healthwatch Derbyshire

‘Our experience of using CAMHS services’

As told by young people, parents, carers and professionals using Child and Adolescent Mental Health Services (CAMHS) in North Derbyshire

Introduction

Healthwatch Derbyshire is the local consumer champion for health and social care. The Healthwatch network is made of up of local Healthwatch across each of the 152 local authority areas and Healthwatch England, the national body.

Healthwatch has a common purpose – to ensure the voices of people who use services are listened to and responded to. The network shares a brand, has common values and comes together to work on priority areas and campaigns.

Local Healthwatch work to provide unique insight into people's experiences of health and social care issues in their local area; Healthwatch Derbyshire is the eyes and ears on the ground finding out what matters to our local community.

Rationale

Child and Adolescent Mental Health Services (CAMHS) is a very high profile service, with national pieces of work on the subject reporting – one example being the policy paper 'improving mental health services for young people', published in March 2015, which is a report of the work of the Children and Young People's Mental Health Taskforce. Clearly there is a national recognition, and national ambition to help improve mental health services for young people and these policy papers will be drivers for this.

Healthwatch Derbyshire listens to local communities to find out what matters to them most. We then use this feedback to choose priorities to work on more closely, to find out more about these specific experinces of using services.

As well as being aware of the national work on CAMHS services, we had a cluster of comments on our database about (CAMHS) – some of which were positive, and some were negative. So, we picked CAMHS as a work priority for January 2015 - March 2015 because we wanted to find out what worked well in these services, and what didn't. We hope that this report will help organisations to learn a little bit of something new about their services, and do some things in a better way for people using CAMHS services.

Between January and March 2015, our Engagement Officers spent lots of time out and about in communities, at groups and in CAMHS clinics listening to what people had to say about CAMHS. Many of the interviews were conducted at CAMHS clinics, which gave the benefit of being able to talk to participants about their experinces at the point of service delivery.

Many thanks to the CAMHS teams for allowing this and making our staff welcome, and also to all the participants who gave up their time to talk to us.

Methodology

Healthwatch Derbyshire have a small team of Engagement Officers who developed a series of discussion prompts to use when talking to young people, parents, carers or professionals about their experinces of CAMHS. These prompts were very broad and worked through time from the beginning of the experience covering topics like referral and access to the service, to what is was like to be using the service, and if they felt it was helping. These prompts were used informally to help steer conversation when necessary but the staff used a flexible

approach with this as a prompt sheet rather than a formal interview style. This is because although questionnaires or structured interviews would have given more measurable data, this could have been a barrier to completion/engagement.

This report covers the comments made during 29 interviews with a mixture of young people using CAMHS services, parent/carers, and professionals. Interviews were conducted between January – March 2015, and responses have since been themed and collated in this report. This sample is not representative of all those with experinces of the CAMHS service, but presents an opportunity to look at the themes in the experinces of the 29 participants and to triangulate with other sources of feedback to build a clearer, sharper picture of patient experience.

The reasons for referral (where known) included:

- Anxiety
- Panic Attacks
- Self-Harming
- Depression
- Suicidal
- Attachment Disorder
- ADHD

Findings

Referrals

Healthwatch Derbyshire heard about a wide range in experiences regarding referrals. Some accounts of referral told of a quick and responsive process, yet others told of a much more protracted experience. Some participants talked about a referral process that seemed cumbersome and does not always work well between different professionals and organisations. Some problems with referrals for foster children were also highlighted.

POSITIVE

- 'Referral was done via a GP who was excellent and had recognised a problem'.
- One family had seen their own GP and within 5 days had heard from CAMHS.
- 'GP referred my child very quickly to CAMHS, we only had to wait 1 month for an appointment'
- School Nurse did an emergency referral - we only had to wait 4 days for an appointment.

NEGATIVE

- 'We had to see our GP more than once to get a referral in to CAMHS.'
- GP referred us to CAMHS as an emergency referral but we waited 5 months for an appointment.
- It has taken 3 appointments with the GP before a referral took place as the young

person, aged 13 years, was diagnosed as 'naughty'. It wasn't until a violent incident that it was taken seriously and led to a referral, which then took 2 months from the date of the incident.

- Young person, aged 12, had been referred by school doctor in June 2014 and first appointment at CAMHS January 2015. Still no diagnosis. The mother referred to 'battling since he was 2½ years" and it is now apparent that the child may have Asperger's.
- 'Re-referral not possible if discharged…. You have to go through same process again.'
- One family experienced a major crisis before they got in to CAMHS, 'it took months'. They felt that had they got in sooner the crisis may not have happened. Their child was admitted as in-patient.
- An account was given of problems regarding foster children, in that they cannot be referred by Social Services to CAMHS unless they are in a stable, long term placement. The problem reported is that if the child does have mental health issues then it is likely they are 'moved on', therefore NOT having a stable home, and in this case can only be helped by the GP.
- One professional said that referral can be very hard. They said that in many cases they found that CAMHS 'bounced cases back to MATS due to behaviour' when it clearly wasn't. 'You feel every referral has to be justified and every single detail included otherwise it comes back as behavioural'. They added, 'I have had to pull teeth to get them here today and it has taken 6 months to get a first appointment'.

MIXED

- 'The school doctor referred to CAMHS, but it took two attempts. The first referral had been made by a GP who had listened, but nothing happened despite a 6 month wait'.
- Our GP originally referred us to see a Psychologist for 6 weeks of CBT and then my child was discharged. Things got worse and we were put on a waiting list for 1 year to see a Psychologist again, we had to go back to the GP to try and speed things up.
- GP referred my child really quickly because of self-harming concerns. I only had to raise it once and the GP acted on it. I had to wait 3 months for an appointment, the GP didn't advise me on any coping strategies in the meantime.

Diagnosis delays

Healthwatch Derbyshire heard about real problems with delays in diagnosis. No positive or mixed comments were made regarding diagnosis. There is also some reference to diagnosis delays in the referrals section above.

NEGATIVE

- Despite parent mentioning to Nursery staff about child's social and emotional behaviour, it was dismissed by staff saying that is was 'due to level of maturity'. By the time the young person reached school age, things were still the same
- No formal diagnosis – we are still waiting for CAMHS
- 'In state of limbo until diagnosis confirmed which takes too long'…
- One mother referred to being passed from pillar to post… *"From Education Psychologist to Visually Impairment to Speech and Language to Occupational Therapy to Child Development. You name it, we've been there and still waiting diagnosis".*
- One parent had five different CAMHS workers. The first one said the child had anger

problems, the second denied it could be Asperger's despite all the traits being displayed. "I have been going 8 years to CAMHS and they still won't label my child"

Appointments

Healthwatch Derbyshire heard that appointments are sometimes an issue in terms of length of time before appointments begin, frequency, duration of appointments and cancellations. Generally appointments do seem to be made to suit working arrangements/school etc. Several clients and/or carers spoke about what the appointments had given them, and spoke of some improvement in feelings.

POSITIVE

- One young person said the appointments had given them a chance to talk about their illness, and had CBT treatment.
- When appointments were made the distance to travel was considered and CAMHS said they would hold appointments at premises near to the child's school.
- Appointments in one case had been quick and subsequently followed by second appointment, some three weeks after which the family thought was good. The appointments were made at convenient times to suit child and parent; there had been no cancelled sessions. Sessions had proved very helpful and child now feels better and making progress.

NEGATIVE

- In one case, it was two months before they saw Consultant Paediatrician who asked 'why has it taken so long?'
- Parent had to cancel appointment due to the fact that child was threatening suicide, and got very little support. Child discharged from CAMHS in November and now has to go through CAMHS referral again.
- It was felt that appointments every 6 weeks is just not enough
- Concerns regarding only one hour for appointments. One family said they felt they were 'watching the clock' and had thought about finishing the sessions as so traumatic.
- Appointment cancelled due to being off sick, re-arranged for some time later. Following the appointment, CAMHS did a follow up phone call by which time child was displaying aggressive behaviour towards a parent. CAMHS displayed surprise that this should happen as thought they had 'built a rapport'…

MIXED

- Appointment was arranged without any consultation with parent but was 'just relieved to get an appointment'. Seen on this date by Paediatrician who referred to Psychologist and said there would be a 10 month wait. Patient also referred to Dietician and Speech Therapy.

Quality of staff

Healthwatch Derbyshire heard mixed views regarding relationships with professionals, although the majority of accounts where positive. Many of those interviewed felt that the sessions were highly beneficial. There is a noticeable peak in the number of positive comments regarding quality of staff compared to other topics.

POSITIVE

- One family were very happy with the CAMHS service. They were attending a 10-week 'parenting' course in terms of coping strategies and Autism awareness so that they could understand their child and the condition. The same family said the staff were all excellent and friendly, including the reception and clinicians.
- 'I really couldn't fault CAMHS'.
- One family said they found CAMHS to be 'friendly, quite comfortable and felt it was confidential'
- MATS team very supportive. One family said they act as a 'go-between'.
- My child has been attending weekly sessions for CBT, I am able to attend sessions every other week.
- …very happy with the sessions at LD CAMHS, they observe well in an appropriate environment and the clinicians engaged well…
- My child has had 4 sessions, we haven't had continuity with staff but we haven't had to repeat anything, the clinicians are really good at communicating. I think the sessions are really helping. We always go into the appointments on time.
- I feel that the sessions are beneficial; the clinicians give me a lot of advice. The receptionist at CAMHS always seems to be really busy, people seem to arrive at the same time and come out of the clinics at the same time, and she always seems to cope very well though with a smile on her face.

NEGATIVE

- Young person had to be admitted as in-patient in Leicestershire. This was miles away for parent to visit. Communication was not good, for example, parent could be told at 10am that there was to be a meeting at 2pm without any consideration for work or distance to travel.
- ..The CAMHS worker was leaving and she informed us that she would refer us onto a level 3 worker who could diagnose ASD but we then got a letter a week after saying that we were discharged….

MIXED

- No cancellations, my child has had continuity with the same clinician throughout. I do think they are helpful but my child doesn't find them helpful because I think they just want a quick fix.
- The main receptionist is very friendly but others are rude and abrupt. You have to press the buzzer when you arrive and the receptionist seems rude.

Information/Support

Healthwatch Derbyshire heard about variable support for parents/carers, and a lack of clarity and information about what does exist. Out of hours support was also raised as a real problem.

POSITIVE

- Some positive experiences were highlighted with groups that had offered support: Parent Partnership x 2, MAT worker x 3, Parents with additional needs x 3, 'Derbyshire Carers Association (DCA) have helped me to apply for a DLA claim' Two additional families had been given information about support/self-help groups/carers information
- 'We were signposted to an autism awareness course which was very useful'

NEGATIVE

- A child had tried to commit suicide and still the mother had no support.
- One carer rang Call Derbyshire to ask for help but 'they didn't want to know'.
- 'There isn't any community support for my child'.
- 'No direct support from DCA' - 3 people said that they had just been sent leaflets. 'Can't access DCA as groups run in day'.
- 'They are out of school for 6 weeks as the school cannot cope but as a parent I don't know where to turn'
- One parent of a 16 year old child is not told anything about her child's visits to CAMHS.
- One carer said that if her child is having a 'breakdown' then they do not know where to turn too… told 'take him to A&E' which doesn't feel appropriate.
- Two participants commented that there is no carer support for parents with children with mental health conditions

MIXED

- Paediatrician did give parent a couple of websites re 'Autism' but as not formally diagnosed parent did not think too helpful. Parent was also informed it might be Asperger's and it might be possible to get the Autism Outreach Team in but not possible until formal diagnosis.
- GP talked about my child accessing some groups but they were in Sheffield, but wouldn't access support groups anyway...
- Little support from CAMHS for Mum when child diagnosed…GP gave details regarding support groups.

How Healthwatch helped during the course of these interviews…

- Healthwatch Derbyshire Engagement Officers signposted many participants to a combination of groups, including Think Carer, Derbyshire Carers, Derbyshire County Council for a Carer Assessment, Parenting Additional Needs, Chesterfield Community Farm, and Everyone Hurts.

Summary of findings

There are patterns in these experinces that would suggest that some parts of the experience works wells, whilst others do not work as well.

The clearest example of this relates to the relatively high number of negatives compared to positives regarding referrals and diagnosis. Sometimes participants spoke about a real

challenge - to get in to the service in the right place, at the right time – although there were positives in this regard too. All comments regarding diagnosis were negative.

Conversely, there were many positive comments regarding quality of staff, the quality of the service and the seemingly positive impact for those using CAMHS. This far outweighed any negative comment.

In short, the comments made to Healthwatch Derbyshire suggest that for some, there would seem to be problems getting in to CAMHS and going through the referral and diagnosis process. However, once participants were 'in' the CAMHS service, they were generally very positive about the experience.

Recommendations

This insight from Healthwatch Derbyshire gives providers and commissioners in Derbyshire an all be it small, limited snapshot – but real, recent experinces as told to an independent consumer champion across health and social care for children, young people and adults.

With this in mind, Healthwatch Derbyshire would recommend that

- Referral systems in to CAMHS are refined and training if required is delivered to encourage professionals to refer in a timely way
- Young people, parents/carers all receive clear information about how long referral might take, what happens next, and coping strategies in the interim are explored
- Referral systems for children in foster care are explored to ensure they are adequate
- Steps are taken to limit and manage the implications when out of county beds are required
- Frequency and duration of appointment is periodically reviewed and young people and their parent/carer is involved in any professional choices made
- Steps are taken to ensure that additional information, support and signposting is helpful, adequate and appropriate.
- The apparent gap in carer support for parents with children with mental health conditions is explored and rectified

Response