



Family Voice Norfolk

Parent Carer Participation Events

Karen Wooddissee and members of

Family Voice Steering Group

March 2017

1 CONTENTS

1	Contents.....	2
2	Executive summary	3
3	Aims.....	3
4	Methodology.....	4
5	Attendees.....	4
6	Findings	5
6.1	General Views	5
6.2	Education	6
6.2.1	General experience of schools.....	6
6.2.2	SEN Support	7
6.2.3	Education Health and Care Plans	8
6.3	Personal Budgets	10
6.4	Transport.....	10
6.5	Health Services – including Child & Young Person Adolescent Mental Health	11
6.6	Short Breaks	12
6.7	Other Findings.....	13
7	Next Steps	13
8	Appendix	14

2 EXECUTIVE SUMMARY

Nine meetings were arranged across Norfolk to get feedback from Family Voice members. The key experiences reported by parent carers were:

- generally, a more negative view this year than previously about their child's experience in school;
- a perception that they had to apply for an Education, Health & Care Plan to get reasonable adjustments made within school/college;
- some positive examples of families being involved in EHCP reviews at school but a sense that it is a post-code lottery as to who gets an EHCP;
- concern about the inaccessibility of Plan Co-ordinators;
- a lack of advice on personal budgets;
- some improvement in transport problems, but increased concern about the practice of sub-contracting;
- frustration at having to battle to get access to Health Services;
- a desire for formal diagnoses in order to know how to help their child;
- difficulty in accessing funded Short Breaks;
- overwhelming support for the county's transition forums.

Family Voice Norfolk works in co-production with Norfolk County Council (NCC), Norfolk Clinical Commissioning Groups (CCGs) and Commissioning Support Unit, Education providers, Voluntary Community Services, and their other partners to influence the planning, design and commissioning of local services so that they better meet the needs of families of children and young people with Special Educational Needs and/or Disabilities (SEND).

Part of Family Voice's contribution to this comes from Family Voice's 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.

3 AIMS

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 Norfolk some clear priorities to inform its work plan.

To use this evidence to continue 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 participate.

4 METHODOLOGY

Nine meetings were arranged across Norfolk in;

Downham Market, Dereham, Sheringham, Norwich, Wymondham, Kings Lynn, Long Stratton, North Walsham and Great Yarmouth.

Meetings were offered during the day and evenings to allow both working Parent Carers and for Parent Carers who have the prime caring role to attend while children were in school – session times were 10.30 – 1.00 and 18.00 – 20.30, including one on a Saturday.

Family Voice’s Membership Administrator invited members to attend two months prior to the first event. The Ambassador Team also hand delivered, or emailed widely, to schools, and shared with as many Voluntary Sector organisations as possible. There was a sustained marketing effort, which included direct email, posters, flyers, social media and local press.

It was decided that a workshop framework would enable the widest set of experiences across the full range of partner services to be heard, with particular emphasis on:

Education – LA service, Early Years, Schools & Colleges including Personal Budgets;

Home to place of learning transport;

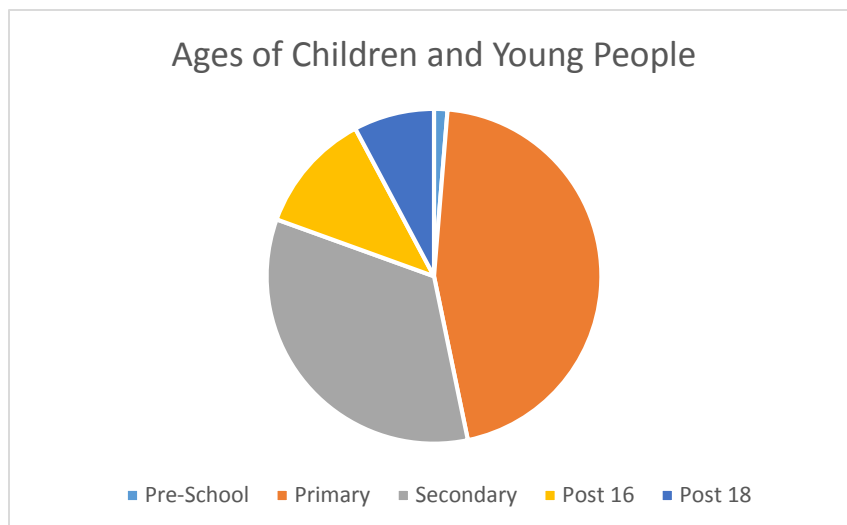
Health Services including CAMHS;

Short Breaks.

5 ATTENDEES

Eighty-eight Parent Carers attended from around the county (see Appendix).

They self-reported the ages and additional needs of their children as:

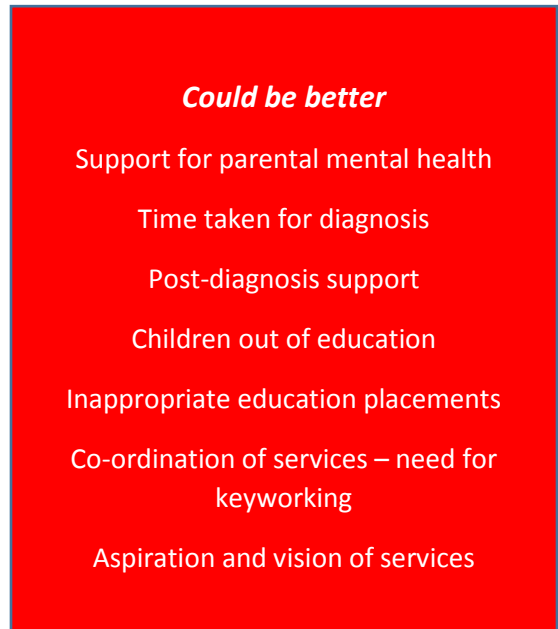
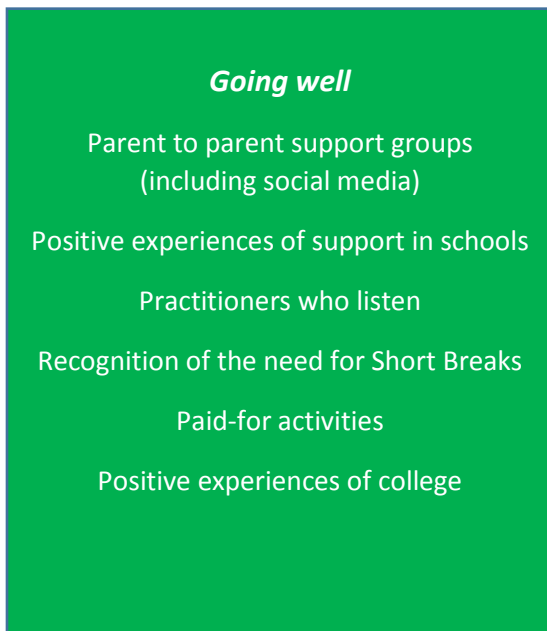




6 FINDINGS

6.1 GENERAL VIEWS

Participants were asked to name one thing that was going well and one thing that could be better. While there were many individual responses, a number came up consistently across the county. Many of the areas for improvement have been raised at previous events, so action is now needed to consider in more detail what needs to happen to improve the experiences of families. This is particularly urgent in the case of support for families before and at the time of diagnosis, as failure to provide the right support at these stages reduces parental capacity and impacts on their wellbeing at that time and at future times of stress. Parents were very clear about the impact of their children not receiving high quality education and explained that this is often a “tipping point” for families.



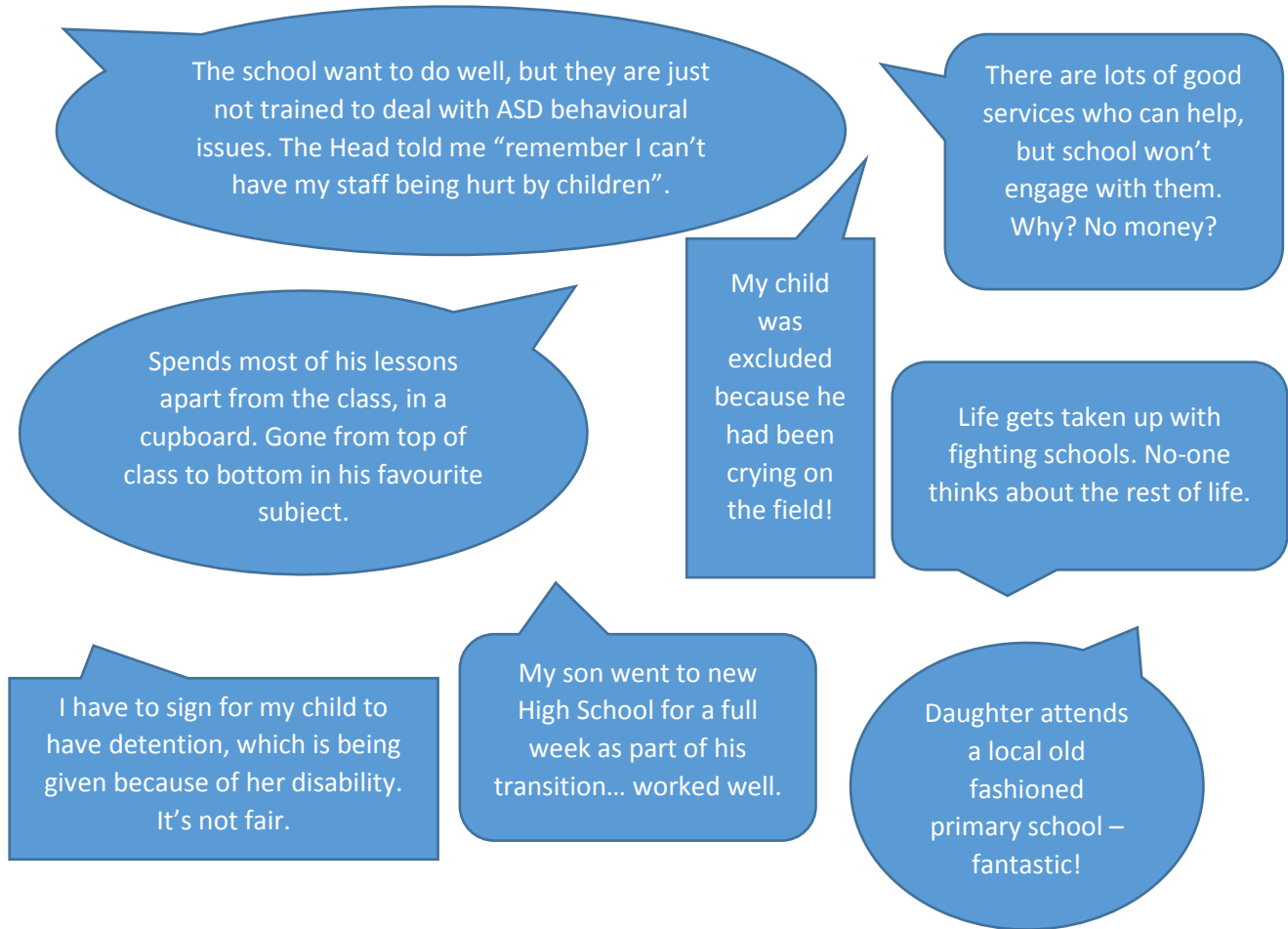
6.2 EDUCATION

There was discussion of the processes that are in place to enable pupils to thrive in their learning environments, the roles of practitioners in providing support and organisations that are available to provide support and advice.

6.2.1 General experience of schools

This year, families reported much more negatively about their experiences in schools than they had previously. For the first time, a number of parents who are Home Educating contributed their views. They told us that they are not doing this by choice, but simply because they have been told that there are no alternatives when mainstream placements break down. One parent explained that her child had had a very positive experience with Red Balloon, but she was told that she must return to mainstream. When the placement broke down again, the young person refused to go and is now being educated at home.

Parents informed us that their children are being given detentions for behavioural issues that are symptomatic of their disabilities. The same applies to exclusions – this was a major concern to parents as they reported that there is no alternative provision being offered. Again, parents felt that exclusions, often with no legal status, were being used to punish children and young people for the effects of their disability.



6.2.2 SEN Support

Parents across the county reported that their children did not have plans or reviews (unless they had a statutory plan). This was given as a reason for many families feeling that their only option was to apply for an Education, Health & Care Plan in order to get reasonable adjustments made within school/college. (The only exception to this was in Sheringham where they spoke of MP3s – nobody knew what the acronym stood for, but they seemed to be effective in getting needs met.) However, parents also said that schools are very clear with them that there is no funding in individual schools to meet children’s individual needs and also that Cluster Funding is not available for their children. They also reported that the schools were telling them that the Local Authority has no money either and therefore there is no point in applying for assessment.

There were positive examples of families being involved in reviews at school. They told of the difference that it made to the outcomes for their child and also of the importance for their own well-being to be given an opportunity to share their own unique knowledge of their child and for that to be utilised to support learning outcomes.

Because my son is bright, he ticks the boxes. School say he doesn't need support, there is no plan to help him with the things he struggles with.

I'm just grateful that the Teaching Assistant is keeping an eye on my son during lessons

The school told me that they cannot find it written in any "official" reports that children with ASD need to "fiddle" therefore it is not a reasonable adjustment that needs to be made.

Who checks that a school is following the SEN Code of Practice? How does the Local Authority monitor how their money is being spent?

There needs to be a willingness to communicate with parents and assume that we DO know about our child and how to help him.
Everyone's a winner!

6.2.3 Education Health and Care Plans

As stated above, parents increasingly feel that their only option left to them is to have a statutory plan in place if their child's needs are to be met. They reported that they understand that this is not a guarantee of support, but that they feel that it removes the barriers around funding and usually means that it changes the nature of the relationship with school.

Messaging to parents is inconsistent and lacks clarity. There is much confusion within schools about what is appropriate and when. Parents feel that it is a post-code lottery as to who gets an EHCP, even within the same school/cluster there appeared to be a high degree of inconsistency. The following are a small, but representative sample of messages to parents from schools:

Your child has an Education need, not a Health need, so you won't get one.

Head Teacher missed the cycle, but said not to worry we'll get one next time!

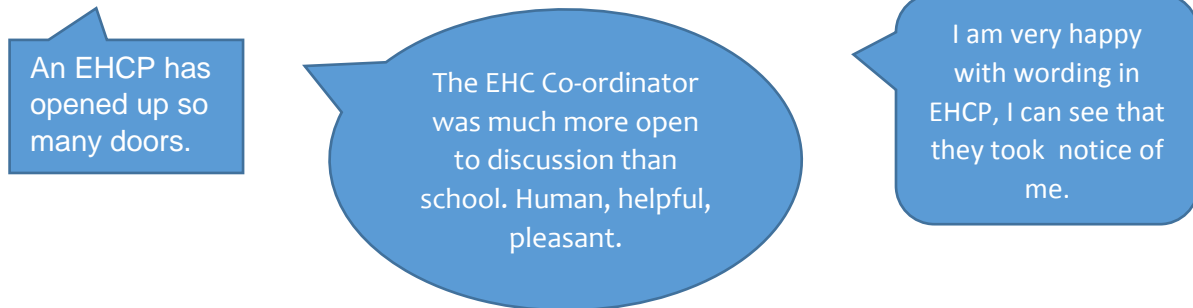
Your child has a Health need not an Education need so you won't get one

We have had three Education Psychologist Assessments, each time they have recommended an EHCP, but we were turned down each time.

The SENCO at our school said that ALL children with SEN should have a Plan.

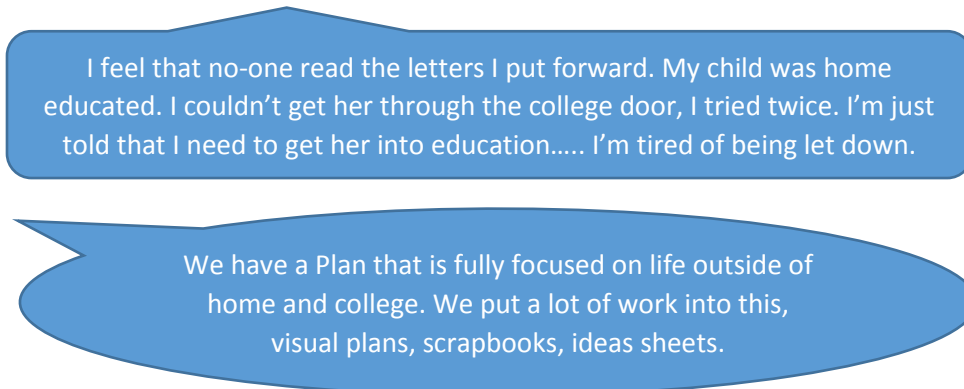
Your child isn't bad enough to have a Plan.

However, there were families who were much more positive about their experience of the process:



There continues to be a wide range of timescales for completion of Plans. Parents reported timescales of twenty weeks to over one year. We met several Foster Parents from across the county. They consistently felt satisfied with timescales, however a parent who had one birth child and one LAC told us that she had experienced vastly different timescales and differing levels of service for her children. She felt very strongly that the involvement of Social Care had ensured that the process was quicker and the involvement of all relevant professionals had been much easier to achieve. Parents told us that they understood that the process should start when a letter is received, but that they were not receiving a letter and so had no way of gauging timescales in these cases.

Many parents felt that their input into the Plan had not been taken seriously, particularly in relation to Social and Emotional needs. They reported that they were expecting a holistic plan, but often it appeared to be a document that had been “cut & pasted” from the previous Statement. They would also like to be given an opportunity to discuss needs without the young person being present.

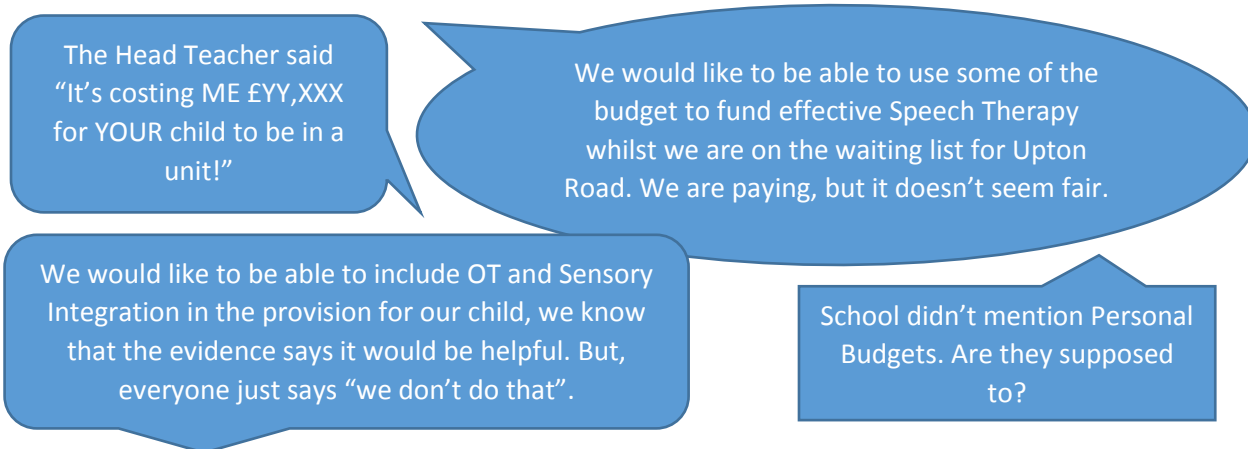


There are concerns about the inaccessibility of Plan Co-ordinators, there seems to be no direct way of contacting them. Parents whose children are attending Complex Needs Schools shared their concerns that Co-ordinators are not going to be present at transfer meetings. They felt it important to have an additional perspective present especially when there are differences of opinion between family and school.

During group discussions, it was clear that parents were being told very different things by practitioners and there is no consistency of message or action with regard to Education, Health & Care Plans.

6.3 PERSONAL BUDGETS

The difference between Personal Budgets and Direct Payments was discussed. Families are very enthusiastic about how a structured conversation about spend on provision could help them to be involved in the decision-making process about how best to support their child/young person to achieve the best possible outcomes. However, for the majority of families who had a plan in place the form had been completed stating “not applicable”. This was considered to be a key area for concern where Co-ordinators are not attending reviews/transfers – who will advise parents about their right to request a Personal Budget?

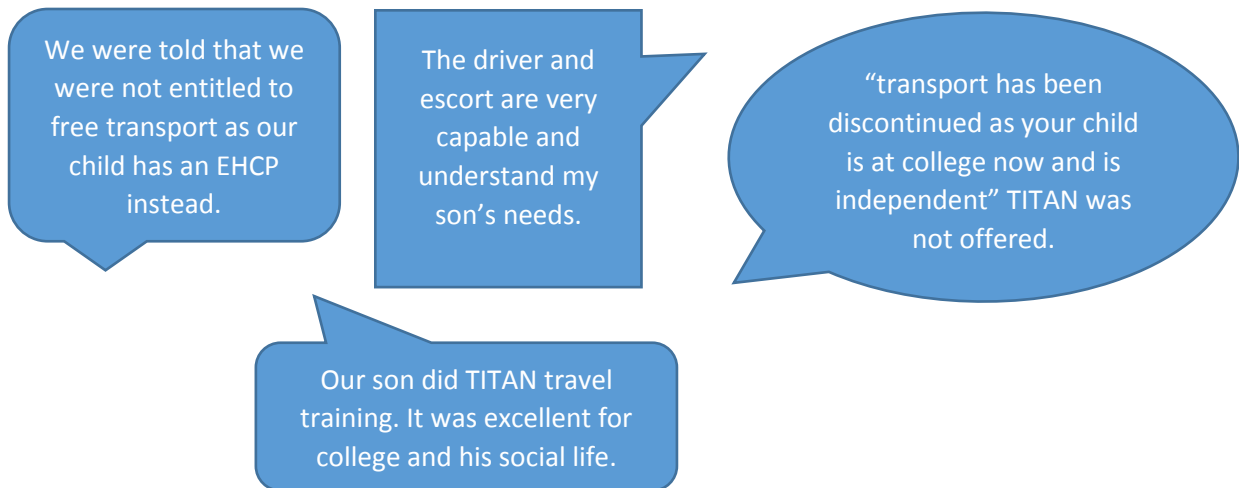


6.4 TRANSPORT

Families were asked if they felt that arrangements had been put in place in good time for the new term. Just two parents felt that it hadn’t been. This represents progress from last year. The majority also reported that they had been offered a “meet and greet” prior to the start of term, but there remains a significant number that were not offered but feel that it would be a benefit. Around half had been sent a One Page Profile and felt that it would be useful for the Driver and/or Escort to have this knowledge. Very few families had confidence that training was specific enough to ensure that their children/young people would be safe and understood.

Parents raised the question as to what training drivers of universal school transport are given. This was raised particularly in relation to behavioural issues in ASD. Again, this is a confidence issue, but also there were reports of children who were being “excluded” from transport because of their behaviour issues.

In a number of instances contracts had been sub-contracted, and parents were uncertain as to whether the Local Authority was aware of this practice and if it was acceptable for this to happen.



6.5 HEALTH SERVICES – INCLUDING CHILD & YOUNG PERSON ADOLESCENT MENTAL HEALTH

Parents were simply asked to share their experiences of Health Services. They did not receive prompts or direction in any way.

Families continue to raise the battle to access Health Services as one of their biggest frustrations. They are experiencing long delays for assessments and diagnosis and they find this particularly tough when they are unable to make an allocated appointment because of their own work commitments and are then pushed back on to the waiting list again.

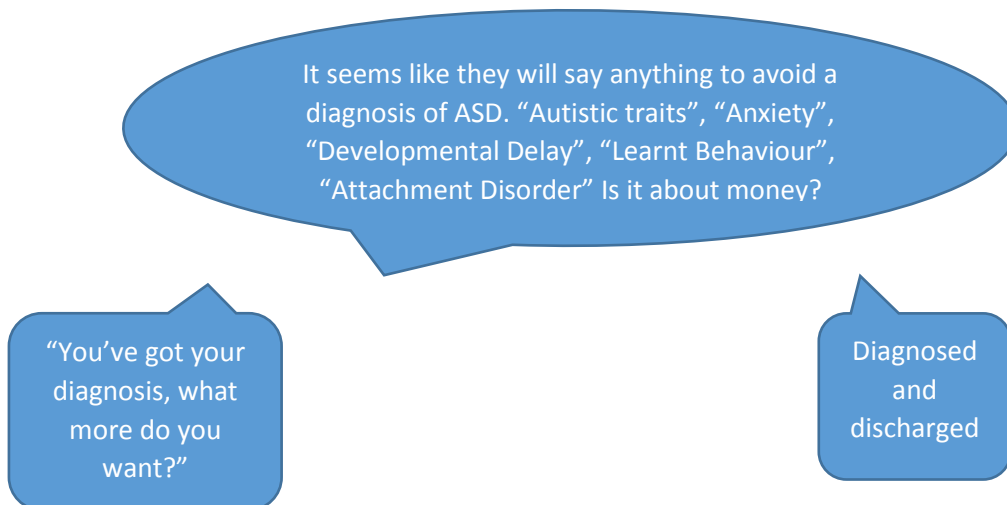
They particularly raised concerns about:

- Access to Sensory Processing Assessments;
- Access to Occupational Therapy;
- Access to Cognitive Behavioural Therapy;
- Transfer to adult health services;
- Starfish apparently not taking on new cases;
- The effects of moving services from Upton Road to the West Norwich;
- Referrals to CAMHS for children/young people with ASD;
- Children being prescribed anti-depressants and discharged;
- Waiting list for Speech and Language Therapy – 9 months;
- Health Professionals telling parents “there are Clinicians who don’t believe that ADHD/ASD exists”;
- NICE Guidance not being implemented;
- No Keyworking.

Keyworking has been raised by families at all the listening events over the past years. They are asking when progress will be made to ensure that this will be provided to families who could benefit.

As waiting lists increase, families are seeking private diagnosis and therapy support at their own cost. They do not understand why they are then being told that the NHS will not recognise the diagnosis or intervention. This effectively leaves them in a vacuum for months or even years.

Parents attached considerable importance to having a formal diagnosis. This is not because they want a label, but because it helps them to know what to do to support their child. It also is key to getting their needs met in school where staff appear to lack training and to being able to access parent-led support groups.



Families are clear that they need support post-diagnosis to help them to know what will be effective to help their child. When this does not happen it affects relationships within the family unit, often leading to breakdown. We met a significant proportion of single parents at these events. They also spoke of their own illnesses and mental health issues that had emerged either during a prolonged diagnostic process or shortly afterwards. They identified that this was a direct result of receiving a diagnosis and then having no emotional or practical support, just a discharge letter.

6.6 SHORT BREAKS

We asked about access to universal services. The majority of families reported that this does not work for a number of reasons:

- Child/Young Person does not want to go;
- Expectation that parent will attend too to provide 1:1 support;
- Lack of funding for Voluntary Organisations to provide additional support;
- Limited training for Voluntary Organisations to understand and make reasonable adjustments.

There were examples of Universal Services that are working well:

- Drama & Dance;
- High Altitude Trampolining;
- Martial Arts – Local Group;
- Various sports activities and venues.

Families were very clear about their priorities for Short Breaks:

- A break from caring;

- To enable child/young person to develop new skills;
- A fun, enriching experience;
- To allow time to be spent with siblings;
- Safe environment with trained staff who understand disabilities.

There were issues raised about the inability for funded Short Breaks to be delivered, generally because of a lack of people available to deliver them.

6.7 OTHER FINDINGS

- Need for support and professional training for Foetal Alcohol Syndrome
- Need for family training – Mental Capacity & Deprivation of Liberty
- Blue Badge – taken away, changes to interpretation of the rules?
- Families like One Page Profiles and would welcome greater use being made of them.

There was overwhelming support for the proposed Forums that would be facilitated by the County Transition Lead. They described this period as terrifying and that they currently have a lack of faith in the system. Parents were keen that these should not become another opportunity for just those families who meet a set of criteria. They also wanted them to be an opportunity for them to meet providers of equipment/aids/support for their young people to meet the Preparing for Adulthood outcomes.

Parenting Courses – Norfolk Steps is held in high regard by families who have accessed the course. However, there was little positivity about generic parenting courses as they did not seem to be relevant to the behaviour displayed by disabled children who do not respond in the expected way. These courses do not provide for the emotional needs of families of children with SEND. They reported feeling judged by course tutors and other participants. Attendance is seen as just another hoop to be jumped through on the journey to diagnosis.

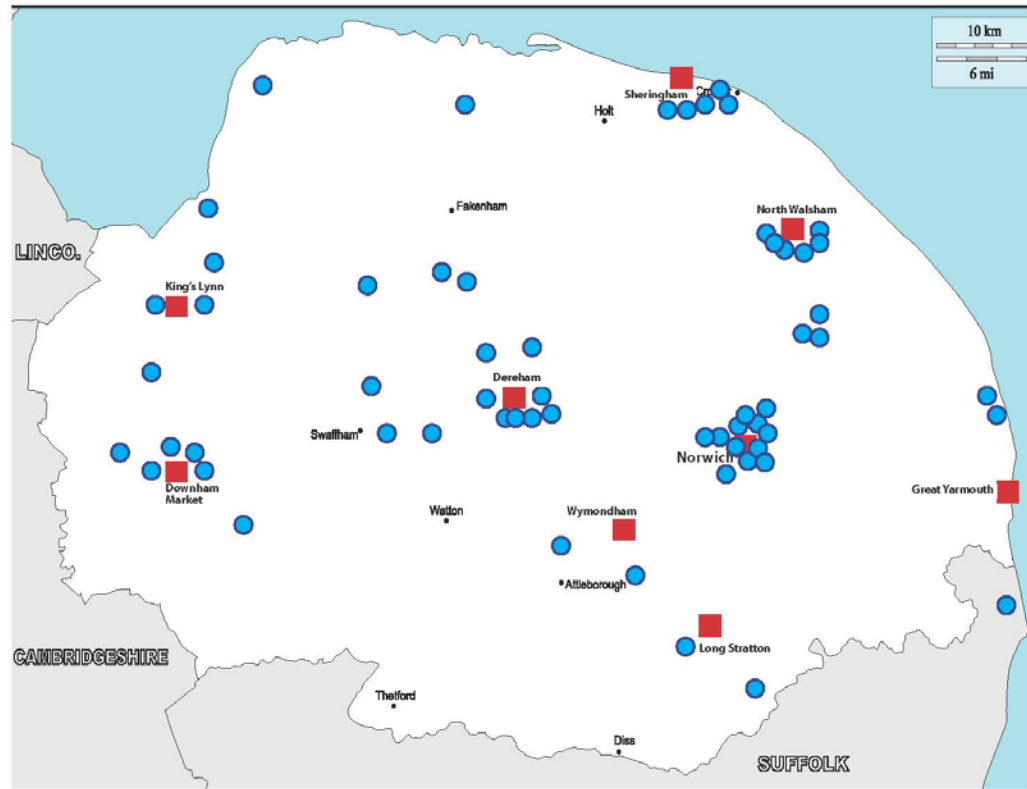
7 NEXT STEPS

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. The information in this report has been presented as it was given, without interpretation. Family Voice would welcome the opportunity to work in partnership with the teams operating in these service areas to ensure better outcomes for these families.

The Steering Group would like to thank each and every parent 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.

8 APPENDIX

Appendix 1
Home areas of those taking part in Family Voice Parent Participation sessions November 2016



Notes

The information above is based on information from participants' feedback forms. Not all participants gave a postcode on their forms, so their data is not captured above.

- Event venue
- Participant