



#KNOWYOURNORMAL

Young people with autism's experience of mental health

What is

'NORMAL'?



‘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’



**Ambitious  
about Autism**

## ABOUT OUR YOUTH PATRONS

Ambitious about Autism work with a wide network of young people with autism, to shape what we do. These young people sit on our Youth Council, on advisory boards we support and create content for our site. Youth Patrons volunteered more than 1000 hours to making the ordinary possible for children and young people with autism in the last year, including running our 'Employ Autism' and 'Know your normal' campaigns.

## ABOUT AMBITIOUS ABOUT AUTISM

Ambitious about Autism is the national charity for children and young people with autism. We provide services, raise awareness and understanding, and campaign for change. Through TreeHouse School, Ambitious College and the Ambitious about Autism Schools Trust, we offer specialist education and support. Our mission is to make the ordinary possible for more children and young people with autism.

## ABOUT THE CENTRE FOR RESEARCH IN AUTISM AND EDUCATION

The Centre for Research in Autism and Education (CRAE) is a partnership between UCL Institute of Education (IOE), University College London, the leading centre for education and social research in the UK, and Ambitious about Autism, the national charity for children and young people with autism.

## ABOUT AUTISM

Autism is a lifelong developmental disability which affects one in 100 people in the UK. It affects the way a person communicates and how they experience the world around them. Autism is described as a spectrum condition. This means while people with autism including Asperger Syndrome share certain characteristics, they will be highly individualised in their needs and preferences. Some people with autism are able to live independent lives, but others may face additional challenges including learning disabilities.

Early intervention, education and support are critical if children and young people with autism are to lead fulfilling lives, learn, thrive and achieve.

\*All names have been changed in this report to protect privacy.

# INTRODUCTION



**In October 2016, 18 young people with autism sat in a room discussing what they thought was the biggest issue for autistic young people at that moment – and unanimously agreed that it was mental health.**

Together with UCL's Centre for Research in Autism and Education, we (Ambitious about Autism Youth Patrons) designed and undertook research about young people with autism to gain an insight into their experience of mental health.

The findings were upsetting to say the least, with four out of five saying they have experienced mental health issues, but only 4% being extremely confident in knowing who to ask for help.

Over two thirds of young people said that if they did ask for help they had little or no confidence they would get what they need.

**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."**

Jane\*

We believe that the findings above are shocking and something a developed nation like the UK should be ashamed of.

We believe that the best people to come up with solutions are those closest to the problem. As young people with autism it's our opinion that it is possible to make a significant difference, if:

- ▶ young people with autism are given the support they need to identify and communicate their problems,
- ▶ the stigma around mental health and autism is reduced and the links and differences between the two are recognised,
- ▶ services are easy to find, accessible and most importantly able to meet the needs of each individual.

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

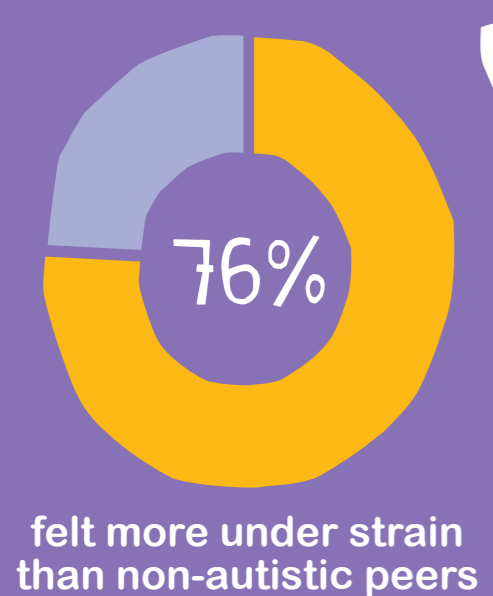
Robert

This report outlines the extent of the problem and how we intend to make a difference. We hope we can count on your support to improve thousands of young people's lives.

**Thomas Kingston L.L.B. (Hons) FRAS  
Policy Co-Lead | Ambitious about Autism  
Youth Council**

# Our research found that **4 OUT OF 5** young people with autism have experienced mental health issues.

Even more worryingly, **76%** said that when they are not experiencing mental health issues they believed they felt more under strain than their non-autistic peers.



“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.”

**Ali**

**Dr Laura Crane** says in the research: “Young autistic people felt that their ‘normal’ was different to that of other people and, strikingly, rather negative in nature. For example, 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 lacked confidence.

It is not acceptable for unhappiness and depression to be seen as the ‘normal’ state for young autistic people. Indicators of the presence of a mental health problem can be

subtle – this may make it difficult for the young autistic people (and other people who know them) to identify that they are experiencing mental health problems. This is a particular issue since young autistic people often reported finding it hard to express their needs.”

“I’m very in tune with my body and know instinctively when something’s wrong. I need help communicating precisely what the problem is.”

**Josie**

## Youth Council’s View We must have support identifying and communicating how we feel



Fern says: “One of the problems with people always looking at people with autism differently is they forget we have shared experiences. So we can get stressed out or unwell too. People spend so much time looking at what makes us different than everyone else, they might miss the signs we’re becoming unwell. And because we get told so often that our unique behaviours are a problem, we might not recognise in ourselves when something is going wrong.

It’s already hard enough for people with autism to seek help for their wellbeing, we often struggle to be taken seriously, and if we are telling people we don’t feel great then dealing with their emotions about that can be difficult too.

And that’s why it’s so important that we, and the people in our lives know what our normal looks like. Knowing how we normally behave when we are well, accepting that and communicating it as our normal is really important. It helps us and the people who care about us tell when something has changed, and makes it easier to seek help.

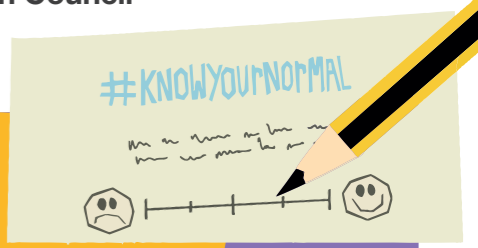
We want autistic young people themselves to have the tools to define and voice their own experiences, allowing them to recognise when and where to get support, be taken seriously and as a result gain independence, autonomy and be healthier.



We’ve created a tool to help with this. Everyone can use it – whether they are autistic or not to help them explain their normal. We hope it’ll tackle the idea that we should all be the same head on, showcase the wide variety of ways we behave when we’re healthy, and make it easier to get help when we’re not.”

**Fern | Youth Patron and Co-Lead Campaigns | Youth Council**

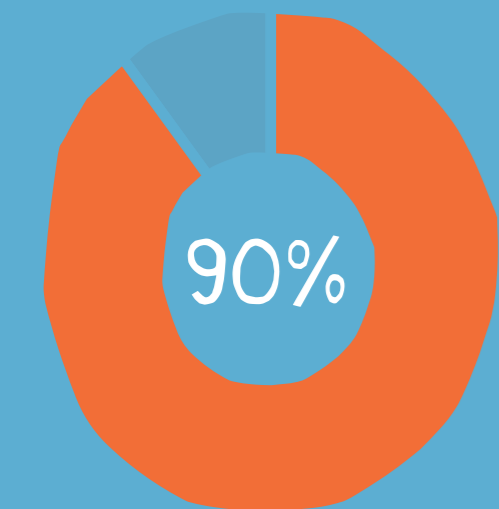
## THREE WAYS TO HELP A YOUNG AUTISTIC PERSON YOU KNOW COMMUNICATE ABOUT OUR FEELINGS AND MENTAL HEALTH:



- 1 **Take the time to understand our preferred method of communication, and regularly use it to listen as well as transmitting information.**
- 2 **Use our toolkit to record what we are like when we are happy and well – so it’s easier to notice and explain if something changes.**
- 3 **Don’t accept that being unhappy or stressed is an inevitable part of autism – it isn’t. If you notice someone’s behaviour or mood has changed encourage them to visit their GP, and use the toolkit to prepare for their appointment and help them explain to the GP what has changed.**

Our research highlighted that **STIGMA** and a lack of understanding about both autism and mental health issues (and particularly the difference between the two) made things worse for young people with autism.

A lack of comfort about disclosing mental health issues to educational professionals was experienced by **90%** of young people according to our research.



felt uncomfortable disclosing mental health issues

“ If I’m actually having a really bad day then [autism and mental health problems] kind of blur into one and I’ll think if I didn’t have [autism] in the first place, then I wouldn’t have got depressed or unwell or anxious or anything like that. 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.”  
Jenny

“ It’s not easy to get support for mental health problems. I’m often told ‘that’s because you’re autistic’ even when I’m sure it’s unrelated/something I haven’t experienced before.”  
Jake

“ I’m definitely more open about [mental health problems] than about the autism.”  
Lucy

“ 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.”  
Kyle

## Youth Council’s View

We must reduce stigma and increase knowledge around mental health and autism.



Jack says: “The stories in our animation are humorous and hopefully people will laugh along with us and realise they do some things that other people might not find normal too, and that actually that is okay.”

We hope people will share their unique behaviour with us using the hashtag **#knowyournormal**. And help reduce misunderstandings and stigma around autism and mental health by concentrating on what we have in common.”

Jack Welch | Youth Patron and Vice Chair of Ambitious about Autism’s Youth Council



Sharing our animation is a great way to explain to people that being autistic isn’t a bad thing, and that if people with autism experience mental health problems, then like everyone else they should seek help.

## YOU CAN HELP

REMOVE THE STIGMA AROUND MENTAL HEALTH AND AUTISM FOR YOUNG PEOPLE WITH AUTISM YOU KNOW BY:

- 1 Ditching negative language. Referring to autism as a problem or a disorder, or using negative language around mental health conditions is unhelpful, and makes it harder for us to talk to you about our experiences.
- 2 Celebrating our individuality – with our autism as a part of that celebration.
- 3 Talking about seeking help and self-care as signs of strength, and making sure you model that for us yourselves.

# The young people with autism we spoke to struggled to access support.

**ONLY 4%**

were extremely confident in knowing who to ask for help.

**TWO-THIRDS**

said that if they did ask for help they had little or no confidence they would get what they need.



“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 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...” Phoebe

“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.” Ezra

“I asked for a GP referral to a service for people with autism, but they didn’t have any to suggest.” Bob

“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.” Louise

“Another 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 and again without an answer.” Nicky

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



## These experiences aren’t inevitable. Some young people talked positively about support they’d received:



We went to somebody who actually knew what he was doing with people on the spectrum, so it means that I find it helpful, it’s meaningful to me in that period of time to focus and recognise what are the specific things with autism rather than having to think slightly more about what was causing the anxiety.”

Joshua



There was a nurse on the ward who was like kind of assigned to me and she was really lovely and she like specialised in autism and she like worked with me and, she kind of explained things to me in ways that I would understand it and she worked with me to like help my family understand me better. She worked with how I could learn and understand things.”

Amanda

## Youth Council’s View

We must be able to find and access suitable support when we need it.



Georgia says: “Providing the right services to autistic young people who are experiencing mental health issues is the right thing to do.

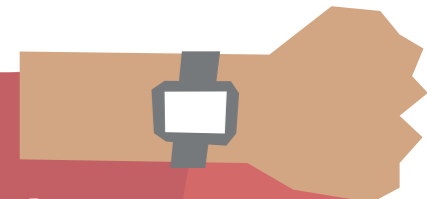
Intervening early maximises the chance of being able to help, and in the long term will often cost less than waiting until we need crisis care. With the right support at the right time the chances of us reaching crisis are reduced.

And what do the right services look like? Well probably they are designed with the people who might want to use them, alongside professionals who understand autism, and the impact that small reasonable adjustments can make to autistic people’s ability to ask for and access help.

We’ve designed some training for health commissioners, people who work in GP’s surgeries and all public health workers to help them think about how they adjust services to better meet our needs.”

Georgia | Youth Patron & Co-Lead Training and Consultancy | Youth Council

## GETTING THE RIGHT HELP AT THE RIGHT TIME WOULD BE EASIER IF:



- 1 Everyone at GP’s surgeries knew enough about autism to plan for our visits to be as successful as possible. This might include offering double appointment slots, providing tools like our ‘Know your normal’ toolkit to help us prepare for appointments, and letting us know when surgeries are running late and how long for.
- 2 Every Clinical Commissioning Group was able to identify where they have staff who understand both autism and mental health, and ensure that GPs know where to refer young people with autism in need of mental health support to these professionals.
- 3 Mental health support services were co-designed with people who are autistic, so our needs are considered right from the start.



Ambitious about Autism

Ambitious about Autism’s Youth Patrons have designed training for health providers about autism and mental health – you can find out more here: [knowyournormal.co.uk/training](https://knowyournormal.co.uk/training)

# SO FINALLY...

It is not okay that 4 out of 5 young people with autism are experiencing mental health problems. Nor is it inevitable.

We hope you'll use our resources to begin to make a difference:

## USE OUR TOOLKIT...

To help young people identify what normal looks like when they are healthy and well and explain any changes.

## USE OUR ANIMATION...

To tackle stigma around autism and around mental health.

## TAKE OUR TRAINING...

To better prepare your team to support us.

ALL OUR RESOURCES CAN BE FOUND AT  
[KNOWYOURNORMAL.CO.UK](https://knowyournormal.co.uk)

## THE RESEARCH AND STATISTICS IN THIS REPORT

A team of academic researchers from the Centre for Research in Autism and Education (CRAE) and young autistic people worked together – as 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.

All statistics quoted in this report are from our research. All quotes are also from the research – names have been changed to protect privacy of interviewees. To find references, statistics or to read the research in full visit: [knowyournormal.co.uk/research](https://knowyournormal.co.uk/research)

### Our Youth Patrons would like to thank:

- ▶ Everyone who took part in the research and the structured interviews.
- ▶ Each other – over 40 young people with autism worked on the tools, resources, research and promotion of **#knowyournormal**. It's been brilliant to work as such a wide team.
- ▶ Laura Crane and Liz Pellicano at the Centre for Research in Autism and Education (CRAE), UCL Institute of Education, for working on the research with us.
- ▶ Juli Crocombe and Ian Davidson for their advice and support.
- ▶ Carole Buckley – for adding the toolkit to the GP's resources.
- ▶ The 500 professionals and individuals who booked tickets or waiting list places for our first ever youth lecture. Thank you for showing us you care about hearing what we have to say.
- ▶ The Department of Health, Comic Relief and Charlotte Grobrien for funding Ambitious about Autism's participation work.
- ▶ Ambitious about Autism's whole staff team – for listening to us, taking us seriously and helping us to get our voices heard.





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