#KNOWYOURNORMAL

'CAUSE I DIDN'T GET AS MUCH AS
I WANTED TO BUT I WAS MADE
TO FEEL THAT THAT WAS
MORE THAN DESERVED

Mental health in young autistic adults

June 2017

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EXECUTIVE SUMMARY

Background

Mental health is a major public health issue. This is particularly the case for the autistic population, who are thought to be especially vulnerable to mental health problems. Despite the UK autism community highlighting mental health as a priority area for research, there is a lack of research on this topic, particularly in relation to young autistic people (16-25 years).

Our Research

A team of academic researchers and young autistic people worked together – as full and equal partners – to explore young autistic people's experiences of mental health problems and mental health services.

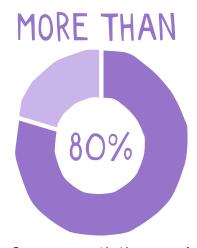
The goal of the research was to find out how best to meet the mental health needs of this potentially vulnerable group. In total, 130 young autistic people took part in the research – 109 completed an online survey, and 21 took part in detailed interviews. We aimed to identify their perception of what 'normal' mental health was for them and, critically, how they knew something more serious might be arising. We also wanted to find out about their experiences of, and their satisfaction with, seeking support for mental health problems.

Key Findings

The research discovered three key findings: (1) young autistic people struggle to evaluate their own mental health effectively; (2) these same young people often find it difficult to identify the right kind of support when it is required; and (3) young autistic people can also face severe obstacles in accessing necessary support.

(1) What's my normal?

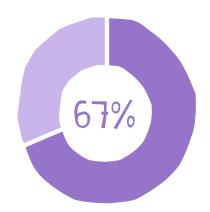
Over 80% of the young autistic people who took part in our survey had experienced mental health problems. They also reported their 'normal' mental health to be somewhat negative and the quality of their lives to be poor. Many of the young people we spoke to explained how it could be difficult to work out whether they were experiencing mental health problems or whether they were experiencing general difficulties associated with being an autistic person in a neurotypical world. They also found it hard to tell whether a 'worsening' of the difficulties they usually experienced in relation to their autism was 'severe' enough to warrant support. Indeed, only 32% of the young people who took part in our survey felt 'very' or 'extremely' confident in knowing whether they were experiencing a mental health problem.



of young autistic people had experienced mental health problems

(2) Seeking support

Of the survey respondents who had experienced mental health problems, 90% had sought support from professionals. Yet 61% of these young people felt 'not at all' or only 'a little' confident in knowing who to contact if they were experiencing mental health problems. Further, 67% were 'not at all' or only 'a little' confident that, if they did contact mental health services, they would receive appropriate support. Asked about the support they did receive, few young people found the support provided by clinical/healthcare professionals (23%) or education professionals (14%) 'very' or 'extremely' useful.



of young autistic people had little or no confidence they would receive appropriate support

Even fewer (14% and 10%, respectively) felt comfortable disclosing their mental health problems to clinical/healthcare or education professionals. In contrast, support from charities, or friends and family, was perceived more favourably.

(3) Barriers to support

The young people told us that they faced several barriers when seeking support for their mental health problems. First, stigma associated with mental health problems made the young people reluctant to discuss their needs with others, such as professionals or friends and family. This was particularly in relation to more 'severe' mental health issues (e.g., psychosis, personality disorder). Second, when they sought help from mental health services, their experiences were often negative. Issues raised included a lack of available services (especially those tailored to their individual needs), poor transitions from child to adult mental health services, and lengthy waiting times. These often resulted in the young people withdrawing or disengaging from mental health services.

Although trusting relationships, usually involving family or friends, were valued, these were not always used as a source of support due to the young autistic people having concerns about burdening those closest to them.

Recommendations

Our report highlights how urgent changes are needed to better support the mental health needs of young autistic people. Based on the findings of our research, these young people need support with identifying whether changes in their thoughts, feelings and behaviours may reflect a mental health problem. It is simply not acceptable for young autistic people's 'normal' quality of life to be so negative and they should be given tools to support them in recognising whether they need help to address their mental health problems.

We also make three concrete recommendations to assist young autistic people with mental health difficulties to secure the services they need:

- (1) More initiatives to reduce stigma of autism and mental health. Young autistic people should not face stigma due to autism or mental health problems. This needs to be addressed via 'better' awareness initiatives, which focus on autistic strengths as well as difficulties. Importantly, such initiatives should be designed and implemented by autistic people.
- (2) Increased training for professionals. Young autistic people want to feel confident that the people from whom they seek help are knowledgeable about autism and mental health difficulties, and show genuine concern for their wellbeing. Increased training for professionals developed in collaboration with young autistic people who have experience of mental health problems is essential.
- (3) Greater autistic involvement in service design and delivery. We need to listen to, and learn from, young autistic people to ensure that that the services that they receive are tailored to their individual needs. Involving young autistic people in the design of mental health services is critical; to increase their confidence with these services and the professionals within them and, ultimately, to make sure that these services deliver the most effective support.

PREFACE

This report was commissioned by Ambitious about Autism – the national charity for children and young people on the autism spectrum.

We are very grateful to Elizabeth Archer for her ongoing support and enthusiasm for the research, and for providing us with the opportunity to work on this important project.

We would also like to thank Dami Benbow and Anna Nicholson at Ambitious about Autism, and Melissa Bovis at the Centre for Research in Autism and Education (CRAE), UCL Institute of Education, for their assistance with recruitment, as well as Marc Stears, for helpful discussions.

We are also indebted to the young autistic people who generously gave their time to complete the online survey or take part in the interview. We have done our very best to convey their experiences as accurately as possible. Any omissions or errors are entirely our own.



TERMINOLOGY

We use 'identify-first' language (i.e. 'autistic person') rather than person-first language (i.e. 'person with autism'), in accordance with the views of many autistic people and their families in the UK (1).

The term 'autism community' refers to autistic people, their family members and the professionals who support them.

Neurodiversity refers to how all human minds and brains are different. Being autistic is a form of neurodivergence.

Neurotypical (or **NT**), an abbreviation of neurologically typical, is a term used to describe people with 'typical' brains. It is commonly used in the autistic community to refer to people who are not on the autism spectrum.

Abbreviations

NHS: the National Health Service in the UK

CAMHS: Child and Adolescent NHS Mental Health Services, which are mental health services taking referrals up to the age of 16-18 years.

AMHS: Adult NHS Mental Health Services, which are mental health services taking referrals for those older than 16-18 years.

A&E: Accident and Emergency, which is a medical treatment centre specialising in emergency care.

SENCO: Special Educational Needs Coordinator, which is an education professional specialising in those with special educational needs, such as autism.

Notes

Row or column percentages may add up to 99% or 101% due to rounding.

BACKGROUND

What is autism?

Autism is a lifelong developmental disability that affects 1 in 100 people in the UK (2, 3). It affects a way a person communicates and how they experience the world around them. Many people challenge the idea of autism as a disability, and see it as no more than a different way of viewing and experiencing the world.

The difficulties autism creates are categorised in a variety of different ways, but there are two main features: (i) difficulties with social communication and interaction, and (ii) displaying repetitive behaviours and activities, including unusual reactions to sensory information (4).

Autism is described as a spectrum condition. This means that while autistic people (including those diagnosed with Asperger syndrome) share certain characteristics, they will all be highly individual in their needs and preferences. Some autistic people are able to lead relatively independent lives but others may face additional challenges, including intellectual disabilities, which can affect them so profoundly that they need support in many areas. Autism can affect a great deal of someone's life and experiences, but it is never the whole story about them.

Mental health in young people

Mental health problems affect approximately 1 in 4 adults (5). As such, mental health represents a major public health issue (6), and a priority for the UK government (7).

Most mental health conditions develop between childhood and adulthood (8-10), and may be at their peak between the ages of 16-25 years (11). However, young people are often reluctant to seek professional help for mental health problems (12-14), resulting in most mental health service needs being unmet (15). Barriers to seeking help amongst young people with mental health problems include: stigmatising attitudes towards mental illness; concerns about confidentiality and trust; and difficulties identifying the symptoms of mental health problems in the first place (16).

When young people do seek help for mental health problems, many encounter problems navigating the healthcare system. In the UK, Child and Adolescent Mental Health Services (CAMHS) typically accept referrals until the age of 16-18 years, while care for adults is provided separately, via Adult Mental Health Services (AMHS). The transition between CAMHS and AMHS can be difficult due to problems getting a referral to AMHS from CAMHS, poorly planned transitions between CAMHS and AMHS, and the shift from the child-centred developmental approach offered by CAMHS to the adult-centred care offered by AMHS (17). These issues result in many young people falling through the 'care gap' (18).

Indeed, researchers have suggested that the "current system is weakest where it needs to be strongest" (19, p. 30). This so-called 'mental health crisis' has led to calls for urgent reforms, including an integrated care pathway that extends from 12 to 25 years of age (20).

Mental health in autism

Autism is not a mental health condition, but mental health problems are common in autistic people. Indeed, approximately 70-80% of autistic children and adults experience mental health problems (21, 22), most often depression and anxiety (23).

Depression is thought to be common in autistic adults (24, 25), with suggestions that rates of depression are higher in autistic children too (26). Yet, it is difficult to determine the true rates of depression in autistic people for several reasons. First, many features of autism (e.g., social withdrawal, sleep problems) overlap with symptoms of depression, so it may be difficult for autistic adults to identify that they are experiencing signs of depression (25). Second, characteristics associated with autism may affect the way depression presents itself in autistic adults (25). For example, autism is associated with alexithymia (a difficulty in describing and identifying feelings and emotions), which could impact upon the way depression presents itself in autistic people (24, 27). However, while the rates of depression in autistic people are difficult to determine, the consequences are not. Autistic adults who are experiencing episodes of depression report high rates of suicidal thoughts, and suicide plans or attempts (28, 29), prompting an urgent need for greater research in this area.

Severe anxiety is also thought to be common in autistic adults (30). Again, it can be difficult to differentiate between autism and anxiety as many signs of anxiety (e.g., avoiding social situations, difficulties with communication) are common features of autism (31). Researchers have therefore started to differentiate between symptoms of anxiety similar to those seen in typical adults ("traditional" anxiety: everyday worries that are difficult to control, symptoms such as restlessness and irritability), as well as autism-specific signs of anxiety ("atypical" anxiety: exacerbated and severe anxiety linked to the key features of autism) (32). Unfortunately, our limited understanding of anxiety in autistic children and adults – and how anxiety might change as children develop into adults – means that we simply do not know whether the symptoms of anxiety are reactions to general challenges associated with being an autistic person in a neurotypical world, or an impairing mental health problem that requires specific help (32).

Despite the autism community calling for more research on mental health problems in autistic people, particularly those which focus on interventions (33), there is limited research on this topic. Even less is known about mental health in young autistic people (16-25 years), and particularly about the broader range of mental health problems experienced (beyond depression and anxiety).

The current project

Traditionally, researchers choose which topics to study, they design and interpret the research themselves, and they engage with the autistic community merely as participants (34). There is growing awareness that this is not necessarily the best approach to advancing autism research and practice. It has also resulted in the autistic community being dissatisfied with autism research (34), especially the disconnect between what gets researched and what they want to be researched (35). The current project addressed these issues by using a Community Based Participatory Research (CBPR) approach. CBPR involves a partnership between autism community members and academic researchers, in which different types of expertise are valued equally, and ownership of the research is shared. The research team comprised young autistic people (the myVoice team; FA, GH and JW) and academic researchers (from the Centre for Research in Autism and Education; LC and LP) who collaborated – as full and equal partners – during all stages, including the design, implementation, analysis, interpretation and dissemination of the research.

The focus of the research

Mental health in young autistic people was unanimously selected as a priority area by the Ambitious about Autism myVoice team, mirroring the findings of a recent consultation with the autism community (33). Mental health was therefore the focus of the current research and an associated campaign – 'Know Your Normal'. This campaign was designed to highlight that everyone's 'normal' is different, with everyone's unique quirks and idiosyncrasies being an important part of who they are. As part of the campaign, Ambitious about Autism's young volunteers helped design a 'Know Your Normal' toolkit. The toolkit was designed to support young autistic (or non-autistic) people to identify what their 'normal' thoughts, feelings and behaviours are; then, if things change, it is easier to explain to other people that they may need help or support.

Research questions

The specific questions we sought to address in this research project were:

- ▶ What are young autistic people's views and experiences of mental health problems and services?
- ► How can we best support young autistic people who are experiencing mental health problems?

THE RESEARCH STUDY

Data were collected using an online survey and in-depth interviews, between February and March 2017.

Eligibility

To be eligible to take part in the research (either an online survey or an interview), participants needed to:

- (i) Be between the ages of 16 to 25;
- (ii) Have received a formal diagnosis of an autism spectrum condition;
- (iii) Be living in England.

Recruitment

The online survey and interviews were advertised via existing databases (at Ambitious about Autism and the Centre for Research in Autism and Education), via social media (Twitter, Facebook), and via personal contacts of the research team.

A total of 109 young people took part in the online survey, and a separate group of 21 were recruited to take part in the semi-structured interviews.

Participants

Information about the young autistic people who participated in our research is presented in Table 1. The use of an online survey and interview limited our sample to young autistic people with good spoken or written language. As such, it is unsurprising that many in our sample were diagnosed with Asperger syndrome, educated in mainstream schools, had gained educational qualifications, and were currently in education/employment. Table 1 also illustrates that although there were a mix of gender identities and regions of England represented in our sample, there was little ethnic diversity (most of the sample was from a White ethnic background).

THE RESEARCH STUDY

Table 1. About the participants

Background variables	Survey (n=109)	Interview (n=21)ª
Age (in years)		
Mean (SD)	20.57 (2.86)	20.90 (2.98)
Range	16-25	16-26
Diagnosis on the autism spectrum		
Asperger syndrome	62 (57%)	6 (29%)
Autism	22 (18%)	2 (10%)
Autism spectrum disorder/condition	24 (22%)	9 (43%)
Pervasive developmental disorder	0 (0%)	2 (10%)
Age at diagnosis		
Mean (SD)	13.34 (6.44)	14.68 (4.22)
Range	1-25	4-22
Gender identity		
Female (including transgender female)	56 (5%)	10 (48%)
Male (including transgender male)	33 (30%)	9 (43%)
Non-binary	17 (16%)	2 (10%)
Prefer not to disclose	3 (3%)	0 (0%)
Ethnicity		
White background	95 (87%)	20 (95%)
Black background	1 (1%)	0 (0%)
Asian background	6 (6%)	0 (0%)
Mixed background	4 (4%)	1 (5%)
Chinese background	0 (0%)	0 (0%)
Any other ethnic group / prefer not to say	3 (3%)	0 (0%)
Geographic location		
East Midlands	6 (6%)	0 (0%)
East of England	4 (4%)	1 (5%)
London	30 (28%)	7 (33%)
North East	6 (6%)	2 (10%)
North West	12 (11%)	5 (24%)
South East	27 (25%)	0 (0%)
South West	7 (6%)	2 (10%)
West Midlands	9 (8%)	1 (5%)
Yorkshire and the Humber	8 (7%)	3 (14%)

Background variables	Survey (n=109)	Interview (n=21) ^a
Education		
Mainstream school	93 (85%)	18 (95%)
Specialist school	7 (6%)	0 (0%)
Specialist units/bases in mainstream school	5 (5%)	0 (0%)
Independent/private school	2 (2%)	0 (0%)
Home school	2 (2%)	0 (0%)
Other	0 (0%)	1 (5%)
Highest qualification		
GCSEs	25 (23%)	4 (19%)
A/AS Levels	45 (41%)	5 (24%)
First degree (e.g. BA, BSc)	18 (17%)	5 (24%)
Higher degree (e.g. MA, MSc, PhD)	5 (5%)	2 (10%)
National Vocational Qualification (NVQ)	6 (6%)	1 (5%)
Other or no qualifications	6 (6%)	2 (10%)
Currently studying?		
No	43 (39%)	5 (24%)
Yes, full-time	56 (51%)	11 (52%)
Yes, part-time	10 (9%)	5 (24%)
Currently employed		
No, not looking for work	46 (42%)	7 (33%)
No, looking for work	13 (12%)	2 (10%)
Yes, full-time paid work	15 (14%)	2 (10%)
Yes, part-time paid work	14 (13%)	4 (19%)
Yes, working voluntarily	9 (8%)	2 (10%)
Other	12 (11%)	2 (10%)
Current living arrangements		
With parents and/or siblings	69 (63%)	12 (57%)
With friends	16 (15%)	3 (14%)
With partner and/or children	12 (11%)	1 (5%)
On my own	0 (0%)	2 (10%)
Other	12 (11%)	2 (10%)

Note:

^a Two adults who took part in the interviews only provided their age, gender identity ethnicity and educational status. All other data presented in the column are for 19 of the young people who took part in an interview.

THE RESEARCH STUDY

Most of the young people – 74 of the survey respondents (67.9%) and 15 of the interviewees (71.4%) – had received other diagnoses, in addition to autism. Details are presented in Table 2.

Table 2. Number of young people reporting other confirmed diagnoses

	Confirmed diagnosis from a healthcare professional		
	Survey (n=109)	Interview (n=21) ^b	
Anxiety disorder	43 (39%)	12 (57%)	
Attention Deficit Hyperactivity Disorder (ADHD)	15 (14%)	3 (14%)	
Bipolar disorder	2 (2%)	1 (5%)	
Depression	35 (32%)	8 (38%)	
Developmental Coordination Disorder (DCD) /dyspraxia	20 (18%)	6 (29%)	
Dyslexia	21 (20%)	3 (14%)	
Epilepsy	2 (2%)	1 (5%)	
Fragile X	0 (0%)	1 (5%)	
Obsessive Compulsive Disorder	10 (9%)	2 (10%)	
Schizophrenia	0 (0%)	1 (5%)	
Tourette syndrome	1 (1%)	1 (5%)	

Note:

^b Data are only presented for 19 of the 21 young people we interviewed.

SURVEY RESULTS

What's my 'normal'?

Survey respondents (n=109) were asked to reflect on a series of statements and rate how their 'normal' (i.e., their typical behaviours, thoughts and feelings) compared to that of other non-autistic people of similar age ('more than other people', 'about the same as other people, or 'less than other people).

As shown in Table 3, the young autistic people felt that their 'normal' was different to that of other people and, rather strikingly, very negative in nature. For example, the young people highlighted how they generally felt unhappy and depressed, worthless, under strain, unable to overcome their difficulties, unable to face up to problems, and lacking in confidence.

Table 3. What's my 'normal'? Young people's (n=109) ratings of how their 'normal' compared to that of other non-autistic people of similar age.

	More than my normal	About the same as my normal	Less than my normal
Able to concentrate on what you are doing	4 (5%)	9 (11%)	68 (84%)
Tend to sleep	22 (27%)	13 (16%)	46 (57%)
Feel you play a useful part in things	1 (1%)	9 (11%)	71 (88%)
Feel capable of making decisions	1 (1%)	13 (16%)	67 (83%)
Feel under strain	65 (80%)	7 (9%)	9 (11%)
Feel able to overcome difficulties	5 (6%)	8 (10%)	68 (84%)
Enjoy daily activities	4 (5%)	12 (15%)	65 (80%)
Feel able to face up to problems	1 (1%)	13 (16%)	67 (83%)
Feel unhappy and depressed	66 (82%)	9 (11%)	6 (7%)
Feel confident in yourself	5 (6%)	15 (19%)	61 (75%)
Feel worthless	56 (69%)	16 (20%)	9 (11%)
Feel happy	2 (3%)	15 (19%)	64 (79%)
Enjoy interests and hobbies	6 (7%)	18 (22%)	57 (70%)
Tend to eat	18 (22%)	21 (26%)	42 (52%)
Spend time with people socially	3 (4%)	12 (15%)	66 (82%)
Spend time on appearance	3 (4%)	21 (26%)	57 (70%)
Have high levels of energy	6 (7%)	7 (9%)	68 (84%)
Engaging in drinking/smoking/taking drugs	24 (30%)	34 (42%)	23 (28%)
Engage in repetitive behaviours	41 (51%)	27 (33%)	13 (16%)

SURVEY RESULTS

Experiences of mental health problems

Most of the young autistic people who took part in our survey (81%) had experienced mental health problems (currently or previously, or both); see Figure 1.

Are mental health problems different to 'normal'?

Of the 88 young autistic people who were eligible to answer this question, 86 replied. As can be seen in Figure 2, 57% thought their mental health problems were different to 'normal', 7% did not, and 36% were unsure.

They were asked to reflect on the same 19 statements they saw earlier, indicating if/how their 'normal' changed when they were experiencing mental health problems ('more than my normal', 'about the same as my normal', or 'less than my normal'). In total, 81 respondents provided this information. Table 4 shows the ways in which young people felt their 'normal' changed when they were experiencing mental health problems.

Many of the changes were in areas that they felt they already differed from other people, particularly in a negative way – and these areas, critically, were exacerbated by mental health problems. For example, many young autistic people reported normally feeling under strain, but felt even more under strain when they were experiencing mental health problems.

Figure 1: Have you experienced mental health problems? (n=109)

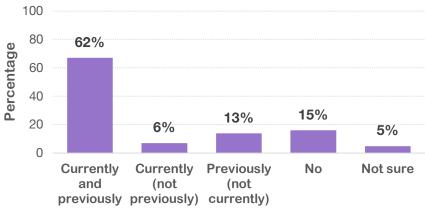


Figure 2: Are mental health problems different from 'normal'? (n=86)

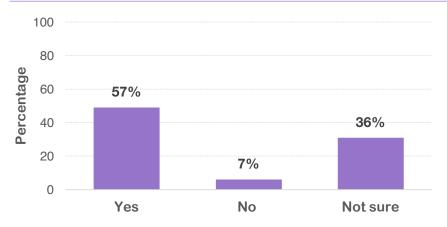
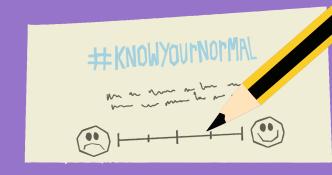


Table 4. How 'normal' changes when experiencing mental health problems (n=81)

	More than my normal	About the same as my normal	Less than my normal
Able to concentrate on what you are doing	4 (5%)	9 (11%)	68 (84%)
Tend to sleep	22 (27%)	13 (16%)	46 (57%)
Feel you play a useful part in things	1 (1%)	9 (11%)	71 (88%)
Feel capable of making decisions	1 (1%)	13 (16%)	67 (83%)
Feel under strain	65 (80%)	7 (9%)	9 (11%)
Feel able to overcome difficulties	5 (6%)	8 (10%)	68 (84%)
Enjoy daily activities	4 (5%)	12 (15%)	65 (80%)
Feel able to face up to problems	1 (1%)	13 (16%)	67 (83%)
Feel unhappy and depressed	66 (82%)	9 (11%)	6 (7%)
Feel confident in yourself	5 (6%)	15 (19%)	61 (75%)
Feel worthless	56 (69%)	16 (20%)	9 (11%)
Feel happy	2 (3%)	15 (19%)	64 (79%)
Enjoy interests and hobbies	6 (7%)	18 (22%)	57 (70%)
Tend to eat	18 (22%)	21 (26%)	42 (52%)
Spend time with people socially	3 (4%)	12 (15%)	66 (82%)
Spend time on appearance	3 (4%)	21 (26%)	57 (70%)
Have high levels of energy	6 (7%)	7 (9%)	68 (84%)
Engaging in drinking/smoking/taking drugs	24 (30%)	34 (42%)	23 (28%)
Engage in repetitive behaviours	41 (51%)	27 (33%)	13 (16%)

Our research found that:

of young autistic people feel unhappy/depressed compared to their non-autistic peers.



SURVEY RESULTS

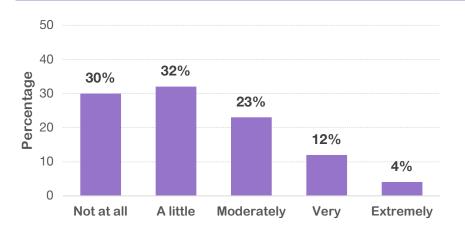
Confidence

When asked whether they were confident in knowing who to contact, should they be experiencing mental health problems, 62% (n=101) reported feeling 'not at all' or only 'a little' confident; see Figure 3.

When young people were asked whether they were confident that, if they sought help, they would get appropriate support, more than two thirds (67%; n=101) reported being 'not at all' or only 'a little' confident; see Figure 4.

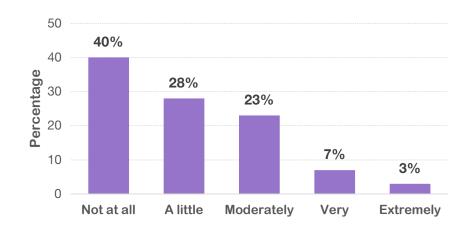
Finally, when respondents were asked whether they were confident in knowing that they were experiencing mental health problems, less than one third of respondents (32%; n=101) were 'very' or 'extremely' confident; see Figure 5.

Figure 3: Confidence in knowing who to contact (n=101)



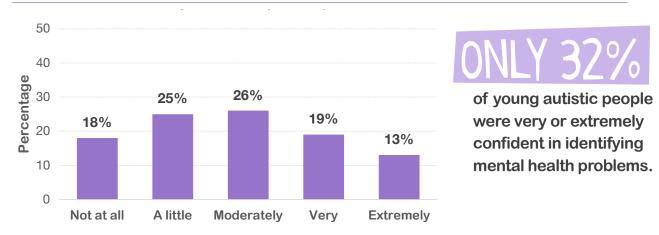
of young autistic people were very or extremely confident in knowing who to ask for help.

Figure 4: Confidence in getting appropriate support (n=101)



of young autistic people were very or extremely confident they would get appropriate support.

Figure 5: Confidence in identifying mental health problems (n=101)

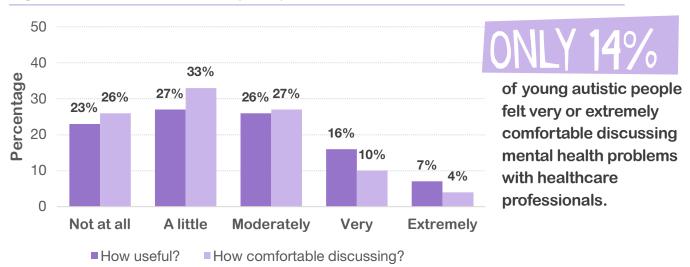


Experiences with mental health services

The vast majority (90%; n=73) of the young autistic people who completed our survey had sought help for mental health problems. Of these young people, all had sought help from clinical/healthcare professionals, with almost 70% (n=51) also seeking help from education professionals. Surprisingly few people (23% [n=18] and 14% [n=7], respectively) found this support 'very' or 'extremely' useful, and even fewer (14% [n=10] and 10% [n=5], respectively) felt comfortable disclosing their mental health problems to these professionals.

Family and friends were common sources of support (in 63% and 32% of the respondents, respectively). Many respondents found this support to be 'very' or 'extremely' useful (48% [n=22] and 39% [n=9], respectively) and also felt 'very' or 'extremely' comfortable discussing their mental health problems with these individuals (41% [n=19] and 39% [n=9], respectively). Charitable support was also perceived favourably, with 41% (n=11) of respondents finding their support 'very' or 'extremely' useful, and almost half (48%, n=13) felt 'very' or 'extremely' comfortable discussing their mental health problems with them; see Figures 6-10.

Figure 6: Clinical/healthcare (n=73)



SURVEY RESULTS

Figure 7: Education (n=51)

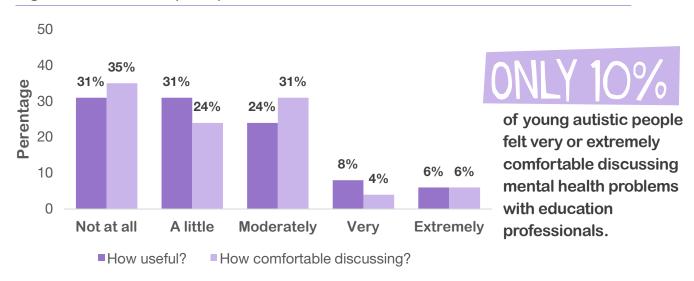


Figure 8: Family (n=46)

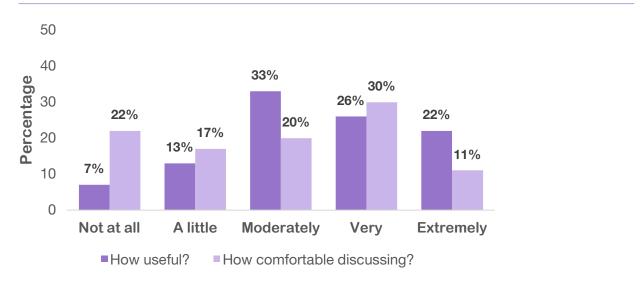
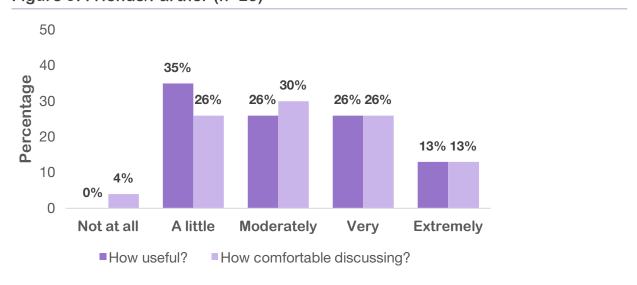


Figure 9: Friends/Partner (n=23)



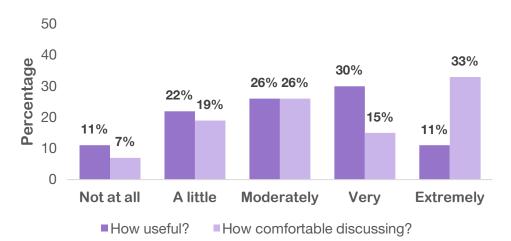


Figure 10: Charity or similar organisation (n=27)

Quality of life

A total of 101 young autistic people completed a questionnaire assessing their quality of life across four key areas:

- Physical health (e.g., how much do you need any medical treatment to function in your daily life?)
- ▶ Psychological (e.g., How satisfied are you with yourself?)
- ▶ Social relationships (e.g., How satisfied are you with the support you get from your friends?)
- **Environment** (e.g., How healthy is your physical environment?)

As shown in Table 5, the quality of life reported amongst the young autistic people in our sample was well below that reported by non-autistic people.

Table 5. Quality of life (n=101).

	Mean (SD)	Range	Population norm (36)
Physical health	57.25 (19.09%)	3.57-89.29	73.5 (18.1%)
Psychological	43.77 (23.05%)	0-87.50	70.6 (14.0%)
Social relationships	46.53 (28.49%)	0-100	71.5 (18.2%)
Environment	55.29 (21.00%)	6.25-96.88	75.1 (13.0%)







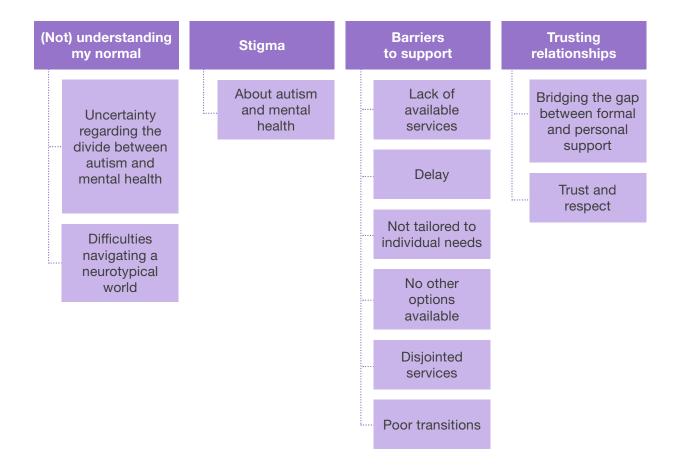




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Twenty-one young autistic people spoke to us about (1) how they felt about their life in general and, more specifically, being autistic, (2) their experiences of mental health problems, and (3) the support they received for autism and/or mental health problems.

Four key themes were common across the interviews:



Our research found that:

of young autistic people felt less able to overcome difficulties when experiencing mental health issues.



(Not) Understanding my normal

Uncertainty regarding the divide between autism and mental health

Many young autistic people were unsure whether the difficulties they were experiencing were due to their autism or due to mental health problems:

"If I'm actually having a really bad day then [autism and mental health problems] kind of blur into one... If I'm having a really good few weeks or months, then I'll think actually, no, there is a clear difference between the two because the autism doesn't have to make me ill, but the depression does".

Some young people could tell that they were experiencing mental health problems due to changes in their everyday autistic traits:

"I usually detect [depression] because my Asperger's traits get worse, like **I have** more meltdowns that last longer and I feel sadder afterwards".

For others, this 'worsening' of autistic traits did not necessarily signal the start of a mental health problem, but could – at some point – lead to one:

"I'm more likely to have mental health issues if I'm feeling overwhelmed because of the autism. Like it just all intertwines". The young people also stressed how, even if a person could identify the subtle differences between their autism and their mental health problems, it may not be obvious to others:

"I can feel a difference but I don't know if it would as easy for someone else to tell".

It was felt that any support offered to young autistic people needed to bridge autism and mental health:

"Not only do [my autistic traits] get worse when I have mental health problems but sometimes the issue's in reverse, that I've had too many things to cope with and don't know how and end up with worse mental health, so the only way to solve that is to address my Asperger traits, addressing the mental health problems in that situation wouldn't change anything".

This sentiment was corroborated by another interviewee, who explained how receiving support for difficulties associated with autism led to improvements in mental health:

"It was linked to not getting the support I needed with my autism because as soon as that support was in place, my anxiety issues went away ... I feel like I'm in control of my life again".

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Difficulties navigating a neurotypical world

Many young autistic people felt that mental health problems resulted from the pressure to act 'normal' in a neurotypical world:

"I almost feel like there's a guide that I've missed out on how to like exist as a person".

The young men and women we spoke to – all of whom were verbally and intellectually able – were often seen as too 'normal' to be autistic and, equally, too 'different' to be 'normal':

"I didn't know what was kind of wrong with me, if you like. I always felt different, massively different from other people and it just frustrated me so much".

They felt this led to delays in receiving a formal diagnosis of autism, and years of hiding their true selves. Young autistic women appeared to have a particularly difficult time, with many reporting that delays in receiving an autism diagnosis were associated with mental health problems:

"Maybe just that I think if I had been diagnosed with Asperger's much younger like many boys are then I could have avoided some of my mental health issues. I think lots of girls are diagnosed too late or are just completely missed".

Over the long-term, this was felt to have negative consequences:

"the reason that so many people with autism develop [mental health] conditions is because of the way that we are treated. From early childhood, **autistic kids are excluded**, frowned upon and made to feel unnatural. We are constantly pressured to be more "normal", whatever that means. I think that 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".

It also presented a problem when trying to discuss difficulties they were having with friends and family:

"[they'd say] **you can't be autistic, you're too normal**"; and healthcare professionals: "The GP seemed a bit – how do I put it – not unbelieving. But when you can cope well, **disability is almost invisible**, in terms of autism and mental health".

Taken together, the links between autism and mental health were seen as incredibly complex:

"You've got to deal with being autistic and having a mental health issue as opposed to just being neurotypical and having a mental health issue, which is difficult enough. You've got to work twice as hard because you've got to interpret things and understand things, as everybody does, but you've got to interpret and understand things from the perspective of somebody who doesn't have autism and

quite often people won't communicate to us as autistic people, we've got to adapt and conform to their ways of communication, their ways of doing things".

Stigma

Stigma was commonly reported; in different ways, by different people. Some young autistic people felt society was (gradually) more accepting of mental health problems, perhaps even more so than autism:

"it's become more normal, not such like a freakish thing ... I'm definitely more open about [mental health problems] than about the autism".

However, young people felt that society had a long way to go:

"I still feel like there's quite a big stigma about mental health and with all like invisible illnesses, people don't seem to take it as seriously as they would like something, like an ear infection – and it's just as important".

Particular concerns were raised about disclosing specific mental health problems, such as psychoses or personality disorders:

"recently there's been a lot more discussion about anxiety and depression and it's much more generally accepted, but the idea of hallucinations, specifically hearing voices, that really freaks people out, that makes people very uncomfortable to be around you, there's misconceptions".

Greater awareness of more 'severe' mental health problems was felt to be needed:

"I've started opening up to [people] about psychosis as well and that helps them and it helps me as well because it stigmatises it, whereas everything in the media at the moment seems to presume that I'm just going to go round stabbing people".

The young people noted that reactions from friends or family (i.e., those who mattered most) could sometimes be negative: "I can tell [mum] doesn't like the thought of her daughter having mental illnesses"; and it was felt to be important for professionals to address issues such as stigma with friends and family members, to ensure that young autistic people with mental health problems get the personal support they need:

"It might have been good if they discussed with my mum how she could support me as I feel she doesn't understand mental illness and certainly sees a stigma around it".

For many young people, the disclosure of a mental health problem led to them (finally) receiving an autism diagnosis, or getting recognition for other mental health problems: "I've got my psychosis to thank for the fact that I got my autism

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diagnosis because they were far more worried about the fact that I was hearing voices, there's more stigma behind that, even though none of them ever came across as violent. And that sort of really spurred them on to diagnose everything and sort of sort out whether there is depression on top of that or OCD or anything like that, which there wasn't to a diagnosable extent".

Barriers to support

The young autistic people we spoke to struggled to access support for several reasons. First, they felt there was a general *lack of available services*. This was in relation to autism:

"I asked for a GP referral to a service for people with autism, but they didn't have any to suggest"; as well as mental health: "if I'm self-harming or if I feel like suicidal or things like that, then there isn't anyone for me to go to other than A&E...I know that there's no support there should I need it and that scares me".

Many young people reported that their mental health problems were not deemed "quite severe enough for support", even when they had formally diagnosed mental health problems. Specific concerns were raised about support only being offered at crisis point, when it might be too late:

"the GP services like only take you seriously when something happens ... for some people it's too late".

When support or services were available, the young people felt that there were considerable *delays* before these could be accessed. Again, this was in relation to autism:

"I was 18, but the psychiatrist told me I had [autism] when I was 17, just I had to wait for the assessment which took quite a while"; as well as mental health problems: "another five, four or five year waiting list in my area and my mum basically said that she wouldn't take me home until they assessed me because it would just end up with me having another breakdown again and again without an answer".

Yet after these lengthy waits, the young people often reported that support just did not materialise:

"I was on the waiting list for months for counselling before I came to university but it never happened".

The young people highlighted several other areas in which improvements were needed. First, they felt services were *not tailored to their individual needs*:

"she was clearly used to working with five or six year olds and I was like 16 and 17 when I was seeing her ... that isn't working for me"; particularly to their autism:

"I don't work like normal people work and so all these techniques that that apparently work for other people have never worked for me. And nobody seems to have wanted to spend the time of day with me to actually figure out how to get something that does work for me".

The young people emphasized how professionals needed to appreciate that "we're all different, we're all unique and we all have our own different needs and it's okay to meet those needs".

Many young people were aware of what would, and would not, 'work' for them, but this was seldom taken into consideration:

"I wasn't allowed to talk about anything at all that I was struggling with, I had to keep within the parameters of issues they'd chosen... think I'd have benefitted more if there had been a therapy tailored to my traits and what I felt like I needed, everything was being decided for me and when I expressed that I wasn't comfortable I was made to feel like I wasn't complying".

Combined, these issues often resulted in withdrawal from clinical services.

Even when the young people overcame the problems associated with seeking mental health support and felt things were 'working' (i.e., they had reached the top of the waiting list, and found the support that they were satisfied with), problems often still arose. One young person recalled how she sought help from a charity as well as via CAHMS, but found out (at a time when things were progressing very well) that this additional support was not allowed by CAMHS:

"CAMHS actually turned around and went, you can't see another person at the same time you're seeing us. And I'm like, 'why not, they're helping me, you're helping me, like what, what's wrong with that?' They told me I wasn't allowed to see two people at once".

Other young people recalled the constant pressure they felt because of services trying to discharge patients from services as quickly as possible, before they were ready:

"if you have one good week, then they immediately think about discharging you ... they were always on my back in that sense and I hated it".

Others reported how funding for these services could be (and often was) withdrawn at short notice:

"up until they got their funding cut earlier this year, I was in a passport system that if anything ever got too overwhelming, I could go back. I thought that was a really good idea but I don't have that anymore, which is a shame".

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Once this happened, there were **no other options available**: "They tried doing CBT with me and going and talking to them helped but the actual CBT did nothing and then after that they kind of just said, we don't really know how to help you".

Young people were unhappy with the way that both diagnostic and mental health services were 'disjointed'. This was noted in several different ways. Those who had moved away from home to attend university commented on how services in different locations did not work together effectively:

"I essentially got bounced around between systems. I registered with a GP in [the town that I first attended university] and talked to him. He referred me to the Adult MH Services, and I had a phone meeting with them where we discussed options and I said that I would prefer counselling to CBT. In the end they said that to do that I should be referred back to [my home town] to see the counsellor there, and then I had a meeting with her and was put on a waiting list for several months, but never actually got anything before I left for uni here...".

Others also commented on the lack of a pathway when transitioning both between and within services:

"I got my diagnosis just after I'd left CAMHS, 'cause I turned 18 ... and if there is a support service that the people that diagnosed me would have been able to offer me they couldn't because they were from CAMHS, not AMHS. So they were kind of like, we can't really do anything ... And they kind of, they sent me a list of support groups and that was about it.

CAMHS were perceived positively by the young autistic people we spoke to:

"even though there's a 0 to 16 service and a 16 to 19 service, they allowed me to stay with the same person from when I was 15 right through to when I was 19... they kind of just did everything they could to work with me rather than just against me and out of a book... I was lucky that I had CAMHS for as long as I did".

Yet, the *poor transition from child to adult services* was heavily criticised, with many young people reporting a sudden decrease in the amount of help and support available: "you hit 18 and all your services just go poof and just disappear".

Child services were found to offer more help and support on an ongoing basis, so the lack of adult services was concerning for many young people:

"Before turning 18, I got regular support but now I'm 18 they say that I'm too well to get referred to anyone. I'm worried about the future. There was always someone there before. What will happen when it gets cut?".

Concerns were also raised about the huge transition from child-centred services to less supportive adult services, and how they would cope:

"there's like been this definite shift in terms of appointments being less regular, you have to kind of book your own appointment, you have to go there...".

The young people also felt that the criteria for accessing support was different for child and adult services, with adult services requiring the individual to be in crisis:

"when I was discharged from CAMHS when I was 19, that was it basically, there wasn't any kind of support from the mental health side of things mainly because to get into adult services, you have to be like acutely mentally unwell there and then, it wasn't like a thing, we'll refer you and then give you support so you don't get unwell, it's kind of like, we'll refer you when you are unwell".

When support was offered via adult services, the young people felt this to be less structured than what they experienced in child services:

"especially after having just come out of CAMHS into AMHS, there just didn't seem to be any sort of pre-existing support system that they had...it was just, we have some support groups".

The exception to this pattern was those still in education, who still had access to quite structured support. Nevertheless, these young people also expressed concerns about what would happen to them afterwards:

"the help I got fluctuated as I've got older and now at uni it's great 'cause I have a teaching assistant, I have a mentor, and I have all of these other things just from DSA, which is great, but next year, I'll probably be graduating from uni ... what's going to happen next after that help has kind of almost disappeared?".

The young people felt that adult services gave more control and power to the service users to manage their own mental health:

"it would be like, no, you need to make that decision or it's very much put onto you, which to a certain extent I can understand because you're an adult, you need to take control of your life but actually like for me, I kind of needed the ideas to start that process off and they weren't willing to give me that kind of thing".

Indeed (perhaps due to experiencing mental health problems), some felt that they were not yet at the stage where they could manage this independently:

"mentally I wasn't an adult. I'd only just come out of hospital, I hadn't experienced like a good couple years of my life, I hadn't been at school. I was still like really immature anyway and I didn't act like an adult and it was kind of like they were there treating me, expecting me to behave like an adult, not taking into perspective what actually had happened in my past kind of thing".

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This was felt to be an issue for any young person, but particularly young people on the autism spectrum: "I think people have this sort of weird perception of becoming an adult but they don't have a perception of what it's like to be a disabled adult, as it were and that's a very different side to it".

Many young people reported that they wanted "something more long term". Others, aware of the limited nature of such services, were particularly pleased to have been given tools and techniques to manage their needs:

"[the support] started to form the basis of when I've been implementing my own self-managing techniques and then that built on further at uni when it was sort of much more about the organisational, you know, how are you going to be able to implement your coping strategies with your lectures on top and that sort of thing. So it helped along that sort of process of independence".

Unfortunately, for other individuals, the support had simply not been of use:

"I've consistently been let down by all of the people that were supposed to be able to diagnose me and be able to know what would support me and all of that stuff. It was just consistent my whole entire life. I don't think I've ever had one particularly useful bit of advice ever".

Overall, interviewees were unhappy about the standard of the services they accessed: "I wasn't very happy with any way that my mental health was handled my whole entire life really".

In spite of this, they were made to feel that should express gratitude that they were receiving any support at all: "I just felt like a burden 'cause I didn't get as much as I wanted to but I was made to feel that that was more than I deserved".

Trusting relationships

Family and friends were perceived as a strong source of support:

"my family have been amazing throughout all of it and like never judgmental about any of it at all".

This was felt to be essential as a lack of professional support resulted in many young people relying on "an informal network of friends and family, who sort of got it and understood it, so if I needed to vent or say, this isn't working, I have no idea what to do, they're able to sort of say something at least".

Yet, many were reluctant to use such support for fear of worrying their family and friends: "I won't really talk to them because I don't want to worry them ... if I told them, they'd worry and they'd probably want me to come home [from uni]"; or burdening them:

"I usually go to my mum or my boyfriend, because they're both really open about mental health issues and don't make me feel judged. It is a bit of a problem though, because they have their own problems too, so if they have problems at the same time then I don't know who to turn to".

Many young people we spoke to wanted to bridge the gap between formal support (from healthcare and educational services) and personal support (from friends and family). Peer support was suggested as a compromise between the two:

"It would have been nice to have someone who understood exactly what I was going through"; "I like having that connection with other people who are, who are autistic. I hold that very dear, and I really feel it's vital to foster that relationship in general in autistic people".

However, they added that this support needed to be tailored to an individual's needs, rather than simply providing access to a generic group of autistic people:

"there wasn't anything out there for girls, like every single person she spoke to was like, we have this group but it's just four or five boys in it and there's no - like why would I want to go to a group with five teenage boys?". There was also a desire for the support to be formal, facilitated by specially trained autistic people: "I got given a mentor [at university] and they were like, 'yeah, yeah, he's done the same degree as you, he's on the spectrum, it'll be great', but it was just like another person on the spectrum (laughs), it wasn't a mentor, it was just like they didn't have any mentoring skills. It was just, it was just like talking to myself".

The young people emphasised the importance of having strong, trusted relationships with friends and family members, and strived for this with professionals too. Unfortunately, there was a general sense of negativity regarding the professionals they encountered:

"I've consistently been let down by all of the people that were supposed to be able to diagnose me and be able to know what would support me and all of that stuff. It was just consistent my whole entire life", particularly due to limited knowledge of autism: "the guy that I spoke to there was utterly useless. He quite literally Googled the symptoms in our meeting, and since I'm quite "high functioning", I was a very mediocre match, so he dismissed the idea...so we decided to get a private diagnosis".

However, some young people highlighted that this very much "depends on the **person you get**", and examples of good practice were noted:

"he took me seriously, he got me the help that I needed, he sent me to the right people and he like referred me to CAMHS and wrote the referral in a way that would mean I would get the help that I needed. And he was lovely and he always

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like, even now, he's still interested in how I am doing and how things are for me, so that's good".

Ultimately, there were a number of qualities that young people felt professionals needed to display, which centred on the principles of trust and respect:

"my CAMHS worker was really good and she kind of didn't patronise me and she didn't annoy me or say things that made me feel worse, she just basically listened and let me just vent to her and tried to get me to explain how I was feeling";

"I had someone I can trust to speak to so like a confident, who I could actually tell how I feel and not have to worry whether someone's listening or being judged for it";

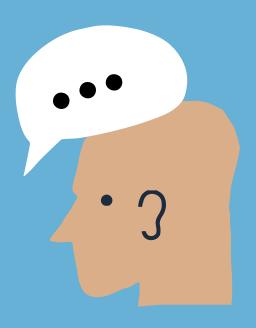
"he kind of let me lead the sessions and kind of asked me what I needed but she knew that I was like, like I knew myself, I knew myself best and she, she respected that and kind of worked with me".

Whilst many young people highlighted the importance of having strong personal support, they felt strongly that this should not take the place of professional support:

"What I'd like is somebody I can trust, someone to talk to and someone who understands autism; a professional person".

ONLY 14% felt very or extremely comfortable disclosing mental health issues to healthcare professionals.

ONLY 10% felt very or extremely comfortable disclosing mental health issues to educational professionals



RECOMMENDATIONS

The young autistic people who took part in our research experienced a range of challenges as they navigated the neurotypical world. Our survey respondents felt unhappy and depressed, worthless, under strain, unable to overcome their difficulties, unable to face up to problems, and lacking in confidence. They also reported their quality of life to be poor. These difficulties were felt to be exacerbated by co-occurring mental health problems, which were present in an alarming majority of our sample (approximately 80%; see also 22, 37). It is not acceptable for "normal" to be so negative for young autistic people. In the words of one young person, "something needs to change".

This change begins with helping the young people identify the challenges they face. Difficulties identifying the signs and symptoms of mental health problems are not unique to young autistic people. Non-autistic young people also have difficulties understanding their own thoughts, feelings and behaviours; they struggle to know whether what they are experiencing is "normal" and whether they need to seek professional help (38-40). Nevertheless, it is likely that there are unique problems faced by young autistic people. Specifically, young autistic people reported finding it difficult to identify the changes in their thoughts, feelings and behaviour that might be a sign of a mental health problem - an issue that could be especially challenging for those who find it hard to express their needs.

As part of the Know Your Normal campaign, Ambitious about Autism's young volunteers have developed a toolkit that aims to support young autistic people in identifying if and how their "normal" thoughts, feelings and behaviours may change when they are experiencing mental health problems. As well as supporting the young people in identifying the presence of mental health problems, it provides a concrete tool to show to other people (e.g., health or education professionals, friends and family, charity representatives).

Having assisted with the identification of mental health challenges, it is also vital to help to secure essential support for autistic young people. In this regard, our results highlight three key areas for urgent action:

1. More initiatives to reduce stigma of autism and mental health

Young autistic people reported high levels of stigma associated with both autism and mental health problems. This made them reluctant to discuss their needs with other people, such as professionals or friends and family, particularly if they were experiencing 'severe' mental health issues (e.g., psychosis, personality disorder). Stigmatising attitudes towards mental illness abound, with mental health problems considered to be one of the most powerful stigmas (41).

RECOMMENDATIONS

Young autistic people with mental health problems may be *doubly disadvantaged* in this respect. This is deeply concerning. The Ambitious about Autism Youth Patrons are leading the way in reclaiming the word "normal" and ensuring that young autistic people should not face stigma or discrimination due to differences associated with their autism or problems with mental health. Yet, unfortunately, autism awareness raising is often scaremongering or negative in nature. Campaigns should (i) stress that autism is associated with skills and talents, as well as potential difficulties, (ii) focus on identifying solutions, opposed to just making people aware of 'problems', and (iii) be autistic-led, to ensure that the 'right' messages are being presented to the public.

2. Increased training for professionals

Young autistic people want to feel confident that the people from whom they seek help are knowledgeable about autism *and* mental health difficulties, understand the unique challenges associated with being a young autistic person with mental health problems, and show genuine concern for their wellbeing.

Many organisations are aware that they are not meeting the needs of their autistic service users and are taking positive steps to address this gap. This needs to be more widespread.

3. Greater autistic involvement in service design and delivery

The young autistic people we spoke to highlighted that they encountered several barriers when trying to access appropriate help and support. Many of these barriers (e.g., a lack of available services, poor transitions from CAMHS to AMHS, lengthy waiting times) are not unique to young autistic people and have been highlighted by young neurotypical people too (8). Yet young autistic adults are, again, doubly disadvantaged – facing a lack of support in relation to both autism *and* mental health – meaning that they are unlikely to benefit from services designed around the neurotypical norm.

To ensure that young autistic people can access mental health support tailored to their specific needs, professionals should involve young autistic people in the design of services that ultimately affect them. Only by listening to and learning from young autistic people – and valuing their experiential expertise – can we truly hope to meet the needs of this vulnerable group.

CONCLUSION

Young autistic people are already potentially at a disadvantage simply because society does not understand what it is like to be autistic. The findings of our report highlight that young autistic people might be particularly disadvantaged because of the mental health challenges that confront them.

These young people find assessing their own needs and securing the support they need to alleviate difficulties in their mental health extremely difficult. To reduce this disadvantage, our findings suggest that more needs to be done to support young autistic people identify what is their normal and when they deviate from it. We recommend creating more initiatives to reduce stigma around autism and mental health problems, improving knowledge of both of these issues in the professionals supporting young autistic people, and ensuring that the voices of young autistic people are included in the design and delivery of services that, ultimately, affect them.

As with all young people, autistic young people need and deserve the very best support to help them enjoy a high quality of life and reach their undoubted potential. The recommendations in this report will help us to achieve that vital goal.

ABOUT US

The UCL Institute of Education, University College London, is both the largest and the leading research and teaching institution into education theory and practice in the UK. It houses the Centre for Research in Autism and Education (CRAE), a unique centre focused on helping to enhance the lives of autistic people and their families (crae.ioe.ac.uk) though (i) conducting ground breaking scientific and applied research to enhance knowledge about interventions, education and outcomes for autistic children, young people and adults and (ii) working with professionals on the ground and with those directly impacted by autism to promote awareness, and acceptance, of autism.

Ambitious about Autism is the national charity for children and young people with autism. They provide services, raise awareness and understanding, and campaign for change. Through Treehouse School and Ambitious College, they offer specialist education and support. Their ambition is to make the ordinary possible for more children and young people with autism.

myVoice is a project for 16-25 year olds with autism. It is funded by the UK's Department of Health, and it aims to connect young autistic people, to allow them to have a say in their local communities.

The myVoice team have been working with Ambitious about Autism on the Know Your Normal campaign (www.knowyournormal.co.uk).

CITATION & REFERENCES

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