healthwatch
Gloucestershire

Experience of Mental Health Services in Gloucestershire:
A carers perspective

Local health and social care shaped by you

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Introduction

Healthwatch Gloucestershire is the county's independent health and care champion. It exists to ensure that people are at the heart of care. A dedicated team of staff and volunteers listen to what people like about local health services, and what could be improved. These views are then shared with the decision-making organisations, so together a real difference can be made. This report is an example of how views are shared.

Healthwatch Gloucestershire has been talking to local unpaid carers about their experiences and views of mental health services in Gloucestershire. This report tells you what they said when we spoke to them about their experiences.

Background

Mental Health services are still a priority for members of the public, support groups and organisations across Gloucestershire. Feedback from the voluntary and community sector, service users and carers of people experiencing mental health illness, continue to highlight the challenges and concerns that people have when trying to access health and care services in the county.

In 2019, Healthwatch Gloucestershire gathered a wide variety of feedback on many aspects of mental health services from people across the county. We identified people who were caring for those who had a mental health illness and who wanted their voice heard. Carers spoke to us about what mattered most to them regarding mental health support for the person they care for. The aim of this report is to highlight their feedback and concerns. The information gathered will be shared with those who pay and provide mental health services. It will help them to shape mental health services and support for carers in the future.

What we did

We created a survey that was available online and in hard copy. This asked for the views and experiences of local people who cared for those who had used mental health services within the last three years.

We attended support groups for carers across the county, to speak to them about their views and experiences. We also attended 30 engagement events and groups, such as mental health carers groups across the county, Mens Sheds and parenting groups. We provided the groups with information about the project and spoke to people about their experiences. We engaged with over 60 carers and visited groups in each district of the county.

Our information leaflet

Five volunteers supported our engagement events and helped to analyse the feedback. Altogether they provided 40 hours of support.

We also:

- contacted 50 voluntary, community and online groups to share the questionnaire and to encourage their members to give feedback, and
- had a continuous presence through website and social media feeds.

Our social media posts

Who we spoke to

Online survey

76 local people who identified themselves as unpaid carers filled in the online survey.

Figures 1. and 2. show the age range and geographical spread of people who took part in the survey.

Figure 1. Age of respondents

Figure 2. Where respondents live

People who we spoke to had experience of many different mental health issues or illnesses with those they cared for; examples are shown in Figure 3. (word clouds show how often a word was mentioned, the bigger the word the more people spoke about it). People had also accessed support from many organisations for the person they cared for, and for themselves, with support through the NHS and those in the voluntary and community services.

Figure 4. shows some of the key support services that people accessed. 86% of people who filled in the online survey had spoken to someone about the mental health issues of the person that was being supported in the last year.

Figure 3. Mental health issues

Figure 4. Key support services

A carers perspective

Focus groups

We spoke to over 60 carers in groups in all districts across the county. The carers all cared for, or had cared for, someone who lived with a mental health illness or issue. All carers in the groups we visited (who were still in their caring role), had spoken to a health or social care professional about their cared for person in the 12 months prior to our visit.
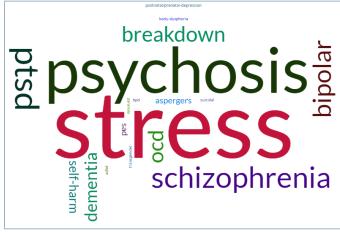
Key messages

Some people were able to access information about services and support easily, however some people struggled to know where to go to get this information. Carers especially felt that accessing professional support or advice for themselves was hard.

People felt the information they accessed could sometimes be conflicting and difficult to understand. Information often came from various sources and wasn't necessarily focussed on carer support. In particular there was little support relating to mental health carers.

Carers felt frustrated that there are barriers to communication, with health and social care professionals not understanding what they are able to discuss about a service user with the carer.

Carers felt they did not have enough support for themselves, short-term or long-term, and struggled to maintain their own health and wellbeing.

Carers felt that if they are there to support the service user, it may mean there are not as many professional support services available to the person they care for.

What people told us

Access to services

We asked carers to talk to us about the mental health care their cared-for person received. We asked about the length of time it took for them to access services, what they liked about the services and what could be improved.

Q. How long did it take the person you care for to access professional support for their mental health issue?

The majority of people from the online survey (42%) had waited for more than six months to access support. 21% waited for 3-6 months for support and 14% between 1-2 months. The remainder of people were seen between 1-4 weeks (15%) and 7% were seen in less than a week. A common theme from the feedback was that it often took for crisis point to be reached before help was offered. Carers also felt there was a difference in waiting times for services to be accessed, which could have a negative impact on the mental health or the person they cared for.

"It seemed difficult to get a consensus on who should take care coordination responsibility."

"It was only when things got really bad that we got a small bit of help, but I wish we could have help earlier on as it would have saved lots of heartache."

"Over the years he has tried to get help, but it takes so long for appointments, and he never seems to see the same person twice, and as his illness makes life incredibly hard, he loses heart before he is able to access any long term support. He has been dismissed as not engaging, but surely that is part of his mental illness and services need to find a way to engage with people suffering in the way he is."

"This person committed suicide as a result of not getting the help they needed; at the time of their suicide their case still hadn't been assessed."

What carers liked about mental health services

Q. When you last spoke to someone about mental health of the person you cared for, were you generally happy with the service you received?

Carers reported that the services that worked particularly well, were those who supported the carers or family members as well as the service user.

GPs were seen as being understanding and supportive, but people realised there was only so much they could do in terms of further help. Carers felt that the GP was often the person who linked themselves and the person they cared for and were able to understand their needs because of this. The GP was also the person who they saw most regularly. Mental health nurse specialists were thought to be positive additions to GP surgeries, allowing people to talk to a professional with specialist skills.

People told us the service was better when they were able to speak to the same member of staff each time, as this helped build trust and rapport, and meant they did not have to repeat themselves. The carers felt this supported them more, because the professional knew their situation and could offer more person-centred support.

> "We have regular Community Psychiatric Nurse support and a support worker, due to the medication which has to be carefully monitored. They are very good and helpful."

Carers also felt the Community Mental Health teams were supportive and offered them a good service.

Psychiatrists were important sources for people, and the majority of respondents were happy or partly happy with the service they received.

Carers felt that informal support was important to them and their wellbeing. Specific support groups and "cafes" found in the community were seen as an important resource. Receiving support in the community was important to people, who felt that this would encourage peer support. It was important these groups were free to access and spread across the whole county.

What carers felt could be improved

Many of the comments from carers referred to their carer role, and the extent to which they were involved in the treatment of those they cared for. Many felt they were not listened to or included in the treatment plans. This was especially difficult when those they were caring for were very unwell. Some carers felt that a lack of good support services, meant that all responsibility was left to them, which often put strains on the relationship.

Carers also spoke about how within the peer support groups, professional mental health support or signposting support would be important to them. Carers discussed how having clear information that was presented in different formats (e.g. online, face-to-face, hard copy) was important for them to know what support they can access for themselves.

Carers spoke about how 'non-engagement' by a service user (e.g. missing a phone assessment or face-to-face appointment) should not be used as a reason to discharge the service user from mental health services, and carers should be more involved when discharge may be imminent. They noted the service user will often not be able to access services due to their mental health condition at the time (e.g. anxiety around phone calls).

They felt that more thought needs to be given on how to engage people with mental illness to ensure they get the support they need. This includes more flexibility for service users around access to appointments (e.g. allowing part of sessions to go ahead if late for appointments). Some carers felt there are too many barriers faced by themselves and the service users.

Some people felt that mental health symptoms were sometimes missed due to a lack of specialist knowledge of GP's.

Carers talked about how they all had experienced mental health issues because of the pressures of their caring role. The support for them personally was limited, and as a result, the majority of people in the groups we spoke to had become acutely unwell with mental illness themselves. They faced long waits for support and counselling, and these tended to be short-term fixes and not long-term support. The long waits for support for the service user contributed to them feeling unwell, and most carers stated the wait for treatment for their cared for person were long and unmanageable.

> "The focus once our son was sectioned seemed to be entirely on him, rather than attending also to the network of family and friends who loved and cared about him. An assessment undertaken solely by professionals who do not know the patient, drawing on information given - inevitably unreliably - by the sectioned patient himself, seems to be both limited and highly inappropriate."

Urgent mental health support

In the survey and at the groups, we asked carers for the feedback on urgent mental health support. The questions focused on who to contact in an emergency, experiences of discharge and follow-up, what was good about the service and what could be improved.

44 people who completed the survey had to contact urgent mental health support for their cared for person. 76% of these carers did know who to contact and had contacted the Crisis Team, GP, called 999 or had accessed the Emergency Department.

24% of people did not know who to contact for urgent support. Calling 999 and attending Emergency were seen as the only option for some carers to access support.

Several carers in the focus groups had accessed urgent support for the service user. Those that hadn't, all stated they knew who to contact if necessary. They all talked about their experiences with contacting GPs, the Crisis Team and calling 999. Some discussed how at the time of the crisis, they had contacted peers from the carers groups for support.

> "This is all very saddening when you care for someone who doesn't want to live, and no assistance is available, and every attempt to gain help is like hitting a brick wall."

Q. What was good about the service?

> "The police handled the case with respect and consideration for the nightmare we found ourselves in"

Again, person centred care, with understanding and caring staff, had the biggest impact on both service user and carer. These professionals included the carers in care plans and shared information with them.

Several people talked about having quick access to urgent care as being important for the wellbeing of the service user. A carer being able to walk into the safe surroundings of a local Emergency Department with the service user, was seen as positive to access professional support in a crisis.

Q. What could be improved?

In the groups, the carers talked about feeling frustrated by professionals not being able to share information about their cared for person, especially when they were inpatients after urgent support. They felt this created barriers to being able to communicate their thoughts about their loved ones care, when they were the experts on that individual.

Carers felt that their need to access urgent support could have been avoided with earlier interventions. The biggest concern mentioned was the carers often felt they were left on their own, not knowing what to do.

Carers often felt helpless when their loved one was having suicidal thoughts or was at risk of harm. They spoke about not knowing where to turn and that information about support was inaccurate or out of date. This led to them calling several agencies or organisations who could not help them.

Carers in the groups talked about having more support available to them after their cared for person had been sectioned and was an inpatient. It was discussed that it is a particularly traumatic time for carers, who will often have had to make the call to request urgent help. It was felt by the carers that they are left with little information or support, especially the first time it happens.

> "The after care is where it all falls down - it just isn't there and a lack of communication is most definitely a worry. And again, just setting people up to fail and undoing all the good work the hospitals do."

Q. Do you feel that the person you care for and yourself received enough support and information after discharge?

> "After discharge you are left to dangle a bit. The medication and care plan are in place but as a carer you then have the responsibility to enact the plan and to manage the medication and to take over from a hospital full of experts. Especially when the person you care for is not mentally healed but just medicated to maintain a functioning level of life."

For some people, patients were discharged without seeing a mental health professional or having treatment. Alongside this, were concerns from the carers about not being involved in their loved one's assessment process or care plans when they were being discharged from urgent care.

Carers in the groups told us that sometimes they were left without information about the person they cared for, and sometimes weren't even aware they had been discharged.

Carers also felt that if they are there to support the service user, it may mean there are less professional services or support available to the person they care for, because they are viewed as being safe.

Support for the carers role

We spoke to carers about their own support networks, what support services they accessed, how they found out about them, what they found helpful and what other support they would like to see in Gloucestershire.

Many of the carers (60%) who completed the online survey had not accessed support for themselves. Those that had, had accessed carer support organisations, their GP, community groups or private counsellors. Carers in the groups that we spoke to, all accessed their community groups as regularly as they could. They also talked about accessing support from the church, voluntary and community sector organisations and had support through friends.

Q. What support have you found helpful?

Carers mentioned the value of having training sessions on different aspects of caring. Often they felt like they were in a role that they had no guidance on, and if they were in paid employment, they would have had formal training on some of the issues they may face day-to-day.

> "One lead nurse within the hospital team at second admission was outstanding in her ability to work collaboratively with us."

The peer-to-peer support groups were valued and seen as places that supported carers in a safe space, where they could seek advice from others and be able to talk openly about their issues. The locations of these, usually closer to home or in their own districts, were also seen as a positive, rather than carers having to travel to Cheltenham or Gloucester. However, in more rural areas, carers felt they do not get enough support locally to them and noted transport as a barrier to getting to support.

Q. What other support would you like to see?

Carers felt support that would improve their wellbeing and lives included increased respite time from their caring role, and a better understanding from health and social care professionals about their roles. Some carers talked about their feelings of their role being taken for granted, and care and support not being given to their cared-for person, because of this.

Carers in the groups talked of their concerns about the future, and having professionals consider this when treating or planning care for service users. A large number of the carers were older and concerned about what would happen when they were no longer able to care, or died.

In the groups, carers of people with mental health illness felt there is less understanding of the individual issues they can face in their caring role. Their own mental health and wellbeing were also issues they talked about as a barrier to their caring role, and this was also something that was not discussed when talking to health care professionals. They felt their roles should be seen as a vital part of a service users recovery and treatment as they are experts, living with patients every day.

Some carers would like a greater understanding from employers about their caring roles. They would also like to receive accurate information and signposting for themselves and their cared-for person.

Carers valued the liaison between carers support organisations and the statutory mental health service, and were keen to see this liaison remain and strengthen.

They spoke about the professional support and signposting being important within the support groups, and how in the past this had a positive impact on their wellbeing and ability to receive accurate information.

> "As carers we do not get enough information about the illness, what to expect and how to cope with it, as well as practical financial advice. When we had a support worker here for the group they used to answer these sorts of questions and always got back to you."

Considerations

- Carers spoke to us about how frustrated they were at the lack of professional support they have in their peer support groups. They struggle to know where to turn and to access correct information. Healthwatch Gloucestershire would suggest that more support is offered to these groups and there is clear and consistent signposting to accurate information.

> "We are intelligent and articulate people and yet we are treated like this and have no thanks for what we do."

- Carers talked about often not being able to access information and advice from the correct place at the correct time. There is a suggestion from the carers that noticeboards in all GP surgeries and pharmacies would be good places for sources of information.

- Carers talked about their frustrations with professionals not being able to share information with them about the service user due to confidentiality rules and consent required from the cared-for person. They understood the constraints on professionals, but feel there is a lack of understanding from carers and professionals about what information can be shared and when. Healthwatch Gloucestershire suggests the training for professionals across statutory and voluntary and community sector services is reviewed to ensure that professionals understand what they can say, and carers understand what they are able to hear.

- Carers are unsure about how carers' assessments can help, and the impact this will have on them. Healthwatch Gloucestershire suggests that the information on these assessments is reviewed and shared with carers.

Next steps

We know it is important that people know what has happened as a result of them sharing their experiences with us. We are already working with commissioners to respond to the issues raised in this report. We will be sharing this report with key partners and will be presenting our findings at the Gloucestershire Health & Wellbeing Board and Mental Health Partnership Board.

This report will be published on our website and be sent to Healthwatch England. We will also follow up on the suggestions in April 2020.

There is a large amount of information and data that has been provided to us through the survey. This anonymised data will be shared with NHS Gloucestershire Clinical Commissioning Group so they can use the views of local people who spoke to us to inform the development of mental health services in Gloucestershire.

Stakeholder's response

This report has been shared with the Gloucestershire Health and Care NHS Foundation Trust. A response was received in an email dated 22 December 2019 from John Trevains, Director of Nursing, Therapies & Quality:

NHS
Gloucestershire Health and Care
NHS Foundation Trust

"Thank you for sharing Healthwatch Gloucestershire's latest report regarding the results of the recent survey about Carers Perspectives on their Experience of Mental Health Services in Gloucestershire.

"Supporting carers and improving their experience is quite rightly established as a very important element of providing mental health services within an effective health and social care system.

"We understand and value the huge role carers have to play in supporting the people who use our services and how important this is in promoting recovery and maintaining wellbeing. This often comes at a personal cost to carers, who also need our full support.

"Our Trust merged with Gloucestershire Care Services on the 1st October 2019. Our new organisation, Gloucestershire Health and Care NHS Foundation Trust, is striving to build on the efforts made by both former Trusts to develop this important area of practice.

"The survey responses and report will be shared with our Trust colleagues and will also help to inform our refreshed plans to develop our new Trust's combined approach for improving carers well-being and support. Thank you very much for providing us with the opportunity to comment on this helpful report and we look forward to updating Healthwatch on positive developments in 2020."

Thank you

Healthwatch Gloucestershire would like to thank everyone who took the time to contribute their views and experience through the engagement activities. Thanks also to our dedicated volunteers who helped to support the engagement activity. Without them we would not have been able to reach the numbers of people that we did.

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Why not get involved?

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