

Nottingham & Nottinghamshire Children & Young People Neurodevelopmental Support Services Survey Report - March 2024

1. Introduction

The Nottingham and Nottinghamshire Integrated Care Board (ICB), in collaboration with the University of Nottingham, conducted this survey to delve into the perspectives and experiences of parents and carers concerning neurodevelopmental referral services for children and young people across Nottingham and Nottinghamshire.

The Nottingham and Nottinghamshire ICB holds a statutory duty to commission neurodevelopmental services for this demographic.

Neurodevelopmental support services are available across Nottingham and Nottinghamshire to support the needs of neurodiverse children and young people. These services are primarily located in three key areas: Nottingham City, Nottinghamshire County, and Bassetlaw.

More information on services in the different areas can be found below:

- Nottingham City - Behavioural & Emotional Health Team | Ask Lion - Nottingham City Directory [Ask Lion](#)
- Nottinghamshire County - Nottshelpyourself Neurodevelopmental Support Service - The Neurodevelopmental Support Team - NST (previously known as the Neurodevelopmental Behaviour Service - NBS) [NottsHelpYourself](#)
- Bassetlaw - [aptcoo.co.uk](#) provides support as part of the General Development Assessment Pathway, Healthier Together [Bassetlaw GDA Pathway](#)

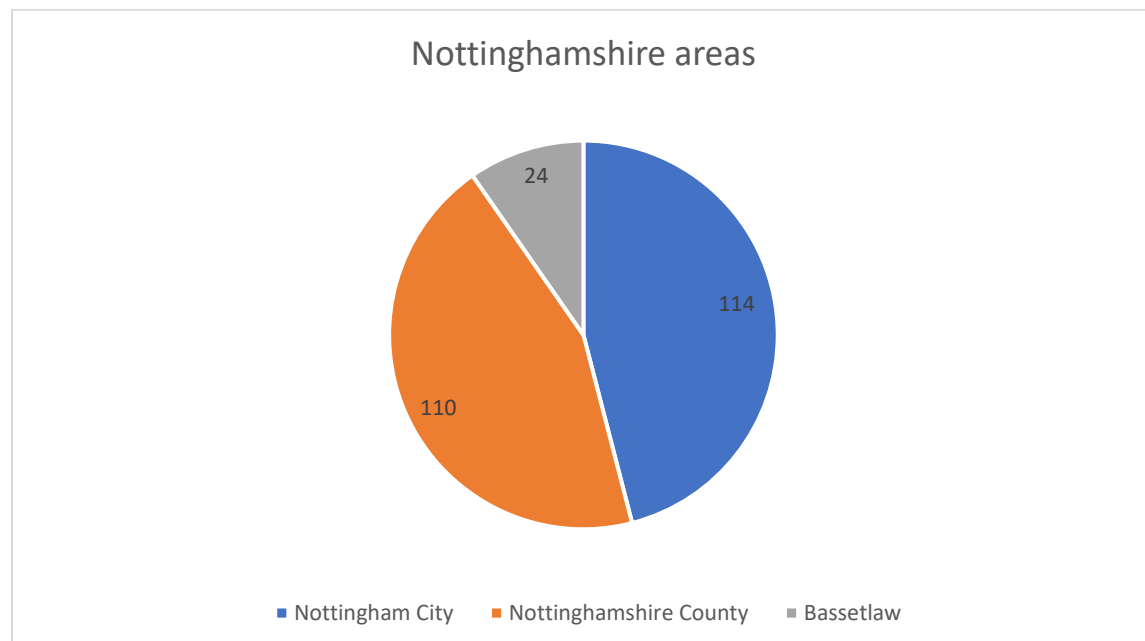
To grasp the experiences of families accessing support services, a survey was collaboratively developed with families who have lived experience, service providers, and health and education professionals. The aim was to capture the journey of those waiting for a neurodevelopmental assessment and support.

The survey aimed to evaluate the support that families would find beneficial whilst awaiting an assessment. The report below outlines the responses of parents from the three key areas of Nottingham & Nottinghamshire as surveyed in early 2024.

2. Survey results

Survey demographics

Between January 30th and February 21st, 2024, a total of 278 responses were gathered from local families via Microsoft Forms. The survey encompassed the three key areas of Nottinghamshire, with 114 responses from Nottingham City, 110 from Nottinghamshire County, and 24 from Bassetlaw.



Support and communication whilst waiting

Communication

The preferred method of communication was email (131, 52% of responses), letters (50, 20% of responses) or phone (45, 18% of responses).

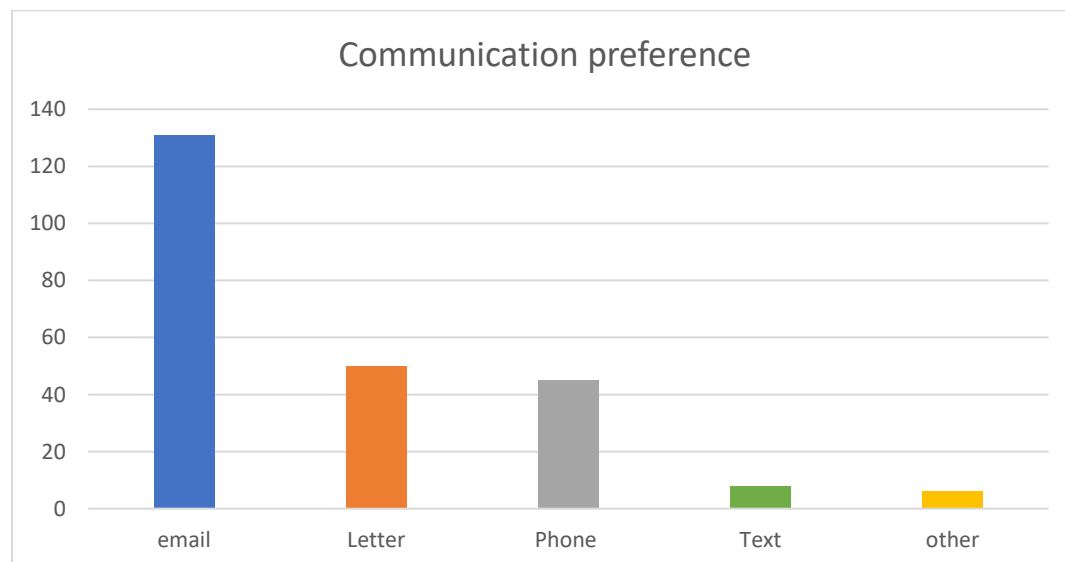
The few responses that stated “other” (6 responses) mentioned that they would prefer face to face contact with services as below:

“The chance for a professional conversation at the point of referral rather than waiting for over 24 months for a conversation that resulted in a conversation with paediatricians.”

“I would like a phone call, followed by a letter.”

“Anything in writing as it is a stressful time and easy to forget things.”

“A letter to back up all info and a call for haste phone and letter.”



The preferred timespan for communication and updates was monthly (146, 58%) or every 2-3 months (84, 33% of responses) with parents rarely choosing longer times.

The families that answered “other” stated as below:

“Weekly would be nice. Heard nothing for months. Such a poor system”.

“It would reduce frustrations if updates could be submitted when situations hit crisis point for home and education.”

“Giving professionals the chance to update the services, escalate their concerns or ask for updates would stop people from feeling forgotten/ignored.”

“Should have received the SALT report as soon as it was done.”

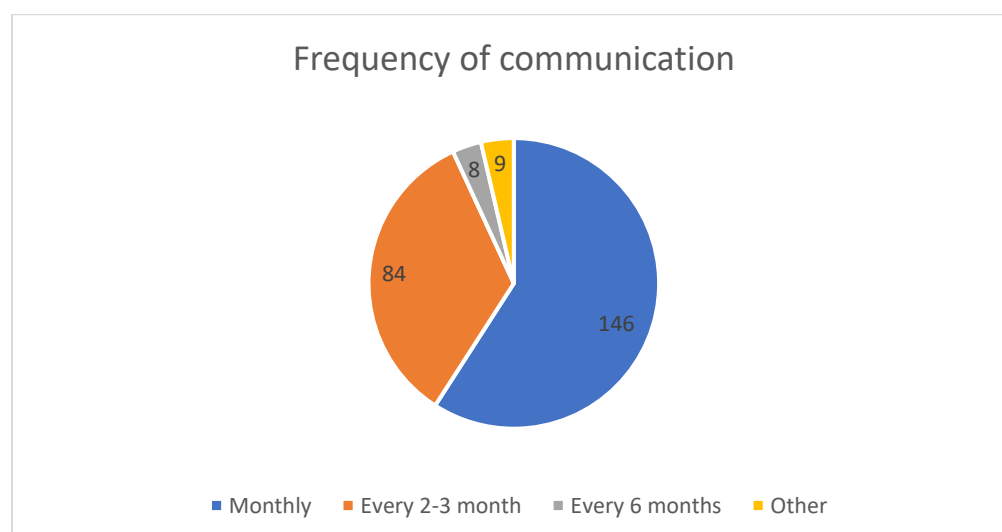
“Every 2-3 months with a guideline on how much longer thereafter it may be a bit like the DLA service.”

“Get the government to fund all necessary services”

“Depends on waiting time. Most importantly there wouldn't be a need for updates if the waits are reduced”

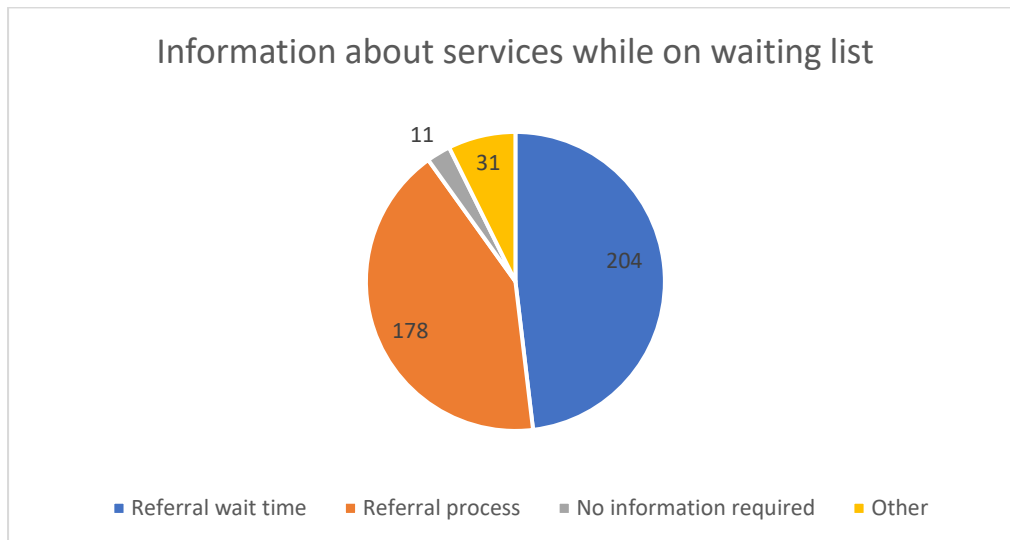
“Monthly at a minimum.”

“It would be good to have an acknowledgement letter to confirm you are on the waiting list. If that included an approx. wait time I don't think you would need further updates. I haven't received anything at all to say I'm on the list so am just trusting the GP surgery to have sent this successfully.”



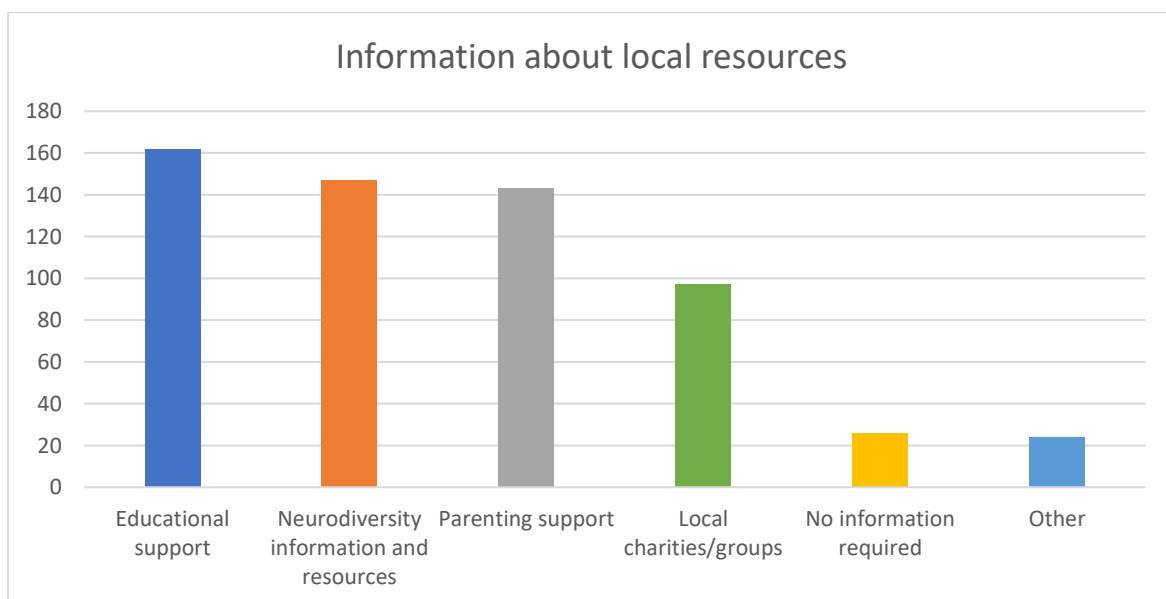
Support whilst waiting

Parents said that they would benefit/have benefited from information on waiting times (178, 71%) and the waiting process (204, 82%)



Parents also said they would benefit from information on

- Educational support (162, 65%)
- Neurodiversity information (147, 59%)
- Parenting support (143, 57%)



Parents gave the following feedback/questions/requirements regarding support whilst waiting for an assessment:

- Guidance on the referral pathway and referral waiting times would be essential
 - Flowchart of process
 - What the process is
 - Why is it so long
 - How long does diagnosis take?
 - Private providers accepted
- Support
 - Available before and after diagnosis
 - To manage child's behaviour
 - Up to date signposting
 - Support for young person
 - Local support
 - Mental health support
 - Social care support
 - Occupational health support
- Communication
 - Prompt acknowledgment of receipt of referral to avoid "not knowing"
 - What to expect during appointments
 - Website for services
 - Services to be accessible by phone or email, being able to talk to someone
 - Regular updates on progress

Additional feedback

Out of the 248 parents who responded, a majority (129) provided additional suggestions. It's clear parents were eager to ensure their voices were heard.

Numerous families expressed challenges in navigating the system, especially regarding timelines. Waiting times emerged as the foremost concern among

families, with many expressing frustrations over the prolonged process without sufficient support.

While providing a comprehensive summary of all responses is impractical, the recurring themes are outlined below:

- Communication
 - Transparency, clarity, and honesty
 - Better communication between the different services
 - More frequent communication
 - Contact parents directly if any issues
 - Advice for siblings
 - Up to date information
 - Details about what to expect at each appointment, what will happen
 - Online portal
- Support
 - Peer support through other families
 - Support for EHCP
 - Access to specialist services (OT, sensory processing etc.)
 - Better signposting
- System
 - Same system throughout Nottinghamshire
 - More staff
 - Not asking the same questions multiple times
 - No cancelled appointments
 - Better support and resources from school

Some more examples of feedback from families:

“Acknowledging that it is a slow and lengthy process (for all kinds of reasons), showing the likely timescales / number of steps and clearly signposting support that's available in the meantime. However, given the questions on this survey it feels like you know this, so I hope this is a step towards managing this issue. Thank you.”

“It’s taken 16 months from referral to being given an appointment with a paediatrician, but we have no idea what to expect. Will our son be assessed that day? If this just an initial appointment, how many more might there be after this and what is the timescale?”

“More information about how the process looks, what happens, what help or support is there for parents”

3. Conclusion & next steps

- Parents would like to be updated frequently at one- or two-months intervals on the status of their referral with their preferred methods of communication being via email or letter.
- The main information that parents would like from the services are in regard to waiting times and the referral process. Especially around, what to expect during each appointment and being kept updated on the referral process.
- Parents felt that they would benefit from local support on education, parenting and neurodiversity information.

Parents primarily expressed concerns regarding communication and support. Although the lengthy waiting times were commonly cited as a barrier, many parents acknowledged this but desired more communication and support during the waiting period.

Improved communication regarding the clarity of the pathway, expectations, and timelines. Additionally, better support for both parents and young people is deemed essential, particularly in areas such as education, mental well-being, and behavioural issues.

The Nottingham & Nottinghamshire ICB is committed to collaborating with the University of Nottingham Research Team, Nottingham(shire) Neurodiversity Network and service providers to address the concerns highlighted by families in the survey findings.