## Generic Mental Health Advocacy



## **Consultation November 2017**

Report January 2018









Sheffield Advocacy Hub is provided by Citizens Advice Sheffield in partnership with Cloverleaf Advocacy, Disability Sheffield and VoiceAbility

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## **Summary**

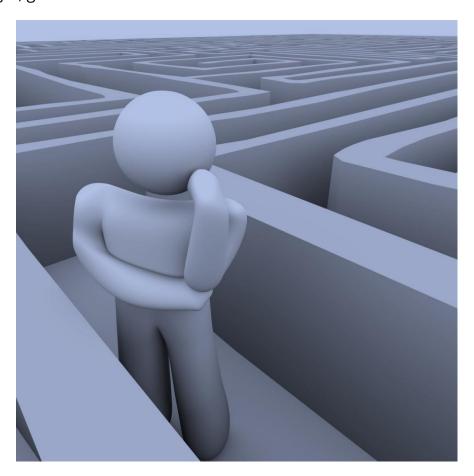
Our mental health advocacy service needs change. We have too many people waiting too long to get the support of an advocate. We need to provide support more quickly to meet your needs. We need to make sure how we share our time is done fairly, as there isn't enough to go round.

We asked you what we thought of our plan, and some people got in touch to tell us and to discuss with us how we could improve it.

We've looked again, and have now decided what we will do.

Our new plan will begin in January 2018 and be fully in place by 1<sup>st</sup> April 2018. We'll need you to tell us how you think its working.

We'll also need you to get involved in our new advocacy groups – so don't be a stranger, get in touch and ask us about this.



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## The background

Sheffield Mental Health Advocacy Service was set up in 2002, as part of what was then the Sheffield Mental Health CAB. The service has continued since that time on much the same basis. It is now part of Sheffield Advocacy Hub, which is a partnership led by Citizens Advice Sheffield.

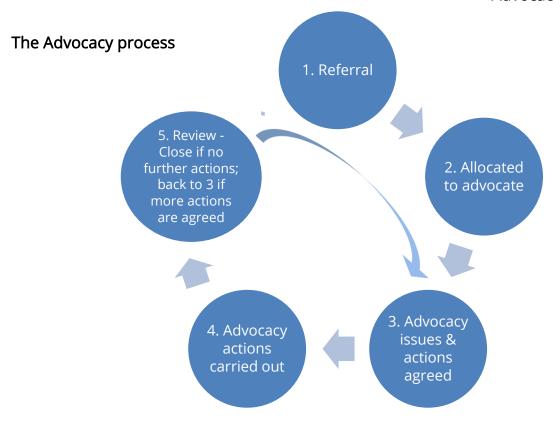
The service seeks to provide independent, free and confidential advocacy support to people using or needing to access mental health services. It provides this support by telephone, email, letter, face to face appointments and by attending meetings with people.

Advocacy has always been provided as short-term, issue-based advocacy, on a first come first served basis. This means that when you ask us for our help, you join our waiting list. When you get to the top of the list, you are allocated an advocate who will talk to you to agree what we can help you with and how we will do that. We then carry out what we have agreed and support you to get your voice heard. When we have completed this work, we will then close your case. If a new issue comes up a month, a year or 5 years later, you can come back to us and the same process would apply.

#### Case Example - Phil

Phil, 38 years old, was struggling with his mental health. He had been to see his GP, but felt that the GP didn't really listen to him properly. Phil contacted our service after a friend suggested it. We talked to Phil and helped him plan what he wanted to say to the GP. The advocate went along to the appointment and although Phil did the speaking, he felt supported by the advocate's presence. The GP made a referral to the Community Mental Health Team for an assessment, and also referred him for counselling. Phil's case was then closed. The whole process from when Phil asked for an advocate took 7 weeks.

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### What are the current problems?

We have a long waiting list for people in the community who would like help to access mental health services, or help to get their views heard by mental health services.

#### This means:

- Many people don't get help when they need it the waiting time between step 1 and step 2 has grown from days to weeks to months.
- Sometimes our support is too late to help with the particular issue, eg support at a meeting

Some people get an advocate and then work with them for a long time, because they have lots of ongoing difficulties with mental health services. We agree what to do at step 3, and then it takes a long time to put this into effect. By the time it has been completed, a number of new issues have come up and we return to step 3.

Sometimes our help is ineffective, as the services are not able to give the person what they want anyway. We can spend a



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long time trying to support the person to get what they want with no realistic hope of success.

#### This means:

- Some people have an advocate for months or years whilst others don't have one at all
- Our advocates are spending time trying to achieve unrealistic outcomes
- The waiting times become longer and longer

The way mental health services are delivered has changed a lot recently, for example:

- Community mental health services have been re-organised
- Priorities for mental health services have changed
- There are less resources, although demand is rising
- Self Directed Support and day services are different from how they used to be.

We haven't changed how we do advocacy even though services have changed. We still use the same process we began with in 2002. Its just not fit for purpose any longer.



### Case Example - Shona

Shona rang to ask for an advocate and told us that she has just received a letter from the Community Mental Health team telling her she has been discharged, and she will no longer be getting support from the Community Psychiatric Nurse (CPN) who has been visiting her every fortnight for the last two years.

Shona told us she is really scared, and doesn't know how she will cope as she really values the support her CPN gives her with understanding what is happening with her mental health, in particular in making sure her medication is right – it took many months when Shona first became ill to find the right medication. Shona, with the support of her CPN, tried a number of different types of medication before finding one that was effective for her without too many side effects.

Shona has been told she will need to talk to her GP in future if she has any problems with her mental health, or if there are any issues with her medication. Shona told us that she doesn't get on well with her GP, and always has to wait several weeks for an appointment if its about her mental health, just to get ten minutes. Shona doesn't know how she will cope.

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We took Shona's details, and added her to our waiting list. Four months later, Shona was still on the waiting list when she rang us back in real distress. Her GP had changed her medication without really talking to her about it and Shona was now really scared. We still didn't have an advocate available who could help Shona, though we talked to her on the phone for some time.

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## Our proposals



We have thought about this a lot, and have discussed different options of how we might improve our service. We came up with a set of proposals that we wanted to consult you about.

The proposals included four different aspects to change how we provide our service.

### Phone and email advocacy

We know a lot of people need some basic information or support at the time they contact us. We think we could provide effective support by email and telephone quickly in some cases. We suggested that:

- We will provide advocacy support by email or telephone wherever possible, instead of just adding you to a waiting list
- We will send you information about services, about how to get your views heard and how to advocate for yourself
- We'd hope to be able to do this within 3 days of you asking us for this support

### Support at meetings

We often get requests to support you to attend a meeting with a mental health professional. Too often, we cannot allocate an advocate quickly enough so we can do this. We suggested that:

- If you've got a meeting coming up with a mental health professional and you need an advocate to support you, we will try to make sure there is an advocate available to support you.
- The advocate will help you prepare and if necessary will attend with you.
- This wouldn't be ongoing support



#### Referral for short term issue based advocacy

We know not everything can be done by telephone, email or attending a one-off meeting. Some issues take longer to resolve. We suggested that:

- If there are ongoing advocacy issues the advocacy team **may** refer you into our service for further one to one advocacy support
- We would support you if we think there is a realistic chance of you achieving the outcome you want
- The advocate would have a set amount of time to spend on your case (which may be spread across weeks or months).

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- If the agreed issues cannot be resolved in this time then this would be discussed by a team of advocates, who will decide if the time can be extended
- We are suggesting the limit should be 20 hours. The average number of hours we spend on each advocacy case is 12 hours. This time includes all work done, including talking to you on the telephone, writing letters or emails, attending meetings with you, and any admin time spent on your case.

### Service user groups

We know that a lot of people have a lot of valuable experience of how to negotiate the mental health system. We would like to support you to share tips and support each other more than we do. This wouldn't work for everyone – but it would be an additional source of advocacy support. We suggested that:

 We would like to begin offering a regular meeting where you could access support through group advocacy, take part in campaigns and tell us how we can improve our service.



## The Advocacy options we proposed

Help at the time
you need it
Providing you with
information
Support for self
advcocacy

An advocate to attend an upcoming meeting with you

Time to prepare beforehand

Time to discuss afterwards

Not ongoing support

For ongoing issues

A fixed amount of work for each person needing it

Based on realistic outcomes

Can be extended if other advocates agree

Service User Groups for

Self Advocacy support and tips \* Campaigning \* Improving our service

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## What you told us

We wrote to everyone using our service at the moment, and all of those who are on our waiting list. We outlined the problems, and our proposed solution much as it appears here. We also talked with our partners and with Healthwatch Sheffield about our consultation and our plans.

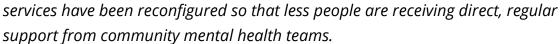
We invited you to attend a meeting and gave two different times. We invited you to write to us and to talk to us to tell us your views.

We had detailed responses from 10 different people, provided in person, by email and letter and verbally. Most of those who responded already had an advocate, and one person was on our waiting list.

We have provided below a full list of the questions and comments we received, along with some of our responses.

### Questions you asked us

- What is the extent of the crisis in demand for mental health services?
- Why is there so much demand on advocacy?
   Our answer: We don't have specific figures but we explained the context more fully. We described how



We commented that a lot more people are ringing us who are in acute distress who do not have any other support, and whilst we often cannot provide any immediate help, we nevertheless take the time to listen and give suggestions for what the person might be able to do.

We explained that casework is taking much longer than previously. A lot of people don't have a service at all now, and this means we spend time supporting them to talk to their GP, to gain a re-referral, then waiting for an assessment appointment. We might attend that appointment when it happens weeks or a month or two later only to find that the community mental health team decides not to provide any support. We then try to support the person to challenge that decision, or to seek other sources of support. This becomes very time consuming.

We also noted that recent changes to how mental health services are organised



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were not communicated beforehand to service users. A number of people have expressed anxiety about these changes.

- How many staff do you have?
   We have about 25 individual advocates in our full team, working on a range of projects. However our funding only allows 2 full time staff to work on this project.
   Although when you call us, you may speak to different advocates, we do not have the resources for all of our staff to work on our mental health advocacy project.
- Participants in the focus group were very surprised by this

### Comments you made on our proposals

### **General Comments**

 There is a risk that services try to manage demand from within and then they impose their own ideas of what is realistic to achieve



- I would prefer a more collaborative approach; it can feel top down rather than a proper dialogue
- Pressure to meet targets can compromise engagement
- I would prefer a less rigid template
- Some people would rather wait than be offered a less full service
- Praise for the approach and support from particular staff
- Isolation is a big cause of distress
- I've had times and still do where a one-off support session would be good. Just for the support, I am quite good at speaking up for myself. Just don't always get much respect.
- Every time I ring up the CAB, they're very nice and helpful. Could there be more help re Rights of Mentally III?
- I am not sure how these changes will affect me.
- Advocates should be able to work with each client fully to meet all their needs.
- I need help to get mental health support [from a person on the waiting list with no current access to services]

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### Comments on our proposal for Phone and email support

- Self advocacy defeats the purpose of having advocacy
- Self advocacy may not be possible because it is about confidence
- Having some kind of information letter from advocacy to take to meetings may be better than nothing (for example setting out my rights)
- Excellent.
- It is a great thing to do, it'll be more efficient.
- I'd prefer to have had initial contact with information rather than have waited without contact from the service for a couple of months.

### One off meetings

- There is great value in having a person with you at meetings
- The greatest help I've had is that having someone there means I get a level engagement. [The proposal] sounds potentially too rigid. Sometimes I'd rather wait to get my preferred option than get less more quickly.



- This should not be a token gesture
- Mental Health services would get to know that advocates only come to one meeting, so the pressure is not kept up on them
- How about taking a volunteer to a meeting (or a friend/relative)?
- I need support (at meetings)
- Yes I agree this is needed
- This is already there (under current arrangements) [ from a client who has an advocate currently]
- one appointment is better than nothing
- I understand that having a meeting at every mental health appointment is too time consuming
- I feel that once my confidence is up and I am over the anxiety of the first meeting then I should be ok attending my own appointment.
- The advocate taking notes at meetings or after is very helpful for someone who
  has bad memory due to meds and health issues sometimes this is the main
  reason an advocate is needed at the apt.

### Short term issue based advocacy

- This is simpler.
- Is there a simpler mechanism?
- Just as ongoing health problems don't get individual attention from a GP,
   people don't expect this from advocates, and may have to wait
- I'd be happy with lower number of hours than 20 and then go back on the waiting list, knowing that someone else is getting some advocacy instead
- Need to prioritise the waiting list
- Waiting is OK
- More one to one
- It would be better to have more support
- Yes definitely, have asked for an advocate but am on the waiting list. I would like to become an advocate if well enough myself.
- This needs to last until clients care needs are met, otherwise the client is left halfway through
- I need this service

### **Group advocacy**

- This could be the Hub and service users working together to increase engagement with mental health services
- Volunteers could make it clear what services are needed
- Groups could do fundraising to support advocacy
- Ben Dorey is already challenging NHS
- People may be open to a group working with Healthwatch on issues
- Anyone who comes to the advocacy service potentially has a role to play in changing mental health services.
- Yes I am already member of mental health service improvement forum.
- I don't understand
- I need the service

### Comment from Disability Sheffield

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How would this work for clients who cannot instruct? If the client has to wait a
long time for the face to face work, it would not be possible for an advocate to
assess capacity to instruct until later in the process.

### **Our Observations**

- People understand the pressure the service is under.
- People mainly felt that the discussions we held were useful and better than expected, though some felt the timescale for responding was too short.
- It appears people are saying they like the idea of being given information and telephone or email support at the point of referral. However it's also clear that this isn't enough in itself where there is a need for ongoing support from a named advocate.
- There appears to be less support for the one off meeting model. We're not sure this was explained clearly enough as think a lot of people would get advocacy support at meetings who don't currently.
- People lack confidence to speak up for themselves, and appear to want a mentor to assist them to build confidence over time. We think the groups might be able to do this for some people.
- There is some interest in the group option(s). These could be used to provide support to people in how to handle meetings.
- A careful review will be needed of the changes we make, so that we can see how they are working out in practice.

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## What we intend to do next

On the basis of our plans and your feedback, we will implement our proposed changes with some modifications.

We will do this between January and April 2018.

We will invite people using our service to give feedback on the new arrangements and to participate in a review after the implementation period.



We will look at how we can set up and facilitate groups for those who wish to participate. We will talk directly with those who have expressed an interest to plan this.

### The modified plan will include:

- Telephone and email based support at the time of referral or within 3 working days. Where we can, we will provide immediate information and support to allow the person needing advocacy to take necessary actions themselves.
   This will include developing our website to provide more information and self help materials (this will be an ongoing project to develop and update).
- Where the person contacting us has a meeting coming up, we will do all we can
  to allocate an advocate to attend the meeting, on a one-off basis though also
  allowing time for preparation beforehand and feedback afterwards.
- Where the person has been referred by someone else, and information suggests they may not be able to instruct an advocate, we will arrange a visit to meet the person and assess their capacity to instruct us. If they are unable to instruct, then we will refer the person for our casework service as below.
- Where the person's advocacy needs cannot be met in the above ways, we will
  refer the person for up to 20 hours of casework from an allocated advocate.
   When the 20 hours has been used up, the case will usually be closed. If the

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advocate believes work should continue, then the advocacy team will take a decision about this within 2 weeks.

- We will review how this is working in practice, and invite feedback from all those receiving these modes of support in the first half of 2018. We will make further changes to improve the service when issues arise.
- We will also seek to establish one or more groups and invite service users to attend. The purpose of the groups will be decided by participants, but we envisage one or more groups which may focus on:
  - Sharing tips for self advocacy
  - Confidence building
  - Campaigning
  - Improving the advocacy service

## How we will implement the changes

We aim to carry this out between January and March 2018. We recognise that it will take some time to contact all of the clients on our waiting list, and to fully explain what we are doing to all of our existing clients. We want to make sure we allow enough time to make the transition to the new arrangements as smooth as possible.



- We will start in January by sharing this report widely, briefing our staff, and starting to plan our group programme.
- Over the three months, we will contact everyone on our waiting list to review their advocacy needs, and to give support where we can under the new process. Those asking for an advocate in this time will be added to this list and contacted in date order.
- We will begin to count the hours of work for those of you we are working with already. When we reach 20 hours, we will plan to close the case, unless there is a clear need to extend this time agreed by the team.
- We will also develop the materials available on our website to help you.

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- From 1<sup>st</sup> April, we plan to have attended to everyone on our waiting list and to have helped those we can using telephone and email support. Those needing more than this will have been referred into our short term one to one service.
- Existing cases where we have done more than 20 hours work since 1<sup>st</sup> January will have been closed unless further work has been agreed by the advocacy team.
- We anticipate our waiting list will be significantly reduced, and we aim to bring this down to single figures if possible.
- Once the new system is up and running, we will invite you to review it with us –
  to tell us how you think it is going, and where it could be improved. However,
  you can get in touch at any time if you have any comments, compliments or
  concerns to raise about the process.
- You can also make a complaint by contacting us or by emailing <u>complaints@citizensadvicesheffield.org.uk</u>