

Advocacy

A Report on Consultation with Service Users for the Department of Adult Care Services, Wiltshire County Council

September 2005

This report has been put together from telephone conversations with and correspondence from Service Users of Health and Social Care in Wiltshire and from discussions over five meetings of a Service Users Working Group
With the exception of Appendix D this report is based entirely on the above mentioned sources.

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Introduction

This report is based on discussions over five meetings with a non-impairment specific Working Group of Service Users, and includes views from meetings with:

People who use Mental Health Services

People with Learning Difficulties

People with Physical and/or Sensory Impairments

Older People

A non-impairment specific group of Service Users

Also included are views received through correspondence from and telephone discussions with Service Users. A total of 56 Service Users have been involved in provision of the views presented in this report. All contributions are from people who live in Wiltshire, and have experience of using Health and/or Social Care Services.

The report has been written under the seven headings into which the views arising from these discussions have been divided.

1. Qualities and experience looked for in an Advocate.

There were many views as to both the qualities looked for in the individual advocate, and in the work of that advocate.

1.a The advocate:

- Among the most important qualities looked for were that the advocate should respect confidentiality, be trustworthy and honest, and have the ability to listen. It was generally felt that attitude and personality were more important than professional qualifications, although a view was expressed that expertise in counselling skills and advice would be beneficial.
- The advocate should be non-judgemental and respect all cultures and diversity. Other qualities looked for were compassion, understanding and consideration. Empathy was looked for, but emphatically not sympathy, and the ability not to become emotionally involved.
- It was felt important that the advocate and service user should meet before starting the 'advocacy relationship'. It was important that both parties in the relationship were comfortable with each other, and that there was, for example, no history between them.
- Having a similar history to the Service User may be helpful, and allow the Service User more confidence. It is important, however, to remember that the need is to listen to the Service User and not use personal experience.

1.b The advocacy:

- An advocate is not a friend. S/he is outside the family/friendship/work groups of the service user and there would be mutually agreed boundaries around the work. An advocate is not a 'befriender', the relationship is one of equals.
- An advocate will listen to the Service User, and any view they express will be that of the Service User not their own view, and not that of the service provider. An advocate has a role to support and enable the Service User - to 'listen to what I want, find out how to do it and support and help me to do it'. S/he will enable and empower the Service User, ensure the Service User's views are heard and rights acknowledged, and promote independence
- It was generally felt that an advocate need not be an expert on a particular subject. An exception to this may be an advocate working with a Mental Health Service User who would need access to, and maybe specialist knowledge of the legal framework concerning Mental Health Service Users.
- There were differing views as to paying advocates. Volunteer advocates should receive appropriate training, understand the commitment required and have appropriate support. They must, as a minimum, be paid expenses. Ideally it was felt that advocates should be paid for their work. This also brought the expectation that an advocate would not be motivated by money.
- An advocate should have status and 'teeth'.

2. When an advocate can help:

- With provision of support when someone does not have the confidence to speak up for himself or herself, and to support the Service User to get his/her views across.
- Getting information and helping someone deal with a problem.
- Supporting the Service User to find their way through 'officialdom' and to help find the appropriate service. Finding information, for example, on entitlements, support with form filling and letter writing and help with applications for direct payments.
- With discussing things with the Service User before a meeting about their wishes, and provide support during the meeting.
- Helping to empower and enable the Service User to make informed choices.
- Having an advocate who listens can sometimes help people to deal with anxiety, which in turn can have benefits for other Service Users in some situations. It was felt that specific advocacy for younger people may be needed.
- Some Service Users can feel assumptions are being made about them and they are not believed. An advocate can provide support in such instances.
- There was a view that there is currently a gap in provision of an advocacy service for People with Physical Impairments, and specifically for people during change from a residential setting.
- A continuity of advocacy for people who employ Personal Assistants was also looked for. Continuity here would help build up trust and the advocate would then also know the history of the Service User.

Appendix C has non-verbatim comments from people on the benefits of having been able to access an advocacy service. They have been heavily edited to ensure confidentiality.

3. Ways of promoting and informing about advocacy:

- Service Users who did know about an advocacy service had often found out about chance. It was often when a Service User was most in need of an advocate that they were least likely to ask for one; for example during illness or hospitalisation. People often did not think about advocacy until it was needed, and provision of this information at such a time would be of great benefit; it is generally not the sort of information people kept 'in case'.
- Information on sources of advocacy services could be given at the point of access to services - a Service User can feel particularly isolated at this time, sometimes feeling that professionals and family are joining together to make decisions about them.
- Under the Mental Health Act the Service User must be informed about advocacy. It is important that this is done in an appropriate manner.
- Information should always be offered in accessible formats.
- A common logo may help to give advocacy an identity and help promotion of the service.
- There were many specific suggestions as to where advocacy services could be advertised; these are listed in appendix 'A'.

4. How Can Advocacy Be Provided:

- Having a contact available, for example at the end of a telephone line, to discuss/talk things over with and get advice/support can sometimes be enough to empower and enable someone speak up for him/herself. Any such contact should be made available in different ways to allow all access; for example a home visit may be needed.
- For some people a relative / friend / member of service provider staff has acted as an advocate - someone who was known and trusted. An advocate to support Service User and his/her nominated relative/friend may be a good option where the Service User has requested this. It is important to remember that the first and main contact with any advocate should be the Service User. Service Users generally felt it was easier to talk with someone outside of friends/family.
- Different advocacy services should work together to share information and expertise and help ensure (agreed) standards are maintained. Advocacy services might join together in a cooperative or alliance.
- If an advocacy service receives an enquiry, it should work with other services to consider which service is best able to help that person. Advocacy services should co-operate and refer across Wiltshire to ensure the service use has the most appropriate option available.
- Advocacy could be available by telephone, with an emergency telephone number available twenty-four hours a day and seven days a week. Any coordination role/central point would need to be funded. All advocacy services would need to be independent from Health and Social Services. A central contact point/helpline could signpost to an appropriate service although care must be taken to ensure that this does not become another layer between the user and the service. Ways of contact must be diverse, for example telephone/email/text/minicom.
- Technological assistance should be looked at to help with coordination and with the spread out nature of Wiltshire.
- If the service is not Service User led it must be able to demonstrate that it is user focussed. A view was expressed that the quality of the service provided was more important than that it be Service User led. It was

generally felt that any advocacy group should have an advisory and/or management board with a minimum of 51% Service Users.

- A view was expressed that a Service User may sometimes look to a Social Worker for support, but it was generally recognised that a Social Worker could not be independent.
- A letter of agreement outlining the boundaries/expectations in the advocacy relationship would be helpful.
- Local drop in centres for advocacy services and local telephone contact numbers would be helpful.
- There are occasions when the Service Users' needs call for more professionally trained workers.
- It is important that there is equity of service around Wiltshire; it was felt that the current provision is patchy around the county.
- Training on provision of advocacy for Service Users could be provided enabling them to become advocates. A database of advocates could be kept available at a central access point.
- A specific suggestion was made of a central contact point being set up to facilitate work of groups providing advocacy services. This would also provide initial contact for the Service User. A model of an 'umbrella' organisation that area/impairment specific groups could join (see Appendix B). This 'umbrella' organisation could identify and look to fill gaps in provision. Advocacy provision organisations could join this group while keeping their own independence. They would, however, need to demonstrate that they meet basic criteria, for example training standards, recruitment and monitoring of advocates. The 'umbrella' organisation could also facilitate group forums and the sharing of good practice. Groups could also seek funding from other sources, and groups funded from other sources could join the 'coalition' if they proved they met the agreed basic criteria.
- There may be occasions when the advocacy will need to be impairment and/or issue specific. There may also need to be interpreters, for example for British Sign Language / Makaton / other spoken languages.
- Impairment specific organisations and Charities may provide support, for example in assisting at Disability Living Allowance Tribunals.

5. Recruitment and Support Of Advocates:

- An Advocate sometimes needs help and support. A co-ordinator and an advisory group could provide this; Service User involvement in advocacy provision would promote confidence.
- Service Users should be involved in any recruitment interview panel. A view was expressed that Service Users should be involved right through the whole process of advertising, interviewing and support.
- A basic amount of agreed and acknowledged training for advocates is important. This training should involve Service Users. The training should include listening skills, finding information, looking at 'the wider picture'.

6. Problems / Things To Remember And Take Into Consideration

- There was a worry that decisions are made with the involvement of the Service User in the decision making, giving a feeling of being 'done to'. This was then often giving rise to the worry that if a fuss was made, the service could be withdrawn/modified.
- Service Provider staff can sometimes feel worried about the involvement of an advocate. Service Providers should be informed and educated on the role of advocacy, be open to Service User use of advocacy and a culture should be promoted that allows, recognises and accepts advocacy.
- Short term funding is not helpful and can lead to constant changes in the advocacy service; having long term stability is helpful. Also staff can waste time chasing funds rather than providing service.
- Wiltshire County Council may have specifications for an advocacy service but there should be independence within this. Constraints around the use of money are not helpful.
- Advocacy can be 'frightening' to some people and difficult to understand.
- Patients in Mental Health Service hospitals are not given information about advocacy. An example was given of an advocacy service visiting a hospital on a regular weekly basis and Service Users not being aware of this.
- Service Users are often saying they will be contacting newspapers and lawyers because they feel powerless and not listened to.
- Families can have a big influence, particularly on Mental Health Service Users, and can collude with service providers.
- Voluntary workers are not valued enough.
- Families are not always around to support a Service User, and a friend is not always the best person to talk to.

- Service Users are not able to find an Advocacy Service in North Wiltshire. The Council, when asked, could not direct a Service User to an advocate who could help with Direct Payments.
- People did not know where to get support in an emergency. For example when looking after a dying relative appropriate support was not offered.
- Social Services give out forms, but no help or advice is offered to help with completion of these forms.
- There may be many people unaware of the concept of advocacy and that such a service may be available.
- Social Services assume a person has no concerns unless pushing for something, and many people may not feel able to do this on their own.
- Funders of services may restrict services to an area and/or client group. For example, a Service User lost the support of an advocate when moving within Wiltshire.
- An experience was related by a Service User who did not feel listened to by an advocate. This can make a service user feel even more isolated. It must also be remembered that not all impairments are visible.
- There is a need for advocacy to be available for people with diverse forms of communication. There may often be a need for Service Users to get to know an advocate over a period of time to allow trust to be built up, and for the advocate to be able to appropriately support the views/wishes of the Service User. (Appendix D Notes following a visit to a residential setting have been included for information).
- A Service User can feel bullied and ashamed to ask for help
- A 'transfer' arrangement should be available. If a Service User has an advocate/advocacy service and moves to another part of the country this would enable a suitable advocacy service to work with him/her after moving.

7. Other Points Raised:

- It is more important that the advocacy service does what is needed than that it is local to the Service User.
- Service Users cannot always find staff to talk to, and can feel abandoned by staff. Occupational Therapists seem to have more time to listen. Some professional people can be helpful.
- Staff have handovers and Service Users do not know what they are saying and writing. This creates mistrust. (this was in a hospital setting)
- People experienced in providing advocacy for one impairment specific group could provide for others. Issue based advocacy can take varying amounts of time. Housing is increasingly becoming an area where advocacy is requested. For example some accommodation may only become available through 'on-line' bidding, which is not accessible to all, and Older people, particularly, can miss personal contact when dealing, for example, with housing.
- Advocates generally go 'that extra mile', and are paid expenses only.
- There are some activities that can lead or overlap with an advocacy service, including mentoring, training, giving of advice, provision of information.
- It was noted that a number of self advocacy groups exist, mainly for People with Learning Difficulties. It was felt that these organisations could be outside the tendering process as they are peer support groups supported by trainers/enablers/facilitators.

Appendix A

Experiences of Advocacy

- Advocacy provided help with meetings, completing forms and writing letters which relieved some of my stress and worries. The support helped me to feel in charge, and to believe my opinion is important.
- Advocacy helped when trying to deal with a problem, when difficulties with health made me feel particularly vulnerable. The support received gave me peace of mind.
- Advocacy helped me have my worries addressed, when I felt no-one was listening. The support I received in making my needs heard was invaluable.
- Advocacy helped me to feel empowered and able to make choices. I was, for example, able to discuss things prior to meetings and had support in getting my point across. It lessened my feeling of isolation.

Appendix B

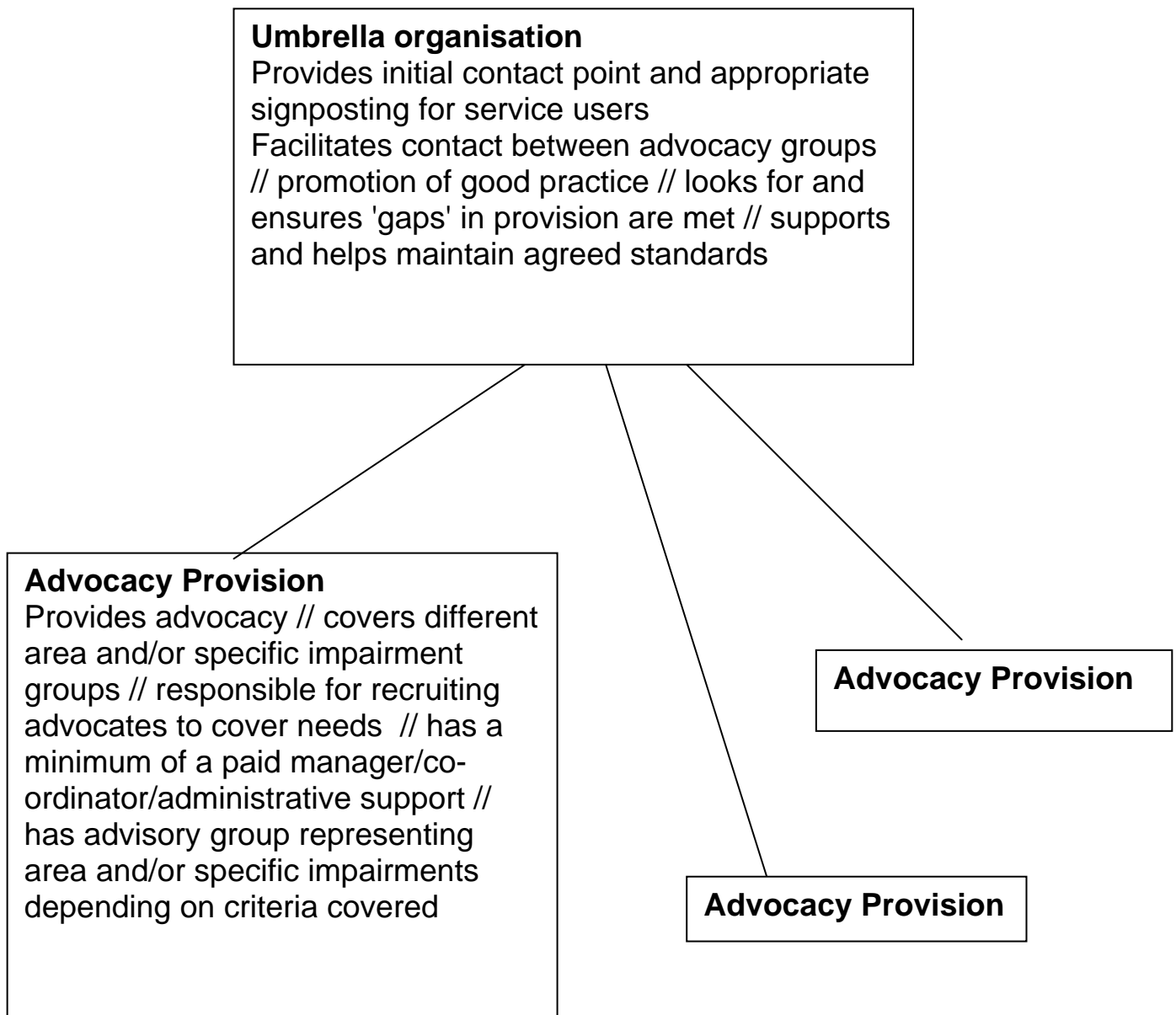
Places where advocacy services could be promoted and advertised:

- CAB (Citizens Advice Bureau)
- Voluntary organisation Libraries, local directories
- On accessing services
- Doctors surgeries
- Patients' forums
- In supermarkets, the internet.
- With Social workers
- Parish magazines
- Info on service provision could include info on advocacy
- Service Users giving out information at venues; for example Safeways
- Service Users talking on the radio
- Newspapers
- Shops
- Magazines
- Local Councils
- Radio / local radio
- On retirement from work
- Hospitals - someone doing this on a regular basis would be helpful ('almoner'). Leaving it to the nurses is unfair - they are already overworked.

- In targeted magazines/newsletters
- Through word-of-mouth/neighbours
- In nursery schools

Appendix C

Suggested model for provision of advocacy:



Appendix D

Notes following a visit to Residential setting in Wiltshire.

The Manager of this service provision has wanted, and not been able to find, advocates for people using the service - a private facility with residents' placements being funded by Wiltshire Social Services, and other Social Services in England.

The manager had, he felt, identified occasions when the residents' interests were not being the main basis for future planning. He also felt unable to 'speak' on behalf of residents, as he would not be seen as independent/impartial.

The manager also felt that the concept of advocacy/and advocate, should be introduced over a period of time to Service Users.

The consultant met with a Service User at the residential setting, but did not discuss advocacy. This was because because she felt the Service User would need to know her over a period of time to feel comfortable with such a discussion.

It seems that there are settings/circumstances when there is a need for an advocacy service running almost parallel to the service provision but completely independent of this provision. It could perhaps also be described as an independent person 'looking after the best interests' of a Service User, which may only be possible when a trusting relationship has been formed.

An advocate/service may also need training in, for example, alternatives to spoken forms of communication, or to have interpreters available. Everyone communicates - it may take time to get to know a person to ensure appropriate communication is shared and ensure an advocacy service is accessible to Service Users.

