



Guidance
for Parents/
Carers with
a Recent
Diagnosis

The Effect of Diagnosis

Your child has just been diagnosed with an Autism Spectrum Disorder. You may have had concerns for a while and the assessment process may have prepared you to some extent for the confirmation you have just received. Or you may have been convinced that a mistake was made and your child doesn't have these difficulties. Regardless of where you are in the range of responses at this point, you will probably be experiencing many different feelings, reactions and thoughts.

No matter how prepared you are the chances are you are now worrying about the future, what next, and how on earth do you explain what you now know to others in the family, friends, your child's school, or your child? This fact sheet is designed to help you begin to understand you and your family's journey with Autism.

Many parents will say, 'what am I supposed to do now?' Some parents would say 'do nothing', some would say 'find out everything you can about Autism, services, rights and entitlements, interventions and therapies and start to fight for your child's needs to be met, while others might say 'how on earth can you manage to begin to help your child when you've suddenly entered a world of disability that you know nothing about?'

There is no right or wrong way to react. We all are different and how we deal with diagnosis differs from family to family and person to person. Other people in your family may well react completely differently from you. Some will try to lessen your distress by telling you he/she will grow out of it, telling you about the latest therapy to cure Autism or telling you the diagnosis is wrong.

Some parents experience a sense of relief at getting a diagnosis. For a number of years they may have experienced judgemental attitudes about their child's behaviour, with people believing he/she was spoilt, attention seeking or lacked discipline. As a parent you often know it's not because of these things that your child is behaving in a certain way. You might have realised that your child's reactions were because of how they were feeling, or experiencing the external world.

What Next?

If there's one piece of advice that can help at this stage it is 'don't panic'. That might be easy to say but harder to put into practice. Yes, you need to find out more about Autism, interventions, strategies, special education and future planning but getting a diagnosis is part of a journey that began when your child was born and will continue during your child's lifetime – 'the journey with Autism.' At times this is an interesting and fascinating journey and at other

times it can be very challenging. But it is a journey and not a race. Cramping your head full of Autism information from any and every source right now is not going to fix things, in fact more likely it will be information that you are not ready for, information that you are not able to judge whether it is accurate or not, or information that you will find frustrating or frightening.

So where do you start? Begin with understanding how your child's Autism affects them. Think back since your child was born, what were the signs that you misunderstood, what behaviours and reactions does your child have to situations and external stimuli? How have you adapted your life to lessen these reactions so far? Chances are you are already supporting your child in ways that you are not aware of. Often post diagnosis parents say 'But I don't know how to help my child' or 'I don't know anything about Autism' when in fact they have been living with and working with Autism in the family without realising it.

So the need at this point is not to start from scratch in your journey with Autism but to enhance what you already know.

The Uniqueness of Autism

Every individual who gets a diagnosis of Autism is unique. Not because they are disabled or because they have special needs but because they are individuals. How Autism shows itself to others is often through behaviours and reactions, particularly in situations that are social and involve contact or interaction with others. Autism is an invisible disability.

Not every child reacts in the same way to the same situation. So helping your child starts with understanding how they experience the world and its effect on them. Observing your child is crucial. Learning what led up to a behaviour is vital. Sometimes asking others in the family or friends what they see can be useful. They may find it easier to identify what behaviour your child exhibits that seems different or they can see triggers you haven't seen, because you are exposed to them daily.

Learning about diagnosis, how Autism is identified and what the Triad of Impairments are can help your observation skills. See Autism NI's 'Autism in Northern Ireland – The Facts' booklet for more information on this.

Why My Child?

When your child receives a diagnosis of ASD many parents want to know why, why their child and why their family? No one knows definitively at this stage why one child shows signs of Autism and another does not. It's

likely that there is not one specific reason why your child has Autism. It may be that a number of different factors came together at a specific time in your child's pre-natal development or at birth that meant your child would have ASD. Many parents want to find a reason, something they can blame. This might distract you from responding to your child's needs here and now.

Autism is a spectrum of developmental disorders. The mind of an individual with Autism seems to be wired differently to a neuro-typical brain, particularly in the area of the brain where social understanding develops. This means that people with Autism experience the social world and other people differently. The social world can be a very confusing and frightening place when you are not able to understand why things are happening and to comprehend the 'bigger picture', even within your own home. Fear and anxiety are often the triggers for the behaviours that your child exhibits. As a parent you can feel powerless to manage your child's behaviour. But understanding why they are reacting as they do means you can look to your child's environment and try to change the cause of the reaction. This doesn't mean that a child with ASD needs 'wrapped in cotton wool' and protected from any sort of stimulus in case that triggers a reaction. After all, your child also has to exist in the real world. However when your child is overloaded they are often unable to cope and will react, sometimes badly, to things or people around them. Teaching a child to cope and manage can take a long time, it has to be gradual and the child has to build their own confidence and control in coping in that situation.

Dual Diagnosis

When you received your child's diagnosis or prior to receiving it, your child may have been diagnosed with another condition. Often when ASD is present other conditions may be present also. Conditions such as ADHD, ADD, Dyslexia, Dyspraxia, Obsessive Compulsive Disorder, Tourettes Syndrome, etc. This fact sheet is unable to explore dual diagnosis but the same advice applies, don't overload yourself but do find out more about your child's other conditions and learn strategies to help them with those difficulties. Check out the 'Contact A Family' website, www.cafamily.org.uk for their online directory of conditions or contact the local office at nireland.office@cafamily.org.uk or ring 028 9262 7552 for more information.

Sibling and Carer Support

Often when a child is diagnosed the whole world seems to revolve around that child, attending clinics, meetings with the school, dealing with the benefit system etc. It can feel as though your entire day is filled with Autism.

It's important to recognise that you need a balance in your life, something outside of Autism. If you have other children they will have needs too. But at times it can feel as though you can't spread yourself across everyone's needs. Of course, last in this list may be you. Recognise that other children in the family need support.

Find out about Sibling Groups or Young Carers Groups in your area. Look to family and friends to give your other children some attention. You could also ask family or friends to look after the child with Autism and spend time with your other children yourself. Find time for you and/or your partner. See what, if any, respite might be available for your family. Register with the Carers Co-ordinator in your area to see what is on offer to help carers. Contact your local Health & Social Care Trust for details or check with local advice or disability services.

Managing Information

Throughout the assessment and diagnostic process you will have received appointment letters, copies of reports and some information leaflets. Now is the time to set up an information system to keep all this information together. As your child grows and develops you may well see different professionals for different needs and it can be confusing remembering names and professions. It's important to remember who's who and how to contact them. Any reports or information about your child's condition may be needed for other things, such as applying for Disability Living Allowance. Keep all this information together because it will be relevant, maybe not straight away but in the future.

Interventions

Often at this stage parents find out that there are a number of specialist interventions that might work for their child. It can be a minefield trying to understand and match an appropriate intervention to your child. At this stage parents are often vulnerable. Many interventions can adopt a 'hard sell' approach, with claims to cure Autism, and by making parents feel guilty that they are failing their child if they don't use a certain approach. Parents adopting some interventions embark on expensive training, travel to different countries to immerse themselves in the approach without examining if this the right approach for my child. It's important to research an intervention thoroughly.

1. Does this intervention make exaggerated claims?
2. Does this approach require intensive input from us as parents that doesn't fit with what we can manage as a family?
3. Is this intervention independently evaluated and scientifically proven to work?



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4. Could this intervention cause more damage to my child?
5. What have other parents' experiences been?
6. Can we afford this, and can we commit to this?
7. If my child's Autism is unique to them how does this intervention meet my child's needs? Is it adaptable, can it be tailored or is it one size fits all?

There's nothing worse than believing claims, spending lots of money, using a lot of time and energy, and finding that in the long run the difference an intervention makes is negligible or worse, damaging. Talk to the professionals who know your child, ask for advice and information, do your homework and if in doubt, avoid an intervention that doesn't fit with what your child or your family can manage.

Isolation

Living with Autism in the family can often be isolating. It is important to link with other parents to add to your knowledge. Other parents will have experienced the challenges you are experiencing. They can offer advice or tips and hints about what worked or didn't work for them. If possible, join a local support group. Log on to www.autismni.org to find out if a support group exists in your area. Just knowing you are not alone can be hugely supportive. Other parents will help you find the humour in living with Autism. Laughter is great therapy and being able to see the funny side of your experiences with your child will lighten your experience. Celebrate your child's place in the world and how they cope with the challenges of life. Other parents can give you insight into the future for your child. They can give you information of what services

Hope for the Future

Every child with ASD has potential. Many parents despair that their child will never talk, or they will

never achieve academically. What is certain is that children with ASD will surprise us, as they grow and develop. We cannot be certain what they will be able to achieve as adults and therefore we should never underestimate their potential. Look back to how much your child has already accomplished. Tapping into their potential is the key to helping them achieve in the future. Special interests can be where they find their niche in life. Never write off a child just because they have received a diagnosis. Celebrate what they can do and don't focus on what they can't manage.

Useful Resources

ACCESS Workshops Autism NI run a number of ACCESS workshops across Northern Ireland at various times. These free workshops are designed for parents with a recent diagnosis and provide an excellent introduction to Autism, interventions, benefits, and who's who in the range of professionals.

Useful Books

Autism:

The Facts by Simon Baren Cohen

Asperger's Syndrome:

A Guide for Parents and Professionals by Tony Attwood

Autism in Northern Ireland:

The Facts (Autism NI)

The Complete Guide to Asperger's Syndrome by Tony Attwood

The Handbook of Autism:

A guide for Parents and Professionals by Maureen Aarons and Tessa Gittens

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Useful Websites & Support

Groups

www.autismni.org: There is a comprehensive list of useful and well informed websites and details of Parent Support Groups available on this site.