

who struggle to make sense of the world around them and therefore find it difficult to cope with change. It also generally takes longer for a person with autism to be able to open up and express their feelings. That's why our young campaigners say it is so important that they see and get to know one person at CAMHS consistently, rather than lots of different people.

"I want to see the same doctor who I get to see for long periods of time."

But they have also had bad experiences with professionals who didn't have a good understanding of autism, so they also want to have the right to see a different person if necessary.

"[My doctor] took away my diagnosis... he didn't get Aspergers."

"I remember a time when I had a therapist who said she was well trained in dealing with people who are autistic... but she was actually used to working with [other] children... so I thought it was a bit of an insult really."

9. The environment should have a space for you to release stress

"I'd like a room where I can break objects, where I'm allowed to wreak havoc."

People with autism sometimes struggle to communicate their feelings verbally, so will look for other ways to express how they are feeling. This may lead them to display unusual or challenging behaviour. Our young campaigners feel it would be helpful to have a room where they could physically release their stress in a safe and controlled way when they are finding it difficult to say how they are feeling.



"[I'd like there to be] a punch bag... if you can just hit that, you can release anger."

"A jump-in ball pool... might take your mind off the stress of going to see someone you're not sure about and you've never met before."

The young campaigners also told us that they found it useful when CAMHS professionals were able to communicate with them in non-verbal ways; for example, by using anxiety scales, emails and texts, or other interventions and therapies.

10. CAMHS should make sure you can see someone when you need it (eg bad day drop-in) or that you can contact them by phone or email

Many of our young campaigners have had times when they really needed help but there wasn't anyone to contact at CAMHS. They also say how hard it was to have to go to an appointment and try to describe feelings that they had days or weeks previously. They want to be able to get support when they are having a bad day, or when they feel able to communicate how they are feeling, and not have the stress and pressure of having to wait to discuss everything at a set appointment time, when they are likely to have higher anxiety levels.

"They just expect me to sit there for an hour of nothing when I don't want to talk to them, because that's the only option I was given... It's 'an hour now and we'll see you in two months!'"

11. CAMHS should offer home visits, along with visits to services and going somewhere neutral

Going to unfamiliar places can be incredibly stressful for a person with autism. Our campaigners don't feel that CAMHS buildings are always the most welcoming of places.



"It feels like you can't get out once you're in there... because you have to press the buzzer it's like you have to get permission to go in there and stuff."

"My building... it just looks like all it's missing is thunder and it's like a horror flick... it looks like a place you go to get worse, not a place you go to make you feel better."



With thanks to our Young Campaigners: Ben, Hayley, Henry, Hollie, Jacob, Kate, Ralph and Simon.

"When you go in it's so silent... and they say 'hang on a second, I'll see you in a minute' and you're just waiting there twiddling your thumbs."

"Some of the rooms have interview mirrors and there can be cameras up there and that's kind of nerve racking... It can be very daunting."

The high levels of anxiety this causes make it more difficult to assess and treat a child with autism appropriately. Therefore, it is often better both for the young person with autism and the professional working with them to meet somewhere where the child feels comfortable. As every person with autism is different, our young campaigners suggest offering a choice between home visits, going somewhere neutral and meeting at the CAMHS building.

12. CAMHS should take you out to help you through scary situations

For people with autism, difficulties in making sense of the world around them and understanding social cues and expectations are a huge cause of anxiety and frustration. Our young campaigners say they would like help to develop practical strategies to cope with situations that they find stressful or frightening and which have a negative impact on their mental health. It can be difficult for a person with autism to generalise and apply techniques learned in one situation to another, so it is easier for them to learn those techniques in the situation in which they will have to apply it.

"I was at the point where I found it really scary just to walk to the shop at the end of my road because I was worried about all sorts of things - but for someone just to do that walk with me and, step by step, talk through all the fears around that walk, would have helped me as opposed to just sitting in the room... just saying it to you as opposed to doing it with you..."

I always find [doing things] a lot better because then the next time you do this you can have in your head the person walking with you and what they were saying... having to take all the things from that appointment into that situation is a lot harder than actually them being with you."

"When they give you solutions, and say 'when you're in that situation, do this or do that', my problem is that by that point I'm already really stressed, and I'm not thinking, 'OK, let's calm down, what did they say?' - I'm more thinking 'freak out, freak out, let's get home!'"

"Something as simple as going to the supermarket to buy some shopping... to an autistic person that can be quite worrying, so having someone there the first time to walk round with you... would be a very good idea really."

Resources for professionals

For further information about our **You Need To Know** campaign and resources to support children and young people, parents and professionals affected by these issues, visit www.autism.org.uk/youneedtoknow

We also produce a wide range of other information and resources for professionals working with people with autism. You can find out more about these at www.autism.org.uk or by calling our Information Centre on 0845 070 4004 (Monday-Friday, 10am-4pm).



Accept difference.
Not indifference.

YOU NEED TO KNOW



Young Campaigners' Charter for child and adolescent mental health services

Young campaigner's foreword

Life is very demanding on the mind, and for those with autism, we might want to state that twice. At the risk of going overboard, the mind is the best tool anyone possesses, and if it isn't kept clear of doubts, worries, or even mental disorders, it is surely heading for disaster.

When you hear about mental health services, what do you think? Perhaps you may feel that the quality of such services does not affect you. It could be that you yourself have had personal experiences: good or bad. Now, let's say that not everyone understands how your mind works. Worse, most people have a handful of misconceptions. You wouldn't take a car to a mechanic that doesn't understand the engine, and likewise, we shouldn't let our friends and families be let down by mental health services that don't understand them.

The NAS Young Campaigners' Group is one of our most promising efforts to improve the system. Together, we drew up a Charter which voices the difficulties and wishes of young people with autism who know the system first-hand. We hand-picked the key issues to improve, after our own experiences, which means that they are the core matters that concern real people in the system today.

Simon
Young campaigner, aged 14

Chief Executive's foreword

In June 2010, we launched our **You Need To Know** campaign to improve support for children with autism and mental health problems. 71% of children with autism also have a mental health problem, and one in ten of the children who access child and adolescent mental health services (CAMHS) each year are on the autism spectrum. It is therefore crucial that the system works for these children.

We know that CAMHS professionals work tirelessly to help all children with mental health problems. To provide effective support for children with autism, professionals will often need to change the way that support is delivered or approach things in a different way.

As part of our campaign we were privileged to work with a group of young people with autism who had previously accessed mental health services and who agreed to share their experiences to help improve services for others. Young people themselves are 'experts' in knowing how their autism affects them, and many told us they want more of a say in the mental health services they receive, and the support they feel they need.

So we worked with these young campaigners to develop a charter for CAMHS, and the experience has been truly inspiring. The 12 points that they have put forward are creative solutions to the difficulties they faced when using services, yet many are simple to put into practice.

We know that you strive to offer the best possible support to young people with autism, and we invite you to look at the support you offer in the context of this charter. I hope that you will take forward our young campaigner's ideas if you are not doing so already.

Mark Lever
Chief Executive,
The National Autistic Society



Accept difference.
Not indifference.

1. The environment should not have ticking clocks and other things that disturb our senses

"[Ticking clocks] drive me crazier than I already am."



Many people with autism experience sensory sensitivity. This means that they may be over- or under-sensitive to certain sights, smells, noises, tastes or sensations. Ticking clocks, whirring fans, a fluorescent light bulb overhead, the smell of someone's perfume or the scratchy fabric on a chair – things that another person might not even notice – can be incredibly distracting and often even distressing for a person with autism.

CAMHS professionals can help by keeping potential triggers for sensory sensitivity to a minimum and asking young people if they feel comfortable in the chosen meeting place.

"You're sat and you're already stressed out and you have to go and talk to someone that you don't know and you have to tell them all about you and you really don't want to – and then you have stuff like the ticking clock, the squeak of the door, the lady or man typing on the keyboard, and every second there's a different noise for you to focus on and it's constantly moving and you can never be able to just stay still for a minute and calm yourself down."

"There should be a list of approved colours to use for something like this... white is very blinding at times... it should be relaxing colours like cream... sky blue or mint green."

"You can't have flowery smells or sickly smells... Air fresheners... for me they stink."

2. The environment should have activities suitable for older children and young people, not just toys for young children

"It's not a place for us."

Most 14-year-olds don't want to play with building blocks and toy cars – it's as simple as that. Our campaigners say that when they come to CAMHS and see toys for young children, it makes them feel unwelcome. Young people with autism will be particularly anxious when they are coming to an unfamiliar place for the first time, so it's even more important to make the environment as welcoming as possible.

"[I'd like to have] something challenging... like a Rubik's Cube, that can just keep you occupied for ages."

"In one of our places there's just this huge whiteboard that covers one wall and they have all of these different coloured pens... it's just really good fun because I love drawing."

"They spend money on colouring-in books which have Noddy and stuff. They'd be better off just getting a whole load of blank paper and pens and things like that."

"Beanbags! You can just jump in them and relax."

3. CAMHS professionals should give different options

"When you've met one person with autism, you've met one person with autism!"

Every person with autism is different, so an approach which works for one person may not work for another. Our young campaigners want professionals to give them different options and work with them to find an approach that helps.

"I had to go back to the doctors the other day and he gave me one option, but I don't want to do that option, so I have to go back again this week to tell them I still don't want to do that option... I feel quite happy they want to see me so much, but..!"

People with autism often find it difficult to imagine things or situations that they have not directly experienced. So open-ended questions like "what do you think would help you?" can be very difficult for them to answer.

Our young campaigners gave examples of where professionals had taken a flexible approach to working with them, and how this had improved their experience of CAMHS.

"My phone constantly goes off with texts... it's the way I keep calm... My mum keeps saying 'If only they'd talk to us through texts, it would make it so much easier'... Most kids nowadays have some kind of free texts on their phone, so instead of wasting loads of money on... sitting in an office for an hour being silent... talking through text is a lot less personal and you don't have to actually talk, so I'd prefer that."



"When I went to see someone to help me through my problems, the person just gave me a piece of paper to draw on and [I could] just draw a few things to help me be calm and then talk... If I wanted my mum to come in I could just say so... it worked well."

"I went to a counselling session where there was a sand pit and there were all these [small toy] figures, and she said 'use them'... it was so much fun."

4. CAMHS should give you choice, not say what you have to do

"Choice is an important thing... it makes you feel better if you're able to choose."

Our young campaigners want individual professionals to give them options during their sessions, but they also want the service as a whole to support them to make choices about what happens when they are there and to develop an individualised care plan with them.

"She gave me a choice of where I wanted to sit and... when I was allowed to come in and when I wanted to leave – everything... It made me feel great."

"I think what would solve all these problems is if they sat down and individually worked out a plan with the person, as opposed to working it out based on what the file says."

"If you find it easier to text, [you should be able to] say that to them... Some people like the way that CAMHS is now... but other people don't... There are lots of different ways. Each and every person is different and that's, I think, what they should do."

5. CAMHS should give more information

"You need a leaflet area in the waiting room."

Not knowing what to expect is particularly difficult and stressful for a person with autism.

Our young campaigners said that when they first went to CAMHS, they didn't know what to expect. They wanted to be given much more information about mental health and the help that CAMHS can give young people.

"Does anyone else feel, not exactly scared, but really out of your comfort zone when you don't know what's going to happen?... A lot of the time they say 'go to this group, it will help', but they don't actually say what's going to happen or anything, and for me that really turns me off from going because I'm not in my comfort zone. They haven't said if I can take my friend or anything, so it makes me think 'if I go I'll be the only one there and I'll be all on my own!'"

"When they give you a diagnosis or something like that they don't actually tell you what it's about, so there should be a lot more information."

6. CAMHS professionals should understand autism and that everyone is different

"[It's bad when] people say we are fine and don't see through the mask."

People with autism often struggle to express their feelings and may take a long time to develop trusting relationships with others. Many of our young campaigners had their mental health problems overlooked initially. They were told they were 'fine' without anyone taking the time to get to know them.

"[A lack of understanding] does lead quite commonly to misdiagnosis... sometimes someone who hasn't had training can tell [if someone has autism] and someone who has had training can't... so really the training and the administration... should be changed!"

But just understanding autism isn't enough. Every young person with autism is different, and it makes a huge difference to a young person if they feel they are listened to as an individual. Many people with autism develop strategies to help them communicate or cope in situations they find difficult or stressful, but without getting to know the person, CAMHS professionals won't be aware of these strategies or be able to adapt their approach accordingly.

"My brother is different... we both have autism, but we're just completely different."

"You're not 'autistic', you're on the 'autistic spectrum'... think of it like a number line... not a hundred different numbers [but] a thousand different numbers."

"I think it's quite important that CAMHS are very selective about who they employ... If they get someone who just knows about the general autistic spectrum and not autism itself they'll just apply the textbook. But if they get an expert who knows about autism [they] can actually interact with the person and know what's going through their head and try and get them to open up more so they can help them in the school and in the home."

"When I get stressed all I need is my water bottle, but even a professional won't know this... without them knowing anything about me they can't know that."



7. CAMHS should work with education

Where CAMHS is working with a child with autism and mental health problems, it's important that they also work with the child's school to make sure there is a consistent approach to providing support and dealing with problems.

Our young campaigners want CAMHS to tell their school what support they need, and to provide training so that school staff know what to do to help. Where possible,

our campaigners want to be able to access support from CAMHS at school rather than having to travel to different appointments in unfamiliar settings. They also feel that CAMHS should help schools to understand more about autism in general. With more support in schools, children would be less likely to go on to need more intensive support from CAMHS – saving money as well as improving lives.



"I've been to a few secondary schools and my secondary school at the moment is everything I might possibly need... So I don't have to leave school to go to all these appointments. I don't have to get to know lots and lots of different professionals. I can just go to one place and it's there whenever I need it. Whereas before my last school I was having to go all over the place... it was just a nightmare... having to talk to all these different people... which I really didn't like doing... One of the good things about the charter is that it could help to get [support like I now have at my school] for others in a similar situation."

"My primary school used to get really stroppy because I'd never had good attendance and usually it was because I'd have three appointments in one day and by the time you've gone to that appointment and spent an hour with them, then travelled to the next one, done half an hour with them, travelled to the next one, then back to school, by that time you've missed almost all the day. And both of my schools got really stroppy with me and it's like, 'it's not my fault!'"

8. CAMHS should give you choice about who you see

"[I want to] have one person to get to know, not lots of different people."

Routine is really important to many people with autism