



Child and Adolescent Mental Health Services Experience Report



December 2015

Introduction

About Healthwatch Barnsley

Managed by Voluntary Action Barnsley (VAB), Healthwatch Barnsley (HWB) is a community led, community driven organisation with a Strategic Advisory Board, responsible for determining the direction of the organisation. We are also assisted by volunteers (Healthwatch Champions) whose role is to gather information and prioritise areas of work, ensuring engagement with all sections of the local population. This also enables us to be representative of as many health and social care service users as possible. We are part of a national network of Healthwatch organisations that involve people of all ages and from all sections of the community in local health and social care services.

We gather views from the community, report these views to the people responsible for local services engage people in decisions about services and monitor services. As part of our work to gather views, we also can exercise our right to visit services through a process known as Enter and View. We also have a role in providing people with information about health and social care services available in the area.

In some areas, Healthwatch organisations provide advocacy for people making a complaint about NHS services. In Barnsley, this service is provided for us by DIAL and their details are at the end of this report. DIAL is not limited to dealing just with health service complaints and can also look at problems with social care services. Through our partnership with DIAL, we have been able to successfully close a number of complaints from our clients regarding their experiences of local services.

Children's Mental Health Challenges

Gathering the views of children, young people and families and access to Child and Adolescent Mental Health Services (CAMHS)

We began looking into CAMHS in 2014. Through our outreach and engagement work in the local community, we had picked up a number of comments and case studies about access to the service and long waits. We had also received some case studies (patient stories) that highlighted that there were problems with the CAMH service which was impacting upon individual's experiences.

Noticing an emerging pattern (and using our powers to receive a response within 20 days) we fed in the comments, experiences and patient stories received to our intelligence sharing networks and were advised of some work which was underway, led by an Expert Commissioning Group (ECG). The ECG had been tasked with looking at how improvements could be made to CAMHS locally and consisted of members of Barnsley Council (BMBC),

Barnsley's Clinical Commissioning Group (CCG) and South West Yorkshire Partnership Foundation Trust (SWYFT) who are the provider of CAMHS in Barnsley.

The ECG responded to us in 2014 to say:

That they had used the comments provided by us to inform a review which they were undertaking, looking specifically at access to CAMHS. We were advised that for this review, the ECG had considered:

- Waiting lists;
- How cases are triaged (or reviewed when the referral is first received);
- Response times for urgent cases;
- Waiting times following the initial 'choice' appointment and how cases are allocated to different clinicians;
- Discharge practice (what happens when the treatment comes to an end);
- The quality of information back to referrers when cases are rejected because CAMHS are not thought to be the appropriate service.

From this activity, they had found:

- Demand for the service is very high and increasing;
- CAMHS is not always best placed to deal with some of the issues that people present with;
- Waiting times are unacceptably long, both for the initial choice appointment and the wait to see an appropriate clinician following the choice appointment;
- There are lots of cases that remain under the care of CAMHS because it is felt that there might not be anyone else (such as GPs) able to do what CAMHS does.

Also in their response to us, the ECG added that they had:

- Agreed an action plan with South West Yorkshire Partnership Foundation Trust (SWYFT) to reduce waiting times for non-urgent cases to a maximum of five weeks, but advised that this would take time to achieve;
- Agreed to some time-limited, one off investment to allow CAMHS to concentrate on clearing a backlog of cases waiting to be assessed for Autism Spectrum Disorders (ASD). They outlined that ASD assessments are important and can be very time consuming, which had an impact on the rest of the cases waiting to be seen by CAMHS;
- SWYFT had devised a new system for children and young people requiring assessment for ASD in future, which should mean that the demand on CAMHS is reduced;
- CAMHS had improved the quality and kind of information they give to referrers when they are not the appropriate service, which should ensure GPs and others

know what to do when a referral has been rejected.

Finally, building on some of our comments and feedback, the Chief Nurse for NHS Barnsley Clinical Commissioning Group was leading on a piece of work to establish what was needed to ensure children, young people and families can be effectively supported to meet their emotional health and wellbeing needs, before they get to the stage of needing CAMHS. This work was undertaken to concentrate on three areas:

1. Improving the ability of staff in the universal workforce (children's centres, schools etc.) to help children and young people with brief interventions to prevent the need for CAMHS;
2. Improving the way they support parents and carers to understand and help their children to be happy and confident and enjoy positive relationships;
3. Establishing a lower level service offer for children and young people who would benefit from access to 'talking therapies' such as counselling.

Please see appendix 1 for the feedback from the ECG.

Understanding the Emotional Health and Wellbeing needs of children and young people in Barnsley

Having received this feedback, Healthwatch Barnsley and our Young Champions planned the next stage of engagement. We wanted to understand from children and young people what they felt their emotional health and wellbeing needs were, what knowledge they had of current systems and where they might like to go for support when it was needed. This would ensure an independent view was considered.

Therefore during 2014, the Healthwatch Children's Engagement Worker and the Young Champions went to schools, parks and community centres to gather the views of secondary school aged young people on the subject of emotional health and wellbeing.

For this project Healthwatch Barnsley engaged with a total of 341 young people, who participated in an emotional health and wellbeing survey designed with the support of the Young Champions. See appendix 2 for the survey

Of the 341 young people surveyed, over $\frac{3}{4}$ of them stated that they have felt stressed over the past 12 months and over half of the young people that completed the survey also said they had often felt stressed.

We also enquired what the main causes of stress were for young people who had stated that they often felt stressed. These are the reasons stated:

- **66 (33%)** young people said **school**;
- **44 (22%)** young people said **family relationships**;
- **32 (16%)** young people said **self-image**;

- 28 (14%) young people said **relationships with friends**;
- 15 (8%) young people said **peer pressure**;
- 13 (7%) young people said **illness**.

We also enquired if a young person was feeling stressed or low, would they talk to someone. A large number of young people (226) stated they would speak to someone if they were feeling stressed and low. Friends and family was the most popular choice amongst young people, with their next preference being to seek support from a school environment.

Unfortunately this work also highlighted that a significant proportion of children and young people in Barnsley did not know of any health and wellbeing support services that were available to them and of those who were aware of the services, they did not know how to access them.

This highlighted that improvements needed to be made in communications and awareness of local services supporting children and young people with emotional health and wellbeing needs. The results also showed that whilst the young people surveyed do not currently access support online, they may like to if they knew the options available to them.

Upon completion of this section of our work, we shared the findings from the emotional health and wellbeing survey with our intelligence sharing networks. These findings subsequently underpinned sections of the CAMHS Transformation Plans for Barnsley and informed Barnsley's Mental Health Strategy 2016.

Please use the following links to access:

Barnsley's Mental Health and Wellbeing Strategy

<http://www.barnsleyccg.nhs.uk/get-involved/mental-health-and-wellbeing-strategy.htm>

'Future in Mind' Barnsley Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing

<http://www.barnsleyccg.nhs.uk/CCG%20Downloads/strategies%20policies%20and%20plans/Barnsley%20Future%20in%20Mind%20Transformation%20Plan%20November%202015.pdf>

Making sure young people receive information about local support services

Healthwatch will be using the information we gathered from this outreach and engagement activity to inform the design of a booklet, which is specifically for children and young people and outlines what services are available in Barnsley. This booklet will also contain the findings from three other surveys carried out in the same time period looking at the school nursing service, drugs and alcohol and sexual health services.

Avoiding duplication and sharing our work

Healthwatch also attended the local Children's Services Scrutiny Committee (now the Safeguarding Scrutiny Committee) as a witness in March 2015.

Our role was to provide feedback on our findings to date and to advise of our next steps to gather views.

If you would like more information on the local Overview and Scrutiny Committees and their work a list of links is provided at the back of this report.

The Children's Services Scrutiny Committee after hearing a report from Dr Lund from South West Yorkshire Partnership Foundation Trust, and reading a report from the Expert Commissioning Group lead, asked a number of questions relating to the following themes:

- Access to services
- Complaints
- Success of work to prevent referrals and reasons for children and families being wrongly referred, including standard referral and rejection procedures.
- Process for identifying CAMHS needs in school

Out of which the following Committee Actions came:

- CAMHS to provide copies of anonymised letters regarding rejections of referrals for the committee to consider so that they can review that sufficient information is being provided with regards to alternative services.
- CAMHS to find out from GPs if there are a number of patients who are accessing private mental health services and advise the committee accordingly.
- CAMHS to continue its work with regards to improving other professionals' knowledge to enable better referrals and early intervention from other services.
- CAMHS to improve its use of data to ensure it can manage demand for services, referrals and reduce response times.
- Committee Members to read the CAMHS Health Select Committee Report when it becomes available over the next few weeks.
- Elected Members to refer any comments/service user complaints they hear of to Healthwatch Barnsley.

- CAMHS need to ensure work is done to manage service user expectations so they are clear how long they will be waiting for appointments and what services they can expect to receive.
- The committee will follow up the above actions and progress of the CAMHS service in 12 months.

These actions will be followed up by the Safeguarding Scrutiny Committee (formerly the Children's Services Scrutiny Committee) at its meeting planned for Tuesday 3 May 2016, where Healthwatch Barnsley will once again be in attendance as a witness and will present this report including our plans to keep up to date with what is happening within the service and undertake an Enter and View in 2017.

At this stage of the project, Healthwatch had engaged with a total of 466 children and young people and as a result of this work we understood young people's experience of access, their awareness and how they might like to use services in the future.

However, we still needed to understand what people's experiences were once they were engaged with CAMHS.

Gathering the views of young people and families engaged in CAMHS

The next stage of our project began in June 2015, when we received agreement from SWYFT to carry out some outreach and engagement within the new CAMHS Clinic, based on New Street in Barnsley.

This work was undertaken by our Children and Young People's Engagement Worker, along with our Champions who once again designed a survey; this survey once in draft form went to the CAMHS Manager and South West Yorkshire Partnership Foundation Trusts Young Ambassadors, before being finalised in September 2015. Please see appendix 3 for the survey

Between October and December 2015, we carried out 12 sessions of outreach attending the CAMHS clinic between 9:30am and 3:00pm and surveyed 54 parents and carers.

What we found:

Of the families engaged with the service at the time of the outreach undertaken, a larger percentage of referrals were for:

- Behavioural 41%
- Attention Deficit Hyperactivity Disorder (ADHD) 24%
- Autism Spectrum Disorder (ASD) 22%

There was often more than one reason for the child's referral to CAMHS.

Of the 54 families surveyed;

- 64% of the parents and carers were pleased with the service they received. Their comments included:

“To this day they have been fantastic”

“Always been very good and always made her feel as comfortable as possible”

“Very good, seeing improvements in behaviour, we will be 2 months into therapy”
- 23 % of parents and carers surveyed were happy with the service whilst they were accessing it, but the long wait for their appointment had given them the impression that the service may not be very good. Comments included:

“Once we finally got into CAMHS it was very good, just the waiting time was far too long”

“Once in the system our first appointment was reassuring, although waited a long time for first appointment”

”Very good for the first visit, but seemed too long for the 1st visit”
- 13% of those surveyed were not happy with their experience, stating their reasons as:

“I know CAMHS is a very busy service but we have now been coming for 2 ½ years and are still no further along with knowing what my son’s condition is, it’s very frustrating as I cannot get any support from others until we know”

“Slow - a long time between appointments and obtaining a diagnosis”

“It seems like you see lots of people and tell them all the same thing before you see who you need to”

“We are still waiting for a diagnosis, my child is due to go to High School, we are concerned about her, and we were supposed to receive a report but have been told it has been delayed because of staff shortages. That’s not my problem we need help now”.

For a full list of comments see Appendix 4

When families were asked about the outcome from their accessing CAMHS, 45 parents and carers completed this question with over half of these parents 25 (56%) advised they were happy with the result, which either meant they had a full diagnosis for the child, or were on the right path to gaining a full diagnosis. 20 of the parents and carers (44%) said they did not have a diagnosis or an outcome and the therapy was still ongoing.

How was the level of support for you as a parent?

We were interested to know what level of support was provided for parents and if families had been offered support in between appointments from other sources, 45 of these parents left comments.

25 parents (56%) found that the support they received was great and it was also accessible.

Full list of comments on Appendix 6

In comparison, 20 of the parents (44%) surveyed stressed that the support for them was minimal and they found it hard to seek support outside of the meetings. They felt they were alone in finding out certain information they may need and they found it difficult to get calls and advice from CAMHS if needed outside of their appointments.

From the 40 parents who left feedback on this question, a large number (68%) stated they had not been offered any kind of support in between appointments.

When asked about what other support had been offered, parents and carers gave the following responses:

- Through school, and also Cygnet Course through CAMHS;
- Social worker and support worker;
- Behaviour worker;
- Disability team Home Start;
- (Practitioner named) was on hand when I didn't understand anything;
- NAS Early Bird Plus;
- Family Partnership;
- I have always just called CAMHS.

Parents were also asked how accessible it was to contact CAMHS for additional support outside of meetings. 43 respondents 64% found CAMHS to be accessible outside of the meetings, with 36% not finding CAMHS accessible.

We were also keen to understand how CAMHS had used opportunities for information sharing to enable the service user to access relevant information at their convenience and asked therefore if they knew where to access information about CAMHS and if they had been provided with additional information to explore during waiting periods.

Reassuringly, a high percentage of families knew where to access information about CAMHS, however most of the respondents had not accessed SWYFT's webpage for information.

A high percentage of families also advised that they had not been provided with additional information to explore whilst they were waiting for their appointment.

Therefore we felt it important to understand what support and information families might find beneficial during their waiting period. They gave the following suggestions:

- Information on other services that may help;
- Support strategies and help on what to do in bad situations;
- More coordination with schools;
- See CAMHS worker a little bit more;
- Some tips on how to cope with my son's anger issues;
- Anything that will help;
- Perhaps contact details for advice;
- More support for parents;
- I have been very lucky and had the help and support from family and friends and also positive thinking books etc. I use but as for parents that don't have this more help and support could be provided such as classes to help deal with their child and help keep their own peace of mind;
- Leaflets and advice;
- Any kind of support;

Lastly we asked those surveyed if they had any additional comments about CAMHS to which they responded:

- Fab waiting area, lots to do for the kids;
- New CAMHS is much better place, the waiting area is fab, the small rooms are ok but could be too formal for the children;
- Brighter colours could be used in the consultation rooms, maybe have them themed e.g. kids characters - make a range for all ages;
- The waiting area could be made a better waiting area for the older kids;
- Very happy;
- CAMHS have always been fantastic when I have needed help and support for my son, even on short notice they aim to please and do their best;
- Been very good (child adopted);

- CAMHS came to visit, all quite quick - at Dodworth - on medication first and would have preferred talking therapy first then medication later - there is no support service for parents to keep them in a good frame of mind;
- Long wait for appointments - causes frustration.

Challenges

Demand	• One in ten children have a diagnosable mental illness • 11% increase in demand on services last year alone
Resource	• Extra central government funding • Pressure on funding for local authorities
Stigma	• 45% of parents never talk about mental health to their children • One in four children with a mental illness have considered suicide due to stigma
Data Gap	• Last nationwide survey of Children and Young People's mental health was in 2004 • Mental Health Services Datasets have started to flow this year.
Treatment Gap	• Only one in four children get the help that they need • Variable quality of care around the country.

Key findings and recommendations

Key Findings	Recommendations	South West Yorkshire Partnership Foundation Trust (SWYFT) response
1. It is clear to see that once a child has an appointment with CAMHS, the service they receive from practitioners and doctors is very good. Parents feel CAMHS helps and supports the child fully, improving their child's condition through the meetings they have.	1. It would be beneficial for South West Yorkshire Partnership Foundation Trust (SWYFT) to look at the Friends and Family Test (FFT) cards they get from parents and carers and other sources of patient feedback, to ensure that any good practice is also monitored closely, thus ensuring continuation.	SWYFT have offered to share the full year report for the FFT test 2015/2016. Families can feedback live in the waiting area which is collated and feedback to the team monthly. The CAMHS general manager will explore how and where this can be displayed in the public areas. The service also uses wider therapeutic alliance measures in sessions such as the Session Rating Scale (SRS)



		and also offers the Experience of Services Questionnaire (ESQ) to families at discharge. The service will explore the ability of the system to extract and report this.
2. Parents and carers were very complimentary about the new CAMHS clinic, which had recently been relocated from the Keresforth Centre to the New Street Clinic. A couple of families had some suggestions about how the clinic could be brightened up further.	2. SWYFT could consider using brighter colours in the consultation rooms and perhaps having some themed rooms with characters on the wall that children can identify with.	Young people were involved in the design of the refurbished clinic by for example selecting colourful furniture, feature colour walls and art work. Due to the varied age range of people in the service and with due regard for offering 'calming' therapeutic space the service will not be able to offer themed rooms. The service will explore with children and families the options for further artwork.
3. Parents stated that their child receives very good care from the CAMHS workers. Most parents we spoke to are very happy with the service their child receives and advised us that they fully support the child.	Again this outlines good practice which must be documented and benchmarked, to ensure the majority of service users, leave the service with this impression.	As response to recommendation 1
4. Healthwatch found that the children and families we spoke to between October and December, still mentioned long waiting times to access the service and a high percentage of the young people referred were	Waiting times are still an issue for individuals engaged with CAMHS, however through our intelligence sharing networks with the Clinical Commissioning Group (CCG) and Expert Commissioning Group (ECG) lead, we have been assured that waiting times to the first choice appointments are	The service achieved the 5 week wait for 'choice' (initial assessment) by March 2016. The 'choice' appointment enables a decision about the most suitable service to be made and for those families where Specialist CAMHS is required a partnership appointment



not seen for 6 months or more, with 13 of those surveyed advising of a wait of over 12 months.	reducing. Where the trust still has issues is with addressing the wait time of the 2nd appointment for Treatment. And therefore it would be interesting to understand from South West Yorkshire Partnership Foundation Trust the plans to improve access to this stage in the treatment pathway.	will be offered (2nd appointment). There are existing and varying waits for partnership appointments across the pathways. The service is currently aligning staff to a pathway model and will be establishing mechanisms to produce reliable information regarding the current waits by pathway. The aim of the pathway implementation is to improve timely access to care. Emergency cases are seen within 24hours by the 'crisis' team.
5. Healthwatch also spoke with families who discussed a wait of between 11 and 18 weeks to the first Choice appointments.	The lead for the ECG has advised that the current waiting time is 7 weeks and it is hoped that CAMHS will reach a 5 week waiting time by April 2016. Healthwatch will be monitoring this through our intelligence sharing meetings and intend to carry out an Enter and View in 2017, to ensure waiting times are reducing as planned, and would welcome working in partnership with South West Yorkshire Partnership Foundation Trust on this.	The service achieved the 5 week wait for 'choice' (initial assessment) by March 2016 and the service will be working to sustain this. Emergency cases are seen within 24hours by the 'crisis' team.
6. Healthwatch also found that for some parents there seemed to be a long wait to achieve diagnosis. In that time the parents and carers felt helpless,	Whilst Healthwatch Barnsley understands the complexities of reaching a diagnosis and the importance of making the right diagnosis, more must be done to provide support for parents during this period. More must also be done to ensure that	The service will review existing literature and explore what further information can be provided to families by the service. CAMHS welcomes the opportunity to work with Healthwatch to undertake



receiving little support.	parents and carers are engaged in discussions with professionals on a regular basis in terms of progression and reports after diagnosis must be received in a timely manner.	this review with families. CAMHS will also be working across the wider network of agencies as part of the Future in Mind Transformation Plan with regard to whole system information for families. CAMHS shared the good practice news that in June 2016 a parent is co-facilitating a parenting workshop for children diagnosed with Autism. Planning is underway to develop a CAMHS Single Point of Access Service (SPA) and we will be working across the whole system to develop this with support for professionals and families being integral to the function.
7. A high number of the parents and carers stated they found the support for them to be minimal and also found it hard to seek support outside of the meetings.	SWYFT and the ECG need to look at what external services are available to support the parents and carers in between meetings. This has been raised by Healthwatch previously with SWYFT who at the time advised that they were aiming to set up some peer support groups, therefore it would be appreciated if in your response to our key findings and recommendations you could include an update on this activity.	CAMHS will also be working across the wider network of agencies as part of the Future in Mind Transformation Plan with regard to whole system support and information for families. CAMHS will welcome the opportunity to work with Healthwatch and Chillipep to interface with local support groups and explore the options for Peer Support.
8. There was not clear evidence in our findings that parents found	SWYFT and the ECG could map the support package they offer, including accessibility to the	As above Recommendation 7. CAMHS will also work with Healthwatch to contribute to



CAMHS very accessible outside of the meetings, once they had engaged with the service.	service outside of scheduled appointment times and ensure that it is accessible and that information on their support package outside of meetings is made available to service users and carers for utilisation.	the children's pages on their website.
9. Most parents had not been provided with information to explore whilst they were waiting for their child to access the service.	SWYFT and the EGC need to think about how they can engage with the local social prescribing service as it develops in Barnsley.	As above Recommendation 7.
10. Have more leaflets and information available detailing support strategies available for parents and carers when waiting to access CAMHS or inbetween meetings.	There must not be an overreliance on web-based interactions and communications, and the service must opt for a mixed marketing approach. Ensuring information is offered and provided in a number of ways and formats.	As above Recommendation 7 and 8. CAMHS plans to participate in the Barnsley 'pop up shop' on July and has invited Healthwatch to join them where education and consultation opportunities can be utilised.
11. Whilst a higher percentage of parents were happy with the service once engaged, we were concerned to note that staff resource is an ongoing issue impacting upon service delivery and communications.	SWYFT and the EGC need to look at average time taken to achieve a diagnosis, and look at the systems surrounding the wait time to ensure systems are in place, keeping service users informed of progress. An audit should also be undertaken to look at staff resources, and they must further challenge authorities both locally and nationally with evidence of shortfalls to ensure resource meets service demand.	The service is currently aligning staff to a pathway model and will be establishing mechanisms to produce reliable information regarding the waits by pathway. SWYFT will continue to review the CAMHS offer aligned to Strategic Objectives and local /national intelligence.

Conclusion

It is clear from the feedback that we have received from families engaged with the CAMH Service that the quality of care is good. It is evident from our findings that changes are occurring within this service and the families we spoke to seem to be very receptive to the new clinic at New Street in Barnsley and are openly offering ideas for improvement in terms of the consultation rooms.

Waiting times are still an issue for parents and carers, but from our work started in 2014 where 2 year waits to an initial choice appointment were reported, we have seen a gradually reducing trend and the parents we spoke to during our visits in October and December 2016 advised of 11-18 week waits.

Healthwatch recognise that there is still a significant way to go to achieve the five week wait for the initial choice appointments and within our intelligence sharing meetings with the Clinical Commissioning Group have been advised that the current waiting time is at seven weeks, with a view to reach a five week wait by April 2016. This is a change which we would like to evidence in our second Enter and View to be undertaken in 2017.

In terms of additional support and access to support outside of meetings it is evident that work still needs to be undertaken in this area.

It is also apparent that staff resource is an ongoing issue which is impacting upon the level of information that parents and carers receive on assessments, next steps and diagnosis.

Whilst Healthwatch welcome the changes occurring in terms of reducing waiting times to accessing C.A.M.H.S it is important that these reductions do not result in poor quality provision and we would like to see assurances of this which will also be included in our investigations in 2017.

Next Steps

Healthwatch Barnsley sent this report to the service provider on the 15th of March 2016 with a request to respond to our key findings and recommendations by the 12th of April 2016.

Healthwatch Barnsley received a response on the 12th of April, requesting a meeting with the Director of Forensic and Specialist Services, General Manager of Barnsley C.A.M.H Service and the Deputy Director of Operations. The meeting took place on the 26th of April 2016 and at this meeting the Key Findings and Recommendations were discussed in detail and a commitment from the team was

agreed to respond to the report in advance of the Overview and Scrutiny Commission meeting to be held on the 3rd of May 2016.

Healthwatch also discussed working in partnership with the trust on a range of initiatives which are outlined in the services response.

Children's Safeguarding Scrutiny Committee Meeting 2016

Healthwatch Barnsley will be sharing this report with the Safeguarding Scrutiny Committee on 3 May 2016, which will include the feedback from the service provider on our key findings and recommendations.

We will also add any response from this committee to this report.

Sharing our findings with the public 2016

Healthwatch will make this report public in May 2016, when feedback has been received from service providers and commissioners, against our own key findings and recommendations and the actions of the Safeguarding Scrutiny Committee. We will also ensure we share this report with the 520 parents and carers we have engaged with.

Keeping up to date with service changes and feeding back 2017

In 2017 Healthwatch Barnsley will be carrying out an Enter and View to CAMH Services. Again we will gather the views of children and their families on how accessible they found the service to be.

What we aim to find out is:

- How long they were waiting to be seen
- What information they have received from services
- How accessible information has been
- What external support have they been provided whilst waiting and between appointment times
- Length of time to diagnosis
- Appropriateness and level of Communications

Special Thanks

Healthwatch would like to thank the 520 families and young people with which we have engaged over the past 2 and a half years, we have been asking some quite intrusive, personal and often emotive questions and have been astounded by your openness and willingness to engage with us.

If you have read this report and have any further questions or experiences you would like to share they will be gratefully received and shared via our intelligence networks. Your continued feedback will also help us to keep up to date with what is happening within the service. Your feedback will also inform us of progress within the service, with the implementation of the local transformation plans, and will also inform our final enter and view to be undertaken in 2017.

Contact us

If you would like to contact us about anything in this report, or about any health or social care issue in Barnsley, you can do so in the following ways:

Address: The Core, County Way, Barnsley, S70 2JW

Telephone: 01226 320106

Text/SMS: 07870 599445

Email: healthwatch@vabarnsley.org.uk

Website: www.healthwatchbarnsley.co.uk

Facebook: Healthwatch Barnsley

Twitter: @HWatchBarnsley

Appendix 1



BARNSELY
Metropolitan Borough Council

Directorate for Children, Young People and Families

Executive Director: Rachel Dickinson

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Carrienne Stones
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Our Ref	RD/LH
Your Ref	
Enquiries to	Rachel Dickinson
Email	racheldickinson@barnsley.gov.uk
Dial Direct	01227 773602
Fax	
Date	30 April 2014

Dear Carrienne

Child and Adolescent Mental Health Services (CAMHS)

Thank you very much for the comments you sent us, they have been very useful in helping us decide what we most need to do to make CAMHS a better and more accessible service. We would be grateful if you could pass on our comments to your members as follows:

We used your comments to help inform a review looking specifically at access to the CAMH Service. Your comments helped us to understand that getting access to CAMHS within a reasonable timescale, for both urgent and non-urgent issues, is really important. This is particularly the case when children and young people and their parents or carers are feeling anxious that things might get worse if they don't have someone to talk to about their problems or issues.

To try and make the service easier to use for those that need it most we used the review to look at:

- waiting lists
- how cases are triaged (or reviewed when the referral is first received)
- response times for urgent cases
- waiting times following the initial 'choice' appointment and how cases are allocated to different clinicians
- discharge practice (what happens when the treatment comes to an end) and;
- the quality of information back to referrers when cases are rejected because CAMHS are not thought to be the appropriate service

What we found:

- demand for the service is very high and increasing
- CAMHS is not always best placed to deal with some of the issues that people present with
- waiting times are unacceptably long both for the initial choice appointment and the wait to see an appropriate clinician following the choice appointment
- there are lots of cases that remain under the care of CAMHS because it is felt that there might not be anyone else (such as GPs) able to do what CAMHS does

What we have done and what we are planning to do:

We have agreed with the provider of CAMH services, South West Yorkshire Partnership NHS Foundation Trust (SWYFT), an action plan to reduce waiting times for non-urgent cases to a maximum of five weeks. This will take time to achieve but we are also working with SWYFT to identify what help we can provide to ensure waiting times are reduced.

We have set out our priorities for the service to improve including how cases are dealt with once a referral has been received. This is work in progress and we will need to consult with you further to check that our suggested improvements will work effectively from your perspective.

We have agreed to some time-limited, one off investment to allow CAMHS to concentrate on clearing a backlog of cases waiting to be assessed for Autism Spectrum Disorders (ASD). ASD assessments are important and can be very time consuming which has an impact on the rest of the cases waiting to be seen by CAMHS.

We have devised a new system for children and young people requiring assessment for ASD in future which should mean that the demand on CAMHS is reduced.

CAMHS have improved the quality and kind of information they give to referrers when they are not the appropriate service which should ensure GPs and others know what to do when a referral has been rejected.

We have worked with the management of Healthwatch to make sure it is understood that where very serious concerns are raised about a service through feedback and / or consultation (such as not responding appropriately to very urgent cases) this should be pursued through formal channels and registered as a complaint. This is particularly important since it allows us as the commissioners to hold providers to account for their service delivery. It also provides formal means for service users to ensure that similar mistakes do not occur again.

Finally, building on some of your comments and feedback from the Barnsley Youth Council, the Chief Nurse for NHS Barnsley is leading a piece of work to establish what is needed to ensure children, young people and families can be effectively supported to meet their emotional health and wellbeing needs before they get to the stage of needing CAMH services. This work is concentrating on three areas:

4. Improving the ability of staff in the universal workforce (children's centres, schools etc.) to help children and young people with brief interventions to prevent the need for CAMHS;
5. Improving the way we support parents and carers to understand and help their children to be happy and confident and enjoy positive relationships;
6. Establishing a lower level service offer for children and young people who would benefit from access to 'talking therapies' such as counselling.

We hope that this has helped to answer some of your questions but if you would like to discuss further then please don't hesitate to contact Richard Lynch on 01226 773672 or richardlynch@barnsley.gov.uk

On behalf of the Children and Young People's Trust, thank you again for taking the time to help improve services in Barnsley. We very much appreciate your continued feedback regarding CAMHS and related services so we can see if our changes are working.

Yours sincerely

A handwritten signature in black ink, reading "Rachel Dickinson", followed by a small dot.

Rachel Dickinson

Executive Director, Children, Young People and Families

Chair of CYPT

Appendix 2 –Emotional Health and Wellbeing Survey the title in place of this

Emotional Health and Wellbeing

In the past 12 months have you felt stressed?

YES NO

Do you often feel stressed? YES NO

*Do you know about the services available for young people
who experience emotional and mental health issues?* YES

NO

*Do you feel confident to speak to someone if you were
feeling stressed or low?* YES NO

*If YES who would you most feel comfortable speaking to
about your Feelings?*

.....

If NO would you access online resources? YES NO



Appendix 3 - Parent and Carer Feedback Questionnaire, collating individuals experiences when engaged with C.A.M.H.S

Parent/carers feedback questionnaire
Regarding your child's care with CAMHS

Reason for child referral (please tick)

Behavioural ☐ Depression ☐ Anxiety ☐ ADHD ☐

Autism Spectrum Disorder ☐ Deliberate Self Harm ☐ Other ☐

Please give a brief description of the reason for your child's referral to CAMHS

How long was your child waiting for an appointment with CAMHS from the time of referral

How was the service your child received?

The outcome from accessing CAMHS?

How was the level of support for you as a parent/carer from CAMHS?

Have you been offered support in between appointments from other sources ie community and voluntary sector? If yes please give details on what support you was offered?

Did you know where to access information about CAMHS?

How accessible was it to contact CAMHS for additional support outside of meetings?

Have you visited the C.A.M.H.S page on the South West Yorkshire Partnership Foundation Trust Website Page? YES NO

If YES how did you find this page to access and navigate?

Have you been provided with additional information to explore whilst you are waiting? YES NO
If Yes what was this information?

If no What support do you feel would be beneficial to you and your family during this waiting period?

Are you aware of the Friends and Family Test?

YES NO

If YES have you used it?

YES NO

If NO provide parent with a card

Additional comments/ issues



Appendix 4 - How was the service your child received

Positive	Negative	Mixed opinion
Great	It seems like you see lots of people and tell them all the same thing before you see who you need to	Ok, still needs some input and support
Good really supportive enjoying services	We are still waiting for a diagnosis, my child is due to go to High School, we are concerned about her, and we were supposed to receive a report but have been told it has been delayed because of staff shortages. That's not my problem we need help now.	Really good, but don't get answers straight away
I think CAMHS are brilliant, they are fantastic for us as a family especially Dr Mona	I know CAMHS is a very busy service but we have now been coming for 2 ½ years and are still no further along with knowing what my sons' condition is. It's very frustrating as I cannot get any support from others until we know	Once we finally got to CAMHS it was very good, just waiting time is far too long
After a referral to CAMHS, routine appointments were given and also worksheets and exercises to help with my child's condition	Ok, it could have been better	Have only just been referred
Absolutely brilliant	Once in the system our first appointment was reassuring, although waited until 21/10/15 for first appointment for treatment	Very good for the first visit, but seemed too long of time for first visit
Very good, seeing improvements in behaviour will be two months into therapy	Slow - a long time between appointments and obtaining a	



	diagnosis	
The service is brilliant we saw a lady called Leslie for a while and she was good with my child	The first GP sent a referral to CAMHS and an appointment was received - went to appointment and they had no record of it	
Good		
Very good		
Excellent		
Good		
Very good		
Good		
Very good		
Brilliant service every time		
Very well and quick		
Brilliant, we got a diagnosis within a year of our first appointment		
Fantastic		
Once diagnosed was ok		
To this date they have been fantastic		
Fantastic		
Always been very good and always made her feel as comfortable as possible		
Very good		
Very good, been under CAMHS for around six years		
Good		
Excellent staff they have created a great bond		
Very good, we have never had a problem		
It's good that my daughter can open up to her CAMHS nurse		
Excellent		
It's very helpful and lots of good advice is provided		
Good		
Still receiving help		

Appendix 5 - The outcome from accessing CAMHS

Diagnosis	Still on going
My child has received medication and support	None really, keep working with the workers
Regular appointments and medication	Just keep seeing her
Really helping, behaviour is improving	Hopefully to help and support him and transfer to other services
Doctors and special needs nurse very good to help child	Ongoing appointments
Positive	Nothing as yet
Very good	Appointments
Medication, well managed behaviour	Not yet got the outcome
Very Good	Ongoing
Good outcome	He is still under CAMHS
Got a diagnosis + Support from DR Charter	Only had one appointment, hopeful it will benefit and equip my daughter with strategies
Diagnosis of ADHD & ASD opened up other avenues to other areas for adult information and training courses	Haven't done it yet
They have helped him loads	Still ongoing
Very good and helpful	Got an appointment but still ongoing
Better behaviour with the medication prescribed through CAMHS	Still ongoing with medication and diagnosis
My child had been diagnosed with ADHD	Still not sure
Got diagnosis + medication plus 1 happy content son	Still ongoing
Been diagnosed with ADHD ASD Bipolar - anxiety and depression	We have a better understanding
Was referred back to the school Psychiatrist and has now identified that my child is on the spectrum of autism	Not yet had a diagnosis
Medication and therapy	Hopefully a diagnosis if needed or just help on



ADHD and Autism statement	sorting his behaviour out
We received help and child received medication	
Diagnosis of ADHD + ASD	
Got a quick diagnosis and regular check ups	
Diagnosis of ADHD + ASD	
A lot better, it is getting easier	

Appendix 6 - How was the level of support for you as a parent/carer from CAMHS

Positive Comments	Negative Comments
Great at really bad times	OK but have to fight for it
Good - Excellent staff, created a great bond	Not really at this point, not much help to me as a parent Good
Good	Routine appointments only
Good	None (so far)
Good - improving	Lot of information given by doctor, although let down by the nurse since one went on leave for 12 months
Very good	Very minimal, I'm the one who is always requesting things. No one contacts me, not even when reviews should be being done due to his medication
Excellent	Not very good
Very good	Its ok, it could be better
Good	None - not had anything yet, we have had support through the school but it is not enough Offered support and help
Brilliant - all support was great	Once diagnosed can ring team or CBT therapist they are aware of my child, but still find it hard not available 24 hours when things are bad
Good	Services need to be provided locally. Son been under C.A.M.H.S for approx. 7 years and its made no difference. Telephone consultations and when he goes they do not know him and he just tells them that hes fine. They are not offering him appropriate treatment that is suitable for his needs. And he does not want group sessions, he wants 1 to 1, but this is not available and no explanation is given to him about why. Son is now 15 and no one is speaking to



	him about post 18. He needs a local services, but there is no local provision and he has to go to New Street.
Very good	
Very good with information and advice	
In my case very good	
Excellent	
Gave us advice and organisations to contact	
Fantastic Satisfying - I have always had answers, plus feel happy knowing she is in good hands	
Good - helpful	
Very good	
Couldn't ask for a better doctor than Dr Middleton	
Very good	
Always good	
Good	
Excellent	

Links;

<http://barnsleymbc.moderngov.co.uk/mgCommitteeDetails.aspx?ID=132>

<http://barnsleymbc.moderngov.co.uk/mgCommitteeDetails.aspx?ID=224>