

Health and Social Services Committee

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Meeting date: 12 January 2004

Meeting Venue: Committee room 3, National Assembly for Wales

Title: Evidence to Health and Social Services Committee from Lorraine Best

Jayne Westlake
Clerk to the committee
Welsh Assembly Government
Cardiff
CF64 2QL

Re: Policy Review: The National Framework for Mental Health: Standard 2-User and Carer Participation.

Dear Colleague,

I am writing to members of the Health and social services committee and, as an individual, a past service user and as chairperson of the committee for Cardiff and the Vale service user Mental Health Forum, I am giving evidence to the committee on the following terms of reference for the review:

1. Review the current requirements and guidance for the involvement of users and carers in the development of individual care plans; and
2. Review the current arrangements for user and carer participation in planning, design, commissioning, delivery, monitoring and evaluation of mental health services.

1. What does 'full' and 'genuine' participation mean to you/your organisation?

Full and genuine participation means that at all stages of mental health service planning, design, commissioning, delivery, monitoring and evaluation that ex and current mental health service users are fully engaged in this process. In theory this may seem to be the case, but to my self and many other service users this does not happen in practice. It is essential that for the satisfactory and accurate representation of service users that agreement by service user organisations be a vital part of any proposals that emanate from the Policy review. For the effective and practical representation of the

many service user organisations it will require a coordinating committee to establish a unified presentation of service users demands.

2. What are the barriers to full and genuine user and carer participation in:

a) The development of individual care plans; and

In the planning, design, commissioning, delivery, monitoring and evaluation of mental health services?

a) The proposals for Care Plans are such that the Mental Health Act does not require voluntary agreement to the Care Plan by the patient. If the patient does not comply with the Plan they can be forcibly detained for successive periods of 28 days. Users feel that forcible detainment and compulsory administering of drugs is not a good way to gain acceptance of therapeutic treatment, or a willingness to participate fully and genuinely in changes to their mental health services.

b) My self and another forum committee member attended the Joint Operational Group meeting as Mental Health service user representatives. We both gave the administrator of that meeting our name and address and were told that we would receive the minutes. This did not happen and consequently we were unable to give feed back of the JOG meeting to the members of the Forum and this also resulted in not having information on the next JOG meeting, leaving service user representatives unable to attend. This is indicative of the poor response to service user requirements throughout the mental health services.

Another barrier to full and genuine participation is that there are not enough service users coming forward and attending the forum: A strategy needs to be put in place, involving communication with existing members of the forum and mental health/support workers from voluntary and statutory organisations, where by we can work towards full and genuine participation.

To overcome these barriers, different levels of training should be made available for service users, in order that they can build on their confidence, self esteem and their existing skills enabling them full and genuine participation.

Another barrier that needs addressing, for full and genuine participation to initially take place, is for those service users on prescribed psychiatric drugs, to have regular reviews on them, by mental health professionals and to be given full information on their side effects, that they may be well informed when making an important decision on the pros and cons of taking them. The nature of intervention from psychiatry using the medical model, more often than not ignores the individual's social situation/ environment and does not offer alternative therapies. Many mental health service users have been taking psychiatric drugs for years, which bring on numerous side effects that include, constant tiredness, lethargy, short concentration to name a few and have no on going support from mental health services to alleviate the condition people find themselves in.

3) How can these barriers be overcome and by whom?

As I have illustrated above in previous answers, the barriers to full and genuine user and carer participation require a meaningful and recognisable consideration of Mental Health service user/carer needs. This can only be achieved by the users/carers themselves and therefore requires a coordinating committee to establish a unified presentation of service users demands.

4) What should be the role of:

- i. the LHB
- ii. the NHS Trust
- iii. the Primary Care Team
- iv the Voluntary sector
- v the Local Authority
- vi the Service User/Carer?

An essential requirement of all these bodies and organisations is communication.

The Welsh Assembly Government is in a prime position to demand the bringing together of all the above parties to bring about a full and genuine response to Mental Health Service User needs.

5) I have been unable to identify a good example of good practice that is worthy of inclusion.

6) As you have asked for responses to be as succinct as possible I will not attempt here to provide the masses of evidence of stigmatisation, which the labelling of people with mental health problems inflicts on the individual. What I will say is that past, present and future (if the proposed New Mental Health Bill goes through Parliament) legislation has done nothing to de-stigmatise Mental Health problems, but has in fact exacerbated the situation.

I would welcome the opportunity to give oral evidence to the committee having had much experience as a victim of the Mental Health System.

Yours sincerely

Lorraine Best

