

Health and Social Services Committee

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

Title: Policy Review of the National Service Framework for Mental Health: Standard 2 - User and Carer Participation - Evidence from Pembrokeshire and Derwen NHS Trust

1. Introduction

The following information was collated in response to the Health and Social Services Committee policy review, in relation to the NSF Standard 2. The information was gained through interviews with the General Managers and Senior Practitioners within the Mental Health and Learning Disabilities division of the Trust. The responses are summarised for ease but include all relevant responses.

2. Terms of Reference

i) Review of current requirements and guidance for the involvement of users and carers in the development of individual care plans

The Trust aims to fully involve users and carers (where appropriate) in the setting of individual care plans. It is felt that this is the most effective way of treating patients as they are far more likely to be engaged with a plan that they have agreed and signed up to and this in turn enhances the chances of their plans succeeding.

The Trust has an Integrated Care Management Policy, which includes the FACE (Functional Assessment of the Clinical Environment) assessment and monitoring tool, and the Care Programme Approach (CPA), and also includes elements of UAP (Unified Assessment Process). CPA will be fully implemented by December and will formalise the processes in terms of patient/carer involvement in setting individual care plans. The model that CPA has been based on is the Joint Care Plan approach, which the Trust currently applies to individual care planning. CPA will therefore formalise and expand on the processes that are already being followed within the Trust. This will ensure that all patients/carers are involved in setting individual care plans.

ii) Review of the current arrangements for user and carer participation in planning, design, commissioning, delivery, monitoring, and evaluation of mental health services.

Mental Health services are delivered across three localities within the Trust, Pembrokeshire, Carmarthenshire and Ceredigion and each of these areas have individual arrangements for local user involvement.

Ceredigion has a patient council established which is used to consult over all aspects of mental health services. The other two localities are in the process of setting up similar patients' councils.

There are Joint Implementation Groups (JIGs) in each of the localities. These contain user representation and meet to discuss mental health services.

The Trust organises mental health events that are taken to each of the localities. These are used to educate patients and the public and also to consult over mental health services.

Each of the localities have many examples of good practice such as inpatient focus groups, representatives on interview panels, community mental health business meetings with user representation, forum meetings etc. However it is not felt that the Trust is achieving 'full' and 'genuine' participation as is discussed later in the report.

3. Local Position

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

Full and genuine participation means involving users/carers and the public in every aspect of individual care, service planning, delivery, monitoring, change, commissioning etc. This participation must be embedded in everyday practice; the views expressed must be actively listened too and acted upon. A model where the views of users/carers and the public are actively sought and acted on in all aspects of mental health services will demonstrate full and genuine participation.

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

a. The development of individual care plans

Often users do not want to be involved in agreeing an individual care plan, particularly in cases where they do not believe themselves to be ill. Also, users do not always have the necessary knowledge of what their options are, enabling discussion with the person developing the plan with them. If they do not know options available to them, then it can be difficult to make an informed decision.

Resources can also be a barrier to full and genuine participation in developing individual care plans, this can mean that there is not always sufficient time put into each individual care plan. Staff training and capacity have been highlighted as a barrier, with staffing levels and resources making this difficult to address.

Advocates may only really become involved in the more 'high profile' patients and so the less conspicuous patients may have less representation and support.

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

Many users/carers are not able to give their time to this work and therefore it is often a small group that attends the majority of consultation events. The concept of 'full' and 'genuine' participation requires substantial consultation and it is not always possible for this small group to do all of this.

The most important issue is a lack of resources to encourage participation from a wider group of users/carers, such as paying travel and work expenses. Also there are difficulties in funding replacement carers costs whilst a carer attends consultation events, taking consultations to a wider range of locations and at various times outside of office hours etc.

Large-scale public consultation can be very difficult for some users, and therefore important to use a broad range of consultation approaches to overcome this, again resource intensive. The geographical difficulties of the area served to make this even more of a challenge, and having extra resources for consultation would help to overcome this barrier.

Past experiences of consultation have not always had the expected results for users and this can be off-putting in terms of further engagement.

3) How can these be overcome and by whom?

The response is included in point 4.

4) What should be the role of:

i. The LHB

Through the collegiate commissioning process:

- To provide extra resources for consultation, user/carer and staff training etc
- To provide facilities for consultation

- To provide resources for increased advocacy services
- To make consultation a key part of the Health, Social Care and Well Being Strategy
- To widen consultation on planning service provision, service evaluation etc
- To act on the responses from consultation work
- To recruit users/carers for consultation
- To provide resources for a dedicated PPI officer within each geographical locality and speciality (Patient Experience Facilitator currently developed between Pembrokeshire LHB and the Trust)

ii. **The NHS Trust**

To work within the collegiate commissioning process to develop:

- Full and genuine participation in all aspects of service provision
- Consultation in a genuine way e.g. to have consultation at all relevant stages of a process, to act on the responses and seek compromises where possible.
- Promote the worth of individual care plans to users/carers and staff
- Provide a dedicated PPI officer within each locality and speciality
- Train users/cares and staff in consultation work
- Through CPA trained staff in all aspects of designing individual care plans, ensuring sufficient time is given to each patient, allowing the best reflection of their wishes and needs where appropriate
- To work constructively with advocates to ensure that patients needs are best met

iii) **The Primary Care Team**

Through the collegiate commissioning process:

- To bridge the gap between primary and secondary mental health services and their development
- To educate users/carers participation and encourage them to become actively involved in their own care, as well as service planning and delivery etc
- To seek user involvement in health promotion issues as well as mental health issues

iv. **The voluntary sector**

Through the collegiate commissioning process:

- To share the responsibility for promoting user/carer involvement and for seeking representatives across all localities and specialities
- Develop user/carer forums providing training and support across all localities and specialities
- To provide advocacy services across all localities and specialities

v) The local authority

- To be involved as equal partners in consultation
- To develop and promote joint consultation work in the same ways as the collegiate commissioning group

vi. The service user/carer

- To be able to give time to be actively involved in individual care planning and consultation
- To represent the views of those that they represent
- To have reasonable expectations where some wants/needs are difficult to meet, and to look for compromises in these situations
- To be committed to working towards the agreed and joint consultation process

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

- Users/carers are invited to form part of many interview panels for senior posts
- PPI training days will soon be delivered to staff from all areas of mental health. Action learning sets will be formed following these training days and PPI action plans will be set and monitored
- The development of a Patients Council at Afallon Ward, Aberystwyth, facilitated by advocates from Ceredigion and Powys. All three localities within the Trust are in the process of developing Patient Councils
- Many inpatient wards within the Trust hold weekly Community Meetings where users discuss any issues that they may have
- There was user involvement in the development of the Bro Cerwyn site, which subsequently received an award for its design. All major service changes within the Trust have significant public and patient involvement
- Joint Implementation Groups in each of the localities have user/carer representatives

6. Do people with mental health problems feel stigmatised and if so what should be done to eliminate it?

Every person interviewed responded that yes, mental health patients do feel stigmatised. The root cause of the problem is a lack of understanding within the general population about the cause and effects of mental health issues.

The media was noted as being particularly responsible for many sensationalised stories and misconceptions. The most effective means of combating this situation is through government policy and initiatives to educate the public and calm the irrational fears that the population have.

Integrating more patients into the community was seen as a positive step, as this will help to break down

the perceptions of mental health and stigmatisation. The consensus was that education was the key.