



BNSSG 3 PCF Joint Health Survey 2025/26 Summary of findings

The three parent carer forums for Bristol, North Somerset and South Gloucestershire came together in December 2025 to conduct a joint health survey. The three areas are currently covered jointly by one integrated care board; however not all services are available in all areas, and where present they are not all provided to the same degree.

Responses:

551 parent carers of children and young people (CYP) with Special Educational Needs and/or Disabilities in the BNSSG area filled out the health joint survey (149 from Bristol, 85 from North Somerset, and 309 from South Glos). Over half (51%) included free text comments, providing data for qualitative as well as quantitative analysis.

Key findings:

Area 1: Widespread experience of services not being joined up

The qualitative data highlighted that many parent carers face significant challenges due to a lack of coordination, poor communication and siloed working within services and systems (education, health and social care). Some reported being passed between services without receiving adequate support or information; creating a frustrating cycle. Communication failures across different parts of the health system were described as frequent, preventing holistic and timely support for CYP. Many parent carers also describe the administrative and emotional burden of providing coordination and sharing information between systems, services and teams:

“We have been ping-ponged between CAMHS and social services, then between disabled children service and 'mainstream' social services... obstruction, delay, obstruction, delay”

These findings were echoed in the quantitative data: less than 10% of respondents thought that services were well joined up. In contrast, 27% felt that services were not particularly well joined up and 33% felt they were poorly joined



up. In terms of accessing information about services and support available, only 14% found their Local Authority Local offer website helpful.

Area 2: Barriers to Support from Community Services

There was qualitative evidence that some educational settings proactively addressed and supported children's health needs. At the same time, many parent carers reported facing significant barriers to receiving community health services including long waiting lists and restrictive eligibility for essential services such as Occupational Therapy, Speech and Language Therapy, Physiotherapy and Child and Adolescent Mental Health Services (CAMHS). Some community health services were perceived to be operating around standardised pathways, rather than actively responding CYP's needs so that the right help was not received at the right time:

"Speech therapy was not good. Therapist was excellent but only had 4 x 10 minute sessions then back on the waiting list. Nothing was achieved"

In addition, waiting lists for assessment services (in particular for ADHD and Autism) were perceived to be excessively long with confusing pathways and little to no support available while waiting. Long waiting times and inadequate provision led some to turn to private care.

Area 3: Children and Young People's unmet and escalating Mental Health needs

There was evidence of a perception of significant unmet mental health need among CYP. While 36% of respondents stated that their child had Social Emotional and/or Mental Health (SEMH) difficulties, the qualitative data demonstrated many concerns about a lack of support for CYP in this area. Limited awareness of and/or access to early intervention services like Mental Health Support Teams (MHST) and school nurses was reported.

Many parent carers whose children struggled with SEMH difficulties described how, in their experience, CAMHS typically accepts referrals only in crisis situations, leaving parent carers unsure where to go for support when needs fall below CAMHS thresholds. This resulted in inadequate support for those with moderate needs, or an escalation of need due a lack of timely intervention:

"CAMHS have been good...The support has helped but if and when she is signed off she will feel abandoned. CAMHS is for crisis only but my daughter needs ongoing support"

While some respondents had positive experiences with CAMHS, others highlighted shortcomings. Overall, the system response to mental health need is perceived as failing to address mental health issues effectively, sometimes leading to reactive intervention only during significant crises.



Area 4: Accessing private healthcare

The use of private healthcare was widespread: 37% of respondents reported having accessed it to meet their child's health needs. Of those who had used private healthcare, the key reasons cited were that NHS waiting lists were too long (65%) or that quality was higher (33%). Qualitative analysis echoed this, with parents reporting frustration with long NHS waiting lists, or stating that NHS provision was unsuitable for their children's complex needs:

"We've had no choice but to seek private help despite the cost and lengthy journeys. Our GP said we'd get no support otherwise. He was right"

The financial burden of private care strains household budgets and is not accessible to all, resulting in unequal access to essential support and widening existing health inequalities.

Additionally, parent carers reported challenges with private or Right to Choose (RtC) assessments were not always readily accepted by GPs or local children's community health services, leading to confusion and delays in care - particularly regarding ADHD medication prescription and monitoring. In addition, while some parent carers reported Local Authorities using private health reports to support the ECHP process, others reported barriers or a refusal to incorporate them.

Area 5: Health Professional Communication and Engagement with CYP and Parent Carers

The responses from parent carers highlight the critical need for clear, compassionate communication between health professionals and CYP and parent carers. While many parents reported positive interactions with various individuals, systemic failures were frequent and noted to hinder timely and effective care:

"individuals are generally absolutely lovely, warm, caring people but systematic issues create blocks"

Some parent carers reported poor experiences, with professionals failing to engage CYP directly, meaningfully involve them in discussions about their own care, understand their unique needs. Overall, while experiences with health professionals can be concluded to be inconsistent, parent carer reports about GPs were broadly negative. Many reported a lack of GP knowledge about SEND needs, the SEND system (including RtC pathways) and/or dismissive attitudes. As most common first entry point into the health system, improving GP understanding and communication is essential for delivering timely, effective care for children and enhancing parent carer trust in the health system.

Area 6: SEND Rights and Entitlements

The Annual Learning Disabilities (LD) Health Check and GP LD registers are designed to help reduce significant health inequalities that exist for people with LD. Knowledge of



the Annual LD Health Check was fairly low. Of those respondents who felt their CYP could be eligible (having a CYP aged over 14 years with a LD) 38% of respondents did not know about it and only 21% reported that their young person now receives it. The qualitative data indicated that there was confusion around eligibility for and access to the Annual LD Health check along with a lack of clarity about GP LD registers:

“GP thought we'd need a LD diagnosis which isn't true. Lack of awareness”

In terms of EHCPs, 48% of respondents reported their CYP had an EHCP. Many parent carers reported a lack of engagement in the EHCP process from health services, or inadequate reports that appeared to be based on available resources rather than individual children's needs. This led some to seek private assessments to ensure the provision detailed in their child's EHCP was accurate and appropriate.

Based on the BNSSG 3PCF joint health survey, what key problems could the CCHS contract respond to?

1. Shift to meaningful needs-led support:

Many parent carers do not experience health services as being led by the needs of their CYP. Support should be flexible and holistic: the right support at the right time based upon need of the child, not the offer or design of the service.

2. Strengthen Mental Health Pathway

CYP's mental health needs are not met by current commissioning arrangements, ranging from early support to more significant mental health intervention.

3. Commission for integrated, joined up working and improved system navigation

Navigating the system(s) is highly complex. Communication between services and effective joined up working is experienced by most parent carers as poor. Many describe having to take on a system navigator role to compensate for this, which impacts on parent carer wellbeing and time.

4. Increase awareness of the Learning Disability Register and Annual Health Checks with parent carers and GPs

The Learning Disability Health Check was not known about by a large proportion of respondents whose CYP may be eligible. Many parent carers also reported little to no GP awareness of the check and confusion about eligibility for the LD Register.

5. Reduce access barriers including waiting times for services

Barriers to accessing health services are significant. These include very long waiting lists for services and assessments. The resulting reliance on private



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healthcare highlights system pressures and contributes to inequitable access to appropriate support.

6. Move from reactive to proactive models of care

Many parent carers experience support as reactive rather than proactive. Early identification of and adequate support for CYP's holistic needs is likely to have positive repercussions across the life course of the CYP.

7. Set clear standards for communication and experience

Direct communication with CYP and parent carers is inconsistent. Some parent carers describe very positive interactions with and knowledge of professionals, while others report dismissive attitudes and engaging in a way which is not child friendly.