

Improving access to healthcare for autistic children and young people

Ambitious about Autism and The Whittington Health NHS Trust have been working together since 2016 to improve access to healthcare for autistic children and young people by tackling the low level of awareness of autism amongst staff members.

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Who are we?

Ambitious about Autism is the national charity for autistic children and young people. We provide services, raise awareness and understanding, and campaign for social and policy change. Through TreeHouse School, The Rise School and Ambitious College we offer specialist education and support. Our ambition is to make the ordinary possible for autistic children and young people.

About our Youth Patrons

Ambitious about Autism works with a wide network of autistic young people aged 16-25 to shape everything that we do. Some of these young people sit on our Youth Council, on advisory boards for the work we do with external partners and create content for our website and other channels. The Youth Patrons tackle marginalisation and isolation and encourage young people to participate in decisions that affect them. Supported by a growing online Ambitious Youth Network, they represent the autistic community by engaging with policy makers, businesses and the media, empowering individuals to speak out and create a perspective shift within society. The only groups of their kind in England, the Youth Council and Ambitious Youth Network have become the foremost authority on the inclusion and representation of young autistic people.

The Whittington Health NHS Trust

Whittington Health aims to help local people live longer and healthier lives by providing safe, personal, coordinated care for the community we serve. They provide hospital and community care services to 500,000 people living in Islington and Haringey as well as other London boroughs including Barnet, Enfield, Camden and Hackney. As one organisation providing both hospital and community services, they are known as an 'integrated care organisation'. Whittington Health is committed to enabling the NHS Improvement standards for learning disabilities and or autism which propose to help NHS trusts measure the quality of care they provide to people with learning disabilities, autism or both.

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The Ambitious about Autism Youth Patrons (a group of autistic young people aged 16-25) identified that they struggled to access healthcare and did not receive care or support that met their needs. They knew that there was not equality of healthcare outcomes for young autistic people and that this needed to change.

Starting in 2016 the Ambitious Youth Patrons have worked with The Whittington Health NHS Trust on a range of co-produced activities to improve autistic children and young peoples' access to healthcare. Being committed to the NHS Improvement Standards, Whittington Health decided to set up the Children and Young People Learning Disability and Autism Working Group in 2018 to enable the changes required. This group has enabled Whittington Health to engage with young people and families and have co-production at the forefront of decision-making and improvement. Staff and Youth Patrons from Ambitious about Autism have played a key part in this group since its formation.

The background statistics

There is estimated to be around 700,000 people on the autism spectrum in the UK and many face health challenges.

- 71% of autistic children have mental health problems, such as depression, anxiety or obsessive compulsive disorder and 40% have at least two other conditions
- Approximately 30% of autistic people have epilepsy

However, medical care often doesn't meet their needs. The National Autistic Society found that:

- 76% of autistic people or parents of autistic children feel the doctor doesn't make changes to meet their or their child's needs
- 88% feel that health professionals don't understand the conditions that co-occur with autism

A study in Sweden, peer-reviewed by the British Journal of Psychiatry found that:

- The average age of death for a person with autism is 54 years, compared with 70 for matched controls, with the two main causes of death being suicide and epilepsy
- The study concluded that social and communication difficulties may mean that autistic people have more difficulty accessing healthcare or discussing health problems, signs and symptoms with doctors and that it is important that people working in healthcare are aware of this risk association

The policy context

- In 2019 a consultation was launched on mandatory learning disability and autism training amongst health care professionals after a petition around reducing avoidable deaths
- The NHS launched its long term plan and is prioritising improving healthcare outcomes for autistic people and those with a learning disability
- In April 2019, The Secretary of State for Health and Social Care, Matt Hancock announced his intention to run an autism awareness campaign in late 2019
- Since the start of 2019, the government has been calling for evidence on extending the Autism Strategy to children as well as adults, meaning that there is more opportunity than ever to influence policy and improve outcomes for all autistic young people.
- Within the Autism Strategy, the government have announced that "reducing the gap in life expectancy for autistic people" is their top autism priority.

What have we done?

- Gathered feedback on the healthcare experiences of young autistic people and their families
- Established an autism and learning disabilities working group – attended by staff from across the Whittington Health NHS Trust and Ambitious about Autism
- Conducted ward inspections of paediatrics and emergency department – and implemented recommendations e.g. better signage, a quiet space to wait
- Delivered Know Your Normal mental health training for 15 staff and Autism Awareness Training for 25 reception and public-facing staff
- Developed resources to support autistic children and young people: a patient passport, ward-specific visual stories and an awareness poster, available on the Whittington's website
- Designed and delivered an Autism Awareness Day for the Whittington Health NHS Trust, attended by up to 60 professionals.



I think autistic people can face lots of barriers in accessing healthcare. They may struggle knowing why and when they need to access healthcare. It can be hard to know whether you need professional help and communication can be hard when you get there.

Rayhan, Youth Patron

What is Know Your Normal?

Know Your Normal is an Ambitious about Autism Youth Patron project with the Centre for Research in Autism and Education focused on understanding young autistic peoples' experiences of mental health. The co-produced research found that four out of five young autistic people have experienced mental health issues, but only 4% were extremely confident in knowing who to ask for help. As well as the research report the Youth Patrons designed and created a toolkit which aims to help explain what your 'normal' is.

Youth Patron Fern explains "People spend so much time looking at what makes us (autistic people) 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. 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."

To complement the research and toolkit, the Youth Patrons designed a training session that was delivered to Whittington Health NHS Trust staff covering autism awareness and how to use the Know Your Normal toolkit with patients.

You can find the free toolkit on the Ambitious about Autism website www.ambitiousaboutautism.org.uk/know-your-normal or in the Royal College of GPs pack.

What are the co-produced resources?

Working with focus groups of Whittington Health NHS Trust staff, Ambitious Youth Patrons and parents of autistic children, we designed the following resources. These resources are available on the Whittington Health website, printed on-site and shared locally through education and social care services.

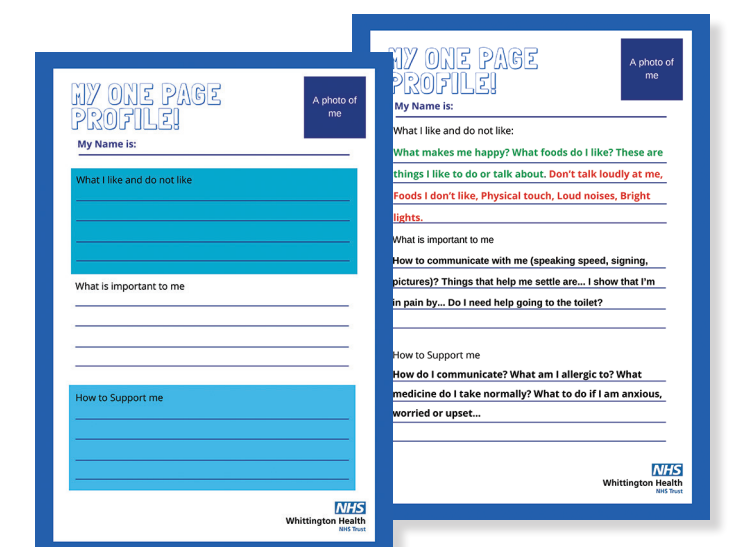
A patient passport

This is a tool to find out more about your patient. This should be kept in a central location and should be linked to their note. The patient or their family should also bring a copy to appointments or inpatient stays. The Youth Patrons think that by finding out more about your patient you can reduce their fear and anxiety and use their likes and dislikes to ensure their appointment or stay is more successful.



Ward-specific visual stories

This is a tool to reduce anxiety about appointments and inpatient stays by reducing the unknown elements. These visual stories give information about the layout of wards, the sensory experience (lights, sounds, smells) and what is likely to happen through photos and simple sentences. Patients and families can use these to prepare themselves beforehand or they can be provided on arrival in a clinic or ward. As well as ward-specific stories, we have also created an empty template for any service to download and fill in.



An awareness poster

Based on the principles of 'Ask, listen, do' this poster outlines what staff promise to do and what young autistic people want staff to do in healthcare settings. These short tips were created by trust-wide staff and the Ambitious Youth Patrons. By printing these posters and having them in wards and rooms, healthcare professionals can consult the list to improve practice and patients can consult it to remind them of the level of care they are entitled to.



The Autism Awareness Day – April 2019

We ran a Whittington Health NHS Trust-wide awareness day to give healthcare professionals more information about how to work with young autistic patients and what resources were on offer. The Youth Patrons introduced the day, sat on a panel about experiences of healthcare and co-delivered a workshop on how to use the resources they had co-produced. The day was focused on learning and sharing examples of best practice.

Before the day began, all HCPs (healthcare professionals) agreed to some extent that they could benefit from further training and over half of HCPs (52.0%) agreed they had previously had little training.

When asked what they were most interested to learn about during the day, responses included: support in practice, improving communication skills, barriers to accessing healthcare services and how best to commission and design services with co-production.

At the end of the day:

- 95.5% of HCPs agreed to some extent that they could benefit from further autism training
- 95.2% of HCPs agreed that they felt they could communicate better with autistic patients
- 83.3% of HCPs agreed that their confidence interacting with autistic patients had improved
- 91.3% agreed to some extent that they had better specific knowledge of autism after the awareness day

The session with the highest-rated evaluation score in learning outcomes was the panel with young people and parents of autistic children about their experiences of healthcare.

What we want to do next and our offer

What we want to do next:

- Continue our work with the Whittington Health NHS Trust with further autism awareness days and training for trust-wide staff, monitoring staff engagement and improvements in practice
- Use co-produced resources and training to work towards reducing the administering of general anaesthetic for routine procedures, achieving financial savings for the NHS and reducing anxiety around appointments and procedures for patients
- Extend the visual stories to cover procedures as well as wards i.e explaining blood tests, MRIs
- Widen the programme to include autistic adults in the Trust
- Work alongside mandatory autism and learning disability training, the NHS long term plan and the Autism Strategy to ensure all outcomes are met

Our offer

We are keen to share evidence and work with other NHS health trusts across England to improve access to healthcare for all autistic young people. Our Youth Patrons are from across England and are experts on healthcare experiences and how to improve practice.

Contact information

If you are interested in a co-produced project with Ambitious about Autism, please contact **Emily** or **Sarah** at participation@ambitiousaboutautism.org.uk. If you want more information from **The Whittington Health NHS Trust** contact **Colette**, Nurse Consultant at colette.datt@nhs.net.