

July 2024

Neurodiversity Transformation Project *Update*



Working together
for SEND families

The Neurodiversity Transformation Project

so far

The Neurodiversity Transformation Project began after changes to Paediatric and Autism assessment criteria were introduced across Bristol, North Somerset and South Gloucestershire (BNSSG) in March 2023. The local parent carer forums together gathered the views and concerns from families in their communities on this subject and fed these back to the Integrated Care Board (ICB). Due to this feedback and other factors, these changes were reversed in April 2023.

The ICB recognised that to be effective, changes need to be agreed upon by services across the system as well as the community, and in September 2023 **The Neurodiversity Transformation Project** was created.

The project, led by the ICB and co-chaired by Bristol, North Somerset and South Gloucestershire Parent Carer Forums also involves the three local authorities; professionals across health, education and social care; the voluntary sector; and the voices of parent carers and children.

The project aims to create a better support model for neurodivergent children, incorporating input from all partners.

This document should be read in conjunction with the July 2024 Appendix: Parent Carer Questions and Comments



Key Info



Rise in Autism assessment referrals between 2020 and 2022

2,500

Children and young people are on the ADHD waiting list, it will take up to 4 years for most children to receive an assessment

5,000

Children and young people are on the Autism waiting list. If no more children were added to the waiting list, it would take 10 years to assess everyone on the list

"My main takeaway from today is the importance of listening, of doing this work in a partnership way, jointly as a co-productive piece"

– Will Pritchard, Strategic Lead for Inclusion and special educational needs, South Gloucestershire Council, November 2023

Timeline

Event	Details	Outcome
November 2023: Discovery conference	Key partners conference to discuss what isn't working well	Picture from all partners including education, health, social care, parent carer forums and including parent carers and young people discussing the difficulties faced by all
November 2023: PCF Local area listening events	Events across BNSSG with parent carers	Understanding from parent carers on the difficulties they and their families face
February 2024: Accelerated Model created	ICB began to realise the scale of the issues faced by stakeholders	A 6 month pilot to test the viability of identifying needs as early as possible without needing an assessment

July 2024

Project update



In July 2024, Bristol, North Somerset and South Gloucestershire Parent Carer Forums held two engagement events to provide the community with an update on the Neurodiversity Transformation project and the six month pilot which will start in August 2024.

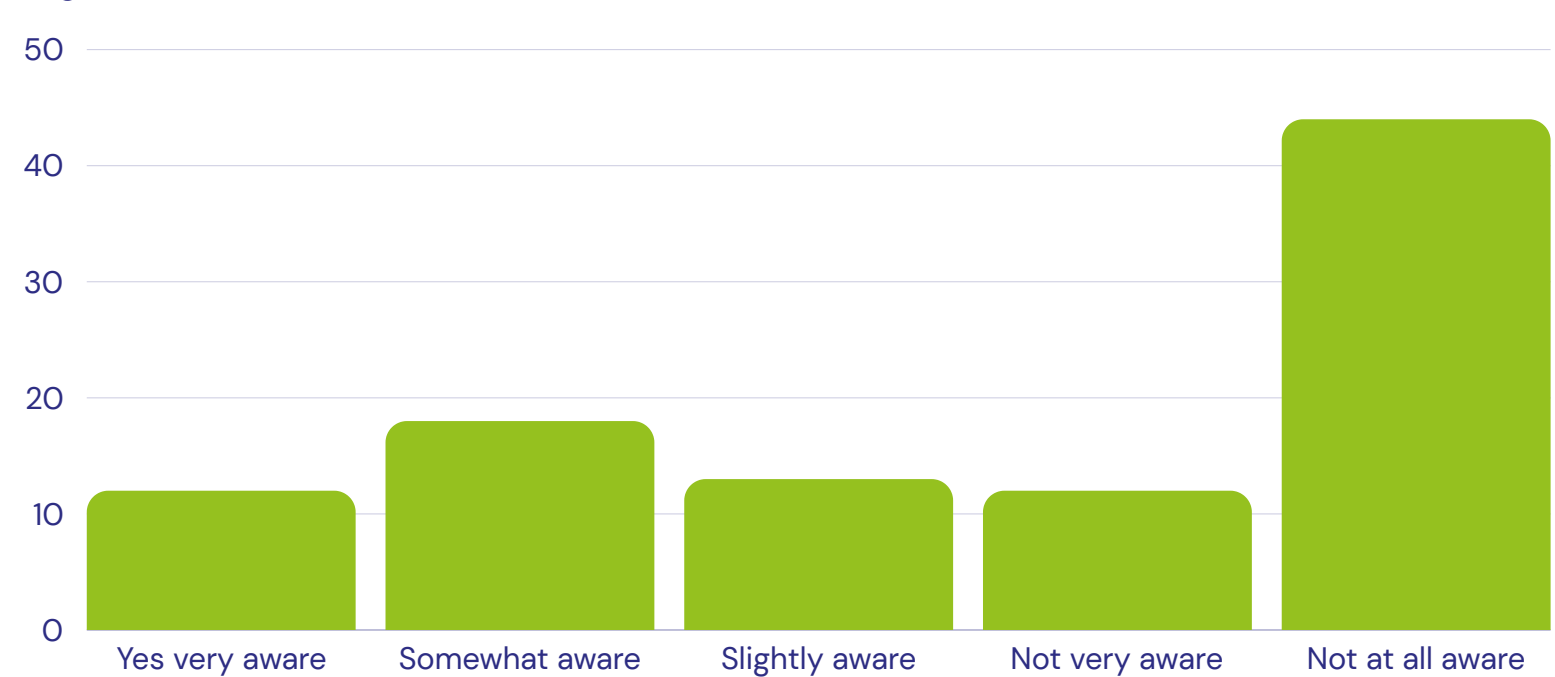
140 parent carers attended either the in-person session held at BAWA Leisure or the online event. Families were joined by colleagues from the Integrated Care Board, Sirona Care and Health and each of the three local authorities across BNSSG.

During the event the parent carer forums updated families on the project and an upcoming accelerated model pilot. Families were also asked to share their views on the project and answer key questions about the pilot.

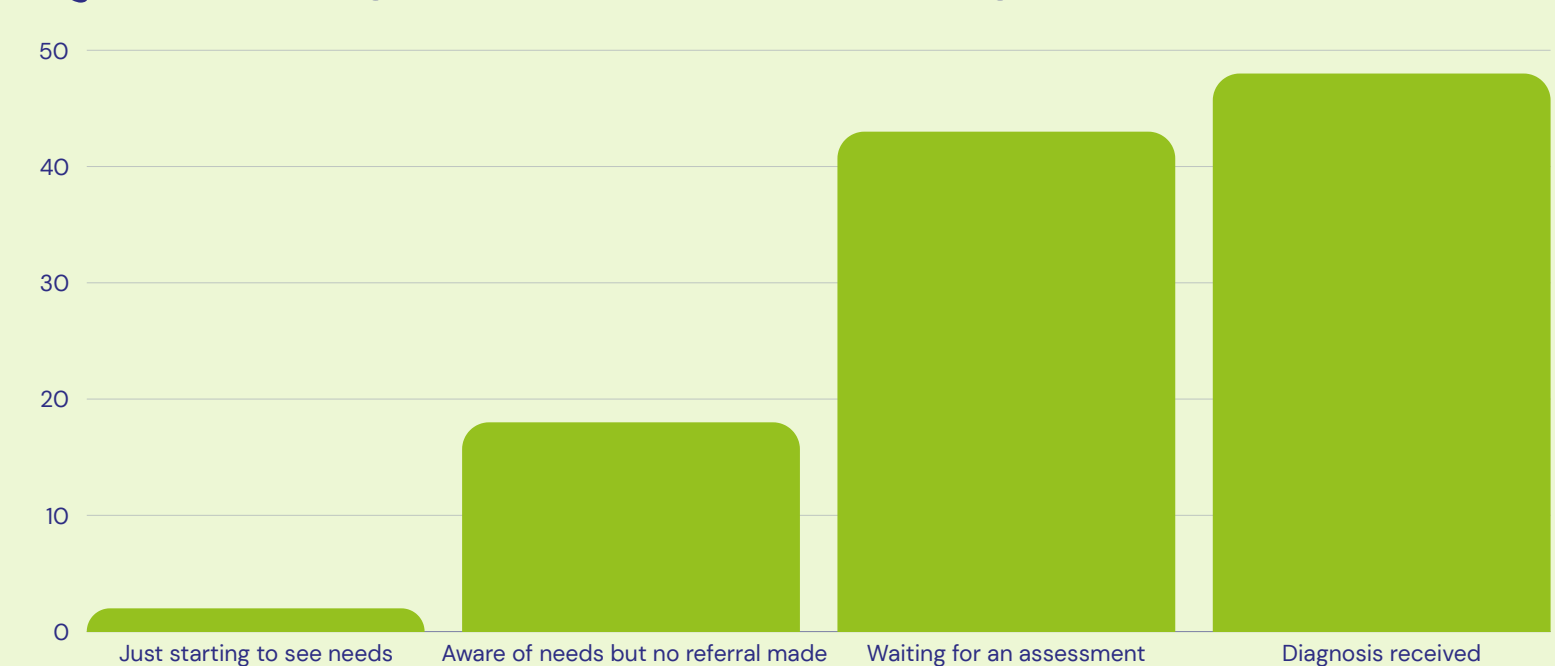
96% of parent carers who attended felt the event helped them understand the Neurodiversity Transformation Project

What did families *tell us?*

Q1 Were you aware of the project before today?



Q2 What stage are you at in identifying your child's needs?



What did families tell us?

Q3 In a few words, can you say how you are feeling about the support currently being provided across education, health and the Local Authority*

*asked at the in person event only



"Finally getting it together although communication lacking"

"It's confusing. I can't seem to find the right person to guide me on where to start"

"I am needing to teach my child's school what to do via my own research"



"Isolated, frustrated, extremely stressed, exhausted from fighting"



"It seems to be available for only the most challenging children but not those who mask"



"Brilliant support but it is not joined up at all"



"Not great, I feel I am teaching them and pushing them along"

"Support varies, sometimes it's enough, sometimes it's really lacking"

"School have been very dismissive and CAMHS wait is so long – GP Great"



"Very supported after 6 years of little support"



"We are awaiting assessment and not aware of any support in the meantime"



"It's a huge battle to get any support, it's painful, slow and demeaning"

What did families tell us?

Q4 What does good support look like for you and your child?*

*asked at the in-person event only



"Reasonable adjustments, being heard and not questioned"

"Being listened to & being supported and helped when they can see your struggling"

"Happy and safe child who feels proud and supported for being different"



"When I say I need help, believe me, don't ignore me"



"Key worker to navigate through the options and multiple services"



"It's hard to say what specific support we need because I don't know"



Acknowledged earlier when concerns are raised "

"Understanding and accommodation of needs and barriers to learning"

"Where is AWP Cahms in this discussion?"



"School being understanding and putting provisions in place"



"Acknowledge sensory needs earlier when concerns are raised"



"Not having to repeat myself all the time and feeling heard"

Accelerated model

“Making changes to the system to really support our children and young people is so important”

– Kenton Mee, CEO, North Somerset Parent Carers Working Together, March 2024



The accelerated model consists of a pilot which will run for 6 months

42

Schools will take part in the first pilot for the accelerated model

13

Different organisations are part of the transformation project and feed into the accelerated model

What is the model?

Support

Details

Outcome

Neurodiversity Profiling Tool

A tool for school staff to use to identify needs in 9 areas

School staff working with health staff to understand children's needs at the earliest possible stage without waiting for a formal assessment

Needs Led Charter

An agreement between all services that lack of diagnosis will not be a barrier to accessing support

All services and school support open to all children and young people offered to those with and without a diagnosis equally

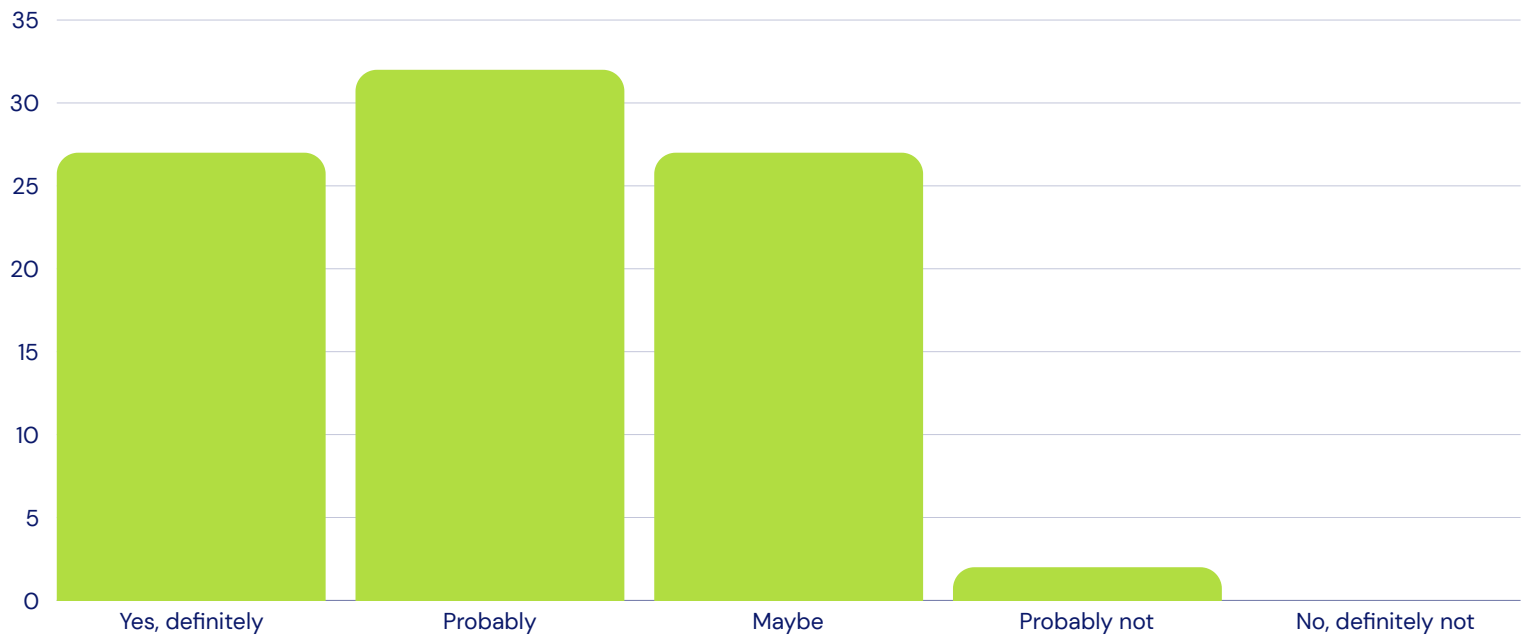
Targeted Communications

Families to receive targeted communications from services

Families receive help and advice from the beginning of their journey so they understand the support on offer

What did families tell us?

Q5 Do you think the Neurodiversity Profiling Tool tool could help children and young people?



Q6 If you answered maybe, probably not or definitely not, can you tell us why you think this?

"It will depend on the capacity of and the relationships with school staff"

"Schools are already under so much pressure, will there be enough support for them?"

"Profiling results won't help schools that lack capacity or training to address specific needs."

"I feel like this pilot is diluting down the need for diagnosis which is essential"

"The model assumes teachers have the answers, they don't, needs clinical support too"

"There will be absolutely no health support to meet any of the needs that are shown"

"If you have a child that masks, school will never use this tool"

"It might be helpful for initial signposting but it won't help improve school support"

Key Themes from families

Please see the attached appendix – *Questions from families* – to read all the comments and questions that were gathered from parents at both the in-person and online event.

We have analysed the information collected and summarised the key themes here:

- Nature of Needs

- Nature of the Pilot

- Health Provision

- Current Assessment Process

- Right to Choose

- Need for Diagnosis

- Schools

- Children and Young People out of School

- Support in Partnership across Schools and Health

- Supporting the Family

- Social Care & DLA

- Other

What's next?

"The engagement event was incredibly informative and made me feel hopeful for the future."

– A Bristol Parent Carer

"..an example of how engagement events should be."

–ICB Comms

"Thank you so much for everything you've done and for pushing us to make this work as good as it could be..."

– Kate Lavington, NHS ICB Head of Design

October 24

The accelerated model will begin

January 25

From January we will analyse data that has been gathered during the pilot to determine its success and gather valuable insights

Wider Work

The transformation project group will continue to look at ways of improving neurodivergent health pathways, these changes won't be able to be tested as quickly as those that are part of the accelerated model

Thank you

We would like to thank all the parent carers who have actively and honestly shared their views, experiences, ideas and questions to provide the valuable insights contained within this report. We greatly appreciate your input.

Together we can achieve positive change.
BNSSG Parent Carer Forums



Key Contacts

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South Gloucestershire Parent Carers

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Sirona Care and Health

www.sirona-cic.org.uk/children-services/resources/advice-and-signposting/

ICB

www.bnssghealthiertogether.org.uk/health-wellbeing/neurodiversity-transformation-programme/what-have-we-done-so-far/