

NEURODIVERSITY: WHY IT'S IMPORTANT TO CONSIDER IN CLINICAL RESEARCH

Exploring the accessibility of healthcare services and clinical research for neurodivergent people, and the potential support initiatives that may improve their experience



INTRODUCTION

It's thought that up to 20% of the global population are neurodivergent.¹ And yet, research shows that healthcare services may be inaccessible to this population.² Which got us thinking — what about clinical research opportunities, are they inaccessible too?

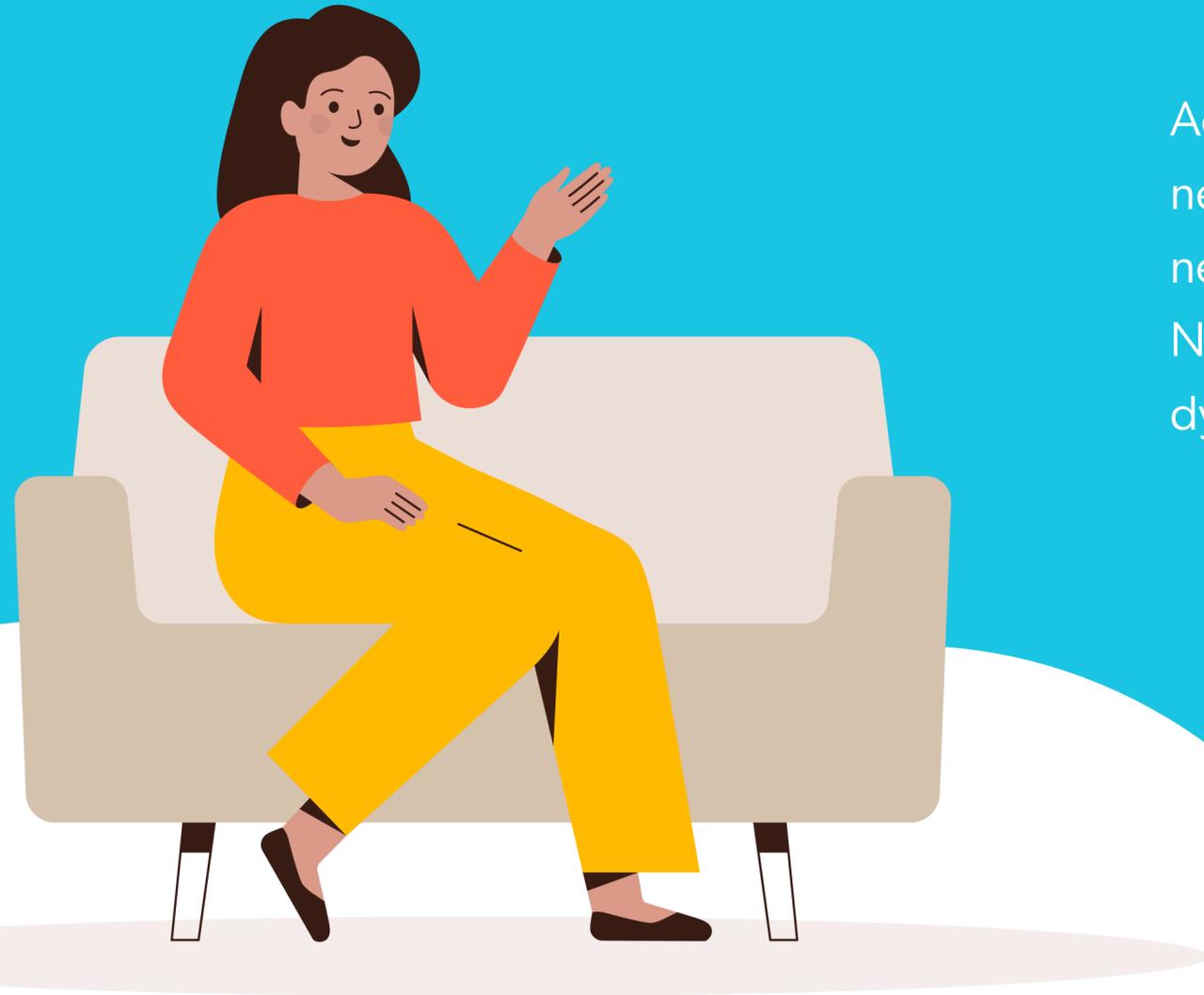


In the UK population, up to:

- 1% are autistic²
- 8% have ADHD³
- 10% have dyslexia³

In the US population, up to:

- 2% are autistic⁵
- 5% have ADHD⁶
- 5–15% have dyslexia⁷



WHAT DOES 'NEURODIVERSE' MEAN?

According to the Oxford English Dictionary,⁸ neurodivergent people show differences in mental or neurological functioning from what is considered typical. Neurodiverse conditions include dyslexia, dyscalculia, dyspraxia, ADHD, Tourette syndrome, and autism.

INTRODUCTION

**SWINGS AND
ROUNDABOUTS**

**NEURODIVERGENT
CHALLENGES**

**HEALTHCARE
SERENITY**

**POSITIVE
EXPERIENCES**

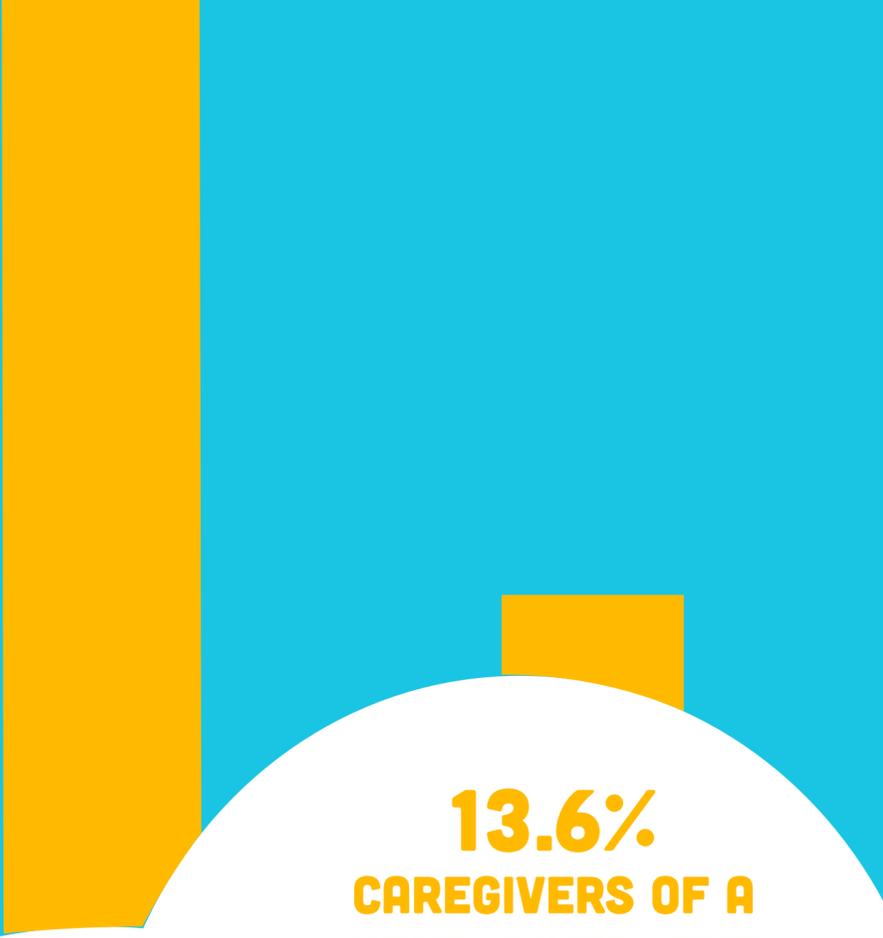
**WHAT ABOUT
CLINICAL RESEARCH?**

**MAKING CLINICAL
RESEARCH ACCESSIBLE**

WHAT'S THIS BOOK ABOUT?

We wanted to understand more about the barriers neurodivergent people experience when trying to access healthcare services and clinical research, and to raise awareness of the ways these barriers could be overcome.

So, we conducted a research project where we talked to 199 people who were neurodivergent or a caregiver for a neurodivergent person, and we asked them about their thoughts, opinions, and experiences relating to healthcare services. Below is a snapshot of who took part.



86.4%
NEURODIVERGENT
PEOPLE

13.6%
CAREGIVERS OF A
NEURODIVERGENT
PERSON

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SWINGS AND ROUNDABOUTS

When people talk about neurodiversity, conversations often focus on 'negative' characteristics. But there are clear strengths of neurodivergent conditions that should be talked about more often.

I often think outside the box.

My neurodiversity makes me unique.

I'm able to recognise patterns more easily than others.

I am artistic and creative.

My neurodiversity gives me heightened intuition.

I'm honest.

I have high attention to detail.

SWINGS AND ROUNDABOUTS

However, neurodiversity can negatively impact aspects of a person's education, career, and relationships.



WHY HEALTHCARE SERVICES AREN'T CREATED WITH NEURODIVERGENT PEOPLE IN MIND

81% of participants agreed that healthcare services are rarely, or never, designed with neurodivergent people in mind.



The challenges faced by neurodivergent people can also act as barriers to accessing healthcare services. Here are the top five reasons the participants find healthcare to be inaccessible.



SENSORY CHALLENGES

Participants reported numerous sensory challenges, including overcrowded waiting rooms, harsh lighting, and being expected to process large amounts of information in short appointments.



MY FAVOURITE HOSPITAL APPOINTMENTS WERE DURING THE PANDEMIC. HARDLY ANYONE WAS THERE, AND PEOPLE CAME ALONE. THERE WERE NO NOISY CHILDREN OR LOUD NOISES COMING OUT OF PHONES OR TABLETS.

2.

DIFFICULTY EXPRESSING SYMPTOMS

Participants with dyslexia said it's challenging for them to find accurate words to explain themselves in appointments, and autistic participants said they can sometimes become mute because of the stress associated with their appointment. Participants with dyspraxia reported challenges in differentiating their symptoms from other diagnoses.



***CONSULTATIONS ARE
VERY STRESSFUL,
AND I WILL DO OR SAY
ANYTHING TO GET OUT
OF THERE.***

3.

STIGMA AND JUDGEMENT

When discussing their diagnosis experience, some participants reported that they often experience dismissal of their symptoms, especially if they were diagnosed as an adult. Due to service-based trauma and a lack of understanding, participants said they were often reluctant to disclose their neurodivergent diagnosis in fear they would be perceived negatively.



AS I WAS AN ADULT TRYING TO GET A DIAGNOSIS, THE DOCTOR DIDN'T THINK IT COULD HAVE BEEN MISSED AS A KID.

4.

APPOINTMENTS OVER THE PHONE

Participants reported increased fear and anxiety about the 'unknown', which included being put on hold for long periods of time, or being expected to answer unscheduled phone calls.



IT'S LIKE THE LONGER I'M LEFT ON HOLD, THE MORE PANICKY I GET. SOMETIMES I THINK I CAN'T DO THIS, AND I HANG UP THE PHONE.

5.

IMPLICATIONS OF HAVING MORE THAN ONE NEURODIVERGENT CONDITION

Up to 70% of autistic people also present with ADHD.⁹ The autistic participants who also have ADHD reported that their symptoms can be contradictory, leading to difficulties in getting a diagnosis, and finding medications that are suitable for both neurodivergent conditions.



THE REASON I DIDN'T GET DIAGNOSED WHEN I WAS YOUNGER WAS DUE TO THE COMBINATION OF AUTISM AND ADHD. I FEEL LIKE THEY CAN CLASH A LOT.

HEALTHCARE SERENITY

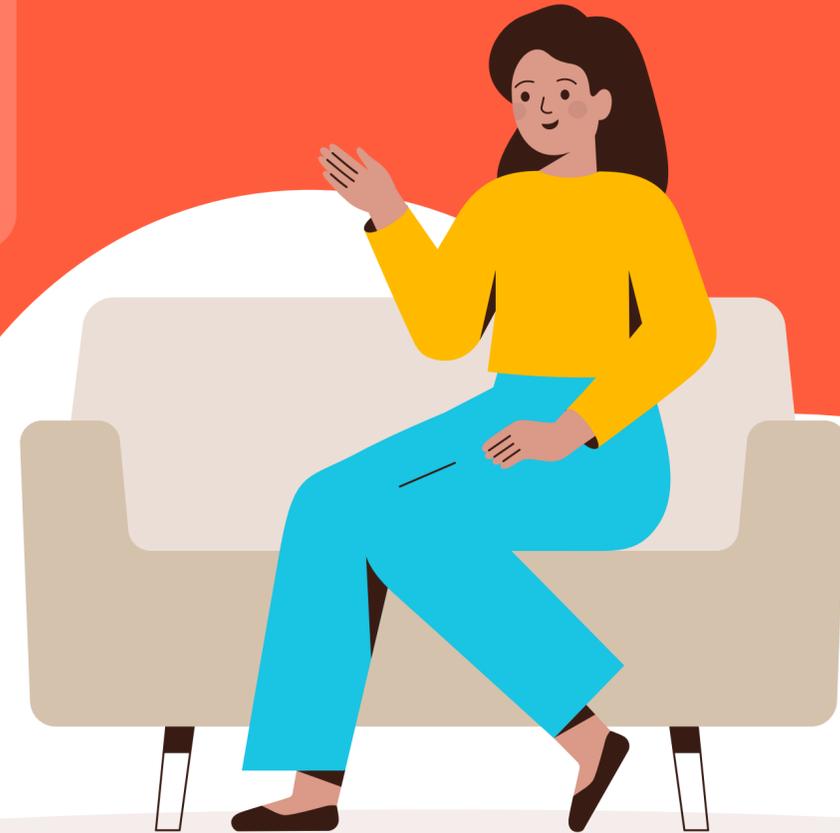
To help make healthcare services less stressful and more accessible for neurodivergent people, the following approaches should be considered.

Hiring more doctors who are neurodivergent.

Providing clear instructions on where to park and who to contact for appointments.

Making doctors appointments longer to allow more time for information processing.

Having more options for virtual appointments, such as texts and video chats.



HEALTHCARE SERENITY

To help make healthcare services less stressful and more accessible for neurodivergent people, the following approaches should be considered.

Providing training for doctors to treat neurodivergent people more appropriately.

Avoiding phone calls as appointments, especially if they are not scheduled.

Facilitating text reminders for attending appointments and taking medications.

MAKING POSITIVE EXPERIENCES COMMONPLACE

While there are areas where healthcare services could be improved, it's important to highlight the positive experiences discussed by the participants, too.

BEING TREATED BY NEURODIVERGENT DOCTORS

"I had an appointment with an ADHD nurse who was so clued up and understanding, my appointment felt really helpful, positive, and validating."

ALLOWING TIME TO ASK QUESTIONS AND PROCESS INFORMATION

"Little things like 'how are you doing' or 'is everything alright' provides that platform for support."

FACILITATING REGULAR CONTACT OPPORTUNITIES

"Regular contact is really good because it just stops it from dropping off my radar."

PROVIDING OPTIONS FOR WRITING OUT RESPONSES INSTEAD OF RELYING ON VERBAL EXPLANATION

"When I was getting my autism diagnosis, they gave me the option to write down all of my thoughts rather than having to have a face-to-face interview. This made it a much easier experience for me."

WHAT ABOUT CLINICAL RESEARCH?

There is little to no research on the impact of neurodivergent conditions on clinical research engagement. However, this research shows that neurodivergent people may experience similar barriers accessing clinical research as they do healthcare services.

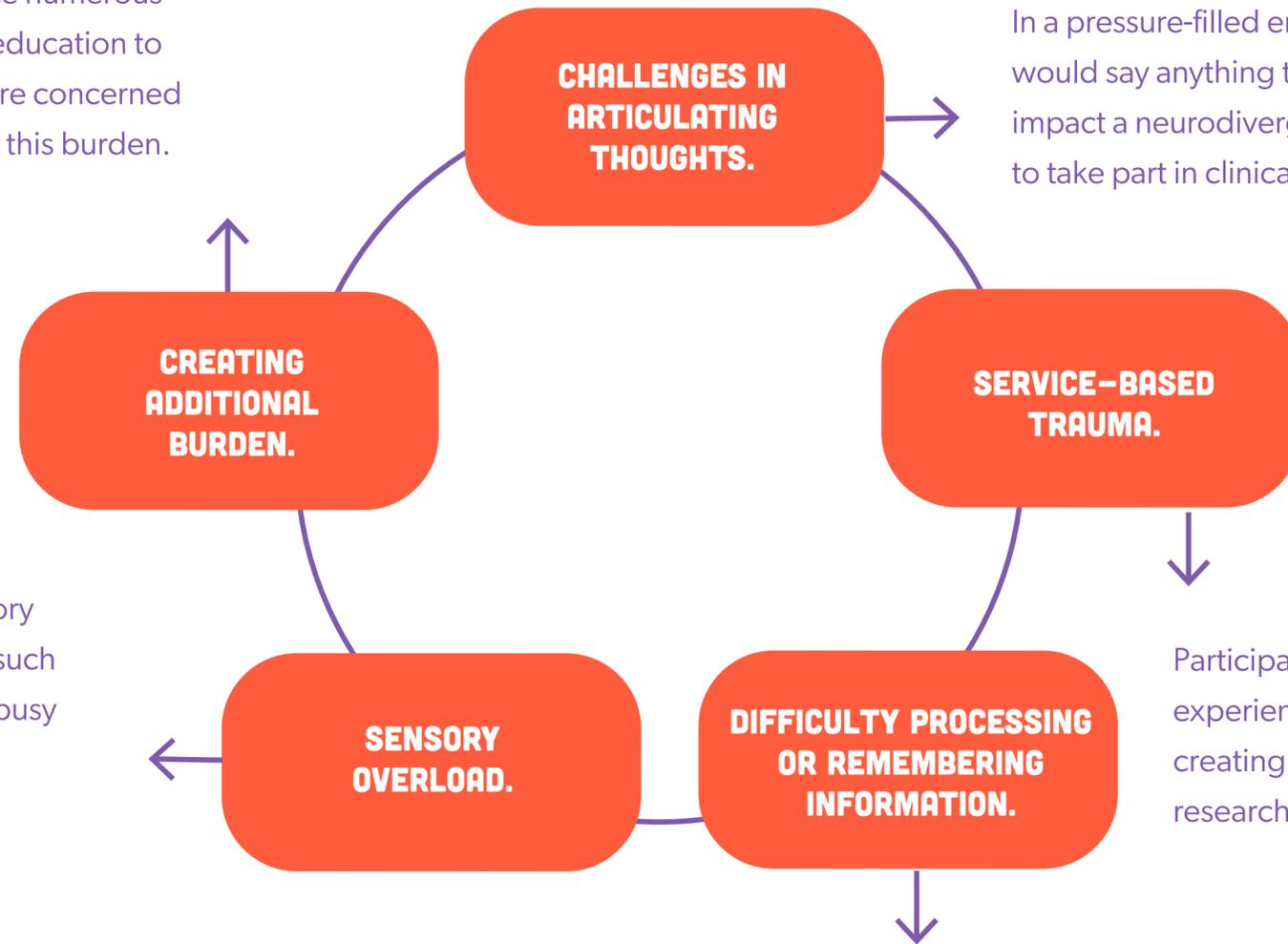


THERE'S A RISK OF BRINGING MORE DIFFICULTIES UPON ME THAT WOULD JUST ADD ON TO THE ONES I ALREADY HAVE.



WHAT ABOUT CLINICAL RESEARCH?

Neurodivergent people experience numerous challenges, from their career and education to their relationships. Participants were concerned that clinical research would add to this burden.



In a pressure-filled environment, participants said they would say anything to get out of the room. This could impact a neurodivergent person's ability to give consent to take part in clinical research.

Many participants described sensory challenges in healthcare settings, such as bright lights, loud sounds, and busy waiting areas. All of these sensory challenges are present in clinical research too.

Participants reported that they regularly had negative experiences when accessing healthcare services, creating a lack of trust in the industry. Clinical research is likely to be seen in the same light.

Participants reported difficulty in processing complex information, and also keeping on top of appointments and remembering to take medication regularly. This could impact a person's ability to adhere to medication regimen, and to navigate complex information or clinical research schedules.

MAKING CLINICAL RESEARCH ACCESSIBLE

Despite the barriers, 61% of participants had considered participating in clinical research.

Yet just 8% had actually taken part. When asked how clinical research could be made more accessible, the participants recommended the following.



BEFORE CLINICAL RESEARCH BEGINS

- 70%** of participants said information should be made easier to understand.
- 32%** of participants recommended using videos and infographics.
- 29%** of participants said to break up any large chunks of text.
- 22%** of participants suggested to provide assistance with understanding research information.

DURING CLINICAL RESEARCH

- 55%** of participants would want medication and appointment reminders.
- 16%** of participants said that appointment flexibility was important.
- 24%** of participants would prefer to keep a digital diary.
- 24%** of participants said they would want all staff to be informed on neurodiversity.

AFTER CLINICAL RESEARCH

92% of participants would want to know the outcomes of the clinical research.



TOGETHER.



I'D WANT TO KNOW THE RESULTS OF THE RESEARCH AS A PRIORITY. I'D PERSONALLY WANT A LOT OF INFORMATION ABOUT THE RESULTS AND WHAT HAPPENS NEXT.

THANK YOU

We would like to thank all participants for taking part in this research, and for sharing their valuable insights on how access to healthcare services and clinical research could be improved for neurodivergent people.

***“SMALL CHANGES ARE ESSENTIAL FOR SOME,
BUT HELPFUL FOR ALL.”***

Demand Diversity is a non-profit organisation that strives to promote diversity, equity, and inclusion within the clinical research industry. We're committed to giving underserved communities and patients a voice, and supporting those working in healthcare and clinical research to be truly inclusive.

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