

Experiences of using NHS 111

111

for autistic people, people with learning disabilities and their supporters

As part of our work with the **Health and Wellbeing Alliance**, the partners of the **Valuing People Alliance - LDE, BILD and NDTi** carried out a survey during March and April 2021 to ask people with learning disabilities, autistic people, families and carers about their experiences of people in using the NHS 111 service.

The 111 first campaign asks people to use 111 for medical care when it urgent but not an emergency. The aim is that emergency care such as ambulance and A&E services are not used unless they are needed. 111 should also mean that people can get help any time of day and can have contact with a medical professional on the phone without always needing an appointment with a GP or other service.

We wanted to find out whether this 111 service was working for people who may not describe or present their symptoms in the same way as others, and whether the service was working for a variety of people. **This report outlines the findings from the survey.**

Who took part?

6 people with a learning disability



4 autistic people



3 family members



1 person supporting a group of self advocates



20 paid supporters



How had people used NHS 111?



33 people used the phone



1 person used the internet



11 people used it for themselves



23 people used it for someone else

How often?



What did people think of the NHS 111 service?

Over 60% said their experience was good or very good, 16% rated it poor



Very poor

3 people



Poor

3 people



Not good
or bad

7 people



Good

15 people



Very Good

6 people

What led to good experiences?

"It was much better than having to go to the hospital"

"The follow up is appreciated by staff on shift - it is reassuring"

"I was taken seriously and spoke to with care and empathy. They phoned back and arranged a GP appointment at a very short time in a place we couldn't get quickly. I felt completely supported and cared for"

We asked people who told us they had a good experience to tell us what made it good.

However, we found even more people answered this question who had, overall, given their rating as middle or poor. This might be because some of the service they received was good.

The image opposite shows the rankings of the top 7 things that people ticked to describe what made their experience a good one.

- 1 I was put in touch with a doctor or clinician 23 people
- 2 It was easy to use or get through on the phone 20 people
- 3 The questions they asked helped me describe what was wrong with me/ the person who was unwell 19 people
- 4 They communicated in a way that worked well for me 17 people
- 5 I had a quick response from someone who could help 12 people
- 6 The service made reasonable adjustments in how they helped me/ the person I support 10 people
- 7 I was given a prescription to help 5 people

Preparation helps...

We had some additional comments about what created a positive experience for people. Some people were prepared before they made the call - and this helped them have a positive experience.

"Had an absolutely brilliant experience. However, I thought very carefully about key information that 111 needed to know. So we I rang I was very clear"

"I am phoning for my 16 year old daughter who has a learning disability and then I described clearly what was the concern. 111 were superb. They asked to speak to her. Spoke clearly and confidently to her and explained who they were and what they were going to do. We were referred after 111 triage to a nearby doctor quickly. Wonderful outcome. Perfect Shared Decision Making throughout! I just learnt that term recently and wish I had heard it before... this is what I need to care for my daughter. Everyone working together and her being included and happy in decisions about her."

A number of autistic people who had contacted NHS 111 described very helpful care and interventions:

"Very patient with me. First time I called and answered the questions. Second time my partner called, I spoke also to 111 suspected TIA - rapid response swiftly arrived and here when my stats plummeted and oxygen and aspirin swiftly given. Taken to hospital twice, both times paramedics confirmed I needed them"

"Personally: patience received. Help received swiftly. Everyone calm, reassuring and I'm recovering from the latest but would have been far worse off if the help had not arrived so soon. Some would say 999 but as an Autistic person I knew something wrong but hard to explain, I swiftly deteriorated and help already despatched."

What led to bad experiences?

- 1 It took too long to get the help I needed 10 people
- 1 They didn't make reasonable adjustments for me/ the person I support 10 people
- 3 It was hard to use or get through on the phone 9 people
- 4 The questions asked didn't make sense to describe what the matter was 7 people
- 5 They didn't communicate in a way that worked for me 6 people
- 6 I didn't get any help from a doctor or clinical expert 2 people

Not everyone had good experiences. 19 people answered questions about the things that made theirs a bad experience. This is more people than rated the service overall as bad - only 6 people said it was poor or very poor. But some people were neutral and probably had a mix of positive and negative things happen.

Some people chose to describe their experiences which hadn't gone so well:

"I work with people who can't communicate verbally, this can make it difficult to answer some of the questions asked. most 111 calls have been accommodating of this"

"I find it hard to answer the questions. I describe my symptoms without using pain scale numbers. I find it hard to know the correct descriptive words".

"I rang about breathing difficulties in my brother. The standard questions I had to answer in his behalf were totally inappropriate for a patient without verbal communication. There should be a fast track to a clinician in this case. I was scared to call 999 as we have been shielding and didn't want paramedics to come into the house unless it became absolutely imperative because of the risk of contracting covid".

What did people say could make NHS 111 better?

- Sometimes those with health anxiety and a learning disability can find some unrelated questions distressing and confusing: explain and reassure
- The call handler could talk more slowly and make sure they do not use long words.
- Get some training from people with learning disabilities
- Help callers be really clear in what their needs are and what their concern is. If you don't understand why telling people you have communication or access issues ... Other people cannot make reasonable adjustments and take you seriously. There is key information you need to share and people need to feel comfortable to do that. And of course many autistic people may not have a diagnosis so 111 might need to include some key questions to help establish reasonable adjustments are needed to access health care where people have a physical or mental issue they are concerned about.
- It would be easier if I could be allowed to speak to a nurse who will listen to my description and ask me questions based on my description. If you say you have an additional need it would be useful to speak to a call handler with experience or training in adults with additional needs. The call handlers language levels needs to change but not voice tone. Have call handlers who can ask the pain scale in face emotions. Sad for pain, happy for no pain. Do not send an ambulance if unsure. Get a nurse or doctor to telephone first. Only send an ambulance if it is clinically critical.
- Since the covid19 pandemic there is a very long process and automated messages (press this number, press that number) before you actually get through to speak to anyone. As a autistic person (and a very unwell person at the time of calling) it was very hard to follow all of it. I'm worried other people may do the same and this may be a barrier to them getting the medical care they need.

What does this mean for NHS 111?

The importance of using NHS 111 to get help quickly is clear from the answers above.

Quick Access, reassurance and a caring person

Most people found the quick access to help, and someone who was reassuring and caring made all the difference to them.

Reasonable Adjustments

Making reasonable adjustments are important for people with learning disabilities or who are non-neurotypical. The same number of people gave reasonable adjustments as a reason for a positive experience, as the number who said no reasonable adjustments were made for them.

There will always be variation in how call handlers work, and the skills they have to find what people need. And perhaps some people need different reasonable adjustments that might be harder or more easy to make for them. For the people for whom 111 didn't work well, it was linked to not only being able to get through, but the communication and questions asked.

Understanding Questions and answers

There is concern that sometimes people's health conditions might not be recognised and they might not get the treatment the need if they describe or experience these in a non-typical way. This can lead to diagnostic overshadowing, where a person's disability is seen more than the health condition.

19 people said that the questions helped them say what the matter was, but another 7 said the questions didn't make sense to help them describe what was wrong. NHS 111 staff will need to be aware that for some people symptoms might look different or they might not be able to describe those symptoms. Where that is the case its important they hear that there is some concern and help the person get seen by someone. It seems that this often does happen.

A special thanks to all of the participants for their honesty, suggestions and feedback in their survey answers.

For more information about this resource and the survey contact:
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As part of our work with the **Health and Wellbeing Alliance**, this work was carried out by the partners of the **Valuing People Alliance** - LDE, BILD and NDTi



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