

Health Scrutiny Committee

(Sub-committee of the
People Scrutiny Commission)

7 December 2023



Report of: Bristol, North Somerset and South Gloucestershire Integrated Care Board (BNSSG ICB) and Sirona care & health

Title: Bristol, North Somerset and South Gloucestershire neurodiversity workstream update

Ward: All

Officers Presenting Report:

Jan Potts, Interim Deputy Chief Operating officer, Sirona care & health

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Recommendations:

Members are asked to review this update and provide any feedback that may further help us to develop our approach.

The significant issues in the report are:

The report provides an overview of the work being undertaken to transform services and support for neurodiverse children, young people and their families.



1. Summary

The purpose of this paper is to provide an update on an early-stage project being co-led by the Bristol, North Somerset and South Gloucestershire Integrated Care Board (BNSSG ICB) and BNSSG parent and carer forums, which aims to transform approaches across education, health, and social care for supporting neurodiverse children, young people and their families.

Whilst this paper outlines the transformation work taking place to improve access for the future, there is significant work taking place to make changes now. It is important to recognise that support should be around the needs that a child has and not be diagnosis dependent; some of the most complex children do not fit the diagnostic category but their need for support is the greatest.

The paper also looks to address specific questions raised by members with regards to autism spectrum disorder assessments and assessment criteria.

2. Context

2.1 Background

- 2.1.1. Education, health, and social care services have a responsibility to actively identify and respond to the needs of children and young people, including those needs reported by their families. This responsibility aligns with relevant legislation, such as the Special Educational Needs and Disabilities (SEND) Code of Practice and the SEND Area Inspection Framework.
- 2.1.2. Families commonly share experiences that reveal a lack of support until their child or young person receives an assessment, or until the child or young person's needs reach a critical stage. The delay in accessing support can lead to the emergence of serious mental health issues, school placement breakdown, and conflicts within the family, amongst other issues. The limited support available without a diagnosis creates a dual challenge:
 - As more families are referred, the waiting list exceeds service capacity, intensifying service challenges.
 - Some families with the means to do so seek private assessment to identify their children's needs before they escalate to a critical stage. This disparity creates inequality within the system, as do not usually provide post diagnostic support.
- 2.1.3 The ICB has established a gateway process for major change and transformation programmes, which consists of a number of gateways that provides the infrastructure and grip to support and prioritise projects. Through this process the ICB have committed a Design Lead within the newly formed Transformation Hub to undertake an exploratory and discovery piece of work which focuses on autism and the increase in demand for a diagnosis. This in turn will inform a future model to supporting children and young people with neurodiverse needs.
- 2.1.4 This work follows significant developments in the spring of this year when the National Framework for Autism Assessment Services was published and £1m funding for the continuation of a waiting list initiative was confirmed. This period also saw the final stages of

the approval process for a system wide transformation programme to ensure all partners in health, education, local authorities, parents and families work together to consider how we deliver services differently so that all children with neurodiversity needs can access appropriate support in a timely way. Therefore, and as a result of concerns raised around a change to the referral process, we re-started accepting referrals as per the pre-March criteria although continue to triage referrals based on clinical need and vulnerability as we have always done.

- 2.1.5 Autism Spectrum Disorder (ASD), is a neurodevelopmental condition which is part of the neurodiversity spectrum. Autism affects the way a person communicates and interacts with others. Repetitive behaviours, intense interests, sensory differences and difficulties managing change are also features. One autistic person will be different from another and need different types and levels of support. There are defined diagnostic criteria that need to be met for someone to be given an autism diagnosis. Some people that do not meet the diagnostic criteria may still have traits that overlap with autism and will benefit from some of the same interventions.
- 2.1.6 Sirona care & health provides assessments for children and young people with neurodiversity needs and suspected autism causing them very significant difficulties in their daily life despite appropriate support. A diagnosis is not required to support a child/young person with their neurodiversity needs including those associated with autism and there are useful strategies which can be put in place which are helpful.
- 2.1.7 Referrals can be made for children/young people who are registered with a GP in Bristol, North Somerset and South Gloucestershire and are identified as having needs that may be associated with autism that are significantly impacting their daily life despite support and intervention.

2.2 Gateway 0 – discovery process

- 2.2.1 The benefit of the gateway 0 discovery process is that it generates new data and insights, analyses themes in the data which informs the design of solutions and supports an inclusive ideation and design process generating a number of models for improvement to be tested in gateway 1.
- 2.2.2 The gateway 0 discovery process involves:
- Understanding user needs – gaining a deep understanding of the users, their families and their needs. This will involve reviewing and consolidating existing evidence and insights and conducting bespoke user research which lead to a deeper understanding of issues and opportunities for improvement.
 - Engagement is key within this work to not only understand the impact of the current pathway but also the experience for children and young people and parent carers as well as professionals who support this cohort, such as schools and teachers. We will explore how we can capture the presenting needs for support and a diagnosis as well as the current barriers our partners and population face.

- Conducting a deep dive into the cause of increase referrals to the autism pathway and increased presentation of needs, and literature review about the evidence.
- We will firstly explore what we already know across the system, pulling in system partners and the valuable insights they have, this will not only focus on activity and performance but also insights and engagement into CYP and family's needs, wants and experiences. There has been a significant amount of work already undertaken through various workstreams in this area which will form a basis to identify gaps and further engagement requirements.
- Confirming the problem definition – iterating the problem definition during the discovery phase will help to define the problem to be solved in the design phase. It provides clarity on the issues with the current pathway for users which the design must address. This ensures subsequent phases are aligned to user need.
- Ideating effectively – involving a variety of partners including patients and carers to review the evidence collated and focus on the problem to generate a series of options for improvement, to be tested in gateway 1.

2.3 Progress so far

- 2.3.1 It is more important than ever to create a sustainable system that meets the needs of families, children and young people while also considering the resources of organisations linked to these pathway changes. The project aims to co-design what a sustainable offer might be and has just concluded an early planning stage as to how this work will be delivered, including the key people who need to be part of the planning process, especially as engagement and co-production will be key within this project and drawing on people with lived experience will be vital to providing a root cause analysis through to designing a new model.
- 2.3.2 With co-production and engagement at the heart of understanding the problem and designing a sustainable solution, we have been discussing the problem with the three Parent Carers Forums leads across BNSSG to identify how we can have a co-led project with them, ensuring the child, parent or carer is at the heart of designing a future solution that takes a neurodiverse approach and identifies needs and provides support earlier, rather than waiting for a diagnosis.
- 2.3.3 There has been other workstreams that have already taken place, which the project will capture the learning from such as:
- A sustained waiting list initiative
 - User experience digital project
 - Changing the assessment criteria
 - Development and introduction of a Keyworker Team
 - The testing of new or expanded “needs-led” neuro support projects
 - The BNSSG Autism Hub.

2.4 Next steps

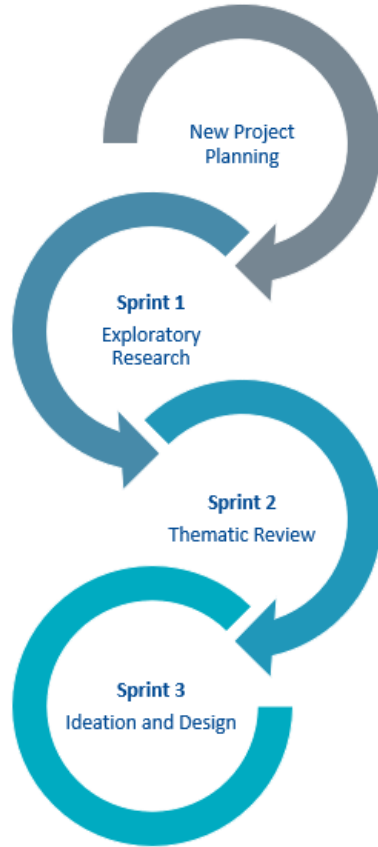
- 2.4.1 The project has been agreed to enter into gateway zero of the ICB process which solely focuses on discovery and understanding the problem. We wrote out to each local authority and other system partners who work in this area to invite them to be part of the project group, which

was initiated on 19 September. This group oversees the delivery of the project and facilitate any information/ data requests, as well as any future decision-making requirements.

- 2.4.2 The project group will also be responsible for ensuring we capture the views and experience of our delivery partners, CYP and parent carers, key to this will be engagement with our local authority partners and schools, to ensure we create a systemwide approach. We have nominated leads from the local authorities who will support this work and there are several education forums that we will engage with. From the initial discovery phase, we will bring together all the insights work done to date which will highlight any gaps in information and what further engagement is needed within our education partners.
- 2.4.3 The group successfully ran a Neurodiversity Discovery conference on 23 November 2023, which brought together more than 85 delegates from system partners, including education and parent carers across BNSSG. Within the conference we facilitated table discussions to further understand and evidence the problem from the organisational data as well as insights and engagement work previously carried out. We also discussed and identified other areas of engagement needed to fully understand the problem and people’s views.
- 2.4.4 We will hold a second conference which will bring everyone together again to focus on “ideation”, taking into consideration the outputs from the discovery phase and identifying potential options to explore a “Test & Learn” pilot in gateway one. This is likely to be early February and will be confirmed once the project group have finalised an engagement plan.
- 2.4.5 Further information and a high-level timeline can be found below along with the revised problem statement that was co-produced with the Parent Carer Forum representatives.

Neurodiversity, Transformation Hub Gateway 0 process

Discovery phase



Problem statement: With the increase in referrals and the desire to adopt a Neurodiversity approach, we need to understand what is driving diagnosis rates and the benefits a diagnosis brings.

New project Planning	The aim of this phase to establish a project plan, which identifies;	Sprint 1 - Exploratory Research	This phase focuses on information gathering, insights and engagement (existing and new), we want to work with service users/ parent carers as well as partners to co-produce the approach for this phase, to ensure we gather valuable insights and evidence.	Sprint 2 - Thematic Review	Within this phase we will review the outputs from the exploratory research and create a final insights and evidence pack, to be shared with stakeholders.	Sprint 3 - Ideation and Design	The final phase is an Ideation and design conference, which will provide an opportunity for stakeholders reflect on the key findings to inform and develop potential models to test.
The different stages of the project	Key stakeholders (including service users and Parent Carers)	Key engagement groups					

Process phase	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	
Agreed to enter Gateway process	★										
New project planning		█									
Sprint 1 – Exploratory research		█						★			
Sprint 2 – Thematic review							█		★		
Sprint 3 – Ideation and Design								█			★



	Delivery	★	Milestone	★	Stakeholder conference
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Neurodiversity Problem Statement

What is meant to happen

Education, health, and social care services have a responsibility to actively identify and respond to the needs of children and young people, including those needs reported by their families. This responsibility aligns with Childrens and Families Act legislation, as well as the SEND Code of Practice and the SEND Area Inspection Framework.

Once a diagnosis is made a support plan can be developed, including supporting access to education.

Early recognition of needs and intervention can greatly improve outcomes for children with autism and other neurodiverse conditions, so it is important children receive prompt assessment and support.

What is currently happening

- With an increase in demand and insufficient capacity to meet that demand, we now have very long waits that do not facilitate early intervention for both ASC and ADHD.
- The waiting list profile is set to deteriorate for the longest waiters as the new criteria prioritises most vulnerable, not time they have been on the waiting list. This risks pushing more children to crisis point before receiving intervention.
- Families commonly share experiences that reveal a lack of support until their child or young person receives a diagnosis, or until the child or young person's needs reach a critical stage, Many are discouraged/told a diagnosis not appropriate by schools / GPs - particularly for children who mask in community environments. The delay in accessing support can lead to the emergence of serious mental health issues, school placement breakdown, and conflicts within the family, amongst other issues. The limited support available without a diagnosis creates a dual challenge:
 - As more families are referred, the waiting list exceeds service capacity, intensifying service challenges.
 - Some families with the means to do so seek private diagnoses to address their children's needs before they escalate to a critical stage. This disparity creates inequality within the system.

What has already been tried	Insights/evidence
Community Paediatrician recruitment	Rise in demand – 350% increase in referrals since April 2020.
Waiting List Initiative	
User X	60% of current waiting list (Nov 2023) waiting over a year.
Changing criteria	Children from the most deprived areas make up more of the waiting list and wait on average longer than children from less deprived areas.
Keyworker teams	
Needs-led projects	
Autism Hub	80% of families in BNSSG felt receiving a diagnosis will help access support with education

Challenges

- Different pathways for ASD and ADHD with some people seeking a diagnosis for both
- Shift to early intervention, pre-diagnostic to provide support based on need will require long-term cultural change within all partners.
- National narrative (i.e. recent ASD National Framework) remains diagnostic-focused as opposed to considering neurodiversity
- Capacity in education settings is very low to manage to assess needs and provide support to meet those needs.
- Insufficient Specialist workforce capacity within Heath and educational settings

Potential causes

1. High demand for assessment – as autism and ADHD awareness has increased there has been an increase in demand, combined with legacy impact of lockdown on children's development.
2. No system process to identify and escalate needs early and therefore support needs are not identified until points of escalation.
3. Limited access to diagnosis resources - shortage of specialists and difficulties with recruitment and retainment of these.
4. High 'value' of diagnosis – despite aspiration for services to provide support based on need, families face blockers accessing education support without a clinical diagnosis and the funding that is allocated according to this. This is continuing to drive referrals.

Meaning...

- Support needs not being met
- Negative impact on parents and children (particularly education)

Meaning...

- Deepening inequalities
- Potentially more school exclusions

3. Policy

- SEND Code of Practice
- SEND Area Inspection Framework
- NICE guidelines

4. Consultation

Our approach is co-designed with Parent Care Forums and engagement and involvement will be undertaken at a number of points during the course of the project.

5. Public Sector Equality Duties

- 5a) Before making a decision, section 149 Equality Act 2010 requires that each decision-maker considers the need to promote equality for persons with the following “protected characteristics”: age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, sexual orientation. Each decision-maker must, therefore, have due regard to the need to:
- i) Eliminate discrimination, harassment, victimisation and any other conduct prohibited under the Equality Act 2010.
 - ii) Advance equality of opportunity between persons who share a relevant protected characteristic and those who do not share it. This involves having due regard, in particular, to the need to --
 - remove or minimise disadvantage suffered by persons who share a relevant protected characteristic;
 - take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of people who do not share it (in relation to disabled people, this includes, in particular, steps to take account of disabled persons' disabilities);
 - encourage persons who share a protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low.
 - iii) Foster good relations between persons who share a relevant protected characteristic and those who do not share it. This involves having due regard, in particular, to the need to –
 - tackle prejudice; and
 - promote understanding.
- 5b) As the project is in the discovery phase, a full Equalities Impact Assessment (EIA) has not been completed. Once the projects enters into the ideation phase and is agreed to enter into gateway one to facilitate a test and learn pilot, an EIA will be completed.

Appendices:

None.

LOCAL GOVERNMENT (ACCESS TO INFORMATION) ACT 1985

Background Papers:

None.