

# Bristol Health Scrutiny Committee

## 20 March 2023

### Public Forum



#### Public Forum Statements

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#### Public Forum Questions

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## **PUBLIC FORUM - STATEMENTS**

### **STATEMENT 1 – JEN SMITH**

Cutting back on the ability for all children and young people who are showing signs of being autistic and introducing restrictive criteria to access an autism assessment, must be one of the worst decisions I have heard come out of Bristol in recent years.

With the state of SEND in the city, that's a big achievement.

The mental health damage inflicted on neurodivergent people who do not understand why they are the way they are, is life-long and never goes away.

That children and young people in Bristol – as well as the other Local Authorities – must be at crisis point before being able to access an assessment is creating years and years of trauma.

This is the time where there should be early intervention. A chance to interrupt the predictable path of children thinking there is something wrong with them and adults treating them as if there is something wrong with them. Because that's the reality of it.

As a neurodivergent family in Bristol, I have seen the barriers a lack of diagnosis and extremely late diagnosis creates in education. There is then no support in social care, children do not achieve levels of education of which they are capable.

It impacts on employment, enjoying life and then as an adult, you live in the judgement of others who do not understand why you are incapable of playing the Neurotypical Game of Life.

You do not create fewer autistic people in Bristol by cutting back on assessments and you do not save money in the long-run.

It would be laughably naive to think that other services will swoop in to support children not eligible for an assessment in the interim. If that existed, the Bristol SEND team wouldn't feel swamped under the number of requests they receive for an EHCNA.

This decision to implement this restrictive criteria blocking access to autism assessments will prove to be a costly and discriminatory decision that proves Bristol never deserves to call itself autism friendly.

## STATEMENT 2 – FIONA CASTLE

I am the parent of an 11-year-old boy, who was diagnosed as autistic at age 4. I am also a member of the group 'Assess for Autism' and I am speaking to you today on behalf of both myself and this group.

As of the 1<sup>st</sup> of March 2023, the Integrated Care Board (ICB) in partnership with Sirona Care & Health, have imposed new eligibility criteria for NHS assessments for Autism in under 18s. These criteria are extremely restrictive and new referrals are effectively now only being accepted when the child or young person and their families have reached crisis point.

There are now 6 points of eligibility, which include the risk of breakdown of school placement, or risk of breakdown of the family unit. Furthermore, children meeting these criteria will only to be considered as eligible for assessment when 'all other means of support have been exhausted'. Thus, it is no longer enough for a child's family unit to be under pressure of dissolving, for example. The family must have sought and exhausted all other possible means of support, before the child will be accepted onto the waiting list. The wait, once a child and their family has reached such a crisis point and been accepted for assessment, maybe still as long as 2 years.

When I first started noticing unusual behaviour in my son, he was 9 months old. By 18 months he had become physically aggressive and by 2 and a half, I was at my wits end, emotionally and physically. On several occasions, I raised concerns with my health visitor and eventually she did a home visit. During the visit, she declared that my son was "definitely not autistic and just had a boisterous, type A personality". Less than 18 months later, he was diagnosed as autistic. He went on to require an EHCP, full time 1:1 support at school in primary and now attends a specialist autism secondary school.

The journey for us as a family, post diagnosis has been long and hard. I have had to fight for everything my son was lawfully entitled to and have first-hand experience of Bristol City Council's 'fractured relationships with parent carers'. The fight for support has at times cost me my physical health; relationships with friends and family; employment prospects and the mental health of not just me, but other family members. My son's autism diagnosis was for us, just the start of a very long and arduous road, littered with a lack of resources; an unwillingness for professionals to follow the law and years of watching my beautiful boy, being failed by the education, health and care systems in Bristol.

And yet, we had a diagnosis of autism. We had the certainty that comes with a diagnosis: that despite what I had been told by my health visitor, we were not imagining problems and we did need help. I have spent the last 7 years advocating for my son and helping other SEND parents, mainly with children diagnosed as autistic, to advocate for them. I have embraced my son's neurodiversity and work hard to spread the message of acceptance and inclusion for the neurodiverse community.

I can only imagine how difficult this journey will be for families without an autism diagnosis. When they finally become eligible for assessment of their children, they will already be broken and their children will most likely be traumatised and in need of much more support and intervention, than they would, had the autism diagnosis been achieved earlier. And even at this point they will have to endure a further 2 years on the waiting list before assessment. Despite what Sirona says in its literature, support without a diagnosis is much more difficult to get and this is in a system that already seems to view supporting SEND children as a voluntary concept.

This change in assessment criteria has happened under the scrutiny of Bristol City Council, as well as North Somerset and South Gloucestershire Councils. These suffering children, young people and families are your constituents. The NHS is a service that should be available to all and under your watch, it has been allowed to close its heart and mind on a huge portion of the next neurodiverse generation. You should hang your heads in shame and I urge you to do all you can to force Sirona and the ICB to reverse eligibility criteria for assessment. These are not numbers on a spreadsheet. They are children and families and they are being ignored and left to suffer.

**STATEMENT 3 – JAIME BREITNAUER**

I wish to make a statement relating to the new autism assessment referral criteria for under 18s introduced by Sirona CIC and the ICB this month. But first I want to tell you a story, and I am afraid some of the details might be distressing.

There is a young man I know who is close to my family. I know his family intimately. This young man, a few years ago now, was experiencing his needs not being met at school. He was labelled disruptive, naughty, a trouble maker. Reasonable accommodations were ignored, he was suspended twice, made to sit alone in the classroom and followed at lunchtime by a member of staff. He was a pariah. Children who had been his friend for years ignored him. Whole class birthday parties went ahead without him receiving an invite. He became isolated and distressed and as a result, his behaviour became more problematic for those around him, and his needs were still not met. Eventually, he was so distressed that he attempted suicide on school grounds - a teacher saved his life.

The fall out from this event was huge, and still reverberates now:

- He missed months off school while his parents fought to bring him back from the depths of a mental health crisis. He has never returned to school full time, and although he was once a high achiever, he is now academically years behind his peers.
- One parent gave up work and the other went part time to support his needs - he self harmed for months after and couldn't be left alone even when asleep at night. The family ended up in £40,000 worth of credit card and pay day loan debt which they are still paying back, and both parents have PTSD and have not been able to return to work full time.
- The young man's sibling developed a deep and penetrating anxiety disorder, and is now also on a part time timetable at school. Previously this child enjoyed many clubs and lots of friends. They are now a reclusive loner.
- Two teachers at the school had to be signed off on long term sick leave, and eventually resigned. Some of the young man's classmates needed psychological support.

This young man is autistic, and because he already had a diagnosis he was able to get swift and appropriate crisis mental health support. But under the changes made by Sirona CIC, it only would be at this point the young man would be eligible for a referral. Not an assessment, not a diagnosis, but a referral, and then they would have to wait around 2 years to see a professional and get the help they need.

Additionally, this story also demonstrates that Sirona's claim a child doesn't need a diagnosis to get support is simply not true. This child was already diagnosed, but months if not years of unmet needs in an educational setting drove him over the edge.

The change to the referral policy is naive, inappropriate and dangerous. The change to this policy will cost lives. The story of this young man is 100% true but perhaps what is more shocking is that it is not unusual. Sirona's new referral policy will make cases like this even more common. Research shows that autistic people are twice as vulnerable to suicide and in undiagnosed autistics the risk is exponentially higher.

I am supporting the group Assess for Autism to bring a judicial review in regard to these changes made by Sirona CIC. But I also hope it won't get that far. I hope that this story and others you hear will help you understand the utter madness of this change, and that appropriate swift action will be taken to reverse the decision and provide Sirona with the resources they need to keep our young people diagnosed and supported.

## **PUBLIC FORUM - QUESTIONS**

### **1. QUESTIONS FROM JEN SMITH**

Questions regarding the change of criteria to autism assessments for children and young people

Q1 - What exactly was the nature and feedback from the co-production that took place with families, along with which representatives attended, regarding this significant change to the autism assessment criteria?

Q2 - Please can we have the Equality Impact Assessment made available to the public in answer to this question?

Q3 - The referral criteria for an assessment includes those whose education placement has broken down, those at risk of permanent exclusion, transfer (presumably managed moves) school attendance difficulties, family breakdown, children in care or child protection, those open to CAMHS, repeated offending and those with very low levels of communication.

If all the other children and young people who may be autistic are refused an assessment, they are likely to hit this crisis point as well.

Why has the BNSSG Integrated Care Board created a referral criteria which will push autistic children and young people to crisis point before being able to access an autism assessment?

Q4 - Why is the BNSSG Integrated Care Board using outdated and offensive terms such as 'school refusal' in their referral criteria?

Q5 - Have you considered how blocking access to early diagnosis will impact on the budgets of education, the High Needs Block and the ability of children to be placed in autism specialist schools and how will these expenses be mitigated by health?

Q6 - Was anyone at Bristol City Council involved in discussions or decisions around this change?

Question regarding CAMHS

Q7 - Is discharging a child who's waited a year for a CAMHS assessment, saying to re-refer if necessary and then the child refusing to attend school due to SEMH related needs the following week not just a way of cutting back waiting lists whilst offering zero support?

### **REPLY FROM CHAIR OF HEALTH SCRUTINY COMMITTEE:**

*Thank you for raising these questions.*

*We are very sorry but we are not able to respond directly at this point to these questions as they relate to Sirona Care and Health's autism assessment service for BNSSG and a change to the way they manage their waiting lists, which has changed from 1 March, as you know – see link:*

<https://www.sirona-cic.org.uk/nhsservices/childrens-services/referral-for-a-specialist-autism-assessment-service/>

*These questions would be more appropriately directed to Sirona as lead for autism assessments.*

*However, the points and issues as set out in your questions are noted, and as Chair of Bristol's Health Scrutiny Committee, I will be proposing to the Committee at Monday's meeting that we look into the issues raised by this policy/criteria change in depth. We have a very full agenda on Monday and so will only have limited time available to discuss this matter then, but I will propose that we look into this as a matter of urgency as part of our work programme.*

## **2. QUESTIONS FROM ANNA HOUGHTON**

Please find below questions I would like asked of the committee in relation to the changes to the children's autism referral eligibility via Sirona Care & Health ([Referral Criteria – Sirona care & health NHS services \(sirona-cic.org.uk\)](#))

1. How long is the referral process and waitlist anticipated to be effectively closed for?
2. What provisions are being made for children excluded by the new criteria? For example, will CAMHS receive more funding and capacity to take on additional patients? Will they be able to relax their referral criteria as a result?
3. Will guidance be given to local school SEN teams giving them the authority to support children without an 'official' diagnosis? Seeing as thousands of children will remain undiagnosed over the next few years, a more relaxed approach to giving necessary support to these children will be necessary to prevent these children experiencing unnecessary difficulties in schooling and their mental health. (I am aware support should be needs based, not diagnosis based – but in reality this is never the case and a diagnosis is always needed in the first instance)
4. Will schools, LA's and GP's etc be instructed to be more willing to accept and act upon private diagnoses seeing as NHS diagnosis is no longer accessible for many? Many parents are now seeking private diagnosis instead but this will be pointless if the support is still not forthcoming.
5. Given that many parents are actually very understanding of the extremely long waitlist and understand the difficulties involved, why is there not an option to join the waitlist regardless? We were prepared to wait the expected 3 years for an assessment and to now not even be able to submit our referral forms because we are 2 weeks too late due to a delay with the school completing their part, seems drastically unfair.
6. Why is the 'right to choose' pathway via GP referral not being utilised in our area to help clear the backlog? Surely this could help with the waitlist and prevent so many children being excluded from the chance to be diagnosed?

### **REPLY FROM CHAIR OF HEALTH SCRUTINY COMMITTEE:**

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### **3. QUESTIONS FROM SANDRA THOMAS**

I am writing in relation to the change of criteria and the stopping Autism Assessments from the 1st of March which means referrals received will be prioritised on the needs of each young child, young person and family by Sirona Care and Health.

I find it shocking that requests for assessments will only be considered if the child and young people meet the referral criteria in which the education placement is breaking down, not in Education or employment, children and young people whose family are at risk of breakdown, children who are in care or CIN plan, or children who are under CAMHS, so basically a child needs to be at Crisis?

Every child and young person has the right to have their educational needs met, their health needs met, their social care needs met.

Simply by ignoring a child has needs will only cause further mental health problems. The criteria to access CAMHS is unattainable and the therapy offered is behind in the times. Children and young people have the rights to be supported in their health and well being.

The system is failing our children, we are our children's/young persons advocates, our voice/their voices need to be heard, to understand the impact of not having needs met, by having needs undiagnosed, for not being 'disabled enough', for having a hidden disability. By not receiving support will lead to mental health crisis, and more young adults taking their lives.

The criteria is discriminatory!

#### **Questions**

1. Has the Bristol Autism Team or Bristol Autism Support had input into this new criteria? When was the meeting held? Who was invited?

2. Has CAMHS/PIMS had any input into this and how they are going to support children whom do not meet the criteria? and especially as CAMHS do not deal with school based anxiety.

3. Has the following been discussed?

- The Equality Act 2010-A child/young person must not be discriminated because of their disability, every child has the right to enjoy the highest possible standard of health, to access health and other related services and to facilitate for the treatment .
- Disability Discrimination - Section 6 of the Equality Act?
- Safeguarding children- ( Empowerment, Prevention, Proportionality, Protection, Partnership, Accountability) by allowing this new criteria is going to cause harm to children and young people.

4. Why isn't more funds made available to train up more staff to assess for Autism as it is only a team of three, who work term time only, surely if more trained assessors are available all year round then this will indeed help the waiting lists?

5. Why does a child need to reach crisis point for an assessment?

6. You cannot access support without a diagnosis e.g a specialist school as quite often part of a school intake criteria is a diagnosis is needed.

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#### **4. QUESTIONS FROM HELEN SLOAN**

Before this week we were expecting a 30 month wait for assessment, which is already unacceptable.

We recently received a letter, from the assessment team at Sirona, which mentions a 2 year wait, but goes on to say no estimate can be given as to when she will be seen as she is not a priority.

We have now been told that due to the new referral criteria, she is not a priority. Only children who meet a very high bar for support (those effectively in crisis or unable to communicate) will meet the criteria for new referrals.



The diagnostic criteria hasn't changed, therefore I cannot see how it can be legal to withhold assessment from autistic children!

The mention of a 2 year wait followed by refusal to give a wait time is also confusing and frustrating.

Please can some clarification be given?

Thank you.

**REPLY FROM CHAIR OF HEALTH SCRUTINY COMMITTEE:**

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