

Parent / Carer Post Diagnostic Handbook

Helping parents at the start of their autism journey



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Introduction

At the North East Autism Society we know that getting a diagnosis for you and your child can often be an emotional journey. It can leave you with conflicting emotions, some of which you may never have thought possible. Many of our parents tell us that after the initial diagnosis they felt lost, alone, and didn't know where to go or what to do next.

We have created this guide to help you as parents/carers at the start of your 'autism journey' and have based it on the wisdom and experience of other families who are also finding their way along this path.

Your journey will be unique; therefore, we realise that the information in this booklet may not answer all your questions, but we do hope that it provides you with a positive starting point after diagnosis.

We would like to thank all the families who have contributed to the content in this handbook; without your contributions, this would not have been possible.

About NEAS



For over 40 years we've led the way in providing autism-specific care and education for children, young people and adults across the North-east of England.

Recognised for our innovation and excellence, everything we do stems from an unswerving belief in providing bespoke person-centred support. It's at the heart of who we are to recognise the uniqueness of every human being, and to understand that no two autistic people, or in fact any two humans, within an understanding of neurodiversity, will have the same needs or wants.

We passionately believe that autistic children and adults have significant skills and strengths, which can be developed throughout their lifetime.

Our approach aims to support individuals to participate in society as independent and valued citizens, enjoying equal rights and opportunities but also enriching the world around them.

Diagnostic Process

If you think your child may be autistic your first port of call will be your General Practitioner (GP). You may find it useful to write down all the observations you have made before the appointment and take it with you. If your child attends school, ask their teachers if they have made any observations that may be useful to share. You can also ask your child to share their experience with you prior to your appointment.

After listening to your observations your GP may decide to refer you on to an autism diagnostic service or specialist.

Please note according to NICE guidelines: 1.2.7 autism should not be ruled out on the basis of the following:

- good eye contact, smiling and showing affection to family members
- reported pretend play of typical language milestones
- a previous assessment, that didn't result in a diagnosis, if new information becomes available

Waiting for the assessment process to start can be a very difficult time for parents/carers, and you may feel overwhelmed. Remember that you are not alone, and even at this point it may be worth tapping into a support service such as your local carers organisation.

The autism diagnostic process should start within three months following a referral to the diagnostic team (NICE Guidelines 1.5.1). But be aware that in reality this may take longer due to demand.

The diagnosis process may involve:

- discussion with your child (where appropriate)
- observation of your child in a variety of settings
- detailed discussion about your child – you may be asked questions about your child's early years and family history
- an autism assessment tool, there are a variety of different ones that may be used. Some include ADI, ADOS, CARS, GARS
- other assessments (intellectual ability and learning style)
- physical Examination

Medical investigations are not routinely carried out as part of the autism diagnostic assessment, however genetic testing may be considered based on physical observation, and the child or young person's profile.

Be aware that there may be some uncertainty about the diagnosis, particularly in:

- children younger than 24 months
- children or young people with a developmental age of less than 18 months
- older teenagers
- children or young people with a complex cooccurring condition, sensory impairment (for example hearing or visual impairment) or a motor disorder such as cerebral palsy (NICE guidelines: 1.2.12)

The length of time the diagnostic process will take will depend on many factors and may vary between geographical areas.

Autistic people are individuals and like all people present individually; however, for a diagnosis to be made, a person will usually be assessed as having:

- persistent difficulties with social communication and social interaction
- restricted and repetitive patterns of actions, activities or interests (this includes sensory behaviours)
- these actions, activities or interests should have been present since early childhood, and to the extent that these “limit and impair everyday functioning”.



The clinical team may also identify the level of need a person has. There are three levels:

- requiring support
- requiring substantial support
- requiring very substantial support

This can allow the clinician to give an indication of how much the condition affects an

individual and how much support they need.

You may also hear the word 'specifiers' mentioned. This is so the clinician can identify additional or associated conditions e.g., learning difficulties, genetic conditions and other co-occurring conditions such as dyspraxia.

Please note a diagnosis of 'social communication disorder' may be given if your child doesn't display restricted and repetitive behaviour.

At the point of diagnosis, you should receive a written report which explains the findings of the assessment and the reasons for any conclusions drawn. You may be asked to give consent for the report to be shared with other key professionals involved in the child's life. It is important that other professionals know how to best support your child's needs.

You may be offered a follow up appointment within six weeks of diagnosis. If you are not offered this, you are within your rights to request one.

To find out more information about the diagnostic process, we recommend that you look at the 'Autism in under 18s: Recognition, Referral and Diagnosis (NICE clinical guidelines) this document outlines evidenced based recommendations and outlines what should happen and when.

Personal stories of diagnosis - Ed



My feelings when I received the diagnosis for Ed (then aged six) was initially one of relief as I had spent so many years trying to convince professionals that his behaviours weren't 'just normal toddler' quirks. This feeling was quickly replaced by confusion and a form of grief for the life I had previously imagined. I started thinking about GCSEs, college, university and family life. I woke up in the middle of the night questioning whether he would ever have any of this.

So many questions flooded my head and I felt like I couldn't ask them out loud to anyone. It was a very lonely time as although Ed hadn't changed, I somehow felt that I was now doing something wrong and was missing some vital information in order to help him. I soon realised I had two choices; be consumed by the guilt, and sadness I felt, or get informed and plan ahead. I chose option two. I became an insistent Googler (sometimes not always helpful) joined a family support group and found out as much as I could about autism. I also asked Ed what autism meant to him. I became an empowered parent and not only helped my own son but other families too.

Four years on, I look at Ed and think how proud I am of him and everything he has achieved. Yes, some days are harder than others... but he is worth it.

Personal stories of diagnosis - Alexander



Alexander was three when he started nursery. On the first day he ate the teacher's sandwiches and flooded the bathroom. From that day he was the 'naughty boy.' Everyday my poor mam, who picked him up for me, was hauled in and told about the series of events that occurred that day.

Apart from having a student on a work placement with me for a week at work, I had limited experience of autism. So, when Alexander started showing quite a few traits, to me he was just a bit quirky. He was obsessed with trains, knew everything there was to know about them, and we lived at the local train museums.

We would go to model train shows and he just used to stand and watch the displays going round and round. He grilled the owners about it sometimes, they would move on to another display when their patience was wearing thin.

He also didn't have a local accent and spoke really posh. The main thing for me was the bouncing. First thing in the morning and last thing at night Alexander would bounce and I just called it getting his 'bounce out'. He bounced all the way on metro journeys and in the cinema, so much that people often asked us to move or moved themselves.

I started internet searching all his traits and autism kept popping up. Then in January a new teacher started at the nursery and we did not know that she had a background in working with autistic children. She asked us in for a meeting and told us her concerns and what things she was going to put in place, she was like a breath of fresh air. The school put in a referral to the Educational Psychologist, and we put in a GP referral and lucky for us they both happened the same week and they both said without a doubt, he was autistic.

The hard bit for us was trying to explain to family members when you know nothing yourself. We had one big, massive learning curve and just learned from our mistakes. We knew not to use the hand dryers in the toilets, not to go in busy pubs or restaurants, check what was going to happen at children's birthday parties before we went, discos and anything "Frozen" was a no go as he took an instant hate to both characters.

Alexander has no fear; he can't tell the road from the paths and bounces on everything like it was a trampoline, so we were advised to put in a referral to the play therapist which we did. We learned so much about Alexander. It was wonderful. We got loads of tips on the type of play he liked, which involved spinning and swinging, which he never gets dizzy from.

Alexander has gone from one obsession to another obsession, and we have hundreds of trains and transformers that will probably never be played with again but I dare not throw them away just in case they come round again.

Alexander is now doing really well at school and has a group of friends who don't see him as any different from them.

I don't think I would do anything differently as we have met some great people and made contacts with certain agencies we wouldn't have if we had been spoon fed everything. One thing is for sure no one forgets Alexander and he entertains me every day.



Personal stories of diagnosis - Aidan



Aidan was diagnosed with autism in October 2013 when he was nearly four years old. Looking back, it was a quick process of six months but at the time it felt like forever. As a family we knew nothing about autism, and it took a close family friend who works with children with additional needs to suggest we put Aidan through the assessment in the April of 2013.

Although it was a shock it answered a lot of questions about behaviours, sleep, fussy eating, not settling at nurseries... and what I know now as sensory issues. The suggestion of autism came at a good time for me, I was at breaking point thinking I just wasn't cut out to be a mum.

A hearing test initially ruled out any problems in that area and we moved on to see a general paediatrician who saw a lot of autistic traits, so passed us on to see an autism specific paediatrician. We put his name down for an early support nursery for children with additional needs. Whilst waiting we got portage, so a worker came out to see us weekly with educational tasks and games for Aidan and got to know him. An educational psychologist also came to the house to assess Aidan's needs and realised quickly that his seemingly good vocabulary and conversation was just delayed echolalia from his favourite TV shows.

The multi-disciplinary meeting (MDT) was a little daunting with all of the professionals in attendance and my biggest fear was not getting a diagnosis and being left to flounder with no support. As it was, everyone was in agreement that Aidan was autistic. This opened up access to an autism course to teach parents more about young children on the spectrum which, more than anything, was helpful to meet other parents in similar positions.

The diagnosis in the end was a huge relief and the start of a new chapter and learning curve for us all.

Top Tips (for parents from parents)

After diagnosis:

- Before, during and after diagnosis you may experience lots of different feelings. Know that this is ok and allow yourself time to process them.
- Knowledge is power, so start finding out as much as you can about autism from reliable sources.
- Learn from the autistic community, they can give a real-life insight into the experiences of autistic people. Remember autistic adults were once autistic children.
- Spend time watching your child and engaging with them on their level, so that you can find out what is important to them.
- Make yourself familiar with places that are aiming to be 'autism friendly'.
- Join an online support group. They often give you the chance to ask questions to other people in a similar situation. NEAS has an online Facebook group called Family Networking, which you may find useful. Search for 'North East Autism Society -Family Networking¹ on Facebook.
- Join a support group in your local area. These are usually very friendly informative groups where you can spend time with people in a similar situation to yourself. A parent of a group that we run tells us: "It's a breath of fresh air, to be around people that know what I am going there for. It's lovely to know that I have a place where I can ask any questions I need answering".
- Plan ahead, in small steps. One parent told us: "sometimes it's about getting through the day, other days it's about getting through that moment, there and then."
- Choose your battles. You are only human and some days you will feel stronger than others.
- Check out what is available through your council's 'local offer'. This is a directory of services in your area and can be found on the internet by typing in (town/city) then 'local offer'.
- Celebrate the achievements. Even if others around you think they are small and insignificant as they may be massive for you and your child. Take photographs of these moments and when things get tough have a look at them.
- Approach 'Doctor Google' with caution. There can be lots of negative and unhelpful information on the internet.
- Keep a diary with important appointments in and a notebook to write up important information from meetings. You may want to record meetings

using 'voice memos' on your smartphone but permission from all attending must be sought first.

- Be cautious around anyone offering 'cures for autism'. Autism is a difference in neurology and cannot be cured.
- Request a copy of the minutes from meetings that you attend and put them all together in a file.
- Be prepared to hear a lot of advice you didn't ask for.
- Work together with other agencies and find out what is available in your local area.
- Always consider the possible impact of environments on your child. Many autistic children can have a difference in how they process sensory information and this can cause confusion, distress and sometimes pain.
- Try to become a behaviour detective. It may be the tiniest of things that's causing a problem for your child. Keep a behaviours diary so you can start to track behaviour and find potential triggers.
- Make a priority list of things you need to do and deadlines.
- Enjoy spending time with your child!

Please remember that your experience is individual and may be different to that of other families. Be careful not to fall for 'text book narratives'.



Telling others about your child's diagnosis

Telling other people about your child's diagnosis is a personal decision and you should not feel pressurised into doing so.

Public awareness around understanding autism is increasing and it is likely that the person you are telling may have heard about autism already. There are however still a lot of misconceptions and misinformation, and autistic adults are often fighting for the right to be accepted in society. Explain to the person about your child as opposed to a text book clinical version of autism.

Initially you may feel anxious about going out into the community with your child, worrying about other people's perceptions. Often, over time, this worry will reduce, and you may find yourself with a 'so what' approach to other people's judgements.

Remember that we are living in an inclusive society, therefore, it's about changing the perception of others and the environments, as opposed to changing our children. Your child has the right to live in a world where they are valued and accepted. Never forget that!

What is autism?

For many parents the word 'autism' may be a new term and after receiving a diagnosis many are left wondering what autism is. For the purpose of this handbook, we have put together some brief information but it is important to note that autistic people can present in many different ways due to many different factors and your child is unique like every other human being.



Key information about autism

- Autism is an unchanging neurological difference, and increasingly believed to be genetically related
- Autistic adults were once autistic children and autistic children will become autistic adults
- Research published by Newcastle University in 2021 suggests that around one in 57 (1.76%) children in the UK will be autistic. In our experience, serving autistic people and their families for 40 years, and from new research trends and beliefs, we estimate this to be much higher
- Some autistic people may appear inflexible in their thinking, this is often driven by anxiety
- Being neurologically different does not make autistic people less than, broken, damaged or wrong
- Sensory issues can make up an enormous part of an autistic person's profile. These can sometimes be debilitating.
- There are some conditions that are commonly present in autistic people. It is important to remember that co-occurring conditions are not autism, but can impact greatly on a person's life

Differences in autism

Communication and social interactions

Communication differences will vary from person to person. It may be that your child has a vast array of language but struggles to understand what others are saying, whereas your child may use no language but has an excellent level of understanding. Remember that just because someone doesn't use verbal language it doesn't mean they can't communicate. Everyone communicates in their own way.

Common differences to non-autistic communication styles include:

- Differences in the interpretation of humour and figures of speech
- Difficulty maintaining eye contact
- Differences in autistic body language
- Differences in perspectives – neither is necessarily wrong

Processing

There is a part of the brain responsible for executive functioning. This is a little bit like the conductor in an orchestra or the air traffic control centre at a busy airport. We all need these executive skills to complete the most basic of tasks like making a cup of tea or sending an email.

Executive functioning skills include the following:

- inhibition (thinking before you act)
- working memory (holding information in memory, while completing tasks)
- emotional control (ability to manage emotions, to achieve goals) attention
- task initiation (ability to start an activity) planning/prioritising
- organisation
- Flexibility



Many autistic individuals can have executive functioning difficulties.

Examples of these include:

- John arriving at school having forgotten his packed lunch box, swimming kit and school bag
- Emma is given an instruction in class but can't remember it long enough to complete the command
- Lisa spends two minutes on a jigsaw, she doesn't complete it and instead goes to the painting table to start a picture

Sensory

Many autistic people have difficulty processing everyday sensory information. The senses may be hyper sensitive, which means they are overly sensitive to stimuli, or hyposensitive which means they are under stimulated. These sensory differences can have a massive impact on a person, and you may see them acting differently to what you would expect because of it.

For example:

If a child is hypersensitive, they may not be able to tolerate certain noises, have difficulty wearing certain clothes and refuse to eat certain foods.

If a child is hyposensitive, they may be constantly on the move, eat inedible objects and make lots of noise.

Please note that the examples given here are just to give you an idea. There are many more behaviours your child engages in which could be because of sensory differences. The best person to get involved from a sensory perspective would be an Occupational Therapist with specific training in autism.





Who does what?

Before, during and after the diagnostic process you may be involved with a variety of different professionals from many different areas. Parents have told us that this can sometimes be overwhelming and confusing and, in some cases, may not fully understand the professional's role and how this may be able to help them.

We've put together a list of some of the professionals you may meet along your autism journey.

General Practitioner (GP)

For some this may be the first step to getting a diagnosis for your child. GPs are responsible for the general health of their patients and can make referrals into specialist services.

Speech and Language Therapist (SALT)

The main role of the SALT is to assist and support people who have communication difficulties. This can include supporting them to communicate in different ways.

Occupational Therapist (OT)

OTs can work in a variety of different environments but for you it will be an OT that understands sensory differences in autistic individuals. The OT will help to identify sensory differences and advise on therapeutic approaches.

Health Visitor

Health Visitors are trained nurses who specialise in the development of preschool children. In some cases, they may be the ones to highlight any concerns about development.

Portage Worker/ Portage Home Visitor

Portage Workers provide a home visiting service for preschool children with additional needs. They also run groups in certain areas.

Family Support Worker

The role of a family worker is to give emotional and practical advice to families experiencing short- or long-term difficulties.

Child and Adolescent Mental Health Service (CAMHS)

The CAMHS offer a range of therapeutic services for children, young people and their families who experience moderate to severe emotional / mental health problems (for example self-harm, depression, anxiety, bipolar). Direct therapeutic work offered includes cognitive behavioural therapy (CBT), group work, play therapy and family therapy. They may be involved in the initial diagnosis but don't usually provide post diagnostic support around autism.

Children and Young People's Service (CYPS)

CYPS provides a single service to all Children and young people aged 0-18 years living in South Tyneside, Newcastle, Northumberland, Gateshead and Sunderland who present with mental health difficulties. CYPS are a tier three service where as CAMHS is a tier two service. Depending on the level of need you may be referred to CYPS if you live in one of the above areas.

Clinical Psychologist

Clinical Psychologists are involved in the diagnostic process and can provide recommendations for support

Educational Psychologist

Educational Psychologists would consider the child's development from an educational perspective and may also be involved in the diagnostic process.

Paediatrician

A trained doctor with a specialist in childhood development

Early Help

Early Help is a service that offers families advice, support and interventions at the earliest point of identified needs. Early Help supports families by providing strategies to implement before problems escalate, therefore, decreasing the chances of the family needing a statutory intervention.

Social Worker

Social Workers will assess you and your family's care needs. If you were eligible, they would be able to advise you on a range of services including respite provision. Social Workers work across a variety of settings, the one your family would most likely be involved with would be from the Children's disability team.

Special Educational Needs Coordinator (SENCO)

A trained teacher who is responsible for ensuring the school follows the SEN code of practice for all children in the school who have additional needs. The SENCO would be heavily involved in any implementation of Education, Health, Care Plans (EHCP).

Physiotherapist

Physiotherapists work with anyone experiencing problems which affect movement, using exercise and massage techniques.

Music Therapist

Music therapy is an established clinical intervention which is delivered by registered music therapists.

Play Therapist

Play therapists work with children, using play as a communication tool to help children understand the world around them.

Geneticist

A Geneticist is a biologist who studies genetics, the science of genes, heredity and variation of organisms.



How to access services

Local offer

The children and families act (March 2014) requires local authorities to publish a local offer, setting out all in one place information about provision they expect to be available for children and young people in their area who have SEN. Each area's local offer may be named something different, to find your local offer it is best to do an internet search for local offer followed by the name of the local authority you are looking for.

Social Care

Every local authority children's services department provides social care. This can include things like overnight short breaks, access to holiday clubs, and help in the family home. If you feel you need these services, you should contact your local authority Children's Social Care team. You will be asked several questions to see if you are eligible for the service and a more detailed assessment may be carried out.

Occupational Therapy

Occupational therapists can play a vital role in providing valuable insight into your child's sensory needs and regulation. They will help identify sensory differences and develop strategies to best meet your child's needs. Occupational therapists are often involved in the diagnostic process, but it may be that you need some support after diagnosis, or later, which may mean that you need to be referred into the service. To access occupational therapy a referral must be submitted from a professional from health, social care or education. For example, a health visitor, GP, social worker or teacher. This is unless you go to a private occupational therapist which you can self-refer too. For more information on how to access occupational therapy in your area speak to your GP or contact your local council.

For more information visit - www.nhs/conditions/social-care-and-support-guide

Speech and Language Therapy

It's likely that you will have been involved with a speech and language therapist throughout the diagnostic pathway, and you will have been given strategies to best support your child. We recognise that children's needs change and sometimes you may need to get back in touch.

Most authorities accept referrals from parents and professionals that know the child.

To find out more speak to your child's health visitor, teacher, GP or other professional involved in your child's life. Or use the following links to find out more:

Durham, Darlington, Stockton and Hartlepool - www.nth.nhs.uk/services/speech-language-therapy/children/

South Tyneside / Sunderland - www.stsft.nhs.uk/services/speech-and-language-therapy

Gateshead - www.qegateshead.nhs.uk/services/childrens-speech-and-language-therapy

Newcastle - www.newcastle-hospitals.nhs.uk/services/speech-and-language-therapy/childrens-speech-and-language-therapy/

Northumberland / North Tyneside - www.northumbria.nhs.uk/our-services/childrens-services/childrens-therapies/childrens-speech-and-language-therapy#31c98216

Middlesbrough / Redcar and Cleveland - www.southtees.nhs.uk/services/children-and-young-people/community/speech-and-language-therapy/



Education

Choosing the right education for your child is a big decision and you would be right to explore your options and ask lots of questions.

There are several different types of schools available but remember the choice of school will be based on lots of information:

- Mainstream school – with or without additional support.
- Enhanced mainstream provision (EMP) – this is a mainstream school with enhanced provision, for example, onsite access to therapies.
- Specialist unit within a mainstream school – children are based in a specialist unit but can access the rest of the school as appropriate.
- Home education – home education is increasingly becoming more of an option for autistic children. For more information have a look at <http://edyourself.org/>
- Specialist school – Specialist schools may cater for children with a variety of additional needs or could be specifically for children with an autism spectrum condition diagnosis.
- Residential school – Children stay at the school on a weekly or termly basis.



When looking for schools in your area we would recommend looking at your local authority's local offer website as this should list all Ofsted registered education provisions

in the area. We would also recommend reading the most recent Ofsted report for the education setting you are looking at.

Education, Health and Care Plans

I keep hearing about EHC plans, what are they?

An **EHC plan** is a legal document that describes a child or young person's special educational, health and social care needs. It explains the extra help that will be given to meet those needs and how that help will support the child or young person to achieve what they want to in their life.

Does my child need an EHC plan?

The local authority must carry out an EHC needs assessment if they believe your child's needs may require more help than a mainstream education setting can initially provide.

How do I get an EHCP?

You, your child or the education setting can make a request to carry out an EHC needs assessment although the local authority can refuse if they don't feel that an assessment is needed.

The EHC process can be daunting and confusing and we would recommend you get advice and support to help you.

Each local authority has a dedicated team, to give specialist advice around Education.

Durham	0191 5873541 www.durhamsendiass.info.uk
Gateshead	0191 4784667 daiss@barnardos.org.uk
Newcastle	0191 211 6255 sendiassadmin@newcastle.gov.uk
South Tyneside	0191 4246345 sendiass@southtyneside.gov.uk
North Tyneside	07792 008 890 0191 643 8313 sendiass@northtyneside.gov.uk
Northumberland	01670 623555 / 01670 620350 iass@northumberland.gov.uk
Sunderland	0191 537 5764
Stockton On Tees	01642 527158 SENDIASS@stockton.gov.uk
Darlington	07930 303213 / 01325 405878 iass@darlington.gov.uk
Middlesbrough	01642 300774 EX: 225 southteessendiass@barnardos.org.uk
Hartlepool	01429 284876 HARTLEPOOLIASS@hartlepool.gov.uk
Redcar	01642 444527 SENDIASS@redcar-cleveland.gov.uk

Grant information

As a busy parent it can sometimes be difficult to have the time to research what grants you could apply for. Some of our parents tell us they are at a total loss and don't know where to begin. With this in mind we asked some of our families to tell us about some of the grants they have used in the past.

Please note each provider will have their own eligibility criteria

<p>Family Fund - Contact Info: 01904 550055 info@familyfund.org</p>	<p>Details - One of the biggest charities, providing grants for families with autistic children.</p> <p>For children under 17 and living in England you can apply once a year certain eligibility criterion applies, can be used for sensory equipment, games, books, music, kitchen appliances, recreation and household, day trips, computers and family breaks.</p>
<p>Merlin's Magic Wand - Contact Info: www.merlinsmagicwand.org</p>	<p>Details - Provides free days out to Merlin attractions across the UK. Applications are welcome for children aged two-18 with life threatening illnesses and disabilities.</p>
<p>Sunshine Fund- Contact Info: 07593 298 541 Bev.Wright@thesunshinefund.org</p>	<p>Details- Provides equipment to hundreds of disabled children in the North-east every year.</p>
<p>AbleKidz Contact Info: 0300 365 4102 info@ablekidz.org</p>	<p>Details- Provides grants for specialist learning equipment, IT equipment and specialist software.</p>
<p>Greggs Hardship Fund Contact Info: 0191 212 7626 grants@greggsfoundation.org.uk</p>	<p>Details - Can apply for up to £150 of household equipment</p>
<p>Jessie's Fund Contact Info: 01904 658 189 info@jessiesfund.org.uk</p>	<p>Details - Charity supporting children with additional complex needs, to develop communication through music.</p>

	Priority will be given to children who are none verbal
Cauldwell Children Contact Info: 0345 300 1348 charity@caudwellchildren.com	Details – Provides charity funded assessments, sensory packs and therapies as well as specialist equipment grants
Children today Contact Info: Childrentoday.org.uk 01244335622	Details - Provides grants for specialist equipment such as aids, educational resources, and trikes.
Boparan Charitable Trust Contact Info: 01212149373	Details – Provides funds towards specialist equipment such as trikes, sensory toys, books and computer equipment. Can also provide funding towards therapies such as speech and language therapy.
Remembering Rebecca Contact Info: https://www.rememberingrebecca.co.uk/	Details- The charity offers financial assistance, specialist equipment grants as well as respite breaks to children, from birth to 16 years, with Lissencephaly and other neurological conditions.
Tabitha’s Toys Contact Info: Info@tabithastoys.org www.tabithastoys.org	Details - The aim of the charity is to loan out specialist toys to children that may need them. For example bubble lamps and fibre optics

Benefits

You may be entitled to claim certain benefits such as Disability Living Allowance and Carer's Allowance.

For more information on what you may be entitled to and to try out the free benefits calculator visit: www.directgov.uk or www.turn2us.org.uk

Entitlements

Disabled Persons Railcard

You can apply for a railcard if your child is in receipt of/or is diagnosed with:

- personal independence pay (PIP)
- disability living allowance (DLA)
- assistance allowance (AA)
- visual/hearing impairment
- epilepsy

The railcard costs £20 per year and will give you 1/3 off train tickets for the disabled person and the adult travelling with them. If your child is aged 5-15 they can still have a railcard but it will only be eligible for the adult travelling with them.

For more information check out: www.disabledpersons-railcard.co.uk

Disabled Persons Bus Pass

Contact your local authority to find out which agency issues bus passes in your area as part of the English National Concessionary Travel Scheme.

Local authority website details:

www.gateshead.gov.uk

www.newcastle.gov.uk

www.northumberland.gov.uk

www.durham.gov.uk

www.southtyneside.gov.uk

www.sunderland.gov.uk

www.hartlepool.gov.uk

www.darlington.gov.uk

www.stockton.gov.uk

www.middlesbrough.gov.uk

www.redcar.gov.uk

Radar Key Scheme

The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the country. Toilets fitted with National Key Scheme (NKS) locks can now be found in shopping centres, pubs, cafés, department stores, bus and train stations and many other locations in most parts of the country.

RADAR keys can be bought from reception at Disability North. They cost £2.65 if purchased in person from the centre or you can order a key by post by sending a cheque or a postal order for £3.65 made payable to Disability North. Please remember to enclose your name and address.

For more information call: **0191 2840480**

Cinema Exhibitor cards (CEA)

The CEA Card is administered and run by The Card Network. The card allows carers to get in to the cinema free.

The card costs £6.00 and has to be renewed on an annual basis to apply for the card you will need to be in receipt of the Disability Living Allowance, Attendance Allowance or Personal Independence Payment. You will be asked to provide a doctors letter outlining the child's disability.

Please note the card is only available for children aged five and above. To find out more about the card contact: 01244 526 016 or check out www.ceacard.co.uk

The Max Card

The Max Card is designed to make days out more financially accessible for families of children with additional needs. It offers discount, at over 1500 attractions UK wide.

For more information check out www.mymaxcard.co.uk or contact at hello@mymaxcard.co.uk or phone 0113 3947 951

The Hidden Disabilities Scheme

Not all disabilities are visible – some are hidden and not immediately obvious, such as learning difficulties, mental health as well as mobility, speech, visual or hearing impairments. Living with a hidden disability can make daily life more demanding for many people, but it can be difficult for others to identify, acknowledge or understand the challenges you face.

Be visible when you want to be wearing the Hidden Disabilities Sunflower discreetly indicates to people around you including staff, colleagues and health professionals that you may need additional support, help or a little more time.

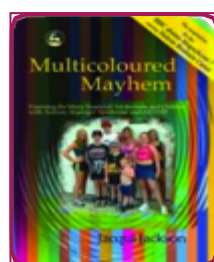
For more information visit: <https://hiddendisabilitiesstore.com/>

Recommended books for parents from parents

We asked our families to tell us about a book that was useful to them and why. Please note that every child will be different and some of the books tell an individual story and may not accurately reflect the experiences of your child. If you are going to be reading the book with your child make sure you read it first to avoid any confusion.



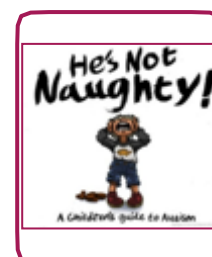
Two really inspirational books, written by someone who is autistic. It gave me a real insight into the way someone with autism sees the world



This book made me feel like I am not the only one trying to juggle all the demands of family life, while bringing up autistic children. I found it really refreshing



I have used this book, to try and educate other family members about my son.



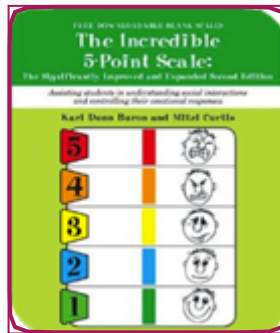
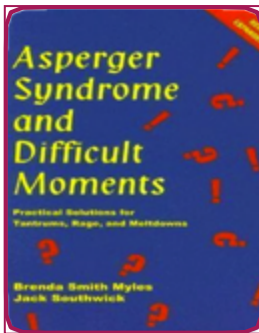
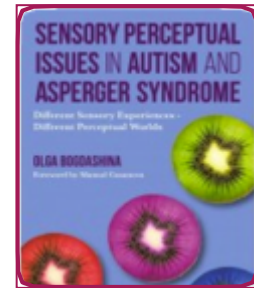
Hands down this book. It made me evaluate and change my approach to dealing with my son and how to communicate with him better. It's hard to describe how much this changed my view on autism



I found both these books really easy to understand and taught me so much about why my child does certain things.



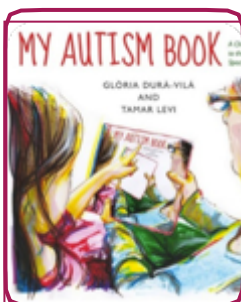
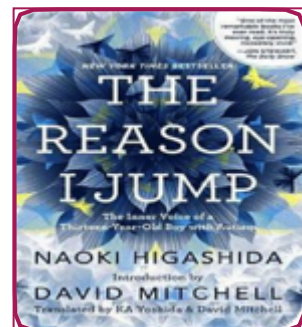
My son had dreadful anger issues and this book helped me to understand and manage them.



Brilliant..... This book helped me understand my child much better



I recommend this book because it's written by an autistic boy. It was so nice to hear things from his point of view to help us parents understand the reasons our children struggle as they do or behave in a certain way.



We found this book the very best. It explains why my son feels and acts the way he does to himself, it also shows positive traits of being autistic which I feel is vitally important.

Recommended Websites

www.disabilityrightsuk.org

Provides information regarding your rights and entitlements as a parent of an autistic child.

www.autism-alliance.org.uk

Autism Alliance is the major UK network of specialist autism charities.

www.mumsnet.com

Provides forums and chat facilities to link with other parents in similar situations

www.cerebra.org.uk

Cerebra provides information for families on many topics in the form of a selection of handbooks. They also have a sleep service and a lending library where you can borrow books and sensory equipment.

www.ipsea.org.uk

IPSEA stands for Independent Provider of Special Education Advice. They offer free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND). We also provide training on the SEND legal framework to parents and carers, professionals and other organisations.

www.skybadger.co.uk

Sky badger is a charity that finds help and adventure for disabled children and their families all over the UK. We do this by building bridges between disabled children and the charities and services available to help. We find everything from disabled sports clubs to sibling groups to 'make a wish' charities and tell families about them through our website, social media platforms, videos, information packs and helpdesk

www.specialneedsjungle.com

Many families do not get the help they need because they do not know where to look or how to cut their way through the increasingly complicated system. Special Needs Jungle aims to highlight resources and inspire and empower families to do this successfully by providing resources, tips, facts and examples.

www.theautisticadvocate.com

This website incorporates Kieran's experiences as an Autistic person and an Autism Professional but, much more importantly, it is a place of collective stories, reflecting on the barriers facing Autistic people. It addresses the negative narrative of Autism, focusing on Autism as an Identity, as an acceptable Neurology, while at the same time addressing the aspects of being Autistic that can be disabling, both by society, but as a Disability too.

It's a resource for Autistic people, Parents and Professionals to help you understand various concepts around Autism, get practical advice and take on the highly valuable inside perspective.

Key documents that you may find useful

United Nations Convention in the Rights of the Child (UNCRC)

The UNCRC is a legally binding international agreement setting out the civil, political, economic, social and cultural rights of the child regardless of their race, religion or disabilities.

The guide can be viewed at www.savethechildren.org

Special Educational Needs Code of Practice (SEN COP)

The SEND code of practice provides statutory guidance on duties, policies and procedures of local authorities in relation to the educational provision and support to children and young people with special educational needs and disabilities.

The guide can be viewed at www.gov.uk

NICE Guidelines

The Nice Guidelines are evidence based recommendations for health and care in England. The NICE autism guideline covers recognizing and diagnosing autism in children and young people.

The guideline can be viewed at www.nice.org.uk/guidance/cg128

The Equality Act

The Equality Act replaces previous discrimination laws with one single act. This act has nine protected characteristics including disability, sex and age.

The act can be viewed at: [Equality Act 2010: guidance - GOV.UK \(www.gov.uk\)](http://www.gov.uk)

Useful contact information

Organisations providing autism specific services

Organisation	Address	Contact Details
North East Autism Society	15 Lumley Court, Drum Industrial Estate, Chester Le Street, DH21AN	0191 410 9974 info@ne-as.org.uk
Main Project	11th Floor, 73-75 Albert Road, Middlesbrough, TS1 2RU	01642 608012 info@iammain.org.uk
Daisy Chain	Daisy Chain, Calf Fallow Farm, Calf Fallow Lane, Norton, Stockton-On-Tees, TS20 1PF	01642 531248 info@daisychainproject.co.uk
Toby Henderson Trust	The Toby Henderson Trust. Earth Balance, Bedlington, Northumberland, NE22 7AD.	0300 365 3055 support@ttht.co.uk
Autism In Mind	Autism In Mind Suite 305, The Place Business Centre, Athenaeum Street, Sunderland, SR1 1QX	0191 567 2514 info@autisminmind.com

Community Activity Centre's

Organisation	Address	Contact Details
The Tim Lamb Centre	Rising Sun Country Park, Whitley Road, Newcastle Upon Tyne NE12 9SS	info@pathways4all.co.uk 0191 266 5233
The Alan Shearer Centre	West Denton Hall, Newcastle Upon Tyne NE15 7LU	enquiries@alanshearercentre.org.uk 0191 267 8118

To find out about local support services and groups going on in your area, please give the family development team a call on 0191 410 9974.

Carer's Support

Each local authority will have its own parent/carer forum group, these groups are for parents and carers of children with Special Educational Needs (SEN) and disabled children aged 0 – 25. They may provide things such as:

- Advice
- support at meetings
- training courses
- short breaks support
- complimentary therapies
- carers emergency card
- carers discount card
- coffee mornings and meet ups

Group	Contact Details
Gateshead Parent Carer Forum	info@gatesheadparentcarerforum.co.uk
Newcastle Parent Carer Forum	contact@newcastlepcf.co.uk
Northumberland Parent Carer Forum	enquiries@npcf.co.uk
North Tyneside Parent Carer Forum (NTPCF)	0191 4060018 info@ntpcf.co.uk
South Tyneside Parent Carer Forum	info@stpcf.org
Making Changes Together (Durham)	0191 587 3541 info@mctdurham.co.uk
Sunderland Parent Carer Forum	07393129858 SPCFoffice@sunderlandpcf.co.uk
Stockton Parent Carer Forum	07985245668 info@stocktonparentcarerforum.co.uk
Parents 4 Change (Middlesbrough)	01642 956742 / 07975 621843 info@parents4change.co.uk
Together For Better Darlington Parent Carer Forum	07956 531351 info@darlingtonpcf.co.uk
1 Hart 1 Mind 1 Future (Hartlepool)	07896 054361 HartMindFuture@yahoo.co.uk
SEND Family Voice, Redcar and Cleveland	infosendfamilyvoicerc@gmail.com

As well as parent carer forums there are independent charities based within each local authority offering young and adult carers support. To find your local carers charity visit <https://carers.org/help-and-info/introduction>

Family Resources... Free, For You



Made possible from a wealth of experience gathered over four decades serving the North-East we've created a Family Resources section of our website just for you.

Brought together by our Family Development team, members of our Neurodiversity think tank and from families sending us their tips and advice we've put together a bank of free resources to help you, as part of our valued community, to navigate the day-to-day challenges of life.

These are by no means exhaustive in their approach, but instead offer 'nuggets' of wisdom or hints and tips that may just be enough to aid with the small victories we all aim for each day.

Whether you are autistic or recognise one of the many Neurodiverse differences in yourself, or you are a family member or friend of someone who would benefit from having additional support, we've tried to keep this as simple as possible to make it as accessible as possible.

To begin with there will be a few sections populated but our aim is to continually add to this providing what we hope will be a comprehensive free resource for anyone who will need it.

Social Media

Many of our families use social media as a way of keeping up to date with current information and to communicate with others in similar situations. There are many Facebook groups in circulation and sometimes it can be difficult to know which ones to join.

We asked some of our parents which ones they would recommend and have compiled the following list:

- North East Autism Society Family Networking
- Gateshead Autism Information Hub Group
- Autism Parents South Shields
- Autism Parent Support Group County Durham
- Durham Neurodevelopmental Family Support Hub
- Autism Support North East (Parent, Carers, Educators)
- Support for Parents, family and friends of Autistic Adults (SPAA)
- Autism Parents Teesside
- Autistic North East
- North East - Act Now For Autism (Tyne, Tees, Wear and Northumberland)
- Sensory Processing Disorder Parent Support Group North East England
- Little Treasures Autism Charity (parent/carer support page)
- SPARCS (Support for Parents Living with Autism and other related conditions)

Recommended Blogs



The Life of Reily, autism and us.
www.thelifeofreilly.org
a blog written by a mum of this little boy.



www.daddyfool.com
a blog written by the dad of this boy.



The Autistic advocate
www.theautisticadvocate.com



Final Note

We hope that this booklet has been useful for you and your family and it has helped you at the start of your autism journey.

Among all the text books, the reports, the meetings and the terminology we can sometimes forget that our children are much more than an autism diagnosis.

The world can be very challenging for autistic people. There is no one-size-fits all service, group or organisation that can eliminate the many challenges, but there is always a vast support network and many positives – other individuals and families experiencing autism, inclusive social and leisure groups, funding and grants, professional services and people who know autism. Having an autistic loved one and being autistic can be extremely isolating because of the many myths and unfounded stigma in the world.

The first step is to reach out...





Contact us

North East Autism Society
Unit 15 Lumley Court
Drum Industrial Estate
Chester-Le-Street
County Durham
DH2 1AN



0191 410 9974



info@ne-as.org.uk



www.ne-as.org.uk



north east
autism society