

Family Voice Norfolk Consultation on Access to Speech and Language Therapy Services for Norfolk County Council Health Overview Scrutiny Committee on 10th October 2019

Consultation

Parent carers of children and young people with Special Educational Needs and/or Disabilities (SEND) were consulted via an online survey to inform this report. This report will be presented to the Health Overview Scrutiny Committee (HOSC) on 10th October 2019.

Background

Family Voice Norfolk (FVN) is a collective of parent carers from nearly 900 families across Norfolk and represents over 1,100 children and young people with SEND. FVN has been the strategic voice of parent carers working in partnership with Norfolk County Council (NCC) and the five clinical commissioning groups (CCGs) since 2006. It is funded through a direct DfE grant (administered through Contact), by NCC and the five CCGs.

Parent carers were invited to complete a questionnaire online and had the opportunity to write comments on their experiences of access to Speech and Language Therapy (SALT) services. The survey ran from 21st May to 19th July 2019. FVN received 119 responses.

A list of acronyms and abbreviations can be found at the end of this report.

Key findings

- Overall there has been some improvement in the SALT services that children and young people are receiving and their parent carers are reporting greater satisfaction with the ECCH service than previously;
- Waiting times to access SALT services are still far too long;
- Communication between ECCH therapists and parent carers needs to improve;
- Some schools are not providing follow-on therapies either due to lack of qualified staff or lack of resources;
- Norfolk needs a jointly-commissioned service that provides a seamless service between health and education services;
- There is a perception that funding is still not adequate to meet the needs of children and young people within Norfolk who require SALT services to meet their potential.

From 2017 to today

Family Voice Norfolk presented a report on SALT to HOSC in September 2017. Many key concerns at that time are still being raised by parent carers:

- **Long waiting times to see a professional.** Over 60% of parent carers who are waiting to see a professional have been doing so for over 6 months, with 23% reporting that they had waited over a year;
- **Long waiting times between the sessions.** Parents feel that these are not frequent enough to benefit the child or young person;

- **No consistency** in sessions being provided. The therapist is often a different person each time, which means that progress is more difficult to monitor and relationships between the child and their therapist cannot be established;
- **Poor communication** and feedback from the therapist to the parent carer;
- **A lack of proactive advice**, strategies or ideas to help both the child and the parent carer wanting to help their child;
- **A lack of a jointly commissioned, seamless service** where SALT services work with various educational settings, ATT and other services to provide a holistic package for children and young people.

We have also seen a significant increase in the following concerns:

- **Long-term speech and language needs are not being met.** Some parent carers had the impression that children and young people are not receiving sufficient sessions because ECCH has to “meet targets”;
- **Having to re-refer** because child or young person is discharged too soon;
- **Schools are not being supported**, with sufficient professional development, when ECCH transfers services to schools. One parent reported:

"I have paid for private speech therapy to provide training to my child's school."

- Schools are not co-operating with the balanced model. **There are insufficient teaching assistants (TAs)** to provide daily or weekly sessions;
- Parent carers are not having their expectations of the services managed effectively. **ECCH is not communicating their core offer** such that all parent carers are aware of ECCH's balanced model and how that meets the needs of children and young people;
- Parent carers feel angry and disappointed about a **perceived lack of funding for SALT** services;
- Of those families currently accessing SALT services, 63% are receiving services from ECCH, while 19% are **paying for services privately** and 4% feel the need to supplement ECCH services with private, paid-for provision. That 23% of families receiving SALT services who responded to our survey are funding these themselves seems to point to a disturbing and growing trend. Parent carers are only doing this because they do not feel that the services from ECCH (or lack of them) are meeting the needs of their children. There may be many more who are equally concerned but unable financially to take this action. Those accessing private SALT services reported significantly higher levels of satisfaction with the service they were receiving.
- Many of the parent carers feel that their **child or young person with ASD would benefit from SALT** but report that they had been told that interventions are not available for these children or young people;

"I'm still shocked that a child can be assessed, needs identified then that service say sorry we are not funded to help. It's madness. It's well documented early intervention is key to positive outcomes. But what's the point assessing children to tell them what's the issue and then not actually help them?"

- **Communication aids and training are not being supplied** even though they are stated in their child's EHCP;
- **Families having to provide communication aids** for their child or young person, at great expense;
- **Lack of funding is cited as a reason** why children and young people are not having access to communication aids and training;
- Being concerned that when SALT transitions services to schools, **the school does not have adequate funding to provide services.**

Over 80% of parent carers who responded to this survey have children under 11 years old. These are young children that deserve timely and adequate access to speech and language therapies, communication aids and training that will help them reach their potential.

SALT services are still inaccessible to many Norfolk families either through long waiting or the lack of sessions provided. There also appears to be significant **inconsistency in the quality of service** from ECCH, which may point to problems in management or performance monitoring. Both these comments are from families accessing services from ECCH:

"Took nearly 2 years to be seen, no relationships being built up as different therapists with different opinions."

"Our therapist is fantastic. Has been with us for 6 years through thick and thin. I know all I have to do is call her and she's there to help."

Key Recommendations for Improvement

Many of the recommendations from this report reiterate the *Bercow: Ten Years On* report that was published in March 2018 and updated this year. They mirror the five key areas that still require urgent action nationally.

Supporting long-term speech and language needs

- Reducing waiting times for children and young people to access SALT services;
- Improving communication with parent carers so that they are
 - adequately updated on how long they should expect to wait and how to follow up if they have not received any correspondence within a reasonable time period;
 - receiving regular information and feedback on progress;
 - provided with proactive advice, strategies, training and ideas to help their child or young person;
- Providing sufficient and regular sessions to meet the needs of the child or young person;
- Enabling the therapist and the child or young person to establish a good and consistent relationship;
- Ensuring early intervention with pre-school children to alleviate potential issues later in life;
- Providing appropriate communication aids to allow development of speech and language.

Vulnerable groups

- Providing interventions for children and young people with ASD to enable them to reach their potential.

Professional development of those working with children and young people

- Ensuring that schools have sufficient and appropriately-trained teaching assistants so that children and young people can receive SALT services to meet their individual needs;

Incentivising schools

- Ensuring schools continue with the SALT sessions once SALT services from ECCH finish;

Joint commissioning

- There needs to be adequate accountability, through jointly commissioned services, so that once ECCH have agreed a programme for a child or young person, the communication aids and training for them and their parent carers are actually provided;
- Schools need to receive adequate funding to ensure that the balanced model provides the correct level of services for children and young people.

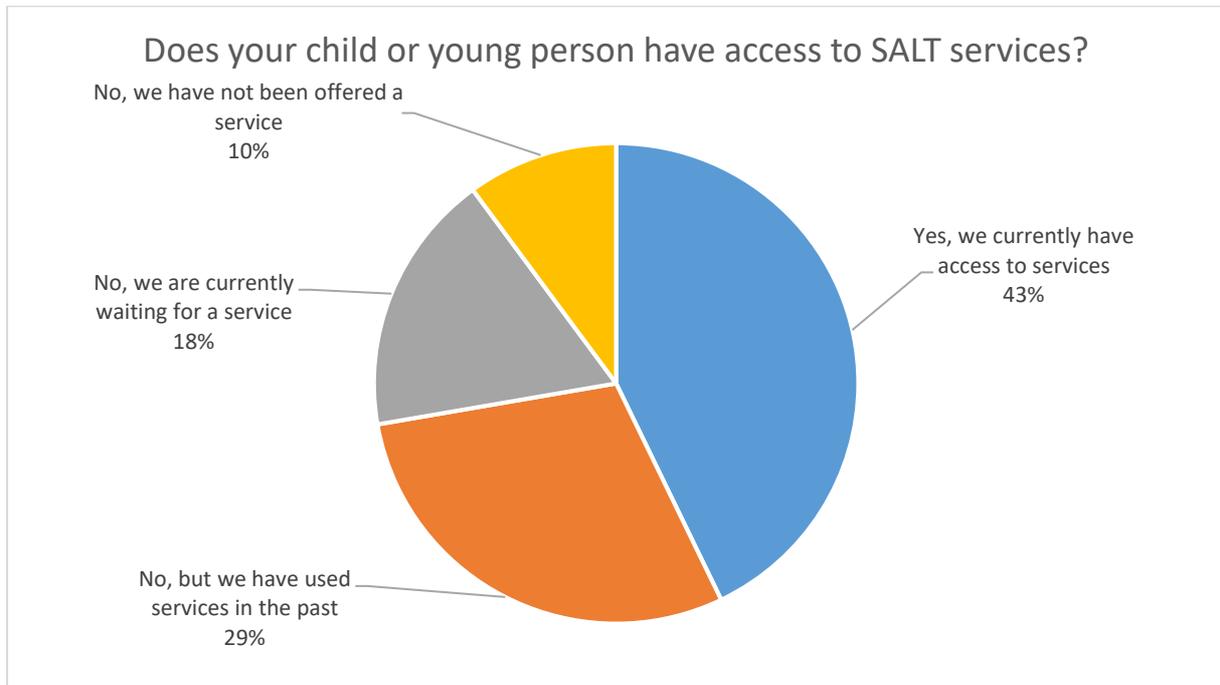
As one parent told us:

"The new changes sound promising but ONLY if schools are given the funding to access training and are made accountable for a child's SALT needs if they are discharged from ECCH and the care transferred to the school. We have been here before when the service first started and whilst the model is good it needs to be fully funded and workable as too many children are falling through the gaps. Clear pathways for ASD, DS, Social communication need to be made. I know this is happening but so many children [are] not getting ANY help."

Main Findings

The survey segmented parent carer responses into four distinct groups. Parent carers whose children and young people were:

- Currently accessing SALT services – 43%;
- Previous recipients of SALT services – 29%;
- Waiting for SALT services – 18%;
- Not in receipt of SALT services – 10%.



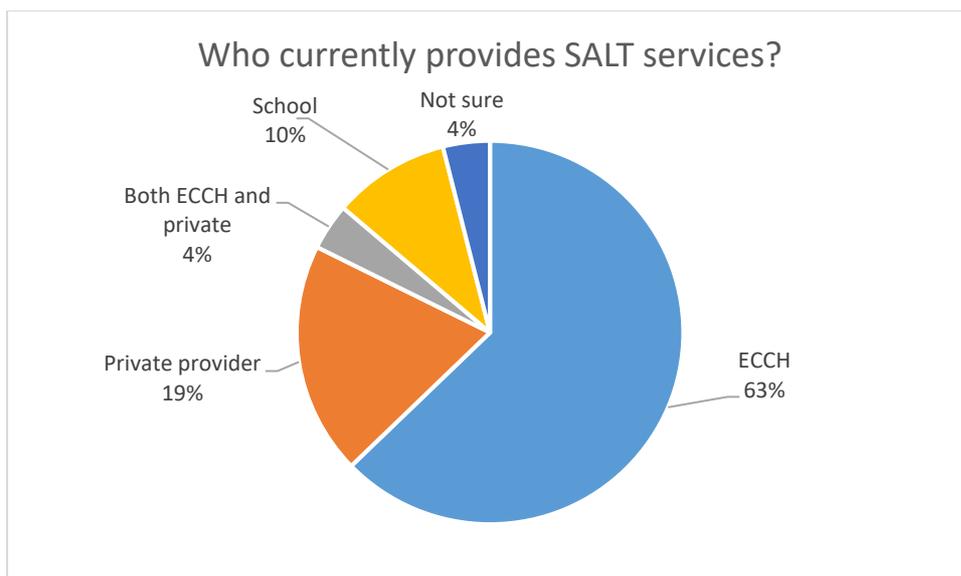
Each group were asked separate questions relating to their experiences of SALT services. This was then followed with a series of questions about communication aids and training.

Currently Accessing SALT Services

43% of all parent carers who responded to this survey are currently using SALT services. The data provided in this section relates to the 51 parent carers that answered questions specifically relating to the current services that they are receiving.

This group of parent carers were asked who currently provides the service for their child or young person.

East Coast Community Healthcare currently provides exclusive SALT services to 63% of children and young people, with the private sector providing 19%. A small number of parents supplement the ECCH provision with services that they pay for privately.



Parent carers were asked where their child or young person received their SALT sessions. Some children and young people access SALT services at more than one location. Over 80% received them in an educational setting, with 33% receiving them at home. Only 6% received a SALT session at a drop-in centre.

Parent carers were asked if they were happy with the services that they were currently receiving. Overall, only a third of parent carers currently receiving SALT services were happy with the service their child or young person was receiving. Parent carers were happier with privately provided services than those received from ECCH.

| | Yes | No | Partly | TOTAL |
|-----------------------|------------|------------|------------|-------------|
| ECCH | 12% | 18% | 33% | 63% |
| Private provider | 17% | 2% | 0% | 19% |
| Both ECCH and private | 0% | 2% | 2% | 4% |
| School | 2% | 0% | 8% | 10% |
| Not sure | 2% | 2% | 0% | 4% |
| TOTAL | 33% | 24% | 43% | 100% |

Of the 67% of parent carers who were not happy or only partly happy, the main reasons given were:

- Only receiving six sessions, which does not fully meet the needs of the child;
- Long waiting times between the sessions. These are not frequent enough to benefit the child or young person;
- No consistency in sessions being provided. The therapist is often a different person each time, which means that progress cannot be monitored and relationships between the child and their therapist cannot be established;
- Long waiting times to be seen in the first place. Cases of over a year and up to two years;
- Poor communication and feedback from the therapist to the parent carer;
- Lack of proactive advice, strategies or ideas to help both the child and the parent carer wanting to assist their child;
- That there is an impression that children and young people are not receiving sufficient sessions because SALT has to “meet targets”.

Parent carers that were happy with SALT services cited regular sessions, good relationships with therapists and informative feedback. Often this was because they either had paid privately for sessions or were supplementing sessions with private ones.

Below is a selection of comments from parent carers who are happy, partly happy and not happy with the current services that they are receiving. The full set of comments can be found in Appendix A on page 11.

“He is only seen 6 times a year which is not enough for a child who loves to talk but has a severe speech disorder.” – receiving ECCH services

“When we once raised why he could not receive more [sessions], we were told that as his speech needs were so significant, they could not achieve target impact with him like they could with other children.” – receiving ECCH services

“Took nearly 2 years to be seen, no relationships being built up as different therapists with different opinions.” – receiving ECCH services

“No consistency in appointments or feedback given to us. We never know in advance when SALT is attending our son in school. Can be weekly then months!” – receiving ECCH services

“Our therapist is fantastic. Has been with us for 6 years through thick and thin. I know all I have to do is call her and she’s there to help.” – receiving ECCH services

“Private sessions are tailored to our needs at a time and place convenient for us. The wait for NHS services has been so long.”

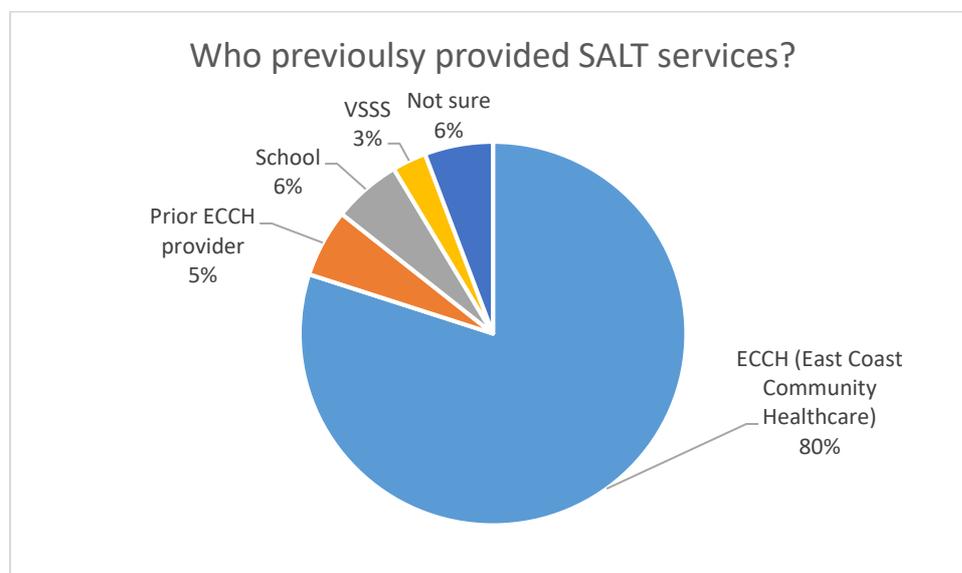
Areas for Improvement

- Providing sufficient and regular sessions;
- Establishing a good and consistent relationship with the therapist and the child or young person;
- Ensuring parent carers receive regular feedback on progress;
- Providing parents with proactive advice, strategies and ideas to help their child or young person.

Previous Recipients of SALT Services

29% of all parent carers who responded to this survey have previously used SALT services. The data provided for this section relates to the 35 parent carers that answered questions specifically relating to the services that they have previously received.

This group of parent carers were asked who previously provided the services for their child or young person. East Coast Community Healthcare provided SALT services to 80% of children and young people. No parent carer said that they had previously used a private provider for SALT services. This indicates that parent carers are now considering private providers when looking for SALT services for their child or young person.



Parent carers were asked where their child or young person had received their SALT sessions. Some children and young people accessed SALT services at more than one location. Over 70% received them in an educational setting, with 23% receiving them at home. 23% received a SALT session at a drop-in centre. This is a significant change from those currently receiving sessions and indicates a reduction in the use of the drop-in service.

Parent carers were asked if they were happy with the services that they had previously received. Overall, only 14% of parent carers who have previously received SALT services were happy with the service their child or young person received. Parent carers who are currently receiving SALT services are much happier than those who have received SALT services in the past (33% v 14%).

| | Yes | No | Partly | TOTAL |
|---------------------|--------------|--------------|--------------|---------------|
| ECCH | 5.7% | 31.4% | 42.6% | 79.7% |
| Prior ECCH provider | 0.0% | 2.9% | 2.9% | 5.8% |
| School | 2.9% | 2.9% | 0.0% | 5.8% |
| VSSS | 2.9% | 0.0% | 0.0% | 2.9% |
| Not sure | 2.9% | 0.0% | 2.9% | 5.8% |
| TOTAL | 14.4% | 37.2% | 48.4% | 100.0% |

Of the 86% of parent carers who were not happy or only partly happy, the main reasons given were:

- Long waiting times to be seen;
- SALT services start the sessions but “off-load” to the school, which sometimes does not have the resources or professional development support to pick up the therapy sessions;
- Poor communication and feedback from the therapist to the parent carer;
- Lack of involvement with the therapist and the parent carer. Parent carers often did not know what was going on with their child;
- Advice was given but not sufficient training for parent carer to feel confident to help at home.

Many of these issues echo those from 2017, which suggests that improvements have not been consistently made.

Below is a selection of comments from parent carers who are happy, partly happy and not happy with the SALT services that they had previously received. All comments can be found in Appendix B on page 14.

“Long waiting lists. Long wait for report. Poor feedback after visit, it took weeks for her to ring. Then no therapy provided.”

“Son is non-verbal and struggles to communicate. SALT appear to see him once, and then tell the school what to do so he is ‘off their books’ so they look efficient with a small caseload when in actual fact, they are not working with children who need it.”

“I don’t feel particularly informed or involved with what is/did happen because it took place in school. I’m not sure if there is on-going work happening or not.”

“I was informed my child is too complex for this service.”

“They gave good advice for us to fulfil exercises at home but it’s not practical to deliver these a) as a parent with a child that will not co-operate like they do with a professional and b) due to lack of knowledge about what I’m supposed to be doing with the exercises.”

Areas for Improvement

- Reducing waiting times for parent carers;
- Ensuring schools continue with the SALT sessions;
- Ensuring parent carers receive regular communication and feedback on progress;
- Providing parents with adequate training to help their child or young person.

Waiting for SALT Services

18% of all parent carers who responded to the survey are currently waiting for SALT services. The data provided for this section relates to the 21 parent carers that answered questions specifically relating to currently waiting for SALT services.

Parent carers were asked how long they had been waiting. Over 60% of parent carers have been waiting over 6 months to see a professional so that they child or young people can potentially have access to SALT services.

| | |
|---------------------------------------|---------------|
| Less than a month | 0.0% |
| Over a month but less than 3 months | 28.6% |
| Over 3 months but less than 6 months | 9.5% |
| Over 6 months but less than 12 months | 38.1% |
| Over 12 months | 23.8% |
| TOTAL | 100.0% |

Areas for Improvement

- Reducing waiting times for parent carers;
- Ensuring parent carers are adequately updated on how long they should expect to wait and how to follow up if they have not received any correspondence with a reasonable time period.

Not in receipt of SALT services

Finally, 10% of all parent carers who responded to the survey are have not been offered SALT services. The data provided in this section relates to 12 parent carers and of these, 83% feel that they child or young person should be receiving SALT services. Many of the parent carers feel that their child or young person with ASD would benefit from SALT but that interventions are not available for children with ASD. Other parent carers have been told that their child is too young for SALT services.

Below is a selection of comments from parent carers. All of the comments can be found in Appendix C on page 16.

"We were told that we could ask for a referral but that there would be no point as they do not provide interventions for children with ASD."

"I don't know [why we have not been offered SALT services]. He has just turned 2. He has Down's syndrome. So upset has not been offered yet. We have SALT involved for feeding issues only."

"My child has struggled with speech their whole life. They find it difficult to find the right words when speaking and therefore, often doesn't bother to contribute to the conversation."

Areas for Improvement

- Early intervention with pre-school children would help alleviate potential issues later in life;
- Providing interventions for children and young people with ASD to enable them to reach their potential.

Communication Aids and Training

This section aims to find out the different types of communication aids and training that children or young people have access to, both provided by parent carers or through schools and SALT sessions.

53% of all parent carers said that their child or young person did not have access to any communication aids or training and that many of them had to provide this for their child personally. From this cohort, a third of children and young people are currently receiving SALT services. Parent carers are saying that communication aids and training are not being supplied even though they are stated in their child's EHCP.

Parent carers are having to personally provide, at great expense, communication aids and are using PECS, tablets and Signalong at home with little or no training as their child does not have access to these at school. Lack of funding is cited a reason why children and young people are not having access to communication aids and training.

The other 47% of parent carers are receiving one or more types of communication aids, with 23% receiving tablets or laptops to assist with their communication and 18% using PECS.

| | |
|--------------------------|-------|
| Tablets and / or laptops | 22.8% |
| PECS | 17.5% |
| Signalong | 14.0% |
| Other | 7.0% |
| BSL | 5.3% |
| Eye Gaze | 1.8% |

Below is a selection of comments from parent carers. The full set of comments can be found in appendix D on page 17.

“Communication aids are essential to reduce the likelihood of a child becoming frustrated which then leads to poor behaviour. If you don't equip a child with these tools then you are creating difficulties for them and those they associate with.”

“I'm still shocked that a child can be assessed, needs identified then that service say sorry we are not funded to help. It's madness. It's well documented early intervention is key to positive outcomes. But what's the point assessing children to tell them what's the issue and then not actually help them?”

“Never been offered the use of aids or training despite son's EHCP saying he needs these.”

“It would be a good idea for SALT training such as talk boost or Eklan courses to be offered to parent/carers instead of just schools. Parents /carers can work on SALT at home and not just rely on schools to do the therapy.”

Areas for Improvement

- There needs to be adequate accountability, through jointly commissioned services, that once SALT have agreed a programme for a child or young person that the communication aids and training for them and their parent carers is actually provided;
- Children and young people need to be provided with the appropriate communication aids that will allow them to develop their speech and language;

Final comments from Parent Carers

One hundred and nineteen parent carers completed the survey on “Access to SALT Services” for their children and young people. Over 80% of parent carers who responded to this survey have children under 11 years old. These are young children that deserve timely and adequate access to speech and language therapies, communication aids and training that will help them reach their potential.

| | Mainstream | Special | Early Years | Home Schooled | Other | Total |
|--------------------|--------------|--------------|--------------|---------------|-------------|---------------|
| 0 to 4 years old | 10.9% | 0.8% | 14.3% | | 5.9% | 31.9% |
| 5 to 11 years old | 32.8% | 13.4% | | 4.2% | | 50.4% |
| 12 to 16 years old | 2.6% | 5.0% | | | | 7.6% |
| 17 to 21 years old | 2.6% | 3.4% | | 0.8% | 0.8% | 7.6% |
| 22 to 25 years old | 0.8% | | | | 1.7% | 2.5% |
| TOTAL | 49.7% | 22.6% | 14.3% | 5.0% | 8.4% | 100.0% |

Parent carers are:

- Disappointed with the long waits to get access to SALT services;
- Angry and disappointed with the lack of funding for SALT services;
- Having to re-refer because child or young person is discharged too soon;
- Feeling forced to seek private services for their child or young person;
- Concerned that when SALT transitions services to schools that the school does not have adequate funding to provide services;
- Concerned that schools are not co-operating with the balanced model. There are insufficient teaching assistants (TAs) to provide daily or weekly sessions;
- Not having their expectations of the services managed effectively. ECCH is not communicating their core offer such that all parent carers are aware of ECCHs balanced model and how that meets the needs of children and young people;
- Suffering financial impact of providing private services for their child or young person.

Appendix E (page 19) gives parent carers' final comments from the survey. Below are a few of these comments.

"The new way of referring is not helpful. You get one appointment then you are discharged and have to re-refer for another."

"The service my son received from the speech therapists was very good. Both practitioners were extremely competent in their specialist areas. However, once assessed for discharge, I feel my son would have benefitted significantly from follow up assessments. To implement support if needed."

"I feel let down and feel like we can't seem to access the care our son needs."

"ECCH need to stop discharging children when it's very obvious that they have SALT issues."

"A better understanding of what might happen and when - and why (for good reason) some things won't happen. Help manage expectation."

Parent carers were asked if they were happy with the service they were receiving and why?

Parent carers who have access to ECCH and are not happy

- Kept being discharged. Been fighting for 3 years to get more than 6 hours a year. Finally, been offered a trial 6-month period of fortnightly provision, but if progress isn't shown to be quick enough in meeting new targets will be reduced to monthly provision. Disagree with that theory.
- They only provide assessments, not dedicated SALT sessions
- No real strategies, ideas, or help with communication development
- My son has high levels of speech and language needs which are a very big barrier for him. He receives one visit per half term, often from a different speech therapist. When we once raised why he could not receive more, we were told that as his speech needs were so significant, they could not achieve target impact with him like they could with other children as he would make slower progress.
- He is only seen 6 times a year which is not enough for a child who loves to talk but has a severe speech disorder. The therapist keeps changing and so cannot identify progression etc. and keeps coming up with ideas that are unsuitable as they do not know him.
- There is too long a gap between the delivery of a block of sessions and reassessment.
- Very long times between contact.
- We never see them! Appointments cancelled and long waiting times.
- My son's usual speech and language therapist is fantastic but is off for a long term reason at the moment and we have little to no support from anyone who is supposed to be covering her? My daughter is nil by mouth and tube fed but supposed to be trialing tasters we need help with this and no help is being given I'm guessing we will be forgotten about until our usual therapist comes back in a few month's time. My son is also on the waiting list for help in school and has been since December still no sign of any help

Parent carers who have access to ECCH and are partly happy

- Surprised we aren't being asked to come back given my son's delay
- Saw a therapist at a drop in. She was very good. Phoned to find out when review would be and was told it be a year.
Terrible service.
- Took nearly 2 years to be seen, no relationships being built up as different therapists with different opinions. Thankfully our current therapist has been brilliant, she comes out once a month and has built up a relationship with my son.
- The SALT visits very infrequently and often doesn't offer follow up appointments
- We fought to receive the enhanced offer for my son but I still don't believe it is enough for his needs.
- I would feel more comfortable if the speech and language therapist would take the sessions, I feel it is important for them to assess the sessions as they are held , not do the first session and then not see them again for another 3 months.
- Long wait times between sessions
- No consistency in appointments or feedback given to us. We never know in advance when SALT is attending our son in school. Can be weekly then months!
- Not much in the way of proactive advice on how to improve his speech. Mainly watching/listening to my child and noting what he is doing. Not very useful.
- More is needed to make normal progress
- Service is good but few and far between. 26 week wait!!

- Happy with the service but there's just not enough of it. My son's speech is similar to a one-year-old (he is 6) and he has been granted 6 sessions (which took about 3 referrals before they agreed to it). The 6 sessions are being spread over 6 months.
- We have had two home visits as part of my daughters ASD assessment, 2nd one was to check how PECS was going that I introduced myself and we now have to wait another 6 months for a support person to come out to try and progress PECS (limited to 4-6 sessions)
- Waiting to hear what provision will be
- There has been poor communication, reports not provided for keyworker meetings/EHCP reviews
- My daughter should have been seen every 6 months and wasn't. I put a complaint to the patient liaison officer and she organised a meeting between myself, SALT services and the patient liaison officer, where we discussed my concerns with the service and the lack of support for my daughter. The issues have now been resolved but I shouldn't have to make complaints to get my daughter support that she needs.

Parent carers who have access to ECCH and are happy

- Now receiving weekly visits
- Good relationship with therapist - she calls to tell us when she is visiting school, telephones the results of the visit - changing targets etc. The written reports are detailed. School have upskilled their TA. ECCH, TA and family are all communicating well and our child is making slow steady progress.
- The SALT therapist is good at explaining what she is doing with our son and the teaching assistant. We also get a report at the end of the 6 sessions to explain what has been done and how much progress our son has made etc.
- Our therapist is fantastic. Has been with us for 6 years through thick and thin. I know all I have to do is call her and she's there to help.

Parent carers who have access to a private provider and are NOT happy

- Haven't seen or heard from SALT since my son started at his complex needs school.

Parent carers who have access to a private provider and are happy

- So far seems to be going ok, but my son's 1-2-1 support at school left in May and his new 1-2-1 does not have any experience or training
- Regular sessions, updated assessments and advice for home
- Have had this private service for many years, trusted, reliable, thorough, well qualified.
- The private provider can carry out social communication therapy which ECCH cannot. The provider is very qualified and goes above and beyond for my child.
- Weekly sessions are very supportive of my child's social communication needs which is a provision that ECCH don't provide. We secured a personal budget to enable our child to receive this invaluable support.
- My son is having weekly sessions delivered by a private provider and he has made so much progress
- Private sessions are tailored to our needs at a time and place convenient for us. The wait for NHS services has been so long.
- Expensive but fortnightly sessions have really made a huge difference!
- After fighting for years to get a service and paying privately my child we now see a therapist monthly

Parent carers who have access to SALT via school and are partly happy

- Not enough time on child
- Not enough time per child. Full terms between being seen. No reports
- We are happy that our son is getting the help he needs, but unhappy it has to be so far away

Parent carers who have access to SALT via school and are partly happy

- Not the fact that we had to go to court to get the help we needed.

Parent carers who have access to SALT via school and are NOT happy

- Monthly visits in school from a trainee therapist. No contact with the therapist himself. I do not feel my child's speech has benefited at all from this intervention. We pay for private weekly sessions.

Parent carers who are unsure of provider and are happy

- My son's speech is improving and the SALT therapist has emailed my few times about his progress

Parent carers who are unsure of provider and are NOT happy

- Don't know anything about how often, for how long, what exercises or progress my son is doing.

Parent carers who had access to ECCH and are not happy

- I felt he was abandoned whilst still needing help. He is a non-verbal autistic boy with global development delay.
- My son needs a lot of support & he just is not getting the support needed which should be weekly
- Son is non-verbal and struggles to communicate. SALT appear to see him once, and then tell the school what to do so he is 'off their books' so they look efficient with a small caseload when in actual fact, they are not working with children who need it and who will have to be treated and referred again and again.
- Long waiting lists. Long wait for report. Poor feedback after visit, it took weeks for her to ring. Then no therapy provided.
- Some advice was given but no monitoring or support services offered and sit and wait services are always oversubscribed. On top of which other referral services are not clear and are very long.
- Was not kept in touch with what was happening
- Early signed off/not met the target but discharged
- No communication of the assessments or conclusions/reports have ever been sent to me.
- After 10 mins of meeting my child it was decided that she wasn't ready she was nearly 3 and having a level 5 in childcare I know she was

Parent carers who had access to ECCH and are partly happy

- I was given some very useful tips and some help on how to help my little boy's speech started but would prefer a regular SALT therapy.
- Long wait for help
- Long waiting list to be seen, under staffed and under funded
- My child is now beginning to speak / make recognisable words but I am unsure how to request that the service is re-started
- Child has stammering that comes and goes on a regular basis, can be very severe, i.e. every word. Then disappear for days or weeks then suddenly reappear. Very difficult to assess as so irregular, however when assessed he was graded above the level for support. His school teacher is excellent but no additional speech and language support is offered to him at school or through NHS therapy. I was told he would probably grow out of his stammer. My son is six years old.
- I was informed my child is too complex for this service.
- My child was discharged after assessment and school training/programme. School have continued this programme with my child for 2/3 years and he still benefits from it. If I felt it was necessary, I would need to contact SALT for another assessment but as I haven't tried it, I don't know how easy it is.
- I don't feel particularly informed or involved with what is/did happen because it took place in school. I'm not sure if there is on-going work happening or not.
- It was only one visit
- When accessing the service he got on fantastically, but due to demand on time of the SALT because he could communicate, albeit through mixed up sentences, they decided he could access the support directly through the school, however the school do not see him as a priority so he was put to the bottom of the pile
- Long waiting list and not a real ongoing service
- Better to be kept on.
- They gave good advice for us to fulfil exercises at home but it's not practical to deliver these a) as a parent with a child that will not co-operate like they do with a

professional and b) due to lack of knowledge about what I'm supposed to be doing with the exercises.

- only had 2 visits from them
- By the actual therapist yes but the fact nothing was able to be delivered despite it being highlighted was pretty rubbish

Parent carers who had access to ECCH and are happy

- They did help and the help that the school staff received also helped my child.
- Lots of information given and needs met
- Gave my child the help that they needed

Parent carers who had access to NHS SALT services and are NOT happy

- My child needs on-going support
- I was never told when or if he was having speech therapy

Appendix C – Comments from parent carers who have not been offered SALT services

- No language issues despite ASD profile
- My son was very late in starting to talk, preschool were going to put a referral through but by the time it was sorted he was catching up
- Service did not assess correctly or able to provide for social communication difficulties
- As she is autistic, the local SALT service is not commissioned to offer it
- We were told at the family voice conference on their stall that they can accept referrals for children with ASD but cannot provide any intervention so it was a waste of our time trying to access their service.
- We were told that we could ask for a referral but that there would be no point as they do not provide interventions for children with ASD.
- Because they don't cover ASD
- I don't know. My child has just turned 2 and has Down's syndrome. So upset has not been offered yet. We have had SALT involved for feeding issues only.
- Capacity
- No idea? My child has struggled with speech their whole life. They find it difficult to find the right words when speaking and therefore, often doesn't bother to contribute to the conversation.
- Told not necessary at this stage [child is under 4 years old].

Appendix D – Comments from parent carers with regard to communication aids and / or training.

Comments from parent carers who are currently accessing SALT services

- Getting SALT is a fight (same as everything else in the SEND world).
- ATT don't see the importance of parents helping or being trained only school and there's no monitoring or how the equipment is being used by school staff.
- Cost, availability & getting a suitable mobile system
- Our daughter's requirements are beyond our level of delivery
- ATT is under staffed and overstretched meaning no-one is getting a service. I had to send in a personal iPad for over a year whilst we waited.
- As soon as your child goes to complex needs school ATT take back the iPad unless it is in place of a child's voice. So my child who has Down's syndrome and a visual learner, getting on well with the apps, had them taken away. Yes, complex needs school has a whole communication approach the iPad and apps enhanced her learning. They have one session with iPads a week and don't have the Down's syndrome education apps. I applied for a charity grant from radio Norwich for an iPad, applied crayon and apps and was successful
- Never been offered the use of aids or training despite son's EHCP saying he needs these.
- It is stated he needs these on his EHCP but none are provided.
- It would be a good idea for SALT training such as talk boost or Eklan courses to be offered to parent/carers instead of just schools. Parents /carers can work on SALT at home and not just rely on schools to do the therapy.
- Receive most communication support from Sensory Support and portage not ECCH
- The information that the non-private SALTs give is good; however, it is not enough for children with significant speech and language needs. The non-private SALT service is poor, but this is in no way a reflection on the therapists themselves.
- Communication aids are essential to reduce the likelihood of a child becoming frustrated which then leads to poor behaviour. If you don't equip a child with these tools then you are creating difficulties for them and those they associate with.
- We also use now and next language
- have had Talk Tools at Special School, at College this hasn't been provided yet PECS and Signalong generally used in class.
- I have been very unhappy with my son's progress regarding his speech. We feel he has regressed and I have asked for a review of his speech sessions and was told he had to have his school yearly review in order to trigger a possible increase in funding for him. All this has been done. He has been assessed in April. We are now in July and NOTHING has been given to me regarding information about his speech AT ALL. I feel that my son is being let down by the NHS once again and I am furious that because he has a learning disability, expectations of his speech are so low.
- My child has used a variety of electronic communication aids but they've either been lost by school or haven't been appropriate
- My daughter was meant to be getting a communication book haven't received it as of yet
- Signalong is used at his school
- Terrible service all around

Comments from parent carers who have accessed SALT services before

- I've seen how important it is for any support with aids/training to extend to home and respite providers as well as school setting.

- urgently needed
- I'm still shocked that a child can be assessed, needs identified then that service say sorry we are not funded to help. It's madness. It's well documented early intervention is key to positive outcomes. But what's the point assessing children to tell them what's the issue and then not actually help them?
- My little boy is going to be 3 in a month. Most of the time I was told that he's too young for SALT.
- Far too eager to discharge every time
- He is shown PECS in setting
- I have paid for private speech therapy to provide training to my child's school.
- Kept asking school and other agencies about my child's speech but to no avail. Just received PDA diagnosis but still no help
- My son wears hearing aids in both his ears, we need more support with signing
- Some apps were silly prices to access, so support to connect to these would have been good
- The SALT explained that the talk tool sessions were provided by school staff as if this was their specialty! They are not specialists!!! Why is this acceptable???
- These aids were available when my child was at [complex needs school].

Comments from parent carers who are waiting to access SALT services

- I'm using PECS and also school using them, however i didn't have any training provided, I had to learn everything myself.
- My son has not been seen by SALT yet

Comments from parent carers who have not been offered SALT services

- My child will be 18 this year and although they had some help during primary school years, they didn't have any at high school. My child is now at City College.
- I'm teaching myself basic signs & teaching my son, he's not signing any words at present.

Comments from parent carers who are currently accessing SALT services

- A better understanding of what might happen and when - and why (for good reason) some things won't happen. Help manage expectation
- Children should be seen in the time frame and there should be better communication with families and other professionals
- ECCH need to stop discharging children when it's very obvious that they have SALT issues.
- Having to wait nearly 2 years to be seen is disgraceful. Our children need consistency with the therapists in order to make progress rather than the "lucky dip" system that seems to be in place since ECCH took over.
- I feel extremely well supported by SALT and although they are under pressure, I always feel they are there if we need them.
- I feel that there isn't much support that can be offered to a child that is not yet talking
- I have to go private in order for my child to get seen in a timely manner. Very disappointing NHS service.
- I would like to see more regular SALT input
- In my experience not enough support is given in the early years. I looked into training myself, but there are no courses available, unless you work in the field. Only when we threatened to look at out of county education in year 4, and having had a private assessment done ... did he receive regular focused SALT. It was too late really, he had fallen so far behind. The SALT he saw was from ECCH SALT, through sensory support, it was the first time a tailored approach was used.
- It has been a nightmare, we only got extra support for one of my children because we went to court, if we didn't we had no help. One child got signed off, they will need help for life. It's a disgrace that we have had to pay for private support.
- It is still woefully inadequate for children with complex needs.
- NHS service would make a real difference
- No reports come back and long waiting times to see anyone, it is not operating properly.
- The service is poor. Our daughter has SALT sessions in her EHCP. ECCH will not start providing these sessions until the following term after the EHCP. In our daughter's case, because the EHCP was issued at the start of the summer term, she will receive no support until the beginning of the next academic year, missing months of desperately needed therapy.
- Sadly there was a gap when my son did not have SALT as his school (mainstream primary that seemingly didn't think he needed it) but since moving to a complex needs school this has restarted and improvements made.
- Services are mostly conducted at school, parents aren't involved much and it's hard to keep up with what your child is working on and what you should be doing at home with them.
- The advice has been very disappointing. I was expecting more support from this service in regards to developing communication, even if it was at pre-verbal stage
- The new changes sound promising but ONLY if schools are given the funding to access training and are made accountable for a child's SLT needs if they are discharged from ECCH and the care transferred to the school. We have been here before when the service first started and whilst the model is good it needs to be fully funded and workable as too many children are falling through the gaps.

Clear pathways for ASD, DS, Social communication need to be made. I know this is happening but so many children not getting ANY help

- The new changes to the speech and language system from September are ridiculous for anyone working in a pre-school setting. Totally unfair.
- The new way of referring is not helpful. You get one appointment then you are discharged and have to 're refer when for another.
- The NHS discharge you at the first opportunity and then you have to refer and wait on a list again.
- The SALT service is not good enough, I'm lucky we have a Personal Budget for my son but if I didn't he wouldn't be getting the therapy he needs.
- The service is significantly lacking
- The service provided is still distinctly lacking for many families and children and waiting list times are unacceptable
- The wait for NHS services is far too long. I've taken a second job to pay for private sessions while we wait for our NHS sessions start. I feel it's too important to wait.
There isn't much communication while you are waiting to get to the top of the list.
- They are over worked and not enough support or general support particularly in schools. Teachers NEVER get involved
- This so called service has been shocking since ECCH were commissioned. I have another son who's also on a waiting list to be seen. I will end up going private
- Useless
- Very long wait for services
- We are lucky that we can afford to pay for additional speech and language sessions for our son. However, if we could not, then using only the standard SALT service would in no way meet his needs.
- We pay for private SALT fortnightly whilst we have been fighting ECCH for increased provision. Have lost faith in their service & believe they will probably drop to monthly provision after the 6-month trial, which I will challenge. Keeping private SALT as I don't want my child's potential to be continually jeopardised through inconsistency. Ideally would prefer a Personal Budget & not have ECCH.
- We were denied access to the service in 2014 when it moved from Upton Road to ECCH so we went to a private provider for consistency, but we could not afford to sustain this cost indefinitely.
- Why does the service have to be done through the school? I feel I have no say or control or input as a parent about what is going on. The school is absolutely useless at passing information as well. I have asked many times for details and always been dismissed.
- Would love to be able to say something positive about this service but after around 7 years of experience, things are still very poor.

Comments from parent carers who have not been offered SALT services

- As parents we should be able to access other providers who are able to respond quickly - early intervention is key
- Awful
- How can assessment be made without a meeting face to face
- I'm aware resource is low with SALT in Norfolk, group sessions may be a good way to start if not enough staff currently to provide individual sessions.
- It should cover all areas, including ASD
- They are non-existent in Norfolk
- We feel it's disgusting that as our children needs stem from her autism and she does not have a learning disability, no-one will offer any help or support about her communication needs.

Comments from parent carers who are waiting to access SALT services

- A leaflet advising certain exercises and an EHCP application that was turned down prior to assessment
- Being a disabled parent with a disabled child I wasn't able to access the drop in sessions that you needed to do to access. Eventually we got through to speak to someone. We then got put on a waiting list for an assessment. They then put us on another waiting list for a therapist and said it can be up to 12 months. We've already waited 2 years.
- Dreadful. Very long waiting period to be seen and fobbed off with come back in 6 months if still worried. Few pre-printed exercises to practice in the meantime
- Hopefully we will not have to wait too long for this service
- I feel let down and feel like we can't seem to access the care our son needs
- I'm worried for how long we will have to wait. My daughter has had a problem for 10 months. I was told she couldn't be seen until she'd had the problem for at least a year and was told when to go to the drop in session to get her name added to the list. However, I've found from other parents that the waiting list is over a year so I shouldn't really have delayed to get her name down for help. We are now additionally waiting for an assessment appointment as part of a multidisciplinary team assessment and I have no idea how long that list is. Too many children in our area have issues and have been waiting so long that help which should have been supplied before the children start school has not been provided.
- It's getting worse having had two older children with SALT needs I worry even more for my 2-year old son being able to access this service, looks like I will have to go private again. ECCH is not fit for any kind of service.
- Make it clear to families how long the wait is (up to 18months - 2 years!) at the start of the referral rather than telling them they will be seen within x amount of weeks.
- My daughter has been referred to SALT on several occasions by myself and her medical team due to her speech not developing which was expected due to her congenital condition. SALT repeatedly states they could not support as she was under 2 and therefore pre-language and her support should come from portage. SALT is the only service she does not yet receive (although we are now on the waiting list) everything else she had as early intervention. Her speech is the most delayed. Personally I am very disappointed in the lack of support.
- My doctor has been trying to get my teenage daughter a speech therapist. He got very angry as they wouldn't take her on as she's got learning disability. She's had SALT from age 3-12. She has her diagnosis then so why say that now. I just need help for her to communicate.

- Non existent
- People need to be seen quicker
- SALT services are non-existent for me as the waiting period is just beyond everything
- The services are very poor for me as my son has been discharged from services in nursery however his speech didn't improve. We had to reapply again when he started school and still on the waiting list. I'm sorry to say but SALT service is non-existent for me
- Too slow to get seen, long waits, not convinced then the limited sessions will be enough. Be nice to see same SALT therapist too as I know this isn't always the case. Accessed drop-in at my Children's Centre but worried this will go for other families as my Children's Centre is closing.

Comments from parent carers who have previously accessed SALT services

- Direct therapy intervention is not even discussed in this questionnaire. Why not? It is evidence based and appropriate to provide in many instances.
- East coast signed off and now my son is taking private therapy
- ECCH is very under-funded and doesn't have enough staff to support the children in education that needs support
- Extremely angry and disappointed parent. Very angry at the Government for cutting funding and forcing the CDU to close and leave children in needs with mediocre services. Shameful!
- I feel like they just want to get rid of you as soon they can. Same happened with my daughter after her ASD diagnosis. As soon as they are diagnosed, you're out the door and left feeling unsupported and helpless
- I feel that although the therapists in the speech and language service are great that if referrals are down it is not due to effectiveness of service but most likely the inaccessibility and lack of support leaving parents feeling it's not beneficial.
- I have 3 children with special needs. I struggle to get one child to school, to leave the house. I have a letter to say that I should have help but I have none. Sorry if this does not make sense. I also have dyslexia.
- More funding and more therapists required. Bring back the NHS SALT service!
- My child's current situation is difficult as they find day care too busy and lashes out.
- Needs improvement
- Not sufficient! This is the service we struggle to access the most. Very frustrating for us all.
- The opportunity for drop-in sessions is amazing
- The service my son received from the speech therapists was very good. Both practitioners were extremely competent in their specialist areas. However, once assessed for discharge, I feel my son would have benefitted significantly from follow up assessments. To implement support if needed.
Now at school, his stammering is still very much part of his daily speech, this unfortunately limits his communication and language skills. I also believe that further guidance for schools and teachers how to support children that have borderline needs would be beneficial. Especially stammering as it can, in our case come and go but can be severe. Without support this could have a detrimental effect on his learning and mental health.
- Very long waiting list
- We're just so disappointed that there is no real service offered
- Would of like to have had my child's needs assessed further before being dismissed. Due to the fact he can talk although he cannot express his feelings or general needs.

Acronyms

SALT – Speech and Language Therapy
ATT – Access through Technology
PECS – Picture Exchange Communication System
PDA – Pathological Demand Avoidance
ASD – Autism Spectrum Disorder
ECCH – East Coast Community Health
CDU – Child Development Unit