More and more is being done to raise awareness of mental health problems at a public and a policy level, and understandably so. One in six adults has a common mental health condition and a fifth of adults have thought of taking their own life at some point. Young people are a particularly vulnerable group, given that most mental health conditions develop between childhood and adulthood and may be at their peak between the ages of 16-25 years. But what about mental health in young autistic people?

Although autism is not a mental health condition, around 70-80% of children and adults on the autism spectrum have experienced mental health problems. This isn’t an issue that has gone unnoticed, with autistic people, their families, and the people who work with them highlighting mental health as a priority area for research. Despite efforts to address this gap in knowledge, little work has explored the mental health needs of young autistic people.

Our research

We are a team of academic researchers (based at the Centre for Research in Autism and Education) and a group of young autistic people (from the charity Ambitious about Autism). Last year, we worked together to ask 130 young autistic people about their mental health needs, and their experiences of seeking mental health support in a co-produced research study; that is, the young people worked with the researchers to design, conduct, analyse and interpret the results – at all stages of research process.

What did we find?

Shockingly, our results highlighted how 80% of the young people had experienced mental health problems. Not only that, these young people told us how they generally felt unhappy, depressed,
worthless, under strain, unable to overcome their difficulties and lacking in confidence. Many young people felt that these problems stemmed from the pressure to act ‘normal’ in a neurotypical (non-autistic) world. As one young person told us:

“if somebody who wasn’t autistic grew up being excluded, bullied, and pressured to be something that they are not, they would very likely develop the same conditions.”

Many of the young people found it hard to tell whether changes in their thoughts, feelings and behaviours might be a sign of a mental health problem; struggling to know what’s “normal” for them and if/when they needed to seek professional help. Even when the young autistic people did recognise that they needed mental health support, 62% of them told us that they had little, if any, confidence in knowing who to contact, and 68% said they lacked confidence in getting appropriate support for their mental health needs.

Most of the young people had sought help for mental health problems, mainly from clinical/healthcare or education professionals. Yet surprisingly few people (less than 25%) found this support useful and even fewer (less than 15%) felt comfortable talking about the mental health problems with these professionals.

Further, the young people that had accessed mental health support said that they faced major problems in getting the help they needed. They experienced stigma (about being autistic and about having mental health difficulties) and felt that services failed to meet their needs. As another young person told us:

“I know that there’s no support there should I need it and that scares me”.

The importance of “Knowing your normal”

Our research involved listening to young autistic people, but this isn’t enough – how do we meet their mental health needs? More needs to be done to support young autistic people to work out what “normal” mental health is for them, so they can identify when something’s not quite “right”.

Ambitious about Autism’s volunteers have developed a toolkit for young autistic (and non-autistic) people that aims to address just this issue. This freely available resource helps young people describe what “normal” is for them, such as how often they sleep and how much time they spend on their hobbies. Not only does this help them to identify if and how their “normal” changes (so they can work out when they might need to get help), it can be used to help them to explain this to other people (e.g., healthcare professionals).

We also need more initiatives to reduce stigma around autism and mental health problems, increased training for professionals working with young autistic people, and greater involvement
of autistic people in the design and delivery of services that, ultimately, affect them. As with all young people, those on the autism spectrum need and deserve the very best support to help them lead flourishing lives. Only by listening to – and learning from – young autistic people will we be able to achieve that goal.

Further information

- Read our research article that was published in the journal Autism (open access).
- Read the policy report about the Know Your Normal campaign.
- Here are our video and blog about our experiences of working in partnership for this research.
- Watch an animation about the Know Your Normal campaign.
- Visit the Know Your Normal website

References


