

# Health & Social Services Committee

## HSS(2)-14-04(p.6)

Date: Wednesday 24 November 2004

Venue: Committee Rooms 3 & 4, National Assembly

Title: The National Service Framework for Mental Health: Standard 2 – User and Carer Participation: Response from South Wales Advocacy Network

### 1. Full and genuine participation

Genuine service user & carer participation means that people who use the services of an organisation or who wish to contribute to service planning, etc have real opportunities to get involved and influence decisions.

For example, in terms of staff recruitment, genuine user involvement could mean running two parallel recruitment processes - one undertaken by service managers and one done by service users. This has been used by, amongst others, Mental Health Matters (Bridgend) and in the recruitment of the 2 Mental Health User Involvement Development Officers in Bro Taf (as was). Both these recruitment exercises involved

- A presentation to both panels
- Separate interviews by managers and service users
- Joint decision-making on the outcome - neither panel could over-ride the other's decisions

This represents real involvement, rather than the (arguably) tokenistic approach of simply having 1 or 2 service users or carers on a recruitment panel.

### 2. Barriers to user/carers participation

#### 2.1 Care planning

Service users and carers are often at a disadvantage in care planning because they do not have the same levels of knowledge about available treatments and services as professional staff.

Service users (and probably carers, too) can sometimes feel intimidated by staff when care plans are being discussed at multi-disciplinary meetings, since there are often many staff present.

A further difficulty is that staff have power, in certain circumstances, to enforce compulsion through use

of the Mental Health Act 1983. Sometimes, the effect of this can be to prevent the service user from articulating their true wishes and views.

Advocacy services, which can support service users through care planning, are very thinly spread and under-resourced.

Advance directives, setting out what service users want in terms of services, treatment, etc, should be encouraged and taken seriously.

## **2.2 Service planning, commissioning, etc**

If service users (and staff!) are familiar with a particular model of service, they can be reluctant to see it change. Everyone involved in this work should be offered opportunities to visit areas with different service models, so that decisions can be made on the basis of informed choice.

Service users are very often disadvantaged by a lack of resources to enable them to participate fully in this work. This includes access to computers and the internet (for information) and money - for travel and subsistence.

There can also be problems caused by the timing of meetings (early mornings are sometimes difficult for people who are on certain types of medication) and the jargon used at meetings. This latter issue is increasingly problematic, as both health and mental health are highly complex areas and a great deal of "shorthand" is used when discussing them.

Tokenism is also a big problem. As in point 1 above, simply inviting one or two service users to participate in - for example - joint planning meetings does not constitute genuine service user involvement! Ideally, the service users who sit on joint planning groups should be mandated by a wider group of service users who have had the time and opportunity to discuss the agenda items and arrive at a view on them. This is difficult to achieve at present because of the following

- Agendas and papers for meetings often not being sent out well in advance of the meeting - hence, service user reps have not had an opportunity to discuss the issues with their colleagues
- The absence across most of Wales of User Involvement Development Officers (UIDOs), whose job it is to support service users to have a say in decision-making. This can involve developing and supporting forums of service users who meet regularly to discuss mental health issues and services and who can brief service user reps on joint planning. UIDOs must be independent of service providers, so that they are free to provide the kind of support that service users want.
- Professional staff who also sit on joint planning teams must have received some training on user involvement, so that they understand why it's important and valuable (can be another role for the UIDO). They also need to be clear that if genuine service user involvement is to work then

decision-making will take longer since more people are involved. The practical steps that can be taken to make involvement a reality (eg. timing of meetings, venue, sending out of agendas, etc) also need to be discussed and agreed. There also needs to be a common understanding that service user views will be listened to, minuted and acted upon where possible!

- Planning and commissioning mental health services seem to be either very poorly - or not - linked. Thus while service users may be involved in some way in planning, this often bears little relation to commissioning! Service user involvement in planning is tokenistic if there is not a robust link between planning and commissioning.

### **3. Overcoming the barriers**

#### **3.1 Care Planning**

All service users who are subject to care planning should be offered the support of a competent Advocate.

Care plans should not be drawn up at large multi-disciplinary meetings.

Service users should be encouraged to draw up advance directives and these should be followed by professional staff unless there are serious reasons why the advance directive can't be upheld. Advance directives must be included in care plans.

#### **3.2 Service design, planning, etc**

Every Trust area should have a UIDO whose role would be to support service user involvement and work with the statutory sector to help them in achieving service user involvement. The UIDO should be independent of service providers. (See the Bro Taf UIDOs for a model of this type of service). UIDOs should hold a budget to pay for travel expenses, hire of meeting rooms, etc.

Statutory organisations need to recognise that if service user involvement is to be genuine, decision-making will take longer, since more people will be involved. This will need to be built into their plans. This will also affect WAG, since it will need to give statutory organisations more time to implement guidelines, respond to initiatives and consultations, etc if those statutory bodies are to involve service users in their discussions and decisions.

### **4. Roles**

#### **4.1 Health**

Should mainly fund UIDO posts, since Health is the biggest provider of mental health services.

## **4.2 Voluntary sector**

If funded, should employ UIDOs and provide advocacy services. Should continue to lobby for greater user involvement in mental health.

## **4.3 Local authorities**

Should contribute to funding of UIDO posts.

## **4.4 WAG**

Should provide prescriptive guidance on user and carer involvement

Should devise performance management criteria for user and carer involvement

Should provide prescriptive guidance regarding the planning and commissioning of mental health services, making explicit mention of user and carer involvement

Should roll out the User Involvement pilot projects in Bro Taf across the whole of Wales

Should continue to make user and carer involvement a SaFF target in the medium term, until there is clear evidence of equitable and successful user and carer involvement across Wales

## **5. Examples of good practice**

The 2 WAG funded pilot projects in the old Bro Taf Health Authority area. The external evaluation of these projects, whilst not yet completed, has been favourable.

## **6. Evidence of stigma**

Whilst I can't speak for service users on the issues of stigma and discrimination, I understand that there is a great deal of evidence to show that stigma and discrimination continue to be major problems for service users.

Clearly, tackling these issues is not easy. Suggestions for so doing include strengthening the law on discrimination and running a public information and education project on mental health (I believe this has been undertaken in Scotland).