

## LMHAG TRAINING

### WHAT IS INDEPENDENT MENTAL HEALTH ADVOCACY?

#### PURPOSE

- \* To safeguard the rights of service users – both rights under mental health policy and law and those under general law.
- \* To empower service users to make informed decisions about their care and treatment and to take greater control over their lives.
- \* To support service users in being heard.
- \* To represent the views of service users, if asked, with the same energy as if they were their own.
- \* To protect service users who are particularly vulnerable for reasons of their illness or their lack of capacity.
- \* To feedback advocacy issues raised by service users to service providers so that services can be continually improved.

#### WHO IS IT FOR?

Mental health advocacy is available to people using mental health services, either hospital or community-based and for those wishing to access them or leave them.

#### PRINCIPLES OF INDEPENDENT ADVOCACY

**Independence** – There should be no conflict of interests for the advocate. They must not be associated with any direct service provision affecting the service user's lives.

**Empowerment** – Advocates work with an individual rather than for them. An essential skill of an advocate is to be able to work in an empowering way. The process of advocacy is intended to be an empowering experience for the service user whatever the outcome. As far as possible every step of the negotiations is decided by the service user. Advocacy exists on a continuum from protection to empowerment.

**Non-Judgemental** – The advocate must always see the service user as a person first and foremost however ill they may be. They must not allow any of their own opinions or cultural baggage influence the nature or quality of the support they give.

**Inclusive** – Advocates will support anyone involved in mental health services.

**Confidential** – Discussions between an advocate and a service user are confidential. Consideration of breaching confidentiality will only be made where there is serious risk of harm to the individual or to another person. Wherever possible, discussions will take place with the service user before anything is disclosed. In secure settings, confidentiality can also be breached when there is a risk to the security of the institution.

## FREE – ADVOCACY MUST BE FREE TO THE SERVICE USER.

It can empower a person to express their views and needs and, in a sense, the empowering process of advocacy is as important as achieving an outcome. Many people accessing advocacy feel that for the first time since becoming involved in mental health services, they are accepted for themselves, rather than as a person with a 'mental illness' or a particular diagnoses.

## INDEPENDENT ADVOCACY

For an advocate to be on someone's side, the advocate should be independent of the service system. An independent advocacy can be clear that their loyalty and accountability is to the person who needs the advocate. They can focus on representing the interests and wishes of the people who need an advocate and be clear that this is their role. A person working for a service providing organisation can not be independent – the potential for conflict of interest exists. They may look out for and speak up for the person they are working with, but if they take up an issue against the organisation, there is a conflict of interest. They may be seen as acting unprofessionally or being critical of the employing organisation.

It is particularly important for an advocate working with a person who is detained under the Mental Health Act to be conspicuously independent. The user must know that the advocate is not connected in any way with the organisation that authorised or brought about their detention.

## A DEFINITION OF MENTAL HEALTH ADVOCACY

Mental health advocacy happens every time someone speaks on behalf of another person or group who uses mental health services and every time someone supports another person or group to speak out for themselves. Mental health advocacy is about standing up for a person or a group, taking their side, supporting them get their point across. It is about safeguarding individuals who are in situations where they are vulnerable.

Mental health advocacy exists to:

- \* Safeguard the rights of service users – both rights under mental health policy and law and rights as citizens
- \* Empower service users to make informed decisions about their care and treatment and to take greater control over their lives
- \* Support service users to get their views heard.
- \* Represent the views of service users with the same energy as if they were their own.
- \* Protect service users who are particularly vulnerable for reasons of their illness or lack of capacity
- \* Provide feedback on issues raised by service users to those providing services so that services can be constantly improved.

## PRINCIPLES OF MENTAL HEALTH ADVOCACY

### MENTAL HEALTH ADVOCACY MUST BE:

#### INDEPENDENT

Advocates cannot work for or be associated with any organisation, services or people involved with or affecting the service user's life. The advocate must be free to express the service user's views without risk of compromise or conflict of interest. An advocate is essentially responsible to the service user. This is a relationship that can only exist on the basis of trust.

#### EMPOWERING

An essential skill of an advocate is to work in an empowering way. Advocates try to ensure that whatever the outcome of the advocacy issue the process itself is an empowering experience for the service user. As far as possible every step of negotiations to achieve the desired outcome is decided by the service user e.g.. it is up to the service user to decide whether to speak for themselves with support from the advocate or for the advocate to speak on their behalf.

#### NON-JUDGEMENTAL AND UNCONDITIONAL

Advocates must not judge the service user. When a service user is experiencing severe mental distress, an advocate may be the only person s/he sees who is not responsible for assessing, treating and monitoring their illness/condition. This means that advocates must listen to and hear the service user's report as their truth and therefore valid.

#### FREE

Advocacy services must be free to the service user and cannot discriminate on grounds of wealth or poverty.

#### INCLUSIVE

Advocacy should be available to anyone who is using mental health services and to their carers

#### CONFIDENTIAL

The discussions between an advocate and a service user are confidential. Consideration of breaching confidentiality will only be made where there is serious risk of harm to the service user or to others. Discussion with the service user will take place if possible before confidentiality is breached. Where advocacy is delivered in a secure setting, issues around breach of confidentiality arise when there is a risk to the security of the institution.

#### SOME POINTS OF CLARIFICATION

Mental Health advocacy differs from advice-giving. Advocates can provide information and explore options, enabling the individual to make informed choices but they do not give advice.

Mental health advocacy is different from service user involvement. Advocacy is about putting across the views of the user or users as they define them and at the time they need to do it. User involvement works to broader planning agendas in a more consultative framework.

## MENTAL HEALTH ADVOCACY IS NOT

- \* Befriending or social support
- \* Campaigning
- \* Counselling
- \* Working in the 'best interests' of service users
- \* A form of legal representation – legal representation should be done by lawyers.

## MENTAL HEALTH ADVOCACY AND OTHER MENTAL HEALTH SERVICES

Many organisations providing mental health services now say that advocacy is part of their service, or that staff offer advocacy to their users. It seems important that some of the issues around how and where advocacy is delivered are clarified.

It is accepted in this report that mental health advocacy is provided in many different settings. A housing support worker in a voluntary organisation or a nurse on a hospital ward may provide advocacy. However, there is a difference between this and the advocacy being discussed in this report. In the first instance, this is not independent advocacy. In addition, it seems more accurate to describe this work as a member of staff using advocacy skills in their supportive relationship with a service user.

In the broader advocacy movement, and in this report, it is necessary to be clear that the advocacy that is needed is a dedicated advocacy service, where an advocate acts only as an advocate and not as a support worker. Only when this advocacy is available in an independent service, can an advocacy relationship be formed where the advocate can speak up for the service user, or enable the service user to speak up for themselves.

An advocate would, in general, work with service users on specific issues and would end the contact when the work is complete. No time limit should be set, as service users may have very complex issues they need support with, or may have a series of issues concerning them. However, advocates are not there to provide on-going support which is not dealing with specific issues, nor should they substitute for work other mental health workers should be providing.

## BACKGROUND TO NATIONAL AND LOCAL DEVELOPMENT OF MENTAL HEALTH ADVOCACY SERVICES

National Service Framework for Mental Health:  
Specific arrangements should be in place to ensure advocacy is available.

Nationally, mental health advocacy developed as a result of increasing concern about the quality of mental health services in post war Britain. The 1983 Mental Health Act and Code of Practice brought greater awareness of legal and human rights of patients and rights to proper information and representation. In 1986 the first Patients Council was set up in Nottingham and Survivors Speak Out (a national self advocacy network) was established. By 1992 there were over 100 similar survivor groups. These amalgamated to become the United Kingdom Advocacy Network (UKAN).

The government began to recognise the contribution that advocates could make in ensuring that service users were able to take an active part in the planning and delivery of their care (DOH 1994 p54).

In Leeds, service users, voluntary sector organisations and service providers realised the need for a reliable independent advocacy service. Services began to develop in the 1990's with the introduction of Mental Illness Specific Grant (MISG) and Joint Finance, which enabled Social Services Departments and Health Authorities to fund independent advocacy services. LMHAG, the first independent mental health advocacy service in Leeds began in 1993, funded by MISG and Joint Finance to provide Citizen Advocacy and Patients Councils with trained volunteers. One to one, representational advocacy was provided by 2 full time equivalent workers in the Health Advocacy Unit service based in LCC Equality and Rights Department. Advocacy and interpreting for three local minority cultures was provided by AIS.

More recently (1999?), advocacy for black and Asian communities receiving secondary services has been provided by an advocate at Leeds Black Mental health Resource Centre.

Six months after the closure of the Health Advocacy Unit in 1998, LMHAG changed their service from volunteer advocacy to one to one advocacy provided by the workers.

Advocacy for people with dementia is currently divided between people over 65 and those in residential or nursing home care by Leeds Age Concern. People with dementia of any age in hospital or in their own homes was initially provided by an advocate at the Health Advocacy Unit. This worker is now based at LMHAG.

All these groups, together with other advocacy organisations in Leeds became part of Advocacy Network - Leeds 3 (2?) years ago. The Network established a Definition of Advocacy and a Code of Conduct that is endorsed by Leeds health Authority and Leeds Social Services. They deliver regular accredited training sessions in advocacy to any voluntary sector organisation in Leeds who wish to participate.

## THE CURRENT NATIONAL SITUATION

The Government, with its declared aim of social inclusion and service user involvement in the development and delivery of services, is recognising the value of independent advocacy. While plans are underway for funding advocacy for children in care and people with learning disabilities, their proposals for mental health advocacy have not yet been finalised.

National Service Framework for Mental Health states that Health Authorities must have arrangements in place for (independent?) advocacy\* and it is in this context that this report is being written.

## THE HEALTH AND SOCIAL CARE ACT 2001 STATES:

It is the duty of the Secretary of State to arrange, to such extent as he considers necessary to meet all reasonable requirements for the provision of independent advocacy services. (S12)

The NSF – Section on Configuration of mental health services ‘Specific arrangements should be in place to ensure – advocacy arrangements’ (sic). In reply to a recent Parliamentary Question, health minister Jacqui Smith stated that whilst the government has no plans to introduce a statutory right to advocacy for users of mental health services not subject to compulsory powers, the NSF makes clear that mental health service providers should ensure that specific arrangements are made for the provision of advocacy services.

The white paper, “Reforming the Mental Health Act” (2000) proposes for the first time a legal right to independent advocacy:

Providers of health and social care services will be required to ensure that patients who are subject to care and treatment under compulsory powers have access to independent specialist advocacy services. Health Authorities will ensure suitable independent advocacy is made available (5.11)

The role of specialist advocates will be to provide information and, if appropriate, help the patient represent his or her views in discussions with the clinical team about his or her care and treatment under formal powers. (5,12)

In November 2001, the Government published: *Involving Patients and the Public in Healthcare*. This outlines plans for 2 new bodies PALS (Patients Advice and Liaison Service) and ICAS (Independent Complaints Advocacy Services). The plans for both services refer to existing mental health advocacy schemes: ICAS will complement existing advocacy services and so are not intended to replace, for example, current mental health advocacy services. (3.14)

In Leeds, the development of PALS (including mental health PALS to be set up this year) has included working closely with local advocacy organisations, for example, all PALS workers will receive training in the differences between PALS and independent advocacy.

The picture that is emerging on the interface between PALS and independent advocacy services is that PALS workers may be able to pick up issues directly concerning standards in service delivery that are part of the work of currently practicing advocates. This would release independent advocates to provide a wider service than is possible at present.

It is intended that ICAS will provide independent support for people who wish to complain. This is not dissimilar to the current role of the Community Health Councils.

All the above legislation and reports acknowledges the value of independent mental health advocacy. However, it is still not absolutely clear what aspects of advocacy maybe established as a legal right and how the Government intends this to be funded.

#### Possible Future Development of Independent Advocacy

At the time of writing, the government is due to publish *Guide to Best Practice in Independent Specialist Mental Health Advocacy in England and Wales*, the report commissioned from Durham University on the principles and good practice in the provision of advocacy.

This report: Will inform the development of standards for specialist advocacy services. (Reforming the MHA, 5.13)

Once published there will be a further period of consultation. From the draft of this report (and we believe the government intends to publish it in full) the emerging model is of a core service for detained patients with additional elements (e.g.. for voluntary patients and those receiving treatment in the community; minority cultures; CPA, forensic etc) funded according to local need.

Reforming the Mental Health Act proposes that specialist advocacy will be responsible to a new Commission for Mental Health who will be responsible for training and practice standards and for monitoring and reviewing the provision of advocacy to detained patients.

## TRAINING

Respondents to the Durham University Report strongly agreed that:

Advocacy should be clearly defined and professionally delivered by people who are provided with good training, management, support and supervision.

The emerging idea is for an agreed, accredited, standardised training programme that would be adopted by individual groups and or local networks.

Advocacy Standards would cover access, record keeping, policies and procedures, staffing, training, accountability, monitoring and evaluation, feedback, Code of Practice as well as the Key Principles of:

- \* Independence
- \* Confidentiality
- \* Inclusion
- \* Empowerment
- \* Free to the service user

## MODERN MENTAL HEALTH SERVICES NEED GOOD QUALITY INDEPENDENT ADVOCACY

1. Recent examples of service users requesting advocacy include:

\* A young woman who requested advocacy support at her CPA, to change her medication, have regular support in the community and to access psychotherapy after asking for it for 3 years without success. All these were achieved.

\* An older woman who has experienced considerable traumatic life events and has been placed on a ward where she had further bad experiences in the past. She believes people on the ward and outside are plotting against her. The advocate has successfully negotiated her moving to another ward.

\* A man who is involved in complicated divorce proceedings initiated by his wife. There is a great deal at stake for him but as a result of his current state of mind he doesn't feel able to attend court at all or other meetings without an advocate to support him. In court his advocate attends with the status of next friend.

2. Service User Views on having an Independent Advocate:

In a recent survey of service user views on the effects of advocacy interviewees were asked whether anything had changed for the better as a result of having an advocate. Responses included:

- \* The psychiatrist treated me more on a level, with more respect, more credibility for my views and feelings.
- \* Someone else who understood how I was feeling; to communicate that to the doctors, like having a second shoulder to lean on.
- \* When the advocate is not there they treat you as if you don't understand English.
- \* My stay on the ward was adjusted to give me more time to prepare for discharge more fully.
- \* My confidence with having someone to help deal with the situation.
- \* Going through my case with someone neutral – help to think out and plan my appeal.
- \* Help us to get things clear in our own minds (group)
- \* My life!

### 3. Better outcomes for people

Advocacy makes a difference to what happens to people. It leads to decisions about treatment and services being tailored around the individual. People feel better about themselves and their situation. They are more likely to change a situation that they are not happy with. Recent research in Australia (Rosenman 2000) suggests that with advocacy support, people are likely to leave hospital earlier and are less likely to return to hospital.

### 4. Empowerment

Empowerment is now widely acknowledged in health policy as an essential contribution to improving the health of people who are vulnerable and to the health of excluded communities. Advocacy empowers people who are being ignored, giving people support and information to make their own decisions and to take more control over their own lives.

### 5. User-Focused Services

Advocacy schemes in Leeds provide information and feedback about how well services are meeting the needs of their users. This can inform future need and priorities and can assist systems of clinical governance within the Trust and best value in local authorities. Advocacy schemes provide a challenge to service providers to improve what they do and help focus service provision on the needs of service users.

1 LMHAG: Independent Survey of Service User Views, due for publication February 2002