

Health and Social Services Committee

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Date: Wednesday 2 March 2005

Venue: Committee Rooms 3&4, National Assembly for Wales

Title: Policy Review: The National Service Framework for Mental Health: Standard 2 – User and Carer Participation - Response from Newport City Council

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

The aspiration is to create a level playing field – where in the true meaning of partnership everyone whether user, carer or professional is of equal value and has the opportunity to voice their views and be heard. Furthermore the ideas and comments put forward by users and carers need to be actively listened to and acted upon. This is to ensure that participation is meaningful and rewarding experience for all parties. Users and carers should never be treated as or made to feel inferior or second rate.

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

a) The development of individual care plans;

For some people the fear of criticising a professional or a service could be daunting especially if that person is treating them, or they rely on them for access to services.

There are also resource and capacity constraints as participation takes time and skills on the behalf of the professional assessing needs and organising individual care.

Individuals also need comprehensive and up to date information on the range of service options available to meet their needs before they can make informed choices.

Some individuals may lack capacity to understand all the issues involved and may require additional help in order to maximise their involvement in decisions regarding their own care.

Professional jargon.

b) The planning, design, commissioning, delivery, monitoring and evaluation of mental health services?

Professionals and organisations need to recognise that there are real barriers to user participation and understand that we need to change our approaches to overcome these barriers.

Generally a major barrier to full and genuine user and carer participation is the lack of processes and resources which support people to participate. This includes the time commitments required to attend meetings read documents and canvas other users/carers views.

Furthermore users and carers need to know how and where decisions are made so that they know where to focus their influence.

There are issues around the written and spoken language and how the use of jargon and acronyms can be confusing for service users and their carers.

In regard to consultation documents and bids for developing new services there are often very tight deadlines which militate against maximising user and carer participation.

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

Ensure the process of involvement is regular and consistent. Users and carers tend to be invited to participate when there is something specific to ask them. Organizations need to be more systematic in reviewing services on a regular basis, getting feed back and views from people who are using services and obtaining their views on how and what services they feel should be developed.

Professional and organisations also need to make clear that we will respond to their views and that we are not just involving people for the sake of it. If we do not change it then we at least need to tell people why.

There needs to be a genuine desire from all parties to promote user and carer participation. User led training and other strategies can be aimed at changing the professional culture.

The barriers could be helped to be removed by working more closely together, really listening to what people say and having good advocacy services which support people to have a voice.

Professionals and organisations need to employ a range of models and techniques in order to maximise participation. The strategy should be proactive and seek out views in a variety of ways.

4. What should be the role of:

i. the LHB

They should take a lead in developing user involvement when commissioning health services.

ii. the NHS Trust

As the major healthcare provider trusts should collect and collate comments and feedback on services delivered.

iii. the Primary Care Team

As first point of call for most of the population they are important in reaching out to the broadest cross section of the population possible.

iv. the voluntary sector

The role of the voluntary sector is twofold. Firstly to provide services which complement and enhance those provided by the statutory authorities. Secondly to help users and carers to voice their opinions through independent advocacy, self help support groups, campaigns and pressure groups.

v. the local authority

As a democratically elected organisation councillors are ideally placed to lobby on behalf of their constituents. Also as a major provider of services their officers have access to a wide range of the population.

vi. the service user/carer?

Issues in regard to representation are sometimes raised particularly in regard to user representation on planning committees.

5. Please identify examples of good practice in encouraging full and genuine participation by users and carers in all aspects of mental health services.

In regard to individual care the recovery and tidal models provide principles and practice guidance to inform professionals and users alike. Both facilitate a self management process where the user retains maximum control of their life and are supported to realise their potential in the areas they choose. This

requires services and professional adopting a whole person and whole systems approach to mental health which recognises that people with mental health problems may require help in many aspects of their life not just management of their illness. Issues relating to accommodation, relationships, finance, leisure, physical health and employment are equally if not more important for service users and their carers.

Hafal in Newport have developed a respite care and drop in service that recognises the needs and wishes of both users and carers. Users and carers are encouraged to organise and manage activities at the centre, to become volunteers and some eventually members of staff. Similarly staff are able to support users and carers representatives on planning committees by explaining issues in depth before and after meetings and providing relevant information on current issues.

6. In addition, the Committee would be interested to have evidence on whether people with mental health problems feel stigmatised, and if so what should be done to eliminate it.

Consultation on the Health Social Care & Wellbeing Strategy with users of mental health services provided clear feedback that stigma and discrimination are very important issues. This has been well documented.

Standard 1 of the National Service Framework for Adult Mental Health provides an opportunity to look at tackling stigma as part of a mental health promotion strategy. However due to uncertainty and ambiguity as to who is responsible for this area of work, i.e. WAG, LHB's, Trust, Local Authorities, Independent sector, there is a danger of this important component becoming the poor relation within the NSF. WAG need to take a clear lead and provide dedicated adequate funding if the aims and objectives of Standard 1 are to be met.

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