



Family Voice Norfolk

Parent Carer Participation Events

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2 INTRODUCTION

Family Voice Norfolk are working with Norfolk County Council (NCC), Norfolk Clinical Commissioning Groups and Commissioning Support Unit, Schools, Voluntary Community Services, and their other partners, to co-produce Norfolk's response to the Governments SEND Reforms as detailed in the Children and Families Bill (2014); and the revised SEND Code of Practice.

As part of our contribution to this project, we identified a need for the experiences of a wider group of Parent Carers to be captured, shared and acted upon.

3 AIMS

To explore and evidence the experiences of families of children with Special Educational Needs and/or Disabilities (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 Norfolk some clear priorities to inform the work plan.

To use this evidence to continue our representational work with local partners to improve services for children with SEND in Norfolk.

To increase the Membership of Family Voice and encourage more Parent Carers to get involved with Participation.

4 METHODOLOGY

We arranged eight meetings in;

Downham Market, Holt, Aylsham, Diss, Norwich x 2, Wymondham and Great Yarmouth

Meetings were offered at alternate times to allow working Parent Carers to attend and for Parent Carers who have the prime caring role to attend whilst children were in school – session times 10.30 – 1.00 and 18.00 – 20.30.

Our Membership Administrator invited our members to attend on 22/10/15 – 2 weeks prior to the first event. Our Ambassador Team also hand delivered, or emailed, to schools as widely as we could, and shared with as many Voluntary Sector organisations as possible.

We developed a Workshop framework aiming to hear the widest set of experiences across the full range of partner services;

Education – LA service, Early Years, Schools & Colleges

Home to place of learning transport

Health Services – diagnostic and therapies

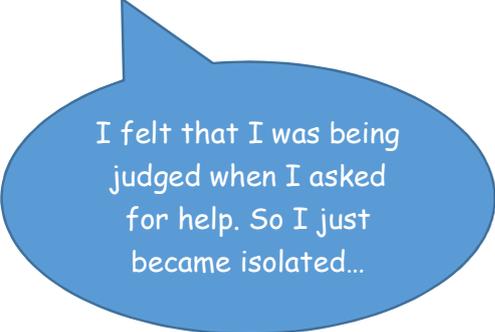
5 FINDINGS

5.1 Family Journey

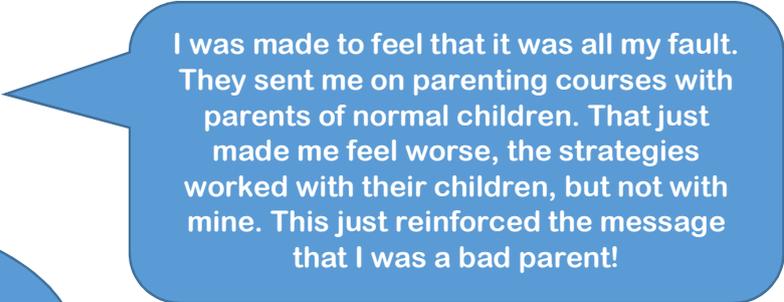
We asked Parent carers to consider their family journey to date and tell us when they had felt most supported and when they had felt isolated, unable to find the support that they needed

5.1.1 Pre-Dignosis

Parents consistently reported this to be the most difficult time when their child has a Developmental Disorder – ASD, ADHD, GDD etc. They felt that the practitioners that they were in contact with were not listening to their concerns and they did not feel empowered to seek further help from others.

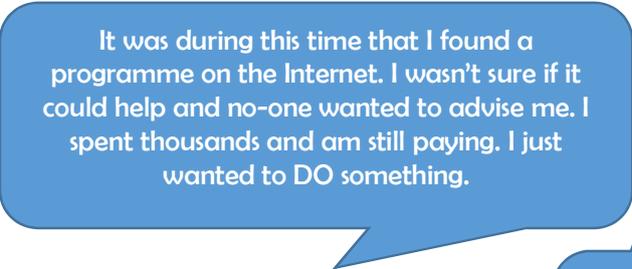


I felt that I was being judged when I asked for help. So I just became isolated...

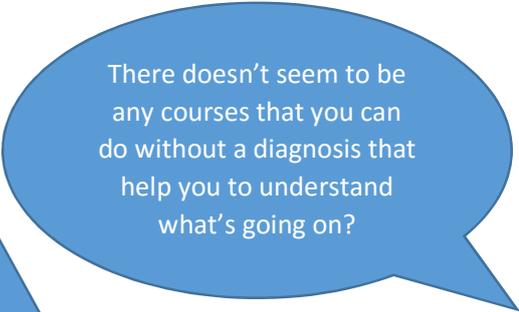


I was made to feel that it was all my fault. They sent me on parenting courses with parents of normal children. That just made me feel worse, the strategies worked with their children, but not with mine. This just reinforced the message that I was a bad parent!

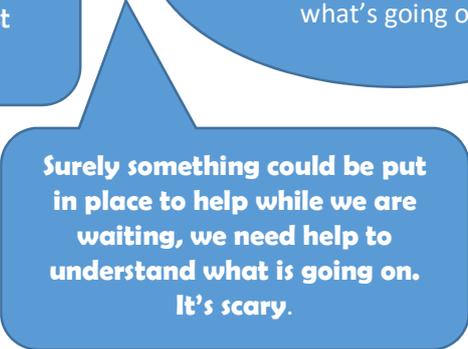
They also told us that they had had to wait from between 18 and 24 months to start a diagnosis process. During this time they had not been offered any support and had not found it easy to access information about reliable sources of help.



It was during this time that I found a programme on the Internet. I wasn't sure if it could help and no-one wanted to advise me. I spent thousands and am still paying. I just wanted to DO something.



There doesn't seem to be any courses that you can do without a diagnosis that help you to understand what's going on?



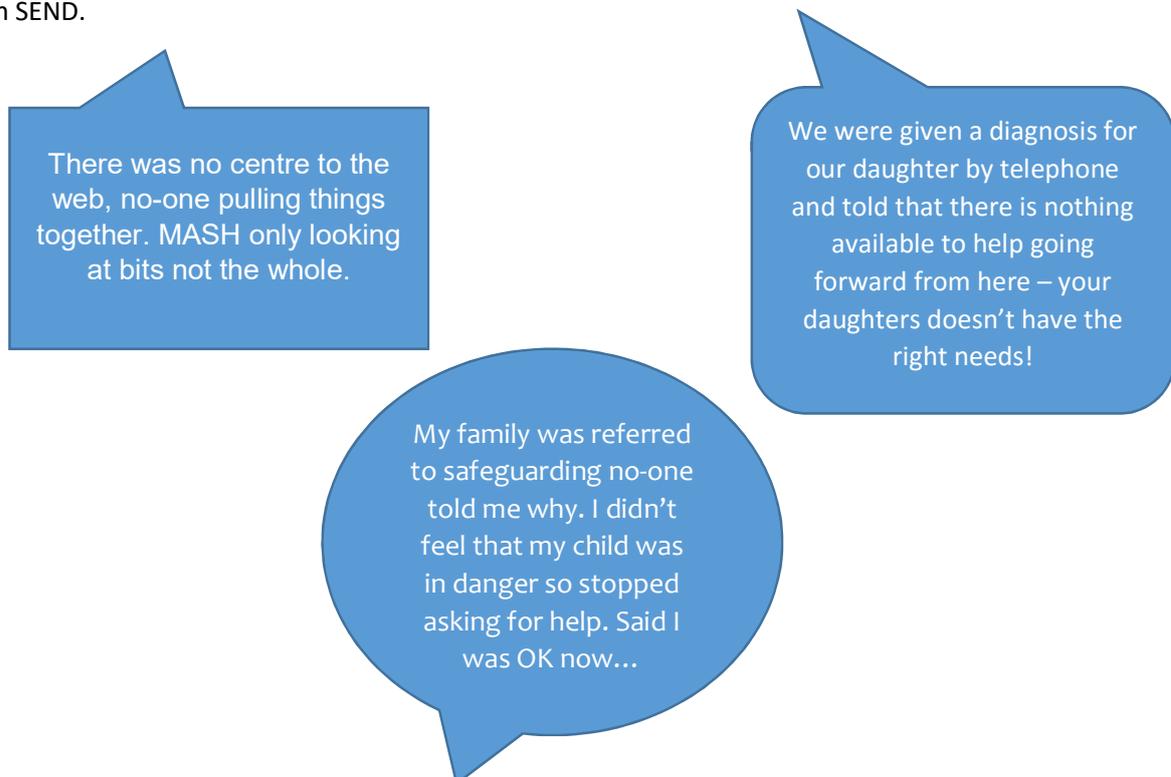
Surely something could be put in place to help while we are waiting, we need help to understand what is going on. It's scary.

5.1.2 Diagnosis

For the majority of families actually getting a diagnosis had been as positive an experience as it could have been, Addenbrookes and other tertiary centres had also made positive contributions at times of sharing news.



However, there were families for whom this was not the case and whom seemed to get a different level of service. Many reported that they had had long waits for Early Bird/Early Bird Plus and have just had letters informing them that the courses are no longer running! There is also considerable misunderstanding about the role of the Multi Agency Safeguarding Hub in relation to families of children with SEND.



5.1.3 Starting School/Changing school/Moving to College

This was highlighted as a time when families are very concerned about making the right decisions for their child and considered it to be a very stressful time and described their fear about making the wrong decision for their child. Parents had found it extremely unhelpful to receive long lists/books of schools, many of which were outside of Norfolk, with no qualitative information or guidance. Whilst they understood that the decision needed to be made by them and not by others, they consistently felt that they needed support in making that decision – someone to make visits alongside them, help to know what questions to ask so that they could make informed decisions about the right provision for their child. Some of this lack of confidence relates directly to having felt devalued during the Early Years particularly pre-diagnosis.

5.1.4 Leaving school/College

Parents continue to experience this as a cliff edge! Even with the new protections that the Children & Families Act put in place, families felt that practitioners had no understanding of the changes and therefore were unwilling to support them and described that they themselves seemed to be more knowledgeable about the law and had to keep explaining their child's rights. There seemed to be a consensus that there is a lack of choice for young adults and that they are not being treated as individuals. The general feeling was that there are a large number of intelligent, employable Young People for whom there is little support and are therefore contributing to the NEET statistics, parents reported incidents of their sons and daughters getting into trouble with the Police because they didn't have an appropriate outlet or way to channel their talents.

My son was very worried about leaving school, he had loved it there. He became very anxious about what would happen to him next. He wanted a job but no-one seemed to be able to help.

What are young people supposed to do? What does happen to them after they leave school? No-one seems to know what my daughter could do next.

"Can't help he will be an adult soon"
Childrens Services

"Can't help he's not an adult yet"
Adult Services

5.2 EDUCATION PROVIDERS

We asked parents about their experiences of each stage of their child's education. There are definite differences both at age stages and in types of provision.

5.2.1 Early Years

Parents told us that even though this is a very difficult time for them, they felt that Early Years Providers (including Portage) had been very welcoming and supportive and that on the whole they tried to do their best for children. But, they were constantly told that providers would only be able to take their child if they were awarded funding which left parents not only very anxious but also confused as to how money was agreed and concerned that their child could be left without any early education.

"If we get the funding we will..."

Everyone wanted to take my daughter but could only do so if they got the money from the LA.

The nursery has been amazing! They have tried different support assistants to find the one that my child responds best to. They make sure that they include other children in activities that she is doing, they understand how important it is for development.

5.2.2 Schools

Sadly, this is the area that caused parents most concern. There was a broad consensus that mainstream schools do not want our children and do not want us as parents. There were some good relationships with individual staff and this was identified as being very important when a child has additional needs and may not communicate what is happening at school with family or what is happening at home with school – without good relationships parents felt that their children were even more vulnerable, which in turn was identified as a source of stress for parents. However, there were examples of good practice too!

Other specific concerns expressed by parents included;

- General lack of knowledge/training/understanding by school staff. Families identified that it is important that this is not just confined to teachers and whilst training for TA's is crucial, all staff within the school need training.
- Schools just don't believe parents, they seem to need another professional to tell them everything. Our knowledge needs to be valued.
- Schools do not have aspirations for our children they seem to be content for them to just "be there" not for them to achieve the very best that they can.
- Many schools do not appear to have understood that they now have a duty to make arrangements for the medical needs of children and parents still being told that schools have no responsibility for epi pens or support for epilepsy. Other examples given that for children with diabetes care seems to be organized around the needs of the school not the needs of the child.

- Parents are continually being told that schools do not have enough funding to meet the needs of their child. Schools need to be careful with their budgets so that they don't disadvantage the education of the majority of learners for just one child.
- School meals service not able to cope with individual dietary needs, which results in children not being part of regular lunchtime with peers and the relative formality of communal meals. Parents considered mealtimes to be a learning opportunity that their child is being excluded from – even when they have full-time support to help them.
- Parents felt that "Inclusion" seems to be interpreted as their child having to fit in with the whole of their Peer Group, rather than adjustments being made according to their needs. This includes homework as well as class work. Parents told us that their children used to have Individual Education Plans but now there seems to be no individualised plan, no outcomes identified for their child, no review and no parental involvement at all. (Not one parent could tell us anything about SEN Support).
- Specialist Resource Base provision, very mixed experiences – when they work well parents are very happy, but this is not always the case. Some of this is a lack of clarity regarding the remit for SRBs. Many families feel that their child is placed there as they "do not fit" in either mainstream or Complex Needs Schools or that CNS are oversubscribed and cannot offer a place.
- Complex Needs Schools, work hard to meet the individual needs of child, instill confidence in parents that they have training and understanding, but not always aspirational enough.

There is a complete lack of aspiration for my daughter, mediocre is OK. School are pleased if she's been well behaved, I want to understand – what did she actually learn?

School continually tell me "tried really hard" "had a good day" but the same two books have been in bag for over half a term, one is too hard, the other is just pictures so how has my child progressed?

Son is in a Special School now. It's a very different feel, it suits him. It was a fight to get a place, but he is happy now!

Schools have all the power not the parents!

Aspirations? School don't have any for my daughter. How can they say that about a five year old? Who knows what may happen in the future?

Teacher at High School communicates with me via email. It's great and makes such a difference

The Local Authority told me that "No High School will do 1:1 for any child" so not worth asking for. How will my child manage?

Strategies that have previously been put in place and really helped are not allowed in mainstream.

We were encouraged to consider a Complex Needs School, not because of ability but because of support arrangements in local High School.

5.3 EDUCATION HEALTH & CARE PLANS

Parents reported that they are beginning to experience this process. They were clear that it felt like a better process but they had many concerns;

- Long meetings and sharing lots of personal information which is not then reflected in the Plan.
- Not being told about Independent Support.
- No information given about the Local Offer.
- Timescales – examples given included; Applied for transfer 2 months ago - no contact since, Application May draft September, EP Report produced in July – understand that Plan is still being written.
- The information required on the request form does not match with the information needed for Plan.
- Young People (16+) in placements without final Plans and without provider named on Plans.
- Plans are not always aspirational or have Specific, Measurable, Achievable, Realistic & Timebound Outcomes.
- No-one had been offered a Personal Budget, if they had been mentioned parents felt that they were “glossed over”.
- Parents do not seem to be able to find a telephone number to contact Planners, this is very frustrating and creates a barrier for families.

It's the best thing ever!

We had a Statement Review, the Co-ordinator told me that it was going to be changed to an EHCP. But, when the document arrived in the post 4 months later it was another Statement – no changes at all!

It all seems to be very haphazard, you need to be on the ball as a parent

My child moved to High School this year with a three year old Statement which still named Primary School. There had been a meeting, but the person had left and all the paperwork had been lost.

We have a Plan, but it's not aspirational. Child is intelligent, but no-ones thinking about A levels.

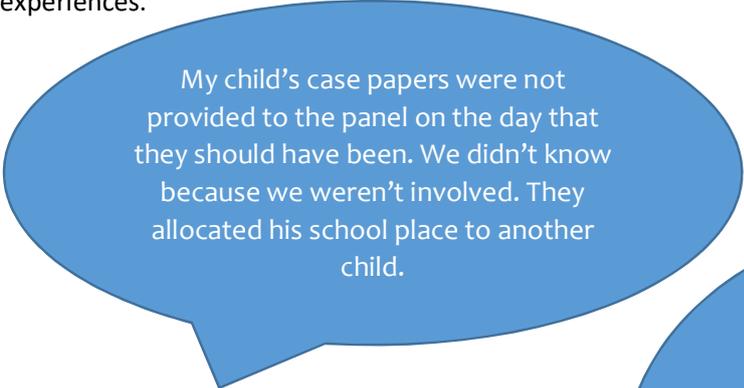
5.4 LOCAL OFFER

The Workshops that are currently being offered in Children's Centres are highly praised, parents who had already attended recommended to others in the room that they should attend too. Parents who had used the Local Offer felt that it is a good resource. However;

- Concern was raised about the School Finder, which was reported to have been changed and is no longer separated into phase, making it difficult to navigate.
- The biggest concern is that professionals involved with families are not sharing this resource with families. It is not being mentioned at meetings or by anyone involved in care or assessments – included Family Focus and Therapists.
- Those who had used it to look for Health Services had not found it helpful – there are no Pathways and no thresholds or who gets what, where, why and when information on the Heron website that the Local Offer links to.
- School information Reports are a mystery to parents, they are not aware of them, have not been involved in developing them and the links to many that we tried to access either do not work, take you to a basic SEN Policy or in one case a Safeguarding Policy and in another to “Le Monstre mangait les oeufs”!! This is a major concern as parents were very clear about the information that they wanted to access about schools when we consulted with them in 2013 (Previous FV Report 2013).
- Parents who do not use IT were not certain about how they could access the information that they needed.

5.5 FUNDING PANELS

These are a major cause of stress to families who feel that they are shrouded in mystery, exclusive and inaccessible and arbitrary. Parents told us that their child's provision being decided by a panel of unknown and therefore unaccountable individuals had been one of their most disempowering experiences.



My child's case papers were not provided to the panel on the day that they should have been. We didn't know because we weren't involved. They allocated his school place to another child.

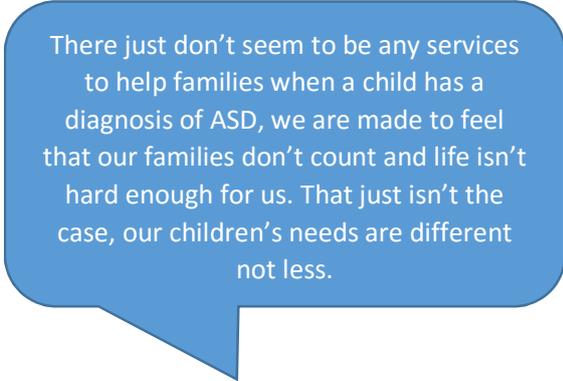


My daughter had had a fantastic placement for a year. The funding was then removed, not based on a change in my daughter's needs, but because that provider couldn't prove that they had strategies in place. “Panel do not accept subsequent evidence” “Panels decision is final”

5.6 HEALTH SERVICES

As noted in the comments about Pre – Diagnosis above, the long wait for diagnostic services for children with ASD/ADHD is a major cause of stress for families and they feel totally unsupported whilst they are on a waiting list.

- Once they have a diagnosis they are placed on another waiting list to access Early Bird/Early Bird Plus or Cygnet as referenced above these courses are being cancelled.
- Support with Sleep Counselling is valued but is inequitable and not available in all parts of the County, parents feel frustrated and discriminated against by virtue of where they live in the County.
- Parents feel that their expertise is not valued by Health Professionals and sometimes their contribution is discounted during meetings/consultations.
- The ADHD Nurse and the Specialist Health Visitors were both services that are highly praised and valued by families, but there is not an equitable service across the County again leading to a feeling of discrimination.
- Services for dyspraxia are also deemed by parents to be inequitable, they reported that there is no service for children over the age of ten. Many children and young peoples dyspraxia goes under the radar and is not diagnosed until they get to High School or College.
- Parents described issues with language barriers, not just when either the practitioner or family does not have English as a first language but also in terms of jargon and terminology.



There just don't seem to be any services to help families when a child has a diagnosis of ASD, we are made to feel that our families don't count and life isn't hard enough for us. That just isn't the case, our children's needs are different not less.



Our Specialist Health Visitor; knew the answers to our issues, helped to make sense of problems, & knew what to do.

This was so important!

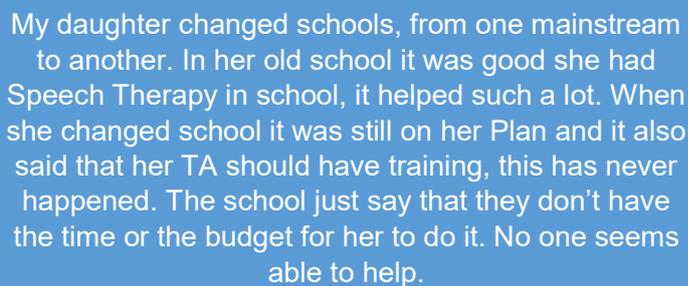
5.6.1 Occupational Therapy

Parents described a series of valuable and valued six week interventions. However, they felt that there were no clear outcomes and no join up with school. They also told us of that they were paying for private treatment to maximise the results of therapy, this was the situation for children with Statements and those with an EHCP – they had not been offered Personal Budgets which would allow them to purchase services to meet the agreed outcomes. They also talked of long waiting times and a lack of contact once their child was on the waiting list.

Families were clear that this appeared to them to be a service that was only available to children who had specific diagnoses and did not feel equitable or needs based. They identified a need for support with Sensory Needs which is not currently being met.

5.6.2 Speech & Language Therapy

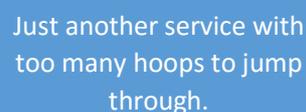
Speech and Language Therapy is another service valued by parents, they consider that it is of great value to their children, particularly for promoting speech for children. However, there is no clear definition or understanding about what Speech & Language Therapy actually is, which is accessible to parents. The search from the Local Offer under Health Services links to the HERON website when “speech therapy” is entered as the search term it returns four possible services – none of which are helpful to families. Parents remain unclear about who can access the service when. Or who is responsible to ensure that agreed actions happen.



My daughter changed schools, from one mainstream to another. In her old school it was good she had Speech Therapy in school, it helped such a lot. When she changed school it was still on her Plan and it also said that her TA should have training, this has never happened. The school just say that they don't have the time or the budget for her to do it. No one seems able to help.



I was told that Speech Therapy isn't for children who can talk!

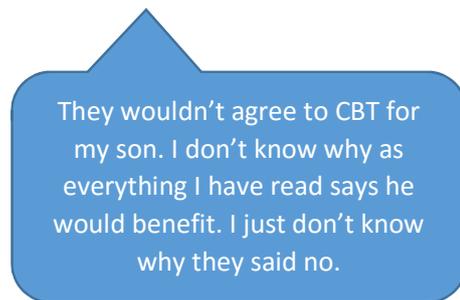
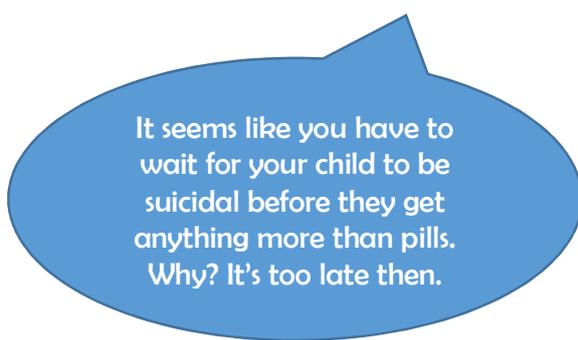


Just another service with too many hoops to jump through.

5.6.3 Child & Adolescent Mental Health Services

This was consistently described as an inaccessible service, that parents did not understand. The Local Offer describes eligibility for Point 1 (Tier 2) services as “children and young people who have mild to moderate mental health issues that would benefit from effective early intervention”. This is confusing for families as they feel that their children would benefit from early intervention, but practitioners seem to have a different perception of what the threshold means.

They also felt that there was a tendency to offer children with ADHD/ASD/Anxiety issues prescribed drugs rather than being offered talking therapies.



5.7 TRANSPORT

This is an area where parents felt that the Local Offer didn't help them to understand “what the rules are”. There doesn't seem to be a clear way for families to find out what should be available to them or how to apply. Parents shared the aspiration that their child should be independent whenever possible, but it was not clear how this was decided other than for those young people who are offered a place on TITAN. There seemed to be no clear pathway to TITAN either, some had been offered it and others had not – it was not clear who made that decision and on what grounds? Parents are aware that there are different rules for children aged 18 and above, but they only seem to be being applied to young people in Complex Needs Schools. Parents had not been offered Personal Budgets for school/college transport.

Parents raised many concerns about the training offered to Drivers and Escorts, they didn't feel that they knew or understood the needs of the children that they were transporting. They described that there had not been any opportunity to share information and that they had not been asked to provide any. It was a source of stress to parents that they didn't understand how the drivers/escorts would know what to do for their child particularly for those with complex medical needs or behaviour needs. Most had never been offered a “meet & greet” opportunity before the start of a new contract/school year/change of team. This was another area where parents felt that their knowledge and expertise about their child was not valued or listened to.

A number of parents were aggrieved that they had, on occasion, forgotten to make payments to the LA Transport Department and felt that there should be some understanding that this may happen given the nature of our stressful and busy lives. When this had happened transport had been withdrawn without warning, resulting in additional stress not just for the parents but for children too.

My daughter is only three, we already have TITAN on her Plan

TITAN need to consider Safe Havens for YPs who are not travelling to Norwich.

School was named on agreed Statement. We had to agree to change the school because they couldn't afford the transport.

5.8 SHORT BREAKS

The few families that we met who had access to Short Breaks expressed clear concern that they had been “warned” that their package of care was likely to be reduced or withdrawn over the coming months. Their understanding was that families would be needing to prove that they are at breaking point to receive any support, this was considered to be counterproductive as once the family unit has broken down it is unlikely to be put back together again which would result in even higher needs.

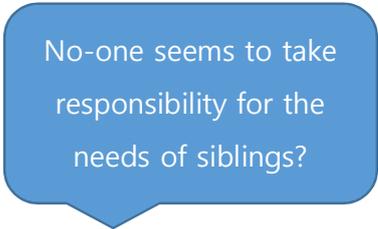
Just knowing that I can spend some time with my other children has made such a difference, we really make the most of that few hours.

We've been asked about changing our overnights, when our son goes away, for someone to come and care for him at home. How would that be a break? Our house is small, we'd still hear him, how can you hear your child in distress and not go to him?

5.9 OTHER COMMENTS

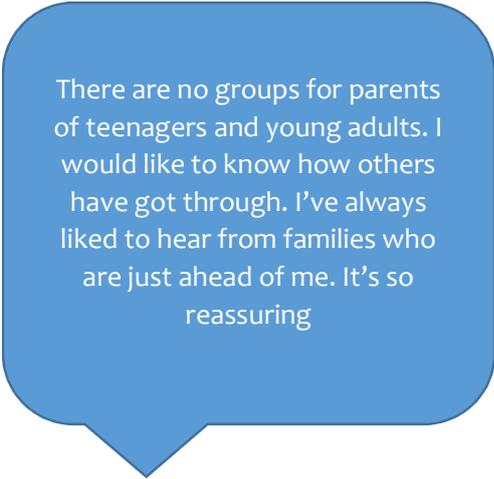


Exceptional people really do commit to helping children to achieve their best. Others just pay lip service.

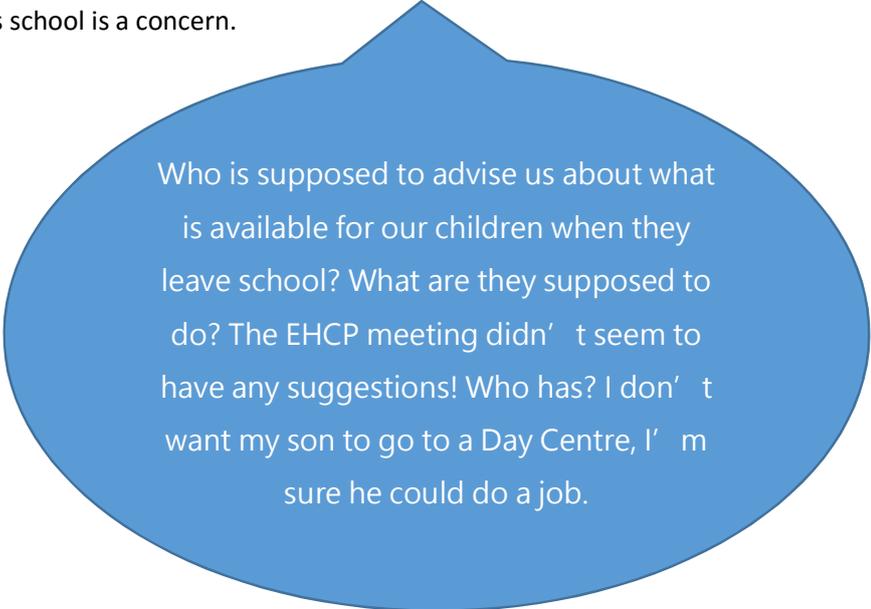


No-one seems to take responsibility for the needs of siblings?

Support for parents when their child leaves school is a concern.



There are no groups for parents of teenagers and young adults. I would like to know how others have got through. I've always liked to hear from families who are just ahead of me. It's so reassuring



Who is supposed to advise us about what is available for our children when they leave school? What are they supposed to do? The EHCP meeting didn't seem to have any suggestions! Who has? I don't want my son to go to a Day Centre, I'm sure he could do a job.

We discussed the provision of Parent Carer Social Care Assessments as legislated within the Children & Families Act (2014). None of the Parent Carers had been offered one or been advised of their right to be assessed.

6 NEXT STEPS

Family Voice Norfolk would welcome the opportunity to work with the five CCGs and the NHS Providers covering our area and Norfolk County Council to address the areas of concern that are highlighted in this report. We have presented this information as it was presented to us, we have not sought to interpret the opinions and experiences of families. We would like to do that in partnership with the teams who are working on these service areas.

We would like to thank each and every parent who gave up their precious time to meet with us and so generously shared their experiences and thoughts with us in such an open and honest manner. This document seeks only to give them a voice, for their views to be heard. We would also welcome their support to take forward the issues that matter to them as individuals, they would be welcome to join our Representative Team.