

**Supporting Autistic Children and Young People's
Mental Health Participation:
A guide for parents and professionals**
Amplified Power Pack





What five words come to mind when you think of autism?

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 CAMHS, they 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 for parents and professionals

“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 ASD diagnosis.

**We want to change perception that every problem in their lives was because of autism.”
Rose Taylor, Routeways Project Co-ordinator**

Routeways Top Tips for Parents and Professionals

Everyone young person and 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:

Pre-diagnosis

Diagnosis

Treatment

Management

"We are not any more neurotic any more than other parents!"

For Parents

- Find parents in similar circumstances if you can. It's so helpful in so many ways
- Join online communities:
 - National Autistic Society;
 - Autistic-Not-Weird;
 - Asperger's Advocacy
 - The A-Team
- Be patient. "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"

Pre-diagnosis

"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"

For Professionals

- The young person should be 'briefed' beforehand, so that they know why they are attending meetings and what to expect.
- Photos of the workers who will be there, clear aims for the session in simple language or an agenda can be helpful
- For any questionnaires, ensure that the language is simple and easy to understand. We recommend: traffic lights systems, smiley faces.

"Clarity and patience are key"

For Parents

Establish how much the other services and professionals in your child's life understand about autism; don't assume that they know everything

Find out which support groups are in your area – don't be alone with this

For some families diagnosis comes a huge relief.

This might feel like the end of a long road; it may just be the beginning.

In an ideal world...

Is there an up-to-date register of support groups in the area?

Is there a cohesive process that links from pre-school into primary into secondary and further education?

Diagnosis

"It's crucial to help parents understand from an early age, supporting them through the diagnosis. More information available much earlier on; avoid them having to guess the next steps"

For Professionals

Identify the strengths of each young person

Accepting the answers that young people and their families give when consulted is important.

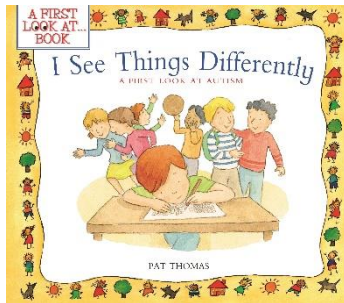
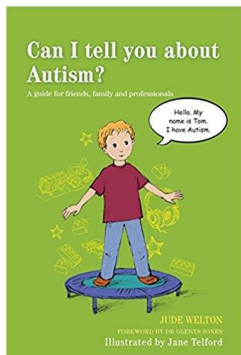
Professionals should allow time for parents and young people to trust and open up and recommended that that contact should be on a one-to-one basis.

Relationship building is crucial to do this effectively: engaging young people in groups with games or icebreakers can be a good way of getting to know people and breaking the ice and getting familiar with staff.

"Listen to what they say and don't dismiss it."

For Parents

- Communicate with an adult with autism (whether online or read their books/blogs). They can give you such an insight to how your own child may be thinking or feeling - a different perspective will help you understand and support.
- Learn as much as possible. Even if you're not a keen reader, take time and start small. There are also books for children, so siblings or others in their lives can learn about autism.



Treatment

“You will learn to adapt your life around Autism. Your life will not be the same as other people’s, and you will need to mourn this to a degree”

For Professionals

Understand the sensory needs of each young person. This could include reviewing your environment:

- No bright lights and neutral colours.
- Non-clinical, comfortable, warm and inviting.
- Quiet spaces, not too busy and without too many distractions.
- Have access to age appropriate activities.
- No clutter including flyers.
- Having a good receptionist who is autism trained.

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



For Parents

- Look at the Portage system for younger children: <https://www.portage.org.uk/>
- Mermaid cushions and weighted blankets were recommended by parents



- For support young people can access on their phones, try <http://braininhand.co.uk/>
- When accessing services, you could try a “Buddy System” where young people are paired with someone (a worker or volunteer), who is Autism trained and can set clear boundaries and give clear instructions. This can lessen their dependence on you

Management

On group support:

“The Rooted Project has helped my child to develop and gain confidence. Always looking forward to going “

“It gives us a little break”

“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.”

For Professionals

Make use of practical resources:

- 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.
- In some situations, it might be helpful for the young person to have access to disability cards.
- Some young people may wish to have fidget box or other device.
- Use visual resources such as yes/no cards.
- Technology is usually a good way of gathering feedback from young people.



Transforming participation across young people's mental health

youngminds.org.uk/amplified

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