healthwatch East Sussex

Healthwatch East Sussex

Navigating Mental Health Support in East Sussex: Identifying the Road Blocks

August 2015

The role of telephone support in East Sussex

Contents

1. Executive Summary

1.1. **Between April and May 2015, East Sussex Community Voice, through its Healthwatch East Sussex functions carried out a piece of work to investigate the role of telephone support for those in mental health crisis.**

1.2. The aim was to seek the views and experiences of people with mental health needs, their families, carers and supporters, on what helplines are useful at times of crisis, and people's experiences of the helplines that are available.

1.3. This report is a summary of the key findings, priority areas and actions for Healthwatch East Sussex (HWES) and local partners to consider developing.

Stakeholder feedback

1.4. Stakeholders receiving this document are requested to work with HWES to explore any issues raised in the research, and to:

- Comment on the key findings; and
- Identify potential next steps for collaborative working, and / or service change.

2. Background

In December 2013 East Sussex Community Voice (ESCV), commissioned Age UK East Sussex (AUKES) to deliver five listening events for users of mental health services in East Sussex. The listening events raised a number of concerns for people in navigating their way around the mental health care services. One aspect was getting access to accurate information or support as and when they need it.

2.1. A further concern raised in the research, was by people who need to access support in a crisis. In particular there were questions around the role and experience of telephone support provided by the Mental Healthline run by Sussex Partnership NHS Foundation Trust (SPFT).

2.2. This service is available only at evenings and weekends in East Sussex. However it is commissioned for 24 hours in West Sussex. How the different delivery models are experienced on the ground is not clear. The report made the following recommendation:

"The appropriateness of responses to mental health crises by out of hours services would bear closer monitoring, together with the general issue of the availability of services at the weekend. Only the helpline, the Samaritans or A&E appeared to be available".

2.3. This recommendation formed a key part of the rationale and design that led to this next round of evidence gathering and this report.

3. Methodology

A number of means to gain the views and experiences of people with mental health needs were used. Contact was made with Sussex Partnership NHS Foundation Trust (SPFT) to seek their assistance. Meetings were held with various members of staff within SPFT including a manager of a local Assessment and Treatment Centre; and other managers spoken with on the phone. A range of voluntary organisations were either met with or contacted including:

- Sussex Oakleaf
- Together for Mental Wellbeing
- Homeworks
- Seaview Project
- Fulfilling Lives
- The Links Project
- Friends, Families and Travellers
- Care for the Carers
- Recovery College
- Ice Project
- Action for Change

3.1. Some of these organisations work with people who are homeless, or from minority groups, such as travellers. It was felt to be important to try to seek feedback from such organisations and the people they assist, as they may experience additional problems accessing services.

3.2. Several groups of people were met with. These included; people with mental health needs in Uckfield, Hailsham, Eastbourne and Bexhill, a group of carers, and a group of people who are currently inpatients at the Department of Psychiatry in Eastbourne and Woodlands in St Leonards. A few people were met with individually. In total 70 people were met with.

3.3. A questionnaire and introductory leaflet were circulated, to seek people's views. About 700 surveys were circulated through the above mentioned organisations. A freepost envelope was given with all surveys, so that there was no cost to people completing the form, to encourage as good a response as possible. Two organisations asked for the forms by email and this was provided. 27 survey forms were returned and a couple of people provided a more detailed response.

3.4. SPFT managers who oversee the Mental Healthline were met with and they provided some data on usage for a three month period. Managers in South East Coast Ambulance Service NHS Foundation Trust (SECAmb), the organisation that manages and runs the NHS 111 service locally, were also contacted. They very usefully provided data on usage of that number, specifically for those where mental health was the key factor and reason for the call.

Due to a number of issues being raised about the Mental Healthline, a further meeting was held with the manager of

the service to provide some verbal feedback on the key issues identified and raised by people receiving the service

4. Observations and findings

As listed above, a range of groups were attended to seek the views and experiences directly from people who have used the services. Key issues raised include:

- At one group in Bexhill, attended by 25 people, a discussion was had in relation to contacting the Assessment and Treatment Centre at Hastings (Cavendish House).
- A number of people in the group raised concerns about getting through to a mental health worker by phone. Many see this as their emergency 'helpline' at a point of crisis.
- Several people stated that they had phoned the Centre and were told someone would phone them back. Often this may be at the end of the day and sometimes not until the following day.
- They felt they had to explain why they wanted to speak to a mental health worker, and then had to repeat it all to the person when they eventually got to speak to someone.
- One person stated that this means they have to wait in all day, as they are not given any indication when the worker will phone them back.
- This can be a problem for them as they suffer from anxiety, and one of their coping mechanisms is to go for a walk.
- Some described a number of staff who answer the phone as "officious". One person got the view that some staff did not want to be there and may have been redeployed into the role from a service that had closed.
- People met with in this group concluded that there are insufficient mental health workers to cope with the demand in the number of people asking for help.

4.1 Many people in one group had used the Mental Healthline. The majority stated that they would probably not use it again. They gave a number of reasons:-

- A lack of understanding from some members of staff, especially one person who some had spoken with and felt was very uncaring.
- One person stated that they had raised this with the member of staff at the Healthline, who had suggested they put the phone down and try again, as they may get someone different next time.
- All those who had phoned the Mental Healthline raised the problem of only having a set period of time, 20 minutes was mentioned. One person thought they only had 10 minutes and could not phone back until at least an hour had elapsed.
- The advice they had been given by the Mental Healthline was to use their coping mechanisms or go to A&E.
- One person had used the NHS 111 phone number. Their view was that this was quite helpful, as they were put in touch with a doctor and could have seen this person at the Irvine Unit at Bexhill Hospital. They thought this was a better option than what was

usually suggested to people out of hours, which was to go to A&E.

- Two people in this group had phoned the Samaritans. They stated that at least they listen to you and give you time.
- This group recognised the difficulties staff in SPFT, and at Cavendish House, are facing and understand that there is not enough staff, with many working very hard.

4.2 An issue for many was the lack of access to the crisis team unless you go through your GP or A&E. The latter is the only option out of hours.

- The group concluded that they were uncertain about the option of extending the Mental Healthline to 24 hours every day, unless all staff showed empathy and a degree of caring about the people they were talking to.
- They also concluded that they were not happy that the only real option at times of crisis and out of hours was to go to A&E, as they did not think this was a suitable place for them to go to receive help.

4.3 A group of inpatients were met with at both the Department of Psychiatry in Eastbourne and Woodlands Hospital at St Leonards. Key issues from these groups were:-

- At one group, only one person had used the Mental Healthline and this was about two years ago. They did not find this helpful, but could not remember the reason for this. One person in this group did not like to talk on the phone, as they would not know the person and they would not know them. All stated that they had a named worker and this would be the person they would approach if they were in crisis. They also stated that friends and family were their main source of support at such times.
- The other group were very scathing of the Mental Healthline. One person described it as “useless”. They stated that the member of staff had simply told them that their time was up and put the phone down. They also stated that the only advice they give is to go to A&E. Another person stated that they had used the Mental Healthline once but found the staff member to be “uncaring” and “didn’t seem interested”.
- One person had phoned the Samaritans who had listened to them. They said they had found the text support service from the Samaritans to be particularly useful.
- This group also stated that there can be a long wait to get through to speak to anyone at Cavendish House, Hastings.
- They also stated that there is no access to the crisis team, when they are in crisis. One person stated that their care coordinator had referred them to the crisis team, who were unable to help. They got back about two days later but the person had already been admitted to hospital due to deterioration in their mental state.

The issue here is; would the admission to hospital have been avoided if the crisis team had been able to support the person intensively through their crisis?

- When phoning the local Assessment and Treatment Centre people stated that they may be told someone will phone them back, but they could wait all day.
- One person stated that if your named care coordinator is not there, they tell you that they will put your name "in the book" and / or someone will phone you back. No estimated time of a return call is given, so you have to wait in all day. They thought there was a 'buddy system' now, so that if your care coordinator was not there one of their 'buddies' would take the call.

This could be a better option, as it means a smaller group of people will know you and the issues you have and also mean they may be in a better position to understand and help you.

- There is the problem of having to explain your situation twice; once to the receptionist and then to the mental health worker.
- Staff, when you do speak to someone, always ask you, "have you tried your coping mechanisms", and are told to "use distraction". People stated that they had tried both of these and as a last resort phoned the Mental Healthline or Assessment and Treatment Centre. They found this unhelpful.

4.4 A group of eight people receiving a service in the Uckfield area was met with. Three people stated that they had used the Mental Healthline, although others may have done so, but did not state this. The support group is accessed by many people from rural areas and so transport is an issue. The views of this group included:

- One person was very positive about the Mental Healthline. They had used it and found it very helpful.
- However, two other people said they had used it and their views were more negative. One person described it as "useless". Reasons given for it not being a good service were:
  1. The member of staff was too interested in going through their checklist to get information about the person, and so less time listening to them about why they phoned the service.
  2. They felt the fact that it is time limited (20 minutes) is not helpful.
  3. The cost of the calls was also mentioned, especially from a mobile phone.
- Some felt the Samaritans were better as they listen to you and don't have their own agenda.
- There was general agreement that access to their care coordinators was good.
- There are problems accessing services from North Wealden such as Forest Row. There used to be a drop in / support group there, but this no longer operates. As a result they are dependent on patient transport or public transport to get to Uckfield.
- For those dependent on patient transport, this is not available in the

evenings and so they cannot access the support groups that run in the evenings. There is one in Uckfield but some people cannot attend.

4.5 A group of about fifteen people in the South Wealden area were met with. They raised a list of key issues both covering the helplines, but also about access to mental health services in their area. These included:

- Five people stated that they had used the Mental Healthline. None were able to say anything positive about the service. As a result, they said they would not use the Mental Healthline again.
- One person stated that they were not happy about only having 20 minutes, and once the phone was put down on them when they were mid-sentence as their 20 minutes were up.
- Some felt the people answering the phone were not interested. They just tell you to have a bath or make a cup of tea. Some concluded that this was patronising.
- Samaritans listen to you and so this is helpful.
- Some people reported that there is an issue contacting the local mental health services. When they phone, they are told someone will phone them back, but sometimes no one does so.
- One person stated that they waited about two months for an assessment meeting and was then told they were not eligible for a service and were referred to another service. They then had to wait another two months before they were seen.
- Referrals for services have to come though the GP, and there are problems getting an appointment and so this delays accessing services.
- Some felt there were problems accessing the crisis team.
- The group stated that there is no local office in South Wealden and so they generally have to go to Eastbourne to get a service. This introduces travel problems and issues.
- One person stated that they took an overdose on Friday, went to A&E but were discharged the same day, with no support over the weekend.
- Many in the group felt that the best form of help was from their support group, as they support each other, not only in the group but outside as well. They know other people will give them time, listen and understand.

4.6 A group of about eight people were met with in Eastbourne. They raised similar issues as those from previous groups. These included:

- Some would not use the Mental Healthline, as they had used it in the past and found some of the people answering the phone to be uncaring.
- They also thought some were “patronising” as they simply tell them to “go for a walk, have a bath or shower, have a cigarette or a cup of tea”.
- They also raised the issue of the length of time available with the Mental Healthline being a maximum of 20 minutes, which they did not think was sufficient.

4.7 One person was spoken with individually.

They thought the crisis team could only support those people in hospital, to assist them to move out of hospital, i.e. acted as a discharge team rather than a crisis team. The other issue raised was that staff direct people to the Mental Healthline assuming it can offer more than just a referral to A&E. Staff may be raising peoples' expectations. This could account for some of the negative views given above of the Mental Healthline.

4.8 An employee from a voluntary organisation that works with migrant workers and asylum seekers was met with. This group has its own specific issues to address and encounter additional difficulties to access services. These include:

- Language resulting in communication being an issue. There can be problems obtaining the services of a translator.
- Often their experience of public services is at point of entry to United Kingdom and this would not be exactly welcoming. This results in people being extra reluctant to seek assistance from any official body.
- As a result, this group can take up services too late, when they are in crisis.
- They generally would not be able to access the Mental Healthline due to lack of knowledge of this service and language issues.
- Keeping appointments can be difficult, even where the voluntary organisation attempts to go with them.
- The worker stated that it was unlikely he would use the Mental Healthline, but would call an ambulance for someone if they were in crisis.

4.9 A worker for a voluntary organisation working especially with the travelling community was met with.

They explained that the people they support have similar issues as those raised above for migrants and asylum seekers. There is reluctance in the travelling community to accept mental health and so there can be denial that this is an issue. There is a great deal of stigma attached to mental health. This can result in late diagnosis and a delay in seeking assistance. Some may not have a GP and there are additional difficulties accessing services without a GP, as generally referrals to mental health services need to come through a GP. There can be a lack of understanding from mental health workers about the culture of the travelling community, which can put people off going back to the service. For example, one person being supported to attend an appointment with a mental health worker had to cancel because of a funeral in their extended family some distance away. There was a lack of understanding that attending funerals is a key element of the community, and the person had to attend and be away for several days.

4.10 Another worker with the travelling community was contacted and she made some very useful points.

The travelling community is not a homogenous group and includes British Romani / Gypsies, Roma and Irish travellers, all having distinct cultural backgrounds and needs. Someone from the Romani community with mental health needs would be described using a term that is derogatory, used to shame. These communities would only respond to face to face interventions, based on building trust. There is no cultural precedent of seeking help from an unknown person at the end of a phone. Therefore, they are very unlikely to use a phone helpline and would have difficulties accessing mainstream mental health services. Friends, Families and Travellers (FFT) used to have a health visitor who had been able to build up good and positive links with the travelling communities but the funding for this post ceased. Similarly, the funding for the mental health worker in this organisation has been reduced and so this will also have an impact on the availability of services and support for these communities.

4.11 A carers' support group was met with. All were caring and supporting someone with mental health needs, one for more than forty years. Interestingly, the worker for this organisation stated that they do not give out the Mental Healthline phone number due to the extent of the negative feedback from carers in the past. They also stated that workers have to push to get a service from SPFT. They have to persevere and often people just give up trying to get the support and help they need. Carers' views included:

- None were aware of the Mental Healthline or knew anything about it.
- One had phoned the Samaritans and found this helpful.
- They said there is a problem of access to services and have to chase workers in the statutory organisations and stress the urgency of the situation. Even then, it's a struggle.
- They are often told by workers that they cannot talk with the carer due to confidentiality. They recognised the importance of this, but also that this can prevent someone getting the help they need.
- They felt that GPs prescribe medication for mental health needs but that they are not experts and so the medication may not be helpful.
- If the person they are caring for does not have a care coordinator, then there is a major problem accessing services.
- They all felt that there is an expectation that carers will cope with little or no support. However, the carers themselves may "breakdown"

due to the stresses of caring and supporting someone with mental health needs. This will impact adversely on the person who may also deteriorate. This had occurred to two of the carers at the meeting.

4.12. A representative of a Patient Participation Group in the North Wealden area was met with. She raised some important issues related to the particular, difficulties of people living in rural areas, such as North Wealden. These included:

- There is a lack of drop in facilities, with the nearest being in Uckfield.
- Many people this person had contact with in the area have found the SPFT Mental Healthline to be a valuable resource. Some use it regularly and they get to know some of the people answering the phone, and so do not need to go over 'old ground' when they speak to the person.
- The representative said that it is important to know what the Healthline can and cannot do, and so plan your call accordingly. In this way, you get the most benefit from the service and it can be helpful. With a lack of services in rural areas, the Mental Healthline becomes more important as a source of support. Many would want the service to be extended to include 'in hours' as well as out of hours.
- However, the quality of the service from the Mental Healthline is dependent on who answers the call. Some are very good, caring and empathic. However, a couple are not, and so some people put the phone down as soon as they know whether it is one of the "uncaring" people who answers the phone. This is a major issue for many people.
- There can be delays getting a response from the Mental Healthline, especially when one of the more caring members of staff is on duty.
- There are problems getting through to the local mental health team and the duty team. There is a problem getting through to speak to someone due to the gate keeping played by receptionists. Duty teams are also "very stretched".
- There is a view that people in rural areas have an additional gate keeping process, "distance". The example given was a lack of access to the crisis team as the time to travel to North Wealden from the bases for the crisis teams in Eastbourne and Hastings, reduces the probability of the team supporting someone, because it limits their availability by taking out a worker for long periods of time, due to travel time.
- The lack of mental health services in North Wealden and the inherent travel problems of rural areas, adds to the sense of anxiety for many people and a problem of access to services.

4.13. The manager and a senior staff of the Mental Healthline were met with.

West Sussex Clinical Commissioning Groups (CCGs) commission the service but East Sussex do not. Brighton and Hove CCGs commission the service on an out of hours basis only. This has resulted in a two tier system, with West Sussex residents being able to access the Mental Healthline at any time, but Brighton and Hove and East Sussex only having access out of hours.

SPFT took the decision that they would provide a limited service to these authorities even though they are not funding it. They explained that the Mental Healthline is available to anyone, including GPs and other healthcare professionals as well as people themselves and friends and families. They do not directly refer to other agencies or support services, only to A&E or 999 if it is deemed to be an emergency.

4.14 A second meeting was held to provide a verbal feedback on the key issues raised.

At this meeting, it was confirmed that the Mental Healthline is not a crisis service and is a listening and sign posting service.

4.15 A very useful discussion was had with the manager of the Crisis Team in East Sussex.

He stated that out of hours, there is a senior nurse practitioner and an unqualified worker at each of the Hospitals in East Sussex, i.e. Conquest Hospital and Eastbourne District General Hospital. They will respond to requests to see people with mental health issues at each of the A&E units. The team receive referral from a range of healthcare professionals and these are verbal referrals. The aim is to respond to each person being referred, who is accepted as appropriate for the team, within 4 hours. They will work with an individual for a short period until either the issues have been resolved or a decision made that they need longer term support and so a referral will be made to another service, including those run by SPFT.

4.16 Some thought is being given to developing the out of hours services to include a rapid response team.

This would work similarly to the street triage service that now operates in Hastings and Eastbourne. The latter is a joint project between SPFT and the Police, whereby a mental health worker accompanies police to an emergency call when mental health issues are evident.

5. Analysis of survey forms

Approximately 700 survey forms were sent out through a range of organisations including each of the Assessment and Treatment Centres, Crisis Team, Department of Psychiatry and Woodlands and a range of voluntary organisations including Sussex Oakleaf, Together, Care for the Carers, Fulfilling Lives, Seaview Project, The Links Project, Friends, Families and Travellers, the Homeworks offices and ICE Project.

5.1 Approximately 500 survey forms were distributed to a variety of organisations, both statutory and voluntary. The latter included; Clued Up, in Crowborough, My Time, based in St Leonards, Care for the Carers and COPES. These accounted for about 130 survey forms. The rest of the forms were distributed through various CAMHS services with the majority (about 300) being through the CAMHS local offices. As stated above, some offices were very slow in starting to encourage people to complete the surveys and so it is likely that only a relatively small proportion of the 300 survey forms were actually given out to people.

5.2 Despite this, 43 survey forms were returned. It will be useful to provide an analysis of each of the questions asked, as well as any of the additional comments made.

Question 1. Please circle the part of Sussex you live in:

Lewes	Wealden	Eastbourne	Hastings	Bexhill	Rother
5	5	3	10	4	5

Although Hastings was well represented, rural areas such as Wealden and Rother also provided some responses

Question 2. If you are receiving help from Sussex Partnership Foundation Trust, how long have you been getting this support?

Less than 1 year	1-2 years	2-3 years	3-4 years	Over 4 years
10	2	1	2	8

There was a good representative mix of people in terms of time with the services. Of those who answered this question, 43% had only been receiving a service for less than one year and so were relatively new to mental health services.

Question 3. What sort of support is this, e.g. counselling, group support and meetings, inpatient in hospital, other.

The highest number of people stated that they were receiving counselling. Others mentioned support groups they were attending and Community Psychiatric Nurse (CPN) support. Some indicated that they had been, or were, inpatients. Therefore there was a broad spectrum of responses and so one source of support did not dominate.

Question 4. If you have been in crisis in the past, what help did you get to support you through the crisis and where / who was this from?

There were no patterns in terms of responses to this question, with a variety of sources of support being mentioned. These included; Together, Cavendish House, Crisis Team (4 people), Samaritans (2 people), Hospital, A&E, Health in Mind, telephone support, Homeworks (3 people), CPN. Some people mentioned friends and family as a source of support.

Question 5. And how did you gain access to this support when last in crisis e.g. via GP, A&E or Police or by calling a number you have been given or by another route?

10 people stated that they gained access to services through their GP, with 5 people stating this was through A&E and 2 people mentioned the police. Other means to access services, mentioned by only 1 person each, were; CAMHS, The Samaritans, social worker, psychiatrist, probation and 1 person said they had self-referred to services.

Question 6. Have you used any of the helplines (such as the Mental Healthline, NHS 111, the Samaritans, local office number or any other) and if so, which one and roughly at what time?

7 people said they had used the helplines and 10 stated they had not. 5 people mentioned the Samaritans, 4 people the Mental Healthline and 1 person the NHS 111. Very few people stated what time they tended to use these services but those that did, 6 mentioned night time.

Question 7. Were the phone numbers easy to find and how did you know about them?

Nearly all those who responded to this question knew about the helplines and their numbers (16 people). Many stated that they knew about them from either a voluntary organisation or through the SPFT services, such as Cavendish House. Some had the information from a leaflet about mental health services. 1 person stated, "I keep emergency numbers in my mobile and written in my diary, or keep cards in my wallet".

Question 8. How useful did you find the helpline service, giving a rating from 1-5 with 1 being poor and 5 being excellent?

Score 1	Score 2	Score 3	Score 4	Score 5
2	2	6	3	1

The same number of people gave a low score (1 and 2) as gave a high score (4 and 5). Most scored it in the middle, as average.

Question 9. If you have used a helpline, would you use it again and why?

6 people said they would use the helpline again and 5 would not. However, 2 people said they probably would use it again. Therefore more people felt they would, or probably would, use the helpline services again.

Question 10. When in crisis, what service has been the most helpful and why?

It may be helpful to list all the answers for this question;

- Together and Cavendish House.
- A&E.
- My mother.
- Together.
- GP and Cavendish.
- The Samaritans. GP during surgery hours.
- A&E.
- Crisis.

- GP or mental health team.
- Samaritans. I have emailed a few times and had excellent replies every time.
- Homework's and Social Services.
- None.
- Homeworks.
- Homeworks – they were able to bring in other agencies by identifying issues that were affecting my well-being.
- Newhaven Clinic.
- Psychotherapy – someone to talk to and an outlet.
- Samaritans had longer time available for call. Mental Healthline helpful to a degree.
- Actually, the Police. They take you to a place of safety but don't 'crowd' you or ask such ridiculous questions! They give you 'space' to recover a little.
- My GP and care worker.
- GP. It can be difficult to phone Cavendish for duty because reception staff are sometimes difficult to talk to and unhelpful.
- GP, Health in Mind, Together.
- Friends / family only.
- 'Friends, Families and Travellers' because they are the only ones there for me.
- FFT, GP and hospitals.

The voluntary organisations that people attend are seen positively. GPs are mentioned 6 times. People's own families and friends are also mentioned as the most helpful form of support and statutory agencies, such as Cavendish House, are also seen a helpful for some people.

Question 11. What is the best thing about the services you have received/are receiving to support you?

Again, it may be helpful to list the responses:

- Social interaction, meals, counselling, staff time.
- I was listened to. I was treated with respect and my wishes regarding inpatient services were respected.
- Support worker.
- Talking with people.
- Psychiatric help excellent.
- Hospital - around the clock support. Crisis (when eventually have them). Regular support.
- They're always there when you need them and they're all professionals now.

- Understanding.
- Finding the Old Chapel in Hailsham is the best thing that's happened to me.
- Knowing someone is there.
- CPN is a big help.
- Help with benefits and correspondence.
- Having and knowing that there is someone there who can make sure that I'm getting the right sort of help.
- Locality.
- Recent contact with CPN at Cavendish House helped me understand how to complete Mood Chart and gave me the support I needed. This is a very difficult question to answer from a personal point of view – my experiences in the mental health system have been very poor overall.
- When sectioned and with the care worker.
- CBT psychology has helped me most – it is excellent.
- Workshops e.g. sleep courses. The ability to pursue activities which I enjoy e.g. art therapy, craft work, singing. Also enjoy the company of others.
- FFT (Friends, Families and Travellers) because they listened and understand me.
- When I am listened to and my mental health has been understood.

A high number of people make reference to the support they receive from a range of voluntary organisations and groups, with support groups being seen as a good service. More formal support is also mentioned as a positive, such as through CPNs, social workers, and hospitals.

Despite the number of more negative comments being made in the survey, it is important to note that the vast majority of people were able to identify some positive aspects of the mental health services.

Question 12. What changes should be made to make the support services much better?

Again, a wide variety of responses were made to this question:

- Easy access to Cavendish House.
- Nothing.
- Better responses and help from duty officer. Nobody there. Say ring back. Never happens. Engaged at 9.00 a.m. presumably opening time.
- Not to have to fight to get them.
- More easily accessible local help where the staff have time to listen.

- More psychiatric staff.
- Better listening skills.
- Shorten waiting lists for other services. Make it clear to clients what support to expect from each service – and make sure services work together to make best use of resources.
- We need to be seen sooner! I have been waiting since September 2014.
- More timely call back for support when calling office – this number was the one given to call if help needed before next appointment - expected response within 6 hrs. Had to call back. Excellent when contact made with CPN.
- They should stop these cuts that are often resulting certain parts to be cancelled
- People on helplines and on reception at Cavendish House should have a little training in mental health.
- Weekend opening of centres. More media reporting and discussion to allay stigma of mental conditions and illness.
- I have been waiting two months for help, still nothing, too long a wait, need help now.
- If I had continued support from MH team after I left hospital as in an outreach nurse.

Question 13. Anything else you would like to say?

A range of comments were made:

- Generally services are good but run on a 'shoestring' through lack of Government help. Buildings a bit 'shabby' need to be able to buy cooked hot meals, especially in winter. Better cloakroom facilities and first aid / rest room.
- More funding into mental health.
- Just that it was probably very helpful that I was seen in my own house most of the time.
- Great deal of help from Recovery College. Conflicting information from GPs, Psychiatrist. Feel like a ball between two bats.
- Health in Mind completely rubbish, phone interview, totally missed the issue.
- Big improvements need to be made. All the services are overstretched and it's noticeable as a patient.
- I was in crisis at Christmas and tried to speak to someone but I had to wait until May this year before I had help. I am still in self harming but we don't have any psychiatric hours or doctors. I have Samaritans number and have phoned them. I don't want to be ill for ever.
- My situation is not typical – and it has taken time to identify the help I need. It would have made things easier if there had been a key worker there at the beginning to liaise with client / agencies.
- We need to be more aware of what is available such as Recovery College, and fitness stuff that is available so we can help ourselves.

- I appreciate the services are overstretched. If the Trust provided more community mental health nurses the situation would be better and it would be easier to access services when in crisis.

One person sent in a detailed letter outlining the services she and her family had received. This person raised a number of issues. They stated that they received very little written information following the initial assessment. They had been told to complete a mood chart but a template had not been provided. When this was raised with the mental health worker, they were told to download a form from the internet. The care plan took three weeks to arrive. When they called the duty worker they were told someone would phone them back. After six hours, no one had phoned, so they phoned the office again. The service once they had spoken with the duty worker was “excellent”.

This family also raised some issues about their daughter’s care after she had taken a second overdose. Whilst she received excellent care in the Intensive Therapy Unit (ITU), she discharged herself on Friday afternoon and there was no follow up support over the weekend, despite the overdose being a very serious one resulting in an admission to ITU. Only after the GP made a referral did the Crisis Team get involved. They describe the three day service from the Crisis Team as “woefully inadequate”. The key issues they raised are that none of the Crisis Team attempted to work with her on her depression, but concentrated on the suicide risk assessment. They waited nine months before CBT counselling was offered.

6. Data from NHS 111 and SPFT Mental Healthline

Some data was obtained from SPFT regarding the numbers of calls to the Mental Healthline and from NHS 111, on the number of calls taken using strict criteria of mental health needs.

6.1 NHS 111 provided information on the number of calls received in February 2015 which were assessed as being for mental health needs. A distinction was made between 'in hours', defined as 8am until 6.30pm from Monday to Friday, as this is the timeframe defined by NHS 111 to record and collate information. The data is not collated according to local authority boundary but are recorded for all of Sussex, i.e. including East Sussex, Brighton and Hove and West Sussex.

	In hours	Out of hours
From patients	18	101
From relatives	2	32
Other (e.g. care home)	2	14
Total	21	147

6.2 SPFT provided information on the number of callers to the Mental Healthline for the three months of December 2014, January and February 2015. The data is not collated according to the time of the call and so it was not possible to assess how many of the calls were received 'in hours' and how many 'out of hours'. However, as Brighton and Hove and East Sussex only have access to the service during out of hours and so it is assumed that all the calls received from these local authorities were out of hours.

6.3 A large number of calls were recorded as not known which area they were from. These have been ignored. Some of these may have been in relation to people living out of the area and may have been split across all three local authorities.

6.4 Anyone can call the Mental Healthline including people wanting to seek advice about mental health and not just people or their friends and relatives, who may be phoning on someone's behalf.

Local authority	December 2014	January 2015	February 2015
West Sussex	1518	1276	1137
Brighton and Hove	275	257	249

East Sussex	433	474	492
From service user, East Sussex County Council	373 (86%)	413 (87%)	434 (88%)

6.5 The data from NHS 111 shows that, using a narrow definition of mental health, few calls were made to NHS 111. However, the data illustrates that the vast majority of calls are out of hours (87.5%). Also 71% of the calls were made by the patient themselves. Therefore, these figures indicate that the main time that people need to call NHS 111 is out of hours and so this is the crisis time for them. The vast majority of calls are from people themselves rather than others calling on their behalf.

6.6 East Sussex and West Sussex have a variance in the size of population (about 250,000, with East Sussex the lesser). Even allowing for this difference in population, the number of calls to the Mental Healthline from West Sussex is substantially more than from East Sussex. The total calls for the period December 2014 until February 2015 from just West and East Sussex are 5330. 3931 were from West Sussex, which is 74% of the calls. The implication is that people living in West Sussex make calls to the Mental Healthline 'in hours' and this would account for the huge difference in calls from the two local authority areas.

6.7 More people themselves made calls to the Mental Healthline than to NHS 111. The lack of calls to NHS 111 during the day could be due to people calling local mental health teams, Assessment and Treatment Centres and gaining support from local groups and activities. This would seem to contradict the above statistics when comparing the West Sussex and East Sussex number of calls to the Mental Healthline, where the implication is that people in West Sussex use the Mental Healthline during the day.

6.8 East Sussex County Council's commissioner of mental health services was contacted to ascertain whether a contract or agreement is in place for the Mental Healthline. He confirmed that East Sussex does not commission this service and so there is no contract in place. This means that East Sussex has no formal control over the service or any mechanism to review the quality of the service provision.

7. Conclusions

From the data provided by SPFT Mental Healthline, there is some evidence that people in East Sussex would use the Mental Healthline service if it were available throughout the day, rather than being restricted to out of hours only.

7.1 From the responses provided by people receiving a service, although many of those met with held negative views of the service, the responses from the surveys were more positive. For example more people said they would, or probably would, use the helpline again. The question on giving a rating for the helplines was also a balanced one, with 6 giving it a score of 3 which was average, with 4 people giving it a higher score and 4 a lower score.

7.2 There are some key themes arising from this project, see below, and section 7.12 gives the overall conclusion.

7.3 Mental Healthline

Some people said they would not use the Mental Healthline due to past experiences. One of the reasons given by a variety of people, from different settings and groups, was because there are some staff at the Mental Healthline who they say are not caring. One particular person was mentioned. It is concerning that a person phoning the service was told that they could put the phone down and ring again, as they might get a different person, when they challenged the lack of care being shown by the worker.

Many people said that they felt that the worker was not listening to them, but had their own agenda and checklist which they had to go through. Whilst accepting that no checklist exists, some staff on the Mental Healthline may have a regular routine of how to answer the calls and may have a checklist, if only in their head, that they run through.

Some people stated that some staff at the Mental Healthline gave little warning when the 20 minutes were up. Two people, from separate groups, said the member of staff had put the phone down even though they were still talking to them.

Having said this, some people spoke very positively of the service and felt it met their needs. They tended to be people who knew what it could offer and used it accordingly. Some also spoke positively about some of the workers on the Mental Healthline, saying they were very caring and very good.

A few people mentioned the cost of the calls especially from a mobile phone and said this was a factor in not using it.

In rural areas, there was a more positive view of the Mental Healthline and people saw this as a vital part of their support system. This was related to a seemingly lack of support services and facilities in rural areas, primarily North Wealden and North Rother.

7.4 Raised expectations of the Mental Healthline

The details of the Mental Healthline are given out by the offices of SPFT, including on the letters that go out to all clients, and also given out by some voluntary organisations. The answer phone messages for the office also include the telephone details of the Mental Healthline. The answer phone messages for three offices were checked. Health in Mind and Cavendish House, Hastings, referred the caller to the Mental Healthline for all out of hours calls. The answer phone for St Mary's House, Eastbourne stated that if you "need urgent help" then you should call the Mental Healthline. The notices advertising the service do not state clearly that it is a listening and sign posting service, and not a counselling service or that it is time limited, i.e. to 20 minutes. The SPFT website, on its home page, had a button marked 'help in a crisis'. This leads to a page which states that out of hours, the person needs to phone the Mental Healthline. This states that the number will be on the person's 'Crisis Card'.

The implication of this is that, out of hours, your first call should be the Mental Healthline. Most people phoning the office of an Assessment and Treatment Centre out of hours, will be seeking urgent assistance and so they expect the phone number they are given to provide such a service. They will then be let down when the Mental Healthline does not meet this identified need. This will increase the likelihood of the person not using the service again and result in them having a very negative view of the service.

7.5 Issues with Assessment and Treatment Centres

Some people said there are difficulties getting through to the duty person at the Assessment and Treatment Centres. They felt that they had to explain to the person answering the phone, all their details before they could be considered to get a call back from the duty member of staff. Many people said they had been told to wait and someone would phone them back, but often they did not or else it may have been at the very end of the day. This meant they had no choice but to stay at home all day. As one person said, one of her coping strategies is to go for a walk, and so having to stay in all day waiting for a call back will not help. Also, if the reason you are phoning the Assessment and Treatment Centre is due to high levels of anxiety, being told someone will phone you back, but giving no idea when, will not reduce the levels of anxiety.

Similar to some issues raised about the Mental Healthline, some people thought those answering the phone were not very empathic or caring as they did not listen to what they had to say.

Some people stated that there were major delays in receiving a service including waiting for an initial assessment. The problems gaining support from the local Assessment and Treatment Centres, adds weight to the argument that people in East Sussex should have full access to the Mental Healthline.

7.6 Some staff are patronising

This was in reference to both some staff in the Mental Healthline and some at the Assessment and Treatment Centres. For some people, being asked "have you tried your coping strategies" and suggestions like "have a bath or shower, have a cup of tea, go for a walk or have a cigarette", were not seen as helpful. As one person stated, I will only phone the Mental Healthline after I have tried my coping strategies and they haven't worked.

7.7 Samaritans and NHS 111

A few people had used these services and made favourable comments about them. Many people said that the Samaritans listen to them and can give them time. One person found their text service very good as this enables them to have text conversation whilst they were with their family, who they did not want to hear their conversation. One person thought NHS 111 was useful as it put them in touch with the out of hours GP service and through them could access the mental health services.

7.8 Crisis Team

Some said they had struggled to get access to the crisis team and that the gate keeping level is very high in order to get a service from this team. Whilst both the crisis team manager and the manager of the Mental Healthline stated that the latter could refer to the former, it was not clear what criteria are used for such a referral. The impression gained is that nearly always anyone who needs urgent help will be advised to go to A&E, rather than make a referral to the crisis team directly.

One issue is that many people expressed concern that if they needed urgent help the only option seems to be to go to A&E. All those who discussed this agreed that A&E is not the most appropriate place for people with mental health needs. The street triage service is working well. The idea of a similar scheme and service, such as a rapid response team, would meet many people's needs and be a more appropriate response to people in crisis than giving out the number of the Mental Healthline.

7.9 Issues for specific groups such as migrants and travellers, and people who may be homeless

The report highlights the specific issues and difficulties accessing mental health services for these groups. Whilst funding for Fulfilling Lives seems to be secured for the time being, the funding of mental health workers in some other organisations that work with these groups is either in danger or has been reduced. This will have an impact on the level of services for these groups of people with mental health needs.

7.10 A recognition of how stretched the mental health services are

Many of those people who were met with or responded to the surveys, recognised the difficult circumstances in which mental health services had to work, and many people used the word “overstretched” to describe the services. Many people recognised that once they had gained access to services, the members of staff who worked with them were generally good and some saying they were excellent and very good.

7.11 Access to services

Linked with the above is the issue of access to services. For many people they felt that they had to fight to get a service. One person said you need to be really bad to get support. There is also an issue of the waiting time for an appointment, which many thought was too long.

7.12 Overall conclusion

The main issues identified are; how are people supported at times of crisis, and are services available, at all times, to provide effective support?

There is evidence from people receiving a service that there are major gaps in service.

The conclusion is that people can find it difficult to access services during the day from local Assessment and Treatment Centres, being told that someone will phone them back, however this may not always happen the same day.

Out of hours, people are told to contact the Mental Healthline, although this is not a crisis led service, but primarily a listening and sign posting service.

It can be difficult to access the Crisis Team and so the only effective alternative is to go to A&E. The vast majority of people stated that they did not see this as the appropriate place to go at times of mental health crisis.

As a result, there is a gap in provision, to ensure good and effective support is available, at a place that meets people's needs at times of crisis.

8. Recommendations

Many of the issues identified by people receiving a service, carers and workers in voluntary organisations could be resolved by additional funding; however this may not be realistic in the current economic climate. It is felt the recommendations made in this report (see below), have little or no financial implications and so are achievable and realistic.

1. The issue of the concerns raised about one particular person at the Mental Healthline needs to be investigated. This could include the use of 'mystery shopping' and the introduction of a quality assurance / auditing system, carried out on a regular basis to assess the quality of the work being carried out.
2. Where necessary disciplinary and / or competency procedures need to be instigated.
3. Regular refresher training needs to be provided for all staff on the Mental Healthline, such as the training to be completed by staff specifically for people on telephone support systems. This needs to concentrate on listening, communication skills and use of empathy.
4. Consideration needs to be given as to how the Mental Healthline is advertised, to ensure people know what the service can do, and more importantly what it cannot do. This needs to be linked with working with local offices and voluntary organisations, so that any answer phone messages referring to the Mental Healthline provide a realistic outline of what it can offer.
5. Consideration needs to be given as to how local SPFT offices respond to urgent phone calls. This could include giving an estimated time when the duty person would phone them back. Ways of minimising the person having to explain the same issues twice also need to be explored.
6. Those answering the phones at Assessment and Treatment Centres would benefit from the specific training mentioned above for staff on the Mental Healthline.
7. Consideration needs to be given as to when staff refer to coping mechanisms and the advice to "have a bath, shower" etc. In order to avoid any sense of being patronising.
8. Consideration could be given to clearer and more transparent criteria for access to the Crisis Team.
9. The idea of a Rapid Response Team, or something similar, would go some way to resolving the issue raised by many people, that the only option out of hours to get urgent support and help is to go to A&E, which many felt to be inappropriate place. Linked with this is the need, if A&E is to be the place to seek urgent help, then better facilities should be identified and made available at A&E for people with mental health needs who are in crisis.

10. The support provided to specialist services and organisations for such minority groups as migrants, travellers and homeless people, needs to be explored to ensure they are funded and enabled to continue to operate.

11. East Sussex Health and Care commissioners need to investigate the advantages to extending the Mental Healthline, or investigate how services can be commissioned to provide effective response to people in crisis during the day.

12. The availability of patient transport in the evenings needs to be explored to ensure people can access support groups at such times, where necessary.

13. Agencies need to investigate how they can provide effective support to carers.

9. Response from Sussex Partnership NHS Foundation Trust

Sussex Partnership NHS Foundation Trust wishes to thanks all those concerned in compiling the comprehensive Healthwatch East Sussex report on the mental health telephone support line.

9.1 As a Trust we welcome this report, its content and recommendations. The report provides an opportunity for an open and positive conversation about a service that has obvious value across the range of services and communities in East Sussex. As a Trust we are keen to engage in these conversations and support improvements.

9.2. The report was extensive and detailed. It contains many themes and recommendations that are constructive and meaningful. The Trust has noted the key themes and recommendations and is actively responding to the particular operational issues highlighted. The Trust recognises the overall themes relating to communication, training, access, promotion, expectation, pathways and purpose. As a result the Trust has decided to launch a project to review the function and operation of the mental health telephone support line. The Trust will liaise with and include Healthwatch East Sussex in the review and will ensure that the outcomes of the review are shared. The review will provide a real opportunity to consider the support line in conjunction with other similar initiatives and services such as the NHS 111 Helpline.

9.3. Once again we thank Healthwatch East Sussex for the in-depth report and we look forward to future collaboration.

10. Disclaimer

Please note that this report relates to findings observed on the specific dates set out in the report. Our report is not a representative portrayal of the experiences of all service users and staff, only n account of what was observed and contributed at the time.

Contact us

Address:

(Freepost)
RTER-HZEA-YGKU
Healthwatch East Sussex
85b Ashford Road
Eastbourne
East Sussex
BN21 3TE

Phone number: 0333 101 4007

Email: enquiries@healthwatcheastsussex.co.uk

Website: www.healthwatcheastsussex.co.uk

We confirm that we are using the Healthwatch Trademark (which covers the logo and Healthwatch brand) when undertaking work on our statutory activities as covered by the licence agreement.

If you require this report in an alternative format please contact us at the address above.

Healthwatch East Sussex is delivered by

East Sussex Community Voice Community Interest Company