

## Initial Engagement with Mental Health Support Groups

### Introduction

Healthwatch Newham (HWN) had received ongoing anecdotal feedback from service-users about their concerns with mental health services. In some cases it was not clear which provider delivered the service. HWN visited two groups to listen to experiences and to find out what service-users thought would help make things better.

This report provides a summary of the feedback. We have also included some recommendations for action, to help focus on the next steps, whether that is further engagement or action. We are aware that the issues may not relate to just one provider of services. We hope the report is helpful in identifying on-going concerns and ways to improve communication with and experience of services.

### About Healthwatch Newham

Healthwatch was established through the Health and Social Care Act 2012 to give service users of health and social care services a powerful voice both locally and nationally. Healthwatch Newham was established in 2013 and is part of a national network led by Healthwatch England.

We listen to people's views about Newham services, both good and bad. If there are concerns about the quality or safety of services, or there are unmet needs, we feedback patients experiences, to local commissioners and decision makers, in order to improve services. We aim to work constructively in partnership with Newham residents and organisations.

### Healthwatch Newham's Engagement

In order to create an atmosphere in which people could contribute, we asked a series of general questions about the participants' experience of mental health services. In total we received in-depth feedback from 11 service-users. We found this a useful approach as it provided in-depth consistent feedback from service-users and aligned with other anecdotal feedback we had previously received, through our on-going engagement and our NHS Advocacy Service.

### Service-user's and Staff Feedback

The following information is the feedback on various aspects of mental health services:

#### Care Co-ordinators

- Some service users knew what to expect from their care co-ordinator, found them helpful, knew how to contact them between appointments and had no particular issues or positive highlights.
- Some service-users did not know how to contact their care co-ordinator between appointments, (although one felt this was not a problem as they saw the care co-ordinator regularly).
- One service user said they had long-standing and complex needs and had received support from a care co-ordinator and the Home Treatment Team. However, whilst between services, they felt their GP was not helpful when their mental health deteriorated.

#### Carers

- Service users felt that the system did not always support both their caring responsibilities and mental health support needs.

### **Complaints**

- There was a long discussion about issues in making complaints: how vulnerable people feel, how impenetrable the system is, how people are not sure what service standard they can expect, the lack of information on mental health services, pathways and treatment options. People would like more information including, videos, apps and leaflets.
- Members did not always feel listened to when they ask for help; carers seemed especially reluctant to make a complaint.
- In terms of the complaints process, people don't know how, fear negative consequences or want to avoid the stress associated with a complaint process.

### **Pathways/signposting**

- There is a lack of information on how mental health services fit together and where patients are in the system, and a lack of information on pathways and treatment options.
- One person had been told by letter, they were losing their care co-ordinator but didn't know why.
- There is uncertainty about the process around hospital discharge. Service users don't know what to expect and seem unsure of where they stand. We understand that patients should be provided with a copy of their discharge plan which would have details of on-going mental health services, if applicable.
- One member with a complex condition received a rare home visit for an assessment, which was the only way they were able to access the service as they were homebound. More flexibility like this within the system would be very good.
- One member was referred to the Enablement team but didn't know by whom and what support they were going to receive. They felt the support did not address their long standing anxiety and panic attacks. Upon discharge, sedatives were recommended for anxiety, and this person felt this did not address the problem and service did not provide support needed.
- Staff commented that since Day Hospitals closed staff receive weekly calls from service users unaware of the closure and hoping it could be an option for them again if they had used it in the past.

### **Appointment system**

- A member was sent a routine psychiatrist's appointment which they couldn't attend. They were offered a later appointment, but were told the computer system couldn't offer anything any earlier. Eventually the psychiatrist intervened to enable an earlier appointment, but the person's mental health was aggravated by the delays and inflexibility of the system/staff.
- A member was referred to mental health services but couldn't make the sessions due ill health. Although the person explained this to staff, they subsequently received a letter discharging them from the service because of non-attendance. The staff member subsequently denied having been contacted and this has made the member reluctant to use the service in future.
- A member was discharged from a quarterly psychiatric appointment and told to contact the duty if needed. These appointments were cancelled twice within an hour of the appointment time and once seen the patient found it unhelpful to see a doctor that did not know them or their history.

### **General**

- Some mental health services are not person-centred enough, can be inflexible and unforgiving. Mental health services should recognise the impact on of mental health issues and make reasonable adjustments for this.

### What is Working Well

- Participants highlighted good support they had received from Care Co-ordinators.
- Home visits by GPs were appreciated.
- Healthwatch Newham recognises that East London Foundation Trust is pro-active in implementing and reviewing its feedback and complaints procedures. We aim to gather more feedback to help clients/patients use the services well.
- East London Foundation Trust and Newham Council have responded positively to this initial review. Whilst recognising that these have been on-going concerns, they have expressed their commitment to working together. For example, one mental health group is holding a specific forum to look at complaints and feedback in November.

### Recommendations

- Issue: Concern that service users are given insufficient information when being transferred to or discharged from services. Service-users are concerned or confused about their entitlement to services.
- ✓ Recommendation: Improved and increased information is provided, in writing and verbally and at key points during the discharge from, transfer to and delivery of services. This will help inform, remind, and reassure service-users about their health and social care services, eligibility and entitlements. This particularly applies to care-coordinators and discharge from hospital or psychiatric services.
  
- Issue: Lack of confidence in and reassurance about the complaints process.
- ✓ Recommendation: Engage with service-users on the complaints, compliments and any other feedback processes or forums to identify what is working well and how improvements can be made.
  
- Issue: there is a concern that caring responsibilities are not recognised or supported adequately, leading to an exacerbation of mental health conditions.
- ✓ Recommendation: Engage with service-users about the challenges they face and identify what additional support or access to services can be implemented.
  
- Issue: The inflexibility of the appointment system or staff results in an over-complex and difficult situation for service-users, sometimes resulting in them being unnecessarily discharged and causing stress.
- ✓ Recommendation: Review the appointment system, and ensure it can accommodate changes to scheduled appointments, without penalising the service-user, so it does not result in discharges or long waits for appointments.