

SUBMISSION TO THE HEALTH SELECT COMMITTEE ON CHILD AND ADOLESCENT MENTAL HEALTH SERVICES IN NORTHAMPTONSHIRE - March 2014

Healthwatch Northamptonshire is the independent consumer champion for people in Northamptonshire who use, or could use, health and social care. Established in April 2013, our aim is to gather the views and experience of patients, service users, carers and the wider public. We report these views and experiences to health and social care decision makers to influence and improve the quality of care. Our vision is to make a positive difference to the quality of care and improve health and wellbeing in the County.

Healthwatch Northamptonshire conducted an engagement campaign, between October and December 2013, with children, young people and families to inform plans to re-design children's community health services. The re-design of services include child and adolescent mental health and emotional well-being services, as well as services for children with complex care needs and services for children with special education needs and disability

Healthwatch Northamptonshire wanted to ensure that the views of children, young people and families were gathered and heard through the re-design exercise and that these views positively influence any changes to current services. We have gathered views and experiences through a survey; discussion groups; attending meetings and talking individually to children, young people and families as well as health and social care professionals. We have done this to add to the engagement activity also being undertaken by the clinical commissioning groups.

If you would like more information about this submission; the work of Healthwatch Northamptonshire and how to get involved please email enquiries@healthwatchnorthamptonshire.co.uk reference: Children and Young People or ring us on 01604 893636

What we heard during our engagement campaign:

- **Access is a problem:** We heard very widespread concern about the limited availability of Child and Adolescent Mental Health service in Northamptonshire. People said CAMHS (Children and Adolescent Mental Health) services are usually good once they have been able to access the service, but the issue is getting access. Many people said that waiting times for CAMHS are unacceptable. While waiting times in Northamptonshire may be average (according to the local Clinical Commissioning Groups), the sense is from the people we spoke to that this can feel like a very long time when there are urgent health mental health needs. This was a view echoed by nearly all the children and young people who spoke to us about CAMHS. For some this has resulted in having to seek diagnosis privately.

“Everywhere I go there is a long waiting list and it’s hard to cope with when I am suffering from depression”

- **Problems with access to counselling services and early intervention/preventative services:** Children and young people are not aware of where to go to for support. Children and young people with urgent needs talked to us about being turned down or contact with services not being followed up. Several people talked about a lack of continuity of care. **We heard from one young woman who had 12 counsellors in 4 years.**

“My mum contacted [a serious assault counselling service] but they didn’t get back to us and I didn’t get any help for two years”

“When I asked to get a different counsellor they sent me to xxxx. I didn’t get a proper counsellor, so I left.”

- **Access to other services, including CAMHS:** Many children and young people told us that they don’t get the right support at the right time - not just CAMHS, but other services. Several young people and parents described the “*struggles*” or “*fights*” they have had to get services. Many people talked about the high level of need they have to

demonstrate in order to get any support. The impact this has on the lives and wellbeing of children, young people and families is significant, at times overwhelming, and makes it difficult to plan for independence and is life-limiting in the long term.

- **The role of schools:** There is concern about the quality of health and wellbeing within schools. There is a perceived gap during school holidays and people talked about the need to maintain continuity during this period . Some of the children we spoke to said they didn't want to approach their teacher to see the school nurse. There was specific concern about inconsistency in school support, in particular in relation to the management of Autism Spectrum Disorder which resulted in children being expelled from school because of behaviour which the school was unable to manage. Many parents told us they felt schools give up on children with challenging behaviour and complex needs. One family reported that they had been advised by CAMHS to call the police if their child with autism displayed particularly challenging behaviour. The family was then offered behaviour management support, which they didn't feel was effective, while they waited for advice and treatment from a CAMHS consultant.
- **Lack of general knowledge and awareness around mental health:** Some of the children, young people and families we spoke to said they felt "penalised" when their child exhibited symptoms, for example, by being excluded from school, but then not meeting the criteria to be eligible for CAMHS. Children and young people talked about their perceptions that the police don't seem to have a general awareness of mental and emotional wellbeing of children and young people.

Recommendations for change: When we asked children, young people and families what decision makers could do to help, responses included:

- **A joined up approach:** A whole system approach to mental health and wellbeing of children and young people, which stops young people falling through the net
- **Skilled services:** Services need to be equipped to deal with adolescent mental health and challenging behaviour

- **Meaningful involvement:** People said that children, young people and families should be involved in individual decisions about care and also in the design of services. We heard from quite a few young people who said that peer led, around issues such as self-harm, could be a potential solution
- Ensure clearly and easily accessible information on mental health support for Looked After Children
- **Direct access:** to counselling for children and young people without having to go through teachers or miss school
- **Greater awareness:** of mental health and wellbeing of children and young people, particularly by the police who encounter children and young people with mental and emotional needs
- **Training:** Ask potential providers to demonstrate how they will ensure their staff will be providing consistent services, which are fit for multi-disciplinary and multi-agency partnerships and working?; ask providers to demonstrate their commitment to meeting the needs of challenging children, including those who do not have formal diagnoses
- **Pathways:** Clear pathways with simple information for children, young people and families about journeys through healthcare. Providers and statutory agencies also need to work with the voluntary and community sector to ensure continuity, consistency and contingency for fluctuating mental health needs
- **Information and signposting:** Many respondents said they didn't know where to go and that there needs to be really clear and accessible information everywhere - schools, leisure centres, pubs and clubs, social media, GP surgeries, A&E - wherever children, young people and families go. Information should include easy to understand information on care pathways, statutory support services, community and voluntary services
- **Partnership with service users:** More robust information should be used in contracts which require providers to demonstrate how they seek the views of service users
- **Coordinated care:** The new Education Health and Care plans present an opportunity for all agencies to work together to promote the child's educational, medical, psychological and other needs. Providers should promote inter-agency working to focus on the outcomes of the child, which go beyond diagnosis and consultation and should ensure the voice of the child/young person is heard

Healthwatch Northamptonshire has:

- surveyed children, young people and families - through a paper survey and via the Healthwatch Northamptonshire website, Twitter and Facebook. 53 surveys were completed. The survey is attached as Appendix 1
- attended a range of events to hear the views and experiences of children, young people and families (a full list can be obtained on request)
- talked to health and social care professionals around the County who work with children, young people and families
- held focus groups with families and young people at Time 4 Support, Dreams Youth Café and New Ark Foundation
- circulated information to local communities through schools, early year's settings, children's centres and GP surgeries. Shared information with various organisations and agencies that have posted it on their websites and publicised our engagement activities through Facebook, Twitter and other media. These include: East Northamptonshire District Council , Northampton Borough Youth Forum, BBC Radio Northamptonshire, Inspiration FM, Northamptonshire School's Bulletin, Northamptonshire Parent Forum, Time for Support Parent Group, Northamptonshire early years and children's centres bulletins, Deaf Connect and Northamptonshire Early Help Fora.

Make your Voice Count about Childrens and Young Peoples Services

Thank you for taking the time to complete this survey by Healthwatch Northamptonshire. Your feedback will help us get the community's view on services for children and young people and where we can make a difference. *Make your voice count!*

1. Please name the services that you use the most and tell us where it is (for example, "Complex homecare support in Northampton")

2. How good do you think this service is?

- Not very good
 OK
 Very good

3. What do you like most about this service?

4. Is there anything you don't like about this service? Please tell us what.

5. What would make this service better?

Make your Voice Count about Childrens and Young Peoples Services

6. Does this service give you the help you need?

- Yes
 No
 Sometimes

Please tell us why

7. Do you use any other services?

- Yes
 No

8. Have you found it easy or difficult to get the help you need?

- Easy
 OK
 Difficult

Please tell us why

9. Is there anything else that you would like to tell us? Please write it here:

Make your Voice Count about Childrens and Young Peoples Services

14. What is your ethnicity?

- | | | |
|--|--|--|
| <input type="radio"/> English | <input type="radio"/> White and Black African | <input type="radio"/> African |
| <input type="radio"/> Welsh | <input type="radio"/> White and Asian | <input type="radio"/> Caribbean |
| <input type="radio"/> Scottish | <input type="radio"/> Any other mixed background | <input type="radio"/> Any other Black/African/Caribbean background |
| <input type="radio"/> Northern Irish | <input type="radio"/> Indian | <input type="radio"/> Arab |
| <input type="radio"/> Irish | <input type="radio"/> Bangladeshi | <input type="radio"/> Any other ethnic group |
| <input type="radio"/> Gypsy or Irish Traveller | <input type="radio"/> Pakistani | <input type="radio"/> Prefer not to say |
| <input type="radio"/> Other white background | <input type="radio"/> Chinese | |
| <input type="radio"/> White and Black Carribbean | <input type="radio"/> Any other Asian background | |

15. Do you have a disability

- Yes
- No
- Prefer not to say

16. If yes, please tick appropriate

- | | |
|---|--|
| <input type="checkbox"/> Mental health | <input type="checkbox"/> Physical disability |
| <input type="checkbox"/> Hearing impairment | <input type="checkbox"/> Learning disability |
| <input type="checkbox"/> Sight impairment | |

Other (please specify)

17. We will always take necessary steps to ensure that your information is protected and treated securely. Any details you give us will be held in accordance with the Data Protection Act 1998 and our data protection policy (part of our overall Information Governance Policy) and code of practice on confidential and personal information.

We will only collect personal information volunteered by you, such as:

- feedback from online forms.
- email addresses.
- preferred means of communication.

All personal information about you will be used in our day to day work and to improve the quality and safety of care. This may include any personal information that you choose to share with us, but we will treat this as confidential and protect it accordingly.

We will never include your personal information in survey reports.

- By ticking this box I consent to my details being used as explained above