

**Talking together about an autism diagnosis:
a guide for parents and carers**



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Dear parent/carer,

Following an assessment completed by the Neurodevelopmental Assessment Team at North Lincolnshire CAMHS, your child has received a diagnosis of Autism Spectrum Disorder (often referred to as Autism, ASD or ASC).

What does this mean?

Autism is a term used to describe a spectrum of presentations and level of need. There are around 700,000 people with autism in the UK, which is more than 1 in 100 people. Autism is characterised by difficulties in social interaction and communication, restrictive and repetitive behaviours and specific interests. Despite these areas of difficulty, people with autism still have lots of strengths in other areas. Please see your child's assessment report for details on identified areas of strength and needs.

What next?

Having a diagnosis of autism is an opportunity to understand your child and learn about their strengths and needs. Every child and adult with autism is different and this will impact how they manage the world around them.

A diagnosis of autism may also help your child, your family and you receive support that you may need. This may include support with areas of difficulty and help in school. We have made a list of recommendations following the assessment, which are in your child's assessment report.

Now that the assessment is complete, your child will be discharged from the assessment pathway.

What if I have more questions?

We have provided you and your child with an information pack, alongside the assessment report, which includes lots of information about autism, where to look for advice and the support available to you. Your child's school's SEN co-ordinator (Special Educational Needs) may also be able to answer questions.

Yours sincerely,

North Lincolnshire CAMHS Neurodevelopmental Assessment Pathway

Thank you for coming to see us at CAMHS. After looking at all the information we learnt about you, we have agreed that you are autistic.

What is autism?

Autism's proper name is Autism Spectrum Disorder, which can be shortened to ASD. When people have autism, we can say that they are autistic.

- Lots and lots of people have autism in the world.
- You cannot tell if someone is autistic by looking at them.
- Autism is not a disease. It is something that people have all their lives.

Every person who is autistic is different. Some people need more help with things than others. But every autistic person has special skills and things that they are really good at.

What does this mean for me?

Knowing that you are autistic means that the people around you can learn more about what you need and what you're brilliant at.

You may also be able to get more help in school or at home.

What next?

If you need more help with how you're feeling or things that you're finding difficult, you may meet more people in the future. They might be at school or other places.

How can I get help?

It is important that you tell an adult who you can trust if you think you need some help or if you're finding something difficult. It doesn't matter if the problem seems too big to manage or too small to talk about. You could tell someone in your family, or a teacher. They can then make sure you get the right help.

North Lincolnshire CAMHS Neurodevelopmental Assessment Pathway 2020

Please note: we have chosen to say that someone is autistic, rather than say they 'have autism'. This is to promote and validate neurodiverse identity - recognised as Identity - First Language by the Autism Self Advocacy Network. We understand that this term may not be for everyone, so please tell those around you if you find a term that works best for you.

Neurodiversity

Neurodiversity means variations of the brain.

This means that there may be some differences with learning and thinking.

But brain differences are normal.

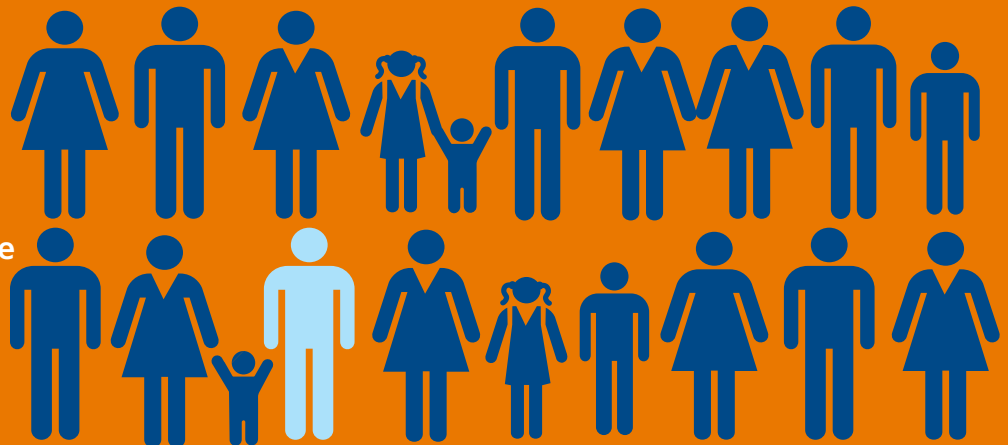
Diversity and difference means strength and resilience.

Celebrate difference, encourage strength, support weaknesses.

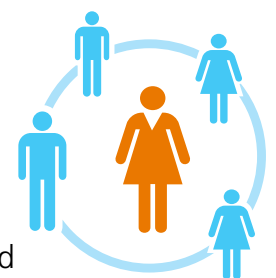


Neurodiversity is used to describe the 1 in 20 people who have any of the following:

- Dyslexia
- Dyscalculia
- ADHD
- Autism
- Tourette's syndrome
- Dyspraxia
- Dysgraphia



1 in 5 humans are Neurodiverse, therefore this must be part of the natural diversity in human evolution. This argues that Neurodiversity is not an error in genetics but it is part of our growing understanding of the diversity of minds, intelligences, abilities, and differences that are part of humanity.



Celebrate neurological differences – celebrate successful individuals and help spread Neurodiversity awareness.

Boost self-esteem – embrace the special interests and successes of young people with neurological differences, this can help to boost feelings of self-worth and avoid feelings of not fitting in.

Recognise mental health issues – be vigilant of any signs of emotional or mental distress, it could be that specialist support is required or they may just need a friendly, safe space.

Autism and Camouflaging

Camouflaging is when a person hides or covers up parts of their personality in order to fit in with the people around them. Research has found that people with autism camouflage for lots of reasons but the main ones are trying to 'fit in' and wanting to connect with others. This camouflaging consists of three key components: Compensation, Masking, and Assimilation.



Camouflaging in people with Autism

Assimilation

Adopting strategies to fit in with others.

Talking to people in public even if they don't want to just to be polite e.g. saying hello to workers in shops.

Keeping a close eye on trends and learning about them/feigning interest to fit in.

Masking

Hiding their autistic traits.

May not talk about a topic of interest.

Stopping themselves 'Stimming' while at school.

Compensation

Strategies that can be used to work around things that they naturally find difficult.

Planning and rehearsing conversations before an event/situation.

Forcing themselves to make eye contact with others.

Research has found that camouflaging is more common in girls and women with Autism but that does not mean that boys will not camouflage. Camouflaging has a number of negative consequences, some of which you may see in your child if they camouflage. It is reported that children will camouflage at school and this can result in a 'meltdown' at home or upon school pick up as the child has devoted so much of their energy to appearing 'normal' that they are exhausted. For more information on camouflaging and to read people's accounts of camouflaging use the links below:

<https://kids.frontiersin.org/article/10.3389/frym.2019.00129>

<https://www.spectrumnews.org/features/deep-dive/costs-camouflaging-autism/>

<https://livingautism.com/autistic-fatigue/>

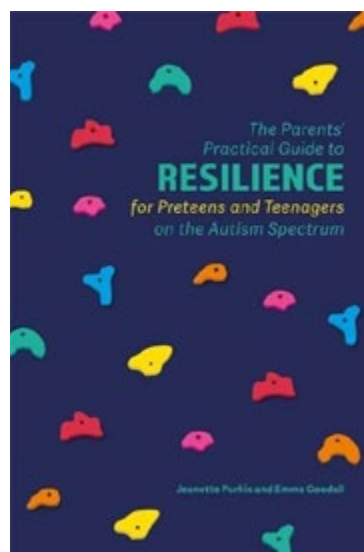
<https://www.sciencedaily.com/releases/2019/07/190723190851.htm>

<https://i.pinimg.com/originals/58/22/54/5822542f4f2fff9b9fbab4843f516ec1.jpg>

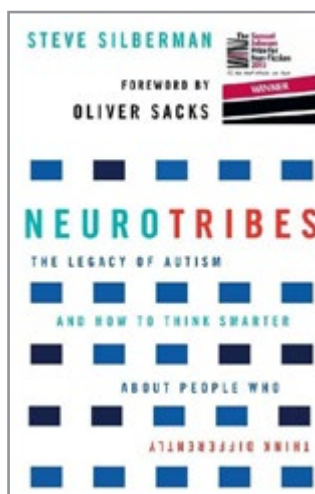
Books about Autism for parents



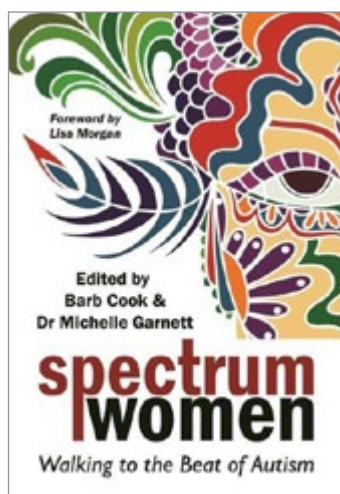
Therapeutic Adventures with Autistic Children: Connecting through Movement, Play and Creativity – *Jonas Torrance.*



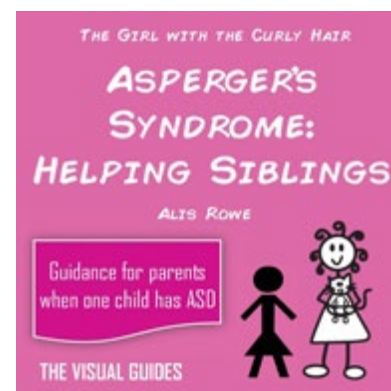
Teenagers on the Autism Spectrum (Parents Practical Guide to) – *Jenn Purkis and Emma Goodall*



NeuroTribes: The Legacy of Autism and How to Think Smarter About People Who Think Differently – *Steve Silberman.*

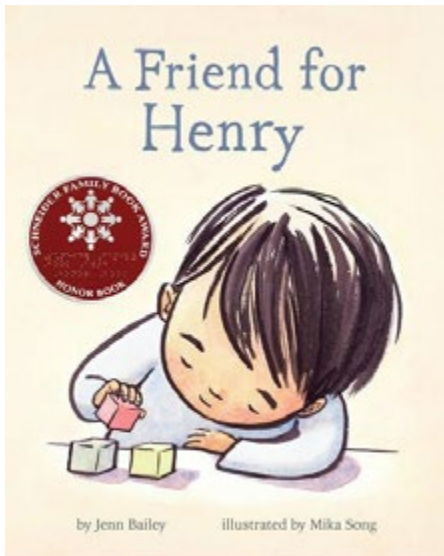


Spectrum Women: Walking to the Beat of Autism – *Barb Cook and Dr Michelle Garnett*

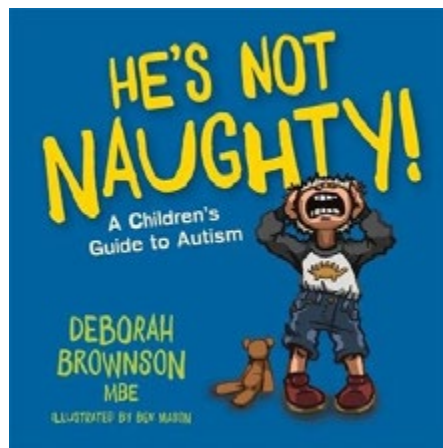


Asperger's Syndrome: Helping Siblings: by the girl with the curly hair (The Visual Guides) – *Alis Rowe*

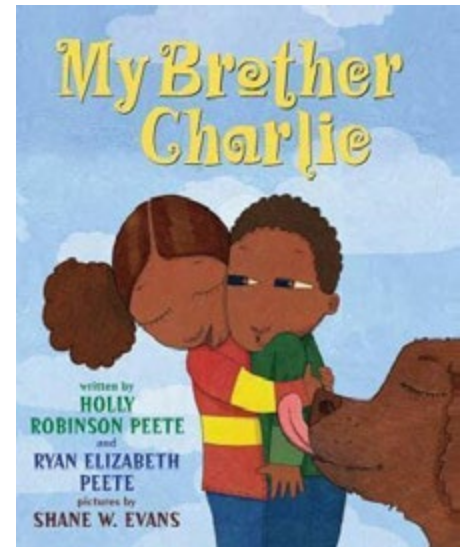
Books about Autism for children and teens



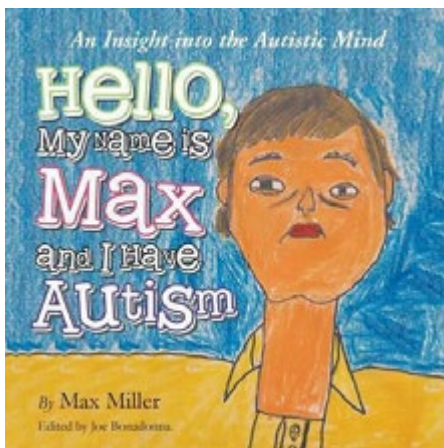
A Friend for Henry – Written by Jenn Bailey and illustrated by Mika Song



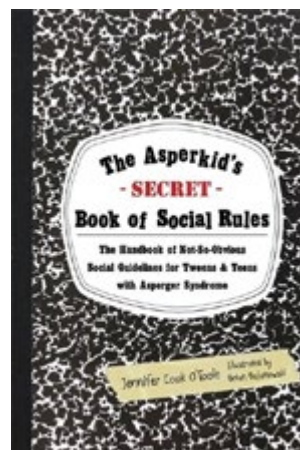
He's Not Naughty! A Children's Guide to Autism – Written by Deborah Brownson and illustrated by Ben Mason.



My Brother Charlie - Written by Holly Robinson Peete and Ryan Elizabeth Peete. Illustrated by Shane Evans



Hello, My Name Is Max and I Have Autism: An Insight Into the Autistic Mind – Written by Max Miller.

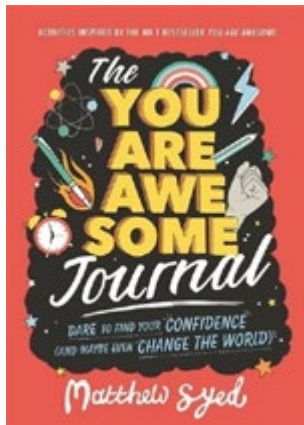


The Asperkid's (Secret) Book of Social Rules: The Handbook of Not-So-Obvious Social Guidelines for Tweens and Teens with Asperger Syndrome - Written by Jennifer Cook O'Toole and illustrated by Brian Bojanowski.



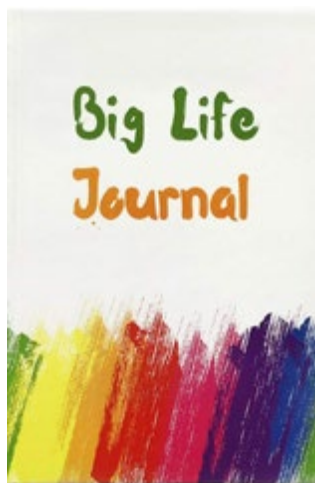
The Awesome Autistic Go-To Guide: A Practical Handbook for Autistic Teens and Tweens - Written by Yenn Purkis and Tanya Masterman.

Activity books and journals for children and teens



The You Are Awesome Journal

An interactive journal full of life hacks, challenges and activities to give kids the confidence to come up with their own plan of action to be the best they can be. Whether setting out their goals, planning the best practice ever, keeping calm with breathing exercises or making paper aeroplanes to understand marginal gains, readers will love the brilliant activities in The You Are Awesome Journal. This is the perfect toolkit for anyone who dreams big - and who wants to make those dreams come true.

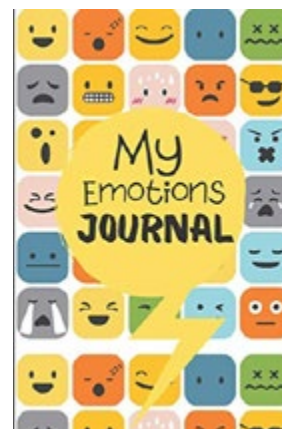


The Big Life Journal

Packed with stories, poems, quotes, illustrations and writing prompts, this guided journal is the world's first growth mind-set book created specifically for children. Growth mind-set activities help children to recognize their ability to learn and motivates them to harness the power of their own mind. It helps children learn to embrace challenges, to persevere, and how to grow from feedback.

My Emotions Journal: Feelings Journal for Kids and Teens - Help Children and Tweens Express Their Emotions - Through Drawing and Writing

Everyone feels better when they can recognise and express their feelings and this can sometimes be difficult for kids to do - and even more so for those children coping with conditions such as autism or ADHD. This fun journal will give your child an outlet for their emotions, in a creative way through both writing and drawing.



Social Skills Activities for Kids: 50 Fun Exercises for Making Friends, Talking and Listening, and Understanding Social Rules

Social Skills Activities for Kids gives children the confidence to successfully navigate social situations at home, school, and the world in between. These engaging activities help kids develop and use their social skills super powers.



Support services for you and your child

Following your child's diagnosis of an neurodevelopmental disorder (autism/ADHD) you do not have to feel alone. There is a breadth of support in the community and online that you and your child can access.

North Lincolnshire Parent Carer Forum

A registered charity run by and for families of children and young people who have Special Educational Needs and/or Disabilities (SEND). They:

- have weekly drop-in sessions that provide information, peer support and activities
- put on activities for the whole family, such as bowling, soft play/sensory sessions, roller skating and male parent care sessions
- provide training workshops, a peer support service and a counselling service.

Family Lives website

Provides advice and information on every stage of a child's development. There is a section for SEND which provides information on special educational needs/disabilities, sleep advice and fun activities.

There is a confidential helpline for emotional support, information, advice and guidance.

0808 800 2222

Parent to Parent Service

A service run by trained parent volunteers that provides confidential emotional support for parents of autistic children over the phone. The volunteers can:

- provide an impartial listening ear
- support to identify key issues and strategies
- direct to appropriate services and information.

ADHD Foundation

Provides useful resources and tips to help parents, carers and young people understand and cope with and ADHD diagnosis. Families can find links to training courses and other events across the country.

www.adhdfoundation.org.uk

National Autistic Society website

Provides useful information and tips for various factors such as communication, behaviour, education, transition and adult life. There is information about their services for example their specialist schools, support in mainstream schools, community support, and home and work life support.

Other useful websites:

www.northlincslocaloffer.com

Mental Health Foundation

YoungMinds.org.uk

Autism Initiatives

NHS website

MindED.org.uk

Mind.org

Relate.org.uk

Autism Society