Understanding autism

people with learning disabilities finding out and raising awareness together



About this booklet



Antony Davenport from Asist Advocacy Services worked with members of Reach in Staffordshire.

This booklet uses thoughts and ideas from our work on autism.



We have made up the stories in this booklet to help you think about autism and how people can be supported.

There is space for you to write and draw your thoughts and ideas.



You can keep this booklet to yourself or share it with someone you trust.

You can work in groups to help each other to think about and understand autism.

About autism



There are lots of medical words to describe autism:

- Autistic Spectrum Disorder
- Autistic Spectrum Condition
- Asperger's Syndrome
- Autistic Spectrum Difference
- Neuro-diversity



Autism affects about 700,000 people in the UK.

At least 4 times more males than females are diagnosed with autism.



The cause of autism is not known. It is a condition people are born with and it lasts for a lifetime.

Autism can affect anyone in the world.

Reality is a confusing mass of events, people, places, sounds and sights.



Understanding autism

Autism is a spectrum condition which means there are lots of different ways that autism affects each individual person.



Autism affects the person and the people around them.

Some people's lives are not affected very much by autism, but other people's lives are affected a lot.



People with autism can have other conditions too.

Some people need support on a daily basis, and some need support now and then.

The 3 main areas of difficulty experienced by people who have autism are:



1. Social communication

People with autism can find it difficult to understand verbal and non-verbal communication:

- recognising what people's facial expressions mean
- understanding what people mean from the tone of their voice
- working out how people feel from their body language







It's easier to communicate one-to-one.



2. Social interaction

People with autism can find it difficult to make and keep friends. They may experience difficulties:

- expressing their own feelings and emotions
- understanding and recognising other people's emotions
- joining in and fitting in with other people







New things can be too much for me. 99



3. Social imagination

People with autism can have difficulties with people around them and with day to day life:

- making sense of new ideas
- understanding what people do and what people may do next
- coming up with new ways to sort out every day problems







66 We spend most of our time trying to work out what is going on around us. ??

Abilities, symptoms, and challenges.

People with autism can make choices. They can feel confused, struggle with communication and changes.

They have interests and hobbies. People with autism can also be sensitive to touch and sounds. They can feel lonely because they find it hard to fit in.



Remember, each person with autism has their own likes and dislikes, just like everyone else.



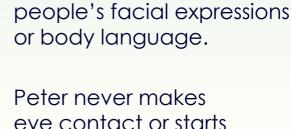
Since a young age I've struggled to cope. ??





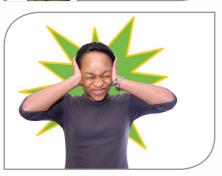
Peter is a 17 year old student who lives with his mum and step-dad.

Peter can't understand





Peter never makes eye contact or starts conversations with people.



Sometimes Peter gets angry because he is sensitive to people's tone of voice.

People get cross because Peter doesn't always answer when they speak to him.

You can write notes or draw pictures about this story.



How does autism affect Peter?



How do you think Peter feels?



Who could help Peter?

What could help Peter?

Please **T** tick the **'yes'** or **'no'** box to show what could help Peter.

Giving Peter information in short sentences and plain language	Yes	No
Being able to talk with his family, friends and support groups	Yes	No
The college not knowing Peter has autism and how to help him	Yes	No
Talking to Peter in a quiet place without distractions	Yes	No
People being patient and giving Peter the time he needs	Yes	No
Understanding that Peter's actions are sometimes linked to his autism	Yes	No
Not judging Peter because of his autism or treating him like a child	Yes	No





Samantha's Story

Samantha is 34 years old and lives in supported accommodation in the community.



People think Samantha is unusual and strange.

Samantha doesn't always understand how people feel and what they mean.



She struggles to socialise and make friends.

Samantha keeps away from people and ends up spending lots of time alone.

You can write notes or draw pictures about this story.



How does autism affect Samantha?



How do you think Samantha feels?



Who could help Samantha?

What could help Samantha?

Please **✓** tick the **'yes'** or **'no'** box to show what could help Samantha.

Knowing what support is available to her within her community	Yes	No
People getting to know Samantha and learning to understand her	Yes	No
Being able to talk to her support person or key worker	Yes	No
Being able to share her feelings and talk to someone she trusts	Yes	No
People not understanding that it's ok to be different and unique	Yes	No
Advocacy support to help her speak up and make her own decisions	Yes	No
People being patient and giving Samantha the time she needs	Yes	No



Life is complex, but I enjoy routines.

Hassan's Story



Hassan is 70 years old and lives with his wife Safia who has a learning disability.

Changes to Hassan's routine cause him to be upset, confused and distressed.



Hassan gets anxious about new things happening.

He doesn't understand how people are going to react or what people expect him to do.



Hassan finds it hard to come up with ideas to sort out everyday problems.

You can write notes or draw pictures about this story.



How does autism affect Hassan?



How do you think Hassan feels?



Who could help Hassan?

What could help Hassan?

Please **T** tick the **'yes'** or **'no'** box to show what could help Hassan.

Supporting Hassan to prepare for changes in the best way for him	Yes	No
Having someone Hassan can trust, to talk to about his worries	Yes	No
People accepting his differences, and not discriminating against him	Yes	No
Seeing Hassan as a person not a condition	Yes	No
Having information about support groups in his local area	Yes	No
People not speaking to Hassan using clear and plain language	Yes	No
Getting to know Hassan and understanding his ways	Yes	No

Now think about what could help you to understand autism.



What is important to you about autism?



What do you think people should know?



What do you want to find out?

1'm not abnormal but not normal at the same time.



About your rights

Every person is different and has the right to be accepted and valued.



You have the right to be respected and treated in a fair and equal way.

No one should discriminate against you.



People with autism have the right to be included, accepted and understood.

Everyone should have the support that is right for them.

This booklet is funded by



Contact



Sue Read Professor of Learning Disability Nursing, School of Nursing and Midwifery, Keele University, Clinical Education Centre, UHNS, NHS Trust, Newcastle Road. Staffordshire, ST4 6QG.



01782 679653



s.c.read@keele.ac.uk





Some of the information in this booklet is from: www.autism.org.uk www.learningdisabilities.org.uk www.autistica.org.uk



Thanks to



for some of the images used.

October 2014

First Edition