

Plain-language summary

NeuroNatal Academy CIC | 20 October 2026

NEURONATAL VOICES

THE UNHEARD

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



What is NeuroNatal Voices?

NeuroNatal Voices is a survey about neurodivergent people's experiences of maternity care across the UK and Crown Dependencies.

Neurodivergent people include autistic people, people with ADHD, dyslexic people and people with other differences in how they think, learn or process information. We wanted to understand what maternity care was like for neurodivergent people during pregnancy, labour, birth and after having a baby.

We asked what helped, what made care difficult and what maternity services could do differently. We wanted to hear directly from the people receiving care.

Who took part?

The survey ran from 4 May to 1 June 2026. 261 people responded. We included 241 responses in our final analysis.

People could take part if they:

- Were aged 18 or over.
- Identified as neurodivergent, with or without a formal diagnosis.
- Had used maternity services in the UK or Crown Dependencies within the previous five years.

Most respondents were White women aged between 30 and 39. Most people who shared their location had received maternity care in England. This means the findings do not represent every neurodivergent person's experience.

We need to hear from more people from different ethnic backgrounds, gender identities, age groups and parts of the UK and Crown Dependencies.

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What did we find?

Many people were not asked what they needed. People often had to ask for support themselves.

79.5% said support or adjustments were not offered unless they asked for them. 64.5% said they were not always given enough time to think about and process information.

Many people described difficult experiences.

87.5% described some part of their maternity care as upsetting, overwhelming or traumatic.

These percentages are based on the people who answered each survey question. They do not tell us how common these experiences are among all neurodivergent people.

The 87.5% figure does not mean that everyone had clinically diagnosed birth trauma.

82.6%

Not asked about sensory or access needs

82.6%

Not asked how they preferred to receive information

77.9%

Not asked how they preferred to communicate

Only 4.2% felt maternity staff understood neurodivergence well enough.

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What made it difficult?

People described several problems with their care.

Some found maternity environments too noisy, bright, busy or overwhelming. Others found it difficult when information was given too quickly, only explained verbally or changed between different members of staff.

Some people needed more time to understand information, ask questions or make decisions.

Many described having to explain their needs repeatedly.

Even when people had told staff about their neurodivergence or had written adjustments in their care plans, those adjustments were not always followed.

Some people felt dismissed or misunderstood.

Pain, fear, exhaustion and sensory overload could make it even harder to explain what they needed.

Many people described maternity care
as **upsetting, overwhelming** or
traumatic.

People **should not** have to repeatedly
fight for care that meets their needs.

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What did good care look like?

Not everyone had a difficult experience. People also told us about maternity professionals who made them feel **safe, understood** and **respected**.

They valued staff who **listened, believed** them and took their **needs** seriously.

Helpful changes included:

- Explaining what was happening and what would happen next.
- Giving information in writing.
- Allowing more time to think and ask questions.
- Reducing noise, bright lighting or other sensory input where possible.
- Respecting people's choices.
- Reading care plans and following agreed adjustments.

Sometimes small changes made a big difference. **Good care did not always involve specialist equipment or services.** Often, it meant taking the time to understand the individual.

What needs to change

Four practical steps for maternity services

Ask

Ask people about their communication, sensory, information and access needs.

Do this before someone is struggling.

Listen

Listen to what each person says helps them.

Needs can change during pregnancy, labour, birth and after having a baby.

Record

Record agreed adjustments and share them with staff providing care.

Then people don't have to keep explaining their needs.

Act

Put the agreed adjustments into practice.

Always check if they are helping and make changes when needed.

An adjustment written in a care plan only makes a difference when it changes the care someone receives.

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What happens next?

This is an early report of the **NeuroNatal Voices** findings. We plan to look at the written survey responses in more detail to better understand people's experiences.

We hope **maternity services, universities, professional organisations** and **policymakers** will use these findings to improve care. We also want future work to include people whose experiences were less well represented in this survey.

About the survey

NeuroNatal Voices was carried out by NeuroNatal Academy CIC. Taking part was voluntary. People chose whether to complete the survey, so the findings cannot be used to describe the experiences of all neurodivergent people using maternity services.

The survey was not an NHS or university research study.

Neurodivergent people should not have to fight to be understood, accommodated or treated with dignity.

This plain-language summary is based on the report **NeuroNatal Voices: The Unheard** (2026).

Read the full report: www.neuronatal.org

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