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USER INVOLVEMENT IN MENTAL HEALTH SERVICES:

THE ROLE OF ADVOCACY

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USER INVOLVEMENT IN MENTAL HEALTH SERVICES: THE ROLE OF ADVOCACY

INTRODUCTION

User involvement is a wide-ranging and extremely complex subject but in this briefing we hope to give CHCs basic information about it.

The provision of mental health services has traditionally been based upon paternalism. That is, users received services without question in the belief that the professionals/experts knew best. This belief has been challenged for some time, particularly since the early 1980s. Since that time there has been a gradual emergence of individuals and groups of people who are no longer prepared to be the passive recipients of services. These people are striving to become actively involved in the planning and provision of mental health services.

Government policy documents of recent years encourage user involvement. For example, the introduction to *Local voices*¹ states that the '...aim should be to involve local people at appropriate stages throughout the purchasing cycle: a combination of information-giving, dialogue, consultation and participation in decision-making and feedback, rather than a one-off consultation exercise.'. However the pursuit of user involvement has not been an easy task because there has not been a wholehearted recognition or acceptance of the possible value of user input. If there is to be a total recognition and acceptance there will have to be a change in attitude both by professionals and users.

Although this briefing concentrates on the role of advocacy in promoting user involvement in mental health services it should be noted that the underlying principles can be applied to many people and to many areas of life. For example, people with learning disabilities, elderly people and people from minority ethnic groups use advocates in order to improve their access to services, and on an everyday basis people generally look to others who have more experience or power than themselves for help.

It is important that user involvement becomes the 'rule', in all health related areas, rather than the 'exception'. CHCs can have a role in making this the case.

TERMINOLOGY

'Mentally ill', 'mentally distressed', 'user', 'client', 'recipient', 'patient', etc. Which term or terms should be used? This is a difficult question since there is in fact no consensus. What may be acceptable to some people may be unacceptable and even offensive to others. There are beliefs however that: no one should use language about others without their general consent; that decisions about the exact meaning of each term should be made individually - people should not have labels imposed upon them; and that since there is no consensus common terms such as 'user' should be kept under review. Whatever the

terminology it should be remembered that people have a right to self-definition ie to choose how they would wish to be described.²

ADVOCACY

One of the many ways in which user involvement has been pursued has been through advocacy. Advocacy is a concept that is rapidly gaining interest, but what does it mean? At the present time many see advocacy as meaning 'giving power to the powerless' or 'including the excluded'. Advocacy involves giving people the opportunity to express their views and needs freely, listening to their views and taking account of them.

There are different forms of advocacy: self advocacy, citizen or lay advocacy and paid or formal advocacy. The 'means' differ but the 'ends', empowering and enabling people, are the same.

Self Advocacy

'People in high authority should listen to people with special needs. It is important that we should get together to sort problems out.'

(Self advocate - Calderdale Advocacy)³

Expressing an opinion or making a complaint about something is to act on your own behalf or to act as a self advocate. People act as self advocates in pursuit of their own beliefs and interests. This is something that most people take for granted. However there are some people who find it difficult to express themselves or whose views are considered to be of less importance than the views of others. This is often the case with users of mental health services.

The psychiatric system is such that users have very little say about how services are or might be provided. Outside of the system the stigma attached to mental health users by the wider society serves to devalue what they say. The 'mentally ill' label tends to undermine what people have to say.

In order to express yourself you have to value yourself and believe that what you say will be listened to and taken notice of. In everyday life many people choose to remain silent rather than face the humiliation of being belittled or ignored.

In mental health self advocacy people with mutual concerns often come together in order to try to instigate change, whether this be in the provision of services or in an effort to change the attitudes of the people in the wider society.

Self advocacy groups often work to change the local situation, for example, the conditions in a particular hospital. After years of reluctance, many professionals have come to realise that participation by and consultation of users is the most effective way of ensuring that service provision meets the needs of users. There are some national self advocacy networks, for example *Survivors Speak Out*, which concern themselves with wider and more general issues such as the use of compulsory treatment.

As well as aiming to bring about change, self advocacy groups also offer support to individuals. Members of the group help themselves as well as helping each other.

Support Workers

Self advocacy groups sometimes work in alliance with professionals in a support/advisory role for example, giving advice on setting up committees or on how best to tackle a particular issue.

As is the case with citizen advocacy, support workers must guard against doing too much for a group which would in effect be disabling, rather than enabling. They must also guard against doing too little for a group. It is possible that opportunities might be missed without the guidance and contribution of the support worker.

Support workers should have access to training and support in order to help them to maximise their usefulness to self advocacy groups and to help them to minimise potential conflict between themselves and the groups they are serving. For example, a support worker needs to accept that the group may take decisions with which s/he disagrees and the worker may even need to be able to cope with a decision made by the group that could be potentially damaging to the worker's own career.

Citizen Advocacy

'I don't think anyone ever knows how much they can gain and learn until they become involved as a citizen advocate and until they can see the difference that one person can make to another person' (Advocate - Calderdale Advocacy)⁴

Citizen advocacy also known as lay advocacy is a one-to-one partnership between an individual who is in some way disadvantaged - the partner, and another who is not - the advocate.

The advocate in these circumstances will take a personal interest in the partner and will aim to make sure that the partner's interests are effectively put forward. Advocates must however guard against imposing their views on their partner.

The advocate should be independent of service provision and should at all times act in the best interests of his/her partner. It is possible that loyalty to a partner may at times result in conflict between the advocate and the partner's relatives or friends. Relatives and service providers may think that they know what is best for the partner but this may not necessarily be the case, eg relatives may make decisions based upon what might ease pressure on themselves, rather than on what is best for the partner.

Who Needs an Advocate?

Citizen advocacy can help a wide range of disempowered people:-⁵

- people who live in hospitals or are just leaving for community living
- people who are at risk from others for various reasons, for example, as a result of learning difficulties or mental distress
- people whose voice is not understood, like those who have speech problems or do not speak English
- people who lack a voice, such as children and some elderly people
- people who are unable to safeguard their rights for themselves

Citizen Advocates

Citizen advocates are unpaid volunteers from all walks of life who have chosen to spend a regular amount of time with their partner. In citizen advocacy it is important that the role of advocate is not seen as a job by either the partner or the advocate. Often the main non-disabled people in the lives of those, for example, with disabilities, are those who are paid to be there.

It is important that the relationship between partner and advocate should develop over a long period because in that time those involved will be able to build up a relationship of trust and often friendship. It is often easier to express your true feelings with someone you have known for some time. Long term development is also important since people who suffer from protracted illnesses often meet large numbers of people who just come and go in their lives, eg consultants, GPs. A longer term relationship will offer some stability.

Citizen advocates sometimes have to tread a very fine line between doing too much for their partners and not doing enough. Doing too much can lead to dependency and would in some cases defeat the object of working towards self advocacy, whilst doing too little can lead to a sense of letting the partner down.

An important aspect of citizen advocacy is that of being a friend of a 'valued' person. It is unfortunately sometimes the case that staff, members of the public and others show more respect to someone who has an advocate, that is, someone who has links with a valued person; **'They can be quite patronising, these consultants. Having somebody there who has authority makes all the difference. They treat you with some respect.'**⁶

Citizen Advocacy Schemes

It is the role of citizen advocacy schemes to locate and match partners and advocates and to provide support for those relationships. Ideally one member of staff should be a paid full-time co-ordinator to ensure long term continuity of the scheme. Just as advocates should be independent of service provision so too should citizen advocacy schemes.

Citizen advocacy offices should be independent from service providers in funding and location. Their services are likely to be more effective if people are aware of their independence. Citizen advocacy schemes should ideally be run by a management committee which includes the following local people: people with disabilities; people with influence in the locality; people with skills useful to the organisation eg fundraisers, accountants; and advocates and partners.

Advocacy schemes should aim to create a diverse set of citizen advocacy relationships. They should aim to give people, including those of different ages, sexes, ethnic minorities, and disabilities, the opportunity to form a citizen advocacy relationship. The schemes should aim to encourage advocates with different backgrounds to volunteer.

Some citizen advocate schemes offer training but many, rather than offering formal training, prefer to offer support and guidance when required.

Paid Advocacy

In paid or formal advocacy, paid advocates use their professional skills to represent individuals and in some cases defend their rights. In such cases the relationships between partners and advocates are usually on an ad hoc and short term basis ie the partnerships are usually formed to deal with a specific issue.

Legal Advocacy

Paid advocacy is largely considered in terms of legal advocacy which involves providing formal legal advice and representation for a wide range of problems. Legal advocacy services are not well developed in England and Wales but the Legal Department of MIND offers some specialist legal advice and representation, and Citizens' Advice Bureaux can offer some legal advice.⁸ The most notable legal advocacy project in this country is that at Springfield Hospital in London.

The Project at Springfield Hospital, known as the Advice and Legal Representation Project started in 1982 as a legal advice service for mentally ill people in the hospital.⁹ The aim of the Project, initiated by a group of workers from law centres in the area, was to make legal services accessible to people in psychiatric hospitals. The Project was eventually set up within the hospital. Importantly, although the service is run from the hospital it is independently funded - the Project is a registered charity.

The Springfield Centre provides advice and representation to inpatients, outpatients and day patients on matters relating to the Mental Health Act 1983, housing, welfare benefits, crime, matrimonial and child care issues and acts as an educational resource. Hospital staff can also use the Project providing there is no conflict of interest between patients and the staff involved. If necessary people are referred to outside agencies, such as CHCs, for independent advice.

The Springfield Project has been a continued success but a King's Fund evaluation states that the Management Committee 'believes

that, with the increasing emphasis on Community Care, advice facilities in the community should be made more accessible to the mentally ill.¹⁰

Community Health Councils as Advocates

CHCs can be said to be formal advocates. CHC staff often provide people with information about services - allowing them to make informed choices, rather than having someone else's choice imposed on them. They also assist people with complaints - the sheer complexities of complaints systems are daunting to most people and as such can be disabling. In addition, they represent or assist complainants at official hearings, for example, at FHSA Service Committee hearings. The assistance of CHCs gives people the confidence to pursue their complaints in the belief that the presence of CHCs makes their concerns more likely to be listened to. It is often more difficult for authorities to dismiss a CHC than it is to dismiss an individual. As well as acting as advocates some CHCs have been involved in setting up or supporting advocacy schemes.

THE WAY FORWARD

Users should be involved in the provision of services from the planning stages. Involvement at this stage means giving users the opportunity to articulate their needs and to express their opinions. There is little point to including users when plans have already been formed since their involvement at this stage could be seen to be little more than a token gesture.

User involvement should be an ongoing process where users are encouraged to comment upon service provision whether the comments be negative or positive. These comments should then be incorporated into any systems of monitoring service provision.

It is difficult to see how user involvement will become widespread practice unless there are positive changes in attitude by both users and professionals. Professionals and users will have to recognise that it is not always the case that 'professionals know best'; professionals will have to acknowledge that user input does not have to be perceived as a threat; and it will be necessary to make efforts to remove the stigma attached to a diagnosis of mental illness - mental illness can affect anyone at any time.

It is essential that any developments in user involvement are underpinned by equal opportunities policies. Discrimination can be a very real obstacle to user involvement. People who have been labelled 'mentally ill' often face discrimination on the grounds of their psychiatric history and are treated as conditions rather than as people. Mental health users come from a wide range of communities, therefore when recruiting advocates, workers, etc, they should be selected from backgrounds that reflect those of the users.

User involvement does not mean consulting with those who are perceived as being 'easy' to manage, ie handpicking a few people because it is known that they will not challenge the views of the providers. Neither does it mean choosing the same groups of

people to represent the wider communities. Different issues will require the involvement of different people or groups of people.

There should be equality of access to all health services. To secure their rights of access some mental health users may need advocates - providers and purchasers of services must be aware that this may be the case and should act accordingly.

Resources

Increased user involvement cannot be achieved without cost. For example, training costs must be met - advocates may need training in how best to represent their partners; users may want or need training in how to read reports and committee skills. Such training would allow the users to participate more fully in meetings, thereby reducing the dominance of professionals.

Expenses will also be incurred for; the establishment and day-to-day running of individual schemes; information exchange; and also for encouraging people to attend meetings - amongst other things it may be necessary to provide transport to and from meetings and creche facilities.

The CHC Role

Information

CHCs are well placed to be able to provide users, professionals and members of the public with accurate information about, for example, the availability of services or about the nature of different types of 'mental illness'. Such information would enable users to make informed choices and decisions; would demystify mental illness for members of the public - thereby breaking down some of the barriers between users and non-users; and could provide professionals with user views and perspectives, enabling them to tailor services appropriately.

Participation

CHCs can establish mental health working groups or sub committees where mental health issues can be discussed and outcomes fed back to the policy makers. CHCs should encourage participation in these groups from representatives of users or ex-users as members or co-optees.

Practical help

User groups will often be faced with severe financial limitations. CHCs can help to ease financial difficulties by providing practical assistance, such as the use of rooms for meetings, secretarial support, photocopying facilities etc. Such help may only be necessary whilst a group establishes itself.

Contracting

When purchasers are contracting for services CHCs can encourage user involvement and urge purchasers and providers to consider user perspectives.

Consultation

CHCs can consult with users to find out what they want. Consultation can be in the form of surveys, user forums and networking with local groups in the area.

Establishing Advocacy Schemes and Advice Centres

Sponsorship for the establishment of such schemes is usually by DHAs, Social Services Departments or both, and is as a result of establishing the need for the provision of such services.

Bradford CHC has recently set up an advocacy scheme with joint finance from the DHA and the Social Services Department. The finance has enabled the CHC to employ and manage two professional advocates on a part-time basis and a clerical officer. The advocates currently act on behalf of elderly people and people with learning disabilities - encouraging them to speak up for themselves. They will also look at issues that affect people from minority ethnic groups.

South Bedfordshire CHC in conjunction with the DHA is setting up an information, advice and advocacy unit. This development has come about largely as a result of the requirements of the Patient's Charter and the need to make information about services clear and accessible to residents in the district.

CHC PUBLICATIONS AND PROJECTS

Publications

Users' views of acute psychiatry -Great Yarmouth and Waveney CHC (1989)

Multi Ethnic Women's Health Project: health advocacy for non-English speaking women - City and Hackney CHC (1985)

An Experiment in Advocacy: The Hackney Multi Ethnic Women's Health Project - City and Hackney CHC and The King's Fund (1984)

What Is Needed For Mental Health - Waltham Forest District CHC and Waltham Forest Association for Mental Health (1983)

Barnet Linkworker Project: our first two years - Barnet CHC (1988)

Advocacy - Report of a conference held on 19 June 1991 - GLACHC (1991)

The First 24 Hours [after admission into a psychiatric hospital] - North and South Manchester CHCs and Manchester Mind (1992)

Having A Voice!: for people who use mental health services in North Manchester - North Manchester CHC

Being Vocal: views of mental health users about experience of services from first contact to community care - Richmond, Twickenham and Roehampton CHC (1990)

Projects

S W Surrey, N W Surrey and N E Hants CHCs held discussion day about advocacy (1992)

Barnet CHC set up a 'Mental Health Day' (1988)

Trafford CHC set up a Mental Health Task Force and surveyed mental health inpatients and carers (1989)

Newcastle CHC worked with DHA to establish consumer councils within mental health units (1990)

Nottingham CHC organised training day for advocacy skills (1990)

Calderdale CHC produced leaflet on 'Calderdale Advocacy' (1990)

Tameside and Glossop CHC held advocacy and user involvement in mental health services conference (1991)

Richmond, Twickenham and Roehampton CHC held a day conference for mental health service users and informal carers (1990)

Richmond, Twickenham and Roehampton CHC held a conference for users, carers and professionals (1992)

FURTHER READING

MIND Publications, The MIND Guide to Advocacy in Mental Health - Empowerment in Action (1992)

Lawrence R, The Volunteer Centre , Volunteers as Advocates (1982)

Wertheimer A, The King's Fund, Making Our Voice Heard - Strengthening Alliances Between People Who Use Services (1989)

Values into Action (Formerly Campaign for People with Mental Handicap), Self Advocacy Pack

Butler K, Carr S, Sullivan F, National Citizen Advocacy, Citizen Advocacy: A Powerful Partnership (1988)

Survivors Speak Out, Self Advocacy Action Pack (1988)

King's Fund, The Advice and Legal Representation Project at Springfield Hospital 1982-1985 - an evaluation (1986)

Community Care 26 March 1992, Involving Service Users

Good Practices in Mental Health, Power in Strange Places - User Empowerment in Mental Health Services (1987)

Lambeth Link Self Advocacy Project, Charter '90 - A charter of the needs, aspirations and requested rights of people who use and attend mental health services in Lambeth (1990)

Harding T, Upton A, National Institute for Social Work Information Service, User Involvement in Social Services - an annotated bibliography (1991)

USEFUL ADDRESSES

Good Practices in Mental Health
380-384 Harrow Road
London W9 2HU

MIND
22 Harley Street
London W1N 2ED

Citizen Advocacy Alliance
Unit 2K Leroy House
436 Essex Road
London N1

Lambeth Link
30 Acre Lane
London SW2

Nottingham Patients Council
Support Group
9A Forest Road East
Nottingham NG1

Survivors Speak Out
Peter Campbell
33 Lichfield Road
London NW2

Citizen Advocacy Alliance (CAA)
Douglas House
26 Sutton Court Road
Sutton
Surrey SM1 4SY

WALES MIND
Development Officer User Involvement
23 St Mary Street
Cardiff
Wales

Leeds Patient Advocacy Service
Health Unit
2nd Floor
Civic Hall Annexe
Leeds City Council
Leeds LS1 1UR

REFERENCES

- (1) NHS Management Executive: Local Voices - The views of local people in purchasing for health January 1992 (Issued with EL(92)1)
- (2) MIND: MIND's Policy on User Involvement - Policy Paper (1991)
- (3) Calderdale CHC, Calderdale MENCAP, YTV Telethon Trust: Calderdale Advocacy (Information leaflet)
- (4) See 3
- (5) MIND: The MIND Guide to Advocacy in Mental Health - Empowerment in Action (1992)
ACHCEW AGM Workshop Paper: Advocacy (1991)
- (6) Phillips A: Doctor, meet my advocate (*Observer* 14.4.91)
- (7) Butler K, Carr S, Sullivan F: Citizen Advocacy - A Powerful Partnership (1988)
- (8) MIND See 5
- (9) King's Fund: The advice and legal representation project at Springfield Hospital 1982-1985: an evaluation (1986)
- (10) See 9