

## **Family Voice, Family Chat Sessions, June 2018**

### **Subject: Transition – moving on to adult life**

Family Voice Norfolk works in co-production with Norfolk County Council (NCC), Norfolk Clinical Commissioning Groups (CCGs) and Commissioning Support Units, education providers, Voluntary Community Services, and 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 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, regular 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.

During the summer of 2017, Family Voice Norfolk decided on a fresh approach to its parent carer participation events for areas deemed harder to reach within Norfolk. Parent carers had expressed a need to gain knowledge and information from our events and to then share their lived experiences with us. Out of this, the new Family Voice, Family Chat events were born. 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 surveyed its membership during June and July 2017 to find out more about what families want from our events, best locations, most suitable times and most importantly, which subjects were of most interest. The results of the survey determined four locations and revealed that 'Transition', or moving on to adult life, was of high priority. Family Voice Norfolk invited Frank Crowdy from NCC's Transition Service and Wayne Doman, from NCC's Local Offer to work with us to develop a format to explore issues related to transition and we are grateful to them for their enthusiasm and willingness to co-produce the sessions.

The following events were organised:

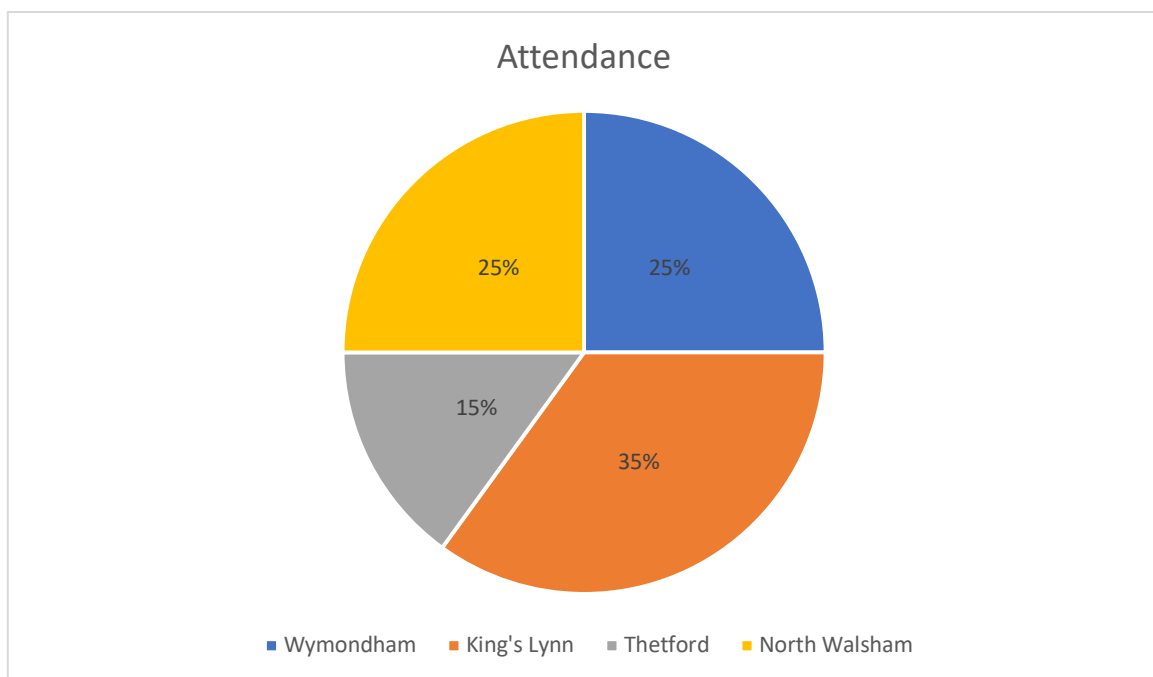
5/6/2018 – Wymondham

19/6/2018 – King's Lynn

21/6/2018 – Thetford

28/6/2018 – North Walsham

60 parent carers attended these events, representing an age range of children and young people from 13 through to 23. Parents told us after one session that an attendee (who did not sign in) was in fact a social worker working with their families. This had made it difficult for them to speak frankly. We do not know if this attendee was also the parent of a CYP with SEND and they left before we were able to establish this. Family Voice respectfully suggests that Family Voice Family Chat events are intended as places where parent carers can speak openly and share their experiences and that professionals have other means of obtaining information. We appreciate that those working in services may well also have personal reasons for attending our groups, but if they make themselves known to us we can ensure that they are able to come to a session where neither they nor families they work with need feel constrained.



Based around the information-giving presentations from both the Local Offer and Transition Service, to better understand the issues faced by families and to facilitate the gathering of information for our membership, Family Voice asked those attending to consider the following questions:

- **Thinking about your own transition to adult life, looking back, what were the important steps? In what ways will things be different for your young person?**
- **What kinds of conversations have you had with your young person about their adult life? Are there things about this that you find difficult?**

- **Who have you found who can help you with these issues? People who really understand your young person and what you all want the future to be like? What has been good about this help, or if you haven't found it, what do you most need?**
- **Transition to adult life doesn't happen overnight for anyone. Having ideas and plans is one thing but making them happen is another. How can you know what next steps are at any stage? After today, what do you feel you need to do next?**

### **The Findings**

While many parents recognised how different their own progression into adulthood will have been from the progression facing their CYP with SEND, very few had begun to make plans with their young people and expressed lack of guidance on how and where to start the process.

School went through this living independently issue with my daughter. She got really excited, she took it literally and thought she could get somewhere (to live)..., not understanding about funding, where money would come from....she just thought that when you get to 16 you can live independently.

In discussion, parents agreed that things that concern most, but not all, CYP with SEND and their families going into adulthood were the same as for many other people: the need for a home, for good health, for money and for a job.

Parent carers, however, reported that they really did not know how to begin to work with their young person, where to find out about what needs to happen and when. For some parents, the idea of having a 'conversation' with their young person was felt to be unrealistic given the complexity of their needs.

We are talking about conversations but there are children who cannot communicate.  
I don't feel I can express his views without help to do so

I feel it is such a huge responsibility. I need someone to help.  
This is how I am feeling.

There is not enough help out there to inform us.  
It's very confusing.

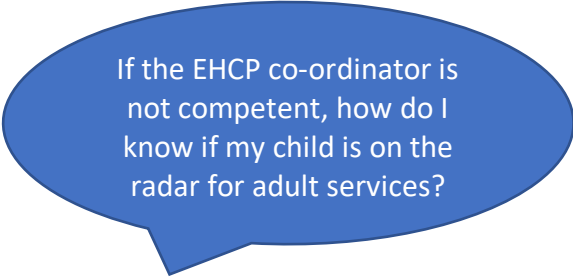
I just want someone to come to me and help me.

## **The Local Offer**

Wayne Doman from the Local Offer presented an overview of the Preparing for Adulthood section from the LO website and his own example, as a parent of a young person with SEND, of the planning he and his family have made together for their young person's future. This gave parent carers an idea of the kinds of things they could be thinking about with their young people and was very well received.

## Preparing for Adult Life

Frank Crowdy spoke to the parent carers in depth about his role in Preparing for Adult Life, the current situation and plans for a future service. The information given was very well received and, for most, was the first time that transition to adulthood had been explained. All parent carers attending the Family Chat sessions emphasised the need for a one-stop service, one point of call and reference for them to find out everything that is needed in ensuring a successful transition into adult life and, for some, into adult services. For most, it was unclear who was responsible for 'driving' the preparation for transition. Few parents spoke of positive experiences with EHCP co-ordinators with many still never having met the co-ordinator responsible for their child's plan. There is still a feeling of lack of confidence with one parent carer asking:

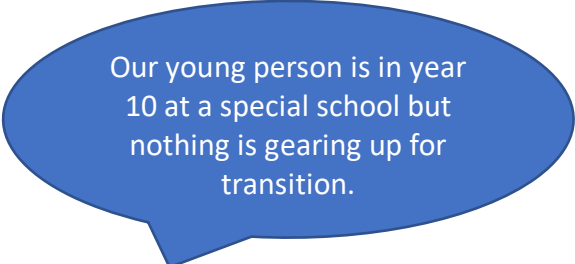


If the EHCP co-ordinator is not competent, how do I know if my child is on the radar for adult services?

The current 'Ten Step Pathway to Transition Planning' was shown and when asked if they had been involved with planning from Year 9 with school and were aware of the year 9 review, the overwhelming response from parent carers was:



No

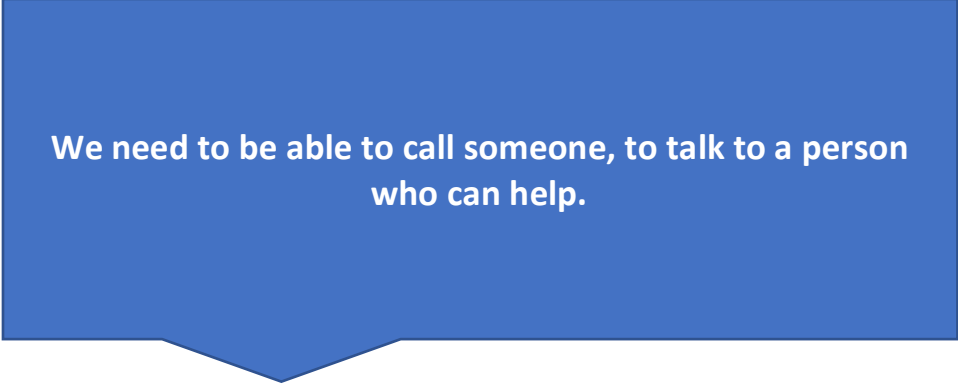


Our young person is in year 10 at a special school but nothing is gearing up for transition.

Only 4 of the 60 attendees had been involved in or made aware of planning from year 9 and the Ten Step Pathway was not familiar to them.

Frank spoke of the Transition Tracking System and with very few exceptions, parent carers were not aware of this. It was explained that young persons likely to require adult services are 'flagged up' by schools and through access to children's services such as Short Breaks. Parents were worried that

their young people might be 'missed' and how could they possibly know if their young person had been captured on the system? A single Preparing for Adulthood service for contact is very much needed to enable parent carers to find out and to ask questions about what needs to be happening in preparing for adult life.



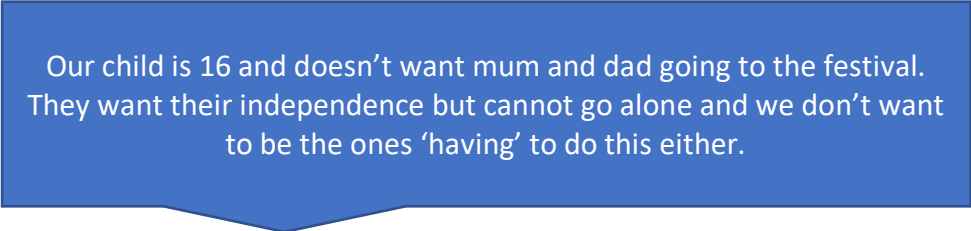
**We need to be able to call someone, to talk to a person who can help.**

Parent carers are frustrated at the current communication systems in place at County Hall, with statements made such as "no-one ever answers the phone at NCC" and a complaint that when phoning the MASH service, the only option given is for the safeguarding team, which is 'off-putting for parents'.



NCC's Customer Services route is so complicated.

As part of the discussions around preparing for adult life and knowing what needs to be happening and when, some parent carers expressed difficulties in accessing Short Breaks and the lack of suitable opportunities for young adults:



Our child is 16 and doesn't want mum and dad going to the festival. They want their independence but cannot go alone and we don't want to be the ones 'having' to do this either.

Young people are entitled to live their life fully without mum doing it all.

It's hard as a parent to say "I am not doing it."

I struggle to find something (activities, groups) where my son feels he fits. Services and possibilities are just not there.

Family Voice Family Chat events enable parent carers to ask questions, discuss with each other and to learn from each other's experiences. Within the discussions concerning moving on to adult life, some questions and themes struck a chord with many parent carers.

**Parent carers asked:**

**'What happens when I reach my expiry date? Our young person would not cope without us.'**

**'Who assesses my young person's needs when I die?'**

**'What happens if a carer cannot physically care? I haven't gone back for help because I was told I would need to be a blubbing wreck to get any assistance.'**

**'What is a learning difficulty and what is a learning disability?'**

**‘What happens with our young person and the two days they are not in college? Can we use Short Breaks funding? Will it be enough?’**

**‘Where do I go for money advice for my SEND young person?’**

### **Statements were made such as:**

**‘There is no automatic transfer of services from one county to another.’**

**‘We have moved from another county. All payments have stopped. I was told I would need a nervous breakdown and psychiatric help before I would get any help for my young person.’**

**‘We have moved to Norfolk from another county where our young person had direct payments for Short Breaks. Children’s Services in Norfolk are refusing to assist with Short Breaks and direct payments because our young person is soon to turn 18.’**

**‘It’s impossible to get a carers assessment.’**

**‘I feel totally let down by MASH who wouldn’t help me, even though my child was not in school for seven weeks.’**

**‘There is no joined-up working.’**

**‘Health and Social Care don’t talk to each other.’**

**‘With a Looked After Child (LAC), the different services don’t come together but try and pass everything to each other.’**

**‘My young person (in an independent special school) didn’t get any of the work placements. Peers have all finished theirs but my child didn’t even get the chance to start.’**

**‘Social worker expectations of my son were poor. They wanted him in day care. As parents it’s all put on us to do the things with our youngsters.’**

**‘The social worker helped my 19-year-old and then dropped us off the system.’**

### **Information was shared between parent carers about:**

**The Local Offer  
DLA/PIP  
SENDIASS  
CEA Card  
Gig Buddies  
Short Breaks**



## Disability Register

### Summary and key points

The information above has been presented as it was given, without interpretation. However, some themes were clear over the four sessions that can be summarised as follows:

- The Family Voice Family Chat format enabled parent carers to gain knowledge and understanding of the process and steps for moving into adult life, giving them clear ideas for planning for their own young person's future and informing of the systems that should currently be in place;
- By becoming better informed, parent carers are empowered to take charge, with their young people, of the processes and steps needed as adult life approaches;
- Prior to the Family Voice Family Chat sessions, many parents were unaware of what should be happening and when for preparation for adult life and who should be 'driving' the process.
- Many parent carers reported a lack of communication between school and home regarding transition and between services involved.
- Many parent carers were concerned that access to services that would feed in to the preparing- for-adult-life system was still proving problematic, such as Short Breaks.
- All parent carers advocated the need for a one-stop Preparing for Adult Life service, a direct line with someone to speak to who can answer their questions and provide help.

The overall picture is one of uncertainty and confusion for parent carers. These families were not isolated. Many had children in specialist settings and the opportunity to speak with other parents. All of the families who came to the sessions had had contact of some kind with workers in social services, education or health services who could have helped them to navigate a way forward or at least initiate conversations about things to consider. The fact that the age range of the CYP with SEND represented by these parent carers was so wide suggests that many opportunities to inform and guide families are missed. Families are used to 'experts' in education and health services advising them about their children or, indeed, taking charge of the management of their education or care. It comes as a shock, then, to many families that no one seems currently to take ownership of the critical and wide-ranging questions regarding a young person's future.

Of course, the main reason is that this ownership belongs to the young people themselves and the families who love and help them. But those families are not used to 'driving' planning, and when they attempt to do so often find that support from services is not there. Yet parent carers know only too well that the day will come when they are no longer able to be the main support of their young people. They want this point to arrive not as a shock and a crisis but as part of a well-planned and

prepared transition. It is the role of all parents to help their children reach a stage where they are no longer needed. Parents of CYP with SEND are no different. They know that for their children, independence will require support from others. There is a clear need for families and young people to be able to voice their aspirations and anxieties, and for services to understand what is needed for families to feel empowered and confident about the future, so that moving on to adult life can be a time of excitement and opportunity rather than confusion and fear.

Family Voice Norfolk would like to thank all parents 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 Wayne Doman and Frank Crowdy 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.

Rachel Clarke

Vice Chair

Family Voice Norfolk

September 2018