

# Children & young people with long term conditions: what support is available for mental health & wellbeing?



A Healthwatch Bradford and District study, in partnership with Barnardo's.

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## Acknowledgements

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## 1. Why we did this study

Nationally concerns have been raised regarding young people's emotional and mental health provision which has resulted in service change being implemented in line with a national document 'Future in Mind', published in March 2015. The ambition is to make mental health provision for children and young people more accessible and effective, with an increased focus on prevention.

Healthwatch Bradford and District listened to some concerns about provision of mental health support for children and young people in the district. These concerns came from young people themselves and from voluntary sector professionals who support them. In July 2015, a young Healthwatch volunteer asked us to explore this in more detail and invited us to work with Barnardo's 'Healthy Minds' group to gather people's experiences.

Based on what we'd heard from young people, and to link with other ongoing Healthwatch work, we decided to carry out a small piece of work finding out about the support for mental wellbeing of those with long-term physical conditions.

The project was welcomed by both the provider Child Adolescent Mental Health Service (CAMHS), Clinical Commissioning Group, and the Local Authority. Bradford District is currently in the process of reviewing the whole system of emotional and mental services for children and young people.

## 2. What we did

Healthwatch worked in partnership with Barnardo's to gather the experiences of children and young people aged 11 -25 years who have long term health conditions. The purpose of the project was to gather feedback on this specific group's current views and experiences of mental health services in relation to their long term health condition, and the impact this has upon their wellbeing.

This was a short, time-limited piece of work, which involved one discussion group with 11 young people at the Healthy Minds Group in September 2015. We followed this with an online questionnaire which went out to other organisations that support young people during 28<sup>st</sup> September - 2<sup>nd</sup> October 2015. The online survey had 14 responses in total.

### 3. Summary of our findings

- Most young people Healthwatch spoke to said that they had to actively seek out information about support services for mental health. These services were not offered alongside the care of the physical condition.
- Young people feel services should not support their physical health conditions without taking into account their emotional and mental health needs and similarly not deal with their emotional and mental health needs without taking into account their physical long term health condition.
- CAMHS was a well-recognised service but there were issues of waiting times.
- School nurse and community organisations were helpful.

**During our discussion with young people we heard how long-term conditions can have a significant impact on emotional wellbeing. Over half of the young people who completed the online survey told us their health condition had affected their life quite a lot or had a massive impact on their life.**

Healthwatch asked young people: what do you think the ideal support for your physical and emotional wellbeing would look like?

The 11 young people we spoke to at the Healthy Minds Group worked in small groups to discuss what services should look like in the future. The overall feeling was the need for a mix of services which addressed the following issues:

- Making the link between physical and mental health; getting the right information
- Addressing waiting times
- Early intervention
- Environment
- Attitude and approach

**These key themes are discussed in more depth in the following section.**

## 4. Key themes

### 4.1 Making the link between physical and mental health; getting the right information.

**We asked young people; were you offered support by your doctor or at the hospital, for your emotional or mental health alongside your physical health?**

Some people in the Healthy Minds group spoke about support from the NHS; this was largely about the support they received from the school nurse and the GP. Others felt that they were given no support by the NHS and no connection was made between the physical condition and emotional wellbeing. This often resulted in difficulties and delays in getting the right support with emotional wellbeing that was relevant to their holistic needs. Some young people also felt they were not given enough information about their physical condition and support with addressing their emotions.

All 14 young people who completed the survey answered this question, 57 % told us they were offered support and 43% told us they were not given support.

Four young people told us they received information and support on services for emotional wellbeing from their GP; six young people said the Hospital Doctor and two got the information from the school nurse.

Six young people said the type of support offered included a mix of psychological therapies - mainly referral to CAMHS and medication. Only two young people said they had been referred to an NHS support group or community group.



#### Getting the right information

**Healthwatch asked young people; did you get information about support for your emotional or mental health from other sources?**

The Healthy Minds group at Barnardo's told us that they mostly received support from family and friends, particularly from their parents who had identified key organisations in the community. Others mentioned youth workers, community centres, and the school nurse. However the group felt they did not get enough support and there were not enough early intervention services available.

One young person told us they set up a small social group among other peers at the hospital who were living with the same condition. By doing this they were able to support one another and share experiences.

*“There was nothing at the hospital, so a few of us who have the same condition just supported each other”*

There was some emphasis placed on the importance and accessibility of community services which helped to meet individual needs, and collectively the group felt there was less stigma attached than hospital or school.

The online survey had 11 responses to the question about information: three people said they found information from friends and family, another 3 received information from school and college, two from a youth worker and one person referred to a national helpline.

Young people talked about wanting professionals to recognise their emotional health needs early and signpost them on to organisations who offer support with emotional health.

*“The first place I go to is the doctor about my condition, they should tell me about what’s available for my emotional health.”*

#### **4.2 Addressing waiting times**

There were mixed feelings about waiting times and referrals once a need for emotional support was identified. Some young people said they had a good experience, referrals were quick and waiting times were short.

*“We only had to wait about two weeks and I saw someone at CAMHS”*  
*Aged 11-14*

Two respondents to the online survey said waiting times for service was less than three weeks and one person said between four and six weeks. One young person said they had to wait 10 -12 weeks and another over 6 months

In the discussion group some people felt the referral route and getting the right support was not easy.

*“GPs not informing families of the services available, sometimes ‘fobbing off’ the families, delaying referrals or school nurses not following through with the referral.”* Aged 15 -19

Others on the online survey wrote about their experience:

*“Sometimes it gets too much and even when I tell my nurses nothing happens...They keep saying I can have someone professional to talk to but it never happens.”* Aged 15 - 19

### 4.3 Early interventions

The Child and Adolescent Mental Health Service “CAMHS” was a well-known and recognised service and young people in the group were familiar with the range of services on offer: talking therapy services, family therapy, art, hypnotherapy etc.



Although some positive experiences were noted where services were accessed quickly, young people talked about the difficulties in getting the right support at the right time and felt it was important to have some interventions whilst waiting for the CAMHS service. Suggestions included having someone to talk to about feelings and emotions other than mental health professionals.

Young people told us it was important to them that there were more early interventions available and that services delivered continuity in care. They talked about receiving ongoing support from one person with whom they can have a trusted relationship as they move between services.

Young people talked about targeted emotional and mental health services in schools such as TIC TACS, young people’s development workers, TAMHS (Targeted Mental Health in Schools) and WRAP (Wellness Recovery Action Planning).

*“There needed to be a bigger range of services to help address emotional needs.”*

*“Will help me discover more of myself for things I can do and what I cannot do.”*

*“More activities available for me to access.”*

*“Support you when your mental health slips...linked in with your medical condition and saying this is common and linked to the condition rather than being labelled as having mental health difficulties” Aged 20 -25*

#### 4.4 Environment

Young people told us they would like the option to attend services away from school within their local communities, this should be a place where young people feel comfortable attending.

Services should be in an environment which is private and easily accessible without young people being stigmatised, bullied or questioned about why they are accessing these services by adults and peers.

*“An open 24 hour service, so you can walk in when you need it.”*

*“I mainly used CAMHS but this was not useful.”*



#### 4.5 Attitude and approach

Some people felt staff attitudes needed to be improved and young people expressed that they didn't always feel respected, or listened to.

We heard mixed feedback on the attitude and approach of staff.

*“Some of the staff at CAMHS had a good attitude and were easy to talk to.”*

*“I didn't go again because I didn't like the person I saw.”*

*“Someone I can talk to easily and regularly who can offer advice.”*



## 5. Recommendations

### Healthwatch Recommends:

- All professionals recognise and take due account of the mental and emotional wellbeing of each young person alongside their long term condition and physical health in assessing and planning their support services.
- Offering a mix of tailored services which recognise both the physical and mental health needs of young people with long-term conditions.
- To explore ways to provide better and more accessible information about existing NHS and non-NHS services that can help support young people with emotional difficulties and their families.
- That commissioners take due account of the issues relating to waiting times, capacity and range of services needed by young people.
- Increasing continuity in care and support during waiting times. Young people have suggested advocates can support young people and help to navigate them through what can be a complicated referral system.
- Where there are long waiting times for particular services, young people and their families should be offered access to self-help or peer support to bridge the gap.
- Both the setting and the staff are important to ensure that young people feel comfortable enough to talk about their feelings. This should be taken into account when planning services.

## Appendix

### Who did we hear from?

Out of the 25 people we spoke to:

- 4 people aged 11-14
- 11 people aged 15-19,
- 3 people aged 20-25
- 7 people preferred not to say

### Postcode

We heard from people in the following postcode areas: 1 x BD1, 2 x BD2, 1 X BD3, 2 x BD6, 1 x BD7, 2 x BD8, 6 x BD9, 1 X BD10 1 x BD15, 1 x BD17, 1 X BD18, 1 X BD22 1 x LS21

### Ethnicity

- 8 White British
- 10 Pakistani
- 1 Black/African/ Caribbean/ Black British: African
- 4 Dual Heritage
- 2 preferred not to say

### Long Term Conditions

The children and young people we heard from had been diagnosed with one or more of the following conditions:

- Bardet Biedal Syndrome
- Dilated cardiomyopathy
- Arthrogyposis Multiplex
- Osteoporosis
- Thalassaemia Major
- Breathing problems/ Lung Condition/ Asthma
- Congenital Adrenal Hypoplasia
- Familial Glucocorticoid deficiency
- Selective mutism
- Inherited Muscle Disorder
- Primary Ciliary Dyskinesia
- Downs Syndrome
- Severe Learning Disability
- Autism
- Rare chromosome Disorder
- Alstrom Syndrome
- Hirschsprung's disease
- Eczema
- Diabetes
- Bowel Condition
- Stammer
- Obsessive Compulsive Disorder
- Sleep problems
- Eczema
- Epilepsy
- Spine problems