:

- To provide an after-school service
- To establish a comprehensive childcare service
- To develop a post-secondary educational programme for young people
- To encourage lifelong learning through the setting up of community learning centres
- To raise the profile of the Foundation to ensure accessibility to all programmes and services particularly amongst those at risk of social exclusion
- To collaboratively work with local and international organisations having similar goals to the Foundation
- To build the capacity of the Foundation by actively seeking additional sources of funding and investing in the development of its human resources.

How can my child benefit from this service?
Klabb 3-16 Winter: Klabb 3-16 is an after-school hours' care service for school-age children.
Skola Sajf: The Foundation for Educational Services is entrusted to organise the Skolasajf programme.
Childcare: Early childhood education and care (ECEC) is a crucial phase in a child's development.

22586810
fes@gov.mt
Facebook: Foundation for Educational Services
www.fes.org.mt

C/o St Nicholas College Boys Secondary School
Triq l-Imtarfa
Imtarfa MTF 1140

HandinHand - Malta

HandinHand Malta offers ABA services to children diagnosed with autism and other developmental disorders. Hand in Hand tutors work using interventions based on an Applied Behaviour Analysis (ABA) framework. The latter is a specialised form of intervention built on behavioural principles. HandinHand provides outcome-focused, evidenced-based ABA therapy. This effective and individualised treatment is used to meet each child's unique needs. It is our mission to allow children to achieve their full potential and enhance their quality of life.

How can my child benefit from this service?
ABA is a methodology that incorporates behavioural principles such as reinforcement, prompting, shaping and generalisation. ABA directly impacts the child's development of language, socialisation and other important skills like attention and waiting. ABA is also used to reduce inappropriate behaviours.

HandinHand - Malta cont.

Children who receive ABA are able to develop skills that allow them to independently participate in a mainstream school settings, whilst families benefit from learning strategies for facilitating their child's use of newly acquired skills and for reducing challenging behaviours.

Application process

Contact Jacqueline Abela De Giovanni who is the managing director of HandinHand. Jacqueline guides parents on how to proceed.

79474692 or 27200318
info@handinhandmalta.com or handinhand.mlt@gmail.com
www.handinhandmalta.com

HandinHand, Cottoner Buildings, No 5, Princess Margaret Street, Msida

Monday to Friday: 8:00am – 7:00pm, Saturday: 8:00am - 4:00pm

Inspire

STEP Early Years caters for children between 2 and 5 years of age. This programme is accredited with the UK National Autistic Society's Accreditation Programme. The programme is based on evidence based practice and offers a range of services to clients whose difficulties span across the autism spectrum. The programme utilises the TEACCH approach and applies the National Autistic Society's SPELL framework to support individuals with autism. Subsequent programmes are offered as the child gets older.

How can my child benefit from this service?

It aims to provide intensive specialized training, education and support allowing the full development of each child's potential and level of independence appropriate for his or her age.

Application process

Contact Inspire's Parent Relations Manager who will go through the application process.

Hours of service

4 hours of one-to-one intervention
70 hours per year of Parent Empowerment Training
50 hours per year of Additional Group Activities

20928100
www.inspire.org.mt
Inspire
BLB801 BULEBEL
ZEJTUN ZTN 3000

Karl Vella Foundation (KVF)

The KVF offers educational and psychological support from its premises in Attard to children whose parent or sibling is suffering from a critical or chronic condition. At the KVF Centre, children are encouraged to do their homework, take part in extracurricular activities such as crafts, art, storytelling etc., interact with the volunteers and other children, and may also be assisted psychologically if deemed necessary.

How can my child benefit from this service?
The aim of the KVF is to help children keep up with their education. While no one disputes the resilience of children, we are aware that educational demands are high and constant, and any interruption to a child's routine can have lasting repercussions. To address this, the majority of volunteers at the KVF are educational professionals: head teachers, teachers and LSAs, who have volunteered to step in and help the children as necessary. Psychological professionals are also available to ensure emotional and psychological well-being of the children. The atmosphere at the KVF Centre is child-centred and created to promote a sense of happiness and tranquillity.

Application process
Children may be referred to the KVF either by a doctor or professional who is aware of the family's medical situation, by filling in the KVF Referral form. Referral forms are available to download from http://www.karlvellafoundation.org/KVF_Referral_Form.pdf

Hours of service
The KVF Centre is open on Mondays and Wednesdays between 2.30 p.m. and 6.30 p.m. There are plans in the pipeline to open more often, so please do get in touch to enquire.

Chairperson
21237928 / 79442050
info@karlvellafoundation.org
www.karlvellafoundation.org

Karl Vella Foundation Centre,
The President's Kitchen Garden,
St Anthony Street, Attard

Malta Autism Centre (MAC)

The Malta Autism Centre provides specialist intervention to individuals across the autism spectrum throughout the different stages of their lives. Guided by autism specific expertise, the Centre helps individuals with autism to acquire functional skills and become socially included in the community. Intervention usually consists of one-to-one sessions and group activities and outings, as well as, support at school or at the workplace. Speech therapy and psychological intervention is offered according to the individual's needs.

Malta Autism Centre (MAC) cont.

How can my child benefit from this service?

Each individual receiving intervention from MAC benefits from a tailor-made programme which addresses the individual needs arising from the condition. In particular, every individual is helped to enhance the social communicative skills and receive training to become more flexible in his/her thinking and behaviour. Every individual is helped to acquire functional skills which will make him/her more independent and socially included in the community. Every school-aged student also benefits from regular contact with the school to ensure continuity and consistency between different professionals. Adults on the spectrum who have a job benefit from work visits to ensure that the adult on the spectrum is well supported at his/her workplace. Autism awareness programmes are also offered to the respective schools and workplaces to increase autism understanding among peers and colleagues. The ultimate aim for every individual receiving services from MAC is to improve their well-being and have a good quality of life. Parents are considered important stakeholders in the education and development of their children and are therefore highly involved in the intervention process.

Application process

Parents/carers can make contact with MAC and the individual will be assessed by the professional team and thereon, an individualised programme will be set up according to the individual's abilities and needs.

Hours of service

Since every individual at MAC benefits from a tailor-made programme, the number of intervention hours depends on the individual's priorities at that particular moment in time. The number of hours and type of intervention vary with age and according to the needs of the individual.

Tel: 21434727, maltaautismcentre@gmail.com

Malta Autism Centre,
Glormu Cassar Street
Mosta

National Parents' Society of Persons with a Disability (NPSPD)

NPSPD is an organisation which caters for the needs of people with disability and their families, and organises a number of activities throughout the year. It is also a leader in bringing forth disability issues to the public domain and engages in discussion with all parties who have at heart the interests of people with disability. Among the activities organised by the Society there are Live-In Weekends, dinners and get togethers as well as educational activities.

National Parents' Society of Persons with a Disability (NPSPD) cont.

How can my child benefit from this service?

The Society has constantly striven to improve the life of the disabled and their families. Its functions include:

- Fostering a sense of friendship, belonging and support to the disabled and their families.
- Supporting the concept of inclusion at all levels of society.
- Introducing and following up initiatives in the field of disability.
- Organising activities for members and non-members on a regular basis, such as get togethers, live-ins, dinners, summer swimming camp.
- Representation on a number of boards and committees.

27246163, npspdsociety@gmail.com, Facebook: NPSPD
www.npspd.org

NPSPD
Binja Binarja Block L, Flat 1
Triq Patri Gwann Azzopardi
Santa Venera SVR 1613

Paediatric Occupational Therapy Services – POTS

Occupational Therapy at POTS provides a service that addresses the individual's sensory processing needs. Methods, strategies and different programmes are developed for the individual by using: evidence based practice, creativity and innovation.

Time and support to the parents are considered important during the OT process. OT at POTS is provided through direct (individual or group) intervention or through consultation. This OT intervention is provided by qualified and dedicated staff within a FUN environment.

How can my child benefit from this service?

Our main aim is to address difficulties in sensory processing (regulation and motor coordination) and developmental skills that are required in daily life in order to help each individual (ages 0 – 16 years) become more independent and successful in life. POTS personnel design programmes following an assessment.

Programmes at POTS address the following areas: Organisation, Attention, Sensory Motor, Activities of Daily Living including Picky Eating, Visual Perception, Visual Motor, Handwriting (starting from formation and progressing to writing paragraphs), as well as Handwriting organisation, quality and speed.

Application process

Assessment takes 2 hours: one parent (or both) and the child need to be present. During these 2 hours, a full assessment will be carried out. Two qualified Occupational Therapists will be present.

Paediatric Occupational Therapy Services – POTS cont

One therapist conducts the interview and the other carries out the assessment with the child. Following the assessment, the therapists conduct approximately 5 hours of scoring and report writing. One of the therapists will then meet with the parents (without the child) to discuss the report with the results and recommendations.

Following this, the parent receives a letter with the goals for the OT programme. If the parents confirm that they wish to carry out the programme for their child, the therapist who will be working with the child will meet with the person who conducted the assessment to design a specific programme for the child.

We usually target problem areas on a weekly basis for a stipulated time and throughout the programme evaluations are made to identify if the child needs more/less input or if the programme needs to be amended. Each session is 1 hour long.

Hours of service
POTS personnel provide service during mornings, early and late afternoons, Saturdays included.

79790411 Josette Sammut
OT services: potsmalta@yahoo.com
Administration and / or products sales/quotations - infopotsmalta@yahoo.com
Talks/seminars - potsmalta@gmail.com

POTS
123, Triq il-Kbira
Zabbar

Service Dog Malta Foundation

A service dog is the key to independence for many disabled people. Beyond opening doors and flicking light switches, dogs offer companionship and emotional support. Service dogs also provide therapy and a means to socially interact with others

The aim of the Service Dog Foundation is to help people with a condition or disability by providing them with a service dog to overcome some of the difficulties they face on a day to day basis.

79617814 / 79049675 - www.servicedogsmalta.org

Special Olympics Malta

Special Olympics offer services, free of charge, to over 450 athletes who receive professional year-round training in thirteen sport disciplines. They also offer athletes the opportunity to participate in international sports events organised by Special Olympics International and/or other Special Olympics Programs around the world.

Special Olympics Malta cont.

How can my child benefit from this service?

The Young Athletes Program is a year-round sports training program designed for children with intellectual disabilities aged between 2 and 7. This program focuses on fun activities that help develop mental and physical growth from a very early stage and introduces young children to the world of sports and the world of Special Olympics. This offers these children to learn new things, play, exercise, and have lots of fun.

Through this Program, the children also develop better social skills, gain confidence and improve their communication skills. The effect of the Young Athletes Program is not only seen on the field. It helps the children in many other ways and benefits are felt at home.

Contact Monday to Friday: 8:00am - 5:00pm
Tel (Malta): 21318648, Mob (Malta): 99891687
Mob (Gozo): 99858224, info@specialolympicsmalta.org

Speech and Language Pathology Department (SLP)

The Speech Language Pathologist offers guidance, diagnostic assessments, intervention, support and information for clients and carers and recommends and encourages changes. The aim of the service is to provide appropriate, effective, therapeutic and rehabilitative intervention to meet the communication needs of our clients. This is achieved through the appropriate assessment of the clients' communication abilities; obtaining an accurate differential diagnosis and providing intervention directly (individually or in groups) and indirectly through other professionals and carers.

How can my child benefit from this service?

Many children with autism spectrum disorder have speech, language and communication difficulties. The SLP offers help and support tailor made to the needs of these individuals.If eligible, children with ASD may also benefit from autism client intervention programs including; Arts in Communication Therapy, Communication through Play and Social Communication Groups.

The Speech Language Department offers training courses for carers of children with ASD and professionals. These include: Introduction to ASD; Supporting Children with ASD in the Classroom; Visual Aids and Social Stories; Social Communication Skills; Using Communication Systems Effectively and Introduction to Picture Exchange Communication System.

Speech and Language Pathology Department (SLP) cont.

Application process

The department operates on an open-referral system. This allows the general public to have the best possible access to the services delivered. This means that referrals can be made directly by the client or carer to the speech-language pathologist. Other professionals and carers may also refer you to a speech language unit. These include family members, teachers, doctors, nurses, social workers, psychologists or other professionals.

Hours of service

Monday to Friday by appointment
21230822, speechlanguage@gov.mt, www.speechlanguage.gov.mt

Speech Language Department, Ingiered Road, Luqa.
You can also contact the nearest speech language clinic at the Health Centre or District clinic of your locality.

St. Jeanne Antide Foundation (SJAF)

SJAF is a social purpose non-profit organisation committed to identifying and supporting, in a holistic manner, very vulnerable and poor families.

How can my child benefit from this service?

Families of children with ASD may benefit from a number of services offered to society at large, however specific to ASD, parents may enrol in the following services

- Early Literacy Programme for Parents of Children with ASD
- Talks for grandparents of children on the spectrum
- Support from a psychiatric nurse

Contact the CEO from Monday to Friday: 8:00am to 5:00pm
Tel: 21808981
sjafngo@gmail.com
www.antidemalta.com

Team for Assessment of Attention and Social Communication (TAASC)

TAASC is principally structured along specific pathways to allow us to best reach conclusions about whether an individual has an Autism Spectrum Disorder or an Attention Deficit/ Hyperactivity Disorder (ADHD), but is also flexible enough to cater for individual requirements.

How can my child benefit from this service?
Different specialists will each complete their part of the assessment at our Multi-Disciplinary Team (MDT) meeting where we will refer to international diagnostic criteria to reach a conclusion. The outcomes, as well as TAASC recommendations, will be discussed with you during a feedback session. The summary of the assessment and feedback will also be provided in the form of a report. Other services offered by TAASC include:

Psychological intervention, Behaviour support services, Speech and Language intervention, Occupational Therapy intervention, Physiotherapy, Psychotherapy, Play Therapy, Psychiatric consultation, Parental skills groups, such as The Incredible Years and Cygnet and Social Communication Skills Groups

Application process
TAASC has an open referral system. Individuals can contact us directly. Referrals from other professionals are welcomed and you are also encouraged to bring any previous assessments you might have.

21498000 , taascmalta@gmail

TAASC, Remedies Clinic, Floor 1, St Helena Buildings, Thomas Fenech Street,
Birkirkara

Useful Websites and Facebook Pages

ASD Friendly
For everyone to share experiences of everyday life with children who have ASD.
W www.ASDfriendly.org

Autism Connect
An on line resource providing information about autism, news and events from around the world and access to discussion forums and other websites about autism.
W www.autismconnect.org

Autism Discussion Page – facebook
Lots of great advice from a seasoned practitioner and a forum for asking questions.
W www.facebook.com/autismdiscussionpage

Autism Europe
An international association whose main objective is to advance the rights of people with autism and their families and to help them improve their quality of life. APA is a member of Austism Europe.
W www.autismeurope.org

Autism Networks
A charitable body run by a group of like-minded parents, carers, professionals and people with autism. One of their aims is to make links with anyone concerned with autism.
W www.autismnetworks.org.uk

Autism Sibs
A list for brothers and sisters to discuss issues about growing up with a sibling with ASD
W http://groups.yahoo.com/subscribe/autism_sibs

Autism UK
An active UK-based list which provides a forum for wide-ranging discussion on many issues related to autistic spectrum disorder.
W http://lists.autismisanotherworld.com/mailman/listinfo/autism

Autistichat

A place for people with autism and related disorders to chat online. The channel is also open to the parents, friends and family of individuals with autism.
W www.autistichat.net

ERIC (Education and Resources for Improving Childhood Continence)

ERIC is a UK children's health charity dealing with bedwetting, daytime wetting, constipation, soiling and potty training in children and young people. ERIC provides information, support and resources to families and health professionals on bladder and bowel problems.
W www.enuresis.org.uk
W www.ericshop.org.uk
E info@eric.org.uk

National Autistic Society (NAS)

The NAS is a UK charity for people with autism (including Asperger Syndrome) and their families. They provide information, support and services and campaign for a better world for people with autism.
W www.autism.org.uk

Rackety's

Rackety's is a clothing company for disabled children and adults.
W www.disabled-clothing.co.uk
E info@racketys.com

Sensory Smart

Clothing solutions for sensory-sensitive children.
W www.sensorysmart.co.uk
E sensorysmart@googlemail.com

Youth In Mind

Youth In Mind is a website which enables you to search for books and websites about different topics for young people, parents and teachers.
W www.youthinmind.com

Glossary

Δ - symbol used by medical / clinical staff to mean ‘diagnosis’

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

ABA - Applied Behavioural Analysis. An approach to teaching which emphasises positive reinforcement and is underpinned with observation and monitoring: interactive and child-centred

ADHD - Attention Deficit Hyperactivity Disorder. A developmental disorder which can cause over active behaviour (hyperactivity), impulsive behaviour and difficulties in concentrating

Agency - an organisation which is statutory, private or voluntary which provides and/ or purchases social care, health care or other services

ASC - Autistic Spectrum Condition - see ASD

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

Asperger Syndrome - a type of autistic spectrum disorder. People with Asperger Syndrome usually have fewer difficulties with language than people with autism and do not have accompanying learning disabilities that some people with autism have. They are likely to be of average or above average intelligence

Assessment - the process of defining an individual’s needs, deciding on the help that they require and determining their eligibility for services

Attention Deficit Hyperactivity Disorder - see ADHD
Autistic spectrum conditions - see ASD
Autistic spectrum disorder - see ASD

Casein - protein found in milk and milk products

Child Health Services - Child Health Services are often referred to as Paediatrics, and are the department that deal with illness in children and young people (including delayed development). They may be based in a hospital, health centre or community clinic. Accessing these services is usually dependant on a referral from another professional

Clinical Psychologist - clinical psychologists work with children or adults who experience mental or physical health problems and learning disabilities. Clinical psychologists aim to reduce psychological distress and enhance and promote psychological wellbeing. They often work as part of a multidisciplinary team, including in hospitals, clinics and community teams

Co-morbidity - term used by medical/clinical professionals to describe the presence of additional conditions/disorders to the initial diagnosis

Counsellor - counsellors help people to explore feelings and emotions that are often related to their experiences. This allows them to reflect on what is happening to them and consider alternative ways of doing things. Counsellors do not give advice, but help clients to make their own choices within the framework of an agreed counselling contract. Counsellors may specialise in working with young people or adults. Counsellors maybe based within health centres, GP practices, schools and colleges or employing organisations

Dietician - dieticians work with people who have special dietary needs, give unbiased advice, evaluate and improve treatments. They may work directly with clients or advise doctors, nurses, health professionals and community groups

Direct payments - a way of choosing and paying for services provided by Social Services which can be adapted to meet your family's needs

Disability - a person has a disability if he or she has a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities

DSM-V - Diagnostic and Statistical Manual of Mental Disorders version 5 - manual used by clinical staff to classify and code diseases and disorders

Dyslexia - Dyslexia causes difficulties in learning to read, write and spell. Short-term memory, mathematics, concentration, personal organisation may also be affected.

Dyspraxia - a difficulty in co-ordinating movement

Echolalia - repeating words or phrases spoken by someone else

Educational Psychologist - an educational psychologist is concerned with helping children or young people who are experiencing problems within an educational setting with the aim of enhancing their learning. They work directly with young people as individuals or in groups and also advise teachers, parents, social workers and other professionals who are involved with the child

Epilepsy - currently defined as a tendency to have recurrent seizures (sometimes called fits)

GFCF Diet - Gluten and Casein Free Diet

Gluten - protein found in wheat

Hanen - a training programme for children who have a delay in developing language

ICD-10 - International Classification of Diseases version10 -Manual used by clinical staff to classify and code diseases and disorders

INCO - Inclusion Coordinator, whose role is to support the teachers, parents, LSAs and School Management Team in catering for the needs of the learners who have received a certificate from the Statementing Moderating Panel.

Intervention - term for any action, such as treatment or therapy, used to improve a condition

IQ/Intelligence Quotient - a score from tests to measure the level of someone's intelligence

Kanner autism - also sometimes called 'classic autism'. An autistic spectrum disorder characterised by difficulties in social communication and interaction and rigidity of thinking. People who have Kanner autism often have a delay in developing language and a learning disability

Learning Support Assistant (LSA) - Learning Support Assistant provide support to teachers and pupils in a school setting. They may work to support the class or a specific pupil. Their work is directed and monitored by the class teacher

Lovaas - a form of Applied Behavioural Analysis delivered in a home setting for pre-school children

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

MDT - Multi-Disciplinary Team which is a team of professionals from a range of different services

MAT - Multi-Agency Team which is a team of professionals from a range of different services

National Autistic Society(NAS) - the NAS is a UK charity for people with ASD and their families which provides information, support and services and campaigns for a better world for people with autism.

Neurology - the study of the brain, its diseases and disorders

Nutritionist - is an expert on ways of giving the body the nutrition that it needs. A nutritionist knows the relationship between diet, food and ill health and how one affects the other

Occupational Therapist - occupational therapy is the assessment and treatment of physical and psychiatric conditions using specific, purposeful activity to prevent disability and promote independent function in all aspects of daily life. Occupational therapists may use a wide range of techniques and strategies to help an individual to achieve and maintain normal daily tasks. Occupational therapists work within a wide range of services, in hospitals, clinics and community teams

Paediatrician - a paediatrician is a doctor who specialises in diagnosing, looking after, and treating children and young people who are ill or who have delayed development

PDD - Pervasive Development Disorder. A general term for disorders which affect communication and social skills and includes autistic spectrum disorder

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

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

Pharmacists - these are specialist health professionals who make and sell medicines and are often called ‘chemists’. They are experts on medicines and the way they work and will make up prescriptions provided by your doctor and can give advice on treatments that can be bought over the counter

Physiotherapist - physiotherapists assess and treat patients with physical difficulties resulting from illness, injury, disability or ageing. They treat children and adults in hospital and community settings

Pica - eating ‘non-food’ such as paper, fluff, etc

Prevalence - one of the main ways to measure the frequency of a disease in a particular population. It is the total number of cases that are present at any one time covering both old and new cases

Prognosis - a forecast as to the probable result of an illness, particularly with regard to the prospect of recovery

PSE - Personal, Social Education - see PSHE

PSHE - Personal, Social and Health Education - part of the school curriculum where children develop knowledge and skills they need to keep themselves healthy and safe.

Respite services - services for people who have a disability and their family to give them a rest and a break

Primary Health Care Services - primary health care services are the health services/ professionals you can access directly, without the need for a referral. These include a GP, health visitor and practice nurse. They deal with a variety of physical and mental health issues and can refer you to other services for more specialised assessment help or support

Psychiatrist - psychiatrists are medically qualified doctors who look after patients with mental health problems. Psychiatrists work with individuals of all ages and usually specialise in working with children or adults. Psychiatrists work as part of a team in hospital, clinic and community settings

Public Sector - (or Statutory Sector) the group of bodies which is required to obtain or provide particular services such as the Local Authority and the Health Service which receives central government funding

Regression - to go backwards. This usually refers to the loss of skills previously acquired, especially those basic skills related to early childhood

School Nurse - a school nurse works in partnership with schools to create an environment that promotes healthy living, as well as responding to the needs of individual children. School nurses promote and support physical, mental and emotional wellbeing and usually work within a number of schools

Semantic pragmatic disorder - a communication disorder where people have difficulty understanding the meaning of words and may use them in the wrong context. It can be linked to autism

Social Services - Social Services Departments are based in local authorities and provide services that support, care and protect individuals of all ages. Social Services have a number of teams who work with individuals with differing needs and usually separate children's and adults' services. Examples of the teams are child protection, adoption and fostering, children with disabilities, protection of vulnerable adults, mental health and learning disability services

Social Stories - these were developed by Carol Gray in America. They are short stories which assist people with social understanding by teaching appropriate social skills and behaviours for specific situations. An example is provided at the end of the glossary

Social Worker - a social worker works with a variety of individuals including those who are socially excluded or experiencing crisis. Social workers work with children and adults. They provide support to enable individuals and their families to help themselves. They may be based within a social services team or within another team or service. Social workers work in a variety of settings including the home, schools, hospitals and other public sector and voluntary organisations

Son-Rise - a home-based, intensive, autism-specific intervention

Special Educational Needs (SEN) - Special Educational Needs

Speech and Language Therapy (SALT) - a form of therapy to support people of all ages who have difficulties with speech, language and communication problems. They may also work with people who have eating and swallowing problems. Speech and language therapists may work privately or through the government in hospital, clinics and community settings

Statement of special educational needs - a document provided by a local authority which sets out a child’s needs and all the extra help they should get

Stimming - repetitive behaviours referred to as self-stimulating behaviour some of which are obvious whilst others are more subtle. Examples of stimming include hand-flapping, spinning, eyerolling, tapping fingers, etc. This repetitive behaviour is used for a number of reasons including self-regulation in times of stress, demonstration of excitement, a way of avoiding a task or activity or to provoke a reaction from others

Support Worker/ Assistant- a support worker can be attached to a variety of teams or professionals and help to carry out the care, monitoring or treatment of an individual. The support worker carries out work under the direction and supervision of a qualified professional e.g. nurse, speech and language therapist or occupational therapist

TEACCH - an autism-specific approach which helps children cope with and understand their environment

Tourette’s Syndrome - a neurological condition, the key feature of which is tics (involuntary and uncontrollable sounds and movements)

Triad of impairments - the three impairments which characterise autism include issues with: social communication, social interaction and rigidity of thinking

Example of a Social Story - Going Shopping

“Sometimes I go shopping with Dad to the supermarket. We usually go in the car to Park Towers. When we get there, we choose a trolley. Dad gives me the list of things we need. We walk up and down the aisles to find what we need. Sometimes Dad lets me get the things off the shelf and put them in the trolley. This is being helpful. When we find the items, I can cross them off my list. Then we go to the checkout. We usually have to wait in a queue. When it is our turn, we take the items out of the trolley and put them on the conveyor belt. The shop assistant scans the items and then Dad packs them into bags. Dad will be pleased if I try and help him. After he pays the assistant, we push the trolley back, get into the car and drive home. If I try to stay calm we will get home quicker. Dad will be pleased with me if I try to stay calm and help with the shopping.”

With Thanks

Handbook layout

APA is forever grateful to Louise Osmond, Matthew Camilleri and the team at EC English Language Centres who produced the layout of the handbook. We applaud EC's social responsibility charter to help our local community.

APA Logo

This handbook sees the launch of the new logo for APA. Our sincere appreciation goes to Chiara Ripard for creating our new dynamic logo.

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VOLUNTARY SECTOR

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