



Neurodiversity Transformation Project *Update*

Appendix: Parent Carer Questions
and Comments



**Working together
for SEND families**

The Neurodiversity Transformation Project

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

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.

BNSSG PCF's held two engagement events in July 2024 to update parent carers and to gather their views and comments on the proposed pilot.

This document should be read in conjunction with the July 2024 update



Questions & Comments from families

The following comments and questions were gathered from parents at both the in-person and online event.

Some of the information came from what was told to Peer Supporters at the events, some of it came from post-it notes or flip-chart paper provided on the tables during the in-person event. There are also transcribes of some of the conversations that were had through the chat function available at the online event.

The comments and questions have been left in their original raw format to ensure that the feeling and message of each entry is maintained.

All the comments have been placed into themes. There may be a duplication with some of the entries noted as these have been collated by all parent carer forums and some overlap may have naturally occurred.

The Transformation Project Group will be putting together a frequently asked questions booklet related to the project which will be completed in September

The key themes:

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

Nature of Needs

- ... Just wondering whether this programme is only about autism and ADHD?
 - ... Does this consider PDA too? Extreme demand avoidance is massive for us but is often dismissed
 - ... Have consideration been made to exploring a complete assessment for a child i.e. ASD/ADHD in one as two pathways = two waits. Causing more distress to the child/families and delays. Now also further wait for titration.
 - ... Why doesn't PDA get noticed as a trait of autism on its own?
 - Bit of a long one this, it's not in the diagnostic manual so from a health perspective it's just a personality type of an autistic person. But ultimately, the aim of the tool is to meet all needs, including PDA ones, by identifying them first
 - As PDA is not in the diagnostic manual it won't be noted in relation to a diagnosis. However, ideally any professionals writing reports on a child will focus on needs which would include 'demand avoidance' and highlighting this where appropriate.
 - It's very hit and miss how much help you get as soon as PDA is mentioned. I was told by an Ed Psych that we wouldn't want to be associated with the connotations of PDA so she didn't want to mention it 😞
 - unfortunately I think it is very misunderstood and often only those of us with lived experience really understand the differences between PDA and general demand avoidance. I always think it is most helpful to identify individual needs and supports for a person as the labels are so easily misunderstood.
 - Agreed, I feel very lucky that the assessor picked up on it immediately but it has been such a battle to get anyone else to take it seriously. I found that it wasn't taken seriously until we were at crisis point.
 - ... Such a shame that children with trauma and attachment needs will not be part of this pilot
 - ... Do you foresee this as a move towards diagnosing multiple neurodivergent conditions simultaneously – i.e. not having to be referred for adhd separately to autism etc?
 - ... Were autistic voices or neurodiverse voices involved in Portsmouth and will they be here?
 - ... How will you help Autistic parents understand the process?
 - ... How are you including the children's hearing centre? Children not responding to their names are often referred to us but they are not deaf, they have ND needs
-

Nature of the Pilot

“Who takes responsibility for ensuring it is being followed?”



Were actually autistic voices and/or neurodiverse voices included in Portsmouth's pilot, and will they be in our pilot / development of the project?



Languages – which are priority?



Is this project part of the PINS project?

-
- Parents and children need to be involved – they are supposed to be now but not always.
 - What's the ultimate aim of trialling and using NPT?
 - How are you including the children's hearing centre? Children not responding to their name are often referred to the hearing centre and they often see the young people referred have ND needs and not hearing loss.
 - What about those over 19 supposed to do?
 - On the ground level, what impact has this made to Portsmouth schools and their SEND families?
 - Who pays for adjustments?
 - Who takes responsibility for ensuring it is being followed?
 - Won't those at the top of the wait list be the most likely to get an assessment already? Will this double up provision?
 - Is this replacing a Bristol support plan or feeding into it?
 - Would the profiling tool be recognised for an EHCP?
 - How will it fit with EHCPs?
 - Early Years – meeting needs at the earliest point may well be in Early Years – so I'm concerned that this seems to be heavily targeted to schools.
 - Can children have a complete assessment, rather than be assessed separately for (for example) autism and ADHD?
 - Will this pilot be working with children on the waiting list, new ones or both?
-

Nature of the Pilot continued..

“In future pilots will it be possible to include children who fall between multiple local authorities?”
- Parent carer

- When does the process of using the tool start exactly?
- Will all information be shared with parents as sometimes hard to get write copy's of this
- Will we be told what schools will be chosen to run this pilot in October?

- Will the profiling tool ultimately help schools to better understand the needs of neurodiverse children and young people – e.g. with a publication?
- Does this mean that less children are going to be diagnosed through this and there just going to be told they have additional needs and written off
- Won't those at the top of the wait list be the most likely to get an assessment already? Will this double up provision?
- Would the profiling tool be recognised for an EHCP?
- How will the pilot consider those children whose needs are not identified by parents but identified by school alone?



Health Provision

“...my child who has lost 3 years of secondary education, the consequences have been devastating, mentally, emotionally and physically to both her and me...she had so much potential, but is blown off course...”

- ☹ No Cahmns input? Primary Mental Health Specialists don't seem to be accepting referrals due to lack of resource, let alone the main CAMHS service.
- ☹ Camhs there a joke they don't wanna give out appointments when our children need them
 - CAMHS have been involved they were on our logo deck; we are talking about meeting early needs
- ☹ These poor children might need someone to talk to
- ☹ My son is under Camhs for Arfid and yet they tell me they can't diagnose as no pathway in North Somerset so pointless appointments coz they don't under arfid 🤔 it's frustrating
- ☹ Support currently Health = no health services are really involved at this stage. We are on our own to help manage anxiety.

“ Where are AWP Cahmns in these discussions?”

“ What will happen to those children who have been on a pathway for years and now reaching 17 1/2 years old and needing to move to the adult services. “

“ If I have a child that presents a danger to themselves and others, where can I get help right away?”

Current Assessment Process

- ☹️ Why are biblic/private reports not considered/accepted by NSCC in relation to EHCP needs assessment when 'clear' needs have been identified (by parents) at an early juncture (e.g. pre-school)?
 - ☹️ I have been told that ICB have paused the funding so one of my lads cant get his adhd report and the other is waiting for his autism assessment. Do we have to start again?
 - This doesn't sound right, can we contact you after this and put you in touch with Sirona?
 - Sorry forgot to say this is funding for right to choose via clinical partners
 - Ah I see a bit more complex this one, we will definitely be in touch
 - ☹️ What will happen to those children who have been on a pathway for years and now reaching 17 1/2 years old and needing to move to the adult services. There has been no Comms.
 - ☹️ What is the current status for application for EHCPs in primary schools in North Somerset, please? I've had conflicting information re TUF.
 - ☹️ How can we improve this service for neurodivergent girls who often slip through the net by masking at school?
 - ☹️ And those with a PDA profile of autism who can also be high maskers and their presentation can be very different to a typical autism presentation.
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Schools

“If the SENCO, who has not made a single observation of my child in a year completed it, then I would not have confidence as they do not know my child.” -

Parent carer

- What is the current status for application for EHCPs in primary schools in North Somerset, please? I've had conflicting information re TUF.
- How can we improve this service for neurodivergent girls who often slip through the net by masking at school? And those with a PDA profile of autism who can also be high maskers and their presentation can be very different to a typical autism presentation.

- How will the pilot consider those children whose needs are not identified by parents but identified by school alone?
- Who is going to fund the time spent by sendcos and TAs on assessing children? Schools tell us they have no money to provide the support already needed?
- Are you saying that SENCOs will be trained to use the Portsmouth profiler? Our senco is so overworked and really needs another member of staff to help her!! But not sure the school will put more funding into that.
- For me it's not really about the assessment tool but what support it could / should unlock
- I think the profiler would be useful to senco's and getting support put in place. However, looking at school placements, going to secondary to year 7, ALL of the resource bases that would be suitable for a neurodiverse child NEED a diagnosis of ASD to even be considered for a place. so diagnosis is part of the 'system'.
- How will it tie in with Early Help / EHAPs?
- What about EYs?
- The attendance updates from September frankly scare me
- Preschools signing up to 'Flexi-schooling' arrangements also
- If my child could stay in a lovely nurturing primary I'd be happier with this. The secondaries that are using 'Ready To Learn' or similar in very ableist and sometimes military style ways, it's a terrifying prospect for both children and families.
- Will Schools be able to amend needs + provision within EHCPs based on the profiling

Schools continued...

"I think this is a brilliant step in the right direction. I hope schools embrace this and remove the years upon years of 'fighting' that parents feel they have to undertake to get any kind of recognition." - Parent carer



It's the opposite of a trauma informed approach – they are causing trauma. It's so sad but seems to be a real 'fashion' in secondary education. I hope this can be addressed urgently in Bristol and maybe this pilot could start that thought process.



This is definitely something Bristol Council are focussing on for sure



Deaf dumb blind (hols place fingers in ears as don't have the time to focus on any single child that isn't disruptive punching teachers and turning over tables)– the child that is a mistress or master of masking means us parents go unheard – lived experience



Unfortunately, parents are not listened to when it comes to early intervention. I have been told that my child may 'grow out' of her 'behaviours', next year she may just get on with school. This isn't only not acknowledging my understanding of my own child but also setting unrealistic expectations for struggling parents.

- Agree, this is something we need to understand, how does the pilot work when schools say children are "fine" there...

- Completely agree I get constantly told wait till they start school then it's too late coz wait times take till they nearly in secondary. Had this problem with my first and looks like it's happening again x and now my eldest suffers so bad with mental health and school avoidance due to not getting early help.

- It's like they don't understand we know our kids better than them

- Agree with you both, definitely valuable feedback to go back to the project group about how this works for families like yours



More placements for specialist is needed.



Upskilling those in mainstream education settings.



How are you going to ensure that schools comply to the profile?



Sendco – do they need training to be one?



Whether the schools are fully on board?



Will schools be able to amend needs and provision with EHCPs based on the profiling?

Schools continued...

"...services that we are signposted to don't understand neurodivergent minds because we are grouped in together with learning disabilities, anxiety and depression..." - Parent carer

... In South Glos the issue of school places needs to be addresses urgently alongside this. We haven't got a place at our closest school and now having been given a school further away our ND daughter has crashed, we are facing EBSA and on a part time timetable in Sept for two hours a day, which has affected our whole family. The support for SEN children is just not there.

... Focus the Senco on the profiling. How to safeguard the senco so they can still do EHCPs etc not covered by profiling "jobs".

... What happens when the SENDCO leaves a school?

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- ... How will SENDCOs have capacity to deliver this? How it fits with EHCPs?
 - ... How does this differ from the process of identifying needs in school? Or is this alongside that process?
 - ... Some schools have very inflexible behaviour policies- how will this work in these schools?
 - ... How do parents access an assessment for their child if the school doesn't support?
 - ... Good schools are already profiling children through My Plans etc – the struggle is schools having the training, & capacity to support those profiled children with strategies – how do we address this?
 - ... Will the profiling tool ultimately help schools to better understand the needs of neurodiverse children and young people – eg with a publication?
 - ... What do parent carers do if they feel school hasn't fully/properly listened to their feedback when completing the tool?
 - ... How do you ensure that schools use funding in the right areas of need, i.e. social emotional classes/ELSA and staff who are properly trained
 - ... How are you going to ensure that schools complete the profile?
 - ... Are the schools fully on board?

Schools continued...

“How are you going to ensure that schools complete the profile fully/properly?”

Who will audit this?”

- ... Who starts this process? When I talk to school, they say all is okay, but what we see at home is not okay.
- ... Who do we contact if schools aren't doing what they should?
- ... How will SENDCO have capacity to deliver this?
- ... Will Schools be able to amend needs + provision within EHCPs based on the profiling?

- ... Will there be a legal requirement for schools to implement needs identified on the profile
- ... One of the challenges I've faced are that the school has such a high turnover of staff/absence that they don't know or understand my child and their challenges/needs
- ... The expectations in mainstream schools for our children are proving impossible to meet – in primary and secondary. Academic, social, behavioural – it is all too much for them. There is a big gap for 'in between' schools – for those children who don't need or meet criteria for full specialist settings but who simply cannot cope with mainstream. Schools are pulled in too many directions and it feels resource is directed to academics and behaviour and there isn't enough left in the pot for the level of pastoral support they need to function at school.

“Will schools be able to amend needs and provision within EHCP's based on the profiling?”

“When I talk to school, they say all is okay, but what we see at home is not okay.”

“What do parent carers do if they feel school hasn't fully/properly listened to their feedback when completing the tool.”

Schools continued...

- How can I make sure school have gathered my child's voice properly? Especially if my child is masking or I have a bad relationship with school?
- How would a school identify which children need to have a profile carried out.
- What do parent carers do if they feel school hasn't fully/properly listened to their feedback when completing the tool?
- How would the child's profile be transferred if they transitioned to a new education setting
- One of the challenges I've faced are that the school has such a high turnover of staff/absence that they don't know or understand my child and their challenges/needs
- Will there be a legal requirement for schools to implement needs identified on the profile?
- Who do we contact if schools aren't doing what they should?
- I know of children who are SEND but parents told their child doesn't even need a support plan in school and so they wouldn't be on any SEND radar at school even though they should be. How help them?
- What teacher training are you going to do in order to help identify need, especially for those children who mask
- When happens when the SENDCo leaves the school?
- How does this differ to theWho is going to fund the time spent by sendcos and TAs on assessing children? Schools tell us they have no money to provide the support already needed? process of identifying Needs in school? Or is this alongside that process?
- Are you saying that SENCOs will be trained to use the Portsmouth profiler? Our senco is so overworked and really needs another member of staff to help her!! But not sure the school will put more funding into that.



“...headteacher openly said that due to lack of adequate SEN budget, she was not prioritised....”

Children & Young People Out of School

“..his EHCP is meaningless as all provision is in school, which he’s been unable to attend for over 2 years.” - Parent carer



Why is there no support for children out of school due to mental health, autistic burnout. EHCP in place now but still no support as cant access school that would be good. signed off from camhs as just agreed with EP provision in Ehcp, but not access it. thankfully specialist for September, but 2 months away and might only be access an hour a day.



My biggest concern is where the child is currently struggling to attend school and that relationship then starts to break down between school and the family. Families are already at breaking point with the pressure of trying to meet attendance expectations and balancing the needs of our children. These families desperately need the help, but if the only way to access this is via school then many won't be able to access this. ·Out of Education / children on Alternative Provision – who will do the profile?



It's hard to imagine Bristol LA care about children not attending school, my son hasn't been able to attend school for 3 months due to anxiety/unmet autistic needs, I have a complaint in with the LA as they haven't responded to requests for a alternative provision and they refused him a needs assessment.



Same in NS, my son hasn't completed a full day since before the pandemic and we ended up flexi schooling so we could still access support. Still took 3 years of fighting before I could get a suitable school though 😞



I have spoke to BAT previously, they can't help because school would have to put my son forward for support and they haven't... if he thinks he could suggest anything different then great yes please.

· Yes, thankfully with support, in the last couple of months we've started making progress. We're getting there but it has been an uphill battle

· 2.5 years out of school here and with an EHCP and still next to no support, certainly not for the mental health difficulties that are at the root of the problems.

· Really sorry to hear about your son. It maybe that support from our Pathways to Shortbreaks team might be a option. Do get in touch.



What about early years?



What about those over 19?

Children and Young People Out of School continued....

- ... I think what is largely keeping children off school is the school behaviour policies being written without neurodivergent children in mind. At secondary schools students get "negative events" for not following "quality audience" rules etc. which require students to have still hands, facing forward, not moving in seats, not making any noise, and making eye contact with the teacher.
 - ... The secondary school I'm thinking of's ethos is "Be safe. Be kind. Work Hard".
 - ... Neurodivergent students are not going to "feel safe" if they have to mask their natural self-regulation STIMS etc. The school are not following "be kind" if they require children to mask to be there. And neurodivergent children can't "work hard" whilst using all of their energy on masking to not receive 'negative events'.
 - Yes very true, there is also a project called the PINS project which is working with schools to improve how included parent carer and children and young people feel in their community
 - I agree. My older child is starting secondary in September and seeing the expectations (eye contact, greeting teachers, smiling, uncomfortable uniform etc) is already worrying me for when my daughter starts in 3 years time.
 - ... Nearly a year out of work with a child 3 years out of school – the distress and family breakdown is lives lost
 - This is so sad honestly the authorities have a lot to answer for my son was doing 1hr a day in school pushed out it's horrible it affects the whole family
 - ... What will happen to those children who have been on a pathway for years and now reaching 17 1/2 years old and needing to move to the adult services. There has been no Comms.
 - ... For children out of education and in alternative learning who will complete the profile?
-

“Why is there no support for children out of school due to mental health, autistic burnout?”

Support Partnership across Schools and Health

- ⋯ How will the Portsmouth profiler be used? Is this for teachers and parents? Or clinicians?
- ⋯ What support will there be to meet needs that are identified?
- ⋯ My son is 19 but still needs help – vulnerable adults need aspects of this
- ⋯ Need further clarification on what your definition of trained is as from experience parents tend to be more trained than a lot of "professionals" I've encountered.
- ⋯ Will there be budget once implemented ?
- ⋯ There are unfortunately thousands of children damaged by not receiving early support who now need support to pick up the pieces
- ⋯ I'm curious as to how broken underfunded schools and a broken underfunded Health Service are going to pull off working together at all, let alone working together successfully.
- ⋯ Sorry, did you also say there would be a team of professionals to support the toolkit?
- ⋯ The profile tool would help teams that aren't adhd/autism specialists, like in schools, but it doesn't replace a professional diagnosis
- ⋯ What about ASC schools which have diagnosis as an admission criteria
- ⋯ Are there any outcomes that could be shared ?
- ⋯ I'm unsure if this is being suggested INSTEAD of a professional diagnosis or as well as?
- ⋯ A child centred approach to education at home or school, yes is definitely needed. Centred around their individual needs.
- ⋯ Support shouldn't be dependent on who you see or which school you attend.

**“How many professionals will make up the support team?
Surely this will simply become overwhelmed by school staff
needing support?”**

Parent carer

Supporting families

- ... Is there any help for parents with assessment forms and process of applying for EHCP?
- ... Is there training for parents?
- ... How will you help autistic parents understand the process?
- ... I also believe it's not just the child with needs need support siblings do as well my daughters are struggling as my son is violent and they go to school upset there depressed and they get no help
- ... So let me get this right, you implement the profile to see if the child has a need that's not getting met and then meet that need, then x amount of years later you get an appointment where someone says your child has autism/adhd. That seems expensive and the wrong way round. One way you could cut waiting list and costs is family diagnosis pathways especially with the strong genetic link.
 - The idea of the tool is to identify needs to meet them as early as possible, then yes, receive a diagnosis later. So that needs do not escalate. We would love to have some outside of the box thinking if you have any other ideas?
 - Totally agree – family assessments would make SO much sense. It seems to antiquated to do everything individually
 - So assess the whole family? Sorry not sure what this means but it sounds interesting!
 - Yes assess the whole family, at one stage there was 7 different neurodivergent referrals being processed. The system is so fragmented and expensive
 - This is such a great idea
 - I completely agree, I have 1 diagnosed and 1 on wait list and 1 suspected. This would massively help and also support for my 1 nt child who struggles massively but instead having to go through the process multiple times and seems to be worse each time x family diagnosis I would 100% be behind
 - I did ask a right to choose provider recently if they did any family offers. There must be so many families all stuck in the system of waiting
 - Agreed. I have 1 suspected Autistic, one expected AuDHD (so 2 different pathways) plus possibly Tourettes – unable to even find a pathway and one with ARFID and told no one is really supporting this area. Family assessment would definitely help here.
- ... My son is under Camhs for Arfid and yet they tell me they can't diagnose as no pathway in North Somerset so pointless appointments coz they don't under arfid – it's frustrating
- ... BPC Neurodiversity drop in hubs would be a more cost effective system for supporting neurodivergent and neurotypical families. I think that's missed, the support that's essential for neurodivergent kids also helps every child in school/ family/ society setting. I have been part of a similar transformational project for cancer and its very cost effective after initial outlay.

Supporting families continued...

- ☞ My gp referred me to social prescribing and I also started on anti depression meds after the long battle with LA, 5 months out of school
It's Bristol Parent Carers for Bristol 😊 Also social prescribing can help, we will contact you after the event. We are also looking for funding for a counsellor for parents, watch this space!
-

“Can I also ask what support is there going to be for parents/carers who are suffering from anxiety and/or stress due to fighting these referrals that are either rejected or bounced back from Sirona or mental health services.”

Parent carer

Social Care and DLA

- ☞ It is need impossible to get DLA with needs led assessment they want diagnosis.
· I got dla for both my children without dx as should be needs based too. Just need good third party reports, sen plans etc
· You don't need a diagnosis for dla it's the child's needs it goes on
· DLA is needs led no diagnosis required to get DLA. Although may be asked to provide more evidence of need.
· You shouldn't need it but from experience of myself PIP and my kids DLA this isn't the case.
- ☞ Support from LA! Very limited support and based on LA services available, not on my CYP's needs.
-

Other

- Communication is poor.
- How it's communicated.
- If I have a child that presents a danger to themselves and others, where can I get help right away?



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

Bristol 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/