

Supporting Young People with Autism to Participate in Mental Health Services:

A Guide for Parents and Professionals



About this Guide



Above: what five words come to mind when you think of autism?

It was about hearing parents say the same things over and over again. The struggle to have an identification of mental health issues and effective support alongside young people's ASC diagnosis.

We want to change perception that every problem in their lives is because of autism.

Rose Taylor, Routeways Project Co-ordinator

Experts by experience:

Navigate ASC

Routeways are a Plymouth based local charity that supports children, young people, families and individuals to overcome disadvantage.

Working in partnership with the Child Development Centre, they also provide parent peer support groups. The focus on their Trailblazer project was supporting families of children with autism.

The group, named 'Navigate ASC', used YoungMinds consultancy to work with families to plan their ongoing projects, as well as co-produce these top tips and insights



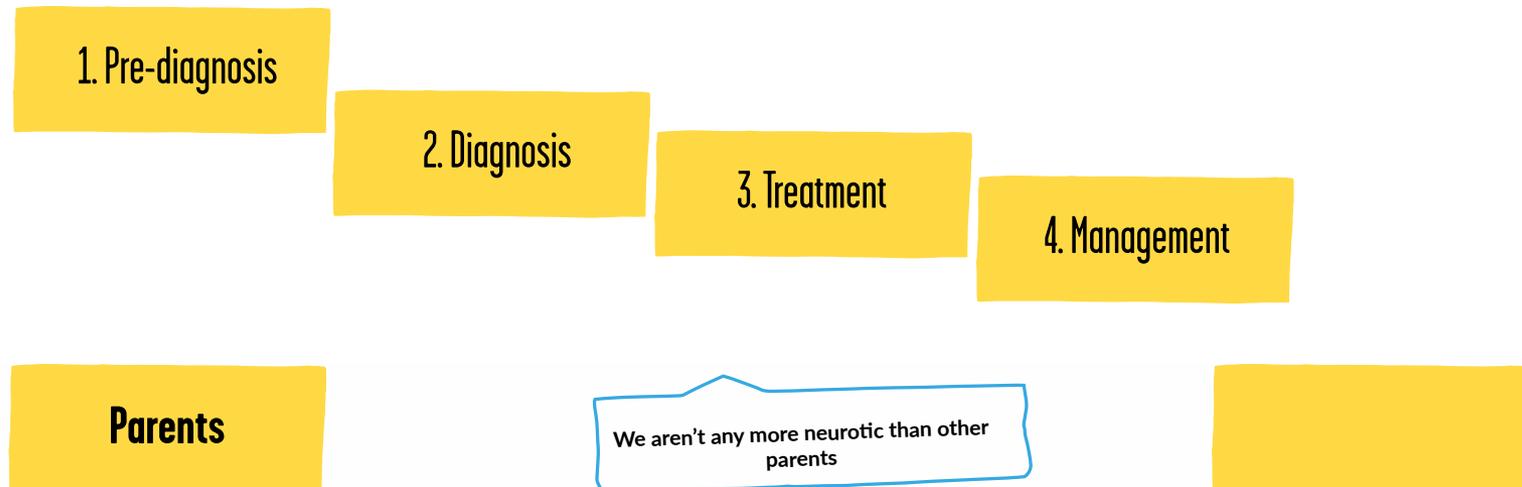
Routeways: Top Tip for Parents and Professionals

Every young person and their family is different – understand their journey...

We 'd ask people to consider the importance of the whole journey, from a thorough and comprehensive assessment to good quality post 18 provision, done in collaboration with the young person and parent.

Parents usually recognise that they're in for the long haul; they want to know they're working in a partnership from the outset.

That's why we've broken the journey down to four stages:



1. Pre-diagnosis

- Find parents in similar circumstances. It can be very helpful with your journey both in terms of emotional support and navigating the process.
- Join online communities:
 - National Autistic Society
 - Autistic-Not-Weird
 - Asperger's Advocacy
 - Your local Facebook network
 - Local parent advocacy groups such as Plymouth Parent Carer Voice
- Reach out to your local authority for information on the 'Local Offer' and any inclusion support they provide.
- Reach out to your local GP, they may have access to helpful resources and a contact for local support networks and professionals.
- Speak to your School SENCO/Special Needs co-ordinator as they often have a list of resources and useful tips to help you manage.
- Keep a diary of questions and worries to take along to your appointments. You can sometimes find useful templates of these on the advocacy websites we've mentioned previously.
- Be patient. The process can be a long one and the system can feel like one long waiting game.
- Some parents say they feel a sense of grief when realising that what they hope for their child may not come to pass. Take time to process that. Things won't always stay the same, know that with the right support everyone's life can change for the better.

Things won't always stay the same. Know that with the right support everyone's life can change for the better...



2. Diagnosis

- Don't assume that the professionals you encounter know everything about Autism. Ask questions to establish how much the other services and professionals in your child's life understand about autism.
- Find out which support groups are in your area, we've mentioned a few in the previous section – don't be alone with this
- For some families diagnosis comes as a huge relief. Don't feel guilty for your personal responses, they are valid and they may change over time.
- The impact of the diagnosis affects the whole family, including siblings, grandparents and yourselves as parents. Everyone will take their own time to process the implications.
- This might feel like the end of a long road, it may just be the beginning... but you don't need to walk it alone.
- The diagnosis of Autism is one of a spectrum; your child will not necessarily conform to a set list of symptoms and behaviours. Be prepared for those behaviours to change over time and you learn to adjust and prepare for them.

For some Families Diagnosis comes as a huge relief. Don't feel guilty for your personal responses.

3. Treatment

- There is no 'treatment' for Autism. There are however a number of therapies that can support the symptoms and help with everyday life. Many of these can be accessed through your GP:

Speech and Language Therapy
Occupational Therapy
Physiotherapy
CAMHS - Mental Health

- Autism is a spectrum; treatments work differently for different people and what works one day may not work the next.

Our young man with autism is the glue that has held us all together as a family, our joyful one, and a truly exceptional young man.

You will learn to adapt your life around Autism. Your life will not be the same as other people's and that is ok.

- Some carers find that reading books and blogs written by young people and adults who are living with Autism can give a different perspective and provide valuable insights.
- Learn as much as possible. Even if you're not a keen reader, take time and start small. There are also lots of books for children available, so siblings or others in their lives can learn about autism.

A few we recommend are:

Freaks Geeks and Aspergers
Martian in the Playground
Blue Bottle Mystery: An Asperger Adventure
My Autism Book: A Child's Guide to their Autism
Spectrum Diagnosis
Different like me
The Childrens Guide to Autism

4. Management

- There are a number of supportive online services that older children can access, be aware some of these have a cost.

Koothbooth
Brain in Hand
Ambitious about Autism

- The **National Autistic Society** can offer some advice on supportive benefits that you may be entitled to such as bus passes and community care services.
- For young children you could look at the **Portage system**; they help build successful home strategies for pre-school children with special educational needs.
- Many local authorities run holiday playschemes or activities specifically designed for young people with Special educational needs and disability (SEND)

- There are a number of everyday objects that may help your child with day to day sensory issues. Objects such as weighted blankets, mermaid cushions, Tangle toys, Playdough, fiddle cubes and dice can easily be bought online.
- Refer back to the support networks you found when you began your journey, sometimes parents in a similar position to you can be an excellent source of guidance.



Parents on the benefits of receiving group support:

The project has helped my child to grow and gain confidence, they look forward to going.

It gives us a little break

It gives my child the opportunity to do activities that they wouldn't normally be able to.



Listen to what [the young person] says and don't dismiss it.

1. Pre-diagnosis

- Clarity and patience are key; People with Autism can have a very literal understanding so be aware of your phrasing and the way you ask questions.
- The young person may benefit from being 'briefed' before their appointment so that they know why they are attending meetings and what to expect. Update their carers as much as you can, especially if there are going to be other people in the room, tests, or anything else which may be stressful.
- If you can, provide photos of the workers who will be involved in the session. If not possible then a clear introduction at the beginning can help relieve anxiety.
- Providing clear aims for the session in simple language or an agenda can be helpful to the young people and their carers.
- If you use feedback questionnaires, try to ensure that the language is simple and easy to understand. We recommend: traffic lights systems, smiley faces and multiple choice options.
- Remember that the family are most likely very anxious and may need reassurance. This is a daunting journey for them; be a port in the storm.

It was really great to have someone really listen to me and tell me that they understood what I was going through and they could help



2. Diagnosis

- Identify the strengths and weaknesses of each young person; ASC is a spectrum, they may not fit every symptom or have learned coping mechanisms
- Accepting the answers that young people and their families give when consulted is important. Many families feel like the information they give isn't really heard.
- Professionals should allow time for parents and young people to trust and open up. It's recommended that contact should be on a one-to-one basis or at least with a constant figure as change can have very negative effects.

Remember to look beyond the autism diagnosis, it's not a one stop shop leading to mental health issues which cannot be fixed. Life changes are harder for a young person with autism to cope with.

- Relationship building is crucial; to do this effectively try engaging young people with games and conversations about their favourite topics to break the ice and get them familiar with staff.
- Ensure reception staff are Autism trained and aware.

In an ideal world, you should be able to identify:

- An up to date register of support groups in the area
- A cohesive process that links from pre-school into primary into secondary and further education

It's crucial to help parents understand..., support them through the diagnosis. More help early on means than parents don't have to guess next steps.

3. Treatment

- Try to understand the sensory needs of each young person. Here are some suggestions that are universally helpful, small changes to the environment such as:

Avoid bright lights; harsh lighting can make the young person feel agitated and exposed.

Is your space inviting? Adding some cushions or a blanket can make a real difference to anxiety levels.

Try to minimise clutter; a lot of flyers and mess can cause anxiety or create unwanted distractions.

Is the assessment space quiet and calm? Loud noises, busy spaces, and heavy foot traffic can make it impossible for someone with ASC to concentrate

- Be clear with any instructions to the young person, don't assume they will know what you mean or be able to interpret the way a neuro-typical child might.
- Have a range of ability appropriate toys and activities that you can access if you need them to help calm, or destress the young person. We have previously mentioned useful objects such as Tangles, fiddle cubes, playdough, dice as well as tactile soft objects.
- Ensure your reception staff are Autism trained and aware.

**Support at its best,
provided by people
with patience and
understanding**

**I have one primary child
one secondary and
two older children with
autism... accessing medical
appointments can be hard,
as one doesn't want to take
them all along**

4. Management

- Make use of practical resources that are available to you. For example:

Double-sided wristbands are available, which can be flipped so that the young person can let people know they do not wish to talk to anyone.

Disability cards are available from the National Autistic Society, the young person may have one that can help you understand their needs.

Emotional Symbol charts can help you understand how they young person is feeling.

A simple hand drawn timeline or instruction list in a notebook can provide enough clarity to prevent an emotional reaction.



- Make use of the fidget distraction toys we mentioned in the previous section to allow the young person to reduce the sensory overload of the situation.
- Use visual resources such as yes/no cards.
- Technology is usually a good way of gathering feedback from young people.
- Remember that repetition of a situation creates familiarity, if you introduce a new person or aspect to their routine then forewarn them.

Understand that the whole family is affected by a young person's mental health. The more parents and siblings receive support, the better they can give support.



Transforming participation across young people's mental health

youngminds.org.uk/amplified



#TeamAmplified