



NEURONATAL VOICES

THE UNHEARD

A UK AND CROWN DEPENDENCIES SURVEY OF NEURODIVERGENT PEOPLE'S
EXPERIENCES OF MATERNITY CARE

Laura Spence | Dr Claire Feeley | Camilla Foulsham | Emilie Edwards

ALERT REPORT | 2026



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Note on language

This report uses the terms women, birthing people and parents to reflect the language and experiences of survey respondents. We recognise that not everyone identifies with the same terminology and aim to use language that respects the diversity of people accessing maternity care.

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FOREWORD

By Jodie Hill, Disability Employment Lawyer

I work in employment law, not maternity care. But reading **NeuroNatal Voices**, I recognised something strikingly familiar from a very different setting: the employment tribunal.

The figures in this survey are hard to ignore. 82.6% of respondents were not asked about sensory or access needs. 79.5% said support was only offered if they asked for it themselves. Only 4.2% felt maternity staff understood neurodivergence well enough.

The setting is different, but the underlying issue is familiar. Too often, the responsibility for making a system accessible falls back on the individual.

We have already seen the consequences of failing to respond to neurodivergent people's needs in employment, where an analysis of published government data found that neurodivergence-related tribunal cases **almost doubled between 2020 and 2025**.²⁸

Our understanding of neurodivergence has grown rapidly, but the support people receive has not kept pace. In my experience, disputes can develop when needs are identified but not acted upon, or adjustments are delayed. Trust breaks down, people may become unwell, leave their jobs and, sometimes, bring a legal claim.

Maternity services should pay attention.

Under the Equality Act 2010, healthcare providers have an anticipatory duty to make reasonable adjustments for disabled people. Services should be thinking ahead about barriers, rather than relying on individuals to encounter them and ask for help.

For NHS services in England, the Accessible Information Standard also requires information and communication needs to be **identified, recorded, flagged, shared, met and reviewed**. Yet **NeuroNatal Voices** reveals a troubling gap between these expectations and the experiences of many respondents.

Who is carrying the responsibility for making maternity care accessible?

For many of the people in this report, it appears to be the individual who needs the adjustment. Yet labour, pain, fear, sensory overload and the pressure of processing information can all affect someone's ability to communicate and advocate for themselves. If access to support depends on someone being able to ask for it, **what happens when they can no longer ask?** Self-advocacy cannot be the accessibility plan.

And this works both ways. Neurodivergent people are part of the maternity workforce too. A maternity service cannot be truly inclusive when the person giving birth has to fight for an adjustment, and the neurodivergent midwife caring for them has to do the same.

Having worked with cases where people have repeatedly tried to explain their needs, only to find themselves in an employment tribunal when those needs were not met, I recognise the importance of listening before things reach that point.

That is why this report matters. **NeuroNatal Voices** gives maternity services an opportunity to learn directly from the people receiving their care. Their experiences show what happens when needs are overlooked, but also the difference made by professionals who listen, understand and adapt their approach.

Employment tribunals offer lessons about what can happen when systems fail to respond to people's needs. **Maternity services now have an opportunity to learn from those lessons, listen to the experiences shared in this report and use them to make meaningful changes to care.**

Recognition alone does not make a service accessible.

What matters is what happens next.



Self-advocacy cannot be the accessibility plan.



JODIE HILL

*Disability Employment Lawyer
Founder, Thrive Law*

ABOUT NEURONATAL

NeuroNatal Academy CIC is a UK-based, not-for-profit social enterprise dedicated to improving maternity care for neurodivergent women, birthing people and their families.

Founded by Laura Spence, a midwife with ADHD, NeuroNatal was established in response to a growing recognition that maternity services are not always designed with neurodivergent people in mind, whether they are accessing care or working within it.

Through education, consultancy, research, advocacy and collaboration, we work with maternity professionals, students, organisations and people with lived experience to improve understanding of neurodivergence and support more accessible, compassionate and individualised care.

Our work is shaped by both professional expertise and lived experience. We bring together neurodivergent parents, midwives, students and other professionals to share knowledge, challenge assumptions and help influence meaningful change.

What we do



Training



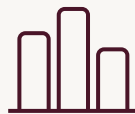
Consultancy



Resources



NeuroMidwives Forum



Research



NeuroNatal Alliance

Our belief is simple: neurodivergent people should not have to fight to be understood, accommodated or treated with dignity.

ACKNOWLEDGEMENTS

NeuroNatal Voices would not have been possible without the generosity, trust and support of so many people who believe neurodivergent women, birthing people and their families deserve better maternity care.

First and foremost, my heartfelt thanks go to every person who completed the survey and trusted us with their experiences. Some shared wonderful examples of compassionate, individualised care, while others revisited painful and difficult experiences. I recognise the time and emotional energy this may have taken, and I am deeply grateful.

My sincere thanks go to Dr Claire Feeley and Emilie Edwards at King's College London for their invaluable contributions to the development of this report. I am particularly grateful to Emilie, an autistic midwifery lecturer, whose professional expertise and lived experience have brought an important perspective to this work.

I am equally grateful to Camilla Foulsham, NeuroNatal Parent Ambassador and Expert by Lived Experience, for sharing her insight and helping ensure neurodivergent parents' perspectives remain central to this work.

To our wonderful NeuroNatal Ambassadors, everyone who shared the survey, encouraged others to participate, reached out personally or supported this work in ways big and small: thank you.

I have been genuinely touched, overwhelmed and delighted by the kindness, encouragement and belief in **NeuroNatal Voices**. What began as a determination to listen has become something I am incredibly proud to share.

And finally, to every neurodivergent parent whose maternity journey is still to come: I hope the voices shared here will help make your experience one in which you feel understood, respected and supported.

To everyone who made this possible, thank you. Your voices matter, and they deserve to make a difference.



LAURA SPENCE

*Midwife | Founder
NeuroNatal Academy CIC*

CONTENTS

Foreword	03
About NeuroNatal	05
Acknowledgements	06
Executive Summary	08
Introduction	10
Methodology	15
Who Responded	21
Findings	25
Discussion	35
Strengths & Limitations	43
Recommendations	47
Conclusion	54
What Happens Next?	57
Be Part of the Change	60
References	61

EXECUTIVE SUMMARY

NeuroNatal Voices explores neurodivergent people's experiences of maternity care across the UK and Crown Dependencies.

Launched by NeuroNatal Academy CIC in May 2026, the survey received 261 responses, with 241 included in the final analysis. Respondents included autistic people, people with ADHD and AuDHD, and people with other neurodivergent identities.

The findings highlight a gap between recognising neurodivergence and responding to individual needs. Too often, people were expected to identify, explain and repeatedly advocate for adjustments themselves.

| Accessible care should not rely on exceptional self-advocacy.

Key findings

82.6%

had not been asked about their sensory or access needs

82.6%

had not been asked how they preferred to receive information

77.9%

said they had not been asked about their preferred way of communicating

64.5%

had not always been given enough time to process information

79.5%

said support or adjustments were not offered unless they requested them

87.5%

described some part of their maternity care as upsetting, overwhelming or traumatic

Source: NeuroNatal Voices survey, 2026. Percentages are based on responses to individual questions.

4.2% felt maternity staff had enough understanding of neurodivergence

Source: NeuroNatal Voices survey, 2026. Percentages are based on responses to individual questions.

What good care looked like

Alongside difficult experiences, respondents described examples of excellent maternity care. They valued professionals who listened, believed them, explained what was happening, respected their choices and made adjustments to meet their individual needs. Often, the difference was not a specialised intervention. It was care that responded to the individual.

What needs to change?

The findings point towards four practical actions that can be incorporated into routine maternity care:



ASK:

Ask about communication, sensory, information-processing and access needs before somebody is struggling.



LISTEN:

Understand what works for that individual, recognising that needs may change during pain, distress or overwhelm.



RECORD:

Document agreed adjustments clearly so people do not have to repeatedly explain their needs.



ACT:

Put those adjustments into practice. An adjustment recorded in a care plan only makes a difference when it changes the care someone receives.

Neuroinclusive maternity care does not require professionals to predict what every neurodivergent person might need. It requires them to **ask, listen, record and act**.

This Alert Report is the first stage of the **NeuroNatal Voices** work.

Further qualitative analysis is planned to explore these experiences in greater depth and identify priorities for future research.

SECTION 01

INTRODUCTION



Understanding how to provide accessible maternity care for this population is therefore not simply preparation for the future.

INTRODUCTION

Neurodivergent people are navigating pregnancy, birth and postnatal care within maternity systems that have rarely been designed with their needs in mind. Yet their experiences remain strikingly under-represented in research.

What evidence does exist has largely focused on autism, describing experiences including sensory overwhelm, communication difficulties, uncertainty and feeling misunderstood by maternity professionals.^{1,4} However, even this evidence base remains limited.

We know considerably less about the maternity experiences of people with ADHD or AuDHD, dyslexic and dyspraxic people, and people with other neurodivergent identities.

A 2024 systematic review examining autism and ADHD across the perinatal period identified only 11 eligible studies, with most of the evidence centred on autism.⁵ Research beyond these diagnoses is even more limited. A large part of the picture is therefore still missing.

Recognition of neurodivergence is increasing, particularly among women and birthing people who may have spent much of their lives undiagnosed. More people are receiving diagnoses in adulthood, including during their reproductive years.

However, increasing diagnosis does not necessarily mean that neurodivergence itself is becoming more prevalent. It means that maternity services are increasingly likely to care for people who are aware of their neurodivergence, alongside many others who remain undiagnosed, are awaiting assessment or may not yet recognise their own neurodivergent needs.

Understanding how to provide accessible maternity care for this population is therefore not simply preparation for the future. It is a response to the needs of people already using maternity services.

NeuroNatal Voices was developed to help address this gap. Rather than focusing on a single diagnosis, the survey brought together experiences from people across a broad range of neurotypes, providing a wider perspective on maternity care than much of the existing research.

We wanted to hear directly from people about what maternity care had actually been like for them, without assuming in advance what support they might need. We wanted to understand what had worked well and what had made care harder to access. Were people asked what they needed? Were those needs understood and acted on? And what would have made their experience better?

Why lived experience is needed

Routinely collected maternity data can tell us a great deal about births, interventions, complications and clinical outcomes. But it tells us far less about what care actually felt like to receive.

A record may show that information was given, but not whether the person was able to understand or process it. It may show that an adjustment was documented, but not whether it was actually made. Clinical records rarely capture the noise of a waiting room, the moment someone became too overwhelmed to speak, or the experience of needing more time but not knowing how to ask for it.

Equally, they may miss the things that made all the difference: a professional who took their time, someone who recognised distress, or someone who had read the notes and adapted their approach without being asked. These experiences help us understand not just what happened during someone's care, but how that care was experienced and why particular approaches helped or caused difficulties.

By listening directly to those receiving care, we can begin to identify barriers that might otherwise go unnoticed, recognise what good care looks like in practice and understand where meaningful improvements are needed.

Accessibility is already part of good healthcare

The issues raised through **NeuroNatal Voices** are not separate from existing expectations around accessible and individualised care.

Under the Equality Act 2010, service providers and those exercising public functions have an anticipatory duty to make reasonable adjustments for disabled people.^{9,27} Not every neurodivergent person will meet the legal definition of disability, and **NeuroNatal Voices** did not assess respondents' legal disability status.

In England, the Accessible Information Standard (DAPB1605) sets out how relevant NHS and publicly funded adult social care services should identify and respond to information and communication needs associated with disability, impairment or sensory loss.²⁶

The six stages are:

IDENTIFY → RECORD → FLAG → SHARE → MEET → REVIEW

That process has clear relevance to maternity care.

During pregnancy, birth and the postnatal period, a person may move between community and hospital services, meet different professional groups and receive care in several settings.

An access need identified in one part of the system is of limited value if that information does not reach the next person providing care.

NeuroNatal Voices was not designed to assess compliance with the Accessible Information Standard. Not every respondent will fall within its scope, and participants came from across the UK and Crown Dependencies, while the Standard applies specifically in England.

It does, however, provide useful context for a question that runs through this report:

Once an access need is known, what happens next?

Aims

NeuroNatal Voices aimed to explore the experiences of neurodivergent people who had used maternity services in the UK and Crown Dependencies within the previous five years. The survey sought to understand:

- experiences across pregnancy, labour and birth, postnatal care and other maternity services;
- whether communication, sensory, information and wider access needs were recognised and supported;
- what made care easier or harder to access;
- what supportive and accessible care looked like from the perspective of those receiving it;
- whether respondents felt neurodivergence or access needs had affected their maternity experience;
- what people believed could have improved their care;
- how these experiences could inform maternity services, professional education and future research.

About this Alert Report

NeuroNatal Voices generated a substantial body of quantitative and qualitative data. That data deserves careful analysis. The open-text responses in particular contain detailed, often complex accounts of maternity care, and doing justice to them takes time. Simultaneously, some findings warrant attention before every stage of analysis is complete.

This Alert Report therefore presents the findings that warrant attention now.

It brings together the main quantitative results with an initial focused analysis of the open-text responses, using participants' own words to add context and show what sits behind the numbers.

This is not the final analysis of the **NeuroNatal Voices** dataset. Further work will examine the qualitative responses in greater depth and explore some of the questions raised by these early findings.

The purpose of this report is to share what can be said with confidence at this stage, without rushing the analysis or reducing a rich dataset to a series of headline figures.

SECTION 02

METHODOLOGY

241 respondents included in the final analysis

METHODOLOGY

At a Glance

Design

Cross-sectional online survey

Platform

Google Forms

Survey period

4 May - 1 June 2026

Final sample

n=241

Recruitment

Open online dissemination through social media, professional and community networks

Participants

Neurodivergent people aged 18 or over who had used maternity services in the UK and Crown Dependencies within the previous five years

Survey design and development

NeuroNatal Voices was a cross-sectional online survey combining closed-response questions with opportunities for people to describe their experiences in their own words.

The survey explored neurodivergent identity and diagnosis, experiences of maternity care, communication and information needs, sensory and other access needs, adjustments and support, mental health, experiences with maternity professionals, and what respondents felt could have improved their care.

It was developed by NeuroNatal Academy CIC, with input from neurodivergent people bringing both lived and professional experience. Contributors included maternity professionals, parents with recent experience of maternity and neonatal services, and NeuroNatal Ambassadors with backgrounds in healthcare, equality, diversity and inclusion, and survey development.

Their input helped shape both the questions and the language used, particularly in areas relating to communication and information processing, sensory experience, reasonable adjustments, continuity, mental health, and experiences of feeling understood or misunderstood.

Who could take part?

Participants were eligible if they:

- were aged 18 or over;
- identified as neurodivergent, whether formally diagnosed or not;
- had used maternity services in the UK and Crown Dependencies within the previous five years; and
- confirmed that they understood the survey was anonymous and how their responses would be used.

Before beginning the survey, participants were given information about its purpose and how their data would be handled. Participation was voluntary. People could skip questions or leave the survey at any point before submitting their response. Consent to use anonymous verbatim quotations was asked separately.

Language and terminology

This report uses identity-first language, including autistic people and neurodivergent people, reflecting terminology preferred by many within neurodivergent communities. We recognise that individual preferences vary.

We use women and birthing people to reflect the diversity of people accessing maternity services. Where findings relate to specific participant groups or previously published research, we retain the terminology needed to describe those populations accurately.

We use people from minority ethnic backgrounds where a collective term is appropriate, while recognising that experiences vary considerably between and within ethnic groups. We preserved verbatim participant quotations, including instances where individuals use different terminology.

Recruitment

The survey was hosted on Google Forms and remained open for four weeks, from 4 May to 1 June 2026. It launched at the start of Maternal Mental Health Awareness Week and was shared through NeuroNatal Academy's social media channels and professional and community networks.

The survey was also shared by organisations and individuals working across maternity, perinatal mental health and lived-experience communities, including Make Birth Better, the Maternal Mental Health Alliance, The Neurodiversity Practice, Home-Start, NHS Trusts and Maternity and Neonatal Voices Partnerships (MNVPs).

These organisations helped disseminate the survey but were not research partners or study sites. Recruitment was open and voluntary.

There was no sampling frame and participants were not randomly selected, so the survey should not be regarded as representative of the wider neurodivergent population using maternity services in the UK and Crown Dependencies.

Final analytic sample

A total of 261 submissions were received. One exact duplicate was identified and removed, leaving 260 unique responses.

A further 19 responses were excluded from the primary analysis. Eighteen respondents did not meet the eligibility requirement of having used maternity services in the UK and Crown Dependencies within the previous five years, and one had not confirmed understanding of the survey's anonymity arrangements.

The final analytic sample was therefore:

241 respondents

Of these, 239 gave permission for anonymous verbatim quotations from their responses to be used. Only responses from those 239 participants were considered when selecting quotations for this report.

Quantitative analysis

Closed-response questions were analysed descriptively using counts and percentages. Denominators vary slightly between questions because participants could skip questions and some items were only shown when relevant to an earlier response. Percentages are therefore reported using the number of people who answered each individual question rather than the full sample of 241 unless otherwise stated.

Some questions allowed participants to select more than one response. In these cases, percentages will not total 100%.

No inferential statistical testing was undertaken. The survey was designed to describe the experiences reported within this sample, so the percentages presented in this report should not be interpreted as population prevalence estimates.

Qualitative analysis

Open-text responses were reviewed alongside the quantitative findings to explore how respondents described their experiences in greater depth.

For this Alert Report, the qualitative analysis was deliberately focused on issues most closely related to accessibility and the main patterns emerging from the survey. These included recognition of needs, communication and information, sensory experience, adjustments, self-advocacy, continuity, the care environment, masking or less visible distress, disclosure, and experiences of supportive care.

Responses were reviewed for recurring patterns and contrasting experiences, including examples of care that worked well. Quotations were selected to illustrate these experiences and provide context to the quantitative findings.

The quotations should not be read as indicating how common a particular qualitative experience was unless that issue was also measured through a closed-response question. This represents an initial focused analysis of the open-text data. A fuller qualitative analysis is planned.

Ethical considerations

NeuroNatal Voices was undertaken by NeuroNatal Academy CIC as an independent lived-experience survey intended to inform service improvement, professional education, advocacy and future research. It was not conducted as an NHS or university research study and did not undergo formal NHS or university research ethics review.

Ethical considerations were built into the survey design. Participants received information about the purpose of the survey, what participation involved, how their responses would be used and the anonymous nature of data collection before choosing whether to take part. Participation was voluntary and questions could be skipped. Consent for the use of anonymous quotations was obtained separately.

Some questions covered potentially difficult experiences, including mental health and maternity care that respondents may have found upsetting. Participants were not required to answer these questions and could leave the survey before submission.

No names or contact details were collected through the survey.

Data management

Survey responses were collected through Google Forms and held by NeuroNatal Academy CIC.

Because identifying information was not collected, individual responses could not be linked back to a participant after submission. It was therefore not possible to withdraw an individual response once it had been submitted.

Participants were informed that anonymous survey responses would be retained for five years following publication of the report.

NeuroNatal Academy CIC is registered with the Information Commissioner's Office (ICO) as a data controller.

SECTION 03

WHO RESPONDED?

Underrepresentation does not diminish the experiences that were shared.

WHO RESPONDED

The final analysis included 241 respondents, representing a range of neurodivergent identities, diagnostic experiences and maternity journeys. Most respondents were aged between 30 and 39, identified as women and were White. Most of those who provided their location had received maternity care in England.

At a glance

74.3% were aged **30–39**.

97.1% identified as **women**.

93.8% identified as **White**.

85.8% of those who provided a location were based in **England**.

These characteristics are important when interpreting the findings. **NeuroNatal Voices** reached a substantial number of people, but it did not capture all neurodivergent communities equally.

Neurodivergent identities

Participants could select more than one neurodivergent identity or difference, reflecting the overlap between different forms of neurodivergence.

Neurodivergent Identity or Difference	<i>n</i>	%
ADHD	105	43.6
Autistic	38	15.8
AuDHD	83	34.4
Dyslexic	34	14.1
Sensory Processing Differences	26	10.8
Self-identifying as Neurodivergent	53	22

NeuroNatal Voices survey, 2026. *n* = number of respondents selecting each option. Participants could select more than one response, so percentages do not total 100%.

The sample was therefore broader than an autism-only or ADHD-only population. It included people who identified with more than one form of neurodivergence, as well as people who believed they were neurodivergent but did not have a formal diagnosis.

Of the 239 respondents who answered the question about diagnosis, **71.5%** had received a **formal neurodivergent** diagnosis and **28.0% self-identified as neurodivergent** without one. One respondent preferred not to say. A formal diagnosis was not required to take part. This was intentional.

Access to neurodevelopmental assessment is uneven, and some people face long waits or may never receive a formal diagnosis unless they are able to pay for a private assessment. Restricting participation to formally diagnosed respondents could therefore have excluded people with relevant lived experience and introduced its own form of selection bias.

Respondents without a formal diagnosis were included on the basis of self-identification. This should be considered when interpreting the findings, as neurodivergent status was not independently verified by the survey.

Maternity experiences represented

Respondents brought experiences from across the maternity journey, including pregnancy, labour and birth, postnatal care, community midwifery, hospital care and specialist services. For around half of respondents, the maternity experience they told us about related to their first pregnancy or birth. Others drew on later pregnancies or previous experiences of maternity care.

This gave the survey a mixture of perspectives. Some people were encountering maternity services for the first time, while others had previous experiences against which they could understand or compare their care.

Many respondents had experienced additional complexity

Neurodivergence was only one part of the picture for many respondents. Of the 238 people who answered the relevant questions, **80.3%** reported at least one **pregnancy, birth or baby-related complication**.

Mental health difficulties were also common within this sample. Of 240 respondents, **87.1%** reported experiencing **emotional or mental health challenges** during pregnancy or after birth. Of the 239 who answered the question about accessing mental health support, **62.1%** had **used mental health services during the perinatal period**.

These figures provide important context for understanding respondents' experiences of maternity care. Some were navigating pregnancy or birth complications, mental health difficulties, neurodivergence and access needs at the same time.

The survey cannot separate the influence of each of these factors, and these figures should not be interpreted as estimates for neurodivergent people more broadly.

Whose voices are represented, and whose are less visible?

The people who responded to **NeuroNatal Voices** were predominantly White women aged between 30 and 39, with most location responses coming from England.

Neurodivergent people from minority ethnic backgrounds were underrepresented in the survey, as were trans and non-binary people, younger and older parents, and people who had received maternity care in Scotland, Wales and Northern Ireland.

Experiences of maternity care are shaped by more than neurodivergence alone. Race and ethnicity, gender, sexuality, disability, socioeconomic circumstances, migration status and other aspects of a person's life may all influence how care is experienced and accessed.

The survey sample was not large or diverse enough to explore these intersections reliably. The findings are therefore presented as the experiences of this sample rather than as representative of all neurodivergent people using maternity services.

Underrepresentation does not diminish the experiences that were shared. It shows where important gaps remain and where future work needs to listen more deliberately.

SECTION 04

FINDINGS

That's the hardest thing, having more needs than most people and having to fight to get them met when you're already struggling more than most people.

FINDINGS

The quantitative data show which difficulties were commonly reported by neurodivergent people during maternity care. The qualitative responses help us understand what those difficulties looked like in practice and how care could feel different when professionals took the time to understand individual needs.

Across the survey, one issue was repeatedly raised by multiple respondents: people's needs were not always identified, and even when they were known, this did not necessarily mean that their needs shaped the care that followed.

Needs were not routinely identified

Most respondents said nobody asked them about basic things that could make their maternity care more accessible.

82.6% were not asked about **sensory or access needs**.

82.6% were not asked how they **preferred to receive information**.

77.9% were not asked about their **preferred way of communicating**.

For some people, this meant having to recognise what they needed and raise it themselves. Others had already disclosed their neurodivergence or had information recorded in their notes, but still found that their needs were overlooked.

One respondent said:

“Every time we mentioned the mother was autistic it was basically ignored, and no accommodations were given. It was on the notes, but everyone was too focused on how they do things...”

Another had taken the time to prepare specifically for birth:

“I had written a neurodiversity specific birth plan that the hospital told me they had a copy of when, in fact, they didn't have it so it was not looked at or followed during my labour and the birth of my son.”

This was reflected in the quantitative findings. **59.0%** said their **support, communication or access needs** had not been written in their notes or care plan, while a further **15.9%** were unsure.

There were also examples of what happened when information was noticed and used.

“The midwife caring for me noticed this, and was able to recognise that I needed less sensory input without me having to specify it... She read my notes and gave me what I needed.”

The important difference in these accounts was whether information about the person made its way into their care.

Communication needed to work under pressure

Communication difficulties were not simply about whether information had been provided. Respondents described how difficult they found **trying to listen, understand, remember, make decisions and ask questions** while also dealing with pregnancy, pain, uncertainty or sensory overwhelm.

64.5% said they had not always been given enough time to **think about and process information**.

62.0% experienced **mixed messages from different members of staff**.

53.4% said information had been difficult to use because it was **only given verbally**.

Respondents also described receiving too much information at once, conversations moving too quickly and leaving appointments without something written to refer back to.

One person explained:

“In order for me to feel calm and safe, I need to fully understand what is happening, which means I often ask repeated questions until I can properly process the information.”

Another described what happened when they asked for more time:

“If I asked for time to think they would go and not come back... which is ok if I’m needing the overall content, but not so great if I have questions.”

For some, the pace of care itself became part of the problem:

“To accommodate what people need and to not just keep talking, write us notes, or let us write notes, it all happens so fast and there is no processing time.”

Only **23.2%** said they were consistently able to ask for an explanation again if they had not understood something. **76.8%** said they could only do this sometimes or not at all.

Respondents had different preferences for how information was given. Some wanted more detail, while others found it easier when information was broken into smaller, manageable steps. For some, written or visual information helped; for others, having more time to process what they had been told, or being able to return to the conversation later, made the difference.

The consistent message was the need for flexibility.

People were often left to advocate for themselves

79.5% of respondents said staff did not offer support or changes without them having to ask. This placed a considerable amount of responsibility on the person receiving care. They had to recognise what was making their care experience difficult, then work out what might help and, finally, explain that to somebody else.

Respondents described how exhausting that could become.

“That’s the hardest thing, having more needs than most people and having to fight to get them met when you’re already struggling more than most people.”

Another said:

“Education for staff on the importance of adjustments. When people ask for them they’re not just being fussy”

For one respondent, the lack of recognition was particularly stark:

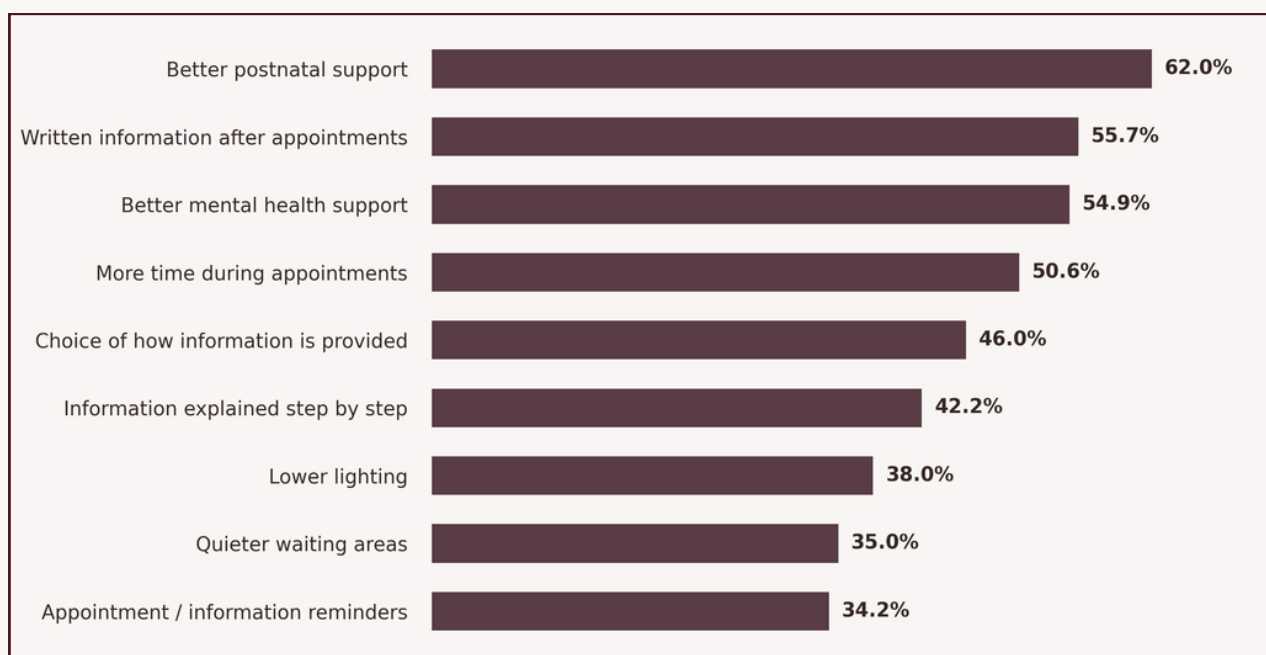
“A latex allergy would have been taken more seriously by my care providers than my ADHD was.”

Self-advocacy was clearly important to some respondents, and many were able to explain their needs very clearly. The difficulty came when receiving accessible care depended on them being able to explain their needs repeatedly, including during periods of pain, exhaustion or overwhelm.

Familiarity and continuity were highly valued

When asked what could have improved their care, **78.1% of respondents said that seeing the same staff where possible would have helped.**

Other commonly selected options included:



NeuroNatal Voices survey, 2026

Written responses gave more context to the prominence of continuity.

“When I had care from my named continuity midwife I felt fully heard and understood she adapted to meet my needs and I felt listened to.”

Another respondent described professionals who:

“...listened to and supported every choice I made... they were great at talking me through everything and didn't rush me to make a decision one way or the other.”

For some, familiarity meant **not having to explain themselves again**. For others, it gave them **time to build trust with somebody who came to understand them**, how they communicated and what helped.

These findings show how highly respondents valued familiarity, consistency and not having to start again each time they met somebody new.

The environment included more than the physical space

However, respondents' descriptions of accessible and inaccessible maternity care went well beyond noise and lighting. Their experiences highlighted how the environment, communication, relationships with professionals and the organisation of care could all shape whether they felt understood, supported and able to access the care they needed.

These experiences often overlapped, illustrating how accessibility is influenced by several interconnected aspects of maternity care.

The four dimensions of accessible maternity care

Accessibility extends beyond the physical environment



PHYSICAL

The sensory environment:
Lighting, noise and sensory input



COMMUNICATION

How information is shared:
Pace, format and processing time



RELATIONAL

How people are treated:
Listening, choice, trust and feeling believed



ORGANISATIONAL

How care is coordinated:
Continuity, documentation, handover and follow-up

Four interconnected dimensions of accessibility

NeuroNatal Voices survey, 2026

Accessibility in maternity care is not limited to the physical environment. The experiences described through **NeuroNatal Voices** highlight the importance of considering communication, relationships and the organisation of care alongside sensory needs. These dimensions are interconnected, and difficulties in one area may compound barriers in another.

A quiet room could help. So could knowing what was going to happen next, having enough time to answer a question, seeing somebody familiar or meeting a professional who listened without making the person justify every need.

One respondent described a professional who asked before proceeding with an examination:

“She asked me if I was happy for a Dr to do it or if I wanted her to... she was so slow and gentle and amazing. I felt very safe.”

Another remembered somebody who:

“...really advocated for me, listened to my needs and made me feel genuinely supported and safe throughout the experience.”

The way professionals communicated and responded could change how safe and manageable the whole environment felt.

Distress was not always obvious

Some respondents described a significant gap between how they appeared to professionals and how they were actually feeling.

One person remembered a senior community midwife who recognised that they were struggling despite appearing outwardly capable:

“It would have been easy to dismiss my distress given that I was healthy and baby was healthy, but she took the time to see through my ‘competent’ persona and realised I was struggling.”

Another reflected:

“My baby was thriving and I was often told I was doing fantastically, but behind the mask I was struggling deeply.”

Others described masking their distress, internalising pain or becoming less able to communicate when overwhelmed.

For these respondents, appearing calm, articulate or capable did not necessarily reflect what was happening underneath.

Disclosure did not always feel safe

A small number of respondents described being apprehensive to share their neurodivergence, mental health difficulties or support needs because they worried about how professionals might interpret that information.

One respondent described:

“Always a balance between being honest enough to get support but not too honest that might risk you losing your freedom or having social services involved. This was a constant fear of mine”

Another wrote:

“There is a level of fear of being declared an unfit parent for seeking help over even minor mental health so simply get on with life”

One respondent described an experience in which their concerns about interpretation had become very real:

“Interpretations of my behaviour and emotions by midwifery staff resulted in a social care referral at child protection level. Following assessment it was deemed there were no safeguarding concerns and no role for social care. This was extremely distressing.”

These accounts cannot tell us how common this experience was across the sample, and the survey cannot determine whether individual safeguarding decisions were appropriate.

They do raise an important concern. If somebody is worried that disclosing a difficulty could affect how they are viewed as a parent, that may influence what they tell their care providers.

Difficult experiences were common

When asked about their maternity care, **87.5%** said some part of it had **felt upsetting, overwhelming or traumatic**.

210 of 240 respondents

The survey grouped 'upsetting, overwhelming or traumatic' within a single response, so this figure should not be interpreted as a measure of psychological trauma.

Among those 210 respondents, **77.6%** felt their **neurodivergence or access needs** had contributed to the experience.

Across the whole sample, **75.5%** believed being neurodivergent had **affected their maternity care** in some way.

Respondents were also asked whether they felt maternity staff had enough understanding of neurodivergence.

66.5% said **no**.

29.3% were **unsure**.

Only 4.2% said **yes**.

Some respondents were clear that they did not see neurodivergence itself as the reason their care had been difficult.

One wrote:

"Being neurodivergent is not what contributed to my experience being traumatic. The widespread discrimination and hostility from staff is what made it traumatic... Patients are NOT the problem."

NeuroNatal Voices cannot establish that neurodivergence caused these difficult experiences. Respondents were describing what happened when their needs and ways of communicating, processing or responding were not met by the care providers and systems around them.

Good care was remembered too

Alongside difficult experiences, accounts were shared of professionals who made people feel safe, understood and supported.

Sometimes the most impactful support was very simple:

“Believed me. Just that.”

Others described professionals who adapted naturally to what they needed.

“My midwife during labour was autistic, she just got me and automatically adjusted my environment accordingly.”

One respondent who had originally planned a home birth described being given a private room when hospital care became necessary:

“We were given a private room off the ward to create a home from home. We stayed there happily for five days. Without it, I’m confident I wouldn’t have coped.”

Another described a member of staff discussing their ADHD before a caesarean birth:

“She made it clear it was fine to take my medication on the day as it was just as important for me to feel calm and in control as everything else going on.”

Across these positive accounts, good care often came down to professionals paying attention. They listened, explained, gave people time, respected their choices and adapted when they could see something was not working.

Respondents remembered those interactions.

The question raised by these findings is how maternity services can make that experience more consistent, so that accessible care does not depend so heavily on the individual professional somebody happens to meet.

SECTION 05

DISCUSSION

For the person receiving care, what counts is what happens next.

DISCUSSION

NeuroNatal Voices adds to a growing body of evidence showing that neurodivergent people can experience maternity care differently. Many of the issues raised by respondents are already familiar from research with autistic women and birthing people, including sensory overwhelm, difficulties processing information under pressure, communication mismatch, feeling judged or misunderstood, and a lack of professional understanding.^{1, 4}

A 2024 review of autism and ADHD across the perinatal period identified only 11 eligible studies, with most focused on autism.⁵ Direct evidence relating to ADHD remains limited,⁶ and we found very little maternity-specific research concerning AuDHD, dyslexia, dyspraxia/DCD, Tourette syndrome and other neurodivergent groups.

This is important when interpreting **NeuroNatal Voices**. Our respondents represented a wider range of neurodivergent identities and experiences than is currently reflected in the maternity literature, which remains heavily focused on autistic people. We therefore cannot assume that findings or proposed mechanisms from autistic maternity research apply in the same way across all neurodivergent groups.

Even so, there is substantial overlap between the published evidence and what respondents described. Across both, a recurring practical problem is the gap between identifying a need and responding to it. A need may be known but not fully understood. It may be recorded but not passed on. An adjustment may be agreed but never put into practice.

For the person receiving care, what counts is what happens next.

Accessible care should not rely on exceptional self-advocacy

Self-advocacy can be valuable. Many respondents clearly knew themselves well and were able to explain what they needed and what helped. The problem comes when the person needing help becomes unintentionally responsible for making sure their care is accessible. Accessible care should not depend on a neurodivergent person being able to repeatedly and successfully advocate for themselves.

Asking for an adjustment requires several things to happen first. The person has to recognise what is making the situation difficult, know that something different might be possible, and find a way to communicate it. They also have to feel confident that asking will be taken seriously.

Those demands do not disappear during labour, pain, exhaustion or sensory overload. They may become considerably harder.

Autistic people have described similar experiences in maternity and wider healthcare research, including difficulties asking for help and having needs overlooked when they were not explicitly expressed.^{1,3,7} Research involving birthing people with intellectual, developmental and sensory disabilities has also identified barriers to effective communication, including limited professional understanding, assumptions about people's needs and a lack of accessible communication support.¹⁵

This is particularly important because someone who does not ask for help may still need it. **NeuroNatal Voices** therefore raises an important question about where responsibility for accessibility sits.

Maternity professionals cannot be expected to predict every individual's needs. They can, however, create opportunities for people to tell them what would help before a situation becomes difficult.

If a diagnosis is already known, this can be as simple as acknowledging it and asking what it means for that individual:

"I can see that you're autistic, have ADHD or are dyslexic. Is there anything about this that you'd like us to understand, or anything we could do differently to make your care easier to access?"

Where a diagnosis is not known, a broader question such as:

"What would help you access your care?"
may reveal far more than asking about diagnosis alone.

Recognition needs to lead somewhere

A recurring theme from the data was the gap between information being known and information being used.

Some respondents had disclosed their neurodivergence. Some had needs documented in their notes or birth plans. Yet they still described arriving in situations where those needs were unknown, overlooked or had to be explained again. This has implications for how we think about identification.

A diagnosis can provide useful context, but it cannot tell a professional exactly how an individual communicates, processes information or experiences sensory input.¹² Likewise, documenting an adjustment has limited value if the information is difficult to find or does not reach the people providing care.

Research into autism health passports has identified similar problems. Tools designed to communicate needs may be useful, but their value depends on whether they are available, read and incorporated into care.^{13, 14}

NHS England's Reasonable Adjustment Digital Flag reflects the same broader principle by creating a mechanism for adjustment needs to be recorded and shared.¹⁰

The current process, if used at all, can break down at several stages:

Where information gets lost

- Identified, but not recorded.
- Recorded, but not communicated.
- Communicated, but not read.
- Read, but not acted upon.

For maternity services, where people regularly move between professionals, teams and settings, each handover creates another point at which useful information can be lost.

Identifying a need is only the beginning. The information has to reach the right person at the right time and influence the care they provide.

The care environment is wider than the physical space

Sensory experience is an established concern within autistic maternity research. Noise, lighting, touch, smell and unpredictable sensory input can all contribute to distress or overwhelm.² Research with autistic adults in wider healthcare settings has also identified sensory overload and communication barriers, particularly relating to background noise, feeling misunderstood and the need for clearer information.¹¹

NeuroNatal Voices supports the importance of sensory considerations, however respondents' descriptions of accessibility were broader. They talked about professionals speaking too quickly, receiving conflicting information, repeatedly explaining themselves, not knowing what was going to happen and feeling judged or dismissed. They also described the difference made by professionals who were calm, predictable, flexible and willing to listen.

This suggests that it may be useful to think about the maternity care environment across four connected areas.

These categories are not intended as a new theoretical model. They offer a practical way of making sense of what respondents described.

- 1 | **Physical:** sensory input, lighting, noise and space.
- 2 | **Communication:** pace, format, clarity and processing time.
- 3 | **Relational:** trust, listening, choice and feeling believed.
- 4 | **Organisational:** continuity, documentation, handover and follow-up.

A sensory-friendly room may help somebody considerably. The same person may still struggle if information is rushed, their care plan has not been read or they have to explain their needs again to every new professional. The people providing care are part of someone's experience of that environment too.

Could continuity have an accessibility function?

Continuity was one of the clearest preferences in the survey. 78.1% of respondents said seeing the same staff where possible would have helped.

Autistic parents have previously described valuing familiarity, trust and relationships with professionals who understand their individual communication and support needs.^{1, 3, 4}

Evidence from the wider maternity population also shows benefits from midwife continuity models, although this evidence was not developed specifically around neurodivergent access needs.¹⁶ There are several possible ways continuity could make care easier to access.

Seeing somebody familiar may reduce the need to repeatedly disclose or explain needs. A professional who already knows the person may also be more likely to notice changes in communication or signs of distress. Familiarity can reduce uncertainty and give both people more time to understand how best to communicate with one another.

Continuity can also extend beyond seeing the same individual professional. It can include continuity of information and greater consistency in how care is provided.¹⁷ This distinction is important because relational continuity will not always be possible. Shift patterns, urgent care, transfers and the need for specialist input mean that people will inevitably encounter different professionals during maternity care.

NeuroNatal Voices did not test continuity as an intervention, and we cannot conclude from these findings that it improves outcomes for neurodivergent people. What the findings suggest is a question worth testing:

Could continuity reduce some of the work that neurodivergent people have to do to make their care accessible?

That could include continuity of care where possible, but also better continuity of information and agreed approaches to ensure consistency when the professional changes.

When someone looks as though they are coping

Some of the most striking written responses came from people who described appearing capable while struggling internally. Masking and camouflaging are well recognised within autism research, although how these concepts should be understood in ADHD and across neurodivergence more broadly is less settled.^{18, 19}

In maternity care, the practical issue may be more straightforward than the terminology. A person may be articulate and still overwhelmed. They may answer questions while struggling to process what has been said. Someone who becomes very quiet may be experiencing significant distress rather than becoming calmer.

Respondents described professionals who recognised this difference, sometimes at moments when others had assumed they were coping well.

It means that observable behaviour cannot always be relied upon as the only indication of how somebody is managing.

This makes routine opportunities to check understanding and ask what somebody needs particularly important, including when they appear outwardly composed.

People need to feel safe enough to answer

Asking about support needs is useful only if people feel able to answer openly. A small number of **NeuroNatal Voices** respondents described fears that disclosing neurodivergence or mental health difficulties could affect how professionals viewed their ability to parent. Some specifically mentioned fears about social care involvement.

Similar concerns have been described by autistic parents, including experiences of feeling judged or misunderstood by professionals.^{8, 20} Fear of consequences can also affect disclosure and help-seeking in perinatal mental health more broadly.²¹

These findings need careful interpretation. **NeuroNatal Voices** cannot tell us how frequently neurodivergent parents experience inappropriate safeguarding referrals. Nor can it determine whether the safeguarding decisions described by individual respondents were clinically justified.

There is also evidence that knowing a parent is autistic can improve professional interpretations in some circumstances.

A 2026 vignette study found more favourable professional judgements when autistic behaviour was explicitly identified as such.²² The issue therefore appears more complex than disclosure simply being helpful or harmful. The impact depends on how that information is understood, responded to and used in the person's care.

Clear explanations about why questions are being asked, how information will be used and what support or adjustments may be available could help people feel safer when having these conversations.

Neurodivergence does not explain every difficult experience

The finding that 87.5% of respondents described some part of maternity care as upsetting, overwhelming or traumatic is important, but it requires careful interpretation. The survey used those three terms together. It did not assess psychological trauma or diagnose trauma-related conditions.

We also cannot conclude that neurodivergence caused those experiences. Pregnancy and birth can involve pain, uncertainty, complications, emergency care and difficult outcomes for many reasons. This was also a sample in which pregnancy or birth complications and mental health difficulties were common.

What respondents frequently described was the interaction between their needs and the care around them. **Difficulties became greater when information was delivered in a way they could not process, when sensory needs were overlooked or their communication was misunderstood.**

The neurodiversity literature offers useful ways of thinking about these interactions, including person-environment fit and the possibility of mutual communication mismatch between neurodivergent and non-neurodivergent people.^{23, 24} These ideas should be applied cautiously in maternity care because the direct evidence remains limited.

They do, however, remind us to look beyond the individual when something is not working. Some neurodivergent people will have substantial support needs regardless of how accessible a service becomes. At the same time, some difficulties can be reduced by changing communication, the environment or the way care is organised.

Good neuroinclusive care needs to recognise both.

Making good care more consistent

The positive experiences in **NeuroNatal Voices** are important because they show that many respondents had already encountered care that worked well for them.

They described professionals who listened, believed them, explained things clearly, gave them time and adapted their approach when needed. Some respondents remembered individual professionals years later because of how safe and understood they had made them feel.

Much of this aligns with existing autism research and guidance around individualised communication, sensory needs and shared decision-making.^{1–4, 12, 25}

What remains much less clear is which specific maternity interventions improve outcomes for neurodivergent people. The evidence is currently much stronger at describing experiences and identifying what people value than it is at evaluating which approaches are effective. We should therefore be careful not to present every adjustment valued by respondents as a proven intervention.

The findings provide a clear basis for practical changes to care while the effectiveness of specific interventions continues to be evaluated.

Maternity services can ask about access needs more consistently. They can give people options for receiving information, record what helps and make that information easier to find. Professionals can check understanding, allow processing time and respond to agreed adjustments wherever possible.

The findings also give us clear questions for future research, including whether continuity has an accessibility function, how best to identify needs routinely and whether neuroinclusive changes improve access, experience or outcomes.

For now, one message runs clearly through both the survey and the wider evidence:

- 1 | Ask people what they need.**
- 2 | Listen carefully to the answer.**
- 3 | Record it clearly.**
- 4 | And then Act on it.**

And then make sure it changes what happens next.

NeuroNatal Voices survey, 2026

STRENGTHS & LIMITATIONS

NeuroNatal Voices provides a substantial collection of recent experiences from neurodivergent people who have used maternity services. This is particularly valuable in an area where much of the existing maternity-specific research has focused on autistic people. One of the strengths of the survey is the range of neurodivergent people who took part.

Participation was not restricted to one diagnosis, and a formal diagnosis was not required. This meant the survey included autistic people, people with ADHD or AuDHD, dyslexic and dyspraxic people, people with other neurodivergent identities, and people who identified as neurodivergent without a formal diagnosis.

The survey also combined structured questions with opportunities for people to describe their experiences in their own words. This allowed us to identify patterns across the sample while retaining some of the context behind them. Respondents described difficult experiences, but they also told us about care that had worked well. Both are important when considering what needs to change.

There are, however, important limitations to consider.

This was a self-selecting sample

Recruitment was open and largely online, through social media and professional, community and lived-experience networks. People chose whether to take part.

Those who had particularly strong experiences, whether positive or negative, may have been more likely to respond. People already connected with neurodivergent communities or NeuroNatal Academy's networks may also have been more likely to see the survey.

Online recruitment may have excluded people with limited digital access, people who do not engage with these networks, or those for whom completing an online survey was itself inaccessible.

For these reasons, the sample should not be considered representative of all neurodivergent people using maternity services.

Some groups were much better represented than others

Respondents were predominantly White women aged 30 to 39, and most of those who provided a location were based in England.

Neurodivergent people from minority ethnic backgrounds were underrepresented, as were trans and non-binary people, younger and older parents, and people who had received maternity care in Scotland, Wales and Northern Ireland.

This limits what **NeuroNatal Voices** can tell us about the inequity of people's experiences when neurodivergence intersects with race and ethnicity, gender, socioeconomic circumstances and other characteristics protected under the Equality Act 2010.

It also reflects a wider problem within the evidence base. Much of the existing research on neurodivergence and maternity care has involved relatively narrow populations.⁵

Future work needs to make a deliberate effort to reach people whose experiences remain less visible.

The survey relied on people's own accounts

Respondents were asked about maternity care received within the previous five years. For some, these experiences were recent. For others, several years may have passed.

Recall will inevitably vary, and the survey was not designed to verify individual experiences against clinical records.

Neurodivergent identity and diagnostic status were also self-reported. This allowed people without formal diagnosis to take part, which was important to the aims of **NeuroNatal Voices**. It does mean that the survey cannot make clinical comparisons between diagnostic groups.

Many respondents were navigating other challenges

A high proportion of respondents reported pregnancy, birth or baby-related complications, and emotional or mental health difficulties were also common within the sample.

These experiences may have influenced how people experienced maternity care.

The survey cannot separate the effects of neurodivergence from pregnancy complexity, mental health, previous experiences of care or other factors in an individual's life. This is particularly important when interpreting findings relating to distress or difficult maternity experiences.

The findings describe this sample

NeuroNatal Voices was cross-sectional and descriptive. There was no non-neurodivergent comparison group and no inferential statistical analysis. The percentages therefore describe what respondents in this sample reported and should not be interpreted as population prevalence estimates or as evidence that neurodivergence caused particular maternity experiences.

Particular care is needed with the finding that 87.5% described some part of their maternity care as upsetting, overwhelming or traumatic. These terms were combined within a single survey response, and the survey did not assess psychological trauma or trauma-related disorders.

The qualitative analysis is still developing

The open-text responses add considerable depth to the findings, but the qualitative analysis presented in this Alert Report is an initial focused analysis.

The quotations have been selected because they illustrate issues identified through the survey. They should not be interpreted as showing how frequently a particular experience occurred unless this was also measured through a closed-response question.

There is considerably more qualitative material within the dataset than could be included here. A fuller analysis will allow experiences such as masking, disclosure, continuity, mental health, self-advocacy and supportive care to be explored in greater depth.

The breadth of neurodivergence is both a strength and an interpretive limitation

NeuroNatal Voices included people with a wider range of neurodivergent identities than is currently represented in much of the maternity literature. This is an important strength of the survey, however it also limits how far existing evidence can be used to interpret the findings.

Much of the maternity-specific research we currently have comes from autistic populations. Evidence relating to ADHD is considerably smaller, while maternity-specific research involving AuDHD, dyslexia, dyspraxia/DCD and several other neurodivergent groups is extremely limited.^{5, 6}

We have therefore drawn on autistic maternity research where it helps place respondents' experiences in context, but we cannot assume that every finding or proposed mechanism applies equally across neurodivergence.

How the findings should be read

NeuroNatal Voices provides a detailed picture of what 241 neurodivergent people told us about their maternity care.

The findings identify recurring problems with communication, information, recognition of needs, adjustments and continuity. They also show examples of care that respondents experienced as thoughtful, flexible and supportive.

They cannot tell us how frequently these experiences occur across maternity services in the UK and Crown Dependencies, whether neurodivergent people experience them more often than non-neurodivergent people, or how individual maternity services compare with one another.

The recommendations that follow are grounded in what respondents told us, considered alongside the existing evidence and guidance. They are intended to help services respond more consistently to individual communication, sensory, information and access needs while recognising that no single approach will work for everyone.

SECTION 06

RECOMMENDATIONS

ASK. LISTEN. RECORD. ACT.

RECOMMENDATIONS

The findings from **NeuroNatal Voices** do not suggest that maternity services need a standard set of adjustments for every neurodivergent person. People's needs varied considerably.

What is needed is a more reliable way of finding out what helps each person, recording it clearly and making sure it influences their care.

The recommendations can be summarised in four words:

ASK → LISTEN → RECORD → ACT

ASK

Ask about access needs routinely

Questions about communication, information, sensory and other access needs should form part of routine maternity care.

At the moment, people may only be asked once they disclose a diagnosis, request an adjustment or begin to struggle. By then, an appointment may already have become difficult.

Questions do not need to be complicated:

Is there anything that would make appointments or maternity care easier for you?

How do you prefer information to be given to you?

Is there anything about things like noise, lighting, touch or waiting that you find particularly difficult?

When you are overwhelmed or in pain, is there anything we should know about how you communicate or what helps?

These questions should open a conversation rather than become another checklist.

Do not make support dependent on diagnosis

A diagnosis may be useful information, but people with the same diagnosis can have very different needs. Someone without a formal diagnosis may also know exactly what makes healthcare difficult for them and what would help.

Access to support should therefore be based on the barriers somebody experiences and the help they need, rather than whether they have a particular diagnostic label. Ask about the person, not only the diagnosis.

Ask again

Needs can change.

Someone who communicates comfortably during an antenatal appointment may find this much harder during labour, after a long induction, when frightened or in pain, or following an unexpected change in their care.

The answer given at booking should not be treated as the answer for the rest of pregnancy.

LISTEN

Take people seriously when they tell you what helps

Respondents often knew what made care easier for them.

Problems arose when requests were dismissed as unnecessary, inconvenient or someone being difficult.

One respondent captured this simply:

“When people ask for them they're not just being fussy”

People should not have to repeatedly justify why an adjustment helps them.

Where a requested adjustment cannot be provided, explain why and work with the person to find an alternative where possible.

Give people options for receiving information

There was no single information format preferred by everyone in **NeuroNatal Voices**. Some people wanted information written down. Some wanted more detail. Others needed shorter explanations or information broken into steps. Some needed time before they could formulate questions.

Allow time to process

Processing time came through strongly in the survey.

Professionals do not always need to fill a silence. Someone may be thinking about what has been said, trying to organise a response or working out what they need to ask. Where a decision does not have to be made immediately, say so. It can also help to make clear what needs to be decided now and what can wait.

Check in even when somebody appears to be coping

Some respondents described being highly distressed while appearing calm or capable to the people caring for them.

Professionals should be cautious about assuming that somebody is coping well because they are articulate, quiet or outwardly composed.

Checking understanding and asking how somebody is managing can allow them to say what may not otherwise be visible.

RECORD

Record what actually helps

Writing ADHD, autistic or neurodivergent in somebody's notes provides very little practical information on its own. Useful documentation tells the next professional what they need to know.

For example:

- Needs extra time to process questions.
- Prefers important information verbally and in writing.
- Please explain before touching or beginning an examination.
- May find it difficult to speak when overwhelmed.
- Finds busy waiting areas difficult and may wait somewhere quieter.
- The person's own wording should be used wherever possible.

Make important information easy to find

Respondents should not have to explain the same access needs every time they meet somebody new. Important information needs to be visible to the professionals providing care and included in relevant handovers.

The person should also know what has been recorded and have an opportunity to correct it if it does not accurately describe what they need.

Make care plans useful

Several respondents described having information documented that was then unavailable, overlooked or did not influence what happened.

A birth plan, care plan or reasonable adjustment record is useful when the people providing care can find it, read it and use it.

Services should therefore consider not only whether a plan exists, but whether it follows the person through their maternity care.

ACT

Follow through on agreed adjustments

Asking about needs can create an expectation that something will happen with the information.

Where an adjustment has been agreed, it should be provided wherever reasonably possible.

That might mean lowering lighting, allowing someone to wait somewhere quieter, giving written information after a conversation, explaining before touching, allowing extra processing time or reducing unnecessary changes to an agreed plan.

Some changes will be easier to provide than others. If something cannot be accommodated, the person should be told and alternatives discussed.

Protect continuity where possible

Continuity was important to many respondents. Where continuity of carer is possible, it may reduce repeated explanations and allow trust and familiarity to develop.

Where seeing the same professional is not possible, services can still protect continuity in other ways. Good documentation, clear handovers and consistency in agreed approaches can reduce the amount of work somebody has to do each time their care changes hands. A change of professional should not mean having to start again.

Build neurodivergence into staff education

Respondents repeatedly described the difference professional understanding could make.

Education should go beyond lists of characteristics associated with autism or ADHD. Staff need practical understanding of how neurodivergence may affect maternity care, including:

- communication and information processing;
- sensory experience;
- processing time and uncertainty;
- executive functioning;
- pain and expressions of distress;
- masking and less visible distress;
- the effect of overwhelm on communication; and
- the importance of individual variation.

Training should also include examples of good care and involve neurodivergent people in its development and delivery.

The aim is for staff to feel more confident asking the right questions and responding to the person in front of them.

Make conversations about support feel safe

People need to understand why questions about neurodivergence, mental health or support needs are being asked and what will happen with the information they provide. Professionals should be clear about how information will be recorded and shared and, where relevant, explain the purpose of safeguarding questions.

Neurodivergence, sensory differences or an unusual communication style should not in themselves be treated as evidence of impaired parenting capacity. Where genuine safeguarding concerns exist, they must of course be addressed. Decisions should be based on the circumstances and evidence available, with care taken not to misinterpret neurodivergent behaviour or communication.

Design services with neurodivergent people

Individual professionals can make an enormous difference, but sustainable change also needs to happen at the service level. Neurodivergent people should be involved when maternity services review areas such as appointment systems, patient information, waiting environments, birth planning, documentation and handover, postnatal support, perinatal mental health pathways and staff education.

That involvement needs to include a breadth of neurodivergent voices. The maternity evidence is currently dominated by autism research, while ADHD and several other neurodivergent populations remain poorly represented.^{5,6} One neurodivergent group cannot be expected to represent everyone.

Making accessibility routine

Many of the changes respondents asked for were practical: more time, clearer information, quieter environments, better continuity and professionals who listened to what they said they needed. The aim should be to identify those needs earlier and respond to them more consistently, rather than leaving people to work out how to make care accessible once they are already struggling. That is what these four actions are designed to support.

ASK → LISTEN → RECORD → ACT

The measure of success is not whether an access need appears somewhere in a set of notes. It is whether knowing about that need makes a meaningful difference to the person's care.

SECTION 07

CONCLUSION

Neuroinclusive maternity care should not depend on being fortunate enough to meet the right professional at the right time.

CONCLUSION

NeuroNatal Voices began with a simple question: what is maternity care like when you experience and navigate the world differently?

The 241 people included in this report gave us a wide range of answers. There was no single neurodivergent maternity experience, and there was no single adjustment that would have helped everyone.

What was much more consistent was the need for maternity care to respond to the individual. Some respondents described compassionate, flexible care from professionals who listened, explained things clearly, gave them time and adapted their approach. Others described having to work much harder to make their care accessible. They were not routinely asked about communication, sensory or information needs. Some had to repeatedly explain the same needs. Others found that information recorded in their notes or care plans did not reach the people providing their care.

A diagnosis can provide useful context, but it cannot tell a professional everything they need to know about the person in front of them.

A more useful question is often much simpler:

What would help you access your care?

The findings also show that identifying a need is only the beginning. Information has to be recorded clearly, reach the right people and influence what happens in practice. Too often, respondents were left filling the gaps when that process broke down.

That responsibility should not sit primarily with the person receiving care, particularly when they may also be managing pain, uncertainty, sensory input, large amounts of information or difficulty communicating when overwhelmed.

The positive experiences in **NeuroNatal Voices** show that neuroinclusive care is not always complex or highly specialised. Good care was often remembered because somebody paid attention. They slowed down. They read the notes. They believed what the person was telling them. They explained what was happening and changed their approach when something was not working.

The challenge is to make that care routine rather than exceptional. Maternity professionals cannot be expected to predict every need or know everything about every form of neurodivergence. But services can build a more reliable way of finding out what each person needs and making sure that information shapes their care.

Ask what would help.

Listen to the answer.

Record what has been agreed.

Act on it.

Neuroinclusive maternity care should not depend on being fortunate enough to meet the right professional at the right time. It should be part of how maternity care is delivered.

ASK → LISTEN → RECORD → ACT

SECTION 08

WHAT HAPPENS NEXT?

241 people told us what maternity care was like for them. Now we need to make sure that listening to them leads somewhere.

WHAT HAPPENS NEXT?

This Alert Report is the first stage of the **NeuroNatal Voices** work. The survey generated far more information than could be explored in a single report. In particular, the open-text responses contain detailed accounts of communication, sensory experience, mental health, continuity, self-advocacy, masking, disclosure and the parts of maternity care that people found either supportive or difficult to access.

The next phase of analysis will look at these experiences in greater depth.

Further analysis

A fuller qualitative analysis of the open-text responses is planned. This will allow us to explore some of the issues identified in this report in more detail and consider how they appear across different stages of maternity care.

More work is also needed to understand the experiences of people with different neurodivergent identities. **NeuroNatal Voices** included a substantial number of respondents with ADHD and AuDHD, while the published maternity literature remains much more heavily focused on autism.

The survey cannot answer all of those questions, but it can help identify where further research is needed.

Sharing the findings

The findings will be shared with maternity professionals, services, researchers and organisations working in maternity, perinatal mental health and neurodivergence. The experiences described in **NeuroNatal Voices** can inform conversations about staff education, accessible information, reasonable adjustments, care planning, communication, continuity and the design of maternity services.

Keeping lived experience at the centre

The people who completed **NeuroNatal Voices** gave us more than survey responses. Many described experiences that were painful, frustrating or deeply personal. Others told us about professionals who had made an enormous difference to their care.

Those experiences deserve to be handled carefully. As this work develops, neurodivergent parents need to remain part of the conversation about what the findings mean and what should happen because of them.

There are also voices that **NeuroNatal Voices** did not reach well enough. Future work needs to make a more deliberate effort to include neurodivergent people from minority ethnic backgrounds, trans and non-binary people, people from across all four UK nations and the Crown Dependencies, and others whose experiences remain poorly represented in both this survey and the wider evidence base.

Questions for future research

NeuroNatal Voices has raised questions that this report alone cannot answer.

We need to better understand whether continuity can improve accessibility for neurodivergent people, how access needs can be identified and communicated effectively across maternity pathways, and which neuroinclusive changes actually improve experience and outcomes.

A much stronger maternity evidence base is also needed beyond autism.

ADHD, AuDHD, dyslexia, dyspraxia/DCD and other forms of neurodivergence remain poorly represented in maternity research. The experiences shared through **NeuroNatal Voices** make that gap increasingly difficult to ignore.

From listening, to change

When difficult experiences of healthcare are shared, it creates a responsibility to do something constructive with what those people told us.

For **NeuroNatal Voices**, the publication of this report is part of that process.

The next challenge is to turn what we have heard into better questions, stronger evidence and practical changes that make maternity care easier to access.

241 people told us what maternity care was like for them.

Now we need to make sure that listening to them leads somewhere.

BE PART OF THE CHANGE

Neurodivergent parents have shared their experiences. Now we need to make sure they are heard.

NeuroNatal Voices is more than a report. It is an opportunity to rethink how maternity services listen, communicate and respond to neurodivergent people and their families. Whether you are a maternity professional, researcher, policymaker, parent or advocate, there are ways you can help turn these findings into meaningful change.

Read and share the report.

Help these findings reach maternity teams, service leaders, educators, policymakers and the people who can influence change.

Start conversations in your workplace.

Use the findings to reflect on current practice. Are neurodivergent people's needs being recognised, recorded and responded to?

Involve neurodivergent people

Include neurodivergent parents in the design, delivery and evaluation of maternity services. Their expertise must shape the changes intended to support them.

Turn recommendations into action.

Review how your service approaches communication, sensory needs, reasonable adjustments and individualised care. Meaningful, lasting improvement requires organisational commitment.

Work with NeuroNatal.

NeuroNatal Academy CIC works with professionals and organisations to make maternity care more neuroinclusive.

Keep the conversation going.

Share the report, talk about its findings and help ensure neurodivergent voices remain part of the wider conversation about maternity care.

**The voices have been heard.
What happens next is up to all of us.**

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