

Family Voice Family Chat Sessions on SEN Support and Education, Health and Care Plans (EHCPs) September and 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. FNV aims to influence the planning, design and commissioning of local services so that they can better meet the needs of families of children and young people with special educational needs and/or disabilities (SEND). It is funded through a direct DfE grant (administered through Contact), by NCC and by the five CCGs.

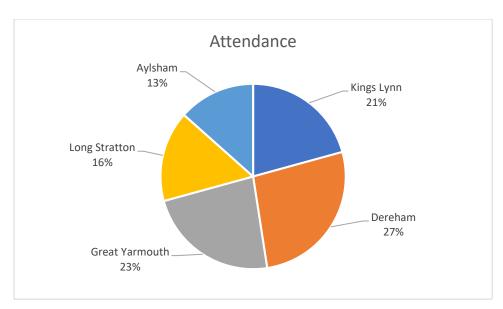
Part of Family Voice's contribution to this comes from its team of parent carer representatives, who represent the views of families. In order that the experiences of as wide a group of parent carers as possible can be shared and acted upon, annual participation events are one of several ways that their views are sought and captured. The aims of such events are:

- To explore and evidence the experiences of families of children with SEND in Norfolk across
 the full breadth of services provided or commissioned by the local authority, commissioned
 health services, early years, schools and further education providers;
- To give the steering group of Family Voice some clear priorities to inform its work plan;
- To use this evidence to continue representational work with local partners to improve services for children and young people with SEND in Norfolk;
- To increase the membership of Family Voice and encourage more parent carers to participate.

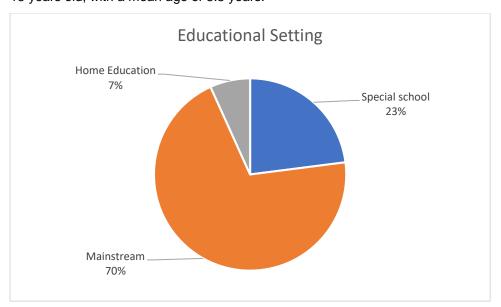
This is the fourth series of Family Voice, Family Chat sessions and aims to give information and knowledge to parent carers while encouraging them to share their family experiences with us. These involve Family Voice working in partnership with other services and organisations to inform and support parent carers within the sessions and to gather and report on the views and experiences of these same families.

Family Voice invited Norfolk SEND Partnership and the Local Offer team to join in five events across Norfolk. We are extremely grateful to them for their willingness to co-produce these events with us. The following sessions were organised:

- 17 September King's Lynn
- 23 September Dereham
- 24 September Great Yarmouth
- 30 September Long Stratton
- 2 October Aylsham



82 parent carers attended these events, representing 74 children in mainstream settings, special schools/complex needs schools and home education. The children and young people ranged from 3 to 18 years old, with a mean age of 8.8 years.



The Local Offer team opened the session with a brief explanation of where to find SEN Support and EHCP information on the Norfolk SEND Local Offer. The SENDIASS team followed with a presentation on SEN Support and EHCPs. These presentations can be found on the Family Voice website: https://www.familyvoice.org.uk/articles-reports/parent-carer-participation-events/

Summary of Findings and Key Messages

The information in this report has been presented as it was given, without interpretation. However, some themes did emerge and need to be highlighted. The main one that parent carers at these sessions stressed was the importance of good communication. In addition:

- Parent carers felt more confident in the educational setting when SEN Support and/or an EHCP was working well;
- Many parent carers did not feel that their concerns about their child or young person were being taken seriously and they often felt that they are blamed for their child's bad behaviour;
- Lack of funding was given as a reason to a third of parent carers for their child or young person not receiving SEN Support;

- Many parent carers are not aware if their child is on the SEN register;
- Parents carers often are not involved in the review cycle of the graduated approach and often do not know what this entails;
- · Home school books were not being used;
- Some schools are reluctant to incorporate inexpensive reasonable adjustments and where adjustments and interventions had been identified, several of these were not implemented or only lasted a short while;
- When SEN Support breaks down, parent carers are "encouraged" to home school;
- Parent carers found it overwhelming and stressful to apply for a needs assessment and an EHCP;
- Documents were often posted to families at the end of term when it was difficult to review documents as their children were at home and life was challenging;
- EHCPs need to be read by teaching staff and incorporated into children and young people's daily school life.

The Family Voice Family Chat sessions empowered parent carers with information and understanding of the SEN Support and EHCP processes so that they could have informed discussions with their child or young person's educational setting.

The Findings

Local Offer

Nearly 40% of parent carers had heard of the Local Offer and this differed widely from session to session. In Aylsham just under 30% had heard of it and in Long Stratton nearly 60% had heard of the Local Offer. The presentation was well received and many parent carers commented on how useful it had been to discover a wealth of information online.

Parent carers also appreciated the advice and information available at the end of the session.

It was really good to find out about the Local Offer website

SEN Support

Around 60% of parent carers had heard of SENDIASS, although many schools, particularly west of Norwich, were not sending out the SENDIASS newsletter to parent carers.

90% of parent carers said that they knew who their child's SENCO was. Many parent carers said that often the SENCO worked part time, which made it difficult to contact them, and that they had little confidence in them. One parent said that the SENCO had left the school and not been replaced, the head teacher was covering.

Our SENCO is very good as she knows them all and their idiosyncrasies

There is currently no SENCO in the school since the last one left. The head teacher is inadequately providing cover

Section 6.45 of the SEND Code of Practice states that "Schools should take seriously any concerns raised by a parent". One of the main themes running through the section on SEN Support was that parents did not feel that the school took their concerns about their child seriously and they did not feel listened too. Parent carers were often blamed for their child's bad behaviour. There were many cases where children appeared fine in school but exhibited challenging behaviour at home and therefore the educational setting did not feel that the child required any additional support.

I was told that my child needed stricter boundaries and more discipline. Then we were given a diagnosis.

She isn't getting the support she needs and every time I suggest something, I get shut down

He masks it so well, so is not getting support

Many of the parent carers, including those whose children have an EHCP, said that they were unaware if their child was on the SEN register. It appears that some schools do not involve parent carers in the Assess – Plan – Do – Review cycle of the graduated approach.

Where special educational provision had been recognised, a number of parents said often planning sessions were organised and agreed but no additional provision was forthcoming or that it would last for a week or so and then stop. In some cases, the planning meetings were being consistently cancelled and review dates were also changed. Parent carers were having to chase schools to make sure that planning and review meetings took place.

School makes suggestions but the support quickly fades away

Word of mouth means nothing; need written document

Parent carers spoke of how schools were reluctant to incorporate inexpensive reasonable adjustments, with one parent saying that the school would not allow their child a fidget spinner because "every other child would want them too." One parent was told by the school that they were reducing the SEN Support for their year 6 child because they would not receive the same level of support at high school.

There were instances of good practice: one parent carer said that their child had received a number of easy interventions such as extra time and the use of a laptop.

The financial implications of SEN Support were often raised by parent carers with a third of them having been told that the school could not afford SEN Support for their child. There were several cases where lack of funding was given as a reason for a child not having 1:1 support

We've been told my child cannot have 1:1 because there is no funding

Where SEN Support has broken down, many parents had been "encouraged" to home school their child. One parent carer said that they were called by the school each morning to go back into school to collect their child, while another child has been out of education for 18 months. 7% of parent carers who attended the sessions are currently home educating their children.

Another theme that was raised was the lack of communication between schools and parent carers:

- Transition points are an additional challenge to many children and young people. Several
 parent carers stressed how they felt unsupported when their child transitioned from one class
 to another. Poor handovers and important information not being passed on caused
 unnecessary anxiety for the child;
- Home school books were either not being used or the school is reluctant to use them. Parent
 carers cited examples of not being able to go into the playground to talk to teachers or having
 to email the school to find out how their child is getting on;
- One parent carer said that they were handed forms at the start or end of the day and asked to sign them there and then without having a chance to read them

No communication at all. It 's horrible!

There were examples of good SEN Support. Parent carers felt much more confidence in the educational setting when SEN Support was working well. Good SENCOs know the children well and understand their needs. Many parents noticed an improvement in SEN Support when their child or young person had finally received a diagnosis. One parent said that had experienced excellent results with SEN Support now that their child was in a special needs school

We've noticed a difference in approach once we had an EHCP. They take us more seriously

My child's primary school has been really good. They have put in all the support that he needs

His special needs school is the biggest thing that has made his life bearable

Teachers that are good can give children confidence and bring them up to speed

Education, Health and Care Plans

Process of getting an EHCP

Nearly 40% of parent carers had an EHCP for their child or young person and this increased to nearly 55% when asked if they were in the process of applying for one.

Many parent carers felt that the only way that they would be taken seriously and that their child or young person would receive the support that they needed was by having an EHCP.

It is exhausting to have to fight to get my child what they need No point in applying; we won't get it

Parent carers found it overwhelming and stressful to apply for a needs assessment and an EHCP and many were "discouraged with having to fill in the horrendous form." Several parent carers had worked with SENDIASS in these processes.

Many parents cited waiting times for an educational psychologist as the main reason that EHCPs were taking so long to be completed. One parent said that if schools put in the SEN Support then educational psychologists would not be in such high demand.

I was told that it would take at least a year for an EHCP We are 24 weeks into the EHCP process and still awaiting a decision to assess. Educational psychologists are holding up the process

EHCP co-ordinators

Many of the parent carers that had an EHCP or were in the process of having one for their child reported poor experiences with the EHCP coordinators with some saying that they have to "blow a gasket" before they are listened to by the coordinator.

Several parent carers complained about encrypted emails being sent to them by the EHCP coordinators that that were unable to access. Documents were often posted to families at the end of term with parent carers then having fifteen days to respond at a time when it was difficult to review documents as their children were at home.

Documents are always issued on the day before school holidays. It's too hard to review this when the children are at home. EHCPs need to be checked and proof-read before being issued as many parents said that statements in their child's EHCP had been copied and pasted from other children's EHCPs, sometimes even leaving the name in.

One parent said that they had waited a year to receive their child's revised EHCP.

However, overall, parent carers felt that the EHCP reflected their child and that they needed the document for their child's long-term plan for transitioning and preparing for adult life.

EHCPs in schools

Once children and young people had an EHCP, the usefulness of them was questioned by several parent carers. EHCPs need to be read and incorporated into children's and young people's daily education, as there were several instances where parent carers felt that they were not being read by teaching staff.

.

Silly question but I think it's obvious: Do teachers have to read the EHCP? A whole year had gone by and they hadn't looked at the plan. It was like they'd just put it in the filing cabinet.

Where they were being adhered to, there were instances where schools were refusing to allow children to take in fidget toys unless it was written into their EHCP or only certain aspects of the plan were being followed.

If I could do the EHCP process again, I would make sure that the reports were quantified and specific

Schools see the EHCP as a menu that they can chose from rather than doing all of it

Health and social care

Only a third of parent carers had heard of Short Breaks. Many parent carers did not know what they were or how to access them.

One parent carer expressed concern that their child was not keeping up socially but that the EHCP did not cover these needs.

Conclusion

Of course, this is a relatively small proportion of parents and we would not have expected parents who felt confident about the EHCP and SEN Support systems to attend. However, without support from their educational setting or a body such as SENDIASS, parent carers do often struggle to understand or find time to learn about how these mechanisms are *supposed* to work and therefore are disempowered to challenge effectively when they do not work. Feelings of panic, isolation and a sense that they or the

setting or both are failing their child is commonly expressed. As this report highlights, communication between all parties is key, and, of course, this needs to be positive, appropriate and honest communication.

The Family Voice Family Chat sessions empowered parent carers with information and understanding of the SEN Support and EHCP processes so that they could have informed discussions with their child or young person's educational setting and ensure that outcomes would be quantifiable and specific.

I now feel more confident to go into school and question why they have not been doing what is in the plan

We no longer feel isolated and alone. It highlights the lack of support that we currently have in place.

Family Voice Norfolk would like to thank all the parent carers who gave up their time to share their experiences and thoughts in such an open and honest manner. This document seeks only to give them a voice, for their views to be heard. We would like to thank Norfolk SENDIASS and the SEND Local Offer for collaborating with Family Voice in the presentation of the events, for providing advice to parents and for their clarity on the subjects discussed. Family Voice welcomes the opportunity to work with services to improve outcomes for our families.

Bernadette Pallister Administration Manager Family Voice Norfolk January 2020