

JOINT PARENT
CARER FORUMS

Needs led approach Survey Outcomes

FEBRUARY 2022



**Working together
for SEND families**

BRISTOL, NORTH SOMERSET &
SOUTH GLOS PARENT CARER FORUMS



Introduction

Autism is a lifelong developmental disability that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as disabled.

In 2022, too many autistic people still face long waits for their diagnosis and do not always receive support that is tailored to their needs at an early enough stage. For autistic children, unmet needs can often lead to school suspensions or exclusions. Just over a third (34%) of permanent exclusions are due to ‘persistent disruptive behaviour’ and the statutory exclusions guidance states that, “disruptive behaviour can be an indication of unmet needs”. As well as an educational impact, there has been a national rise in the number of people identified as being autistic in inpatient mental health services increase and an autistic person can expect to live 16 years less than non-autistic peers.

The need for earlier intervention has led to discussion around a needs-led pathway for

Bristol, North Somerset and South Gloucestershire (BNSSG) health services which currently has over 2000 children and young people waiting for an autism diagnosis. Services to support children and young people with or waiting for an autism diagnosis are varied and diverse across Bristol, North Somerset and South Glos. Some services require a diagnosis in order to be able to access them, while others do not; the age at which support is offered also varies and this information is not always clear to parents, carers or professionals supporting families.

As well as access to ‘higher level’ services, an autism diagnosis can also help young people understand themselves better and realise that they are not alone in the way they feel. A diagnostic label can avoid a feeling of ‘imposter syndrome’ amongst the autistic community and provide a ‘lens’ for others around families to understand the behaviours and needs shown by the child or young person. This is important to highlight because often, late-diagnosed adults report feeling alien and isolated, and are aware of not fitting in (without understanding why) before they were identified as autistic.

Executive summary

BNSSG Parent Carer Forums believe that a needs-led approach to support autistic individuals is essential and is well documented in various health literature. This will ensure better outcomes for autistic people and families across health, education and social and community care living in the BNSSG area.

To better understand the importance of a diagnosis, we asked parents and carers in BNSSG to complete a survey. We received 347 responses submitted by families with a diagnosis (57%), on the hub waiting list (24%) and those that have requested an assessment (19%). 61% of the respondents stated that their child was male.

The national strategy for autistic children, young people and adults 2021 - 2026 hopes that by 2026 autistic people will be able to access a high quality and timely diagnosis. National Institute for Health and Care Excellence (NICE) recommends 13 weeks between referral to the first assessment, which it says is crucial in preventing the escalation of needs.

The BNSSG survey findings highlight why a diagnostic label is important for so many families and why it is imperative that support and diagnosis happen in tandem.

BNSSG Survey Highlights



90% of the families on the waiting list feel that receiving a diagnosis will help others understand their child better (area breakdown: B: 86%, NS: 89%, SG: 91%)



81% of families felt receiving a diagnosis helped others understand their child better (area breakdown: B: 76%, NS: 81%, SG: 84%)



80% of families felt receiving a diagnosis will help access support with education (area breakdown: B: 75%, NS: 78%, SG: 84%)



“
Diagnosis was essential to access specialist education.
”

“
I feel a bit of a cheat without the diagnosis!
It's a very lonely experience.
”

“
When he received his diagnosis at 16 he said, “now I know why I'm different”.
”

What parents and carers said

“
As he gets older it will really help him to hopefully feel empowered.
”

“
Solutions outside of our child's behaviour alone were at last being looked at.
”

“
School would not believe us as they didn't understand masking.
”

“
There is no health support before or after diagnosis.
”

“
Difficult to say if mental health issues were related to diagnosis or were there anyway.
”

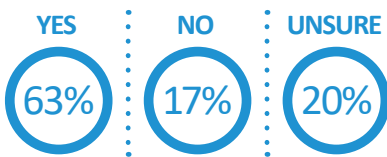


Survey Analysis: Diagnosed

Reading the additional comments parents gave us, respondents stated some of their children were too young to understand their diagnosis. Some young people really didn't like having a diagnosis. However the majority of comments stated the positives having a diagnosis made to them as it was a relief to them and helped them in their own understanding.

Families also stated that having a diagnosis of Autism didn't help them access support from social care, health, or the community. They felt there were not enough services out there that could offer that support. The support out there currently is over stretched or thresholds too high.

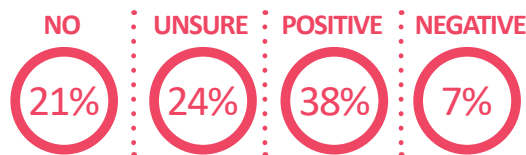
1 Has receiving a diagnosis helped your child understand themselves better?



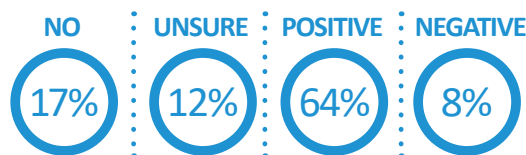
2 Has receiving a diagnosis helped others understand your child better?



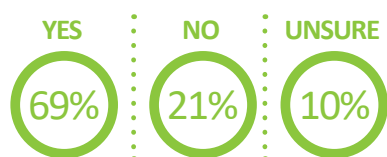
3 Has receiving a diagnosis affected your child's mental wellbeing?



4 Has receiving a diagnosis affected your mental wellbeing?



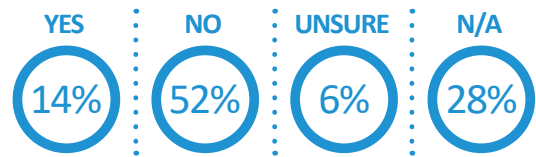
5 Has receiving a diagnosis helped your child access support with their education?



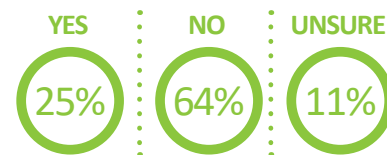
6 Has receiving a diagnosis helped your child access support from health services?



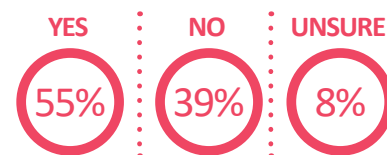
7 Has receiving a diagnosis helped your family access specific social care services?



8 Has receiving a diagnosis helped access specific support at home/community?

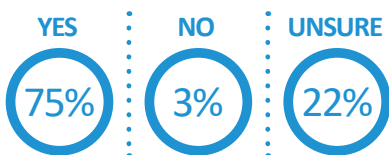


9 Has receiving a diagnosis helped your family access benefits (DLA, PIP, etc)?

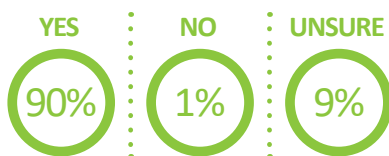


Survey Analysis: Undiagnosed

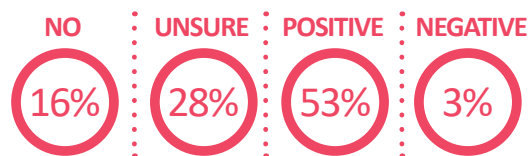
1 Do you think receiving a diagnosis will help your child understand themselves better?



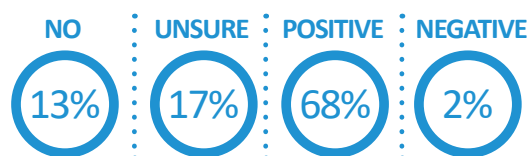
2 Do you think receiving a diagnosis will help others understand your child better?



3 Do you think receiving a diagnosis will affect your child's mental wellbeing?



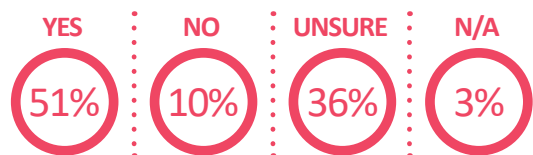
4 Do you think receiving a diagnosis will affect your mental wellbeing?



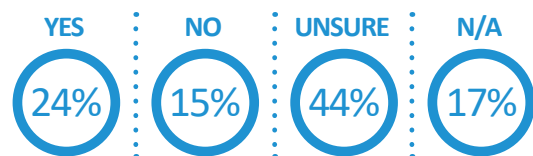
5 Do you think receiving a diagnosis will provide access to support with education?



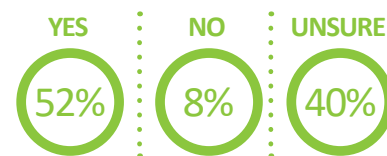
6 Do you think receiving a diagnosis will help access support from health services?



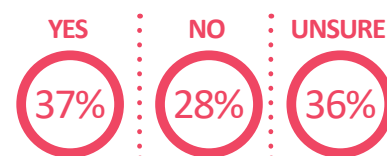
7 Do you think receiving a diagnosis will help you access specific social care services?



8 Do you think receiving a diagnosis will provide specific support at home/community?



9 Do you think receiving a diagnosis will help your family access benefits? (DLA etc)?





Services and Diagnosis Impact:

What parents and carers told us about services that require a diagnosis

It is important to note that different families are told different things which can lead to a lot of confusion. Also the information provided can also differ between Local Authority area.

A diagnosis is key to unlocking these services

- Disabled Student Allowances and disability assessment for Higher Education (evidence is required)
- Specialist School place (resource bases and specialist schools)
- Siblings can be registered as carers to access support (young carers)
- Social Care Assessments
- Support in school & college including reasonable adjustments & access to resources such as Laptops and movement breaks
- Extra time in exams
- Specialist Training & workshops (Early Bird and Cygnet)
- Bristol Autism Project (or on the waiting list) for Bristol families or some short break provision
- Bristol Autism Team for Bristol families
- Bristol Adult Autism Support Service
- Care Education Treatment Review
- Access to the Learning Disabilities Team at Bristol Royal Infirmary

A diagnosis is helpful to access these services

- EHCP (Education, health and care plan)
- Education other than at school (EOTAS/Alternative Provision)
- Personal Budgets & Direct Payments
- Access to Therapy such as Physio, SLT, OT & CAMHS (referral more likely if diagnosis in place however some families stated some of these services will not see CYP with a diagnosis because anxiety or sensory is part of being autistic)
- Transition support (moving between education and health services)
- Parents and carers can register as a carer with the GP
- Mentor
- Respite and short breaks
- Disability Facilities Grant
- Benefits such as DLA, Blue Badge, Universal Credit, Carers Allowance & PIP
- Priority passes e.g. Legoland/Cinema card
- National Autistic Society activities
- Carer discounts/passes
- Clubs - providing support worker (Brownies & Guides)

A diagnosis is not needed to access these services

- Some training/workshops
- Local support groups
- Parent Carer Forums



Conclusion

Support and signposting alongside a timely diagnosis



Parent Carers report that they feel a diagnosis helps them, and others to understand their child better, along with helping the child understand themselves better and having an explanation for why they may have certain characteristics and challenges that others around them do not; highlighting the importance placed on a diagnosis within the community.



Families should be supported by providing information about neurodiversity and equipping them with support techniques for their child, at an earlier stage, within the community. This should be practical support for the everyday challenges e.g. “how to handle meltdowns”, “sleep issues” etc. We should also ensure that we have a consistent approach for those working with the child and family.



Parent carers reported that a diagnosis has helped many of them and their children, with their own mental wellbeing. 68% of respondents waiting for a diagnosis felt that it would positively improve their mental wellbeing and 53% believed it would impact positively on their child’s. This highlights the importance of timely diagnosis to improve mental health outcomes for families.



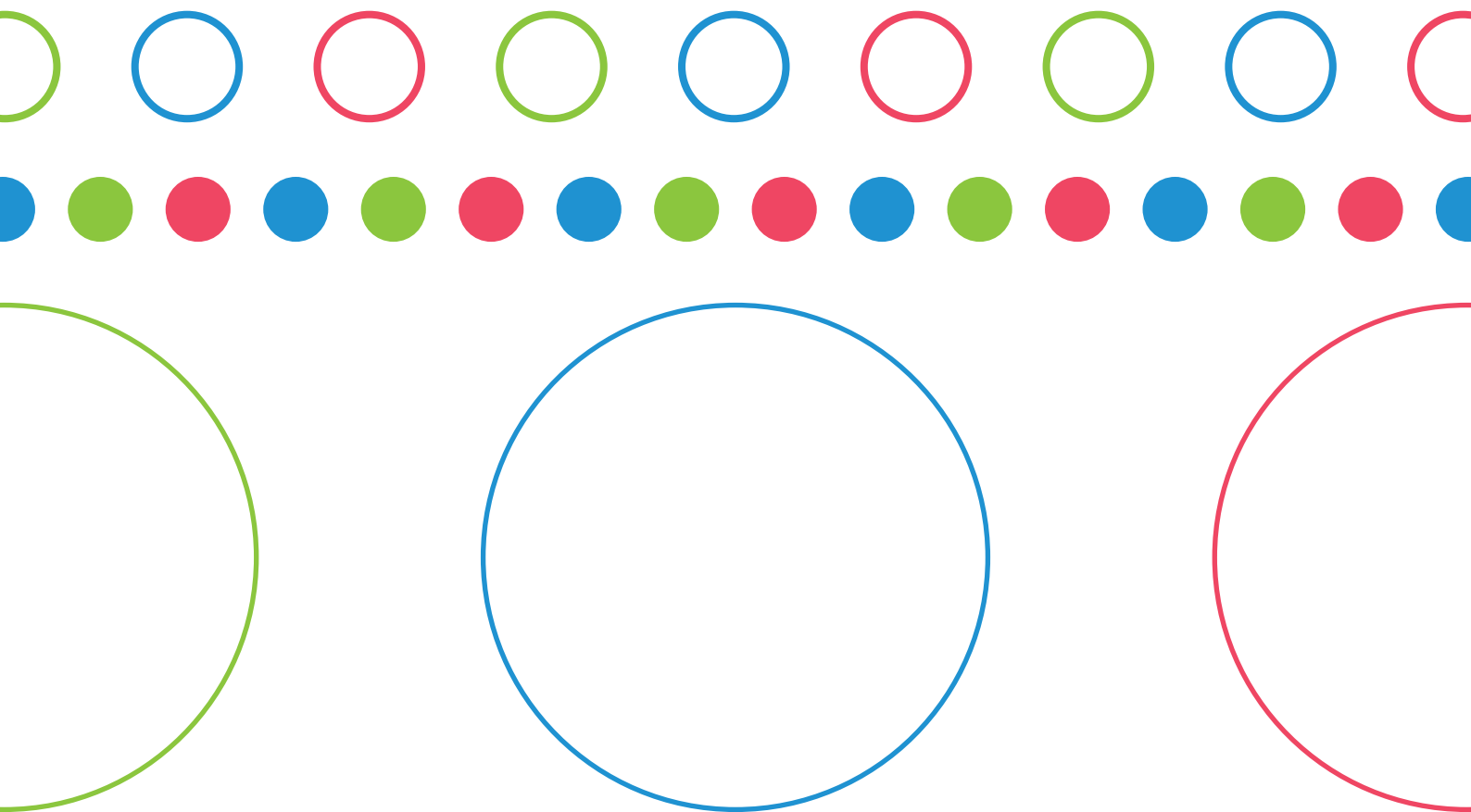
Families should have access to a broad range of mental well-being support within the community supporting the child, the parent carer and the whole family. Wellbeing will also be supported by encouraging peer support within communities.

Diagnosis, in many cases, is still the key to unlocking support or making access to it easier for the child and family. Parent Carers indicate that this is the case across education, health, social care, benefits and for support at home and in the community.

Parent carers have clearly communicated the importance of a diagnosis whilst highlighting the negative impact of waiting a long time and how this is compounded by a lack of support both before and after diagnosis.

A needs led approach in the community, that offers support at all stages and embeds diagnosis at an early stage would seem to be the best option if we are to see effective change.





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