



Bwrdd Iechyd Lleol Local Health Board

Rhondda Cynon Taf
Rhondda Cynon Taff

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Clerk
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Cardiff Bay
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Dear Jane

Policy Review: The National Service Framework for Mental Health: Standard 2 – User and Carer Participation

Thank you for your letter with regard to the Health and Social Services Committee review of aspects of Standard 2 of the Mental Health National Service Framework.

We are writing this response on behalf of the joint planning groups in Merthyr Tydfil and Rhondda Cynon Taff and as the Co-Chairpersons of the User and Carer Working Group that spans both unitary authority areas. The main joint planning partners are as follows:

- Rhondda Cynon Taff User Network
- Merthyr Tydfil User Forum
- Bro Taf Voluntary Sector Mental Health Network
- Interlink
- Voluntary Action Merthyr Tydfil (VAMT)
- North Glamorgan NHS Trust
- Pontypridd and Rhondda NHS Trust
- Merthyr Tydfil County Borough Council
- Rhondda Cynon Taff County Borough Council
- Merthyr Tydfil Local Health Board
- Rhondda Cynon Taff Local Health Board

The following are the response to questions outlined in your review letter:

1. What does Full and genuine participation mean to local partners-

Ultimately it means that service users have more influence and control over what happens to them when they come into contact with the mental health system. Being able to exercise control over what happens to you improves self-esteem and consequently mental wellbeing. Therefore ensuring that people

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can make decisions and exercise control should be at the heart of everything we do as a mental health service.

In the context of planning and reviewing services full participation would mean that users views genuinely have equal influence in shaping the changes that need to happen in mental health services.

2. The barriers to participation –

a. In the development of individual care plans: -

Service users have limited expectations and may not be aware of what other support and services they could benefit from if they only have experience of what is available locally. They may also lack the confidence to ask for something different. Sometimes the horizons of the staff are also limited to what is available. Some staff may also have a view about what is best for the user even if that person would disagree. We don't currently routinely record and feedback unmet need to ensure that the planning system addresses the gaps in services (we are looking to address this through the implementation of CPA).

b. In the planning, design, commissioning, delivery, monitoring and evaluation of mental health services: -

Users and carers often lack confidence. The mechanisms that we use to plan, monitor and evaluate services are often formal and not very lay person friendly so they don't really enable people to get involved. Service users and carers do not always have access to any support to get their views across. Users and carers are unpaid and they become involved as volunteers in their own time. It can be difficult to identify people who want to become involved. Individuals and agencies that exercise control over resources are likely to have more influence over planning decisions and the way services are provided.

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

Individual care planning: – Change the way we train staff to ensure that we encourage the development of skills and attitudes that are enabling rather than disabling. Ensure that users and carers are far more informed about their rights and options. Develop community advocacy provision to assist users to ensure that their views are heard and acted upon. Record and act upon users and carers views about unmet needs.

Planning, design, commissioning, delivery, monitoring and evaluation of mental health services: - Provision of properly resourced support to service users and carers to further build confidence, knowledge and skills. Develop a range of mechanisms for gathering views that don't just rely on people participating in formal planning meetings. Pay service users and carers for the time they spend providing their expertise. Where appropriate ensure that carers are provided with respite support to enable them to participate. Support service users to visit different sorts of services in other areas and to gather information about good practice and new approaches. Ensure user and carer views about unmet need are recorded systematically through the Care Programme

Approach and develop robust mechanisms for feeding this information into the planning system (this is being addressed through CPA). Provide training for Chairs of planning groups to ensure that they enable participation by lay representatives. Provide joint training around user and carer involvement generally. Involve service users and carers in developing specifications for services and in setting monitoring and review criteria. Tackle stigma within mental health services and create support structures so that we can begin to employ people with mental health problems within our own services. Ensure service users and carers are involved in selecting new staff.

4. What should be the role of:

- i) LHBs - As commissioning evolves within LHBs users and carers should be involved in all stages of the cycle e.g. identifying needs, developing strategies, drawing up specifications for services, selecting providers, monitoring and reviewing provision etc.
- ii) NHS Trusts – could ensure that they recruit and train staff with the right attitudes and skills. Staff supervision should focus on these issues. The Trusts should work in partnership with advocacy services and patients councils. They could also develop a wider range of mechanisms for gaining user views.
- iii) Primary Care Team – see above with regard to staffing issues and feedback mechanisms. Advocacy may also be helpful across a number of GP practices.
- iv) The voluntary sector – as above. The voluntary sector also have an important role in lobbying for change and ensuring that service users and carers issues are taking up nationally and locally.
- v) The local authority – see above re other service providers and the LHBs as commissioner.
- vi) The service user / carer – service users and carers need resources to be able to ensure that they can have an effective voice. The key thing that users need is information. WAG can also support user involvement by ensuring that there is a clear message that people must be involved in all WAG initiatives and by monitoring whether local services have meaningfully involved people and by making sure that involvement is not just paid lip service. There should be some incentives and penalties.

All partners need to be better at feeding back to service users and carers about the impact of their involvement.

5. Examples of good practice in encouraging full and genuine participation with Rhondda Cynon Taff and Merthyr Tydfil

User and Carer Development Projects (Welsh Assembly Government Pilot)

Merthyr Tydfil and Rhondda Cynon Taff are two of the four pilot areas for the Welsh Assembly Government funded User Involvement Development Projects. The pilot ends in December 2004 and partners locally are currently in the process of securing longer term funding to ensure this project continues. Rhondda Cynon Taff County Borough Council has also recently appointed a part time Mental Health Carers Involvement Development Officer. These posts are invaluable to the partnership. Merthyr Tydfil has a generic Carers Development post that is employed by VAMT. The Development Officers provide us with capacity to be able to encourage, enable

and sustain the involvement of service users and carers who are essentially unpaid volunteers with limited access to the types of support that most paid staff take for granted.

Mental Health User Involvement Budget

The Local Health Boards provide a budget of £12,000 for user involvement activities across Rhondda Cynon Taff and Merthyr Tydfil. The budget covers user's expenses, publications and information, trips to visit other services, conferences, local events to bring users together, training and administrative support for service users. The Local Health Board and Interlink who administer the budget are currently looking at whether the funding would cover carer involvement activities. Rhondda Cynon Taf Carers Support Project also has some funding for carers involvement. The Carers Support Project have established a database detailing all the carers known to the Project who are involved in planning groups / committees etc.

User and carer participation in the joint planning groups

There are two planning groups – Merthyr Mental Health Steering Group and Rhondda Cynon Taff Mental Health Joint Planning Group. Both groups have service user representation as well as the Mental Health User Involvement Development Officer participating on the group. The Local Authorities in partnership with Interlink and VAMT are currently looking at how we develop carer involvement in planning. Whilst we have had participation from carers in the past it has been more difficult to sustain carer groups and carer representation.

In Rhondda Cynon Taff we are in the process of establishing a number of Working Groups that focus on issue specific areas for service development e.g. accommodation, occupation, primary care, Care Programme Approach, service user and carer involvement etc. Users and carers are being encouraged and supported to participate in groups that deal with their areas of interest.

In Merthyr Tydfil and Cynon Valley the Sainsbury Centre for Mental Health (SCMH) have been carrying out a whole system review of our mental health services. Service users participate on the Project Management Group and contributed to the specification for the project, the recruitment of the consultants and overseeing the different stages of the Project. SCMH have held specific focus days for users and carers to ensure their views shape the review. Service users and carers participated in the stakeholder workshops that will shape the model of service for mental health locally. Stakeholders are keen to ensure that our commitment to partnership working is maintained when we establish the structures for implementing the recommendations from the review.

The Rhondda Cynon Taff and Merthyr Tydfil User and Carer Involvement Working Group

As mentioned Merthyr Tydfil Mental Health Steering Group and Rhondda Cynon Taff Mental Health Joint Planning Group has established a joint User and Carer Working Group. A representative of the service user networks and the LHB jointly chair it. The User and Carer Involvement Development Officers support the work of this group. The

group is made up of representatives from the service user networks, carers, and statutory and voluntary agencies. I have attached the Terms of Reference for this group (Appendix 1). Over the past year the group has been reviewing good practice from Wales, UK and elsewhere and has heard from a number of speakers. The group has developed a four year action plan and identified a number of shorter term priorities for improving user and carer involvement in the next two years. The priorities that come under the remit of your review are as follows:

User Focused Care Programme Approach (CPA) Project

The introduction of CPA provides us with a unique opportunity to ensure service users have maximum influence over their own care plans. Rhondda Cynon Taff Local Authority have managed to secure Scheme of Support for People with a Disability funding and Interlink will employ a service user for 6 months to work with users and others to develop a range of tools that help people prepare themselves for care planning meetings. We have already reviewed a number of tools from England and Wales but may need to adapt these to meet local circumstances. The postholder will also look at how we develop a peer support scheme to encourage the use of these tools. The first phase of this project should be complete by April 2005.

A Guide to Mental and Emotional Wellbeing across Merthyr Tydfil and Rhondda Cynon Taff has been produced to ensure service users and carers are informed about what services are available. This is available as a booklet and is available on a web site.

Tidal Model

Nursing staff across adult in-patient units in the area have started working with the Tidal Model philosophy. This work, pioneered by Dr. Phil Barker, uses a person centred approach to care, emphasising the importance of engagement and collaboration with the client, thus ensuring holistic assessment and promoting shared resolution and problem solving. This work will provide a useful platform on which to build the implementation of CPA.

Joint training initiatives

Both in Rhondda Cynon Taff and Merthyr Tydfil partners are beginning to sign up to the concept of recovery as the value base for services by working together to develop services and support that enables people to achieve their goals and play an active role in their recovery.

In Rhondda Cynon Taff the partners are about to launch a Mental Health Strategy 2004 – 2008 with a series of workshops for all partners to explore what recovery this means in practice. It is our aim to provide further training to staff, users and carers locally to enable them to provide ongoing training and to act as local champions for recovery.

Self Management / Expert Patients

The Service User and Carer Working Group has funding to develop pilot courses to explore approaches to self-management. A small group of service users and staff are currently reviewing similar courses from Wales and the UK to begin developing a programme that we can use locally.

Improving Carers Assessments

In July 2004 Rhondda Cynon Taf Community Care Division revised and updated their carers assessment form. The form is more comprehensive than the previous form and responds to the Carers and Disabled Children Act 2000. It is available to all front line workers via the intranet to allow for any further changes once the form has been in use for 9 – 12 months.

The revised form was finalised following a consultation day in December 2004 which was attended by 75 local carers.

The new form has been designed to allow, if requested and / or appropriate carers to fill in the form in advance of a carers assessment visit. They are also able to ring the Carers Support Project if they require assistance in filling in the form.

Development of User and Carer Involvement Policies

Whilst user and carer involvement has developed in this area we recognise that this is often because we have some strong champions locally. One of the key actions that the group will take forward is the development of policies for individual partner agencies and for the partnership. The development of policies will formalise the commitment to good practice. Service users and carers will also know what they can expect.

Rhondda Cynon Taf Community Care Division have recently published a User and Carer Engagement Consultation Framework 2004 – 07. Each Head of Service is required to produce an action plan in response to the framework by March 31st 2005 to dovetail into their business plans. One heading is the recording of unmet need.

User involvement in recruitment

Stakeholders are particularly proud of the User Involvement in Recruitment Project. This project is steered by a group involving all stakeholders, users, NHS Trusts, Voluntary Organisations, Local Authorities and the Local Health Boards. This group co-ordinate recruitment training that is attended by all partners. Users and staff participate together on selection panels for staff in all partner agencies.

The project has had a significant impact in a number of ways e.g.

- Development of users confidence and skills
- A change in attitudes of staff towards users
- A change in the types of staff we recruit e.g. we are looking more at people's interpersonal skills
- Users can see the direct result of their involvement

In response to your question about whether we would be prepared to give evidence to the Committee we are sure representatives of the partnerships in Rhondda Cynon Taff and Merthyr Tydfil would be happy to do this.

If you have any questions about the contents of this response please do not hesitate to contact us.

Yours sincerely

Yas Jackson

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User and Carer
Involvement Working Group &**

**Service User Representative
Rhondda Cynon Taff User Network**



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Terms of Reference for the Rhondda Cynon Taff And Merthyr Tydfil Service User and Carer Involvement Working Group

1. Principles

Stakeholders are committed to the vision set out in the Strategies and the principles outlined in the Welsh Assembly Government Strategies and National Service Framework.

Fundamental to the success of joint working to deliver the strategy is the:

- Agreement that we will work to a shared vision to work together to develop services and support that enable people to achieve their goals and work towards recovery
- Commitment partnership working to ensure we develop an integrated system of support that makes best use of resources
- Develop of an open culture where partners can build trust and feel safe to share concerns and learn from successes and mistakes.

2. Purpose of the User and Carer Involvement Working Group

Reporting and Accountability: The group is accountable to the Merthyr Mental Health Steering Group and the Rhondda Cynon Taff Joint Planning Group in Rhondda Cynon Taff. The Chairpersons will submit on behalf of the group an annual action plan and a quarterly summary report for the RCT Mental Health Joint Planning Team and Merthyr Mental Health Steering Group outlining achievements, resource issues and any problems that the group is encountering.

The group will act in an advisory capacity to the Mental Health User Involvement Development Officer based at Interlink and the Mental Health Carers Involvement Officer based at the Rhondda Cynon Taff Borough Council Carers Support Project. The group will develop and maintain good links with the Rhondda Cynon Taf User Network and Merthyr Mental Health Forum as well as carers groups.

The purpose of the group is to improve services by making sure those who use them are involved their design and delivery. The group will explore and develop initiatives that ensure users and carers have effective influence over their experiences of mental health services.

The groups will develop, implement, monitor and review the User and Carer Involvement Action plan outlining how we will take forward the NSF Key Actions and Local Objectives in the RCT Mental Health Strategy 16 – 65 and plans that are currently being developed in Merthyr Tydfil.

The action plans will outline:

- Services that could be reviewed and improved and action to bring about these changes
- Gaps in provision and options for addressing these
- Areas where there is some potential for releasing and reinvesting resources
- Gather information about needs, best practice and clinical evidence upon which to base option appraisal and decision making including user and carer views
- Lead responsibility for taking forward actions
- Priorities and timescales
- Resource implications
- Measures of success – how we will know that we have made a difference?

The working groups will co-ordinate the implementation of the action plans by:

- Agreeing changes to existing services outlined in the action plan and more detailed operational plans
- Developing service specifications, business plans and funding bids for new services
- Joint problem solving to address more difficult issues
- Requesting advice and support from the Rhondda Cynon Taff Mental Health Joint Planning Group and the Merthyr Mental Health Steering Group when additional guidance is needed.
- Monitor changes against the measures of success
- Advising Interlink and the Local Health Board about the use of the User Involvement Budget

Chair or Vice Chair of the Working Group to inform the Chair or Vice Chair of the Mental Health Joint Planning or one of the Development Officers of any urgent issues or problems that need addressing between RCT MHJPG meetings.

Dates for quarterly reports: 31st March, 30th June, 30th September, and 31st December

Regularity of meetings: to be established by each Working Group depending on workload and priorities.

3. Membership

All stakeholder groups, users, carers, statutory, voluntary, independent sector providers and commissioners must be offered the opportunity to participate in each working group. It is recognised that some agencies have limited capacity and will not be able to regularly attend all working groups, where

this is the case they may attend meetings where there agenda contains issues of specific interest. Members of the group must have the expertise to inform the development of services, agencies should not send a representative just for the sake of being represented.

The Strategy Group will consist of representatives from each of the key stakeholder groups e.g.

- Service users
- Carers
- North Glamorgan NHS Trust
- Pontypridd and Rhondda NHS Trust
- Voluntary Agencies
- Interlink
- Rhondda Cynon Taf Local Authority
- Merthyr Tydfil Local Authority
- Rhondda Cynon Taff and Merthyr Tydfil Local Health Boards

The group and sub groups may co-opt additional members as appropriate.

The group may also establish task and finish groups as and when they are needed.

The group will establish a buddy system to support new members of the group.

4. Chairing and minute taking

Chairing of the group is shared by a representative of the RCT User Network / Merthyr Mental Health Forum and the Mental Health Development Manager from the Merthyr Tydfil / Rhondda Cynon Taff Local Health Boards. This arrangement will be reviewed annually.

Training will be given to Chairs to support them in their role.

Interlink has agreed to organise for minutes to be taken and for ensuring papers are distributed.