

Norfolk CC HOSC 7 September 2017
Family Voice Norfolk consultation on Children and Young People's Speech and Language Therapy Services from ECCH

Consultation

Parents of children and young people using or wanting to use the speech and language therapy services from Norfolk were consulted via an online survey to inform this paper.

Background

Family Voice Norfolk (FVN) is a collective of parent carers from nearly 700 families across Norfolk including the Gt. Yarmouth and Waveney area. FVN has been the strategic voice of parent carers working in partnership with NCC and the CCGs since 2006. It is funded through a direct DFE grant (administered through Contact a Family) and by Norfolk County Council.

Each of our members was invited to complete a questionnaire online and had the opportunity to write comments on their experiences of the existing service after each question. We had more than 70 responses.

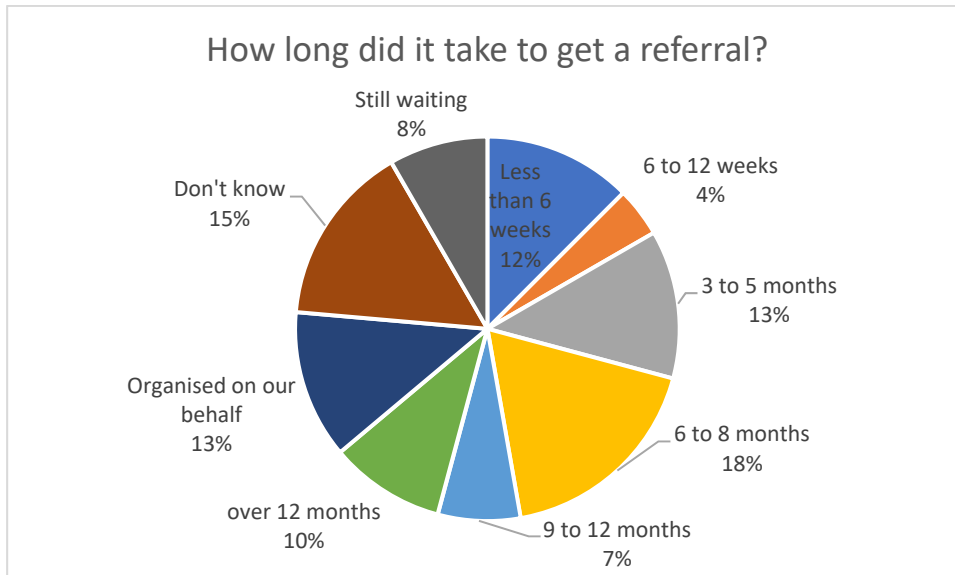
Key messages

Key messages coming out of the discussion on ECCH SALT services were:

- Parents want clear written information about SALT service.
- Parents need to know who to contact to answer their queries / concerns and acknowledge them within a reasonable time limit.
- Parents want a service that identifies their child's needs.
- Parents want a seamless service that works together with various educational settings to provide information, advice and support to Nurseries Keyworkers, Schools and colleges TAs to meet the children and young people's Speech, Language and communication needs(SLCN).
- Parents want to have confidence in the professionals that deliver the service – that they will be compassionate and understanding about their individual child's needs - a person centred targeted service.
- Parents need to know the service is fit for purpose and will deliver the appropriate SMART outcomes for children and young people to achieve their educational targets and fulfill their life's potential – be able to communicate effectively with family, peers and their wider community.

Our online questionnaire asked the following questions:

How long did it take to get a referral?



Of those parent carers that were still waiting for a referral, they have been waiting between 6 and 18 months.

Getting a referral within what parents considered a reasonable time limit was an issue.

Parents made negative comments about the length of the waiting times for initial assessment and received no acknowledgement/information about the service.

“I was told it would be about 12 weeks and it was 6 months.”

“Was told it was an 18 week wait which I thought ridiculously long. Turned out to be 30 weeks only because I rang to see what the wait was only to be told I wasn't in the system!!!!”

“My child was referred to the speech and language team in 2013, so transferred as an existing patient. His original referral took about 4-5 months to come through.”

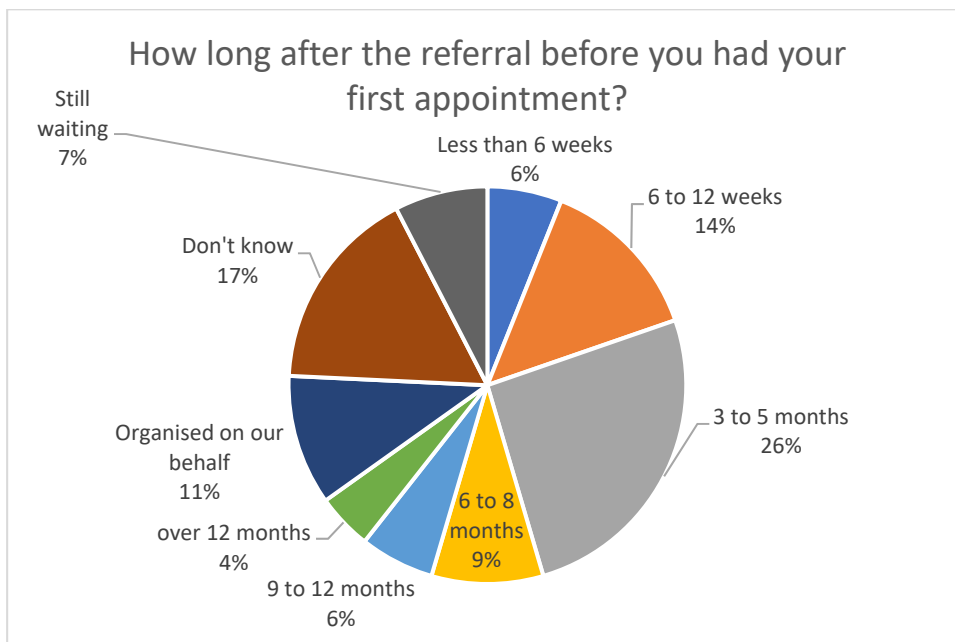
See Appendix A for all the comments relating to referrals

How to improve

Parents value receiving a communication to say the referral had been received, an indication of the likely waiting times as well as a number to call if they had any queries/concerns.

Work with parents to develop written information about the SLCN service, how it works, what to expect and who to contact. The written information should be given to parents when acknowledging their referral. It should also be made publicly available such as on the Local Offer Website, so parents can find out about the service and where to find more information.

How long after the referral before you had your first appointment?



Of those parent carers that were still waiting for their first appointment, they had been waiting between 2 months – over 2 years.

Most of the parents negative comments about referral to assessment timescales are concerned about how quickly the service can identify the child needs and the parents expectations of these waiting times.

An understanding and empathetic approach is deemed essential when dealing with children who have Down Syndrome or Autism – it is not uncommon for children requiring services because of a genetic disorder to also have a SLC need as well.

Under the Children and Families Act 2014 the local authority have 6 weeks to decide if they will agree to assess for an Education Health and Care (EHC) plan. Then the local authority has 10 weeks to get all the assessment information in to decide if they will issue a plan (16 weeks) and then if they decide to issue a draft plan it must be within a 20-week time scale. These timescales are a Statutory requirement on the local authority and if the parents or young person’s feels they have failed to carry out its statutory requirements within these time limits they have the right to take the local authority to the 1st tier SENDS Tribunal.

“A year! How ridiculous... this service is dreadful.”

“There was a significant wait between being seen at drop in [month] and commencing therapy [month]. In this case this could have added risk for my [child]. [My child] presents with a stammer and required a specific therapist directed intervention.”

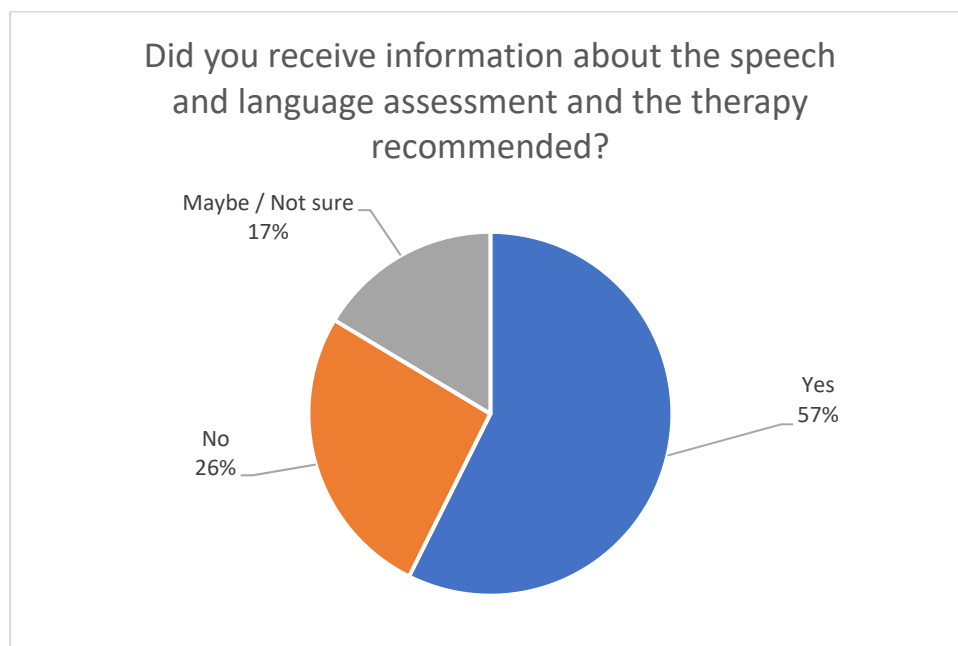
“Under the terms of his statement of educational needs, my child is now meant to be assessed by an SLT twice each term and the SLT is to provide a programme for the school to implement. [My child] is being seen once or twice a year. The Sendco reports that she must chase a lot to get an appointment. I have also experienced ringing up and leaving messages, but no one calls back, so I would say it is hard to get an appointment.”

See Appendix B for all comments relating to first appointment

How to improve

Training for all staff in the many ways various Special Needs/disabilities and associated challenges that children may present with, an empathy and understanding of how scary and frustrating this situation is for children and their parents too.

Did you receive information about the speech and language assessment and the therapy recommended?



26% of parents said they received no information on the assessment or therapy recommended, 57% of parents said they had received information and 17% of parents were unsure if they had received any information from the service.

Lack of effective communication with parents seems to be the theme amongst the negative comments received. Either parents do not receive any reports, the reports are inaccurate or out dated.

Parents want information after every visit with their children/young people. They want to know what target/goals are being worked towards, what progress their child is making and how they can help.

According to the EHCP coordinators there is an agreement between ECCH and Norfolk County Council that parents and educational settings (Nurseries, schools and Colleges) should receive a report within 2 weeks after being **discharged** from the SALT service.

“SALT from ECCH came to my [child’s] school in [term] 2016 - we have had no reports either sent home or to school. We do not know if my [child] has been discharged - even though [my child] has significant SALT communication problems and will for the rest of [my child’s] life.”

“Children don’t receive ‘therapy’ from a trained therapist, they are assessed and recommendations made and that is it. It is a consultation service, not speech therapy. It is failing the most vulnerable children locally.”

“I was given some goals to work towards independently, and discharged. [My child] was not given a diagnosis or summary of [my child’s] difficulties (e.g. Expressive/receptive language difficulties/delay etc.), no long-term goals were given, and the goals set were not ‘SMART’ - despite these being very basic requirements for good clinical assessment and management.”

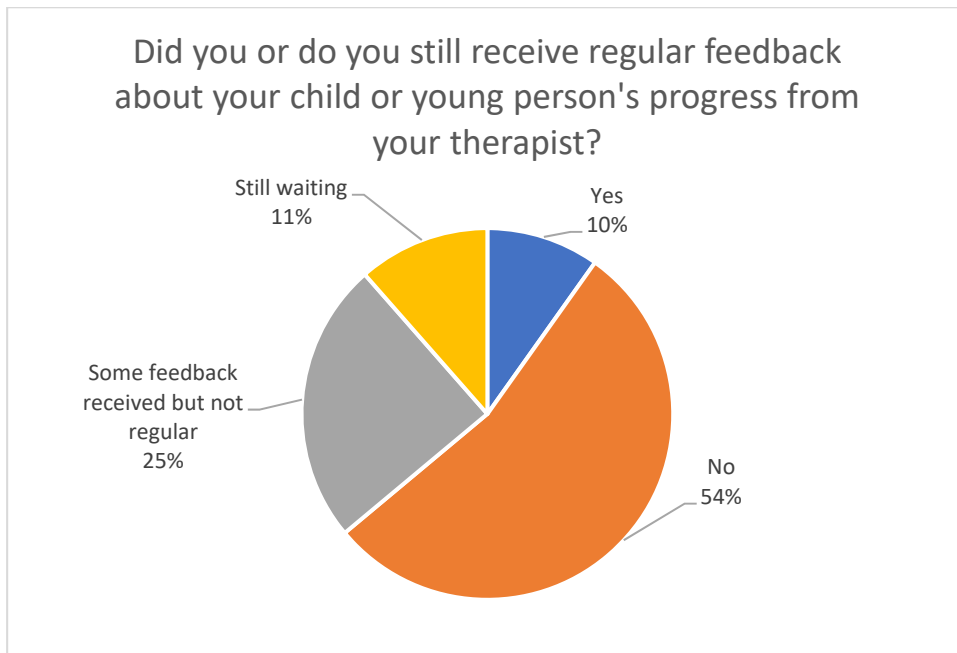
“My child has complex needs - speech and language difficulties being one of [my child’s] main areas of difficulty - and yet we were told we could not receive direct 1:1 therapy and ‘could not’ be kept on the SLT caseload, because the service was not ‘able’ to. So, we were told to re-refer ourselves once [my child] had either met the goals, or not achieved them (but no time frame given for this). I am a qualified SLT who previously worked for [NHS]: if a patient has active goals they should be kept on the caseload and reviewed, not discharged - because they either need therapy (either direct or indirect) and SLT input: or they do not. It can’t be both. My child has received therapy (either direct or indirect) and kept on the caseload of other disciplines, despite her need not being as great.”

See Appendix C for all comments relating receiving information and recommended therapy

How to improve

Work with parents and educational settings to set realistic timescales for reports with recommendations and advice for helping children achieve their targets for either their IEPs (individual educational plan) or their EHC plans after every visit not just when the child has been discharged from the service.

Did you or do you still receive regular feedback about your child or young person's progress from your therapist?



The results of our survey showed 10% of parents receive regular feedback from their therapist, 25% of parents said they received feedback but not regularly. 11% of parents are still waiting to receive any feedback and 54% of parent had not received any feedback from their therapist.

There is a statutory duty on the Local Authority and Health providers that their services help identifies needs, put in place provisions to meet the needs with regular monitoring provided to achieve SMART outcomes that help improve children and young people's lives from 0 – 25 years of age as detailed in the Childrens & Family Act 2014 and code of practice 2015.

The graduate approach: Assess, Plan, Do & Review is how evidence is gathered by educational settings. If targets and progress are not being achieved then specialist provision must be put in place to achieve SMART outcomes. Targets/outcomes are used and measured in Individual education plans (IEPs) every half term and Education, Health & Care plan (EHCp) annual reviews.

A SMART outcome is:

S – Specific, M – measurable, A – achievable, R – realistic and T-timely.

The Annual Review process of an EHC plan should look at:

What outcomes/target have already been met by the provision provided – if not why?

What new outcomes/targets are needed for the next stage of the child/young person's life. (The Act follows 0 – 25 years)

Are there any further assessments needed to identify new or changing needs?

“A report was issued but no more feedback has been offered.”

“It's more of a transcript of the session than feedback.”

“After several years I have received a Speech and Language Therapy Update which failed to mention the eye gaze computer technology which my child has been using for at least 5 years.”

“We were discharged after one 30-minute meeting at the school despite my child having severe speech and communication problems that were identified in an assessment by our old SALT provider a year before and by many other professionals. My [child] has been accepted into an SN school this year due to these problems. East Coast are a disgrace.”

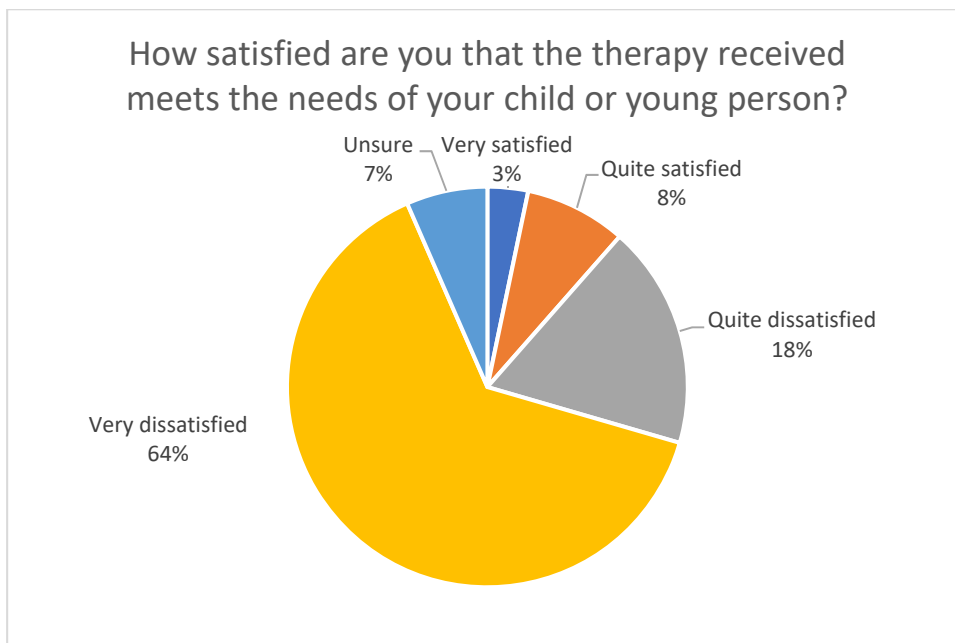
“Not the school, parents or our GP has received anything in writing all year from ECCH. I have made a formal complaint to PALS and intend to take this complaint as far as possible even legal action, I will also be going to tribunal with NCC over EHCP provision of SALT in my [child's] EHC plan.”

See Appendix D for all comments relating to progress feedback

How to improve

Work with parents and Sen advisory service to design a monitoring system with feedback forms to use for SEN support (IEPs) and EHC plans. This could be included as evidence in the graduated approach of Assess, Plan, Do and Review (IEPs) and EHC plan annual reviews. Parents should also be told how to get an earlier review or new referral if their child's needs change.

How satisfied are you that the therapy received meets the needs of your child or young person?



The results of our survey are 3% very satisfied, 8% quite satisfied, 7% unsure, 18% quite dissatisfied and 64% very dissatisfied with the service offered.

Most of the parents had no confidence in the current SALT service meeting their child’s/young person’s needs

“Many more appointments needed, no consistent communication.”

“I think it’s shocking this new approach of training the schools as there is no actual training.”

“No useful information given at the initial meeting and no follow up at all. I am disgusted by this service. We have now gone privately, at a large cost, but I feel for other children and their families who are unable to do this.”

“We were so dissatisfied that we complained to ECCH and NNCCG. This has led to face to face meetings with senior figures from both which has provided some reassurance that things will eventually get better but, by ECCH's own admission, its first year has been very difficult. Our child was to be discharged by ECCH based upon [my child's] EHCP report. However, we challenged this and have secured 6 weekly reviews based upon [my child's] progress and abilities. To be honest, SALT has been a nightmare ever since [my child's] first referral 5 years ago. It has not got better to date and the need to fight for every little thing has been constant. We have resorted to private SALT for over 3 years which has been the only source of progress [my child] has made. [My child] would have made no progress at all if it were left to the service provided by the Council/NHS.”

“I am dissatisfied with the level of input, which is falling short of what has been recommended in my [child's] statement. I think the service is spread too thinly and it is very difficult to get an appointment. The therapists themselves are good, but there are not enough of them to meet demand. I also find it appalling that every child is discharged after each visit and the onus is on the SENCO and/or parents to request a re-referral. There must be children who are missing out on essential support due to this and it must add an extra layer of admin to already over-burdened staff.”

I think it is a cynical attempt to reduce demand on the system. Early intervention will save money in the long run and lead to better outcomes. More investment in this area is needed."

"New procedure to discharge and then re-refer when targets achieved is awful - takes weeks after that re-referral before we can get an appointment. So, weeks of lost opportunities for development and intervention."

"There is no therapy. Having a visit once every 5-6 months isn't therapy."

"Support from feeding specialist is fantastic, we have a different therapist for communication and the experience is unfortunately very different. When talking about my child they described them as a 'Downs child', when I explained my child isn't a 'Downs child', but my child who just so happens to have Down syndrome' the response I received was 'whatever!'"

Simply unacceptable, the first time I spoke to said therapist I was told she wouldn't be aiming for my child to speak as long as she could make needs known. If you never aim for speech how are you ever going to help children reach their potential? I pay for private therapy for my children and they are speaking with correct support and encouragement and somebody who believes in them! They haven't received therapy from East Coast, they have been failed and only had assessments from somebody who barely knows them and given targets for myself to complete. If speech therapy was that easy a university qualification would not be required.

East coast should be ashamed of the 'service' (in the loosest possible meaning!) they are providing the children of Norfolk. The most vulnerable children are being failed and this is demonstrated by the number of parents feeling there is no other choice but to fund private therapy for their children."

See Appendix E for all comments relating satisfaction of therapy received

How to improve

A new system is needed – parents are not happy with current system of only receiving 1-6 appointments and then being discharged only to have to re refer again and go on the end of the waiting lists. Parents have concerns about the length of waiting times and children are not being seen consistently in each half term of the academic year. Some children only receiving one visit per academic year.

Work with parents to clearly explain what ECCH SALT service is – is it just a consultation service or is it a therapy service? And who is supposed to deliver the SLC therapy sessions to the children in the educational settings? ECCH SALT or their assistants? or do they train the key workers and TA s to deliver the sessions?

Offer training to all Nursery keyworkers and School and Colleges TAs on how to implement and support individual children 1 – 2 -1 SLC sessions delivered in their educational settings to help children reach their SMART targets/outcomes for IEPs and EHCp

Clearly communicate to parents what is on offer- What is in the initial assessment, how many therapy sessions will take place, where and by whom? And who to contact if they have concerns/queries.

Communicate with parents by letter after each visit with their child/young person. What have you been working on with their child? what new targets/goals have been set? what should educational settings and parents at home be working on – send information to the parents.

To comply with the C&F Act 2014 – monitoring and reviews of all children/ young people should be taking place who have been identified as having a SLCN needs and where ECCH have been referred to provide the provision to meet the SLCN in the EHC plans, they should also be providing effective continuous monitoring systems to check progress towards SMART outcomes as detailed in EHCP. Remember Annual reviews should set new SMART outcomes.

Has your child been allocated any SALT supportive equipment (i.e. iPad, laptop etc.)?

Only one Parent/ Carer had received SALT supportive equipment with a further 3 still waiting. Waiting time was between 3 to 5 months for 2 parent carers and over 12 months for the third.

How long did you have to wait?

The Parent/ Carer who had received SALT supportive equipment had waited 6 weeks.

- The whole point of the Children & Family Act 2014 is for a holistic and person centred approach to Education, Health and Social Care services.
- Parents need a SALT service that cooperates and communicates with other providers of communication aids and equipment.

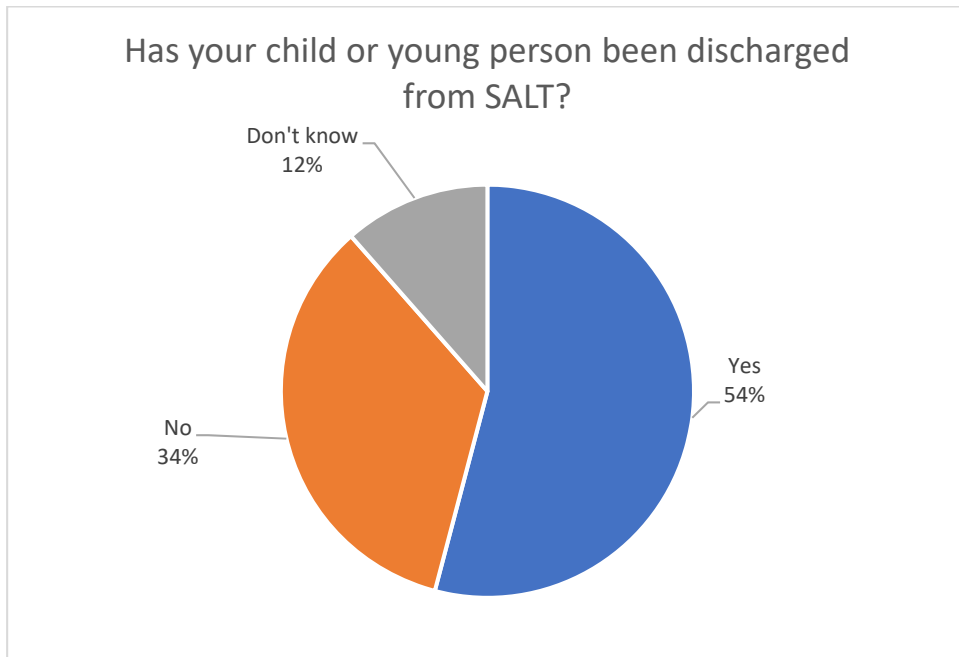
“Our [child] has use of a laptop at school through ATT (Assisted Through Technology service) for [my child’s] communication needs not through the ECCH SALT service – even though ECCH therapist suggested and sent information on ladder techniques used by dyslexics (to help break down tasks) to help aid [my child’s] poor working memory and communication skills.”

“Got a laptop funded through school only.”

How to improve

Work with parents to develop written information about communications aids and equipment, how it works, what to expect, what options parents have and who to contact. This written information should be made publicly available, so parents can find out if their child might be eligible and where to go to find out more information.

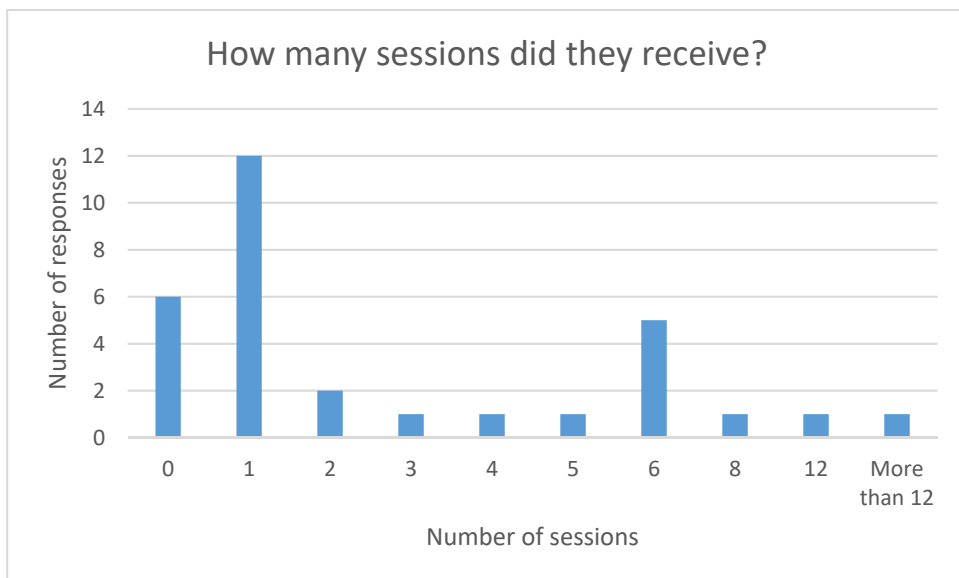
Has your child or young person been discharged from SALT?



34% of parents said no, 12% of parent are unsure and 54% of parents referred to ECCH have been discharged from the service.

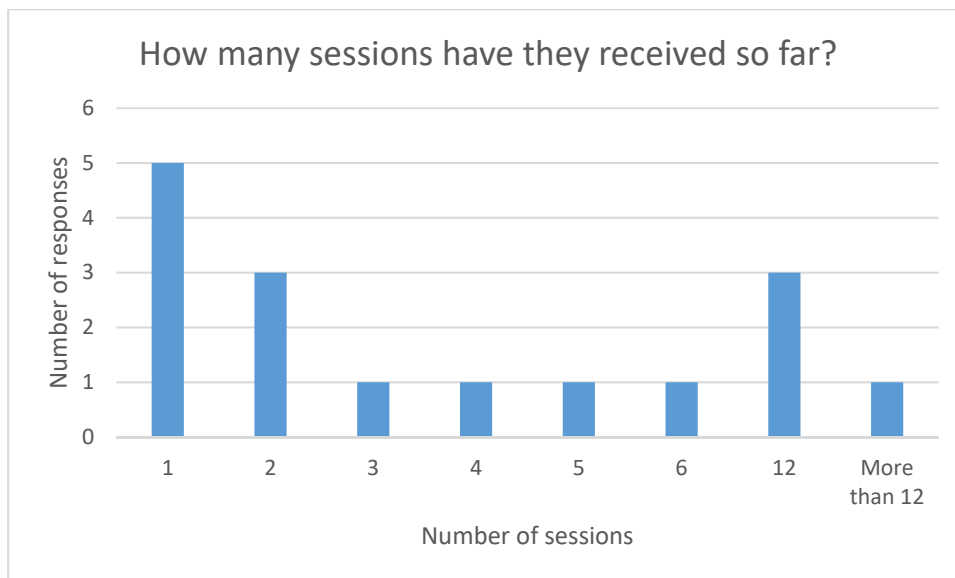
How many sessions were/have been received?

For parent carers that have been discharged, the following chart shows how many sessions the child or young person received.



Parents were offered none to more than 12 sessions before being discharged from the service.

For parent carers that are still receiving SALT services, the following chart shows how many sessions the child or young person has received so far.



Parents have reported that they have received between 1 -12 or more session from the service.

Parent’s negative comments regarding the current SALT service is they are discharge very quickly and must go through the whole process of re referring and waiting again. Those who are discharge with just recommendations and not actual therapy session are extremely dissatisfied with the service. Parents are worried about the time lost between referrals when their child receives no therapy at all – how are children to achieve their outcomes to Improve their language, speech and communication skills with no therapy provision provided consistently throughout the academic year?

“[My child’s] now seen at school. I don’t know when, what happens or for how long unless school tell me. When [my child] recently met [my child’s] targets I then received a report in the post and [my child] was discharged with a new set of targets and 2 activities.”

“Discharged my [child] with receptive/expressive disorder of 3yrs 6 months. He was 6 years 5 months. Despite phoning for two weeks daily informing them my [children’s] EHCP review date with 7 weeks’ notice, they didn’t show, they then showed up some weeks after the review, not communicating with the private speech therapist funded by the LA, they knew the therapist had been working with my [child], had her contact details. But went ahead repeated the same TALC test on my [child], within 10 days of the private therapist. (you can’t repeat the same test within 6 months) then discharged him. What are East Coast Commission full?? Failing our children - disgusting service.”

“Our [child] was under SALT but then they discharged [my child] from clinic [my child] has global developmental delay and undiagnosed Autism [my child] was discharged a year ago saying nothing wrong but clearly there is as [my child] struggles with [my child’s] speech and has speech dyspraxia.”

“Crazy system discharge with work then re refer to wait all over again.”

How to improve

Review and redesign the SALT service contract.

Important question to ask now is the current ECCH SALT service fit for purpose?

- Does this service identify the needs of children and young people in a timely manner?
- Does the service meet the needs of the children and young people identified in either SEN support or an EHC plan with a SLC needs in a timely manner?
- Does the service provision currently offer by ECCH and their discharge and re refer system meet the needs and provides effective monitoring of the needs of children with SLCN in Norfolk?
- Does this service have SMART outcomes – set appropriate targets, monitor and measure achievements regularly?
- Are annual reviews of EHC plans taking place to monitor children and young people’s changing needs throughout their lives?

These are the questions that the area inspection by Ofsted/CQC teams will be asking and looking for answers to.

Parents who took the time to fill in our online survey do not have confidence in the current SALT service offered by ECCH.

Finally, some general comments to be passed onto the HOSC Committee:

“The time it took was such a long time that as a family we ended up paying over one thousand pounds for private speech and language. When both my [child’s] nursery and [my child’s] private speech and language therapist spoke to them they stated they did not have enough staff to come see [my child] at present even though they agreed [my child] needed to be seen. They even commented that they have so many children and so little staff that they can’t keep up. I was also very disappointed to hear that when my [child] next gets seen it will be with an assistant, not even a qualified therapist. I feel the whole department has let my [child] completely down.”

“The whole system is lacking. We waited ages for our [child] to be transferred across to East Coast. Once transferred we waited ages to see a therapist. We then saw a therapist twice and heard no more. After constant ringing and chasing we found she’d gone on sick leave. It took ages for us to then get a new therapist. My [child] had a further 3 sessions in January, February and March. I have been chasing to find out when [my child’s] next session is to be told by [my child’s] therapist they have been told to see referrals rather than continue with children already in the system! How can my child become the best [my child] can without the proper support and specialist intervention [my child] needs?? Why is it left to parents to chase? Why do we ring a general number, unable to contact our therapist? It is diabolical that children with needs are given such little help.”

“It is disgusting that my [child] is having to wait so long for an assessment. [My child] needs help now and the longer [my child] must wait the more behind [my child] is going to be which will have a huge impact on [my child’s] confidence. [My child] starts school next year and really needs the help now but

as [my child] isn't going to get the help [my child] is going to struggle at school. The system is failing my [child] and we feel totally let down."

"We are and have been seeing a private therapist as our [child] requires regular SALT sessions which are not available on the NHS."

"Two of my children were under assessment for their EHCP within a month of each other & both with different therapists yet the advice given was word for word the exact same for both. One is 16 with Asperger's & no behavioural issues.

The other is 8 with ASD that presents as PDA & ADHD who has severe behavioural issues & been out of school for several months!

It seems that as they both have an ASD they must be the same according to the local SALT's seems they send out advice as a standard letter to all! Not really individualized."

See Appendix F for all general comments

Appendix A

Feel free to add any comments regarding the time to get a referral.

- We were already in the old system & was promised we would just be transferred over. They had no record of my [child] & it was only through lots of hassling that we got any kind of service
- First referral was good but the follow up has never happened!!
- My [child] got seen sooner than others as east coast met with parents at the hamlet centre with a few parents of children with Sen to try and iron out any problems and work with us, which of course they haven't
- Only seen for the EHCP We had a speech therapist for swallow and speech and then the system changed and we now need two Salt not one.
- The service was very disjointed and not able to focus on my specific child's needs, one size fits all just does not work. Lots of phoning from me and no response from them for a long, long time. No personal approach and a great deal of stress.
- Extremely slow, many children receiving 1 appointment at the very end of the year.
- We were already "in the system" so no referral needed. The original referral under NHCH was about 3 months - far too long for a child who was 2 at the time.
- Already 'in the system' took 5 months for 1st appointment when previously seen at least every 6 weeks and just before change-over [my child] was having weekly 1:1 therapy which had been beneficial.
- It was ridiculous my [child] had a block of Therapy last September, I was told [my child] would have another one in January. [my child] is now literally having a block and it's nearly a year. The therapist said [my child] had a severe speech disorder which I had been trying to tell them, [my child] now goes to school in September and I have literally only just been told about this special school [my child] can go to. I am very upset by how long everything has taken.
- Would not give an appointment
- Referred in Feb! Still waiting
- My [child] was originally seeing an NHS salt once a month and was put back on a waiting list for 9 months due to this re-organisation, we chased this appointment several times. I feel that the wait for the appointment has impacted on my child's communication. After waiting so long for NHS input we now have support from a private speech and language therapist and have since seen progress in my child's ability to communicate.
- Ended up going private,

Appendix B

Feel free to add any comments regarding the time to get an appointment.

- Still to attend first appointment 14/08/17
- It was decided they would give my [child] 6 one to one sessions with the view to if they were successful they would help apply for a personal budget for regular therapy after the 6 sessions they said yes then changed their minds and offered another 6 sessions after a 3-month break
- My [child] was receiving weekly SALT. It was stopped I was told because of funding cuts and the fact we were in the process of sorting out her statement. I heard nothing and rang up to be told [my child] was on the waiting list for SALT. I could not believe this as she had been receiving regular SALT prior to this being stopped. I was told she was the top of the list. Still nothing so I made a complaint. A therapist was then sent to assess my [child]. Details of assessment was sent and suggestions of things I and school could do. [My child] was then discharged and we were told could ask to be referred again and wouldn't take so long. My [child] can speak but it is [my child's] lack of understanding and social and emotional issues which are [my child's] problem. These issues have been ignored and we have sort private SALT. Presently we have had an EHCP review and are trying to get a personal budget for SALT on there. Very disappointed as you just seem keen to get the numbers of children being treated down without caring about their full needs.
- We ended up going private for 7 years as wait was too long
- Again, no consideration of my child's individual needs, all was poorly planned
- Met SALT after her first visit with my child at nursery. Second visit to nursery 9 months later I knew nothing about until after the visit and received a report this morning!
- We have been told despite a speech delay we will receive nothing.
- After waiting several months, we were discharged after one appointment.
- Over 2 years-my [child] was diagnosed with verbal dyspraxia by NHS in late 2015. [My child] was then offered 3x4 lots of SLT before ECCH took over.

Appendix C

Feel free to add any comments regarding the assessment and therapy recommended.

- Would not come out to 15-year-old only spoke to school and parent over phone and recommended some things
 - Therapy is nonexistent.... only assessments followed by advice
 - It's down to the nursery to forward information on.
 - After the 3 months break my [child's] anxiety was so bad [my child] wouldn't do it, leaving the 3 month break for children with Sen isn't good as they need to build relationship. I've told them not to bother as getting therapy caused me so much stress it wasn't worth it now gone private.
 - Nothing was said before the assessment date, just during it. And I got sent an info pack on some mouth exercises.
 - The information provided was useful, however I was told that my [child] did not need regular input and would be seen in 6 months. The recent educational psychologist reports we received states that my [child] requires regular SALT and that this should be part of [my child's] EHCP. I am therefore pleased that we decided to approach a private therapist to ensure he gets the support [my child] needs. [My child's] communication delays are the main reason we are delaying [my child's] entry to school for a year so that we can ensure [my child] can effectively communicate [my child's] wants/needs.
 - Only had 1 appointment as [my child] is ASD and they don't support that aspect of SALT
 - The speech assessment was in a new format I think. It looked none clinical and was not clear.
 - The swallow salt changed, I received a letter that I didn't agree with but the salt was rigid in her position, even though she had not known my [child] she said things I didn't agree with and we didn't resolve this. Parts of her assessment were wrong and she would not change them.
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- I was very happy with the SLTs who have seen my child and their recommendations were useful.
 - What a surprise... no information...
 - This took over 3 weeks to come through after the school SENCO chased it up.
 - No one seemed to really know what they were doing when the sessions finally began. This was linked information gathering by the services about my [child's] other associated needs, all very poor.
 - My [child] was already in the system but initial assessment under the new service provided [my child] with objectives that were completely unsuitable. I took this further and managed to get them reviewed and completely changed.
 - Therapy recommendations weren't great as she hadn't got to know my child. It takes a few sessions for my child to warm up to someone.
 - As I am a teacher there was nothing shared with me that I wasn't already doing with my child. It was suggested that there was a follow up appointment and after 9 months this has still not happened, even after frequent phone calls. We have now decided to go privately which is very costly, but at least my [child] is getting the help [my child] needs, from a provider who seems to care.
 - Spent the whole time advising me what children with ASD do and not once spent time getting to know my [child]
 - Very quick and felt rushed. Left information that I struggle to read and have had support from Portage to explain.
 - Everything that was advised is already being implemented! [My child] eye contact HAS made a massive improvement as well as social interaction! I have been on the pyramid PECS course in July and if I had been spoken to then the therapist would have known this!
 - Our [child] was seen by therapist who said that [my child] had an open bite so felt that therapy would not be appropriate.

Appendix D

Feel free to add any comments regarding feedback about your child or young person's progress from your therapist.

- My [child] made no progress really, [my child's] had private now for about 8 weeks and has made progress and is a lot happier with the therapist who [my child] trusts
- Took 8mths from assessment date till they saw us again.
- not very positive. never attended any annual reviews
- My [child] has speech problems it is still delayed. [My child] needs a review but this was a year ago [my child's] last appointment. The speech Salt was very lovely but discharged too quickly and I do think now we need to review. My [child's] siblings have speech delay and when they had therapy 5 years ago, at the same age as my [child] they had had a brilliant service. They were monitored at preschool, school and intervention set up and managed. At about age 5 they went to Upton road for specialist speech groups. The current speech service wouldn't know if my [child] would need that.
- The swallow salt discharged and to be honest [my child] had been so difficult/ confrontational in meetings that I'm happy to manage without her. Before this we had a very positive Salt relationship and clear guidance was given. I just continue following the advice of our original therapist.
- We received a discharge basic report, with common sense things on that I could have written
- [My child] initially had one to one and this was incredibly repetitive so he got bored, therapist felt he could not concentrate. Next was group sessions in small group again very repetitive and he got very bored, all parents who sat with me agreed the therapy was poor and the children would get more from being in their playgroup settings. Stated this to the therapist who smiled politely but nothing changed.
- The therapist calls me to discuss when she has seen my [child] but that is very seldom. There has been no program in place to improve [my child's] speech, the focus has solely been on the total communication approach and the use of symbols which, as parents, we have agreed is important but [my child] has such potential to speak much better and loves to talk that to have no focus on making speech sounds is incomplete and wrong.
- [My child's] now seen at school. I don't know when, what happens or for how long unless school tell me. When [my child] recently met [my child's] targets I then received a report in the post and [my child] was discharged with a new set of targets and 2 activities.
- None yet because it's taken so long to have [my child's] Therapy
- Extremely long waiting time, very poor communication
- My [child] was referred to speech therapy at 2 years. They saw [my child] once every two weeks and then once a month for about 2 months. It then changed to once every 3 -4months since then
- I have received two reports one after each visit to nursery! The total sum of visits my [child] will receive as [my child] has now been discharged!!!
- local NHS salt was not able to help as there was no money in pot
- SALT isn't just about the sounds it's also about the understanding. On two occasions that our [child] was under SALT service we were given lots of photocopy sheets and left to get on with it. Our first experience of SALT was through our surgery. Our therapist was excellent and gave us advice that we still follow today. We were disappointed when the service then moved away.

Appendix E

Feel free to add any comments regarding the therapy your child or young person receives or received.

Quite dissatisfied

- If my [child] wasn't at a specialist school now I'd be very dissatisfied. Just before the cut over [my child] had got to the stage where [my child] can engage in 1:1 therapy, [my child] had 6 sessions(weekly) in which [my child] made great progress and was really benefiting. After change-over [my child] didn't see anyone for 5 months (I had to kick up a fuss to get seen). There was no therapy, just an assessment and '[my child's] about to start school now so they'll do it.' I was given a couple of activities to do with [my child] (which I did anyway) and that's it.
- Therapy received was brilliant, informative and helpful for my [child]. I was taught how to help [my child] at home which I still do. My major problem is one to one time spent with NHS speech therapist is nowhere near enough. One hour every 3-4 months does not give therapist enough time at all to get to know the child's progress. Regular and consistent therapy for a child with significant speech and language is key. We have had to go PRIVATE to supplement what the NHS is doing. My [child] sees a private speech therapist once a week term time which has been very helpful.

Very dissatisfied

- The speech technician had no idea how to relate to my [child]
- Just because a child can talk does not mean that they don't really need SALT to be able to function in the world. Receiving a photocopy sheet about selective mutism is not much help.
- I am upset by the service and did lose sleep over it. I can't afford private but I have had children with speech problems in the past so I'm just using my own experience to manage the situation.
- 3 home visits consisting asking my child to point at items in book, & choose an activity from a picture.
- Stated before, no bespoke aspect to the service, my therapist also agreed this was not a possibility even though it was needed.
- It has been minimal.
- Not satisfied at all given [my child's] current level of need, [my child's] unrepaired cleft, [my child's] atypical oral anatomy, the weight of evidence which shows [my child's] conditions' propensity towards speech and language difficulties, and all the evidence which how's how important early intervention is for children with S&L difficulties. The social enterprise may be saving itself money in the short term, but it will doubtless cost the NHS more money in the longer term.
- Too little too late and too long in between
- I was told that my [child] would be getting 3 sessions but only got two. Change of therapist not told that this was happening. During assessment SALT telephone kept ringing.
- Everything advised to us is what we already do! We have made progress but not regarding verbal communication! We have received no therapy around speech and language outside of two visits to nursery! There is a comment about the therapist being involved to help with my child's care and therapy, however as my child starts reception in Sept they are no longer allowed to be involved in my child's therapy!

Unsure

- Local SALT was overwork and not have any places left
- I think it will be good when they actually start.

Appendix F

Please use this opportunity to tell us anything else about your experience with SALT?

- Not willing to help as [child] was 15 years old, autistic and said language and speech would not improve if they come out. Not helpful at all.
- We have not had our appointment yet. I was told it would be after school holidays so [my child] could be seen at school but it came through earlier in the holidays and we had to delay as we are away. It came through faultless quickly but I had already sourced a private assessment as I was told it would be a 4-month wait.
- Not fit for purpose.
- My [child] is still non-verbal and doesn't have any form of communication. We've had to re-refer in. Salt are the hardest professionals to get hold of with the least amount of help.
- I'm not sure how these therapist sleep at night, told me had I considered complex needs school Yet the private therapist has stated my [child] is not a complex needs child, [my child] will manage just fine if he has SALT, [my child's] EP agrees, as does [my child's] teacher. East Coast Seriously failing Norfolk children.
- I spent so much time emailing phoning and chasing them up they gave me so much false hope I just had to give up. I've gone private and it's the best thing I've done my [child] has made improvement and is happy to do [my child's] speech as we have found the right therapist. We are paying now but hoping to get a personal budget. East coast are a complete waste of time
- Haven't seen them enough to have a proper experience.
- Feeding specialist very helpful and supportive, communication complete opposite. Overall a truly disappointing, frustrating, concerning experience that has failed not only my children but many other vulnerable children in Norfolk. My children have very complex needs, medical, feeding, and social and communication. These needs aren't going to vanish and they need continuity and support from people with experience and qualifications that enable them to support their needs.
- The therapist couldn't give us any ideas on how to work on [my child's] speech at the time of the appointment (even though I quizzed her about it) and put [my child's] problems down to having ASD and said the ASD team should have been working with him. I was quite annoyed with this as I know other speech therapists can work on this and the problem was down to [my child's] speech articulation and not necessarily down to ASD.
- She did email us some pictures of speech sounds to practice and suggested we buy an Elklan book.
- In her report she named the speech problem [my child] has and discharged us. I really thought we would have had more help but she didn't seem qualified enough to know how to help.
- Whole process was very confusing and a very long wait, over 9 months to get a letter saying basically not support ASD children. To then query it, wait another few months, then get EHCP team involved and suddenly they want to come out to assess in school. But no ongoing therapy as ASD and can technically talk but as I said earlier talking is more than just the technical, if you cannot talk outside your home that has quite an impact on your ability to progress.
- not that impressed in our situation. It's never ever been explained why our child cannot speak
- Very, very disillusioned and frustrated that my [child] has been casted aside because [my child] can speak. It's [my child's] lack of understanding and social skills that are [my child's] problem but because these are unseen your service does not want to bother with [my child].
- Please change this back to what it was. This is a terrible service, and whilst I understand in theory the whole discharge straight away I think it just means too many children are being made vulnerable by repeated waiting times etc. or are more likely to be missed completely.
- Not happy they still haven't received iPad recommended

- It's non-existent. My [child] has only been seen for [my child's] EHCP assessment, the only info I received was that report. [My child] has been seen twice between Dec and July. [My child] is a non-verbal autistic child, who is making all the correct noises and no words. [My child] needs the additional help from speech and language. Once [my child] starts school in sept the only person [my child] will see is her Pead as then the therapist can no longer be involved in her care. Utterly shocked at the services available to autistic children in Norfolk. SALT was better before the change; before the change [my child] had seen two therapists within 8 weeks!
- Our experience was fantastic until EAST COAST took over SALT last year. Since the changeover no one answers phone calls, no one replies to messages... and all our children are still waiting for the therapy so crucially needed. It's completely disgusting the way parents/children have been left with no information.
- Hard to get service, but when you get it, it's very poor. They discharge you after 6 visits, you must wait for 3 months before putting on waiting list again, & there you can wait another 9 months before you see someone, effectively leaving my 4-year-old with no SALT for a year. Absolutely crazy system & they will end up paying for this cost cutting lunacy in the future. It makes me so angry they are messing with my Childs potential at being successful at school etc., because we are just being abandoned.
- I can only comment on my experience with my child. The school SENCO however has had horrendous issues getting further targets for children that have achieved the ones originally set by the salt. She has rung each week for the last three weeks of term requesting a call back to no avail. Totally and utterly inadequate from the service which is badly letting our children down. Not enough therapists to meet the demands of today's society!
- Poor communication throughout. We went private and in a space of weeks the improvement was astounding. Months waiting and then the service with the east coast and [my child's] speech and confidence got private sessions and then linking this well to other services things are far better. When I spoke to east coast staff they almost seemed embarrassed by the service they are having to offer. My child's therapist was a lovely person but had no skills to get down to my [child's] level, play and interact with [my child]. All very poor, sorry to be so negative.
- Not enough provision so uses a private speech and language therapist.
- I am very unhappy, I have 2 children and both our experience has been poor, I saw the same SALT and she didn't tell us anything that we couldn't have worked out ourselves, I dislike the fact that we must phone up for subsequent appointments and have nothing in-between.
- There is a drive to use PECs as opposed to voca which is not supported by research but they do not take parental preference or child preference into account and have threatened to withdraw services unless PECs are used I find this surprising and narrow in the current climate of holistic education and meeting individual needs
- we have found it much better there seem to be more therapists now especially for deaf children
- my child's development was greatly disadvantaged by the lack of SALT for 5 months at a critical stage of [my child's] life. [My child] was having good support and making progress before the changeover and then everything stopped. [My child] had just started saying a couple of recognisable words and was responding well to 1:1 therapy. When it all stopped I did what I could, researching myself and help from portage but [my child] needed therapy from a professional. I am so grateful that [my child] got into a specialist school last September. [My child] is now with professionals that can support [my child's] speech and language development and I don't need to rely on East Coast.
- Crazy system discharge with work then re refer to wait all over again
- No very happy with the service received. The school did more for my child when phonics was introduced.
- Over many years there has been minimal input from SALT. There seems an unwillingness to work 1:1 with a child over a period to develop their communication skills. Children are quickly discharged without their communication needs being addressed.

- I am concerned that the therapist does not have time to offer a 'gold' standard of therapy. She makes every effort and I am confident that she has the right clinical skills but there is a lack of time to offer therapist directed intervention and regular school visits.
- As I mentioned, my [child] is behind with [my child's] speech and this has been acknowledged and yet we have received NO therapy. I was told it will be YEARS before [my child] catches up and yet [my child] gets nothing. Honestly, what's the point of this organisation?
- It would be better for the salts to recommend reading material for the parents because the tidbits that they provide every 6 months are completely insufficient. To date the recommendations, they have made could have been written on a single A4 sheet and provided by a health visitor. Most of what we do with our child has been wholly intuitive.
- This was a very well organised service with good feedback about areas of need and treatment needed.
- I'm disappointed by the lack of communication we have had. Also, when they say they will ring they don't. I'm very disappointed because if I would have known about this special school my [child] could go to [my child] would have probably got a place from September but as I'm only now seeing a therapist I have only just been told about it [my child] had [my child's] assessment and scored very low. Also, all I keep getting told is they are short staffed and there's nothing they can do.
- dire
- Disappointing
- Myself, my [child's] pediatrician, health visitor and a family support worker have been contacting the service repeatedly over the past 18 months, to be told every time that [my child's] awaiting allocation.
- Poor service, lack of useful information given, signed off my [child] and told phone again in 3-months' time, still awaiting a follow up appointment.
A total lack of interest in what is needed and what has already been provided by the parents, so advice not appropriate for where [my children's] needs were at the time.
- As I have said previous I feel very let down by the SALT team. It has taken many phone calls and emails just for my [child] to be seen. They have given me dates verbally for when they would see [my child] and then never come. When questioned they have said they don't have the time as they are to short staffed. The [child's] speech is very behind and the only reason [my child] is beginning to get better is because we had to pay for private help as the NHS salt team had let us down. They saw [my child] around November last year and done an assessment, stated [my child] was very behind and my [my child] has only just had [my child's] first session.
- Very limited service- assessment only so far within my [child's] nursery setting. We have had to seek treatment privately to meet my [child's] needs. Thankfully we have been able to pay for this but have had to make sacrifices to do so.
- I have had to fight to be seen it shouldn't be this way early intervention is so important.
- It's not been positive - unless we hadn't self-funded private since [my child] started school last September, [my child] would've nothing. Thankfully [my child's] about to start at an SRB in September but I feel that since ECCH have taken over he has been completely let down! If they spent more time offering support to those already on a waiting list instead of churning out 'drop in' sessions, then it might go somewhere to support those that need it.

- SALT sessions- Very good but not regular enough so impact limited. It is hard working with your child as a parent without regular guidelines from professionals. Regular interaction with professionals brings more success. What we have noticed is that after the NHS speech therapy sessions with my [child] became irregular, once every(3-4months), the accuracy of their reports about [my child's] progress declined because they don't see [my child] regular enough to get the true picture of how [my child] is progressing. My most shocking experience with SALT is that they cancelled an appointment to assess my [child] at home in August 2017 before [my child] starts school (Reception) in September. Their reason being that because [my child] has already been assessed at end of July by the Private Speech Therapist and they have got the report about [my child's] progress, it's not necessary to see [my child] again so they will instead see [my child] end of Sept in school. SHOCKING. I thought NHS SALT oversaw my [child] and the Private Speech Therapist is supplementing, not the other way around. Thanks for opportunity for this survey. Might help the NHS do something about it.
- When telephoning staff not very helpful. Have waited in for SALT to telephone at given appointment time but no contact was made. On another occasion, I rearranged my plans to fit in a telephone appointment only to not get a phone call. When I finally met a SALT then discharged and told to contact again when my child has completed tasks. I have got no idea how to do this with my child as not shown. I am left confused, frustrated and feel what is the point of contacting SALT if I then must wait a year to hear from them!
- Not very helpful. Didn't get to know my child.
- It's a joke! Two visits within the nursery setting, only one I knew anything about and only because of my request for an EHCP. I was spoken to only after the first visit with my [child]. No interaction after initial appointment, no discussions with me about the what would help my [child] or what we already have in place, the fact I have done a two-day training course with PECS to help [my child] communicate. How they feel they can make a competent assessment of my [child's] needs and abilities within one setting for an hour observation each time 8-9 months apart and cannot see the progress [my child] has made or find out all the things we already have in place for [my child] astounds me. My [child] is nearly 5 and is nonverbal [my child] has ASD, but we have worked very hard in trying to help [my child] in all aspects [of my child's] social and communication issues. [My child's] eye contact has improved massively since [my child's] initial diagnosis, and [my child's] socialization with close friends and [my child's] brother have drastically improved to the point [my child] will hunt [my child's] brother out for a hug and kiss, and will sit and play with him regularly at home. This is something we never thought we would see. In all honesty with the shocking service and support provided you may as well shut the service down and provide money to each parent towards a private SALT therapist, at least that way their children will be provided with the help they deserve!
- When my non-verbal [child] was 2 they said there was not much they could do for [my child]. When they learnt we were with a private SALT they were very keen to discharge. Apparently, they will visit my still non-verbal [child's] school in September ([my child's] now in reception), observe [my child], inform staff about [my child's] needs, then discharge [my child] again! We've only referred ourselves again to try and prove they can't provide an adequate service and therefore try to access [my child's] personal budget for private SALT. As far as we're concerned there is no service, and we do things ourselves, and we do not rely on the public sector for anything.
- Local NHS salt was not a good experience due to lack of funding and being overworks, a child with more complex need put on a back burner to one that got more understanding. went private in the end and got better treatment and respect for the child and parent.

- When our [child] was first seen by SALT through our surgery it was excellent. We had personal sessions and group sessions. We were also advised to model sentences back which we still do today. The service then moved away from health to education. In infant school, [my child] was seen a couple of times with huge gaps between each session. Our [child] needs consistency and [my child's] school did not have the resources to concentrate exclusively on [my child]. They then decided to write [my child] off. At that time, we were unaware there was a physical problem. At this point I put in a complaint about the SALT. When he started Junior School, [my child] was seen again the new SALT service. [My child] was seen once for assessment where they decided it wouldn't be appropriate given [my child] had a physical issue. Again, they have written [my child] off. I feel strongly that SALT isn't just about the sound but also about the understanding. We still model our sentences back and get here to repeat them. Given our [child] has a learning disability [my child's] learning age is about 2 years behind [my child's] actual age so [my child's] school and we are trying to teach [my child] according to [my child's] learning age. Our experience with SALT hasn't been overly successful.
- I have found the service very slow with reports often not received until months after the assessment visit.
- Three sessions in about 3years, sessions to far apart, not been involved, not impressed with overall experience so far
- Didn't receive any confirmation that referral had been received. No indication how long to wait
- Good advice and support to start with Makaton, but then pretty much left to it. Feel we are falling down a gap. Would benefit from support now but must wait until [my child's] fallen back even further behind to get support again - some progress made, then left to it under new system. We need more SALTs.
- Therapist offered advice and pamphlets on sign language when it was obvious my child needed proper therapy and was advised to call again 4 months later if my child was still not communicating. Absolutely not good enough.
- My child has received speech and language therapy in the past. The last time was a good while ago and to be honest the service was very good.