



Support with Healthcare for Children and Young People with Special Educational Needs and Disabilities (SEND)

March 2026

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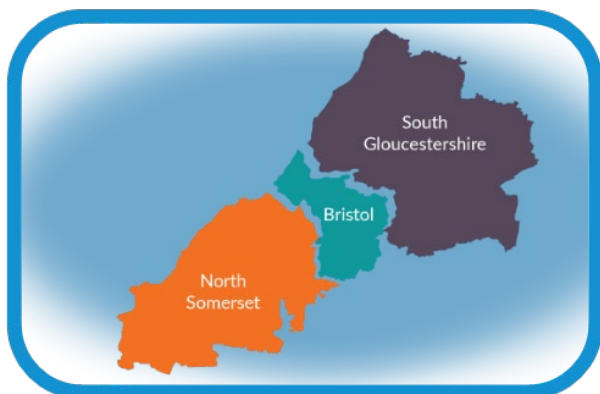
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Introduction

Navigating health services for a child with special educational needs or disabilities (SEND) can be challenging. Their individual needs may make it harder to access healthcare, and they may experience more than one health condition at the same time, leading to more complex needs.

The three Parent Carer Forums across **Bristol, North Somerset and South Gloucestershire** work together as **BNSSG** to ensure the collective voice of SEND parent carers is clearly heard, understood and acted upon locally, regionally and at a national level.

Because these three areas are served by a single **Integrated Care Board (ICB)**, working collaboratively allows the forums to represent families more effectively, share common priorities, and influence decisions that affect children and young people with SEND across the whole BNSSG area. Therefore, the three parent carer forums have come together to conduct a joint survey on issues relating to accessing and provision of health care for SEND children and young people.



Thank You

Parent carer feedback is invaluable and enables BNSSG Parent Carer forums to work effectively with providers to ensure services meet the needs of local families.

We would like to thank the 551 parent carers who responded to this survey.

The survey ran from **1 December 2025 to 18 January 2026**. It was promoted via **email, social media and forum newsletters**, and shared with **healthcare and education professionals** to widen its reach.



**Working together
for SEND families**

Executive Summary



There is no “H” in our EHCP”

Background

The three Parent Carer Forums (PCFs) for Bristol, North Somerset and South Gloucestershire represent the voices of parent carers and work with service providers to ensure SEND provision reflects families’ needs. In December 2025, the forums collaborated on a healthcare survey to gather parent carers’ views and lived experiences of local health services, enabling these perspectives to be represented collectively by the PCFs.

Not all services are available in all areas, and where present they are not all provided to the same degree. This context should be considered as being likely to play a role in the survey responses, and parents carer experiences of health services across the ICB area. Further details of service provision are given in Appendix Two.

This is the first time the three forums have collaborated on a health survey. Bristol and North Somerset previously included health questions in their general annual surveys, and South Glos conducted a health survey roughly every two years.

Methodology

The survey was promoted by all three parent carer forums to their parent carer communities, through social media posts, newsletters and emails. Links to the survey were also given to relevant VCSEs, healthcare and educational professionals for sharing with their communities. (see Appendix Three for further details).

Responses were then analysed both quantitatively and qualitatively. (Further details of the qualitative methodology are given in Appendix Four).

Responses

The survey ran from 1st December 2025 to 18th January 2026.

551 parent carers of SEND children and young people in the BNSSG area filled out the survey (149 from Bristol, 85 from North Somerset, and 309 from South Gloucestershire; a further 8 lived elsewhere but were answering about a CYP living or attending an educational setting in one of these areas).

Over half (51%) included comments, giving data for qualitative as well as quantitative analysis. 48% of responses were about a child or young person with an EHCP. 48% of responses were about a child or young person with an EHCP, with 20% attending a specialist school.

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



It feels like the system is set up to fail our kids when they need help the most.”





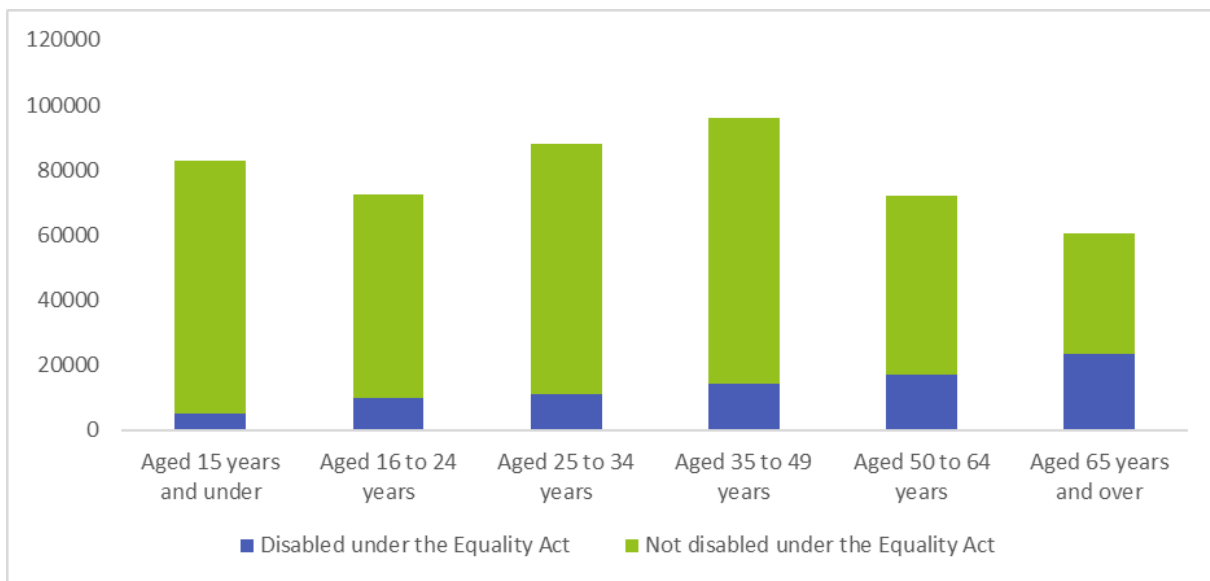
BNSSG Local Context

Not all services are available in the same way in all areas, and where present they are not all provided to the same degree. Community health service providers are outlined more fully in Appendix Two.

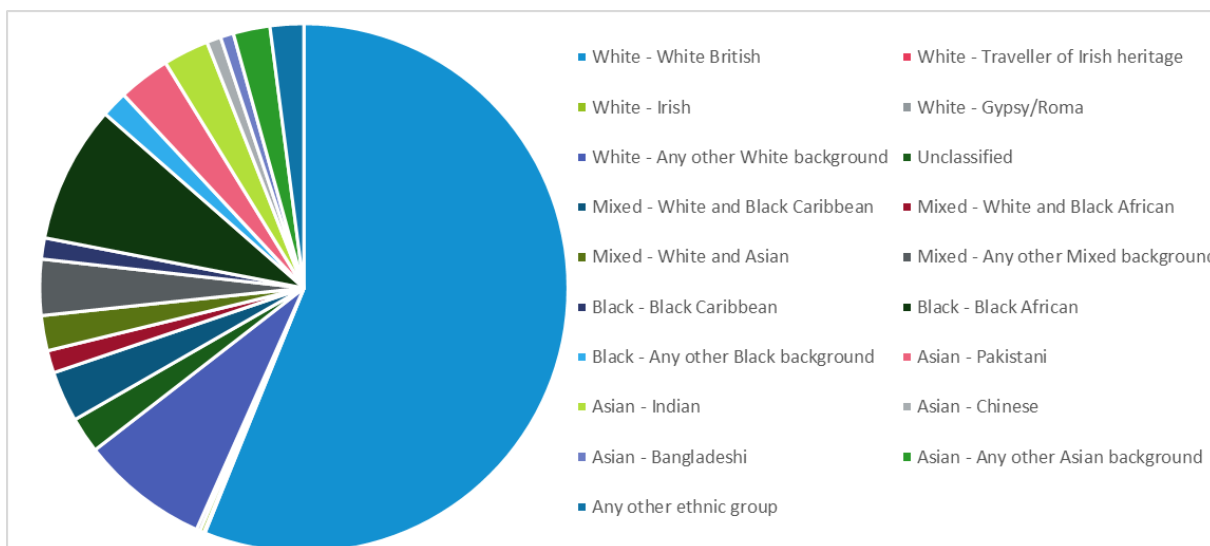
This section provides demographic context to support interpretation of the survey findings. The data presented is drawn from publicly available Government Census, Department for Education statistical services and local authority sources.

Bristol

Bristol is the largest city in South West England. At the 2021 Census, the City of Bristol had a population of 472,000, including 155,000 people under the age of 25. Of these, 15,000 were registered as disabled under the Equality Act 2010.



Of children on roll as pupils at state-funded Bristol settings, 56% are White British, and 73% speak English as their first language. 30% of pupils are eligible for free school meals.





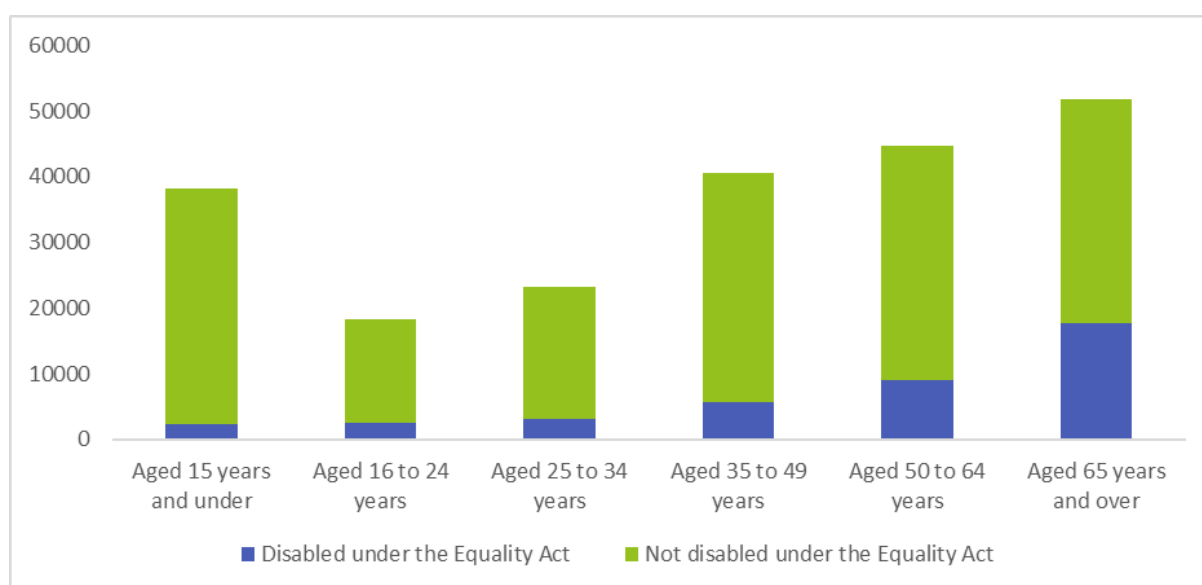
Bristol has the highest proportion of children on free school meals, as well as the greatest level of ethnic diversity. It also has the youngest population of the three areas.

Bristol Parent Carers are a Bristol-based charity run by parents carers of children and young people with special educational needs and disabilities (SEND).

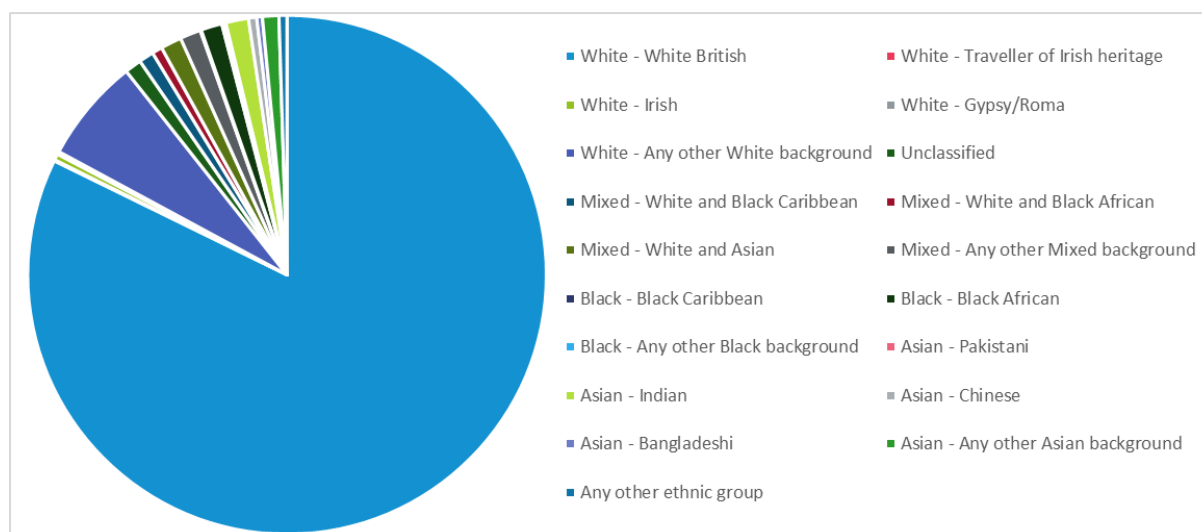
North Somerset

North Somerset is a mixed but predominantly rural area, with four main towns, three of which are coastal. Of the 135 neighbourhoods in North Somerset, 16 were in the 20% most income deprived in England. By contrast, 39 neighbourhoods were in the 20% least income deprived. High levels of income deprivation are concentrated in Weston-Super-Mare, the largest town (ONS, 2021).

At the 2021 Census, North Somerset had a population of 217,000, including 56,000 people under the age of 25, of whom 5,000 were registered as disabled under the Equality Act 2010.



Of children on roll at North Somerset state-funded settings, 82% are White British, and 90% speak English as their first language. 17% of pupils are eligible for free school meals.



North Somerset is the oldest area demographically.

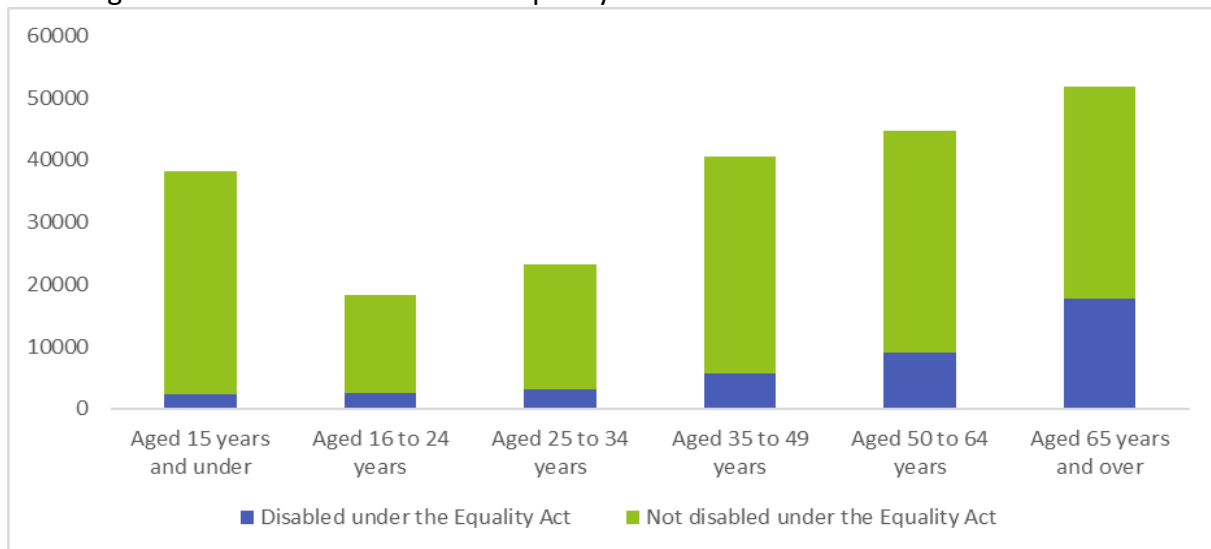




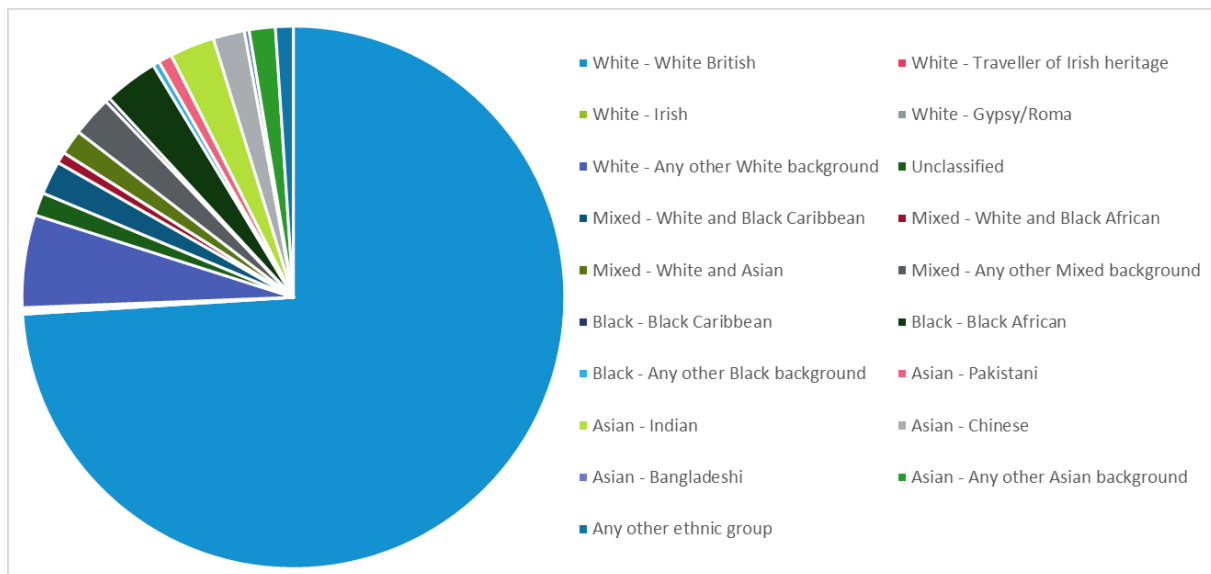
North Somerset Parent Carers Working Together are the parent carer forum for parents and carers in North Somerset.

South Gloucestershire

Like North Somerset, South Gloucestershire is a mixed area, including towns, rural parishes and extensive suburbs on the outskirts of Bristol. At the 2021 Census, South Gloucestershire had a population of 290,000, including 84,000 people under the age of 25, of whom 7,500 were registered as disabled under the Equality Act 2010.



Of children on roll at South Gloucestershire state-funded settings, 74% are White British, and 85% speak English as their first language. 16% of pupils are eligible for free school meals.



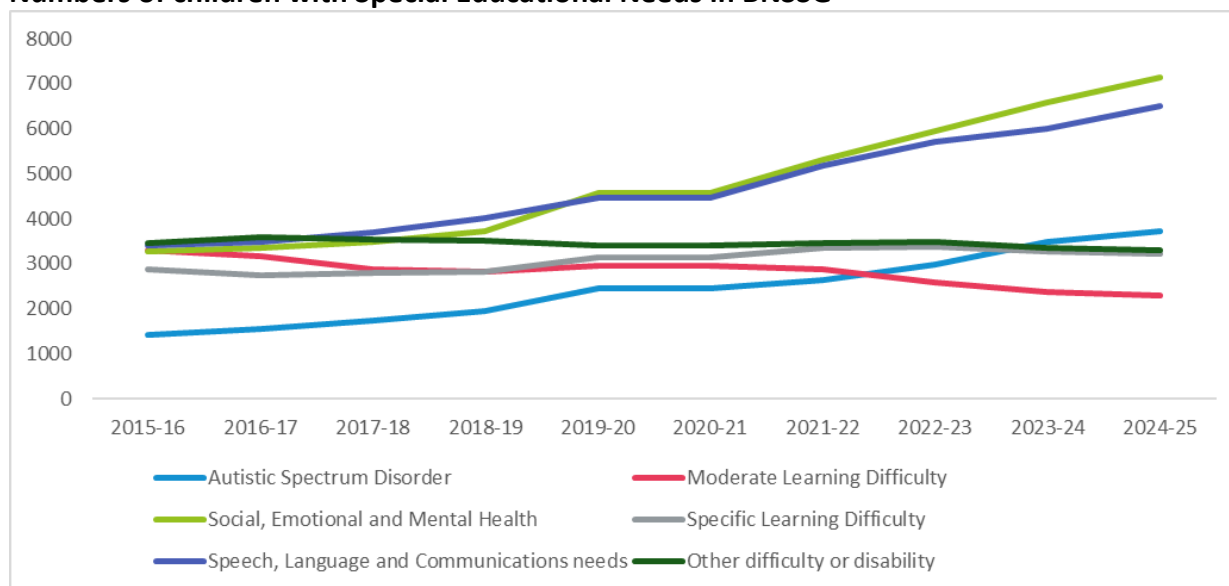
South Glos Parent Carers (SGPC) represent and support parent carers of children and young people (aged 0-25) with special educational needs and disabilities in South Gloucestershire.



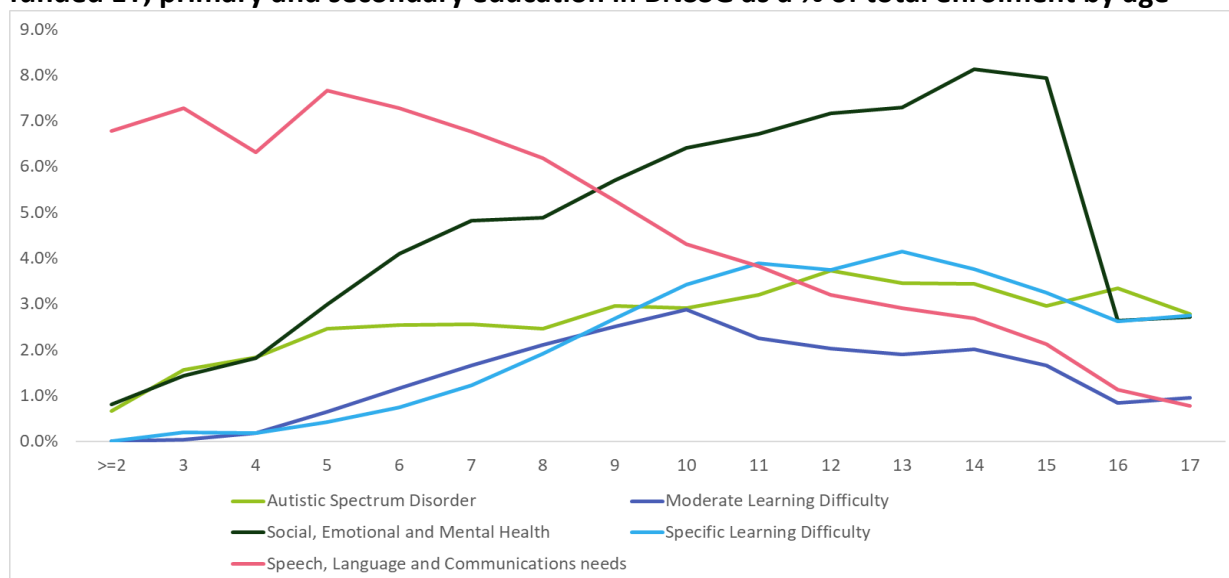
Special Educational Needs and Disabilities in BNSSG

Over the last ten years, numbers of children receiving SEND support or with EHCPs in the three areas has risen. This has been driven by a rise in the numbers receiving support for social, emotional and mental health issues (SEMH); speech, language and communication needs; and Autistic Spectrum Disorder (ASD). Over the same period, the number of children receiving support for moderate learning difficulties has declined. This reflects trends at national level.

Numbers of children with Special Educational Needs in BNSSG*



Primary needs of children and young people with EHCPs or formal SEN support in state-funded EY, primary and secondary education in BNSSG as a % of total enrolment by age*



5% of pupils attending state-funded schools in the area have an EHCP, with 1.75% attending special schools.

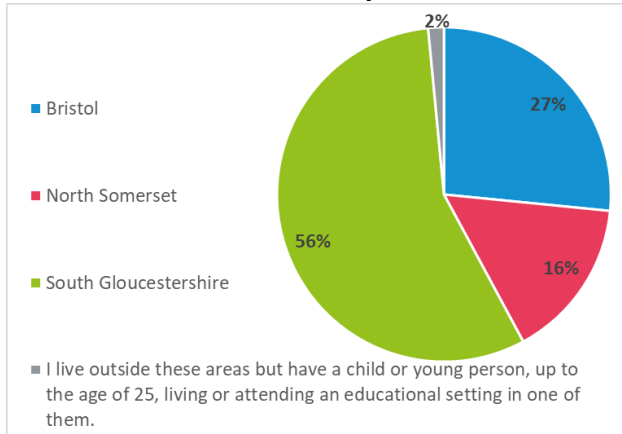
* taken from statistics published by the Department for Education, 12th June 2025. Figures are for children and young people with EHCPs or SEN support on roll at state funded nurseries, primary and secondary schools. They do not include CYP in privately funded education or home educated.



Survey Responses: Quantitative Analysis

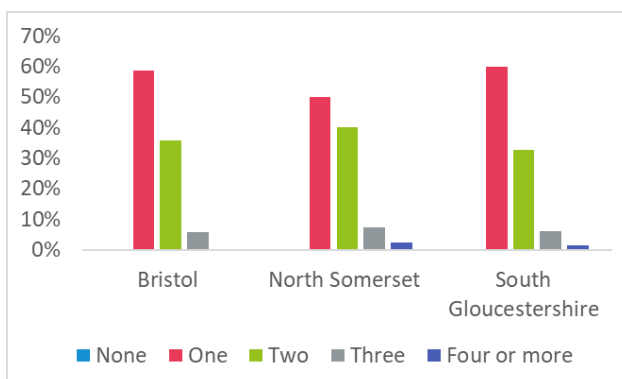
Respondents' Demographics

Please confirm which area you live in.

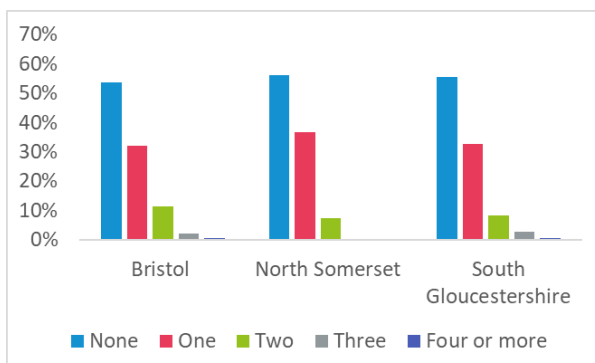


How many children and young people up to the age of 25 WITH and WITHOUT special educational needs or disabilities (diagnosed or undiagnosed) do you have in your household (or support, if they are living away)?

Number of CYP with SEND



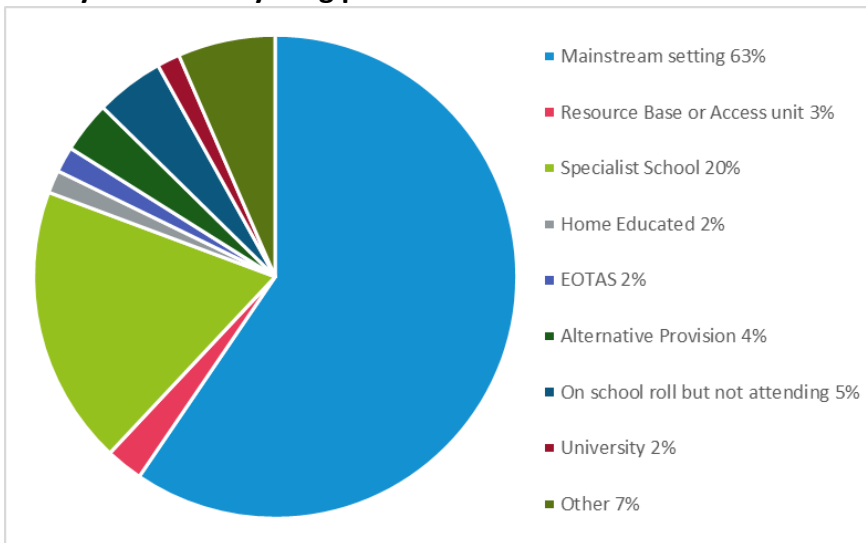
Number of CYP without SEND



These first questions were linked to a filter, to ensure that subsequent questions were only answered by parent carers of children and young people living or studying in the three areas.

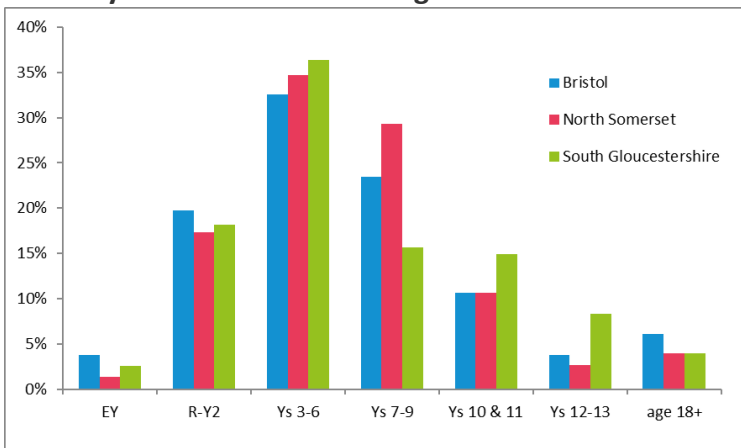


Does your child or young person attend?



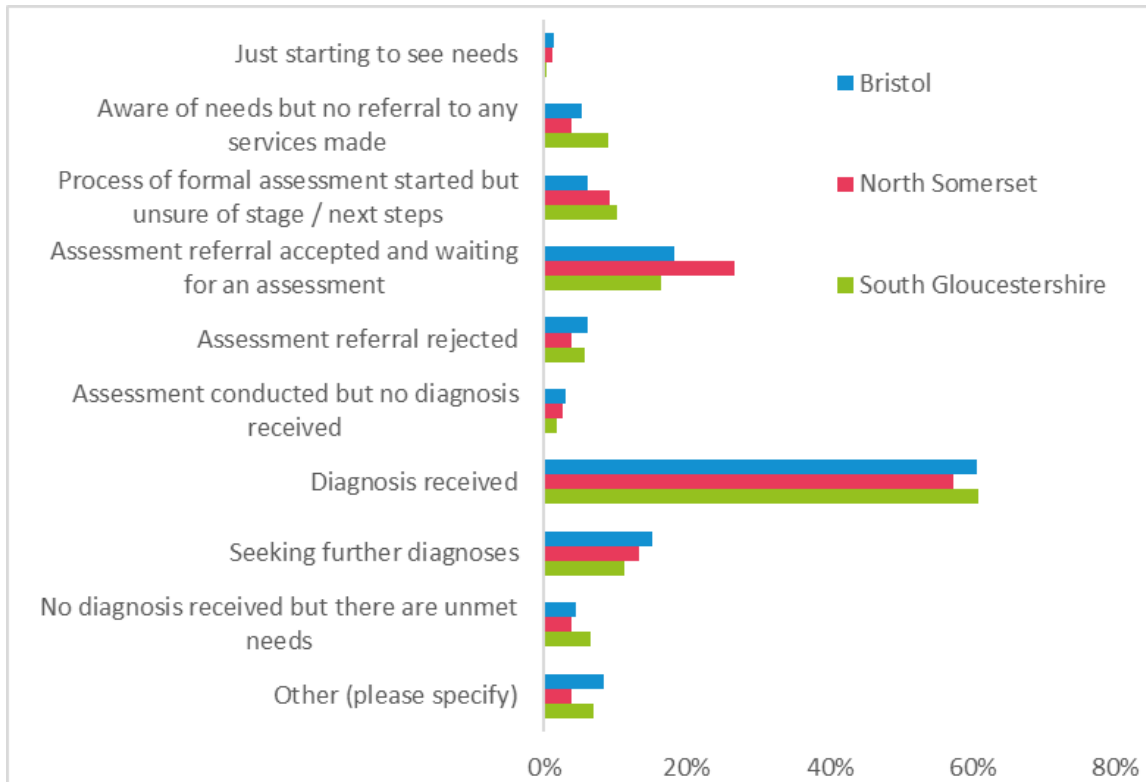
Other includes: Out of county setting; apprenticeship; internship; employment; NEET.

What year group is your child or young person attending at their setting? or would be in if they do not attend a setting.



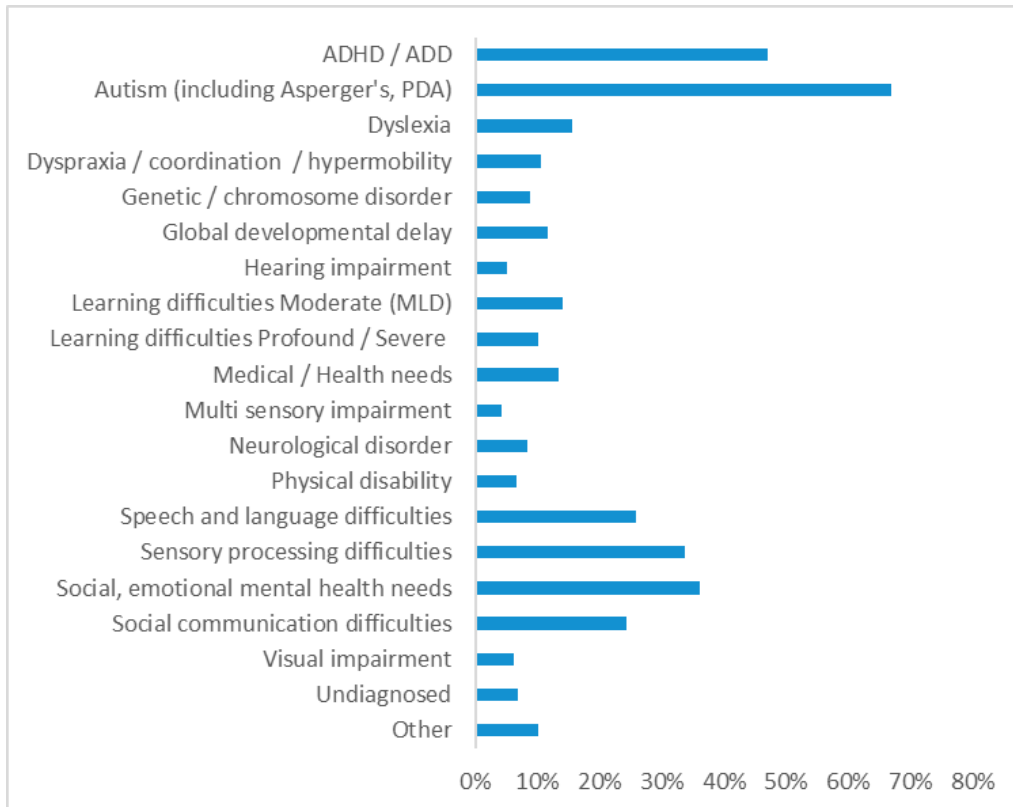
Responses were predominantly about school age children. 20% of the children attend special schools.

At what stage are you with identifying your child or young person's needs? If there is more than one diagnosis, please tick all that apply



Other: mostly expanding on answers ticked above, but also six Diagnosed at birth.

What are your child's additional needs / disability? Please tick all that apply

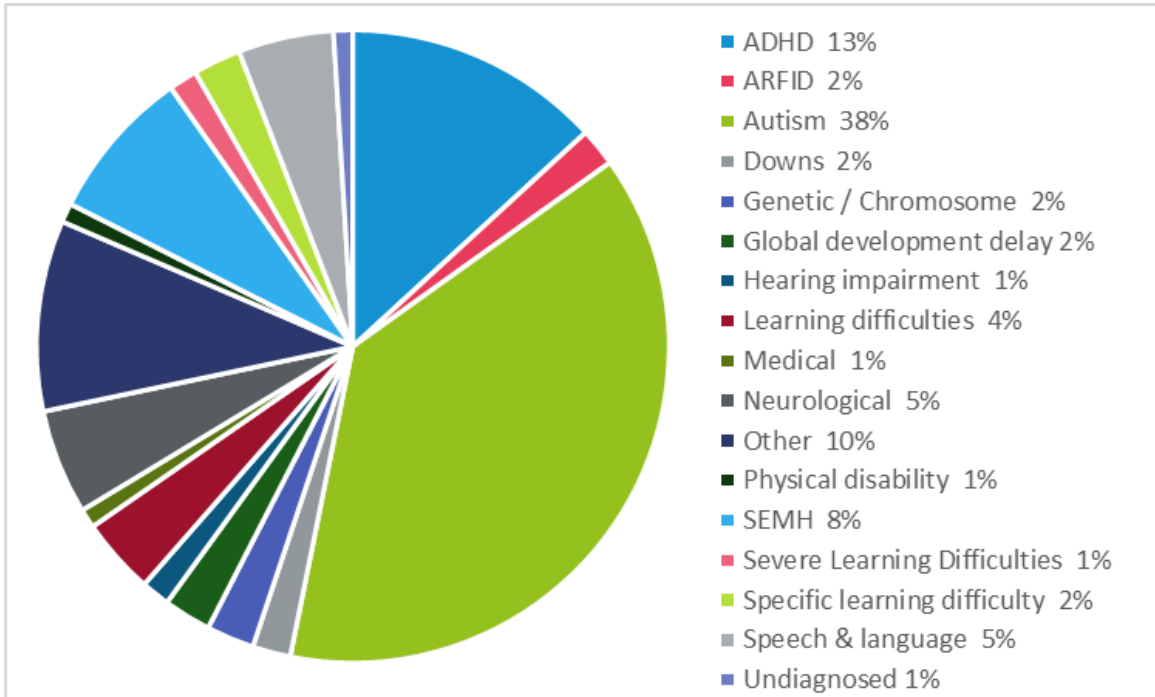


Other includes: multi-sensory impairment; ME; FASD; eating disorders; diabetes.

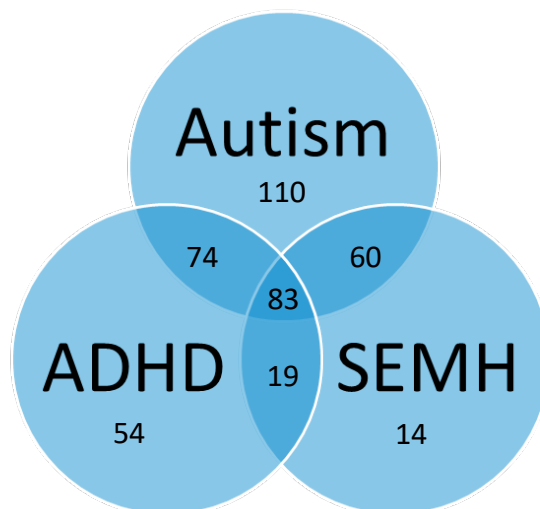
394 respondents reported more than one area of need.

We also asked respondents:

Which of these would you say was your child's primary need?



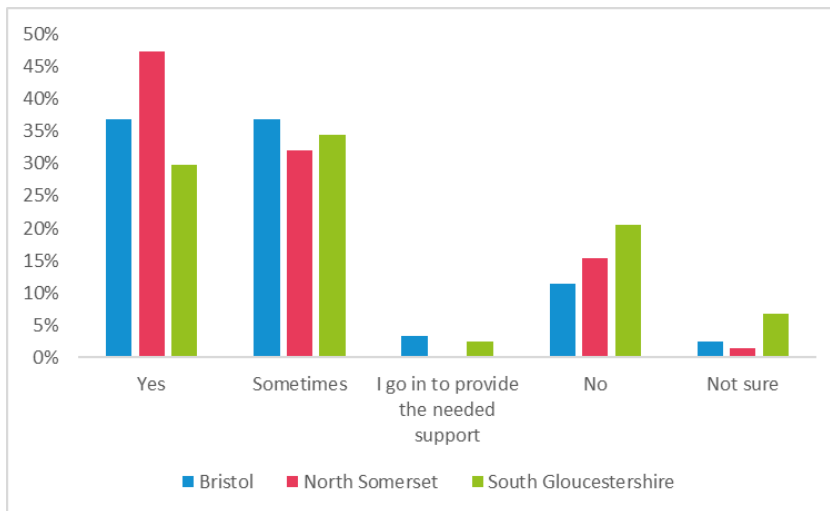
Where both autism and ADHD were reported, SEMH was also present more often than not. Most respondents who reported SEMH also reported additional needs: all but 14 reported autism, ADHD, or both, and only one reported SEMH with no other co-occurring needs.



Co-morbidities between ASD, ADHD and SEMH

Support

Is your child or young person's Setting able to support their health needs?

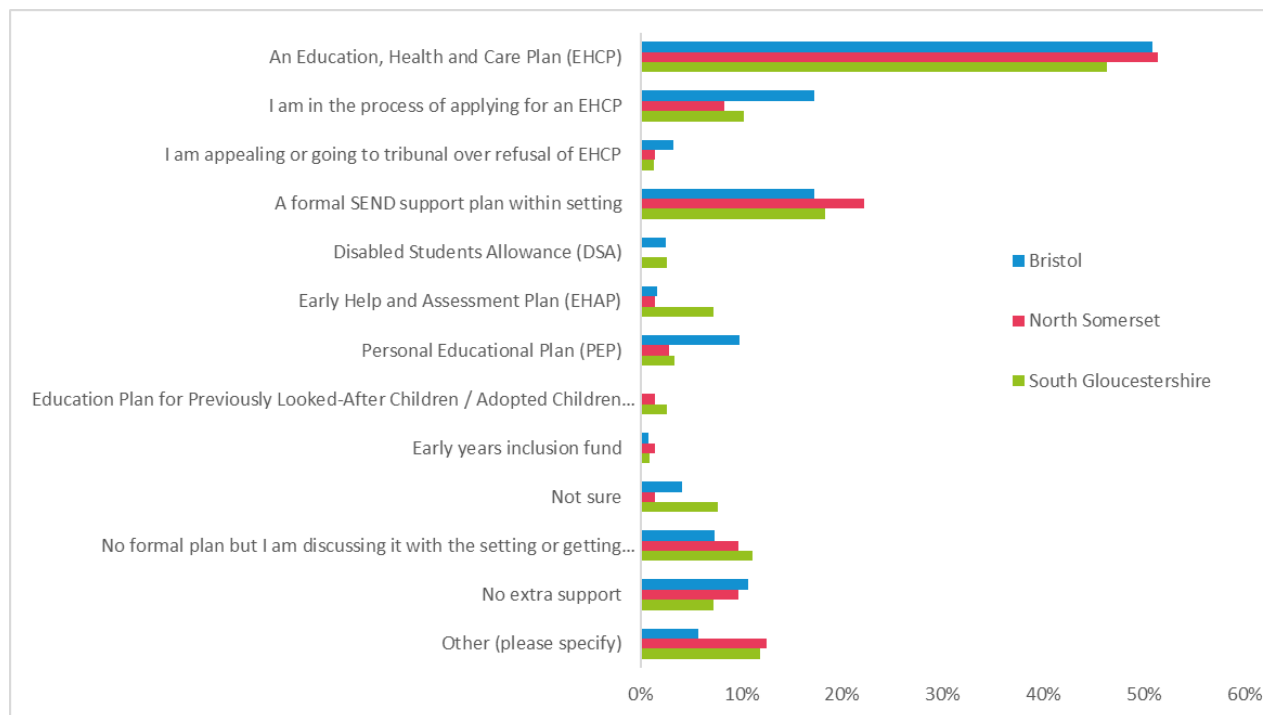


Overall, 2% of respondents reported going into a setting to provide support, with 34% saying the setting was able to support their CYPs health needs, 35% saying they could do so sometimes, and 17% saying the setting could not support their CYP's health needs.

“Mainstream school unable to assist with toileting needs and so I am required to go into school to change him”

“Yes, but physio at school is an ongoing issue”

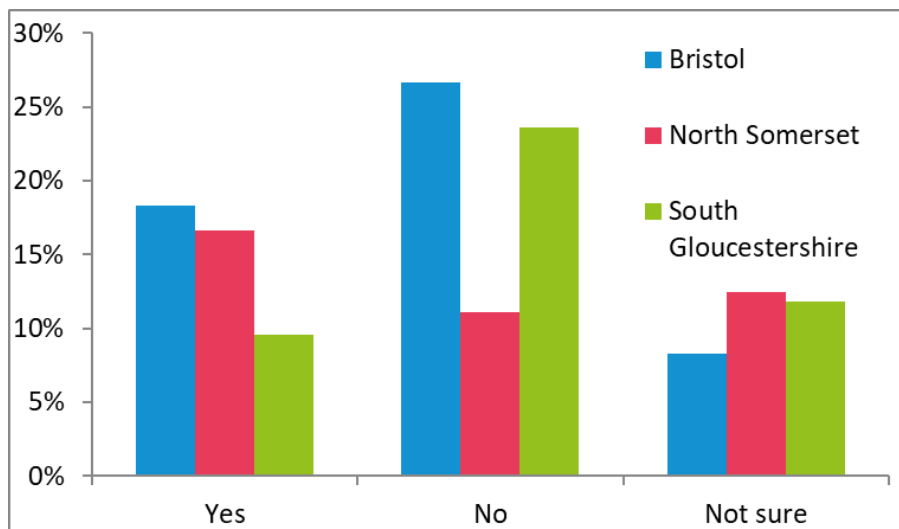
What support does your child or young person have? Please tick all that apply



Other includes: Expanding on answers given above; Care Act assessment; considering EHCP; hospital education; school passport; extra time for exams; CBT; support plan not followed.

Overall, 48% of respondents reported having an EHCP, with a further 19% having a formal SEND support plan (Graduated Response, etc).

If your child or young person has an EHCP, does it cover medical needs?

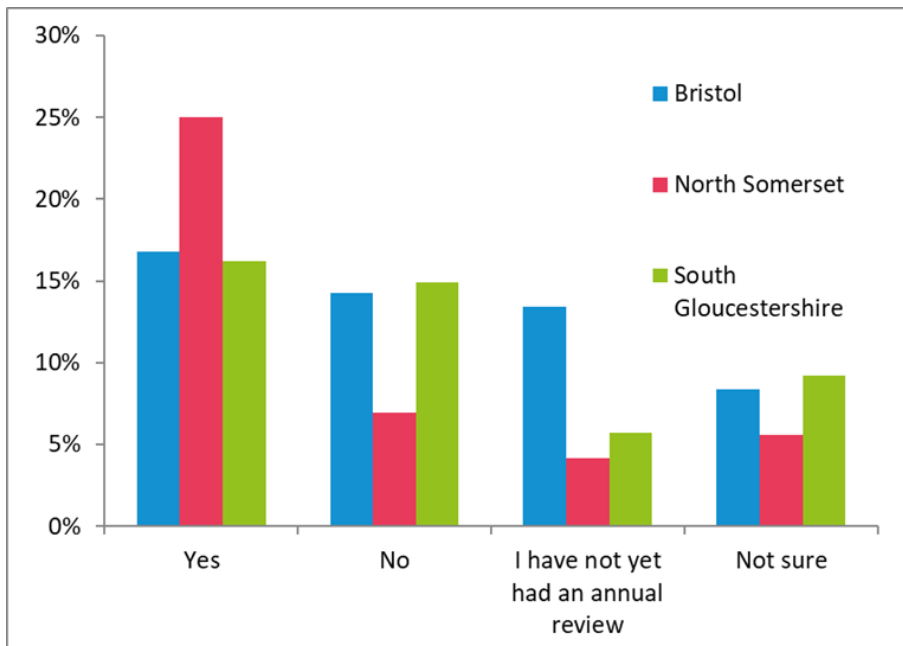


Is there anything you would like to tell us about the health element of your child's EHCP?

“It was a massive fight to get her health needs included”

“It covers health needs to a small degree - whilst in a school setting. But it is fundamentally an “E” plan and health section is scant in detail”

If your child or young person has an EHCP, are health concerns included at the EHCP annual review?



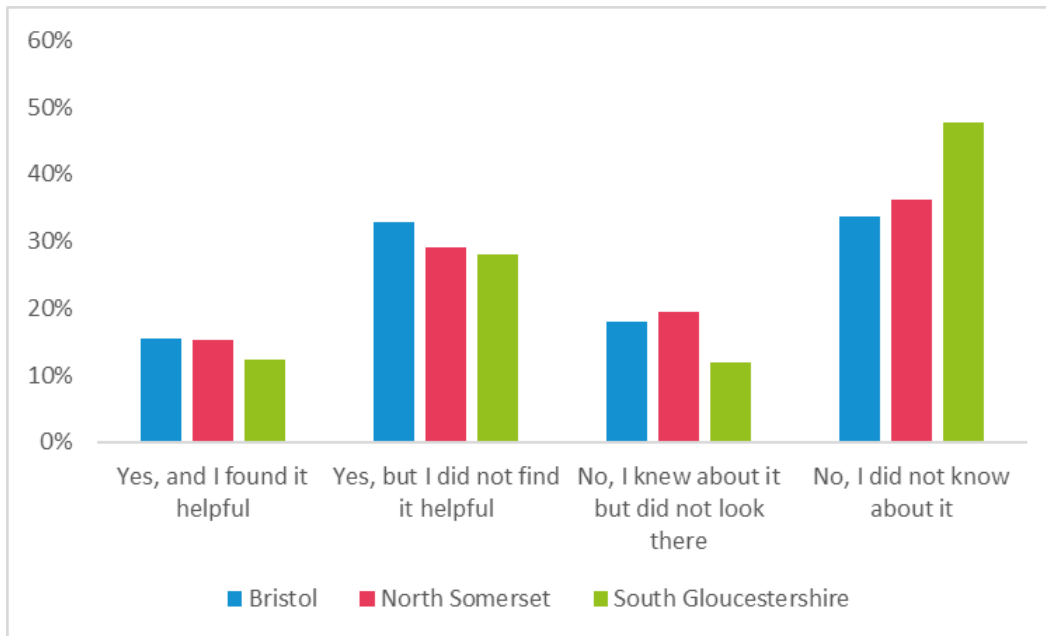
Is there anything health related you would like to tell us about EHCP annual reviews?

Input for health is usually provided by parents as health professionals do not engage in EHCP process once it is initially set up”

“None of her health professionals were consulted for the review. It was only teachers that contributed”

Local Offer

Have you looked at your local authority SEND Local Offer website for information about support with health issues?



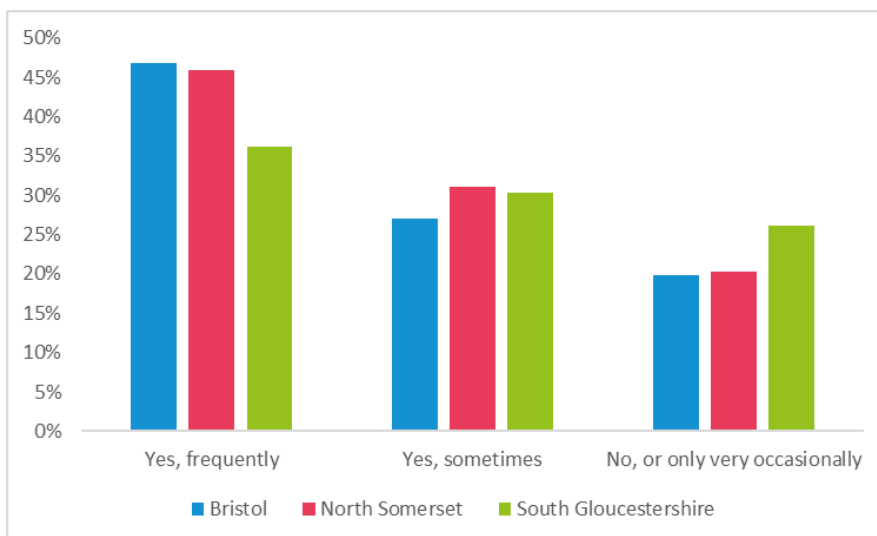
Overall, 42% of respondents reported that they did not know about the Local Offer. 14% found it helpful, 30% did not find it helpful, and 15% knew about it but did not look there.

Access to Local Facilities

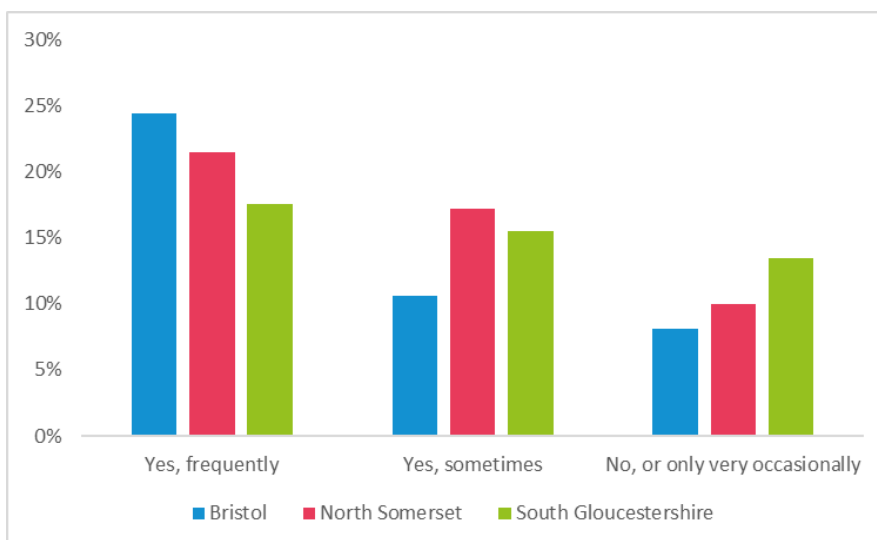
Health issues can affect families' ability to access local facilities, ranging from parks and shops to health services such as hospitals. We asked families to what extent their CYP's health issues affected this. Overall, 49% reported that their ability to access social clubs and activities was frequently affected by their CYP's health, with 41% reporting that access to school was frequently affected. 17% reported difficulties accessing hospitals.

Have your child or young person's health needs affected their ability to access?

School or work?

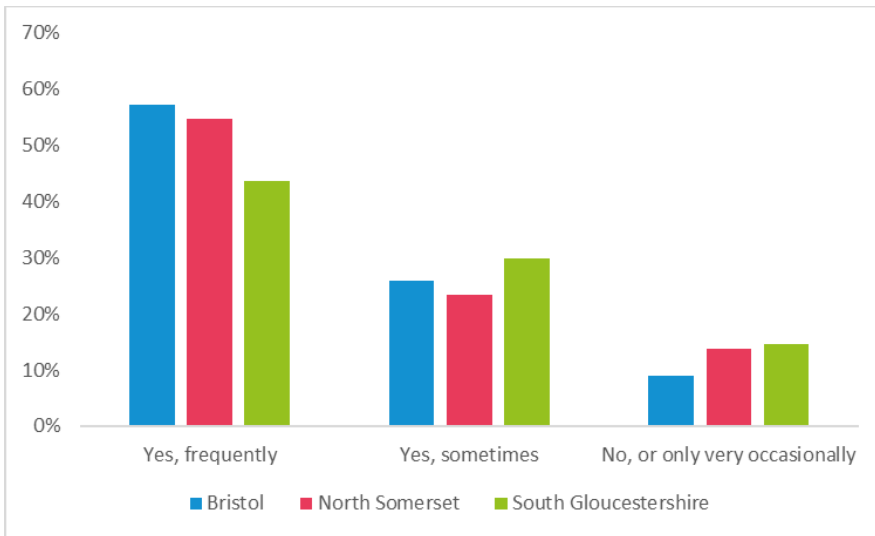


Short Breaks / Respite Care?

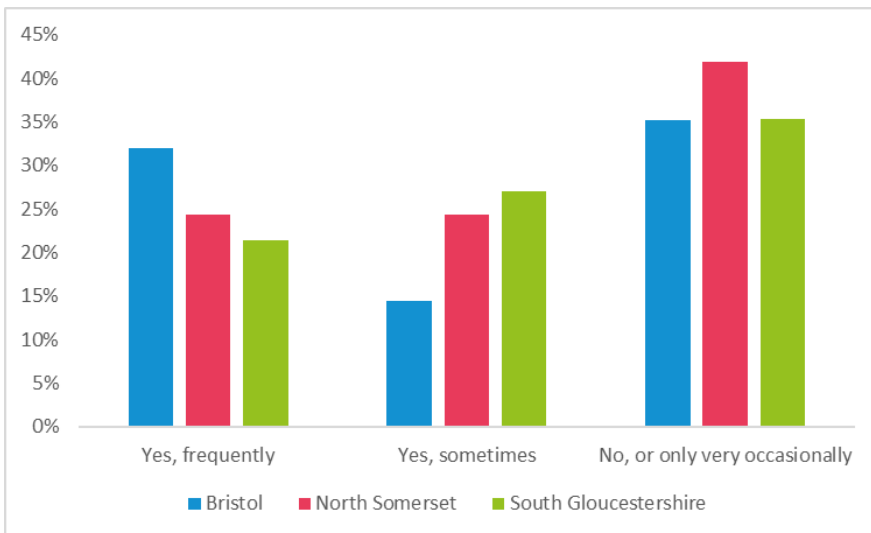


“After school clubs cannot meet need – my child needs an adult to interpret in noisy environments”

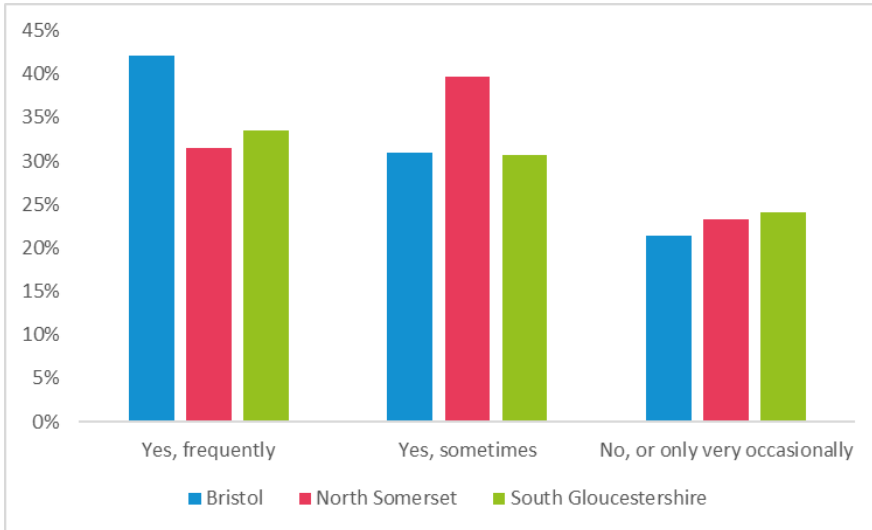
Social Clubs and Activities



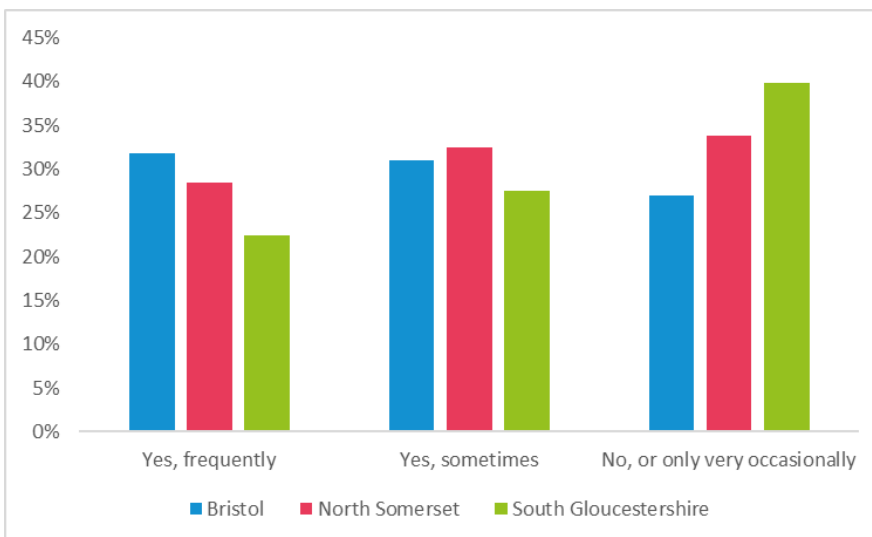
School trips



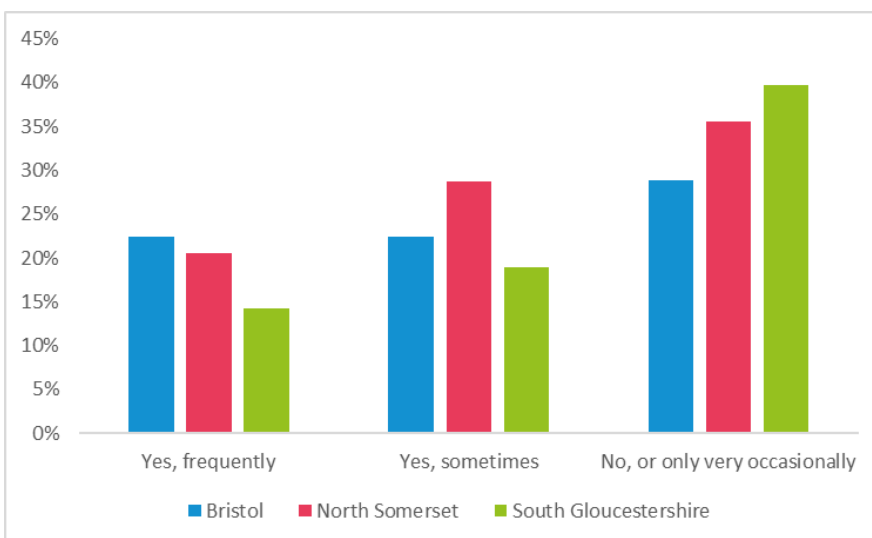
Community facilities (shops, parks etc)




Community health services (GP, dentist etc)



Hospitals



 *Even in hospital they often aren't equipped for a non-mobile child, for example having beds without sides on when she is having investigations”*

“Hardly any part of the medical system is fully accessible for those with SLD and extremely complex medical needs”

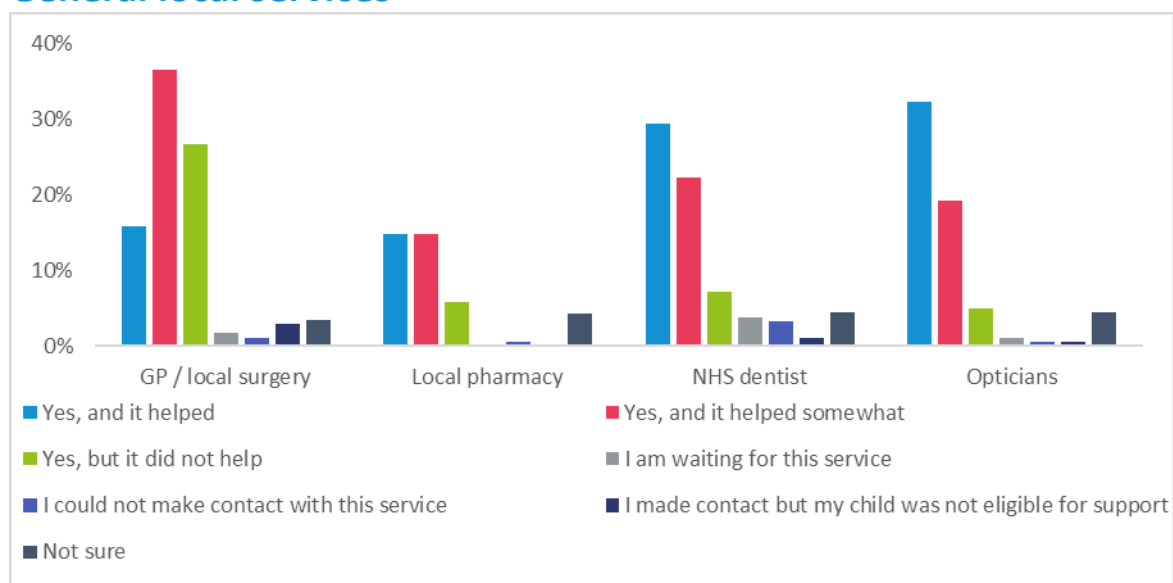
“A&E can be dismissive due to her severe LD”

Experiences with Healthcare Services

We then asked about families' experiences with a wide range of healthcare services – parent carer's perceptions of how easy they were to access, and how effective if used.

On behalf of your child or young person, have you used or tried to use the following services within the last two years?

General local services



Thinking about the local services you have used or tried to use, can you tell us what worked well and what aspects could be improved?

“A complete lottery whether we get a GP who understands autism”

“We have a very amazing GP - she always sees us relating to my child so there is continuity of care”

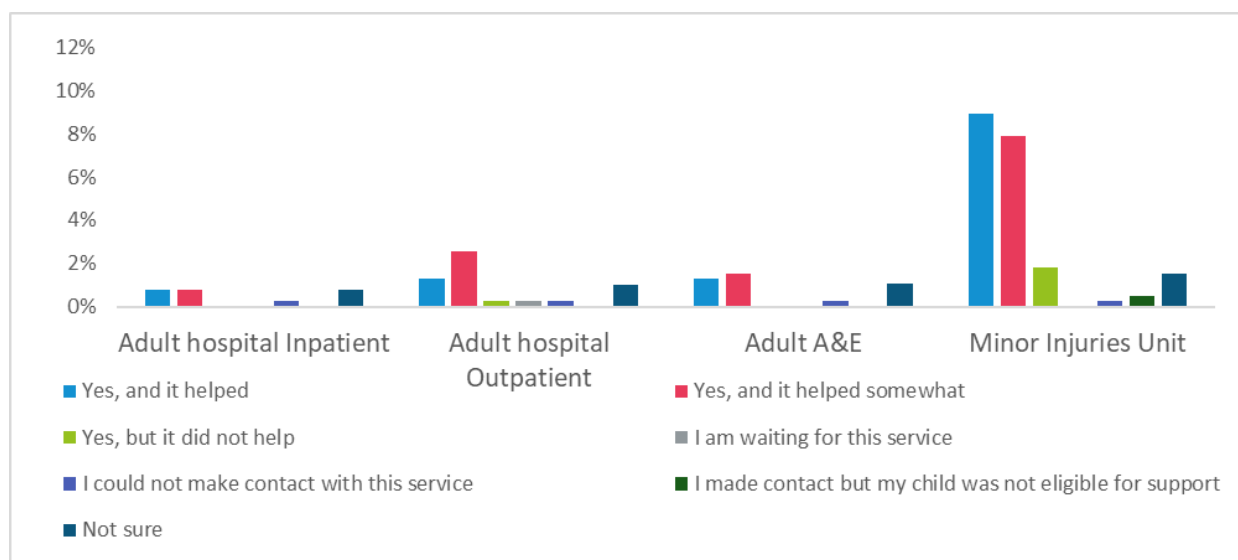
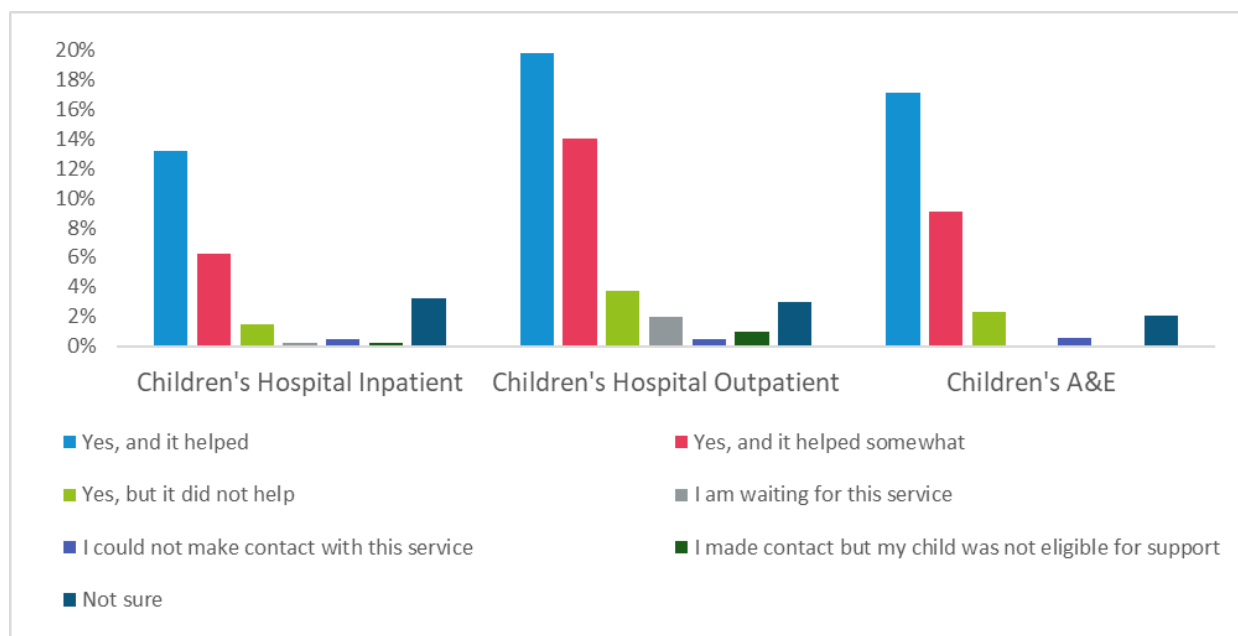
“I don't think my daughter will ever trust a GP to help her again”

“Having a pre-appointment questionnaire, or just information saved on their system, which has clearly been read by the professional, is the most helpful”

“Booking a GP appointment has become increasingly difficult with the introduction of online systems which have been proving difficult to set up and navigate. Does not help that the booking system closes at 4:30 when parents are still working - availability in the evening when parents are able to support would be very helpful”

“More training in how to speak to, and interact with, neurodiverse children - and how to better understand their needs (and why such settings can be very frightening and overwhelming)”

Hospital Services



Thinking about hospital services you have used or tried to use, can you tell us what worked well and what aspects could be improved?

I can't sing the praises of the Children's hospital nurses enough. The ones who we've encountered have been amazing”

"I wore my 'hidden disabilities' and 'sunflower' lanyards but no-one took any notice of these"

"Clear information from professionals about what to expect so son fully prepared"

"Doctors and nurses were amazing once we got to see them"

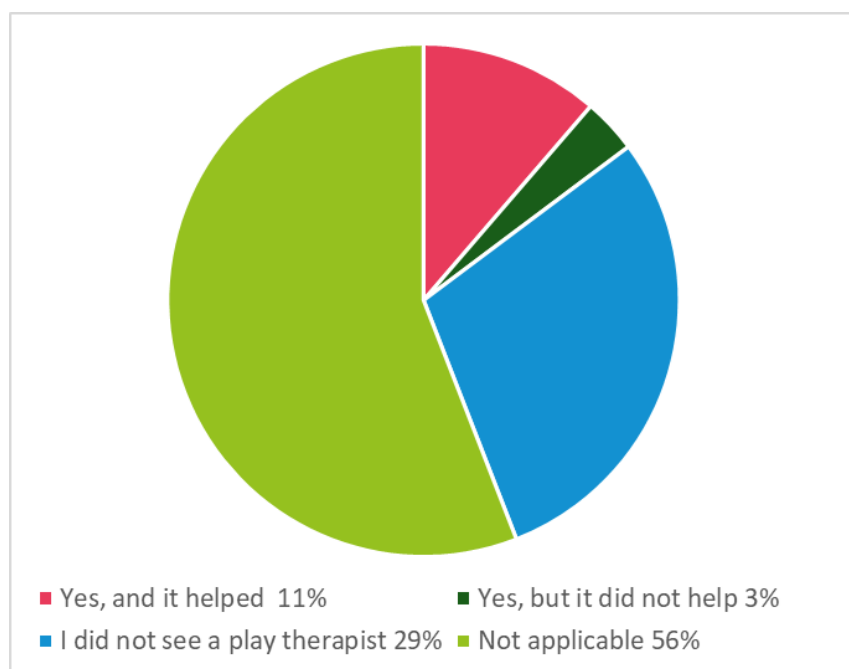
Additional specific questions about hospital services.

Have you used hospital transport services?

Seven respondents had experience of hospital transport services, of whom one had requested but not received help with transport, one had had problems with transport, and five reported it working well.

 *Community transport was very helpful after PTS fell through"*

Have you come across hospital play therapists?



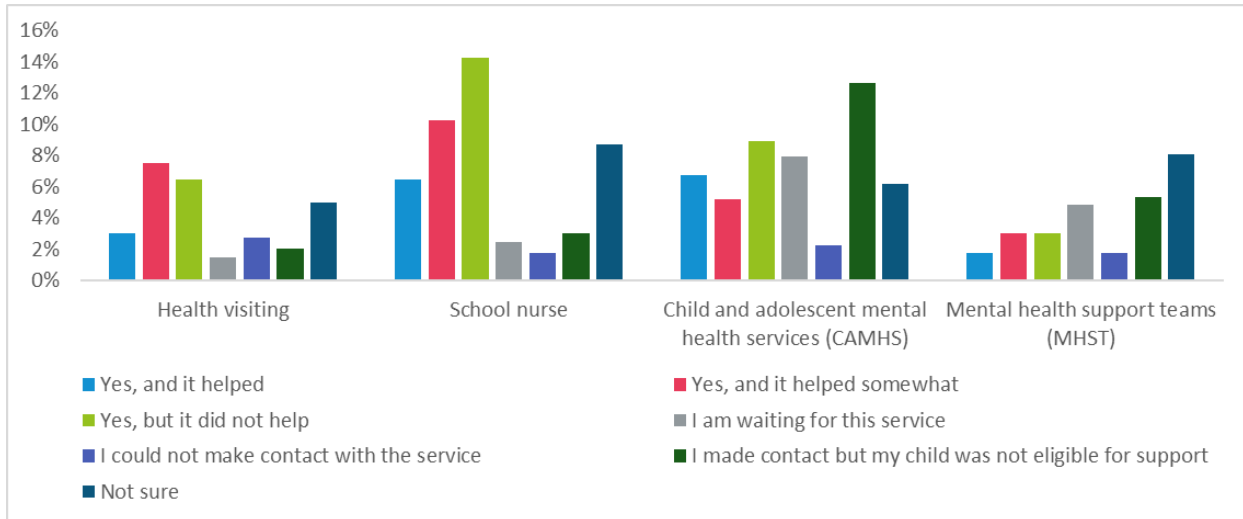
 *Amazing service once you know about it"*

"There were activities! Lego! The therapist really found out all about his interests before we went in. She was amazing!"

"This was absolutely fantastic when my son had surgery. They calmed him down and entertained him whilst he waited"

On behalf of your child or young person, have you used or tried to use the following services within the last two years?

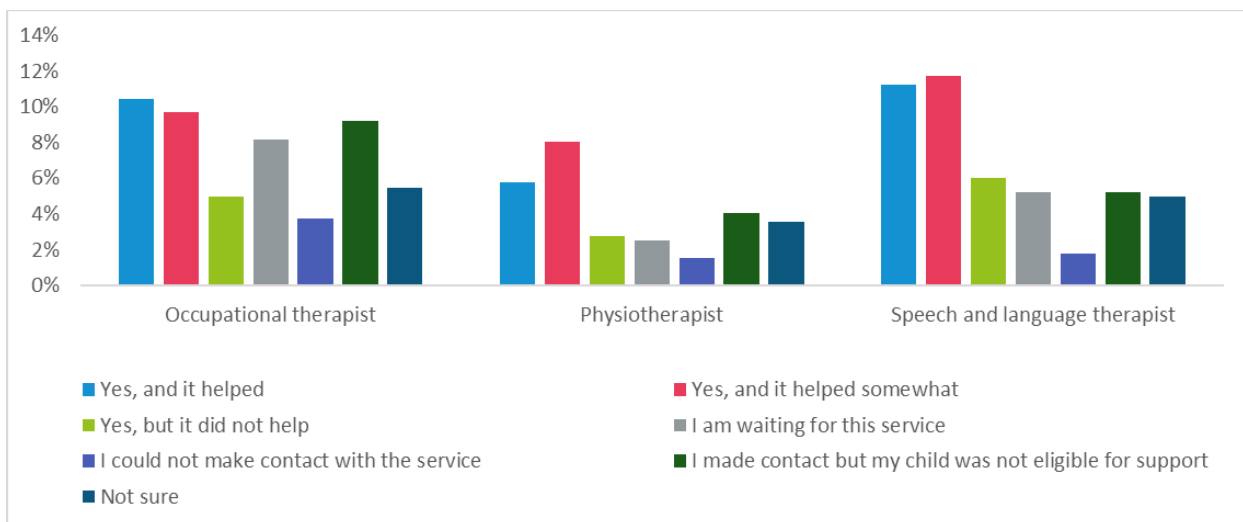
Community based services



Health visiting was helpful 12 years ago and 8 years ago, but not now with my 3 Yr old”

“The school nurse only focused on sleep issues, gave me booklet and only had one meeting with me. Not helpful at all”

Mental health was frequently commented on in the text boxes, and is examined at greater length in Section 2 of the qualitative analysis.



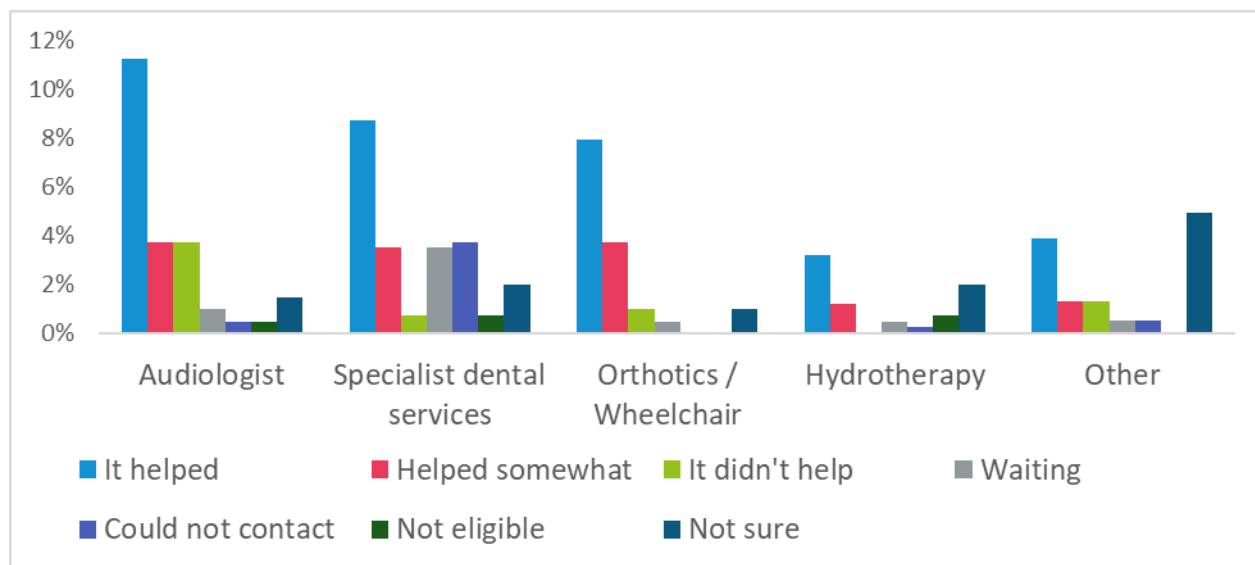
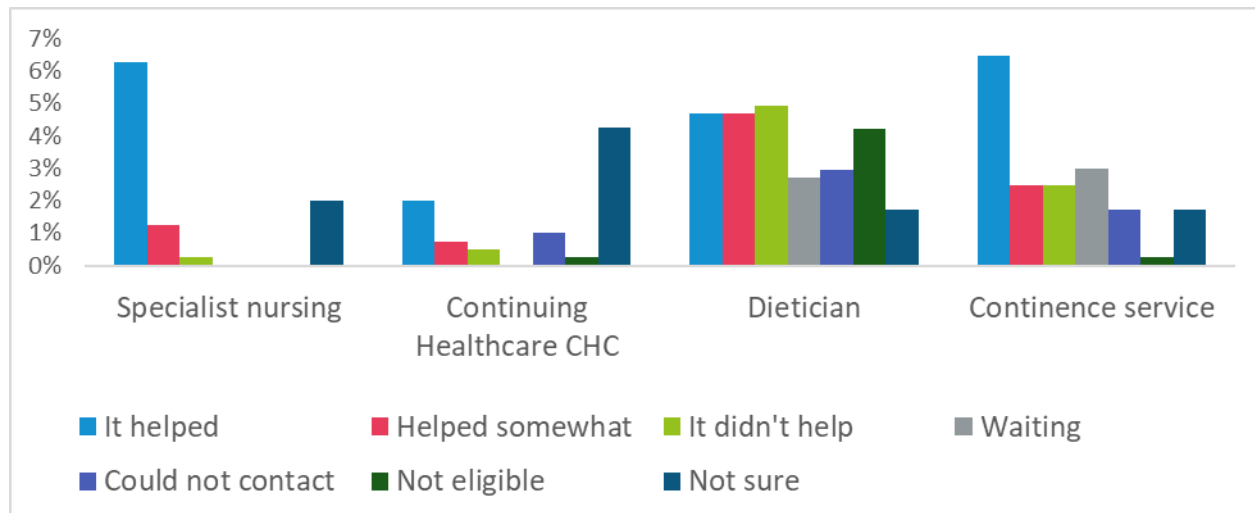
We paid for private SLT assessment”

“We have always had the same OT and the consistency has been great”

On behalf of your child or young person, have you used or tried to use the following services within the last two years?

Specialist services

By specialist we mean those that normally require a referral, for example from your GP.



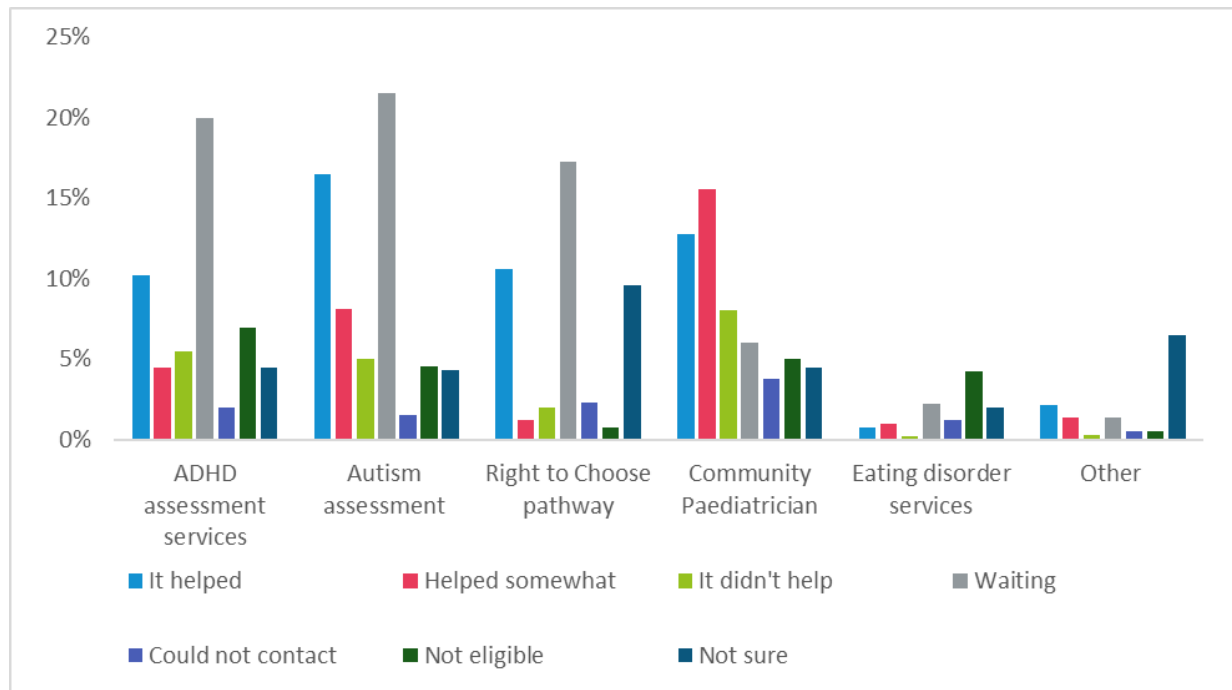
Other includes: fatigue service; eye hospital; Bibic; private clinical psychologist; diabetes team; portage; dental hospital; psychiatrist.

Audiology, Specialist nursing (lifetime), continence and hydrotherapy (provided at school) have all been going well”

“Wheelchair services have long wait times for parts deliveries and repair services when things go wrong - orthotics, no issues”

On behalf of your child or young person, have you used or tried to use the following services within the last two years?

Assessment services



Other: mostly comments on services covered in this question, but also references to Bibic, podiatry, Child in Need assessment, and private vs NHS provision.

22% of respondents were on a waiting list for autism assessment, 20% waiting for ADHD assessment, and 17% waiting on the Right to Choose. The community paediatricians did not have as long a waiting list, but more parents reported difficulty getting in touch (5% reported being told they were not eligible for this service, and a further 4% were unable to contact them).

Paediatrician changes every time we see them, doesn't feel like you can build a relationship for consistent care"

"Right to choose works well - but there's no follow up"

"Dietician can only offer high calorific milk to enable my child to get the nutrients and keep weight on due to limited food. They can't support ARFID as it isn't recognised in this area"

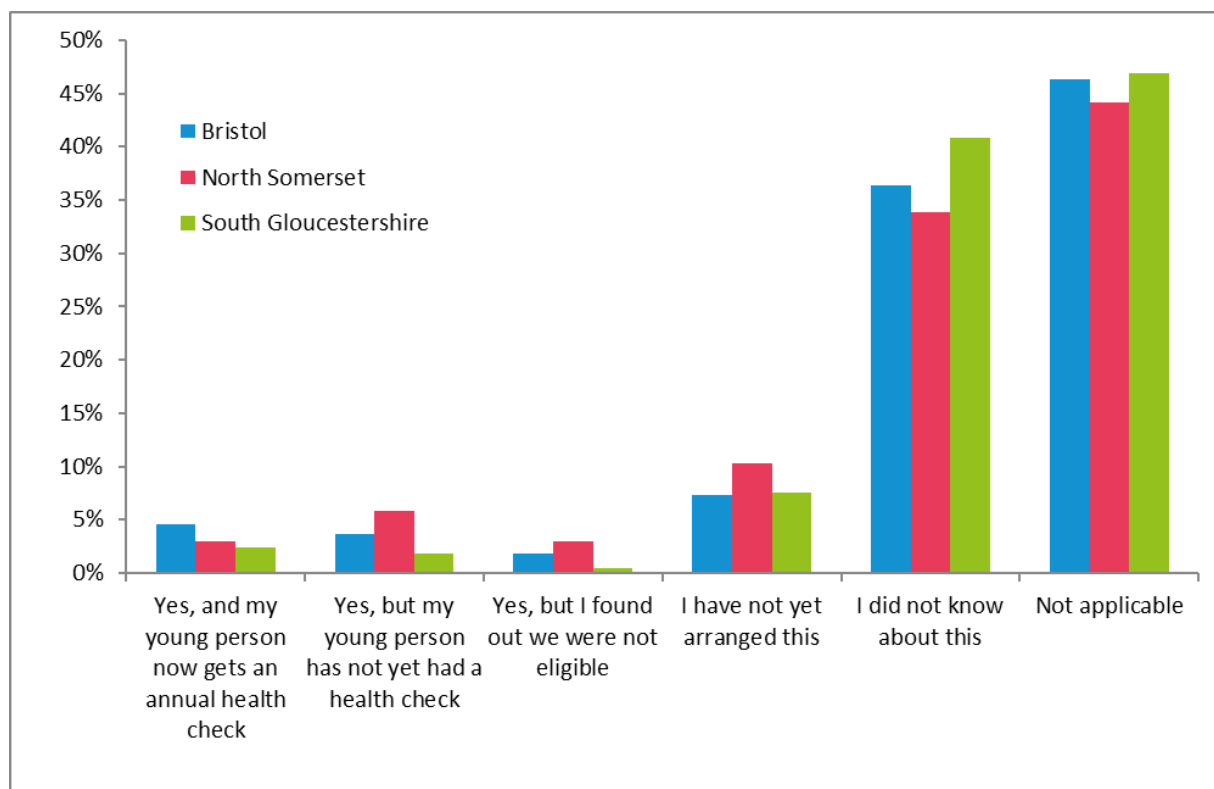
Are there any other health-related services that you would like to tell us about? Please specify which service you would like to raise and tell us what worked well and what could be improved?

Access for children with less severe challenges is very difficult"

Health checks

The NHS offers annual health checks for people with learning disabilities from the age of 14. 38% of respondents did not know about this. Of the 15% of respondents who both knew of it and considered their young person eligible, over half (51%) had not arranged it; 8% found they were not eligible; 20% reported their young person had not yet had a health check; and 21% reported that their young person now gets an annual health check.

If you think your young person might be eligible, have you discussed this with your GP?



In all, of parents who thought their young person might be eligible, 38% reported that they had not known about this service.

Is there anything you would like to tell us about annual health checks?

 *Our child's previous GP had not updated his records to show his SEND needs, so he did not have an annual check-up until he moved out to his own flat and a new GP surgery"*

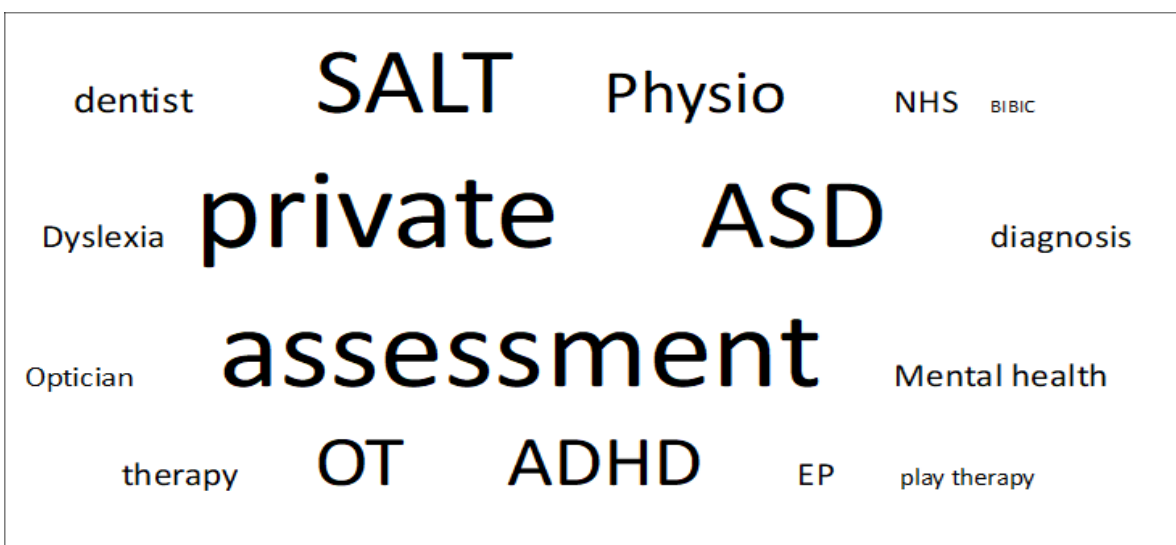
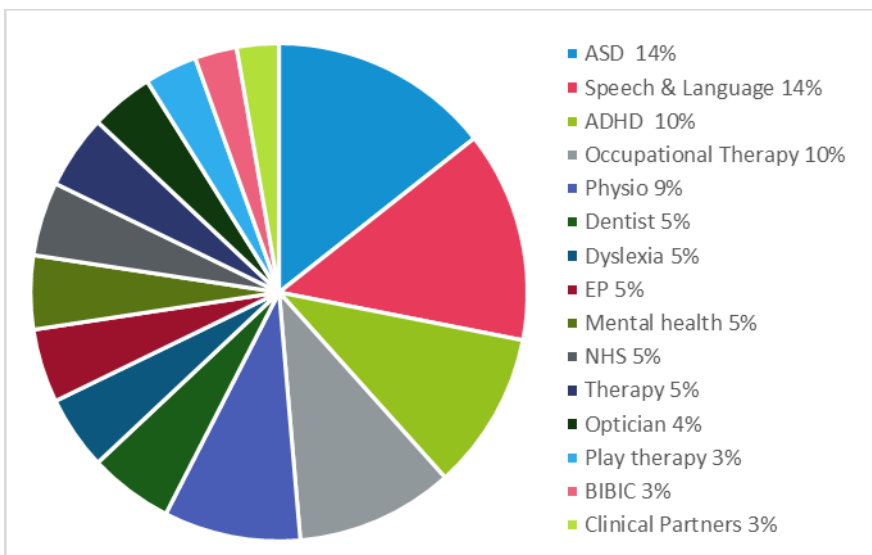
"I didn't know about them. My GP surgery contacted me"

Private health provision

Families' use of private healthcare providers was specifically addressed in this section of the survey; however many respondents had already described resorting to private healthcare in their replies to earlier questions. This is discussed in greater detail in the section on qualitative analysis.

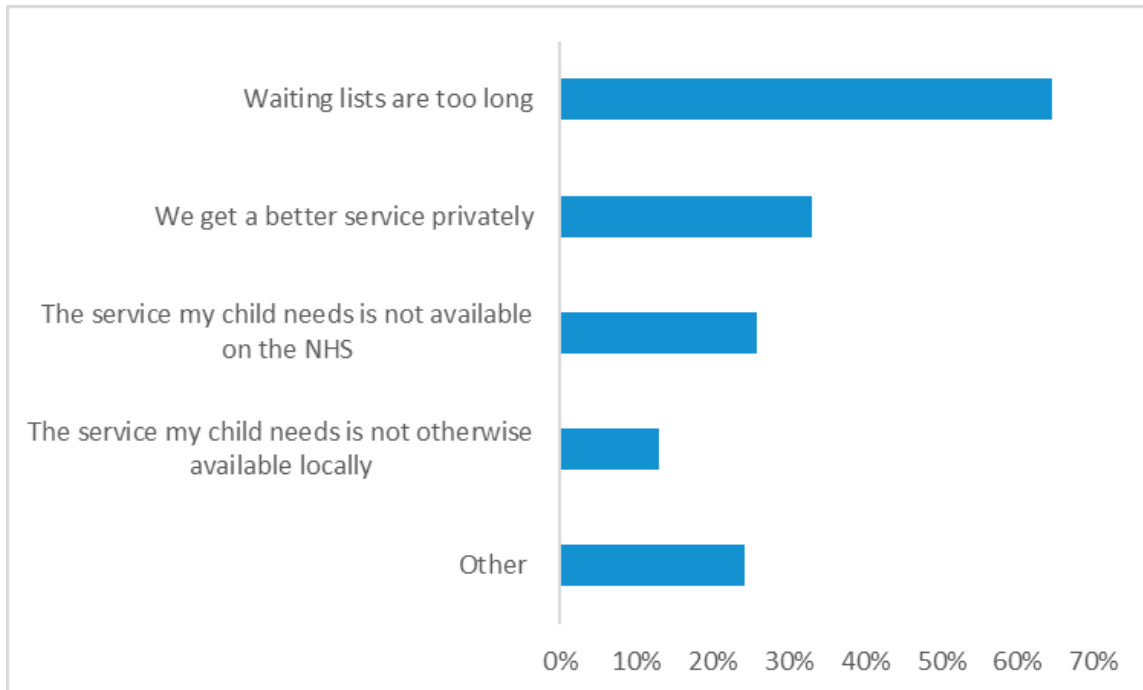
If you have used any private healthcare services in the last two years, please tell us which service / provision you used.

This was a freeform text box. Answers given included: Assessments; diagnosis; ADHD; ASD; Dyslexia; Occupational therapy; Play therapy; Speech and Language therapy; Physiotherapy; Therapy; Dentists; Educational Psychologist; Paediatrician; Optician; Mental Health; BIBIC; Right to Choose; Clinical Partners.



If you have used any private healthcare services in the last two years, please tell us why:

37% of respondents had used private healthcare. Of those, 65% reported doing so because waiting lists were too long.



Other was mostly elaborating on answers given. The reasons respondents give for using private healthcare is discussed at length in the qualitative analysis.

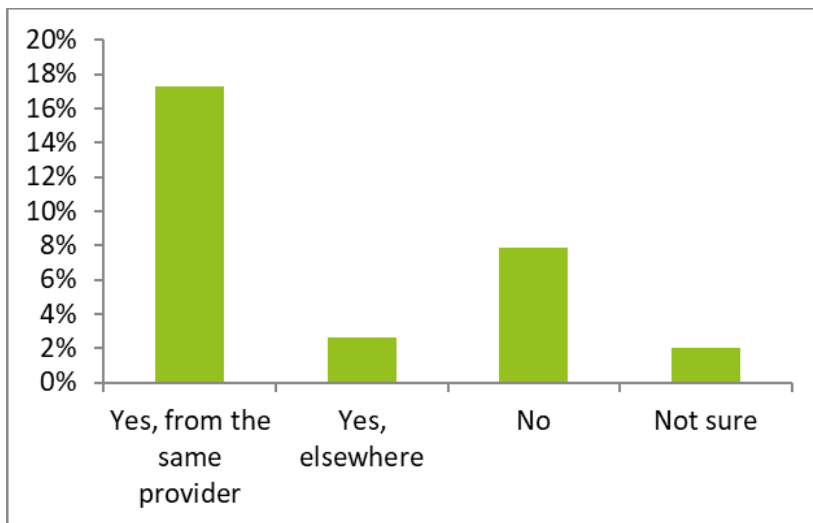
She needs support now"

"Cannot get an NHS dentist"

"Was making zero progress with waiting lists or BCC and desperate to help my ND child before mental health deteriorates and EBSA sets in"

"We were extremely worried by his mental wellbeing which has made improvements since the diagnosis"

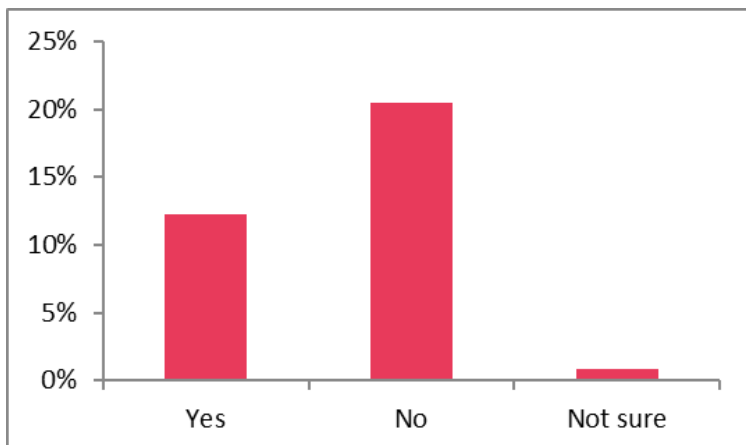
If you have used private healthcare and needed any follow-up care, was it available?



30% of respondents reported needing follow-up care. Of those, 26% were unable to get it, whether from the same or a different provider.

The ADHD assessors did not offer follow up. Medication titration accessed from an alternative provider. Now shared care with GP”

Have you had to buy, rent, or pay for provision or maintenance of specialist equipment (for example, hoists or wheelchairs) to support your child or young person?



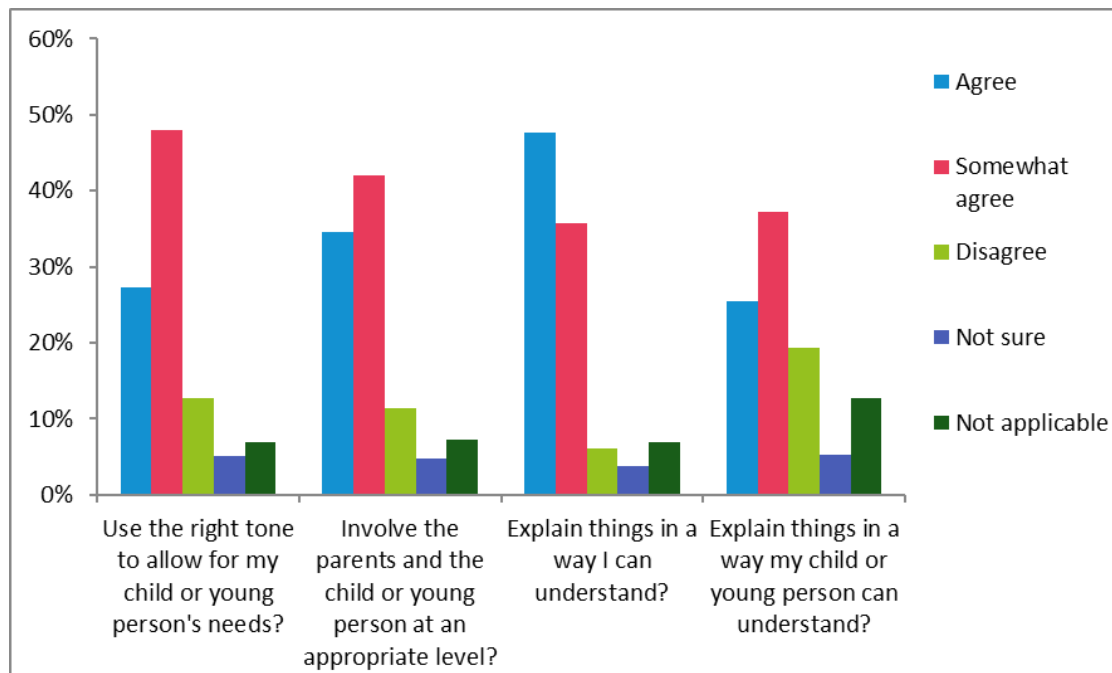
Over 12% of all respondents (37% of those who reported needing special equipment) reported having to pay for it. When asked what they had needed, answers given included:

Car harness - crutches – incontinence pads – specialist buggy – headphones – laptop – mobile hoist – sensory equipment – wheelchair

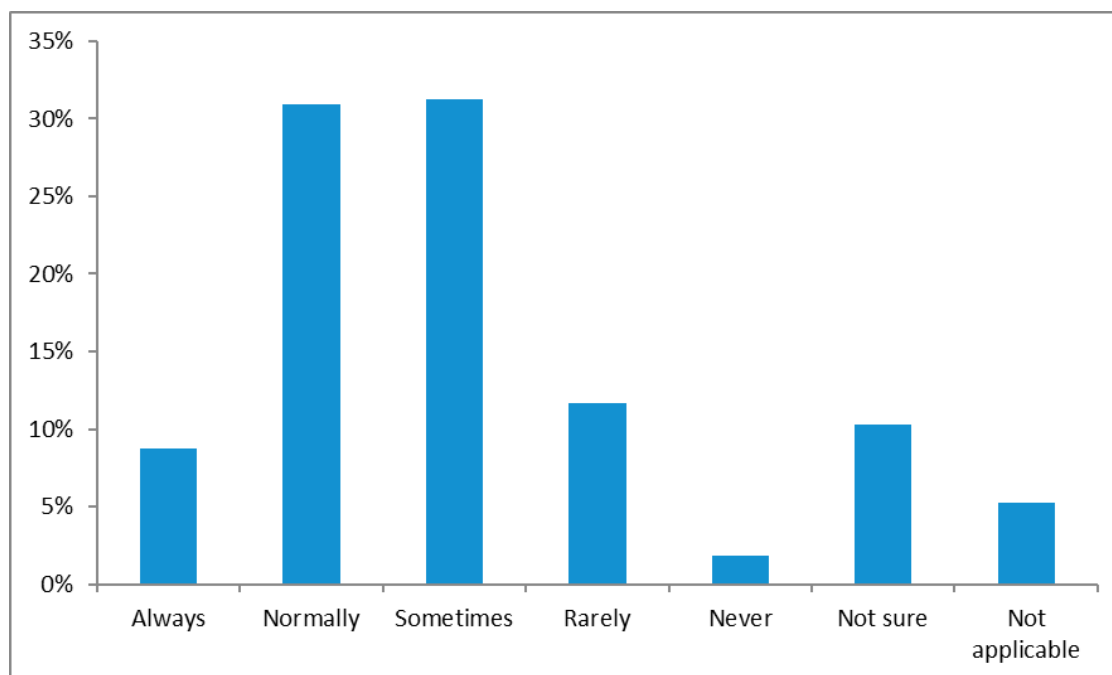
Working with professionals

This was an area that was repeatedly mentioned in comments, indicating that collaborative working is of key importance to parent carers. It is discussed in much greater length in sections 1 and 4 of the qualitative study.

When communicating with health professionals, do they?



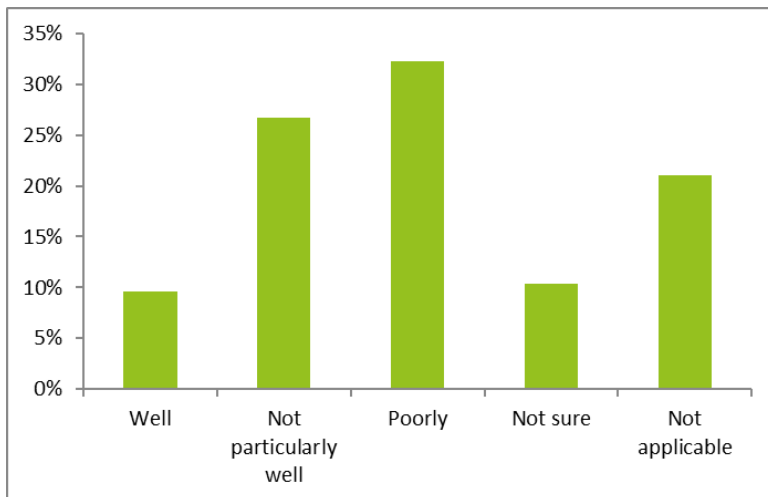
Do the professionals you see have the appropriate training for the issue in hand?



 *One consultant knew Makaton – that was the best appointment ever”*

“Hospital passport is often missed. No special treatment, we just have to cope , or not”

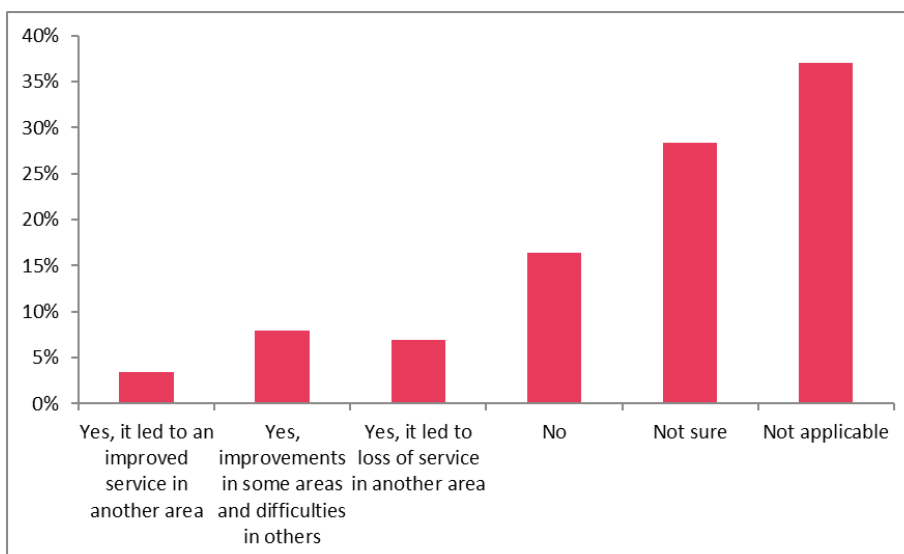
If you need more than one service to collaborate, how well are services joined up?



Communication between services is and has always been poor. This is especially true between hospital and community services”

“GP cannot read hospital notes, hospitals can’t read each other’s notes, Southmead can’t read Children’s Hospital or GOSH notes, none of the hospitals can read Sirona’s and who knows what the school sees!”

Has provision in one area affected the provision you get in another area?

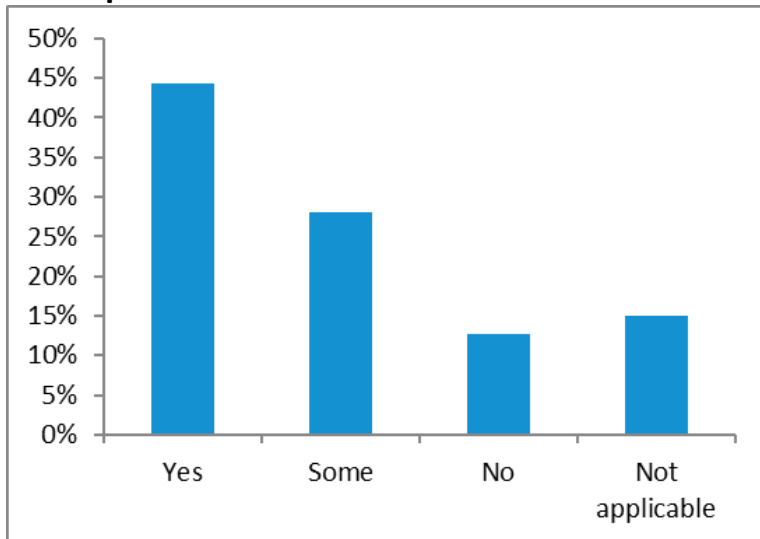


CAMHS wouldn’t help because my daughter was assigned a Family Plus Support worker”

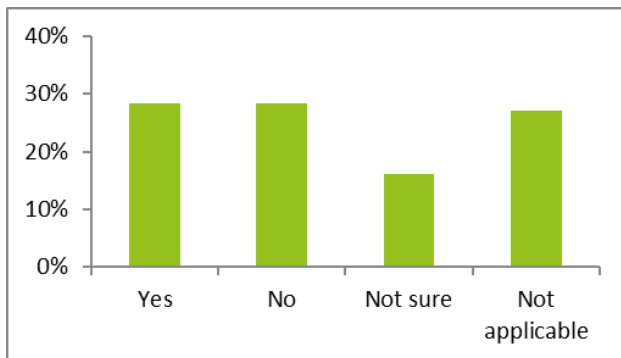
“Get a CAMHs referral and you never hear from your paediatrician again”

Reports

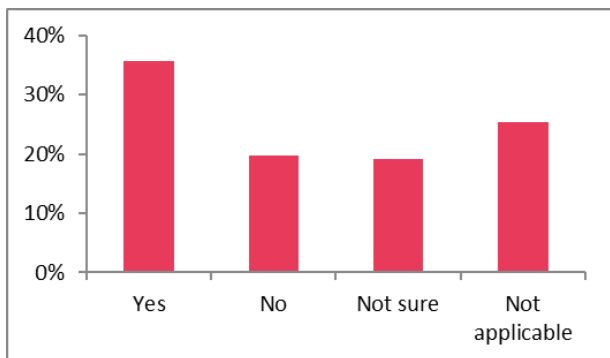
Have you been able to gather any supporting evidence needed for assessments and reports?



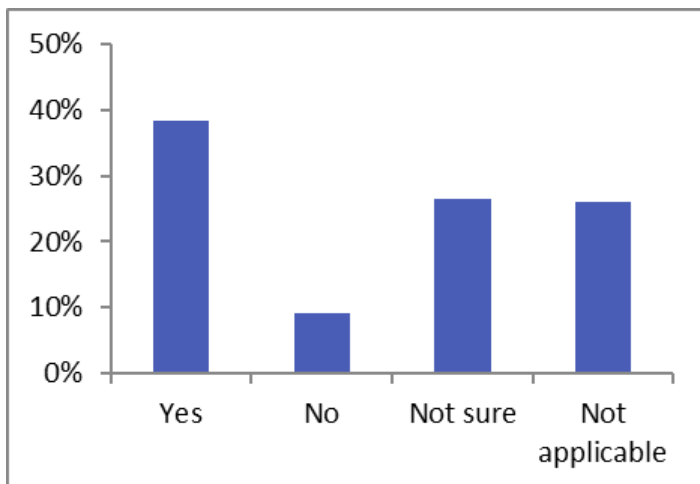
Are health reports timely?



Accurate?



Are health reports accepted by other professionals?



Is there anything particular you would like to tell us about health reports?



We received someone else's ASD report"

"Health reports are not proof read, I have received reports with my sons name misspelt or with other children's names in it, I have also received reports with inaccurate background information"

Do you have any other thoughts you would like to share about healthcare services? We want to know what worked as well as what needs improvement.

What worked:



The physio and OT team at Patchway have always been fab. They are consistently very good with my daughter and give achievable targets and activities. I just wish we could see the same professional every time I refer back into the service"

"The eye clinic at Patchway has always been great - informative, very aware of my daughters rare genetic condition and put my daughter at ease"

"The portage team are just fab!"

What needs improvement:



For a long time I felt like I was being ignored, it was only children in absolute crisis that could be helped"

"Neurology and Neurosurgery are the only services I never have to chase - their letters and appointments arrive like clockwork, when their clinics are full he is seen on a weekend. I wish more health services were this efficient"

"Once you get inside the many many parts of the health service it generally works well. However, it has taken me 15 years of constant interaction to feel that way. The system is generally disjointed and hard to navigate. We have an excellent family GP which helps"

- Murmuration
- NAS
- NDCS
- Off the Record
- NS Nurseries and Pre-Schools
- NS Early Help Services
- SEND and You
- Sense
- Sight Support
- Sirona
- Special Friends
- WECIL
- FE colleges
- Various Sports and Youth Clubs in North Somerset

Appendix Five: Qualitative Analysis Codes Used and number of tags

ADHD medication **10**
ADHD/ASC assessment pathway need **18**
ARFID **8**
ASC/ADHD Assessment CCHS **22**
ASC/ADHD assessment - RTC **42**
Access to assessments (any) **23**
Adult Services for Over 18s **5**
Autism intensive service **1**
Availability of play therapist (hospital) **6**
CAMHS good experience **18**
CAMHS poor experience **33**
CYP MH **37**
Change in provision/care detrimental to CYP **3**
Children's social care experience **9**
Clinician negative experience **19**
Clinician positive experience **18**
Communication poor - education **11**
Communication poor – health **34**
Communication poor – multiple services **2**
Communication with CYP/family **19**
Community Paeds experience **38**
Continence Service **5**
Cost of private healthcare **8**
Dental **23**
Diagnosis opened up access to services/support **5**
Dietician **7**
Dyslexia **7**
ECHNa **7**
EHCP **36**
EHCP Annual review **6**
EHCP Annual review - positive **4**
Experience of LD health check **9**
Eye hospital/opticians **18**
FASD **1**
Family Support Training in SEND **2**
Fatigue **8**
Funding-lack of support **4**
GP booking systems **4**
GP lack of knowledge/support **60**
GP supportive **15**
Health Care that schools can't or won't do **3**

Health Needs not understood-schools 2
Health professional knowledge of neurodiversity/EBSA/Other needs 37
Health visitor 2
Home visits 2
Hospital experience – positive 32
Hospital experience - negative 19
Housing 2
Inconsistent Support 10
Intimate care needs 2
Lack of Health Care Home Support 3
Lack of Support 60
Lack of awareness of LD health check 15
Lack of resource in schools 14
Lack of willingness of schools to understand/meet need 17
Listening to parents 12
MHST 6
Masking in school or other services 7
Mental health needs not understood/met/supported 5
Needs not met/understood/supported 28
Neuroprofiling 2
No longer in school 16
OT 21
Oncology 1
Parent time spent co-ordinating services (advocacy) 15
Parents filling in gaps in care/support 14
Physio 19
Play therapy - negative 4
Play therapy - positive 13
Portage 2
Post assessment support 12
Private healthcare 89
Private/RtC report not accepted 37
Quality of health reports 25
Referrals to health-rejected 20
Repeating child's story 11
Report-time taken 8
SaLT 22
School can't meet need 17
School not supporting assessments 12
School nurse 20
School providing services 7
School tried hard to meet need 10
Schools confident/able to meet health need 13
Sensory service - hearing and sight 3
Siloes of practice/care 13
Skill/offer of NHS health services not adequate 36

Specialist Items purchased 5
Support for deaf children 4
Systems working together poorly 59
Systems working together well 9
Timeliness of health reports 1
Training-good in school 4
Training-lack in schools 5
Transition to adult services 4
Unsure where to access support 47
VCSE sector services 5
Waiting List-Appointments 12
Waiting list for Autism/ADHD 42
Waiting list/access CAMHS 29
Weight management 2
Wheelchair services 2