



Norfolk CC HOSC 12th July 2018

Family Voice Norfolk Update on Children's and Young People's Speech and Language Therapy Services from ECCH

Background

Family Voice Norfolk (FVN) represents the views of over 770 families with children and young people with special educational needs and/or disabilities across Norfolk, including the Great Yarmouth and Waveney area. FVN has been the strategic voice of parent carers working in partnership with NCC and the CCGs since 2006.

Consultation

Our initial report to HOSC on 7 September 2017 represented the views of more than 70 parents. Since then we have gathered the views and comments of parent carers at our annual Conference on 10 March 2018 and also from our monthly Membership Reports for the last six months (January to June 2018), which our Membership Secretary collates from existing members updating their information and new members telling us about their families for the first time.

FVN has been involved in the Task and Finish group for the SaLT Local Offer page. However, having been identified as a key stakeholder, FVN has not had any involvement with the Stakeholder Group, which was a recommendation from the previous HOSC meeting.

FVN also shared feedback with the independent consultancy Better Communications CIC in May 2018. Discussions at that meeting are not included in this report.

Key Messages

Key messages being raised about ECCH SaLT services are:

- Parents are increasingly concerned about the lack of SaLT resources and provision of services;
- Parents are still concerned that their child's needs are not being met;
- The level of or lack of services that children are receiving is causing worry, stress and anxiety for parents. Many feel that they have no support;
- Parents are still concerned that the current system of six sessions is not adequate to meet the needs of their children. They are not aware that there is an enhanced SaLT service that can be accessed, which is over and above their commissioned core offer of six sessions of therapy (this was agreed after the last HOSC review);

- Parents still want to have confidence that the professionals who deliver the service are compassionate and understanding;
- A number of parents are paying privately for SaLT services in Norfolk as they are unable to access the services that their child requires and do not have confidence that such a service will become available;
- Parents lack assurance that the service is fit for purpose.

There are instances where parents are pleased with SaLT services:

“SaLT is a weekly session”;

“SaLT is amazing”;

“Our child likes ECCH speech therapist, they visit once a month”

There have been some successes with the ECCH SaLT contract – the under-5s drop-in clinics around the county are reported as being effective for children under 5 with relatively minor speech-therapy needs, although these are most valuable when fewer families attending means that more time can be given to each child. Busier clinics have been reported as being less effective. Families with children with more complex or profound speech-therapy needs are being advised by ECCH not to attend the drop-in clinics but ask for a referral straight away for a full clinical assessment.

How to Improve

FVN request involvement in the SaLT Stakeholder Group.

A new system is needed so that after the initial 6 sessions, the child is not automatically discharged and then has to be referred again.

The SaLT services contract needs to be reviewed and re-designed so that it is fit for purpose.

ECCH were invited to present a workshop on their service at the Family Voice Conference 2018, which they did. These are extracts from Conference feedback reports from parent carers:

- Problems cannot be resolved in 6 sessions.
- 18 week waiting time for referrals – minimum. Then at least a year waiting on a list for therapy. No prioritising for severe cases.
- ECCH don't provide therapy. Having to pay for private SaLT, which is very expensive. ECCH don't have the resources and say their hands are tied.
- Shockingly bad.
- We have already been to mediation and were lied to over SaLT. We have had an annual review and not seen any paperwork/amendment notices yet. We intend to go to tribunal over SaLT/ECCH services, short breaks provision, sensory integration therapy, CAMHs services and transport to school.
- Our child has mild speech impediment. I telephoned ECCH for an assessment and they tried to do the assessment over the PHONE – not face to face. Our child did not recognise the voice on the end of the telephone and refused to speak. I did not know

what was wrong and ECCH then refused him a service – saying he did not meet their criteria. We have paid for private SaLT service for 20-minute sessions per week for over six months. Our child has a speech impediment which is correctable but does require therapy and exercises. Conclusion ECCH are not fit for purpose and NCC and CCGs are failing children in Norfolk by insisting they keep this contract going until 2020.

- We must pay privately for SaLT and Sensory integration therapy as this is not available to us otherwise.
- I found SaLT really bad, felt like the lady could not be bothered, also my child is coming up to his 4th panel which isn't helpful when trying to get help.
- Need more help with SaLT skills.
- Provision and process are ever-changing but rarely better than non-existent and shambolic!!!!!!
- There is an extreme lack of speech and language therapy in Norfolk. Not only no actual "Therapy" being provided to our children, but no support for our parents either – "just left in the dark."
- Referral timescales and actually getting therapy very different.
- Going into complex needs schools – when does this happen? Our child has achieved their last outcome, need next target. When will we get regular intervention? My child needs aren't being met.
- Workshop gave a very basic lesson on what communication is (pointless) only 10 minutes for Q & As. ECCH explained about service but did not complete presentation.

Issues and Concerns from monthly FVN Membership Reports January – June 2018.

- The whole system concerning SaLT is completely flawed.
- EHC plan – SaLT. We have a plan that states intense SaLT programme, SaLT have interpreted this as two assessments in a whole year.
- SaLT – my child has had an assessment, target set, on waiting list for a block of SaLT. So, we are paying privately now.
- Early bird didn't tell you how to deal with things. At Early Bird course someone said how good SaLT was but all we have had are cancelled and changed appointments. Our child is non-verbal.
- We moved here from Poland, it's hard to find things here, what services, help, therapies are here. SaLT is a weekly session.
- My child starts school soon and am worried our child won't cope because of lack of speech and separation anxiety.
- I put on a brave face – all other parents don't understand at school. Reception is lacking services – Speech and SRB unit. Applying for EHC plan.

- My child has delay in speech and language – working with professional on that.
- SaLT is amazing, Dietician amazing, physio service lacking.
- SaLT went into Nursery, but my child didn't interact. My child only understands two key words. Can't string words together. If sentences are said too quickly he can't follow.
- Our child likes ECCH speech therapist, they visit once a month and set up a program of therapy with LSA in school. High school have paid out for EKLAN training to up skill their LSAs who will work twice weekly with our child. My only concern is our child has learning disabilities and speech and language difficulties and we are not convinced 6 sessions will be enough. I don't want our child to have to be referred to service to wait all over again for an assessment and then waiting list for therapy. That would mean our child would only receive one set of therapy an academic year. The whole systems surrounding disabled children is so flawed and so stressfully for parents.