AUTISM INFORMATION PACK

UNDERSTANDING AUTISM

A guide for Parents







INTRODUCTION

About This Booklet

Receiving a diagnosis of Autism Spectrum Disorder (ASD) for your child can be a stressful and confusing time.

Many parents have shared that when they received a diagnosis, they would have liked to know more about

- What autism is, and what it means for you
- Where to find support for your child and your family
- Options for therapy and funding
- How to speak to their child and others about autism
- How to work with your child's school



This booklet will help you to think about these questions, help you and your family to begin to make decisions, and help you to connect with others who can support you as you move forward.



The questions at the bottom of each section are designed to help guide you as you make decisions for your child and your family.

If you're feeling overwhelmed with information right now, you can access what you need now, and come back to it later.



There are also links at the end to help you find out more when you're ready.



STOP AND THINK...

What are some things that you want to know about autism?

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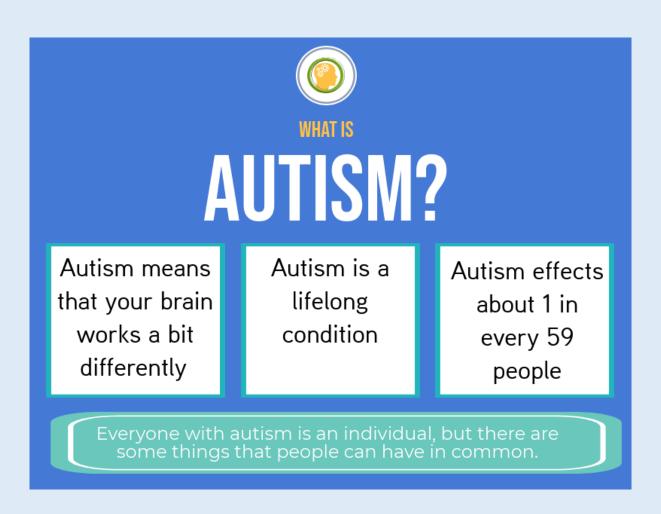
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WHAT IS AUTISM?

When your child first gets a diagnosis of Autism Spectrum Disorder (ASD), it can feel a bit confronting- what does this mean for him, and for our family?

It's important to remember that your child hasn't changed. Getting a diagnosis gives you a new language to explain and explore who he is, what things he's great at, and what he might need some help with.



COMMON FEATURES OF AUTISM

Some features that are common for people with autism are:



Finding it hard to understand relationships with other people.



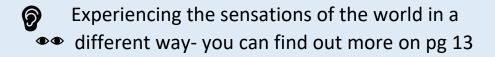
Having trouble understanding communicationthis could be the way that language is used, or the way that people communicate with their faces and bodies.



Needing the world to be predictable and liking things to stay the same.



Having very strong interests, which other people might not share.



(American Psychiatric Association, 2013)

Throughout this booklet, you can find out more about autism, and some ways that you can get support for your family.



STOP AND THINK...

What do the features of autism look like for your child?

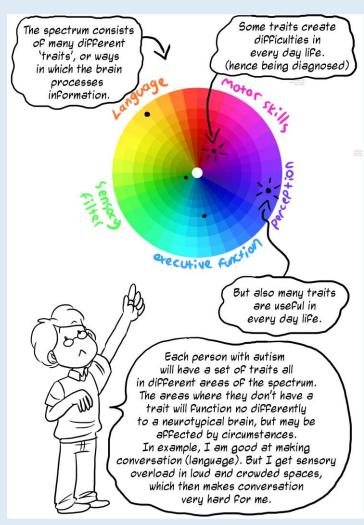
USEFUL TERMS

A guide to the language of autism

Learning about autism can mean learning a lot of new words and terms. Here are a few to get you started.

"The Spectrum"

You may hear people refer to people with autism as being on the spectrum. Some people think that this means that people at one end are a little bit autistic, and people are the other end are very autistic- but that's not correct. The spectrum is a way of talking about the differences between people with autism. The comic below explains how people's autistic traits can show in different ways (used with permission- see the whole comic at www.rebeccaburgess.co.uk).



Neurodiverse

Neurodiversity is a way of describing how some people, including people who have autism, have brains that work in different ways.

Autistic Person or Person with Autism?

Some people prefer the term autistic person, because they feel that autism is an important part of who they are. Others prefer to say a person with autism, because they feel that they are a person first, and autism is just a part of them. The term that you prefer is up to you, and your family.

Meltdown

Meltdown is a word used to describe behaviours that can happen as the body's way of reacting to an overwhelming situation. Sometimes they may look like a tantrum, but the cause is very different, and the person may not be in control of their behaviour.

Transitions

Transitions are times of change. Some may be big transitions, like changing schools, while other kinds of transitions happen every day, like moving classes, or going from school to home. People with autism can find transitions difficult and unpredictable.



STOP AND THINK...

Are there any other new words that you've heard that you need to learn about?

GETTING A DIAGNOSIS

A time of learning for you and your family



"I think I'm kind of still the same person I was before, I want people to know I'm the same. But, I like knowing that there are other people like me, and I'm not weird or stupid for feeling like I do. In some ways, autism makes me better at things, and I like that."

Jamie, 9, talking about his autism diagnosis

"I had mixed feelings when Mia was first diagnosed- I was relieved to finally have an answer about what it could be, but I was worried for her. I felt a sense of responsibility to help her, but I wasn't sure where to start. At first I wanted someone to just tell me what to do, but now some time has passed, I feel more confident to make decisions myself."

Eva, mother of Mia, 17





"It's actually gotten a lot easier since Will got diagnosed with autism. Now I know why he does things and what he needs. Its easier to see how he might be feeling. It can be hard when he has a meltdown, sometimes I feel embarrassed, but it's helped me to understand more."

Jayden, 8, brother of Will,5



STOP AND THINK...

How can your family support each other as you learn about autism?

Things to consider when MAKING CHOICES about autism interventions

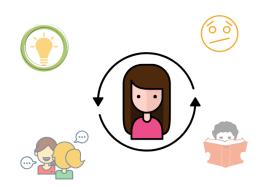
It is normal to feel overwhelmed when you're faced with having to make decisions about what to do next, especially when you're still learning about autism. It is important to know that you are not alone- there is help available to support you as you learn and make choices.

You can find information about the kinds of interventions in lots of ways. You might get recommendations from your doctor, or other parents. You may find information online, or in the community.

The choices that you make about which supports you would like to access need to fit with your family, your needs and your values. Some interventions may be more helpful than others.

Below you will find some questions to guide as you begin making these choices.

1. DOES THIS FOCUS ON MY CHILD'S NEEDS?



Is this program designed for my child's strengths and needs?

Your child should always be respected, and the people working with her should understand her goals, hopes and feelings.

2. IS IT A QUALITY INTERVENTION?



Has this intervention been studied? Is it based on a good understanding of autism?

Not all programs are equal. Try to find programs which have a base of research, and are built on an understanding of autism.

3. IS IT DELIVERED BY OUALIFIED PROFESSIONALS?



Do the people delivering the program have experience working with autistic people?

The people who deliver the interventions you choose should be qualified and experienced in supporting people with autism.

4. IS IT SAFE?

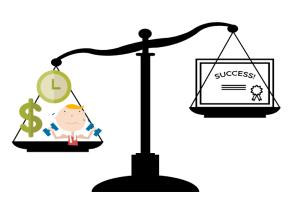




Are there any risks? How are they managed?

Some interventions may have some risks or side effects. It is important to minimise the potential for harm, and get advice if needed.

5. IS IT GOOD VALUE?



Does the amount of improvement worth the time, cost and effort?

You should make sure that your child is making improvements, and that your time, money and efforts are worthwhile

6. IS IT PRACTICAL?



Is it a good fit for your family? Can the skills be used in daily life?

The skills that your child learns should help them in them in their daily life. Your plan should be manageable for your child and your family.

(National Autistic Society, 2018)

If you would like to know more about the types of interventions that are available, there are links available on page 16.

AUTISM IN GIRLS

How is it different?

Although each autistic person is an individual, there are some characteristic that are common. Girls and women can experience autism in different ways than boys and men.



However, it is likely that there are many more girls and women whose autism has not be diagnosed, so the ratio may be more similar.

Females with autism often look very carefully for ways to fit in with their peers.

They may appear to be very social and friendly with others, however, their interactions may be rehearsed or copied from their previous experiences, or from other people. Many girls find that this is very tiring and stressful, as they worry about not making the right social choices.



STOP AND THINK...

Does autism look different for your daughter than what you expected?

MAKING CONNECTIONS

Supporting social development

Many parents worry about their child with autism making friends. Children with autism want to have friends, and they can have fulfilling friendships.

Experiences of Friendship for Children With Autism

- Friendships are often built on shared hobbies and interests.
- Many children with autism have one or two close friendships.
- Understanding friendships can feel like hard work at times, when it is difficult to figure out other people's actions, thoughts and feelings.
- Children with autism like time with others, but also time alone. It's ok to allow them time to play on their own.



STOP AND THINK...

How can you support your child as they build their social skills? What supports can you put in place to help them to make friends?



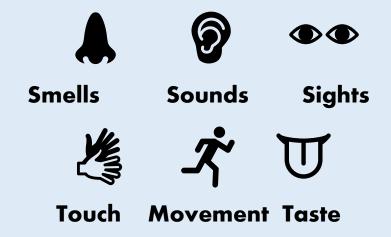
EXPERIENCING THE WORLD

Supporting your child's sensory needs

Most people with autism have some differences in how they process information about the world through their senses.

For some people, this might mean that the sights, sounds and smells of an environment can be easily overwhelming, while others might need extra input to feel secure.

Some senses that people with autism often experience differently are



- Some people find sensory input overwhelming
- Some people need a lot of sensory input
- Some people go looking for ways to get more input
- Some people avoid overwhelming sensations

A person may even find that they react in different ways to different sensations.

These reactions can be so strong that people can experience it as painful, or not be able to control their responses.

An **occupational therapist** can help you to find ways to help your child to manage their sensory needs.



STOP AND THINK...

Do your child's sensory needs impact on their daily life?

TALKING ABOUT AUTISM

with your child, and with others

Many parents feel worried about talking about autism with their child, and with other people. Learning about autism can be an important part of helping your child to understand who they are.

Be Open About The Diagnosis

Being autistic is a part of who your child is, so allow them to ask questions and learn about what it means. Finding out about why some things are challenging can be very empowering for young people with autism.

Be Positive About Autism

Follow your child's lead in your discussions about autism. Embrace their differences and discuss some of the positives that come with being autistic.

It's Ok Not to be an Expert

You don't have to know the answers to all the questions that your daughter may have about autism. You may like to get support from a doctor or other professional.



STOP AND THINK...

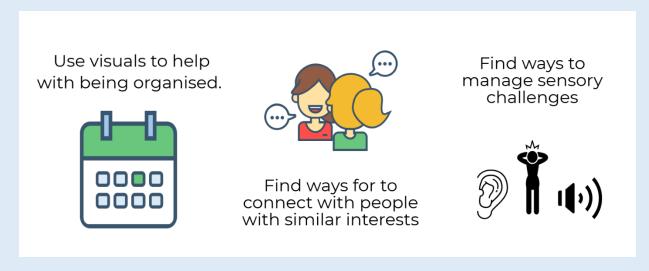
How comfortable do you feel talking to your child and others about autism?

What could make the conversation easier for you?

AUTISM AND SCHOOL

School can bring a range of challenges for students with autism. By working with the school, you can support your child to manage these challenges, and help them to be successful at school. Your school may be able to access funding to help them to support your child.

Some simple things you can do to help your child include



It is important to work with the school to find ways to support your child. When planning with school support staff, you should try to

- Keep communication open
- Include your child in the planning process
- Find ways to support your child's strengths



STOP AND THINK...

What challenges has your child had at school?

Are there any changes that could help with these challenges?

FINDING HELP

What support is available?

One of the big questions is- what do I do now? The great news is, there is a lot of support available to you! It's very important to find support that works for you and your family.

Busy Brains Learning

Busy Brains Learning offers a range of services which can help you and your child. These include

FAMILY SUPPORT AND ADVOCACY

We provide information, personalised support, guidance, advocacy and connection for families who have children with disabilities. We are here beside you every step of the way to help you find your child's strengths, find support to help them develop, advocate and help through challenging times, and celebrate every success!

SMALL GROUP PROGRAMS

We are now taking bookings for small group programs in 2020. We offer a range of programs throughout the school term, as well as school holiday sessions. Our group programs are designed to help with emotional regulation, social skills, early intervention, transitions and school readiness.

INDIVIDUAL THERAPY

We provide individualised programs and services to help your child to address their personal goals across a range of areas. We can help with school readiness, social skills, communication, emotional regulation, cognitive development and life skills.

PROFESSIONAL CONSULTANCY SERVICES

As a highly qualified and experienced Developmental Educator and Registered Teacher, Amy has a high level of expertise in understanding the needs of children with Autism and other developmental disabilities. Amy is able to provide consultation and professional development services to schools and Early Childhood services. Amy is also able to accept limited speaking engagements each year.

Funding for Supports

You may be eligible to access the **National Disability Insurance Scheme (NDIS)**. The NDIS can help with assistance for your child to

- manage your daily life,
- participate in the community, and
- improve your skills.

You can find out more about the NDIS via the NDIS website https://www.ndis.gov.au/ or by contacting your **Local Area Coordinator**, who can help you with your application.

You can find the contact details here https://www.ndis.gov.au/contact/locations

Information About Interventions

The "Raising Children Network" has information about a range of different types of intervention, to help you in decision making https://raisingchildren.net.au/guides/a-z-health-reference/types-of-interventions-for-asd

Support for Your Family

There are a range of family support groups across Queensland. You can find information on a group in your area here https://autismqld.com.au/page/family-support-groups

My Time offers a support group for parents and carers whose children have a disability. You can find the details of local groups here https://www.mytime.net.au/

Mental Health

Taking care of your child's mental health is very important. You can find out more about mental health, and where to find support, here https://headspace.org.au/

Anxiety is very common for young people with autism. You can find out more about autism and anxiety here http://www.positivepartnerships.com.au/en/fact-sheet/autism-anxiety