

NEURODIVERSE & NEURODIVERGENT YOUNG PEOPLES' EXPERIENCES OF SEXUAL HEALTH SERVICES

Brook Annual Consultation
2022-23



FORUM FEEDBACK: WHY MAKE CLINICAL SERVICES NEURODIVERGENT FRIENDLY?

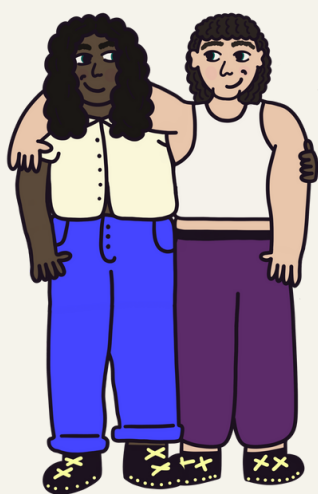
"This will make me feel less anxious"

"Feel connected with the clinician and trust the service more"

"I don't expect everyone to know everything about ND (Neurodivergence) but that is ok, you might not always get it right but you are open to learning more about ND"

"It will make me feel reassured"

"Makes me feel less alienated"



" Makes me feel informed of my decisions"

"This will make me feel in control"



What did Brook do?

In 2023 Brook wanted to understand neurodiverse and neurodivergent young peoples' experiences of sexual health services, and health services more broadly. To do this, Brook met with groups of neurodiverse and neurodivergent young people.

Why did Brook do it?

It is important for Brook to understand what neurodivergent young people want and need from health services, and to better understand ways to make Brook's clinical services more accessible to all young people.

To do this, we wanted to understand neurodivergent young peoples' experiences of sexual health services, and by understanding their lived-experience and journeys in accessing health services, it helped us to identify how access could be improved for neurodivergent young people at each stage of the process.

The findings offer insights into the role of choice, barriers, and transition through services for young people. This can help decision-makers to consider opportunities for adapting interventions and environments to improve a young person's experience at any point on their healthcare journey.

How did Brook do it?

Brook ran a series of focus groups with neurodiverse and neurodivergent young people. We took this approach because it offers a rich, detailed understanding of the experiences and behaviours of neurodivergent young people accessing health services. Working in this way allowed for young people to participate in our research in different ways.

We worked with 23 young people aged 16-25 years old, based across England. Three focus groups took place in-person, and one focus group took place online, using the platform Zoom. Each group lasted approximately 60-120 mins to allow for breaks, different levels of interactions and additional support in answering the questions.

What did Brook Learn?

Brook's research found that choice was important to young people when accessing health services, including:

- Having a choice in the environment of the health service, for example, the type of sensory stimulus in the waiting room.



- Having a choice in the communication throughout the health care appointment from making an appointment, through to the consultation. For example, having verbal and/or written information, digital and/or in-person services.
- Having a choice in how to prepare for the experience of a health care appointment such as having information sent to the young person ahead of their appointment.

The research also found that young people experienced many barriers to accessing sexual health services, including:

- Not having sufficient information and education about sexual health.
- Not knowing where their nearest sexual health clinic is, or even the knowledge that there are health services specifically for sexual health.
- Health care providers lack of understanding about the diversity of needs for neurodivergent people including sensory sensitivities.
- Healthcare providers lack of capacity to meet the needs for neurodivergent people, such as wanting more time in appointments and not feeling rushed.

Additionally, the groups commented upon the challenges of navigating a new path as they switch through services, from child to adult services, sometimes for the first time independently. This comes with its own issues and opportunities.

'GP/hospital appointments with parents, now I am doing it for myself, first time as a young person, struggle in waiting room, the transition is hard'

Focus group participant

How can sexual health services be more accessible for neurodiverse and neurodivergent young people?

The young people had different ideas about how they would like to find out about a clinic ahead of visiting:

- They would like to be able to do everything in one place – find their local clinic, book an appointment and have that appointment go straight to their phone
- They might need parent/carer support to look online to learn more about the service
- An external source like an 'app' or a website to help a young person to understand their own health needs
- They would like to be able to chat with a clinic first to ask questions.
- They would like the option of leaflets to read before their appointment, with easy read versions available.
- They would like for services to advertise that they are neurodivergent friendly and explain how they are accessible to neurodivergent young people



The young people had different ideas on how to help reduce their feelings of worry ahead of visiting a healthcare setting. The ideas varied, but they can be separated into two areas, with the young people's suggestions for how to do this:

1. Make the health care waiting room more vibrant, more welcoming, and give people more choice around what they do while they wait.

- Choice in seating areas, and ability to move chairs to sit somewhere different.
- Having more than one TV playing so there was always one more than one source of entertainment, with subtitles.
- If a TV is not available, having a radio on but with the choice to ask staff to turn the volume down.
- Having posters that give information about what they could expect during their clinic visit, including symbols and large text.
- Having something to do whilst waiting, puzzles, colouring in, games.

2. Make the health care waiting room a calmer environment and reducing sensory stimuli or providing an alternative waiting area.

- Being able to find a space which works for them.
- Being able to sit in a separate room which was quieter.
- Being able to use noise cancelling headphones or having these offered for free use in the waiting room.
- Having areas of the waiting room without posters or TVs so the environment is much calmer.

'Waiting aspect is a struggle/anxiety inducing and get really in your head about it... would like a separate space that I know I will be safe and calm'

Focus group participant


'I like background noise, silence makes me overthink what could happen it's a distraction/could sit separately from'


Focus group participant

There is a lot to be said for offering choice to young people in their environment and creating a waiting room that can be responsive to varying needs.

How can staff interaction & communication help improve sexual health services for neurodivergent young people?

Our research findings demonstrate the importance of staff interaction for the overall experience of accessing healthcare services for a neurodiverse and neurodivergent young person. From making the appointment, through to the waiting room and the consultation, it is important to break down barriers in communication to support the young person to feel more of an active participant in their own patient journey and support their transition into accessing health appointments independently if they choose to do so.





There were lots of suggestions about how healthcare staff could interact with neurodiverse and neurodivergent young people in ways that would help with their feelings of nervousness:

- Give people all the information they need and not assume that they know what to do or where to go.
- Speak slowly and repeat instructions, even if not asked to.
- Write on a piece of paper anything complicated – such as the names of STIs or medications – for the person to read back afterwards.
- Make people feel comfortable and do not rush them, especially if someone needs to ask more questions or have things repeated to them.
- Have trained staff who are confident in how to manage panic attacks or autistic meltdowns and shutdowns.
- Have the staff look at the young person and make eye contact in between writing notes.
- Recognise that neurodivergent people may not present as neurodivergent – assume that everyone needs help and offer to explain again or take more time.
- Have staff showing good hygiene by washing their hands.
- Make sure staff wear their ID badges so that they appeared ‘safe’.
- Make sure staff are friendly, use happy facial expressions and be welcoming in their tone and manner.

‘Be patient – wait for us to get the information and help us if we need it’

Focus group participant

What will Brook do next?

The findings from this research are very important to Brook. We are committing to do the following in the next 12 months:

- Brook will look at all the findings that describe young peoples’ choices around healthcare spaces and apply these where possible in the development of new clinical services.
- Brook will complete a review of the accessibility of its clinics for neurodivergent people.
- Brook will increase its clinical resources available in easy-read formats

Brook would like to thank the young people who took part in the focus groups, the external professionals (based in schools and youth clubs) who helped us to run the focus groups, and Brook staff who supported this research. We would also like to thank our 16-19’s National Participation Forum members who helped to develop and shape this work. We really enjoyed this research.

If you would like further information about this research, or would like to request a copy of the full report, please contact:

participation@brook.org.uk

