



**Ambitious
about Autism**



**How to change
health services**

myVoice

Introduction, why is this important?

In 1990 something happened that should have changed the world as you know it. In rooms hidden from the public, world leaders in the United Nations got together to create and sign something that fundamentally changed the way they would talk and work with you as young people. The thing they created was the United Nations Convention on the Rights of a Child. The UNCRC as it is called created in a single place the rights that you as a young person living in this country and indeed any country (except the United States) can expect from the government.

The Convention was separated into 52 articles or “rights” that govern how you can expect to be treated and how the government works with you. One of these articles is called article 12 and it states that you have the right to an opinion and that opinion should be considered and taken seriously. It states that no decisions should be made about you without your opinion. Article 12 is giving you the concept the democracy, the thing that we say is so important in a country like Great Britain.

Does this paragraph above reflect the way you live in this country? Can you remember the last time you were consulted on something that affected you? When was the last time you were asked about how your school was run? What about your local council? When was the last time you were asked about how your healthcare was provided? This last one is vitally important because the difference between good and bad healthcare can have a massive impact on your day to day life. It can mean the difference between a happy, fulfilling life and a life filled with misery. If we really want to make healthcare meaningful then it needs your input to make sure that is delivering the right service in the right way. No decision should be made about you without you.

Bad healthcare is a problem for everyone but when you have autism the consequences can be even more severe. According to a survey run by the Westminster commission on autism, 74% of people surveyed felt that people with autism receive much worse healthcare than their non-autistic peers. 65% of people surveyed felt that healthcare professionals did not understand autism and how it relates to your physical and mental health. This is happening at a time when we know that people with autism have a 70% risk of developing some sort of mental health problem in their lifetime.

“I have been for help several times, both before and after my diagnosis, each time they would go through the same template that they seem to apply to everyone, saying that my thoughts and behaviours cause me to be like this and I need to change them”

When you have autism you see the world differently and sometimes you need a little bit of additional help. But if the help that you’re looking for is not accessible because you have autism sometimes receiving bad help can be worse than getting no help in the first place. The only way we can make healthcare autism-friendly is by getting people with autism that have lived in experience of knowing what it’s like to be autistic.

Hopefully by reading this guide, we will teach you to do just that so in no time, we will be able to inspect your own healthcare services either by yourself or with friends. The information that will be given to you in this guide is applicable to more than just healthcare. By reading this you will learn how to inspect not just your local healthcare services but also youth clubs, schools, leisure centres, local shops and much more. This guide is written as if you were reviewing healthcare services but by using it and changing a few words, you could inspect anything you wanted and help make this world an autism-friendly one.



This guide is primarily for young people with autism aged 16-25. We are aware that people above the age of 18 will access adult services which differ to the services that people 16-18 will access. However while services may differ they will both face the same requirements in order to become autism-friendly if they are not already.

Due to the nature of this guide it is highly likely that it will also be read by Support Workers and Youth Workers. Please feel free to learn from this if you are trying to set up a project for young people but please remember this is primarily aimed at young people and anything you do has to be informed, consulted and produced with them.

What does good healthcare for young people with autism look like?

There is a classic saying: once, you have met one person with autism you have met one person with autism. What good healthcare looks like to you can differ to what good healthcare looks like to another young person with autism. That being said there is a basic standard which we can measure against that will work for everyone. There are certain things healthcare services should be providing you regardless of whether you have autism or not. What we are suggesting is that good healthcare is not expensive or overly difficult. It's a series of changes that we feel makes healthcare inclusive for everyone. Another classic saying is: once you make something better for people with autism, you make it better for everyone.

Before you can measure how a healthcare provider is providing a bad healthcare you first need an idea of what good healthcare looks like. Below is going to be a little guide of what a healthcare service should be providing you in order for it to be inclusive for all.



Not every service you use can be in a location that is easy to find. Having a service that is on the high street would be great but if there is no space to move the service or it is too expensive to rent a building on the high street then asking the service to move somewhere that is easy to find would be asking too much.

However every service regardless of where it is must give you information about how to find it and that information should be accessible. The service may be somewhere that is hard to reach but by using their instructions it should be easy to find.

When considering this look at the service's website.

Does it have an easy-to-read map that pinpoints the location of the service?

Does it tell you where the nearest public transport is?

Does it tell you a step-by-step guide from recognisable landmarks and public transport of how to get there?

When you get to the service does it have signposts?

Does it have a sign near or on the building that is easy to read from a distance and lets you know where the service is?

A good service will have all of these things. It should have all the information you need in an easy-to-access place that lets you find the service easily regardless of whether you have been there before or not.



The reception area

When you visit a service the first thing you generally see is the reception area and the first people you speak to are the reception team. Your first impression can be a very good indicator of how you expect to be treated by the service.

How friendly the reception staff are and how clean the reception area is will tell you exactly how much the provider treats its service. As the provider will also know that the reception area is the first thing people see they will aim to keep this area as nice as possible and staff will be as friendly as possible.

When you are looking at the reception area think about how easy was it to get to the reception from the entrance? Was it signposted? Did you get lost? How long did you have to wait to see a receptionist? Were they helpful and friendly? Did the receptionist give you all the information you needed and tell you where to go?

The waiting area

We all hate waiting areas but they are necessary and it is important that a service provider pays attention to the waiting area as you will probably be spending most of your time here. This is very important if you have autism as waiting areas can sometimes give sensory overload as you have a large amount of people in a very small space.

When you are in the waiting area think of how easy it was to find? Is the waiting area clean and tidy? How noisy is the waiting area when it's full of people? Is there enough entertainment provided to keep you occupied? Is it clear where you need to go when you have left the waiting room?

“You never get a second chance to make a first impression”

A good service will have a clean and tidy reception area that is well signposted, you should not get lost at any point after entering the service. The receptionist should be friendly and provide you with as much information as you need so you know where to go. You should not have to wait to see or speak to a receptionist or speak to a receptionist. The only time you should have to wait is if the receptionist is speaking to another client. If the receptionist is doing anything else that is not related to a client than it is unacceptable if you have to wait. Although not all services will offer this something else you should look at is whether the service offers a private space for you to talk to the receptionist if you have a private problem that you do not want other people overhearing.

A good service will have a clean and tidy waiting room. It will be designed or arranged in such way that it won't be noisy even when it's full of people. If it does get noisy when it's full of people then a good service will lay out rules to stop that from being the case (e.g. signs that say no mobile phones). A good service will have magazines or other forms of entertainment to keep you occupied while you wait (e.g. a TV that is in full display but on mute with subtitles on). A good service will have some way of telling you how long the wait will be and they will try and stick to that as much as possible. There will also be clear signage, instructions or a staff member which will tell you where to go after the waiting area. A service that is trying to be autism-friendly will have a quiet room available and staff who are able to assist you should anything go wrong.

The service overall

For a service to be autism-friendly there are certain things that it must do in all parts of its delivery. It does not matter if you are in the reception, the waiting room or looking at the website. Accessibility is something that a service must do at all times.

The website must be open, approachable, easy to take information from and easy to read. Any computer systems the service has for users must be easy and instinctive to use. If you have to ask for help at any time then the service is at fault. A good accessible website and computer system should be designed so that a novice is able to access it for the first time without any difficulties.

When you speak to the staff they should have at least a basic understanding of what autism is even if they don't have the advanced knowledge required to meet your specific needs. They should be able to offer you

reasonable adjustments should you require them and have the system in place to give you these adjustments. (i.e. if you need a quiet room there should be one). When talking to the staff about their service you should feel that they are treating you with respect and that they will take your concerns seriously. Remember you are not there to talk at people; you are there to change their service. At all times staff should demonstrate good customer service and you should feel you are being treated with respect.

The most important thing you need to be on the lookout when reviewing the service is the attitude of the staff and the service leads. Do you feel like the staff will make changes to their service based on your recommendations? If your answer to this is no and the service has not given you a very good reason as to why they will not then said service will fail a review regardless of how well it performed in other areas.

What we can't review

Although this guide is written so that it can be used for reviewing any type of service, club or establishment it is primarily written as if you were reviewing a publicly funded health service. With that in mind there are some things you will not be able to do.

When reviewing a health service reviewing the doctor, nurse, dentist or healthcare professional would be useful, unfortunately it would also be impossible.

The only way to review healthcare professionals would be to make an appointment. This would be a waste of time and resources for busy healthcare professionals who will have a long line of patients before or after you. If you are already making an appointment to see a healthcare professional for a personal problem it is not recommended that you review them at the same time. The most important thing when you are making a personal appointment is to focus on your healthcare.

Don't forget you have your own ideas as well

Everyone's experience of autism is different. Reasonable adjustments will differ from person to person. Don't forget that the best person to say what would make a service accessible to you is you. If you have your own ideas of what would make service autism friendly don't forget to add that as well. Autism friendly goes beyond autism awareness training (although it is

useful if all staff attend an autism awareness course regardless). If you have an idea that you think would make the service autism friendly that isn't listed above then say it. The ideas we have given above are just a guide, it's up to you to turn it into something real.



Don't do it alone, get a group together

As we keep saying in this guide everyone experiences autism differently. Your idea of autism-friendly may differ to someone else's idea of autism-friendly. It's a good idea when reviewing services to do it with one or two other people so you can all pitch in and give a more balanced review of the service. If you get a larger group together you can review services in twos or threes and cover more ground that way. It's also a good way to meet new friends and have a louder voice. If you get a large enough group together you will even be able to influence the way the council commissions services.

If you want to get a group together there are plenty of places where you can find people to be a part of it. See if any of your friends want to be involved. Look to your school, youth group, support group and many other places. There are already organisations out there which support young people with autism or review healthcare services from a patient perspective, see if any of the people in these groups would like to join.

If you want to find support groups for young people with autism many organisations offer a list of groups in your local area on their website. The National Autistic Society, SENDirect and your council's local offer website are good places to start.

If you want to find groups that already look at healthcare services and see if they would be interested in working with you to create an autism specific group, look to your local council's healthwatch group. Additionally each local healthcare provider will have something called PALS or Patient Advice and Liaison Service. These are groups of patients that work with the healthcare provider to make the service better.

Training

Once you have your group together it's a good idea to arrange some training so everyone has the basic skills required to be able to carry out a service review. Training doesn't have to be expensive or even cost money as plenty of adults and professional that you know will have skills that they can teach you. When looking at training see if there is anyone you know who can help with teaching your group

- **Talking to stakeholders**
(term for professional organisations)
- **Leadership**
- **Public speaking**
- **Advocacy**
(standing up for a group of people)
- **Mystery shopping**

If you are stuck in trying to find people who can teach your group these skills ask a youth worker or teacher. They will know people who can if they can't already teach you these skills themselves.

If you are doing this as part of a youth club or school project then the club or school may be able to pay so that you can get professional training.



Putting your skills into practice

Before you go out and review any services it may be a good idea if you practice first. Go into a local shop, your school, youth club or anywhere that you already feel comfortable in and put the skills you have learned to the test. Try practicing a mock review of that service and talking to the person you were reviewing about where they did well and where they can improve. It's probably a good idea to tell the person you are reviewing first.



Finding services

As this guide is written as if you were reviewing healthcare services, it will list a selection of the different kind of services that exist. There are many types of services and you are free to find your own. Just remember to qualify it must be local and it must be run by the NHS.

Services you could inspect:

- **GPs**
- **Urgent care centres**
- **Dentists**
- **Walk-in centres**
- **Sexual health clinics**
- **Hospital outpatients (with prior permission)**
- **Hospital wards (with prior permission)**
- **Pharmacies**

There are many different types of healthcare services out there, just think about where you go to receive your healthcare and whether you would like to improve your experience.

However there are some services that although we would like to review we cannot for reasons stated below

• **Accident and emergency**

A&E is always busy 24 hours a day. The staff at A&E are always dealing with patients and will not have the time to help you carry out a review. The people who come to A&E do so because they have had a serious accident. This will be a very distressing time for patients who are there and they would probably appreciate their privacy (keep consistent with A&E post). They may not appreciate you walking up and down A&E taking notes.

• **Mental health services**

Like A&E, mental health services will also be extremely busy and may not have the time to help you carry out a review. In addition to this the people who are accessing this service are doing so at a very distressing time in their life and would appreciate privacy. Just think if you were accessing a mental health service how it would it help your anxiety if you saw someone walking up and down taking notes and wandering around the area.

Reviewing your first service can be a nerve racking experience. This is one of the reasons why it may help for you to do service reviews in a group so you can support each other. It can be difficult to know if you should contact the service before you do the review. We will list out the pros and cons of whether you should do this or not so you can make up your own mind.

Contacting the service before you do the review



Pros

- If the service is aware of the review it means they can put all in the measures to welcome you and make you feel comfortable.
- If you contact the service before you do the review it means you may have a chance to talk to senior staff.
- Contacting the service before the review means that you may be able to see parts of the service that you would be unable to as a normal user
- Contacting the service beforehand may help ease your anxiety about doing a review as the service will be aware that you are coming.

Cons

- If you contact the service beforehand then you will be reviewing them at their best not at their normal. You want to see how they normally perform to get an accurate representation. You do not want to see them give you a performance so they score high marks.
- If you contact them beforehand they may not agree to a review as they will be worried about how they perform.

Not contacting the service before you do the review



Pros

- You will be able to see the service as it operates on a day to day basis. This means you will see them as they are normally like and will be able to accurately assess if they are autism-friendly

Cons

- The service may not let you review them if they have not been told in advance.
- It may increase your anxiety levels to review a service that has not agreed to it.
- You may not be able to talk to senior staff if they are not aware that a review is being carried out on that day.



It's up to you if you want to contact the service beforehand. There are positives and negatives to doing this as this guide has outlined above.

Remember if you are reviewing anything that is connected to a hospital then you must contact them first. This will also be helpful as hospitals provide a lot of services so you may be able to review several services on the same day if you contact them first.

The day has finally arrived. You have got a group together, you have all been trained up on important skills and had a chance to practice those skills. You have picked the service you want to inspect and have chosen the method you want to approach that service. What do you do next?

Reviewing the service itself can be intimidating especially if you are doing for the first time. Remember no matter how anxious you get, you have experience that is valid and needs to be heard. Hopefully any training you and your group has done will help you with some areas that may be difficult, for example talking to senior staff.

Remember when you are reviewing a service your review starts as soon as you leave your house. Finding the service easily is just as important as the service itself. Don't forget to look at the website and the instructions they give that let you know how to get there. Always pretend that you are using the service for the first time and have no idea where it is even if you have been there many times before.

It may help you if you have a checklist of things to measure what you are reviewing and a notepad to write your findings down. We have attached an example of a checklist in both normal and easy to read to help you if you wish to use it. Feel free to add your own things or create a new checklist that suits your needs.

When carrying out a review make sure you are thorough and ask plenty of questions. This is your chance to see if a service is autism-friendly. Don't be afraid to give your own opinion.

Feeding back your results

The entire point of reviewing services to see if they are autism-friendly is so they will make changes to their services if required. If you don't give feedback on your results how can they know how and where to make improvements?

The easiest way to do this would be to write a short report (no more than two sides of A4 paper) and send it to the person who manages the service you have reviewed. They should respond in a few days to say that they have received the report and it should take them no more than a month to give you a proper response. If you have not heard anything from the service in two weeks then it would be a good time to remind the service and ask for a proper response.

If you get enough people together and review enough services then you could potentially contact your local authority service commissioner. If you talk to your Local Authority Commissioner (please only do this if you have reviewed a number of services in your local area) you can actually affect change over your entire local authority and make sure that autism awareness becomes a requirement for services that operate. You could also be involved in the commissioning process for new services to make sure that they are autism-friendly from the outset.

After you have given your feedback to the service and they have had time to implement the changes that you have recommended it would be a good idea to visit the service again. During your second visit you can talk to senior staff about how they implemented these changes and which changes they decided to implement. You can also review the service again to see if it is autism-friendly after they have made changes and see if they need to make any more.

We at Ambitious about Autism worked with the Whittington Hospital to make their Paediatric's inpatient and outpatient services autism-friendly. The Whittington Hospital provides inpatient, outpatient, community services, walk-in services and acute NHS services to two of the largest London boroughs.

In order to get an accurate scope of what our volunteers would be working with when they reviewed the Whittington Hospital's services, staff members from Ambitious about Autism met with senior staff at the Whittington Hospital to discuss what work would be done and how the young people would go about reviewing their services. We decided that our volunteers would review the Paediatric inpatient and outpatient wards. This would give our volunteers a good view of the services that Whittington run for young people that have short and long stays in the hospital.

Before the actual service reviews were carried out we considered it a good idea for our volunteers to meet the staff members at the Whittington hospital beforehand. We felt that this initial meeting between staff members and young people would help our volunteers become more confident in their abilities to inspect services run by the Whittington Hospital.

Following on from this our volunteers inspected the Paediatric inpatient and outpatient wards at the Whittington Hospital (Sample reports of their review can be found at the end of this guide). In general, our volunteers were impressed with the Whittington Hospital's facilities that could be used by young people with autism. However they found things like signage a problem which could make things difficult for someone visiting the service if they had never been there before. As an example of how easy it is to make reasonable adjustments for people with additional needs, Youth Consultants observed that the waiting areas could be overwhelming for a person with autism but rather than suggesting alternative waiting space was provided they suggested that ear defenders be available on request. This would allow a person with autism to share the space while at the same time being a relatively inexpensive adjustment for the hospital to make. Whittington Hospital staff were very responsive to making changes in how they deliver their services and arranging autism awareness training for their frontline staff.

Following on from this the Whittington Hospital has changed the signage to wards, purchasing ear defenders and fidget toys for young people who might require them and a series of other changes. Whittington Hospital is also arranging Autism Awareness training for their staff in order to make sure that all frontline staff that may have contact with young person with autism will have a least a basic understanding. The Whittington Hospital understands that learning what autism is from a young person with autism is also hugely beneficial to their staff so in addition to the autism awareness training they are undertaking they also arranged for our volunteers to join a trainee nurses orientation day to deliver their own brand of autism awareness training.



As you can see from what has been written above although reviewing a service may look challenging it is actually quite an easy thing to do. Hopefully you have found this guide useful. Enjoy reviewing your own services and making the world a more autism-friendly place.




Pears National Centre
for Autism Education,
Woodside Avenue,
London N10 3JA


Tel 020 8815 5444

Email info@ambitiousaboutautism.org.uk

Web ambitiousaboutautism.org.uk

 @ambitiousautism

 /ambitiousaboutautism

 @ambitiousaboutautism

Charity number 1063184 Registered company 3375255