Healthwatch Cambridgeshire and Peterborough

Focus on experience: Accessing mental health support

Purpose

1. This report sets out some of the experiences received by our Healthwatch, the SUN Network and Rethink (see appendix). This and other feedback describes a number of escalating concerns relating to local mental health services for adults and children, and including the transition from child to adult services. With the arrival of the NHS Plan, a strong Healthwatch voice on the most pressing concerns and potential action needs to be formulated and delivered.

Key Issues

2. The problems around timely access to specialist adult mental health services locally have been recognised for the past three to four years. The intelligence Healthwatch receives directly, and via partner organisations, clearly shows that access to mental health services is becoming harder. This is particularly the case for people in the mid-range of risk and need.

3. The intelligence is strongest around adult mental health services and secondly around the mental health services for children and young people. Feedback mechanisms for older people with mental health conditions and their families are not so well developed and so the evidence of their experiences is not so robust but it is reasonable to assume that access to mental health services is an issue for all age groups.

4. New services have been commissioned locally and there is good working across organisations through the Crisis Care Concordat and the Suicide Prevention Programme. Positive feedback is received about the new services; he First Response Service, primary care mental health service (formerly known as PRISM) and sanctuaries. However, it is generally acknowledged these services are not able to meet demand (see sections 12 to 14.)

5. It is clear from our contact with care providers that funding and staff shortages continue to prevent core services from meeting the needs of many of those referred. In smaller services, demand pressures led last year to the temporary closure of some units such as the adolescent eating disorders ward Phoenix House. In larger services such as the Locality Teams such pressures tend to be managed by raising the thresholds for acceptance and making care time limited.

Action required by the Board

6. The Board is asked to:
   - Discuss the intelligence set out in this report and agree the next steps for action.

Authors

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Focus on experience

7. In December we published a story told to us by Amanda about her experience of trying to get help with her eating disorder[1]. Amanda was told she was not ill enough to get a service. Not getting any help had a very real negative impact on Amanda's mental health.

8. We have heard many similar stories from our partner organisations. SUN Network compile quarterly reports on people's experiences of using the primary care mental health service (formerly known as PRISM) and whilst many people are pleased with this service they get, many say they need ongoing support which is not available.

9. Rethink also report similar experiences from people caring for family with mental health needs.

10. SUN, Rethink and Healthwatch are working together to make commissioners and providers aware of these issues. Jonathan Wells has written a report for the Community Mental Health Board and our CEO is raising the issue at the East Anglia Quality Surveillance Group. Appendix 1 describes the experiences that people have told to the three organisations.

The national and local picture

11. Despite increases in funding access to mental health support across the country is increasingly acknowledged as a major issue. The Care Quality Commission reports that in the 2018 national community mental health service user survey patients

[1] http://www.healthwatchcambridgeshire.co.uk/news/eating-disorder-amanda

felt decreasing satisfaction with access to professionals and support[2]. Healthwatch England receives predominantly negative feedback on mental health from over 34,000 experiences (annual conference 2018). Experts in the field are reported as saying that the Five Year Forward View for mental health has not brought about the necessary improvements.

12. Locally the Suicide Prevention Programme is just one example of positive joint working across agencies to improve the effectiveness of services. Many such projects include good service user and carer engagement. key partner organisations meet regularly through The Crisis Care Concordat also has successfully brought together key partner agencies with service users and carers to develop new services such as the First Response Service (NHS 111 Option 2) and the sanctuaries.

13. In line with the Five Year Forward View for Mental Health, Early Intervention in Psychosis Services have been strengthened and 24 hour liaison mental health services in acute hospitals are developing. However, it is generally acknowledged that core mental health services such as community mental health/locality teams are simply not able to meet demand.

14. Primary care mental health services (formerly known as PRISM) were introduced in late 2017 with the aim of bringing professional mental health care to people in GP surgeries, engaging with people at an earlier stage and reducing referrals to specialist community mental health services (known as Locality Teams). These primary care mental health services are regularly evaluated by the SUN Network who have found that whilst people appreciate the chance to be listened to about their mental health issues they can be frustrated about the continued lack of access to actual treatment. These services are still not fully rolled out and are not expected to reduce fully the ongoing demand pressures on Locality Teams.

15. People needing help with their mental health frequently say that they are not sick enough, or too sick, to get a service. service. If they get a service, especially if it is a core service such as the Locality Teams, it is often not equipped to meet their needs. In terms of the overall mental health system, this can lead to increasing numbers of mental health crises, so that the system becomes crisis-driven rather than being based on effective and adequately resourced traditional services.

16. In children and young people's mental health services nationally, there is a target of 35% of those who need NHS funded mental health services getting them by 2020/2021. (This includes parenting groups provided via the local authorities). This target accepts that two thirds of young people will still not be in receipt of such services in April 2021. Like other areas, Cambridgeshire and Peterborough health economy is working towards this target.

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[2] https://www.cqc.org.uk/news/releases/national-survey-highlights-decline-peoples-experiences-community-mental-health

17. There is not a high volume of experience reports available to Healthwatch about children and young people's mental health services, but what we do hear tends to be negative, in the context of a fairly grim national picture.

Themes of concern

18. Looking at the intelligence received, the areas for concern group into these themes:

- Access to services
- Unclear eligibility and pathways
- Opportunities for more user involvement
- Shortages of staff and funding

Areas for discussion

19. National access standards and evidence-based guidelines are not being met for many locally. What can be done to improve compliance and aspirations for improvement, and how can the public voice be harnessed to support change?

20. Further clarity of eligibility and pathways may enable people to know what service they can expect and help those people advising them. What is an effective role for the STP, care providers and Healthwatch and partners so that people can be helped more quickly rather than bounce backward and forward as they seek support.

21. The issues reported are the same for all age groups and transitioning from children's to adult services is frequently reported as problematic. Is there an appetite to bring in more lifelong services?

22. There are models of best practice that increase appropriate service contact time. How best can we promote these in Cambridgeshire and Peterborough?

23. This paper demonstrates our strong links with local service user networks. Can our Healthwatch promote opportunities to increase service user involvement?

Appendix 1

PEOPLE'S EXPERIENCES SEEKING MENTAL HEALTH SUPPORT

Healthwatch Cambridgeshire and Peterborough

- First Response Service (FRS) told the person they use the service too much. Been through the services for the past year; assessment and report now done and told the services cannot help anymore. Primary care mental health service (PRISM) told person that they had to attempt suicide to get a secondary mental health service. Person feels no one can help as they are not low or high risk.

- Person has a binge eating disorder for around 30 years which is now impacting on her physical health as well as her mental health. She is obese with high blood pressure and at risk of diabetes. Previous overdose, seen then by a psychologist for some years, very helpful but then she was 'dropped' and felt abandoned. Regular support from GP but increasingly frustrating there is not any service for her. Not eligible for eating disorder support. Self-referral to IAPT team and was triaged on the phone. No response. Contacted MIND about a month ago and again no response. Person very aware of falling between eligibility criteria for services. Feels abandoned and not worthy, this feeds into issues of low self-esteem.

- Person rang late one evening saying suicidal due to a combination of mental, physical health issues and lack of housing and help with benefits. Rang person back next day, went through options, they have tried all of them but cannot get any support from anyone. Person feels very hopeless and mental health deteriorating.

Rethink Carer Support (Cambridgeshire and Peterborough)

- Person with depression and recurrent suicidal thoughts described how services now operate in a time limited way rather than based on need. Frightened that will suddenly be told that they have had enough chances to respond to treatment and will be offered nothing more by CPFT. Feels that if that happens suicide will be the only option.

- Person rang Rethink, partner has delusional disorder. Is on the books of the Locality Team from CPFT and an Occupational Therapist (OT) calls round about once per month. There was no contact for 4 months when the OT was away. They say they only get help when there is a crisis.

- Middle aged person with borderline personality disorder (BPD) and a history of self harm and depression. They and older parent have no access to a mental health professional to discuss the present and future issues that concern them.

- Parent concerned about adult child with BPD. They feel they are not getting treatment needed and neither of them are getting professional help from mental health services to develop skills in managing crises.

- Parent carer of an older adult with schizophrenia. Receive service from locality mental health team and has a social worker, but the care plan is very limited, and no-one knows them very well. Carer says the Consultant Psychiatrist has not seen them for several years despite his history of violence.

- A carer spoke about her adult child who is autistic with anxiety and depression. Although they had a lot of help from CAMHS they now spend most of time in bedroom; on their computer at night and sleeping in the day. A lot of tension at home and parents feel desperately in need of help in how to help child lead a more fulfilling life. No help from statutory nor voluntary sector.

- Partner phoned desperately concerned about partner who is acutely psychotic, deluded and hearing voices. Despite all efforts not been seen by a MH professional since being sectioned last year. Not able to get any help when deluded and suicidal in December 2017. Not eating and unable to work. GP appointments and police attendance has not led to any interventions nor support.

The SUN Network

- Person admitted to hospital; suicidal wanting to end life because couldn't cope and felt there was no help from substance misuse or mental health services. Needs help with housing and benefits.

- Young person with BPD had to move back with parents and is now struggling as this is not a good family environment. PRISM support available in 6 months' time, but parents cannot cope now.

- Group of people concerned about thresholds and access to services. Felt like they were being fobbed off at GP level by PRISM and that PRISM was preventing them from accessing secondary services. Medication not being reviewed by PRISM.

- Person with own mental health needs and carer for disabled partner. Struggling to get a PRISM appointment for a number of months.

- Individual suffers from their own MH challenges but is a primary carer for their adult child with BPD at a loss of where to turn to next for help. Exhausted all their options and there was nothing left. No-one is interested anymore.
- Young person given information for IAPT but was told there was an 18 month waiting list. Offered no other information, believed as he left the surgery that there was no help available anywhere for him.

- Adult survivor of childhood sexual abuse was offered IAPT but told there was an 18 month wait. Decided couldn't wait that long. Felt there was no support available. (Not advised of any other services available).

- Person rung NHS111 Option 2 and told them that she was about to kill herself, FRS said they would send someone out the next day. Did not deal with the immediate crisis.

- Person advised she cannot get DBT through the NHS, and that she wouldn't qualify for a service because she is not self-harming or suicidal daily, therefore not a high risk, lived with this condition for 20 years as diagnosed and never had any help or treatment, feels lost undervalued and no further forward.

- Person being supported by GP to give up drinking and access MH services told to give up drinking before he could access MH services

- Person told they have BPD, sent away with MIND telephone number, no further help given, or advise on what the condition is and how to get help

- Young person waiting 3 months for appointment after referral from GP to PRISM.

- Person with physical and mental health challenges, says mental health always overlooked in favour of physical health, no support with mental health.

- Person feels bounced around secondary services, either too low to hit threshold or too high but never actually able to access any. Used FRS but not heard of Sanctuary. Never heard of recovery coaches.

- Inappropriate referral to Recovery Coach person says psychiatric and therapeutic help is needed but not available.