



champions of change

# Response to the Review of Advocacy Services - Nottinghamshire and Nottingham City

## **Acknowledgements**

Bright Ideas would like to thank:

- all Champions on the Champions of Change network and in particular those who contributed to the discussion groups about advocacy
- members of the public consulted between 2009 and 2010
- the Champions of Change project team: Lisa Jackson, Simon Morley, Kathleen McKay, and Company PA, Karen Lock.

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## **Background**

Champions of Change, alongside a range of mental health service providers, received the following request from NHS Nottingham City.

We are currently reviewing all advocacy services currently provided in the City and the County. Following this review we need to make some decisions about what advocacy will look like in the future, how it will be delivered and who will be able to access it. We would be interested in your views on this and would be grateful if you could answer the questions below. If you are able to feed any service user thoughts/comments into this process that would be extremely useful.

- 1. What currently works well?**
- 2. Are there any gaps in provision?**
- 3. Given that people who use services will have much greater control over their care in the future, for example through purchasing their own services through individual budgets – what role would you like Advocacy to play in this new way of giving and receiving care?**
- 4. Any other comments.**

## **Champions of Change Response**

The Champions of Change Response was put together as a result of two activities:

- 1. A review of feedback about advocacy collected in year one of the service (September 2009-September 2010)**
- 2. Two specially convened discussion groups.**

# 1. Review of feedback in year 1

During the first year of the Champions of Change Service (September 2009 to September 2010) we had over 1000 conversations regarding issues and concerns about mental health services in Nottingham. These issues and concerns related to a range of different services. We reviewed all comments and discussions and picked out any relating to advocacy. A summary of the comments is provided below:

- The services are very specialised and advocacy should broaden out to benefit a much wider range of individuals. A lot of time (and therefore money) would be saved if people had help with articulating and presenting their views in order to get an early resolution – rather than having events spiralling into crisis. Advocacy would also help people to feel that they were heard and to feel more empowered – less like ‘victims’ of the system.
- People have been forced into using friends and family members as advocates as there has been no other option, and sometimes this (a) puts an unnecessary burden on these relationships and (b) doesn’t work effectively if the person does not wish their friend/family member to know certain information.
- As with many other services, people do not know what advocacy is, what is available and how to access it.
- In terms of the personalisation agenda – there really needs to be some serious awareness-raising with people who use services and their carers. They simply cannot comment on something that they know little or nothing about. There is a lot of confusion and anxiety about this agenda and this needs to be addressed.

## 2. Discussion groups

Champions of Change have recently consulted network members over the review of advocacy services in Nottinghamshire and Nottingham City. This consultation was carried out at two regular meetings with Champions – a Reference Group meeting and a Chat Room session. Conversations were also held with network members who couldn't attend the sessions but wanted to give input over the phone or in person.

The Reference Group meeting with Champions took place on 2 June 2011; four people attended and discussed their views on advocacy. The Chat Room session was held on 15 June 2011; six people attended. It is worthwhile to note that most of the participants are currently in receipt of secondary mental health services.

Before the four questions were posed, network members were asked what their interpretation of advocacy was and who was delivering it locally.

Overall, the majority of people we spoke to had no clear picture of what an advocacy service is or who is delivering the service in Nottingham or Nottinghamshire. Participants mentioned services such as NAG, PALS, Your Life, Carers Federation, Person-to-Person and Advocacy Plus. However, none of them had any clear idea of what type of service they actually delivered.

### **Champions' interpretation of what advocacy is and what it should look like**

- *“An organisation or individual acting on your behalf to meet your requirements or needs or wishes.”*
- *“Somebody neutral who understands you. Somebody sensitive to your needs.”*
- *“Somebody to empower you.”*
- *“Somebody to assist you to present your case: to support you to get a second opinion or support you with your care arrangements.”*
- *“Help communicate from you to the system.”*
- *“Provide information, advice, guidance to allow a person to see the whole picture.”*
- *“Signpost you to other services or gather info on your behalf.”*

- *“Check you are happy with staff/doctor and speak on your behalf.”*
- *“Health professionals can be intimidating so you need somebody to argue your case.”*
- *“Advocates should have a good knowledge of patients’ rights. They should be available on the wards to explain the Patient’s Charter and how they can work independently on your behalf.”*
- *“The NHS complaints system is a tangled web. If you have a genuine concern about something it is difficult to get your point across in a letter or over the phone. An advocate would really help.”*
- *“The benefit of an advocate would be to assist the patient whenever there is a need to intercede on the patient’s behalf.”*
- *“An advocate should be somebody who has been there, who has accessed mental health services in the past; somebody who understands. Also, if you are dealing with an advocate who has recovered this gives you hope and confidence that you too can recover.”*
- *“People should know what an advocate is and how they can help. Before today I didn’t know. There have been times when I could have done with one.”*
- *“Having an advocate is like having a dentist. They should be available at the point of need, when you require them.”*

The group agreed that usually when they are or have been in receipt of secondary services they are assigned a Community Psychiatric Nurse (CPN), a psychiatrist, a social worker or a key worker. Their family doctor is also usually involved. They agreed that you needed one person to deal with all these people on your behalf.

### **Support whilst visiting health professionals**

One Champion stated that recently she was finding it difficult to get her point across to her GP and psychiatrist, that her medication was causing her many physical side effects. Although she has tried to express her viewpoint she feels that her concerns have not been taken seriously. She would like the support of an advocate who is qualified to intercede on her behalf so that she can be confident that she is receiving the right or the best type of medication.

A Champion, who has recently moved to the city of Nottingham, alone, without any family or friends, stated how she had become rather anxious about attending a first appointment with her psychiatrist. Having wanted to come off her medication and try other alternatives she required an advocate to help

to give her confidence to get her point across. However, she didn't know if such support existed or where to look for it. Other Champions agreed that they didn't know either.

Another Champion, from the county, spoke of how very recently he had wanted the support of an advocate to assist him at an appointment with his psychiatrist/GP. After looking through the Nottingham Self-help book he came across a service called 'Advocacy Plus'. He called the service. Although they were very friendly and helpful they could not directly help him because he lived outside their catchment area. Also they were unable to direct him to another service that met his needs.

A Champion spoke of how she felt pressured to return to work after failing an assessment. She is currently on a high dosage of medication which makes her unstable on her feet. She stated that she also has hallucinations and tendencies that could make her a possible threat to the safety of those around her. She has written a letter to the employment services but feels that she could do with the support of an advocate to help her communicate her concerns and to liaise between health professionals and employment services. An advocate with her best interest at heart would give her peace of mind.

## **Participants then discussed the questions posed by NHS Nottingham City.**

### **1. What works well?**

Champions could not comment on what works well as they currently have no access to advocacy services.

### **2. Are there any gaps in provision?**

- *"Advocacy is not uniform across the city and county."*
- *"There is not enough information regarding what is available. There needs to be more publicity from the services themselves about what they have to offer."*
- *"More information on the Internet along with other forms of publicity."*
- *"Lack of choice. People should have more choice on who they choose to represent them."*
- *"There is a need for specialist advocacy services for those first admitted to hospital: somebody who can join all the dots: somebody who can go between the GP, hospital staff, CPN, social services and the family."*

- *“You can be in a real state of confusion when hospitalised and on high doses of medication. What you need is somebody, an advocate, to approach you while in that setting and tell you that they are there for you, for any concerns you may have while in hospital.”*
- *“Advocacy services should be more proactive in getting their services known. They should be making themselves known in hospital settings and out in the community setting.”*
- *“Usually when in hospital you have a CPN that sort of acts like an advocate. But once you are off your meds you have nobody. Knowing there is somebody you can call on when needed to assist you to appointments etc. would be very useful.”*
- *“While in hospital people can lose all they have - their home if the rent is not paid and all their possessions thrown out onto the street. You may not be able to even think about all that until feeling better and back out of hospital. An advocate could help keep everything afloat by informing key people about your situation.”*
- *“You need to trust somebody to present you with choices and help you make decisions that are right for you.”*

### **3. Given that people who use services will have much greater control over their care in the future, for example through purchasing their own services through individual budgets – what role would you like Advocacy to play in this new way of giving and receiving care?**

Champions were unclear about individual budgets. Some felt annoyed they may not qualify for individual budgets. They asked for you to consider the comments already made.

**The feedback was supplied to NHS Nottingham City in June 2011 by the Champions of Change service.**



## NHS Response

Champions of Change received this feedback from NHS Nottingham City in July 2011:

*... Thanks for your feedback. I summarised all the feedback we received and I attach the document I wrote for our commissioners' meeting last week and the Independent Advocacy Forum, which was held yesterday. Whilst this is obviously a brief summary I can assure you that the commissioners have seen and considered the full document you produced. This feedback is being considered alongside some work carried out by current providers of advocacy and is informing our review. I will send you the document that we are putting together following yesterday's meeting - it should be drafted by next week.*

*Sarah Howarth  
Commissioning Officer (Mental Health)  
Adult Social Care and Health*

Note: Sarah Howarth works for Nottinghamshire County.  
The Review of Advocacy Services was a joint review undertaken with NHS Nottingham City.



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**Proud to take a stand**