



Public Health
Research Unit

West Sussex Mental Health Needs Assessment (Children and Young People) July 2014

Background Evidence – Parents / Carers of Service Users

Report by the

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Date: July 2014

Engagement with parents / carers of young people involved with CAMHS in West Sussex

"Listen to parents more. Parents know their children more than anyone and know when something isn't right. Listen to them and don't ignore them and hope it will go away."

"It's constant fighting and you are asking where you can find information out, you just have to find it out yourself, really, because it's really difficult"

"Therapeutic Parenting - made a real difference in the way we parent both our adopted children. It gave us lots of strategies to use and plenty to think about. The therapists were fantastic."

"They say 'it's all early intervention', but then they're all 'wait and see, wait and see'. They think it's just immature behaviour; it takes ages to get an assessment done. They need to make 'early intervention' earlier."

"I think the one word to sum it up is 'frustration'."

"Help us help our children."

"I would like to think that all people could get as good a service as we received, and from such an experienced psychologist who knew just how to get my daughter to change her thought processes in such a positive way."

"Provide the right services to support all young people. Where do parents turn when told supporting a disorder is not within the remit? We have felt utter despair and isolation in obtaining care support and understanding for our daughter and it continues."

"No one talks to anyone else. I have had to arrange meetings myself in order to get people together."

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EXECUTIVE SUMMARY

1. *Method and response to the engagement.* To inform the Children's Emotional Wellbeing and Mental Health Needs Assessment, engagements were held with parents across the county in the Autumn of 2013. Five focus groups were held with parents: the Autism Sussex parents group, a CAMHS group, adoptive parents, foster carers and parents whose children had received counselling help through the Worth Emotional Support Service (WESS).

An online survey was also developed to capture the views and opinions of parents whose children had had some involvement with CAMHS. The findings of these two methods of research are summarised in this section of the wider Needs Assessment.

Other sections of the Needs Assessment report on the engagements with children and young people and with a range of professionals.

2. Parents described the stress and frustration of trying to get help for their children, in some cases over many years.

Significant variation in referral waiting times to see a CAMHS worker was noted. However this was compounded by parents perceiving the wait to be from the time they identified their child's needs for specialist help to actually accessing the service.

Many parents feel they are not listened to and professionals, in some cases, can appear disrespectful.

3. Many parents are unaware of CAMHS and so rely on professionals in contact with their child to identify the need for a referral and to support them through the process. Parents expressed concern that not all professionals have knowledge and expertise of mental health issues and resources. In schools it can be unclear which member of staff has responsibility.

Parents find it more difficult to get advice if their child is home schooled or not in school.

Foster and adoptive parents in WSCC can be referred to CAMHS LAAC by social workers. Those who foster or adopt through agencies or other local authorities are not linked to CAMHS LAAC or to support groups and sources of information. In general, they access support in the same way as other parents through their child's school or GP. This can be problematic.

Foster parents have a social worker to help them navigate services and to support them. It is possible that other parents of children with mental health difficulties could benefit from this level of support.

Many parents found the CAMHS referral process to be confusing; with some reporting that they needed to be proactive and persistent in order to find the most effective route. In addition,

they felt that communication whilst waiting was often poor. Timely information and guidance would have helped to allay their concerns and to manage their expectations.

In order to access services parents felt that they needed a clear diagnosis.

In some cases after a service has been accessed further help can be obtained, but most responses painted a negative picture of parents' ability to get further help.

4. Many parents were convinced that earlier guidance and intervention could have had considerable benefits for their child and alleviated the distress for both the child and family. They do not seem to routinely access parenting programmes or support groups, although there is evidence that these are effective and valued. Parents in focus groups rarely mentioned any targeted school provision for their children, for example, to support or improve social and emotional skills, raise self-esteem or to prevent exclusion. (Some were aware of services for vulnerable children in schools: educational psychologists, school nurses, counselling and the virtual school for children looked after.) It was felt that currently there has to be a crisis before an appropriate service is considered.

5. There is confusion about what services are available. Useful information often travels via word-of-mouth and the main sources of information are key individuals. Parents wanted a clear pathway and information on who to contact if they have concerns about their child and what they can expect. They want to understand why their child is having difficulties and to obtain practical advice about what to do to help. They are also aware of the importance of services to support them as individuals, such as counselling and support groups.

There is a need for better web-based local information for parents and for young people. However, it is important to be aware that parents can sometimes feel overwhelmed by too much internet information and require support to access what they need. There was agreement in one focus group about the usefulness of Facebook since it was accessible at any time and provided a way for parents to support and learn from each other as well as to find out what help is available to them.

Across the groups and survey findings the CAMHS helpline and website was rarely mentioned. Telephone advice is useful for some and it was felt that it should be available for teenagers.

Some parents did not receive advice while waiting for the CAMHS services and others received advice that they did not find helpful.

6. Parents suggest that some professionals need further training to be able to support their children. The parents often recognise that their child is experiencing difficulties at an early age and find health visitors, teachers and GPs do not always have sufficient knowledge and skills to offer advice. Unskilled and unqualified teaching assistants may be given a lead role with

vulnerable children and young people. Some adoptive parents were concerned that teachers generalise from very limited personal experience and would like an expert on adoption available to each school.

Some parents found that professionals welcomed advice. Attention was drawn to parents who passed on their learning from a CAMHS intervention and this was appreciated by school staff. Similarly, some experienced foster carers would like to contribute to training new foster carers.

7. Despite the issues with referral processes and communications many parents reported a good service once they manage to access CAMHS. Some were very positive about the service, feeling it was the first time they and their child had received the help they needed.

Parents who were disappointed with the service included those whose children only received medication or short term support, those with ADHD, teenagers and those in transition to adult services. Also foster carers were concerned that they could not access help for children who had not yet 'settled' in their placement, though they often needed help in the early stages of the placement.

8. Interagency communication is perceived to be poor, with parents often having to re-tell their story, and feeling as though they are being passed from one agency/service to another. When agencies are unable to help they do not all routinely signpost parents to another service.

Parents suggested that Schools and Health Services do not work well together. There is on-going confusion about the interface and pathways between Special Education Needs processes and mental health provision. From the parent's perspective not all schools are taking responsibility for supporting young people with mental health or emotional difficulties.

Parents said that, from their experience, the Common Assessment Framework (CAF) and the team around the child approach did not appear to be embedded.

9. Parents perceive current services to be insufficient in number/range, not to be child-centred, and with systems and processes that are unnecessarily bureaucratic and a barrier to access.

They noted that some primary schools offer support and that the transition to secondary school was problematic for some children.

Parents were concerned about the impact of having a child with mental health difficulties on the whole family. They highlighted that service providers need to be aware that children who find it difficult to socialise may need support to access universal services (clubs, leisure activities etc.) which increases demands on parents and siblings if parents accompany them.

Services were seen to be thinly spread and parents identified a range of areas where they felt an increase in provision was needed, both within CAMHS and in general:

- Early intervention, Tiers 1 and 2 services for children and parents
- Parenting programmes easily accessed at early stage of difficulty
- Information including the use of social media
- Services for children with behaviours issues/conduct disorders and their parents
- Activities for the whole family to benefit siblings
- Advice while waiting for assessment at CAMHS
- Telephone counselling and advice for parents and young people
- Parenting support programmes
- Services for teenagers and for transition to adult services
- Services for children and young people with autism and their parents
- Specialist services for children who are also physically disabled

1. INTRODUCTION

This element of the research gathered information about the experiences of parents whose children: were waiting for, currently receiving or recently having received mental health and wellbeing support services for their children.

Five focus groups were held with parents:

- Parents who were involved with Autism Sussex.
- Parents of children who attended a CAMHS Anxiety group.
- Parents who had adopted Children Looked After.
- Parents who fostered Children Looked After.
- Parents whose children had received counselling help through the Worth Emotional Support Service (WESS) to counter the effect of domestic abuse in their family.

Almost all attendees at focus groups were women.

Individual interviews were carried out with 2 parents:

- The parent of a child who had wide experience of services including WESS.
- The parent of a young man (age 30) with continuing mental health issues, who as a result, had a good knowledge of services.

In parallel with the in-depth interviews and focus groups, 137 parents involved with mental health and wellbeing support services in some way, responded to the online survey. The information from the focus groups, interviews and the survey analysed in this report provides some broad insight into parents' views¹.

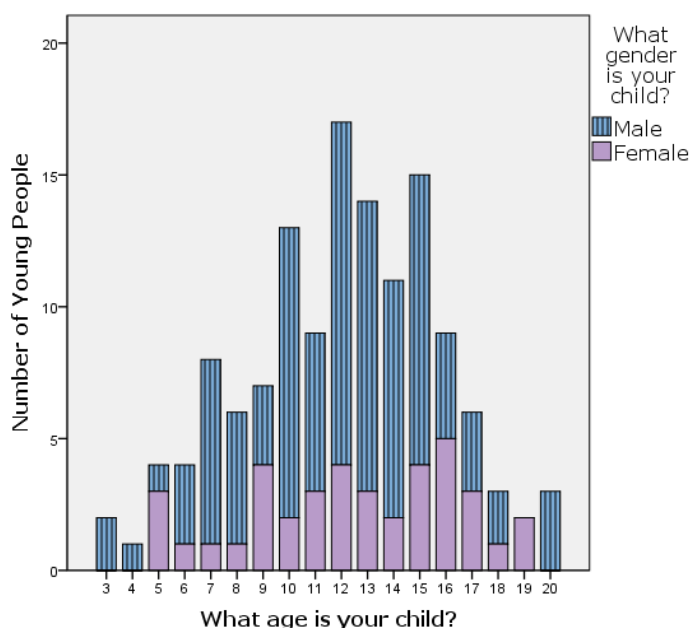
48% of parents who took part in the survey stated that they were either currently receiving or had received help for their children from CAMHS. 19% said they were still waiting to receive help. 33% of respondents did not answer.

It was evident from the survey comments that a relatively high number of parents of children with autism responded to the survey.

The age and gender of the children whom were being discussed is summarised in Chart 1, with 95 males and 39 females (3 did not say). The children are between the ages of 3 to 20, most of them are secondary school age.

¹ 'xx' refers to written quotes from the online survey
"xx" refers to spoken quotes from the focus groups and interviews

Chart 1, Age and sex of children/young people whose parents/carers responded to the survey



Regarding ethnicity, 89% were white British with the remainder spread amongst other groups. This is representative of the West Sussex ethnic distribution. Respondents were asked which town they lived in or near and answers are shown below in Table 1. Twenty six percent of respondents came from Worthing, 2% lived outside the county and the remaining 68% came from across the county.

| Table 1, "What town do you live in or near?" | Number & Percentage |
|---|--------------------------------|
| Bognor Regis | 9 (7%) |
| Chichester/Midhurst | 19 (14%) |
| Littlehampton/Angmering/Rustington | 10 (7%) |
| Worthing | 36 (26%) |
| Shoreham/Lancing/Sompting | 10 (7%) |
| Horsham/Steyping | 15 (11%) |
| Haywards Heath/Burgess Hill/Cuckfield/E Grinstead | 10 (7%) |
| Crawley | 17 (12%) |
| Other (Arundel, Billingshurst, Westergate, Yapton) | 4 (3%) |
| Outside West Sussex | 2 (2%) |
| Not Stated/Not Clear | 5 (4%) |
| TOTAL | 137 (100%) |

The living situation of the respondents is shown in Table 2, with over half the children living with their birth mother and father. A relatively high number of foster and adoptive parents completed the survey. Some of these parents attended focus groups and also took the opportunity to complete the online survey. Others who were not able to attend the group sessions were encouraged to complete the survey.

| Table 2, “Which of the following best describes your child’s living situation?” | Number & Percentage |
|--|--------------------------------|
| With birth mum and dad | 73 (53%) |
| With one parent (mum or dad) | 20 (15%) |
| With birth mum/dad & step mum/dad/their partner | 11 (8%) |
| With other relatives or carers | 1 (1%) |
| With foster carers | 13 (10%) |
| With adoptive carers | 6 (4%) |
| In a care home | 2 (2%) |
| In a children’s home | 2 (2%) |
| Somewhere else | 3 (2%) |
| Not Stated/Not Clear | 6 (4%) |
| TOTAL | 137 (101%) |

It is interesting to compare this with the living situation of the children and young people who completed a survey in the young people’s engagement. The young people completing their own survey were less likely to be living with both parents (36%) and less likely to be in foster care (2%). They were more likely to be living with one parent (25%) and more likely to be living with a birth parent and a step parent (16%). This could simply be a consequence of the small numbers involved or the fact that the young people completing their own survey were generally an older age group than the young people whose parents completed the survey.

When asked a series of wellbeing questions, parents provided the answers across the five point scale shown in Table 3.

62% of the parents thought that their children did not usually, or never felt confident and able to deal with problems. 37% felt that their children did not usually, or never have good relationships with others. Parents had their lowest level of concern in terms of how happy or content they felt their child was, with 22% said to not usually or never feel happy and content.

| Table 3, “How do you think you child feels about themselves and others?” | Always | Most of the time | Sometimes | Not usually | Never | No Answer | TOTAL |
|---|---------------|-------------------------|------------------|--------------------|--------------|------------------|---------------|
| They feel happy and content | 3 (2%) | 50 (36%) | 50 (36%) | 28 (20%) | 3 (2%) | 3 (2%) | 137 (98%) |
| They feel confident and able to deal with problems | 1 (1%) | 13 (10%) | 34 (25%) | 65 (47%) | 21 (15%) | 3 (2%) | 137 (100%) |
| They feel that they have good relationships with others | 4 (3%) | 24 (18%) | 56 (41%) | 45 (33%) | 5 (4%) | 3 (2%) | 137 (101%) |

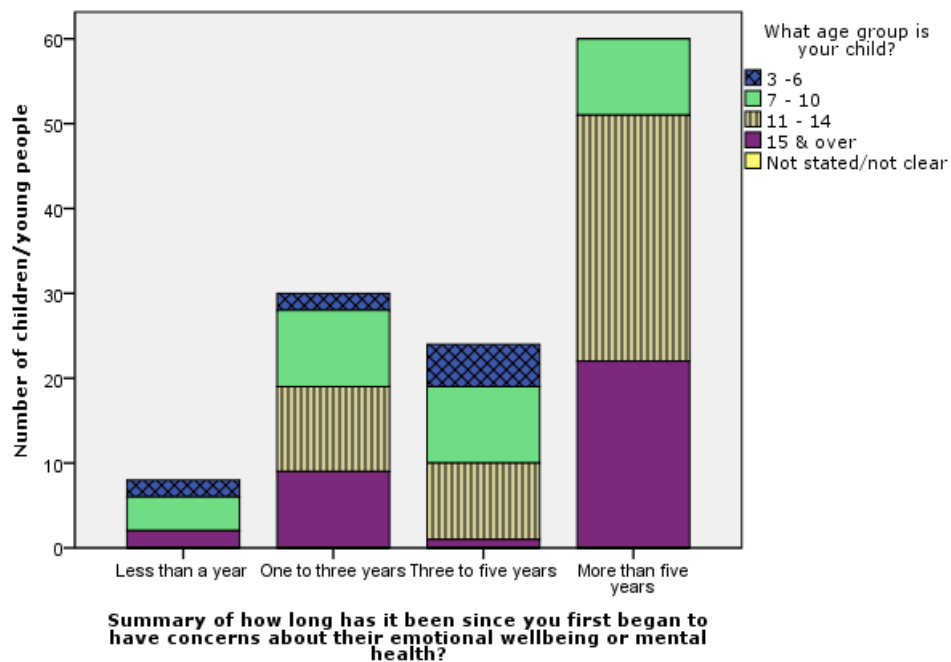
There was an interesting contrast between the responses, with 74% saying their child was happy and content ‘always, most, some of the time’ and only 36% saying their child was confident and able to deal with problems to the same degree. This may highlight a view that being confident and able to solve problems does not necessarily correlate with being happy and content in the eyes of the parent; likewise with having good relationships with others, though to a lesser degree (62%).

In general, parents' perceptions as illustrated in this survey show higher levels of concern than the young people who completed their own survey. The parents' concerns have been apparent in many cases for some years. Table 4 and Chart 2 show that 44% of the survey respondents have had concerns about their child's emotional wellbeing or mental health for more than 5 years.

| Table 4, "How long since you first had concerns?" | Number of Young People & Percentage |
|--|--|
| Less than a year | 8 (6%) |
| One to two years | 17 (12%) |
| Two to three years | 13 (10%) |
| Three to four years | 10 (7%) |
| Four to five years | 14 (10%) |
| More than five years | 60 (44%) |
| Don't remember | 1 (1%) |
| Not stated/not clear | 14 (10%) |
| TOTAL | 137 (100%) |

Chart 2, Length of time since parents/carers first had concerns shown by broad age groups

(Excluding 'not stated/not clear' and 'don't know' answers)



The information about what issues concerning their child were worrying parents is shown in Table 5. 79% of parents reported that their children felt anxious or worried, 63% reported that they did not feel good about themselves, 62% showed extreme behaviours, and 50% reported that their children found it hard to behave or felt stressed.

| Table 5, Issues | Number & Percentage |
|--|--------------------------------|
| Feeling anxious or worried | 108 (79%) |
| If they were not feeling good about themselves (self-esteem) | 86 (63%) |
| If they showed extreme behaviours (OCD traits, autistic spectrum behaviours) | 85 (62%) |
| If they were finding it hard to behave | 69 (50%) |
| If they were feeling stressed (e.g. due to exams) | 68 (50%) |
| Feeling unable to cope | 61 (44%) |
| If they were feeling sad a lot of the time | 54 (39%) |
| Moving from primary to secondary school | 41 (30%) |
| If they were being bullied | 46 (34%) |
| Refusing to go to school | 43 (31%) |
| If they wanted to harm themselves | 40 (29%) |
| If they had eating problems (not able to eat, eating too much, binge eating) | 29 (21%) |
| Moving from one school to another at a different time | 22 (16%) |
| Other worries | 21 (15%) |
| If they were feeling suicidal | 10 (7%) |
| If someone in your family died | 8 (6%) |
| Parents separation or divorce | 7 (5%) |
| If someone in your family was very unwell | 6 (4%) |
| If someone in your family was being hurt or abused in some way | 5 (4%) |
| If they were in trouble with the police | 5 (4%) |
| If someone in your family was in prison | 4 (3%) |
| If they questioned their sexuality | 3 (2%) |

A focus group was held with parents of children with autism and also another with parents whose children were receiving CAMHS support for anxiety. It is possible that these parents completed the survey and encouraged others in a similar situation to do so, which might be reflected in the high percentages where parents noted these issues.

Other worries included: attachment disorders, disabilities, an inability to cope well with their autism, being 'super sensitive' (hyper sensitivity), transition into adulthood and domestic abuse by a child on their mother and sister.

Parents described the stress of trying to get help and in many cases years of frustration. They talked of being 'in a battle' of 'fighting' to get help and of feelings of isolation and loneliness. Foster carers as a group reported that they received more support. However, because there was an expectation that the children they cared for would have difficulties, it can be assumed by some professionals, particularly in schools, that their problems are too serious for them to address.

Parents describe feeling that it may be their fault that their child is having difficulties:

“When she said that, you know, “What your child has is a condition and it’s not due to lack of parenting skills,” and to hear that when you have struggled for so long thinking, “Is it me? What are we doing wrong?” So that one is really very powerful.”

Parents want to understand their child's behaviour and be given advice about what to do:

“My daughter had two appointments each with the child psychiatrist, and the child clinical psychologist, i.e. 4 appointments in total. Some behavioural strategies were offered to us. However, for me the most useful appointment was when I had a 90 minute appointment with the clinical psychologist. This was very good indeed, as she talked about the physiology of someone with ASD, and talked about why behaviours happen. Although we have had good strategies on how to stop behaviours, knowing why (i.e. what physical changes were taking place) was incredibly useful. I really feel that this type of appointment should be offered as a 'group talk' when any child is diagnosed with ASD.”

Parents mainly talked about accessing services for their child or parenting advice and support, but one focus group also talked of their own need for counselling as individuals and how important it was to look after themselves too:

“Also something that [group coordinator] has pushed quite a lot recently is that it's okay to take some time out to look after yourself and how important that is, because you do get to the end of your tether.”

Many parents were very aware and concerned that there are families not receiving services and they felt themselves to be 'the lucky ones'.

Key Points:

- To inform the Children's Emotional Wellbeing and Mental Health Needs Assessment, engagements were held with parents across the county. Five focus groups were held with parents: the Autism Sussex parents group, a CAMHS anxiety group, adoptive parents, foster carers and parents whose children had received counselling help through the Worth Emotional Support Service (WESS).
- An online survey was also developed to capture the views and opinions of parent whose children had had some involvement with CAMHS.
- All except one of the parents in focus groups were female. The comments on the survey indicate a relatively high number of parents of children with autism.
- Parents described the stress and frustration of trying to get help for their children, in some cases over many years. The issues concerning their child that worried them were wide ranging; the main concerns were that their child was experiencing anxiety and stress, behavioural difficulties, and poor self-esteem.
- Parents felt that they needed a clear diagnosis in order to access services. They wanted to have an understanding of why their child was having difficulties and then they wanted advice about what to do.
- Much of the discussion and comment was about accessing services for their child or trying to find parenting advice. Some also recognised the importance of services which would support them as individuals, such as counselling. Parents in the focus groups had successfully accessed services but they were concerned that there were other parents who had not been able to access services for their children or themselves.

2. REFERRAL PROCESS AND THRESHOLDS

2.1 First point of contact:

Survey respondents were asked how professionals responded to them, when first approached. The answers are shown in Table 6. The majority of parents said that professionals did not tend to put them in touch with support groups, although as reported elsewhere in this report, parents placed a high value on opportunities to meet with others in a similar situation. They said that this helps them overcome feelings of isolation and loneliness as well as providing a source of advice.

| Table 6: “How did professionals respond” | Always | Most of the time | Sometimes | Not usually | Never | No Answer | TOTAL |
|---|---------------|-------------------------|------------------|--------------------|--------------|------------------|---------------|
| They took me seriously | 37 (27%) | 25 (18%) | 33 (24%) | 15 (11%) | 7 (5%) | 20 (15%) | 137 (100%) |
| They helped me to understand what was happening | 16 (12%) | 26 (19%) | 30 (22%) | 31 (23%) | 13 (10%) | 21 (15%) | 137 (101%) |
| They referred me to services that could help | 19 (14%) | 20 (15%) | 43 (31%) | 18 (13%) | 18 (13%) | 19 (14%) | 137 (100%) |
| They put me in touch with support groups | 6 (4%) | 6 (4%) | 22 (16%) | 31 (23%) | 50 (36%) | 22 (16%) | 137 (99%) |
| They encouraged me to come back to them if I needed further help | 23 (17%) | 17 (12%) | 29 (21%) | 27 (20%) | 21 (15%) | 20 (15%) | 137 (100%) |

Some frustration for parents stemmed from feeling that professionals do not always appear to listen to or take them seriously. Of the parents who responded to the survey, 45% felt they were always/most of the time taken seriously, whilst 16% felt they were not usually or never taken seriously.

In focus groups, some parents reported what they perceived to be disparaging comments from professionals. The parents felt that some professionals viewed them as ‘internet mums’, alluding to how they might have ill-informed views of their child’s health, based on unreliable sources. Another was told in person that they shouldn’t believe everything they read in magazines.

‘Listen to parents more. Parents know their children more than anyone and know when something isn't right. Listen to them and don't ignore them and hope it will go away.’

Some parents discovered that communication had taken place between professionals without their knowledge. One parent found out many years later that her son’s primary school had written to a doctor asking for advice at the same time as she was being told that they had no concerns. Another was aware a letter had been sent from school but had not seen it:

‘We hear nothing then out of blue an appointment because of letter from school concerns them but we have not seen letter.’

Case study 1:

L's mother believed there was something wrong when he was a toddler, he was a sickly baby and he did not play. When he went to nursery school he became more and more unmanageable and the nursery staff reported that he would not do various things expected of him but no advice was given and he was sent home. When he was in year 1 at school his mother felt she couldn't cope anymore and went to the GP. The CAMHS service went into school but L's behaviour was good during the observation.

Two years later she was still finding it difficult to manage his behaviour at home and she tried again to get help from the GP. She felt that he thought she was making things up but an appointment with CAMHS was arranged. L was assessed as having ADHD (attention deficit hyperactivity disorder) and PDD (Pervasive Development Disorder). L was initially just offered a regular check up and medication. Phone advice was also offered but his mother felt she had received no real help until he was 12 and they were both given the opportunity to take part in a parent and young people's support group.

2.2 Identifying a child as 'in need of specialist services':

Many parents were unaware of CAMHS and so relied on professionals in contact with their child to identify the need for a referral and to support them through the process.

Although most parents in one focus group described recognising their child was having difficulties preschool, only one said that this was picked up (at 22 months old by a health visitor).

Parents in focus groups talked about the importance of support from schools, both in terms of their child's education and because the referral usually involved GPs, whom often rely on schools for further information about the child's difficulties.

Parents could find communication with schools, particularly secondary schools, very difficult. One parent described it as tiring and depressing having to 'go through it all again' every term to new teachers. Another described poor communication at secondary schools as follows:

"[] but secondary school where my daughter's at, you know, that's been a nightmare because you're dealing with so many different people and they don't seem to communicate between each other and you're all the time phoning and sending e-mails".

Often it was unclear to parents who was responsible for referrals to specialist services for assessment and it could be chance whether they found someone with expertise in schools to support them. In some cases this was the SENCO or head of year. In one case a teacher who understood the young person's condition went on maternity leave and no help was given until she returned.

Parents described it as a battle to raise awareness in school staff and school services of their child's mental health and emotional needs:

‘After years of not being listened to, I wrote a massive comprehensive letter to school with many specific details and was then sign posted with months of nothing happening and finally the SENCO pushed until a referral was made.’

It is also important to note that some parents have been unable to get any help from schools because their child is home schooled or not in school.

2.3 Children who are fostered or adopted:

It is recognised that children who are fostered or adopted may need specialist services but, it was reported, that can make it harder to access help:

‘Due to the fact that our adopted child had experienced an abusive start to life, her difficulties were easily explained away by professionals as her having an ‘attachment disorder’. We had to constantly persist in our request for help, it took over three years for the paediatric consultant [] to take us seriously and refer us reluctantly onto CAMHS LAAC, this was following our fears of an adoption breakdown Independent service.’

2.4 Self-Referral to CAMHS:

There appear to be only one or two instances where parents have successfully self-referred directly to CAMHS and in these cases the route was through a personal contact made outside of the usual referral process, e.g. at a conference.

‘Head of CAMHS met us at PACE conference through [name given].’

Apart from rare cases where the parent refers, once a child or young person is identified as needing a specialist assessment, professionals take a lead role. Table 7 provides information about which professionals made referrals to CAMHS:

| Table 7: “Which professional referred you/your child to CAMHS?” | Number & Percentage |
|--|---------------------|
| GP | 45 (33%) |
| Social Worker | 20 (15%) |
| School staff (including Nurse, Head, SENCO, teacher, doctor, counsellor) | 10 (7%) |
| Paediatrician | 6 (4%) |
| Hospital/Hospital Consultant/Specialists | 6 (4%) |
| CDC | 5 (4%) |
| Primary mental health worker | 3 (2%) |
| OT/School OT/SLT | 3 (2%) |
| Other professionals/routes (from a range of agencies) | 7 (5%) |
| More than one professional | 3 (2%) |
| Other comments | 6 (4%) |
| No answer/can’t remember | 23 (17%) |
| TOTAL | 137 (99%) |

33% of survey respondents report that referrals are made through GPs, who are expected/assumed to have knowledge about and contact with mental health services:

[There should be] a simple, quick and easy referral from the GP, everything grinds to a halt after a GP consultation - why is provision for mental healthcare not equal to physical healthcare?

Parents had little information about how to get advice or help and going to the GP was sometimes seen as a last resort. It could be stressful as by then they can feel they have been failing as parents. They had an expectation that their GP would make a diagnosis and refer to appropriate health services. They were sometimes frustrated that access to services appeared to be dependent on an assessment by their child's school, having already had difficulty persuading the school that their child is in need of specialist help.

Parents of children with autism believed that GPs were not necessarily suitably trained to recognise the complex range of behaviours exhibited by their children; successful diagnosis can be "hit and miss", or "pot-luck", which can lead to confusion or helplessness.

In contrast, the experience of consulting with a GP was positive for one foster carer who described her GP as 'absolutely excellent' and 'willing to help', and there were indications that GPs may have a better understanding of the needs of looked after children. Her only concern was that there can sometimes be a delay in the registration process, if they do not have all the documentation for the child.

15% of the survey respondents said that they were referred by social workers. Children looked after by WSCC are referred to CAMHS LAAC by social workers. Carers in the focus group reported that sometimes there is an initial difficulty getting social workers to refer as the child's behaviour may be different when being observed, but otherwise comments about social workers were positive.

Parents were also referred to CAMHS by NHS medical staff including paediatricians and consultants, as well as from CDC.

Only 2% were reported to have been referred by Primary Mental Health Workers.

There was confusion about the referral processes. A small number of referrals were reported as being made by more than one professional. Additionally, in some instances where a parent instigated the referral with a professional themselves, they may feel they were the referrer.

'We kind of referred ourselves via Post Adoption'.

In some instances parents resorted to shopping around to find the most effective referral route.

'[Referral by] School O.T after being flagged up by Child Development Centre Dr. [name given] after parent had emailed at least 3 times, after school had recommended the parent to write directly to Dr [name given]. After hearing nothing for the first 6 months, parent visited G.P to see if child could be referred that way and was told 'as B was already in the system, he stood a better chance of being seen that way' the G.P's way could take up to 18 months.'

The parents in focus groups placed a great deal of importance on the role of the school in assisting with referrals but there seems to be reluctance by schools to undertake an assessment and refer to

CAMHS. This will be looked at in more detail in later sections but the following issues were reported by parents:

- The SEN system acts as a barrier perhaps because schools perceive that action is already being taken
- Conduct disorder is seen as a behavioural problem and not a mental health issue
- Children who internalise difficulties are often overlooked
- Children looked after are sometimes not offered help because it is expected that they will have difficulties and that these will be addressed by other agencies.

Many comments by survey respondents referred to being unsuccessful in getting their child's referral accepted by CAMHS. This will be explored further in the section on CAMHS.

'No one, he didn't fit criteria but trying again.'

'First time we were referred we got told to go away, 2nd time paperwork went missing'.

'G.P. wrote twice, we phoned and begged, arrogant psychologist told would have to wait, still waiting 2 years later'.

2.5 Accessing further help:

Intervention by CAMHS did not necessarily guarantee help in the future, as highlighted in Table 8 below:

| Table 8, "Were you able to get further help if problems came back?" | Yes | Not sure | No | Not applicable | No Answer | TOTAL |
|--|-------------|-----------------|-------------|-----------------------|------------------|---------------|
| It was quick and easy to access further help | 8 (6%) | 11 (8%) | 30 (22%) | 14 (10%) | 74 (54%) | 137 (100%) |
| I had someone specific to speak to | 17 (12%) | 8 (6%) | 25 (18%) | 12 (9%) | 75 (55%) | 137 (100%) |
| I was able to get help even though it was a different issue | 8 (6%) | 9 (7%) | 25 (18%) | 20 (15%) | 75 (55%) | 137 (101%) |

Some of the comments paint a negative picture of parents' ability to get further help, if problems come back.

'If you do not see someone regularly they literally take you off the books. This is not very helpful if you come across a crisis at another time'.

'Received support 6 years ago but still waiting to hear from a referral made months ago. No correspondence at all.'

Parents felt they needed a clear diagnosis if they required longer term help or in order to access further help if problems come back. One young person had accessed the VIP group but did not have a diagnosis which his mother thought may cause difficulties:

“Even though he’s here, he’s outside every little box and bubble and tick and ...because he is below whatever they assessed so I have no idea what happens after this and whether we are on our own again.”

It should be noted that further help can be more easily accessed at WESS, parents using that service felt they would have an easy route back in for further help if they needed it

Key Points

- Many parents felt that they are not listened to and professionals in some cases could appear disrespectful.
- Foster carers in WSCC are referred to CAMHS LAAC by social workers. Many parents were unaware of CAMHS and so rely on professionals in contact with their child to identify the need for a referral and support them. The first ‘port of call’ is often the school; although it is often unclear which member of staff is responsible for identifying a child in need of a specialist service. It seems to be chance whether parents find individuals who have some knowledge and expertise. There seemed to be reluctance by some schools to undertake an assessment or refer to CAMHS. Parents find it more difficult to get advice if their child is home schooled or has been excluded from school.
- Other parents sought access to specialist help through GPs and again found that not all had knowledge and expertise of mental health issues and resources. GPs would sometimes refer to appropriate health services but this may be dependent on school assessments.
- In some cases social workers and a health visitor had been able to support parents in accessing services.
- Parents found the CAMHS referral process to be confusing; with some reporting that they needed to be proactive and persistent in order to find the most effective route.
- In some cases once a service was accessed further help could be obtained but most responses painted a negative picture of parents’ ability to get further help.

3. PREVENTION AND EARLY HELP

Parents were frustrated that they could not get earlier help:

‘what is needed is early intervention so kids have happy times at school with smaller class sizes time to help aid there learning, therapy e.g. music therapy, art therapy, things that will help make a difference so all this will help for them not to be a drain later in life because they have had such a bad time throughout their whole school life and struggled through lack of statements, and budget cuts, local education flaws; they are leaving school with low self-esteem and no job prospects then probably become a drain on society and having even bigger mental health issues.’

Parents looked for strategies to deal with behaviours at an early stage. Many were convinced that earlier guidance and intervention could have had considerable benefits for their child and alleviated the distress for both the child and family:

‘My son has Asperger’s syndrome and behavioural problems, it would have helped immensely to have had a professional help me with behavioural management - I had to spend a year reading about Asperger’s and behavioural problems in order to come up with my own strategies to deal with these behaviours, I really believe if there had been a professional who I could have talked to about my son we could have come up with these strategies much faster which would have made a massive difference to my family over the year I was reading and learning about his disability.’

The consequences of not having earlier help could be very serious.

‘CAMHS referral requested 3 times through GP, was blocked by LA consultant, when eventually obtained appointment daughter’s anxiety was so high she needed medication’

“My daughter is finding it extremely difficult to mix with other people, and has not been to school full-time for most of this year. This is due to lack of support at an early stage. She was referred to CAMHS fifteen months ago, which was refused, this was for self-harming and bereavement counselling. Now we have a daughter who cannot go out and is not functioning on any social level”.

Sometimes children’s behaviour deteriorated, leading to schools excluding them on the grounds they could not meet their needs. This could potentially happen to children with a range of conditions, including those who internalise their difficulties.

Parents in the WESS group also described wanting to have help at an earlier stage before the perpetrator of abuse leaves the family home. This could help them get out of a violent relationship sooner.

When asked ‘If you and your child were offered support/services before referral to CAMHS, to what degree did they help?’ The majority of survey respondents answered that this was not applicable or they did not answer the question. Very few could identify a service that either helped a lot or a little. The service that was identified as the most helpful was the school counselling service by 14 people though views were mixed as 8 people who had accessed that service said it did not help.

Significantly, parents said that professionals did not tend to put them in touch with parenting programmes or support groups, although there is national and local evidence that these are effective and valued.

There was no reference in the focus groups to any targeted school provision to support emotional wellbeing such as counselling or therapeutic groups.

In focus group discussions parents talked of a 'hit and miss' approach. A range of services mentioned as supportive were Home Start, Police, Social Workers and Leapfrog. There was little direct reference to groups in the voluntary sector though Autism Sussex, Winston's Wishes, NSPCC and the Women's Refuge Project were seen as helpful. Some parents felt that certain services offer a listening ear but that they would sometimes like more practical support.

Key Points:

- Parents said they were unable to get help at an early stage. Many were convinced that earlier guidance and intervention could have had considerable benefits for their child and alleviated the distress for both the child and family experience. It was felt that there had to be a crisis before an appropriate service was considered.
- Very few could identify a service that had helped before accessing CAMHS services. Parents did not seem to routinely access parenting programmes or support groups, although there is evidence that these are effective and valued.
- Parents in focus groups rarely mentioned any targeted school provision for their children. For example, to support or improve social and emotional skills or to raise self-esteem. Sometimes children's conditions deteriorated, because they could not access services earlier and they are excluded from school, or education provision is reduced.
- Parents talked of a 'hit and miss' approach to finding services. Some mentioned voluntary sector groups, some school staff, social workers and the police as helpful.
- Some services offer a listening ear but parents would like more practical support and to be advised of what to do to help their child.

4. AWARENESS OF SERVICES AND ACCESS TO ADVICE

4.1 General Information and Advice:

Sometimes parents could not access services because they were not aware of them. They feel they needed support to recognise problems and access the appropriate services as soon as they started to feel concerned about their child (often preschool).

“It’s constant fighting and you are asking where you can find information out, you just have to find it out yourself, really, because it’s really difficult”

“You don’t know what you need”.

49% of survey respondents thought there could have been an easier way to get information and advice.

Parents wanted easier access to advice from CAMHS e.g. about ASD. They wanted support when they were first concerned about their child and more information from professionals earlier, before a crisis occurs. Parents wanted to know what was available and to have confidence that the advice professionals gave was consistent, not contradictory.

Useful information often travelled via word-of-mouth. The parent focus groups used the opportunity to share information during each of the discussions. Often there was confusion about what was available and the parents did not know how to find accurate information.

Main sources of information were key individuals, such as social workers and members of the short breaks team. Parents also turned to school staff for advice, assuming that they would be able to offer services or signpost. It was felt that they did not know enough about Mental Health and CAMHS.

In general, parents wanted a clear pathway and information on who to contact if they had concerns about their child and what they could expect.

‘a folder made accessible to the parents giving all these sign posting as quite often when someone sign posts you - they assume everything falls in place’ and the parent is left hanging, not knowing where to go next. If a folder with information on pathway and ‘who is responsible for what’ with their job descriptions (as more than half the parents do not know what certain ‘job descriptions entail and who they need to see) If a folder with info is available to parents - parents would need to be told of this being made available to them’.

It was more difficult for a parent to obtain information if their child was schooled from home.

“She is being home-schooled now, which I have to say has cut down a lot of her anxiety, because we keep it at a level. She can go into groups that she wants to go to and she can meet people she wants to go to. But, it does mean I have to go out and find all of these services myself, again.”

4.2 Telephone helpline:

Access to informal information and advice was a service that parents felt could have a positive impact. Across the groups and survey findings, the CAMHS helpline was rarely mentioned, but for one parent it had been really helpful and the focus group agreed with her view that a similar helpline should be available for teenagers.

'If you can't see all the families that need your help maybe at least some telephone advice would be a start.'

4.3 Internet:

Parents would like better web-based local information for themselves and young people.

'The Council needs to update their Special Needs Section on their website - frankly it's terrible and is lacking in clear common sense information. If information was readily available, parents wouldn't have to keep bothering council staff with numerous time wasting enquires. We live in a technical world; it's time that the council made better use of this vital resource.'

Websites need to be designed to meet different needs. One parent felt it would help her son in his 20s, through transition to adulthood.

'A dedicated young persons' web access support that is aimed directly at them but most definitely not linked in with teenagers because my son has continued into his 20s to have problems and would not access support with a service he felt was for school and college age people. His age would reflect that he should be accessing adult services but his problems still relate to moving from child to adult.'

There was agreement in one focus group about the usefulness of Facebook since it was accessible at any time and provided a way for parents to support and learn from each other as well as to find out what help is available to them.

Nevertheless, parents could feel overwhelmed when given too much information and need support to access what they need:

"..through CAMHS they said, "Here is a list of websites and organisations you can access for information." Well, just trying to find the time to sit down and read and have a look at these things, and then we become members of it, but I've not actually done anything with it because I just haven't had the time. "

4.4 Adoptive parents:

Those who fostered or adopted through agencies were not linked in to support groups and sources of information. Adoptive parents can get information from Adoption UK but because of the cost some do not subscribe. Foster carers usually got information from social workers, letters from West Sussex County Council or the Foster Carers Association newsletter, but they lacked up to date information about programmes for children looked after.

“You talk [in the focus groups] to pro-active parents who have sought help, there’s the majority of adoptive parents who are at home struggling and don’t know who to ask.”

Parents who had adopted through other local authorities needed information on local provision.

“Until I sort of thought, oh actually I need this but I didn’t know what I needed and I didn’t know necessarily how to access it. I think perhaps adopters, however they come, where, if they live in West Sussex they should be given a sheet of phone numbers or something.”

Having failed to access services, some parents paid privately for help, such as hypnotherapy or counselling. They were unable to get advice from CAMHS or other services about which independent services might be helpful for their child:

“I’ve looked at the internet, I mean, I’ve looked at child psychologists thinking, “Maybe I’ll go down that route and pay,” but then who do you refer to? Because anybody can say they are a child psychologist. You don’t know who you are paying. I asked different doctors. I said, “Is there anybody you would recommend?” and they said, “We can’t recommend anybody.” So there is – apart from what is on the website and just trying to find somebody, but as I say, you’ve got no idea and having to pay a lot of money for it.”

4.5 Advice while waiting:

Some parents reported that referrers were not perceived as helpful. Almost half of survey respondents (48%) said their referrer made no suggestion about how they could help their child whilst waiting for CAMHS help and only 18% of referrers gave any advice or made suggestions. The advice and suggestions given were not always helpful or appropriate.

Some services including GPs, a speech and language therapist, social workers and schools did offer support while they were waiting and this was appreciated, particularly if it was help with parenting strategies.

‘Our SLT [Speech and Language Therapist] was fantastic and offered many strategies to help us as a family, and more importantly our daughter.’

However, some parents felt that suggestions given were not always helpful especially if they involve something the parent has already tried, or to take the child to A&E, or to seek medication.

“It was things we’d already tried - we wouldn’t have needed a referral if it had been that easy to deal with!”

Some parents were left to support their child and themselves.

“Self-taught by reading books and using OCD websites! However, it’s hard to see the wood from the trees sometimes when you’re dealing with your own child, and we would have valued some advice.”

Case Study 2:

K was fine until year 2 at school. He would not put shoes on and complained his clothes were not comfortable. For 6 months his mother took him to school screaming. She went to her GP and he referred to CAMHS but they were 'not interested'. She felt at the end of her tether and not knowing what to do, she paid for a hypnotherapist which was helpful for a while. A year ago the difficulties became worse. K would not go to bed and was frightened to go anywhere without his mother. He was then assessed, but the letter his mother received said that he was not autistic and did not reach the CAMHS threshold for services. His mother took him back to CAMHS and he was assessed as possible having anxiety and referred him and his mother to a CAMHS group. He is 12 now and has no diagnosis. His mother is worried that when the group ends 'they will just be on their own again'. She has looked at services on the internet but is nervous of paying privately, 'you don't know what you are getting'. She has asked advice but doctors are unable to recommend anyone.

Key Points

- There was confusion about what services were available. Parents wanted a clear pathway and information on whom to contact if they have concerns about their child and what they can expect.
- Sometimes parents did not access services because they were not aware of them. Useful information often travels via word-of-mouth. Main sources of information are key individuals.
- There is a need for better web-based local information for parents and for young people. Across the groups and survey findings, the CAMHS helpline and website was rarely mentioned. There was agreement in one focus group about the usefulness of Facebook. Parents could sometimes feel overwhelmed with too much internet information and needed support to access what they need.
- Those who fostered or adopted through agencies are not linked in to support groups and sources of information, especially if they have adopted a child through another local authority. Adoptive parents get information from Adoption UK but because of the cost some do not subscribe. Foster carers sometimes lack up to date information about programmes for LAC.
- Some parents did not receive advice while waiting for the CAMHS services and others received advice that they did not find helpful.
- Advice about parenting strategies was found to be of benefit. Telephone advice was useful for some and it was felt it should be available for teenagers.

5. TRAINING FOR PROFESSIONALS

Parents often recognised their child was experiencing difficulties when they were very young. They expected and hoped for advice in particular from health visitors, teachers or GPs but found they had insufficient knowledge and skills to offer guidance.

'I am concerned about advice professionals give out that are contradictory to advice that should be given for children with attachment disorder, e.g. health visitor telling me to leave my son to cry at bedtime. I didn't follow this advice as it felt wrong but is worrying.'

Many of the parents had negative experiences of dealing with school staff with limited knowledge and understanding of mental health problems and they would like staff to have better training.

The adoptive parents were concerned that teachers generalise from very limited personal experience:

"There needs to be an expert on education and schools dealing with adopted children because every single day. I mean this year we're in a funny situation where we've come across very experienced teacher and we're not having quite the same issues but it's the first time in four years of education. They need to have somebody going into every single school, every single year. "

Unskilled and unqualified teaching assistants may be given a lead role with vulnerable children and young people. In some cases, parents perceived their role to be mainly to control behaviour rather than offer support. Parents also felt that there is a lack of consistency in support to their children which is often only provided after a crisis, usually when a child acts up.

Parents were concerned that some school staff did not understand how to support children with autism and one described the stress this had caused her daughter:

"So last week the IT teacher directed a question, [] to a group of girls where she was. She broke eye contact, because it's very uncomfortable, (this is where he might as well hit her) and then said "right, J. you broke contact, eye contact, you're answering the question". So that was, you know. When I got home she was at home and she was just completely in pieces, because quite honestly hitting her would have been less painful than trying to keep eye contact."

In addition, some parents felt that school staff could add to their own stress and that interactions could be very negative:

"Yeah, well I have found it quite isolating as well being an adoptive parent on the playground, you've got to, like you've got to sort of take the child to preschool and they're talking about, you know, when they had their child but you don't quite fit into the group, the little cliques that are there and then you're on the playground and your child is always being brought out with the teaching assistant and you have to be quite tough skinned to cope with it. I find it quite isolating."

Nevertheless, some members of school staff welcomed training and advice; one parent noted that CAMHS intervention could have a strong influence on school and another said that parents themselves were able to pass on learning from training they have received; a head of year had been pleased with a hand-out she had passed on from the therapeutic parenting course.

Case Study 3:

J was always quieter than her siblings and by the time she got to secondary school she was very withdrawn. Her parents went to see the pastoral leader who said she may have selective autism and her parents started to research this but the pastoral leader left the school at that point and there was no one to follow on. J continued to have difficulties; she had panic attacks and would cry. They asked another senior member of staff for help but he said nothing could be done. A younger child in the family has a disability and his social worker advised their mother to go to the GP. She did this and was referred to CAMHS. The school were threatening her with exclusion 'for not talking' and not accessing lessons until a CAMHS worker spoke with them and offered them training. This has been really helpful and since receiving help from CAMHS J is now doing much better at school.

Key Points:

- Parents often recognise their child is experiencing difficulties when they are very young and find health visitors, teachers and GPs do not always have insufficient knowledge and skills to offer advice.
- Unskilled and unqualified teaching assistants may be given a lead role with vulnerable children and young people, parents would like them to be given more training. Some adoptive parents were concerned that teachers generalise from very limited personal experience and would like an expert on adoption available to each school.
- Some school staff welcome training and advice; CAMHS intervention can have strong influence on school, and parents themselves can pass on their learning from training they have received. Experienced foster carers would like to contribute to training new foster carers.

6. SHARED UNDERSTANDING / CULTURE / RESPONSIBILITY

The Common Assessment Framework (CAF) and the 'team around the child' approach were mentioned but their use seemed patchy and did not appear to be embedded.

'No one talks to anyone else. I have had to arrange meetings myself in order to get people together'.

Schools and Health Services did not appear to work well together. In addition, there was on-going confusion about the interface and pathways between Special Education Needs processes and the pathway to access mental health provision.

From the parent's perspective, not all schools are taking responsibility to support young people with mental health or emotional difficulties and young people can be excluded, or education is reduced, as a result.

Our school said my daughter didn't have a problem, they suspended her illegally but said there was nothing wrong with her; that this was not a suitable environment for her but there's nothing wrong with her, but they can't have it both ways.

In one case a child who was internalising difficulties was almost excluded whilst waiting for a CAMHS assessment.

From when the doctor referred her, to when we came to see P for the first time was relatively quick - it took about a month. But the school were refusing to - they were going to threaten to exclude her for not talking and accessing lessons, which I thought was abysmal.

Parents felt they were passed from one service to another. When services were not able to help they did not routinely signpost parents to another service.

"Provide the right services to support all young people. Where do parents turn when told supporting a disorder is not within the remit? We have felt utter despair and isolation in obtaining care support and understanding for our daughter and it continues."

Key Points:

- From comments made by parents, the Common Assessment Framework (CAF) and the 'team around the child' approach do not appear to be embedded.
- Schools and Health Services did not appear to work well together and there was on-going confusion about the interface and pathways between Special Education Needs processes and mental health provision.
- From the parent's perspective, not all schools were taking responsibility to support young people with mental health or emotional difficulties and young people could be excluded, or education is reduced, as a result.
- Parents felt they were passed from one service to another. When services were not able to help they did not routinely signpost parents to another service.

7. RESOURCES, CAPACITY ISSUES

7.1 Services for parents and children:

Children who find it difficult to socialise may need support to access universal services (clubs, leisure activities etc.) which increases demands on parents and siblings if parents accompany them.

As outlined above, parents would like support groups and parenting programmes but these are insufficient to meet demand. One parent reported that they would like:

'Support group for parents with ADHD. Parenting classes specifically for children with ADHD. Specific help to address social difficulties experienced by children with ADHD –It seems the only thing offered is medication.'

7.2 Voluntary Organisations:

There was little direct reference to groups in the voluntary sector though Autism Sussex, Winston's Wishes, NSPCC, and a Women's Refuge Project were seen as helpful, as was noted in the section on prevention and early help. Support groups for parents to come together and share advice and support were highly beneficial, but were believed to be thinly spread. There were some events and activities for children and/or families and these vary. Some parents said it was difficult to get information about them.

7.3 School Services:

The pupil premium can be useful to purchase additional support but parents suggested that they feel they have to be 'on the ball' to monitor schools' use of the money, as schools sometimes use it for other things.

Some parents were positive about the support offered by schools - particularly some primary schools. Transition to secondary school was problematic for some children and certain parents of primary school children anticipated increased difficulties when their child made the transition.

Schools have a vital role in providing support to develop emotional resilience but the lower Tier services for children and young people, which might support them, seemed to be thinly spread. Tier 1 and 2 school support mentioned by parents in focus groups was school nurses, counselling, virtual school for children looked after and a play therapist.

It is important to note that children with mental health difficulties sometimes struggled to maintain schooling, but those who are not in school cannot access Tier 1 and 2 school services:

'No support offered. My child had to wait 3 months to see the school counsellor. I was told by the school attendance manager that if my child wasn't in school she could not see the counsellor.'

Most parents had not accessed Tier 1 and 2 support for themselves, such as counselling or parenting programmes.

7.4 Educational psychologists:

Parents were often told there is a shortage of educational psychologists. They sometimes felt they were not aware of what assessments had taken place or the outcome. Members of school staff were always present in meetings with educational psychologists and parents then felt unable to challenge the school or have an honest discussion if they thought there had been failures or mistakes.

In one case an educational psychologist told a parent she was less knowledgeable about adoption than clinical psychologists, so was unable to advise the school.

7.5 School counselling:

Access to school counselling was largely considered to be slow and views were mixed.

7.6 Virtual school for children looked after:

The Virtual School was seen as positive in educating schools about children looked after. They do not specifically address mental health issues (in the view of foster carers spoken to) but can help young people avoid exclusion. There was some concern about children being taken out of class for extra help. Communication between schools, the Virtual School and parents could be improved. This includes feedback to schools and foster parents.

Key Points

- There was a scarcity of Tier 1 and 2 services which were considered to be insufficient.
- It was suggested that service providers should be aware that children who find it difficult to socialise may need support to access universal services (clubs, leisure activities etc.) which increases demands on parents and siblings if parents accompany them.
- Support groups for parents to come together and share advice and support were seen as highly beneficial, but thinly spread. Most parents had not accessed Tier 1 and 2 support for themselves such as counselling or parenting programmes.
- Some primary schools offered support. Transition to secondary school was problematic for some children. There were some services for vulnerable children in schools: educational psychologists, school nurses, counselling and the Virtual School for children looked after, were mentioned. A greater range of services was said to be needed.

8. CAMHS SERVICE

8.1 Referrals and waiting:

48% of survey respondents were receiving services or had received services from CAMHS and parents at three of the focus groups were currently receiving services. They had a range of views about CAMHS and their experience varied depending on the efficacy of the referral process, the referral route and service accessed. Communications were believed to be poor during all stages of the process and it was felt that professionals did not always listen to or take parents' wishes into account.

There was significant variation in referral waiting times to see a CAMHS worker as illustrated in Table 9 below:

| Table 9, "How long did it take, after referral, for your child to be seen by a CAMHS worker?" | Number and Percentage |
|--|------------------------------|
| Less than a month | 8 (6%) |
| One to three months | 25 (18%) |
| Three to six months | 17 (12%) |
| Six to twelve months | 16 (12%) |
| Over a year | 24 (18%) |
| Don't remember | 18 (13%) |
| No answer | 29 (21%) |
| TOTAL | 137 (100%) |

Parents in focus groups did not only define waiting times in terms of CAMHS processes. For them, waiting for a CAMHS service had been over a period of years (see Case Study 4).

Case Study 4:

B had been very ill as a baby and from about 18 months his mother noticed that he had become afraid of things like bright lights and he would scream in toddler groups or in shops until she took him away. Things like different clothing would upset him. When he started school the SENCO observed that he had some behavioural problems and anxieties but they thought this was explained by the hospital treatment he had as a baby.

At the end of year one he had what his mother described as a 'massive meltdown' in school and overturned tables and chairs because he did not want to do something. She felt she had been in a battle with the school to try and get help but at this point the school understood some of the difficulties his mother was having. He was referred to the Child Development Centre but they did not accept his mother's concerns so she paid for an independent education psychology assessment. On the basis of this assessment he was referred to CAMHS and diagnosed as possibly autistic. After waiting 4 or 5 months they were referred to a CAMHS Group. Through this, she describes her wait for CAMHS as 'about 4 years'.

Over a quarter (28%) of parents had no further contact from CAMHS staff whilst waiting for an appointment and parents reported experiencing continuous delays. 33% received a letter, 11% a phone call and 5% received an email.

Many comments were from parents who had proactively and repeatedly chased CAMHS to find out what was happening with their child's referral. Further, some parents reported that they were told to do this by CAMHS, suggesting that CAMHS were either aware of the poor communication process or perhaps not taking responsibility for communicating with parents:

"We received a copy of the referral letter sent to CAMHS, and were told to chase if we didn't hear anything within two weeks. We did that. CAMHS told us to chase if we didn't hear anything within four weeks. We did that."

"We had the referral in the February and then in May had a letter to say an appointment would be made for November 2013. It is now the 13th Nov and still no letter or contact. We then phoned to be told we would have a letter in two weeks with a questionnaire. We are now hoping this is not the same questionnaires that both us as a family completed as did the school last May. We wait and see. The waiting is much too long."

Further to this, communication was viewed as poor and the organisation as inefficient:

'The original appointment letter was sent to the wrong address. We would have missed the appointment, except someone called to cancel it and we realised what had happened.'

'Communication with CAMHS is very bad, they constantly change appointments and planned time scales are never stuck to. They don't send out appointments when they are due and you have to constantly chase them.'

Parents reported that each stage of the referral process could be accompanied by some anxiety and there was a shared feeling amongst parents, that timely information would be very helpful in allaying their concerns and helping them to manage their expectations. What information they did receive was often minimal, inappropriate or of little help. Many parents were disappointed that even after a referral had been made they were still left with very little guidance, support or information and were left to their own devices sourcing help for their child and themselves. Over half (56%) stated they had received no suggestions from CAMHS staff. Some parents went so far as to pay for support during this waiting period.

'My son has been diagnosed with severe OCD, and the time between the GP referral and the initial CAMHS assessment was two and a half months. During that time his condition deteriorated, and we felt very alone and worried. It would have been extremely helpful to have some sort of drop-in advice centre available, where we could go and talk informally to someone about the process/how to cope etc. while we were waiting for treatment. It was very frustrating and worrying wondering if he had been "lost" from the system while the referral was processed, and simple low-level communication during the waiting period would have made a big difference to us.'

8.2 Interaction with parents:

Parents felt that they were not always listened to or treated with respect and that their abilities to parent were questioned. One commented that professionals were dismissive or irritated if parents had knowledge of their child's condition. Some believed their views on issues such as medication should be taken into consideration more carefully when decisions are being made:

'Learn from the parents first, we know and understand our children first and foremost. Listen to our cries for help, the world of autism can be a very frightening place for a child and the parent. Respect us, don't belittle us. CAMHS seem to think that medication is the cure for all diagnosis. It's not. But understanding the child is the first step. Communication is the key. CAMHS don't have this priceless gift.'

"Not enough support groups or workshops arranged for parents. We were made to feel inadequate parents and our parental skills were questioned rather than addressing the autism".

Parents felt they had to fit in with the service which is inflexible. It could be difficult to make arrangements for appointments and parents' work commitments were often not taken into account.

Access to services was felt to be hit and miss and sometimes dependent on one observation. Parents suggested that children should be observed in different environments when being assessed as they behave differently:

"CAMHS actually came out to view J in the classroom and I was told, "He is a lovely little boy, off you trot," until we got to year three, four."

Parents were aware that the service was stretched and adjusted their expectations accordingly:

'When accessing support I have always been impressed by the level of professionalism and care received. I am acutely aware of the lack of resources available to the departments I deal with. I would love to access professional advice more often but again feel very aware that they are already at their limit and do not want to impose. I know this is wrong but cannot help it. CAMHS is a vital resource to our families and deserves much more than it is getting. We should not be prevented from accessing the right services for our children purely because of funding but at times our children are suffering because of it.'

Despite the issues with referral processes and communications many reported a good service once they managed to access CAMHS. Some were very positive about the service:

'I would like to think that all people could get as good a service as we received, and from such an experienced psychologist who knew just how to get my daughter to change her thought processes in such a positive way.'

"I think coming to CAMHS for us was a huge relief because, whereas for years it's almost as though we are trying to convince people, "This is the situation." Trying to appeal to them almost to understand that this is what we are dealing with. Suddenly you arrive at CAMHS and they are kind of, "We know that. We understand that. We see this a lot." You think, "Oh, ah," so suddenly you think, "Great, we've arrived," and like you were saying, it's like you think, "Now we lost the last six years, now let's get to work. What can we do to help sort this situation out?" It's incredible".

'Since we've been "in the system" at CAMHS, we have been very pleased with the help and support our son has received. We had three home-meetings with (name given), and found him very approachable and understanding. He recognised immediately that our son needed longer-term, more intensive support, and we were referred up to Tier 3, where we have been receiving weekly/fortnightly support from (name given), who has been very helpful and knowledgeable about our son's condition. We have also felt very supported as parents. We don't feel like our son has to "rush" to feel better, because the treatment is on-going, and we know that if need be, we have all the support we need for him to go onto medication/more intense treatment. I now feel that we are in safe hands'.

Those who had accessed Parenting programmes found these to be very helpful.

'The parenting course I went on with CAMHS was useful not for the specific behavioural problems my autistic son had but was generally useful, certainly it was the most useful thing CAMHS offered.'

'Therapeutic Parenting - made a real difference in the way we parent both our adopted children. It gave us lots of strategies to use and plenty to think about. The therapists were fantastic. They acknowledged the difficulties we experience everyday living with kids who are struggling like ours but at the same time gently reminded us of where our kids had come from and all they brought with them. We stopped blaming ourselves, found more confidence and worked together as a team'.

However some felt that they had not received a good service.

'CAMHS managed to have only a negative effect on our son. This is not the ranting of a crazy parent; I am well educated and rational. Horsham CAMHS is either very over stretched or very incompetent'

'My son sees a Psychiatrist about 2 to 3 times a year to review his meds. We receive no other support from CAMHS. It is therefore not possible to comment on what went well, it has felt that CAMHS were just ticking boxes as regards to going through the process. I understand fully that this is due to the levels of demand and the fact that CAMHS is stretched and therefore unable to provide a level of support that I feel we needed / need.'

Some felt the service was too short term. When asked what was needed one said:

'Anger management therapy/support for my child. Support for parents, longer involvement by CAMHS for long term rather than rushing to sign children off.'

CAMHS was not always seen to be child-centred. Some were concerned that there is lack of preparation for young people who are very vulnerable. In one case an adopted child became frightened of what was happening when she had appointments at CAMHS and always thought she would be taken from her adoptive parents. Another needed more preparation:

"My eldest son, he used to know all the detail of everything, way before and would say, well what's going to happen with this. You know he wakes up every morning, "what are we going to have for dinner?" you know..so he can't he can't just walk into a meeting blind and go "Ok, right I'm ready to talk"."

Some parents felt that the needs of teenagers were not always met.

‘Anger work for teens or anything for teens’

The waiting room at some CAMHS locations was thought to be a pleasant and calming place for younger, small children. However, it was thought that these child-friendly places were not well received by older young people and what is best for the service-users was thought to need reconsideration.

‘Maybe make clear that older young people can wait in the adult waiting room! Small point really. But the CAMHS waiting room is lovely for small children, really friendly and welcoming. For teenagers, though, it makes them feel even more "out of place" than they already do coming to a place with mental health issues.’

Some parents wanted more support/better provision for children with ADHD/autism:

‘Support group for parents of children with ADHD Parenting skills classes specifically for parents of children with ADHD Specific help to address social difficulties experienced by children with ADHD –It seems that the only thing offered is medication’.

‘Appointments are sporadic due to staffing and funding, children with ASD are not as a rule seen by CAMHS as they do not have the capacity to provide long term support ASD children should have access to the CAMHS team to help with all aspects of ASD including depression, anxiety, self-harming’

‘There is a huge lack in services for families with children with Asperger’s / High functioning Autism in Crawley. Specifically for those with kids 11+. We found CAHMS useless.’

After care was also felt to be important by many parents, especially for those children going through adolescence where conditions can reappear or deteriorate.

8.3 Feedback on particular services:

CAMHS LAAC was described by service users as a valued service with a very good understanding of the difficulties being experienced and very responsive when phoned. However a foster child has to be settled in placement before receiving support, so there is a lack of support during the difficult settling in period. Training and support was considered to be good, but focused on foster parents rather than help for the child – they felt they do have more parental strategies but they still felt they would like their child to have specialist one to one help.

CAMHS LAAC facilitated referral to CAMHS when needed:

“We were referred to CAMHS LAAC prior to CAMH. This did help but directed its support at children suffering from attachment disorders only. However, this referral did instigate further assessment of our child by the clinical psychologist, allowing a further referral from CAMHS LAAC to CAMHS.”

The parenting courses were appreciated:

‘The Therapeutic Parenting course run by CAMHS LAAC was fantastic and has made a real difference to how we cope at home and they supported school too. Things can still be difficult but we now have

understanding and strategies at hand to draw on. (Names given) were very knowledgeable and created a great environment where we could share as a group of parents experiencing similar problems. I would recommend this course very highly. It is a shame that only 6 families were able to access this a year, I am sure there are many more adoptive families that would benefit from it.'

Parents were very positive about the Anxiety group and the VIP young people's group, which runs at the same time. There was concern that the Anxiety group was short term; parents did not know what help they would get when the sessions finished.

Case Study 5:

M's difficulties started in her first year at school. She could not cope in large groups and got frustrated; shouting and being abrupt. Her mother was regularly called into school. She is very bright and at age 9 her literacy level was equivalent to that of a 15 year old. She did not really fit in and although the school denied it, her mother believed she was being bullied by other children. She was often tearful. When her behaviour deteriorated she was taken to the school library to read books which she enjoyed and this became a way for her to avoid being in class. Her mother decided to educate her at home. This had reduced M's anxiety. Her mother finds it a challenge as she has to find services and activities herself. She was referred to the CDC by the GP but they asked her to bring M back after a year. Her mother was persistent that help was needed in the meantime so she was referred to a CAMHS group. She does not know what will happen after this short term help finishes.

Case Study 6:

R has anxiety and phobias. She was referred to CAMHS and she and her parents were interviewed; she was put on a waiting list for treatment. For 18 months her parents phoned and asked for help but eventually they found a way to manage things and by the time they were given an appointment they turned it down because they couldn't face 'going through it all again'. Their daughter's condition worsened and she gradually stopped eating and, because she had lost a lot of weight this time, they were offered help much more quickly.

The findings in relation to the service and staff at Chalkhill are based on a very small number of responses and there were no specific questions on this service in the survey. Those parents commented that they felt staff at Chalkhill were not always capable of dealing with young people with complex conditions.

'They had no idea at Tier 3 level or Tier 4 Chalkhill how to deal with daughter's very complex condition.... The only professional person family came into contact with at CAMHS was Dr (name given) who realised the seriousness of the situation but was over ruled on cost grounds and ordered to reassess and found the same findings. Parents' knowledge, expertise and attitude were not welcomed at CAMHS. Visits to Chalkhill resulted in mother being seriously attacked and social worker had to advise that child did not go there for treatment on one occasion due to level of distress and effect it was having as they were unable to engage with child'.

Key Points:

- CAMHS referral processes can be confusing for parents. A referral through another professional, such as a GP, means that parents are one step removed and are not given information about the progress of the referral or told of any miscommunications or administrative errors on the part of the referrer.
- There was significant variation in referral waiting times to see a CAMHS worker. Parents perceived the wait to be over a period of years as they measure the time between identifying that their child needs specialist help and when they actually access the service. During that time they often experienced rejection and/or delay.
- During the waiting time, communication from CAMHS was often seen to be poor. Timely information would be very helpful in allaying parents' concerns and helping them to manage their expectations. Parents said they were given very little guidance, support or information and were left to their own devices; sourcing help for their child and themselves.
- Communication in general was sometimes seen as poor and the organisation seen as inefficient. Parents were aware that CAMHS is overstretched.
- Despite the issues with referral processes and communications, many reported a good service once they managed to access CAMHS. Some were very positive about the service, feeling it was the first time they and their child had received the help they needed.
- Parents who were disappointed with the service included those whose children only received medication or short term support, those with ADHD, teenagers and those in transition to adult services. Also, foster carers were concerned that they could not access help for children who had not yet 'settled' in their placement, though they often needed help in those early stages.

9. INTERAGENCY WORKING AND COMMUNICATION

Two parents gave the West Sussex Parents forum as an example of good interagency work and the structure at Worthing hospital worked well for one parent:

'All of the services were based at the Children's Centre at Worthing Hospital, so had liaised together. Worked well together'.

Generally parents thought interagency working was poor.

'they do their bit, say nothing more they can do and discharge, then you start over again with another service who do the same thing. They are incapable of working together.'

There was evidence that schools were not planning together with Health Services:

'[] The school will not help us because they have no funds, my child is not statemented and it will be too late if she does receive a statement to be able to undertake her GCSEs. We were pushed by her school to try the online learning courses. However the neuro psyc, was horrified with this. It would only serve her agoraphobia more if she was allowed to wallow at home not at school. This is actually what she is doing at the moment for lack of assistance at school with help to settle her and help her overcome her anxieties regarding being at school. The system has not only failed us but has made things far worse!'

There were examples of information not being shared between professionals. Parents described having to take their own notes to a consultation. This increased the stress felt as there was pressure on parents to remember everything; one described being fearful that they would fail to access a service if they forgot to tell CAMHS something. Some parents said they take a file everywhere.

"Yes. It wasn't until we met with Dr [] and I was having another assessment and I was being asked some very fundamental questions, [] thinking, "This should all be there. This is old stuff." Luckily I had my notes and I was literally thumbing through my lever arch file thinking, "Crap," and I was going back to, you know, years ago thinking, "How come they don't know any of this?"

The lack of communication between services was experienced as frustrating for parents. Some had years of appointments with a range of professionals, each time retelling their 'story' and then often not receiving appropriate support.

"I sort of hadn't come prepared with the massive folder that I could have brought, but I just thought they would have the medical notes. They weren't passed on and they were separate, which I didn't know. Yes, so I had to start from the beginning. I couldn't remember half the stuff."

Most comments about interagency communication and services working together were negative and parents described the confusion that arose and the need for them to coordinate and chase. There was concern that not all parents would be in a position to do this.

'very disjointed no communication at all initially until I became VERY stroppy at team around the child meetings'.

Parents wanted improved communication between children's and adults' mental health services and this is covered in the next section.

Key Point:

- Interagency communication was perceived to be poor and parents often had to re-tell their story. Professionals relied on parents to give background information and parents were fearful they may forget something important to the detriment of their child.

10. STRUCTURES

10.1 Service structures:

Parents did not think in terms of Tier 1 to Tier 4 progression. They believed that services are needed across the Tiers, for example extra help at school, individual and family activities, parenting programme and individual therapeutic help.

In general, a clear diagnosis was seen as a prerequisite for accessing services.

Systems and processes seemed to be barriers to services and this was a cause of frustration for parents. For example, the central role of the Statement of Special Educational Needs in particular can be a barrier, not an enabler, to receiving further help:

“And actually Dr [] seemed a bit of a block for us. I don’t mean that disrespectfully because she has helped us a lot in other ways, but she refused to refer our daughter to CAMHS until she had an EP report. But the EP service said they were only producing reports on children who were going forward for statutory assessment. We actually tried to go forward for statutory assessment but we were declined. So we were caught in catch 22 we couldn’t move forward and we just couldn’t do anything.”

Provision is sometimes made without a Statement, but several years later, when different provision is needed, it cannot be accessed because there is no Statement:

The school said, “Don’t have a statement,” because the school was already giving the help. We are now sixteen and now we are trying to access things, the first thing they say is, “Do you have a statement?”

For some families there was a delay in accessing services because of requirements for information and referral processes. Parents also described the difficulty accessing services later.

‘After diagnosis his file was closed but we were told we could phone if there were ever any problems. Within a year we desperately needed to get back to CAMHS for help as his difficulties became worse and he also gained Tourettes. We were told we couldn’t see anyone as we needed to be referred so we had to get someone to refer him then wait for an appointment. When the appointment finally came through we found it wasn’t even with the psychiatrist but an intermediary person who asked us to go through our ENTIRE history before finally at the end of a very long and very inconvenient appointment said we could be referred to psychiatrist. In total from re-referral to finally seeing a psychiatrist and getting meds it took 8 months of my son suffering terrible Tourettes on top of his other diagnosis and 5 months out of class at school. We feel there should be an easier way of getting the help you need if child is already known by CAMHS as re-opening the file for us was not simple and it should have been easier to access’.

10.2 Transition to Adult Services:

The transition to adult mental health caused difficulties for some.

'Communication with the family about the process once the file had gone across to Adult Mental Health stopped. We did not know who to contact in an emergency or when he is next going to meet with anyone. Having 6 monthly appointments with CAHMS suddenly stop when he was in crisis was very harmful and potentially dangerous.'

'CAMHS support whilst at school was very good. The transfer from CAMHS to Adult Mental Health has been on-going now for 18 months and he has yet to receive any support despite a risk assessment from his CAHMS nurse saying he was at risk of harm.'

10.3 Services for children who are physically disabled:

There was a perceived need for more services for children who also have physical disabilities.

'Just providing something for physically disabled. So normal in their mind suffering as they become aware of their disabilities as they were turning into teenagers. It's been hell'

Case Study 7

H was his mother's first child and she did not have an idea what to expect or what to do. H had temper tantrums at toddler groups. Whenever she socialised she had to leave early because of her son's tantrums. He did not speak until he was 4. When he started school he was very quiet but teachers said he was never where he was supposed to be. When he was 11 his parents saw an article on dyspraxia which described their son. They went to the GP in the hope of getting a diagnosis and he was sceptical telling them they should not believe what they see in magazines. He agreed to make a referral to the Child Development Centre. The doctor there said she had never seen a child so dyspraxic. When she found out that he has an uncle who is autistic she referred him to CAMHS for further assessment. Throughout this process his school had not identified that he was a child needing support even though he was not socialising. Initially CAMHS rejected the referral. By this time he was being bullied so much his parents withdrew him from school.

CAMHS saw him when he was 13 and he was diagnosed as autistic. His mother felt that he had gone through years of thinking she was 'going mad' as his school had been telling there was nothing wrong, only to discover that the head teacher had written to the CDC expressing concerns when he was 4 or 5 but had received no reply.

He is now 16. He does not have a Statement and that is now causing difficulties as he has another condition and is a wheelchair user and his parents are trying to access other services for him.

Key Point

- Parents did not think in terms of Tier 1 to Tier 4 service progressions and services for families are needed across the Tiers.
- Services were perceived as not child-centred.
- Systems and checks were seen as unnecessarily bureaucratic and as barriers to services.

11. GAPS IN SERVICES

Some perceived service gaps that have already been outlined above include:

- Early intervention, Tiers 1 and 2 services for children and parents
- Parenting programmes easily accessed at early stage of difficulty.
- Information including the use of social media
- Services for children with behaviours issues/conduct disorders and their parents
- Activities for the whole family to benefit siblings

Gaps or shortfalls in CAMHS services identified by parents as above are;

- Advice while waiting for assessment at CAMHS
- Telephone counselling and advice for parents and young people
- Parenting support programmes
- Services for teenagers and transition to adult services,
- Services for children and young people with autism and their parents
- Specialist services for children who are also physically disabled

In addition the following suggestions were made by parents:

One stop shop:

‘.. In the focus group I didn't particularly agree with the 'one stop' shop approach. After considering it though, I think it could be very useful - my situation had deteriorated slowly over a number of years and I although I was dreadfully unhappy I didn't realise there were a variety of organisations out there who were able to help and advise me (in 2010 we had at least Rise, Worth and Women's Aid - some of whom were geographical, some weren't) and I now remember that I became very confused about who could provide what help and a 'one stop' could help alleviate that problem.’ Email from parent

Key worker/Lead professional role:

Parents often looked for a key person to help them navigate services and talked of how helpful some individuals had been, such as the coordinator of short breaks, social workers, and individual members of school staff. They were disappointed when they lost that one to one support. Someone to guide and support them over a period of time would be helpful.

Key Points:

- Services were perceived to be thinly spread and parents identified a range of provision that they felt was needed.
- Foster parents have a social worker to help them navigate services and to support them. Other parents of children with mental health difficulties could benefit from similar support.

12. THE CHILD AND FAMILY, HOLISTIC APPROACHES:

Parents were concerned about the impact of having a child with mental health difficulties on the whole family. They would like more activities for the whole family as this would be of benefit to siblings, for example an activity at Butlins organised by Short breaks team was much appreciated. One parent gave the example of a voluntary sector group in another county which organised outdoor activities such as camping.

I do get a lot from A saying, "I feel left out," because everything revolves around S because he's in a wheelchair.

Yes, as a sibling, which – again, you wouldn't even think, she just gets almost, "Right, just think yourself lucky you can sleep at night and you don't have these problems." So she almost gets pushed under the carpet a little bit and it's all him, him, him.

Young Carers was mentioned as a possible help for siblings.

Care needs to be taken with the scale and timing of events: adoption social events for example were felt to be too big and infrequent. Also, communication about these events was seen to be poor.

Key Points

- Parents were concerned about the impact of having a child with mental health difficulties on the whole family. They would like more activities for the whole family as this would be of benefit to siblings.
- Care needs to be taken with the scale and timing of events. Communication for some of the county events for adoptive parents is poor.

13. FURTHER RESEARCH

Possible further research identified by this project could be:

- Investigating the needs of fathers/what sort of services they would find most helpful.
- Mapping of Tier 1 and Tier 2 services.
- Investigating the extent to which evidenced based Early Intervention programmes are being accessed across the county as well as their impact and benefits.
- Mapping what activities and groups are offered in schools for vulnerable children and young people (Identifying any issues relating to the change of school status to academies and the decline in central support services).
- Exploring in more depth the needs of:
 - Teenagers and of those in transition to adult services.
 - Those with autism and mental health difficulties.
 - Those with behavioural and mental health difficulties (including attachment).
 - BME groups.
 - Adopted children.