

# Young People with additional needs' access to health services.

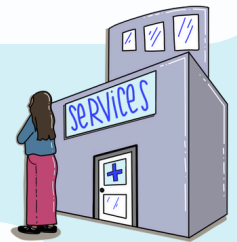
Summary of the project and what we found out.

## Why did we do this project?



- We are a group of parent carers, researchers, charity and NHS staff working together.
- This study aimed to find out from young people with additional needs in North-West England how they access health services like doctors, hospitals and dentists.
- We designed the study with the help of young people.

## What did we do?



- We collected information from neurodivergent and/or disabled young people aged 16-25 years in the North-West of England.
- Young people shared their views in online surveys, one to one interviews and in group discussions.

## Who did we hear from?



- 42 young people aged 16-25 shared their views.
- 29 young people completed a survey
  - 6 young people took part in an interview
  - 7 young peoples took part in a group discussion
- We heard from young people with physical disabilities, learning disabilities, neurodivergence and long-term conditions.



## What did we find out?

We heard that many neurodivergent and/or disabled young people found it hard to access and use health services.

There were 4 main topics the young people told us about.

Young people told us appointments could be difficult;

- They could find it hard to make and get appointments.
- Calling the GP was difficult for them.
- Appointments were often during school or college hours.
- They had to wait a long time to get an appointment.
- They did not understand which service to use or how to access the health care they needed.



“ There is not enough appointments quick enough when they are needed. Always have to wait days or weeks which is too far away during a crisis or needing help. ”

“ I just get too nervous to talk to the doctor, the thought of the language that they use, it's too difficult. ”

Young people told us that communication with health professionals could be difficult;

- They often felt not listened to or understood.
- They often felt rushed and unable to ask questions.
- They often had to go over 'their whole story' every time.
- They often didn't understand the complicated language used
- They often felt unable to tell professionals the best way to communicate with them.



Young people told us that health care environments were often difficult for them;

- spaces were often too noisy, smelly and bright.
- spaces were often busy and did not have enough space.



“ Noise, smells, too many people. All of this is overwhelming. I don't like my name being shown on a screen. I feel like it's a breach of confidentiality ”

“ My wheelchair really couldn't get into the room, and I had to be carried in by some of the people who are seeing the GP just to get inside. ”

Young people told us that they felt that health professionals did not always treat them with **dignity and respect**

- They often felt treated as 'less than human'
- They often felt that health professionals did not really care about them.
- They often felt that health professionals lacked understanding of neurodiversity and disability.



“

*Staff who care and understand, some are good, some try their best and others treat me as less than 'normal' or talk down to me. I'm not a child!*

”

## What impact did these experiences have on young people?

- Young people avoided health services.
- Young people experienced anxiety, distress and trauma when thinking about accessing health care services

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*I am registered with a GP, but it is very tricky to use this.*

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*I just think that the whole system hasn't been set up to be friendly to autistic individuals.*

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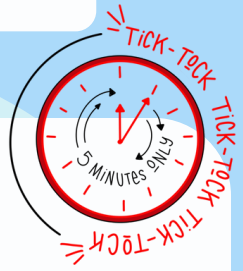
## What did young people say would help improve access to health care?



- For health professionals to check notes and health history before appointments/interactions.
- For health professionals to gain skills in how to communicate with neurodivergent and/or disabled young people.
  - to ask for communication differences.
  - to provide extra processing time
  - to use simple language and resources to help understanding
  - to be friendly.
- For health professionals to be compassionate and caring.

## What else did young people say would help improve access to health care?

- More flexible ways to communicate and book appointments with health services e.g. text/online chat
  - Longer/less rushed appointments.
  - For health care environments to be sensory friendly
  - For health care environments and spaces to be easy to access and disability friendly.



## What next?

We worked with 4 young people to help work out what we should focus on going forward. They told us the most important things were;

- for health professionals to gain skills in how to care for and communicate with young people with additional needs (neurodivergent and/or with disabilities).
- for health care services to be disability and sensory friendly.
- for health systems and records to flag the support needs of young people.
- for there to be more flexible ways to book appointments with health services e.g. text/online chat

## Want to know more or get in touch?

