



Speech & Language Therapy for Children & Young People

My Voice Matters

Healthwatch working with B&NES Parent Carer Forum

Contents

Purpose of the Report	3
About Healthwatch Bath and North East Somerset	3
About B&NES Parent Carer Forum	4
The importance of speech and language therapy	4
Feedback about current provision	5
Key Findings, Recommendations and Next Steps	. 12
Key findings are:	. 12
Recommendations	. 12
Next steps	. 13
Appendix	.14
Glossary	.14
Resources for Speech and language therapy	.14

My Voice Matters is ensuring the voice of people with diverse lived experiences and backgrounds are heard.

We are proud to be able to give the opportunity for seldom heard voices to be heard by providers and wider organisations in their own words.

Purpose of the Report

This report shares feedback gathered by the B&NES Parent Carer Forum in response to concerns about provision of speech and language therapy. It includes feedback about the areas of speech and language therapy that impact their children and views on the adequacy of current provision.

Healthwatch Bath and North East Somerset have worked jointly with B&NES Parent Carer Forum to help strengthen the voices of their community members, to ensure they are heard. The overall aim is to help improve services to meet needs.

About Healthwatch Bath and North East Somerset

Healthwatch Bath and North East Somerset (Healthwatch) are the county's independent champion for people who use health and social care services. We're here to make sure that those running services, put people at the heart of care. As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care.

We are here to listen and understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf. We focus on ensuring that people's worries and concerns about current services are addressed. We are totally independent and can provide you with impartial and independent signposting advice. We are part of a network of 150 local Healthwatch across England and cover the whole of Bath and North East Somerset.

About B&NES Parent Carer Forum

B&NES Parent Carer Forum (PCF) is entirely made up of the parent carers of children and young people with special educational needs and disabilities (SEND) aged from birth to 25 years. They bring their expertise, experiences and knowledge together and provide a voice to represent the views and experiences of parent carers and, where it is needed, to advocate for and bring about change. The PCF are involved in decisions relating to local strategy, commissioning services and initiatives relating to children and young people with SEND.

The role of the PCF is to work in partnership with the Local Authority and other organisations to ensure that parent carers' views and experiences shape the services young people with SEND need and use, to make sure the local offer for children and young people with SEND and their families is genuinely inclusive.

The PCF run information sessions, workshops, events for parent carers, activities for families, and events for children and young people. The PCF also connects with parent carers through their website and via social media. In addition to the events above, there are regular cafes and other social gatherings in an increasing number of locations across B&NES. There are currently 850 members and the PCF continues to grow daily.

To find out more visit www.banespcf.co.uk.

The importance of speech and language therapy

Speech and language therapists (SLTs) provide life-improving treatment, support and care for children and adults who have difficulties with communication, eating, drinking or swallowing.

SLTs assess and treat speech, language and communication problems in people of all ages to help them communicate better.

They also assess, treat and develop personalised plans to support people who have eating and swallowing problems.

Using specialist skills, SLTs work directly with clients and their carers and provide them with tailored support. They also work closely with teachers and other health professionals, such as doctors, nurses, other allied health professionals and psychologists to develop individual treatment programmes.

Speech and language therapy benefits people of all ages, including infants and children:

Infants: SLTs support premature babies and infants with conditions such as Cerebral Palsy, Cleft Palate and Down's Syndrome from very early in life who have difficulties with drinking, swallowing and early play and communication skills.

Children: SLTs support children with primary speech, language and communication difficulties, such as stammering, as well as speech, language and communication difficulties that are secondary to other conditions such as learning difficulties and hearing problems.

(from the Royal College of Speech and Language Therapists Home | RCSLT)

Feedback about current provision

The PCF asked their members in May 2024 for their feedback about current provision of speech and language therapy. In the short timescale available 12 parent carers shared their experiences and views.

This report sets out all the responses received, both positive and negative.

Although a small number of responses, it provides the views of people who really value speech and language therapy as an essential element of the care and development of their children.

Responses have been grouped as follows:

- The areas of speech and language therapy which impact their children
- Waiting list
- Adequacy of provision
- 5 My Voice Matters: Speech & language therapy for children and young people

- Importance of consistency
- Importance of therapy which is appropriate to individual needs, including in schools

Which areas of speech and language impact your child or young person?

Parent carers identified a range of speech and language needs:

"My daughter has significant DLD (Developmental Language Disorder) and this has a huge impact on her learning and social development."

"Speech sounds"

"My daughter was diagnosed by a SALT therapist from HCRG who is their specialist in situational mutism. My daughter was not able to return to mainstream primary after the pandemic in November 2021 as her needs were not being (met) there so she experienced an autistic burnout and has been recovering at home since.

She has EOTAS personal budget through her EHCP she is due to start at an independent specialist school for ASD, PDA, Speech and language differences and SEMH."

"I have two children, eldest is 8 and is autistic and non speaking. She was able to get access to the complex needs team fairly quickly around age 2.5. she's now at specialist school."

"Dysfluent speech, trouble getting his thoughts out as speech"

"I had no idea that speech therapy encompassed so many important principles of self expression. The therapist ran a several weeks workshop that was invaluable. It appears that speech therapy is one of the keys that keeps (my son) from self harm. If he can verbally express his emotions then he has an outlet. I am anxious that there is no on-going therapy. I wish we could get a prescription for regular sessions"

Waiting list:

"Once a referral is made and you're seen by a specialist, the provision is good. It's the unfortunate waiting list. Maybe, like the ASD path, a telephone consultation first gives insight into what areas children need support and things like worksheets or exercises provided while being on the waiting list? Instead of families feeling like it's never ending and their child is just left etc

Every specialist we have met have all been supportive understanding kind and just overall amazing."

"I have been waiting for months for SALT. It would be good to staff the service sufficiently to have a more responsive waiting time. I cannot comment on the service because we were referred at the beginning of February and are still waiting to be seen. My son is nearly 4 and starts school in September.

"I've seen first-hand how many in reception alone would benefit and are on the waiting list for S&L support and with only one lady in our school the list is long!"

Adequacy of provision

"There is not nearly enough specialist speech and language provision in B&NES (or surrounding areas) both in terms of diagnosis, on-going intervention and support or specialist educational settings.

Even when going through a Phase Transfer and the LA specifically requesting reassessment of speech and language needs by NHS this did not take place, presumably due to lack of resource."

"There are not enough therapists, so yes to all of your questions. It's vital for our young adults with speech issues!"

"My youngest is 4.5. I suspect she is also Autistic, we are on the pathway. Basically there's no SALT provision for her because she can speak. She struggles with social communication and there are undoubtedly issues with her communication which I expect will become more acute and affect her more deeply as she gets older. As a four year old friendships etc are fairly flexible but she does not understand standard communication and gets upset very easily because of this. I expect we will have mental health issues as a result of this as she gets older. She is already very anxious. I have spoken with the SALT team but beyond making some suggestions over the telephone there doesn't seem to be anything."

"My son was with preschool team and has now been discharged as he doesn't meet the threshold/ his speech has improved. His speech is still fairly unclear and delayed - so we are trying to get private support. His nursery setting still think it's significantly impacting his learning so just mentioning that as we probably are one of many that fall through the gap a bit (not significant enough delay to qualify for continued support but still does need further support). "

"...from what I've heard about my son going into primary it doesn't sound like there is going to be that much support (unless we can afford to pay)"

"Yes (to support in primary). Just need for more provision full stop. Only delaying the problem for the children."

"Totally inadequate. My son is non verbal, using an eye gaze computer to talk.

In the last year access to specialist SALT has been dramatically cutalthough hidden under the simplicity of one staff member leaving and being replaced. The old SALT would mostly reply the same day, and into the evening! I wouldn't expect that again, but the new person is only in his school one day a week and often doesn't reply to emails on that day. Weeks turn into months while we try to get things actioned. We've been waiting over a year now for some simple 'how to' sheets to be made for my son's PAs.

Critically SALT is only provided during term time – as if communication is only needed in school hours ??!!

I've had to fight really hard to get any SALT provision out of this – with a 'win' of a two hour workshop as a one-off, which is happening at school, so we need to pay travel time and mileage to all his PAs to get there. Using an eye gaze computer is really complicated and it needs someone to be available to answer questions in a timely manner.

The new SALT has said that the current package is adequate for his needs – but it is less than 1 hour a week in which she is supposed to do direct work with him, attend any meetings with us, reply to our emails, train his staff, develop his resources, fix any issues that have arisen (it's tech after all!) – impossible"

Importance of consistency

"We had support from the pre-school SALT team, before we were referred to them we actually had support from the HV which was an intervention where she visited us at home around 4-5 times and did basic language support techniques and play with my son. This was actually more useful than our later therapy appointments as it was in a comfortable environment and we had (the same HV) every time so my son got used to her visits. I learnt a lot too. This early intervention at 2/2.5 years really helped.

Although the staff are great we had a different person for every appointment so my son wouldn't engage which made the appointments fairly ineffective. It's obviously about teaching us as parents how to support too but it's so rushed and difficult to focus that we didn't find it particularly helpful. "

"Currently non-existent. The SALT person who was provided by NHS who used to come to my sons mainstream primary, left in December last year and they haven't been able to recruit anyone since. So my son who is supposed to have 6 sessions each school year (one per half term) isn't getting them."

"My child has been recognised as having delayed speech since his 2 year check." Despite that no one would see him until he was three.... Early intervention is crucial.... Why the wait?"

My child is 6 now, still has a very obvious delay, we seem to get two appointments thrown at us at random intervals.... Nothing seems to be consistent."



"Both my children have benefitted immensely with support from S&L especially the lady provided in school, weekly support has encouraged and improved their language set"

Importance of appropriate therapy to meet individual needs

"My experience of the local NHS speech and language assessments and provision is that it is very stripped back service. You as a parent have to learn how to navigate the system and keep on top of things as it is a very slow and bureaucratic process trying to access appropriate services that actually can offer the right level of support.

Also the SALT is very out of date and their training and approaches are VERY traditional and are not neuro-divergent affirming which they need to be.

Once assessment has happened they can only diagnose and can't actually provide any useful support only recommendations of out of date resources such as basic books. This is why I had to find our own private speech and language therapist.

I found that the general speech and language therapists from HCRG are not trained or able to use a joined-up approach when assessing as part of the EHCP process, for example they are not trained in autism and do not make any connections between ND brains and situational mutism which I could never understand because situational mutism is a common co-occurrence with autism."

"Look at Secondary provision (as well as primary). It seems that all SLCN are 'lumped together' and young people often put into an educational setting which covers ASD and SLCN.

Whilst many young people with ASD do have SLCN their needs are NOT the same as young people with DLD - both the setting and the teaching needs to be totally different.

In addition, putting my daughter with significant DLD (but not ASD) in a specialist school with most ASD students was hugely difficult for her and resulted in high levels of anxiety massively impacting her learning (ie. she wasn't learning at all) and requiring therapeutic support. Once we removed her from this (via Appeal) and placed her in a specialist DLD school she has thrived, doing GCSES and will be far more independent and contribute far more to society as a result. The problem is that this school is 130 miles away as there is nothing closer. There is a lot of emphasis on support for young people with ASD but DLD (which is even more common) is severely neglected."

Key Findings, Recommendations and Next Steps

Whilst the number of respondents was small the parent carers responding have expressed how important speech and language therapy is to the wellbeing and development of their children with care needs.

Key findings are:

- Long waiting lists are a real concern in development terms children are at risk of falling behind, which impacts socially as well as in terms of education.
- Current provision is inadequate in terms of capacity the service appears to be 'stripped back' and cannot be consistently offered in line with assessed needs.
- Thresholds are felt to be high so that once some improvements have been achieved a child may fall out of the service, when further support would be really valuable.
- Where children and young people have been assessed as having a need for a service, due to capacity issues the service is not consistently being delivered.
- Consistency of support from the same person can make a really positive difference.
- Whilst specialist provision is welcomed there are concerns about children being 'lumped together' for one shared SALT need when their other needs are very different.

Recommendations

- Vacant SALT posts are speedily filled so that therapist support is provided in line with assessments.
- Consideration be given to providing a level of useful resources and support whilst children and young people are on the waiting list for assessment and services.

- Where additional 'home/Personal Assistant support' resources are requested additional capacity is made available to meet these requests.
- Parent carers to be involved in decisions about the development and design of future services.
- Further research is undertaken to gain the views of a wider number of parent carers about the benefits of speech and language therapy and the impact when it is not available or is withdrawn.

Next steps

- Healthwatch and the PCF will publish the report on their websites
- Healthwatch will share the report with B&NES Health and Wellbeing Board and across the local NHS area.
- The PCF will share the report with the Local Area Inclusion Partnership and Children's Services
- The PCF will share the report with the other parent carer forums in the Bath, Swindon and Wiltshire Integrated Care Board area.

Appendix

Glossary

ASD Autistic Spectrum Disorder

DLD Developmental Language Disorder

EHCP Education, Health and Care Plan

EOTAS Education Other Than At School

ND Neuro divergent/diverse

PDA Pathlogical Demand Avoidance

SEMH Social Emotional and Mental Health

SLCN Speech Language and Communication Needs

Resources for Speech and language therapy

Speech and Language Therapy Service in Bath and North East Somerset

<u>Children's Speech and Language Therapy | The HUB (bathnes.gov.uk)</u>

Teach Me Too

A charity which provides resources for children with Downs syndrome – including videos produced by specialist teachers and speech and language therapists, focussing on early learning concepts and skills, covering practical approaches to building language skills through play.

<u>Teach Me Too - Free Early Years Resources for Children with Down's syndrome</u> and SEN (learnandthrive.org.uk)

Information and resources for parents including helpline

ICAN CHARITY

Home - Speech and Language UK: Changing young lives

The Royal College of Speech and Language Therapy

About the Royal College of Speech and Language Therapists | RCSLT

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