



Healthwatch Kent - October 2016
Report on: **Children and Adolescent
Mental Health Services in Kent**



Foreward from our Chief Executive

At Healthwatch Kent we undertook a project nearly two years ago to listen to the experiences of people and their families about the Children & Adolescent Mental health service which is also known as CAMHS.

At the time, we promised to revisit the service to talk again to people and hear if their experiences had changed or improved.

That promise has seen us undertake a new project talking to patients and families from all across Kent about their recent experiences of what is now known as Children and Young People services or ChYPs.

We undertook the work in January 2016 and this has led onto lengthy discussions with the organisations that both provide and commission these services. Since then these services have been redesigned and are currently being re-commissioned. It was important to us that our findings were used as part of the design of the new service. We have shared our indepth findings and we are now finally in a position to share them with you too.

You will see that not all our findings are positive and there is clearly more work to be done. Healthwatch Kent will continue to stay involved and ensure that a new service listens and involves patients and their families.

Do get in touch if you have your own experiences of children and young people's mental health services. We can use your experience to help improve services.

Finally, I wanted to thank everyone who took the time to share their experiences with us. We appreciate that for some of you this has been very hard to do.

Steve Inett

Chief Executive, Healthwatch Kent



Contents

| | |
|--|-----------|
| Our Aims | 04 |
| What did we find? What are we recommending? | 05 |
| Our Pledge | 07 |
| More Details | 08 |
| Response | 09 |



Our aims

- To hear from young people and their family and carers about their experiences of children & adolescent mental health services. Although we gathered feedback from all over Kent we proactively visited groups and people in two areas : Swale & Tunbridge Wells.
- We also wanted to hear from professionals working with these services about their views
- To use the experiences of people as the basis for constructive conversations with the commissioner and providers of these services

What did we find? What are we recommending?



52%

identify a positive intervention from the CAMHS service



48%

unable to identify a positive intervention



What did we find? What are we recommending?

1. Autistic Spectrum Disorder (ASD)

Many families and carers told us about the particular difficulties and complications they experienced when trying to get an assessment for a clinical diagnosis or for mental health support for a child who already has a diagnosis of ASD. One person summarised this by telling us ‘We need a comprehensive pathway for young people with autism, as many families in our situation feel abandoned’.

Recommendation:

We heard so much during this work about Autism services that we have agreed to undertake a further piece of work to explore these particular issues in more detail. We will be starting on that work in 2016. If you have any experiences that you would like to share do get in touch with us on info@healthwatchkent.co.uk

2. Waiting times for initial assessment appointments

The majority of people who spoke to us said that waiting times for an initial assessment within specialist CAMHS services still remains a serious issue for young people, parents and professionals today. 35% of young people, 55% of parents & carers and 70% of professionals who completed this survey rated it as an issue.

Recommendation:

The time taken from the point of referral to attending an assessment appointment must continue to be monitored. Commissioners must remain aware of the impact of waiting times on people and their experience of the referral and assessment process.

3. Unclear referral process and criteria for specialist CAMHS services

Anecdotal evidence suggests that many people make numerous referrals, via different routes, over an extended time period before receiving an initial assessment appointment. People explained that getting an initial assessment caused ‘frustration and anxiety’ and that this is experienced by professionals working in services with young people as well as families.

Recommendation:

To ensure that young people, parents and referring professionals are given clear information about what they can expect from a specialist CAMHS service. In the words of a person who took part in the survey ‘At the outset communicate what is happening with regard to procedure, who is responsible for what/when, what the involvement structure is, who each person is and what they do’

4. Follow up appointments

People told us about the difficulties they experienced in receiving ‘reliable and regular’ follow up appointments. People described what they deemed to be ‘poor’ follow up. This included referrals to other agencies which didn’t come to fruition and cancelled follow up appointments and inconsistency in who young people are seeing. These experiences portray a mixed and patchy picture of follow up care for young people, parents and professionals supporting people within the services.

One young person summarised this saying ‘Keep in contact. I feel completely isolated and left in the lurch’.

Recommendation:

To continue to monitor the time taken from assessment appointment to follow up appointment and ensure that commissioners are aware of how people are experiencing follow up appointments.

5. Poor communication

71% of professionals and 54% of parents explained how poor communication added to their difficult experiences of specialist CAMHS services.

In particular we heard about peoples’ experiences of not being able to contact specialist services on the phone and of lengthy delays in follow up letters. This then had an impact on the treatment and support that the young people received from their GP and other community services.

Recommendation:

To ensure people are ‘kept informed better’. Delays in the system must be addressed. Information and treatment plans must be shared more effectively across the agencies that are involved in the young people’s care including GPs.

To ensure that young people and their families have ‘clear treatment pathways with clear next steps’.

6. Relationships with Staff

When asked what area of the service could be improved, the most common answer from young people was that some staff could demonstrate more ‘respect for their clients...be more polite... not dismissing people’.

Recommendation

Where individual members of staff or services have been mentioned and identified by young people, families or professionals, Healthwatch Kent has sought approval to share these directly with the identified service providers. We have asked for these individual cases to be followed up appropriately.



What did we find? What are we recommending?

7. Keeping young people safe

51% of parents and 59% of professionals told us that would like more information about how to keep young people safe, whilst they are awaiting an assessment from a CAMHS service. This is also true for those young people who are not accepted by a specialist CAMHS service but are still self-harming or suicidal. 54% of professionals working in community or education services indicated that they would like more 'clinical' advice and support from CAMHS specialist services to advise their daily work with young people.

Recommendation

Commissioners should consider this gap when considering the future design and commissioning of emotional wellbeing and mental services for young people across Kent

8. Lack of information about alternative support services

Young people, families and professionals all talked about the need to improve the level of information available, both in terms of 'what is available' and 'signpost to other agencies that could be helpful'. One professional working within a community service said they had repeated experiences of 'referrals being sent back with no clear guidance on how to access support in the community'. 21% of parents whose children had not met the criteria for specialist CAMHS service still felt that their child needed mental health support but they did not know how to find out what was available.

Recommendation

Commissioners should consider this gap when considering the future design of emotional wellbeing and mental health services. Wider social care signposting should also be considered which could include information on the rights of young people and carers and how to contact advocacy services.

9. Eating disorders

We heard from a clear group of people asking for 'standalone Kent eating disorders services accessed via GP, as going through CAMHS is a huge delay for very vulnerable young people'

Recommendation

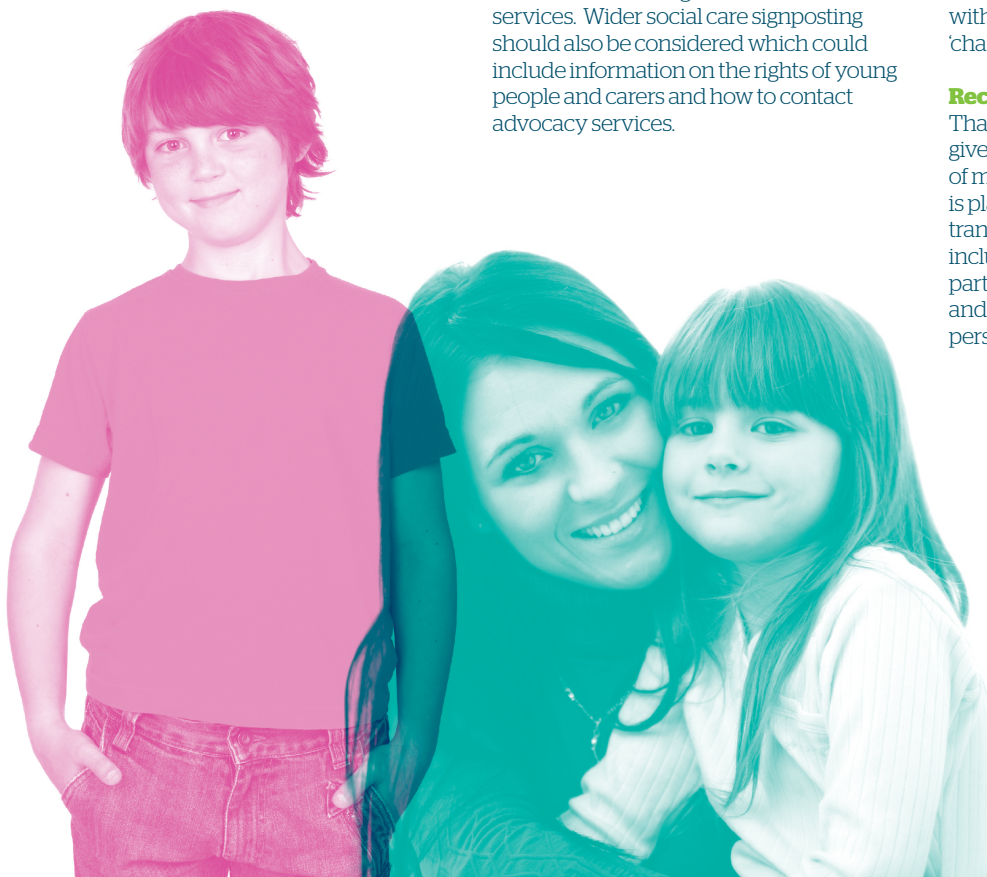
The new commissioning strategy for Eating Disorders will enable people to access eating disorder services via your GP.

10. Transition to adult services

25 people told us about their experiences of preparing for, or undertaking, the transition from CAMHS to Adult Mental Health services. We heard a consistent level of concern from Young People, Parents, Carers and Professionals about this transition with people finding it 'slow', 'unstructured', 'challenging' and 'fearful'.

Recommendation

That young people, families / carers are given clear information about the process of moving to Adult Services and that this is planned well in advance of the agreed transition date. This planning should also include a face to face meeting with all parties and clarification about what support and services will be available to the young person.





Our Pledge

Following this work, Healthwatch Kent is making the following pledges:

- We will continue to raise the voice of all the experiences we have heard as part of this project.
- We continue to give direct one-one support to individuals involved in this project.
- We will undertake further research and talk to the people living and working with the specific issues faced by children with Autistic Spectrum Disorder.
- We will monitor the implementation of the new Eating Disorders strategy. Once this new system is in place we will seek feedback from patients and families about their experience of the direct referral route through their GP.
- We will develop action plans with particular providers who deliver parts of the CAMHS service. We will review these action plan regularly during our quarterly meetings with those organisations and produce a summary review of progress after 6 to 12 months.



The action plan with providers will include:

- Addressing the concerns that we heard about specific services.
- Monitoring their plans to improve the referral and assessment process.
- Ensuring written information is provided to people about the referral process and treatment pathways.
- Monitoring the time taken to receive an appointment as well as the cancellation rates of follow up/ therapist appointments.
- Monitoring their plans to improve peoples' experiences of moving from the childrens to adult mental health services.
- We ensure commissioners including all 7 Clinical Commissioning Groups and Kent County Council are aware of the negative experiences that we heard from people and professionals. All of these organisations are working together to develop a strategy for Emotional Wellbeing and Mental Health Services in Kent.

We will highlight the following areas of concern;

- The need for advice and support to professionals working within education and community services, who are trying to keep young people safe in their daily lives.
- The impact of long waiting times for assessment and delays and cancellation in follow up and ongoing appointments and how this affects the wellbeing of young people.
- To ensure people and professionals are better aware of the range of wellbeing and mental health services that are available to support young people and their families. To consider joining this up with wider social care signposting strategy and commissioning, which could include information on the rights of young people and carers and how to contact advocacy services.
- That young people, families / carers are given clear information about the process of moving to Adult Services and that this is planned in advance of the agreed transition date. This planning should also include a face to face meeting with all parties and clarification about what support and services will be available to them.



More details

How we put this report together

We spoke to 302 people including a range of young people, families, carers and professionals to gain their views, insights and concerns regarding the issues raised in this report using the following methods: face-to-face interviews, phone interviews, submitted personal experiences, an online survey and handing out 'Your comment Count' cards to young people as they accessed services.

Although we proactively gathered feedback from the areas of Swale and Tunbridge Wells, we received response from all over Kent and some neighbouring counties.

95% of people confirmed their experiences were within the last 12 months.

The online survey was promoted to carer groups, schools, professionals within community and young people's groups.

The interview notes, submitted personal stories and statements, as well as comments entered into the on-line survey were analysed within a pragmatic framework using a form of thematic content analysis. This approach uses the actual data, the public's voice, to inform the structure of analysis. The process involves analysing transcripts, identifying themes within the data and gathering together examples of those themes from the text.

| | Total contributions | Young People | Parents Families | Professionals |
|--------------------------------------|---------------------|-------------------------|--------------------------|-------------------------|
| Returned Your Comment Counts | 18 | 9 | 6 | 3 |
| Complete online surveys | 212 | 26 | 151 | 35 |
| Group discussions | 47 | 0 | 42 | 5 |
| Personal stories submitted | 14 | 0 | 14 | 0 |
| Phone Interviews | 11 | 0 | 0 | 11 |
| TOTAL number of contributions | 302 | 35 11% | 213 71% | 54 18% |
| TOTAL number usable data sets | 230 | 35 15% | 157 68% | 38 17% |





Response

Joint response from Sussex Partnership NHS Foundation Trust, Ashford, Canterbury, Dartford, Gravesham and Swanley, South Kent Coast, Swale, Thanet and West Kent Clinical Commissioning Groups

We commissioned this report as we want to do everything we can to deliver excellent mental health services for young people in Kent and Medway. The services continue to improve but we know we have more to do.

We welcome the report Healthwatch has provided and accept the recommendations.

We know how frustrating and difficult it can be for children and their parents who have to wait for treatment. We want people to be able to access our services as quickly and easily as possible. At the moment people wait an average wait of seven weeks for assessment in line with national guidance. 70 per cent of all initial assessments are completed in less than six weeks and 85 per cent in less than 13 weeks. In those areas where commissioners have been able to identify additional investment for mental health we have managed to reduce waiting times and improve care further.

As a direct result of the report, Healthwatch has put us in touch with a number of people to discuss their particular cases in more detail and we are working with them to make improvements.

One of the areas we are most proud of is the positive and compassionate attitude of staff, which is essential when treating young people. Where the report has found incidences where staff attitude has not been up to our high standards we take that extremely seriously and have taken action.

It is clear from this report, and information we have been told in the past, that it can be hard to know where to get help and people feel like they are being passed around 'the system'.

All of our organisations in the health system need to be clearer about who is responsible for which services and where people can get support both from the NHS, social care and the third sector. We are working together to improve this so people experience a seamless service. The clinical commissioning groups and the local authority have been working extensively with young people and families, as part of a full review and procurement of Kent's emotional health and wellbeing services to improve access and waiting times. We are also engaging with children and young people to help us develop our transformation programme, in line with Department of Health Future in Mind improvement programmes.

We want parents, young people and partners to continue to talk to us about the mental health care we provide in Kent and Medway so we can continue to improve and offer outstanding care you can be confident in.





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