

Health & Social Services Committee

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Date: Wednesday 4 May 2005

Venue: Committee Room 1, National Assembly for Wales

Title: Policy Review:

The National Service Framework for Mental Health: Standard 2 – User and Carer Involvement.

Consideration of Evidence

Purpose

1. The paper summarises the evidence the Committee has received in response to its written consultation and the oral evidence it has received. The Committee is invited to reach its conclusions and recommendations on the evidence received.

Background

2. The terms of reference for the review are:

To review Key Actions 4 and 7 within Standard 2 of the Mental Health National Service Framework (NSF), as they apply to adults of working age who are covered by the NSF, and also as the principles apply to the elderly and to children and adolescents. In particular to:

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

The Committee will consult with users and carers as well as service providers and commissioners in undertaking this review.

3. In the consultation letter, issued on 23 July 2004, the Committee asked for evidence on the following issues:

1. What does 'full' and 'genuine' participation mean to you/your organisation?
2. What are the barriers to full and genuine user and carer participation in:
 - a) the development of individual care plans; and
 - b) in the planning, design, commissioning, delivery, monitoring and evaluation of mental health services?
3. How can these barriers be overcome and by whom?
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; .and
 - vi. the service user / carer?
5. Please identify examples of good practice in encouraging full and genuine participation by users and carers in all aspects of mental health services.
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.

Evidence Received

4. The Committee received over 50 responses to the written consultation from service users, service providers and the voluntary sector. (Members have received hard copies summarising the responses.) A list of those who responded is at annex 1
5. The Committee took oral evidence at its meetings on 3 and 24 November 2004, 12 January and 2 March 2005. Details are at annex 2.
6. An analysis of the evidence received is at annex 2. This is grouped in accordance with the six issues identified at para 3 above.

April 2005

People and Organisations Who Submitted Written Evidence

01	Working Futures
02	Pontypridd & Rhondda NHS Trust - Mental Health Directorate
03	US (User and Survivor) Network
04	David Pugsley, Coity Clinic Day Hospital Manager, Bro Morgannwg NHS Trust
05	Anheddau Outdoors
06	Gogledd Gwynedd CHC
07	Conwy & Denbighshire NHS Trust
08	Moonflower Enterprises
09	Neath and Port Talbot Community Health Council – Peter Owen, Chief Officer
10	Robin Williams, Mental Health User Group, Penarth
11	Dave Bowles, Caerleon, Newport
12	Keith Thomson, North West Wales NHS Trust
13	ForUs (Forum for MH users in Caerphilly County Borough, Ystrad Mynach - Emrys Roberts, Chairman
14	Rhondda Cynon Taff Local Health Board, Merthyr Tydfil and Rhondda Cynon Taff Service User and Carer Working Group, Pontypridd
15	Stephen Pearce, Community Care and Adult Services, Newport City Council
16	Linda Newton, Cardiff and Vale Mental Health Project – Bro Taf Voluntary Sector response and Cardiff Carers Network response
17	Heather Hughes, Swansea Local Health Board
18	Mencap Cymru, Liz Neal
19	Dave Hughes, Directorate of Social Services & Housing, Swansea CC

20	Mike Bosley, Children in Wales
21	Phil Thomas, Social & Housing Services Monmouthshire CC
22	Mandy Davies, Pembrokeshire & Derwen NHS Trust
23	Dave Bowles, Caerleon, Newport
24	Philippa Ford, Chartered Society of Physiotherapy
25	Jonathan Davies, Welsh NHS Confederation
26	Lorraine Paul, Gwent Association of Voluntary Organisations
27	Tim Watkins, Depression Alliance Cymru
28	British Psychological Society Division of Counselling Psychology Wales Network
29	Hafal – Liz Griffiths-Hughes
30	The Mental Health Foundation – Toby Williamson
31	Lorraine Best – Past User
32	South Wales Mental Health Advocacy
33	College of Occupational Therapists
34	Bridgend LHB – Chris Moss
35	Powys LHB – GF Lewis
36	Mind Cymru
37	Pembrokeshire LHB – Sue Lewis
38	Meetings of Mind in Carmarthenshire – Penny Gripper
39	Powys Mental Health Alliance - User Link – Celia Cowrie
40	Pembrokeshire Mind – Hywel Davies
41	Gary Rix – Cardiff & Vale NHS Trust, Whitchurch hospital
42	Carmarthenshire LHB – Jill Paterson
43	Pontydd – User Training Consortium – Kay Howells
44	Bro Morgannwg NHS Trust – Victoria Franklin
45	Torfaen CBC – David Williams
46	North East Wales NHS Trust – Andy Scotson

47	Gofal Cymru – Rose O’Driscoll
48	Advance Brighter Futures Wrexham
49	Ynys Mon Mind
50	Gweithredu Dros Iechyd Meddwl Gorllewin Cymru (West Wales Action for Mental Health)
51	Pembrokeshire Mind

Annex 2

Key Themes Emerging from Evidence

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

1. There was general consensus in the written responses that this should mean that services should be user centred. Service users and carers should be involved as equal partners at every stage of service planning, from inception, through planning, implementation, monitoring and evaluation of services. This can be achieved in a number of ways, through small user groups or larger meetings. Equality requires mutual listening and dialogue.

2. Users need support to help them participate. This might include funding for development officers and training, access to information and advocacy. It is also important that they have the necessary information and time to prepare for meetings.

3. In planning meetings it is important that the needs of service users are taken into account as well as those of professionals. Some medication affects people’s ability to concentrate early in the day.

4. The Tidal Model offers a patient centred approach.

5. Depression Alliance Cymru suggested that it was important to involve people who had recovered from illness and those who were receiving preventative or early treatment in primary care, as well as current users.

6. Service users should be involved in a meaningful, not token, way in recruiting, interviewing and selecting staff.

7. Service users and carers should also be involved in planning their own care. They should be given information about their condition and treatments, options and care plans agreed with them. Care plans should include the user’s perception of need and how it will be met.

8. Mencap pointed out that people with learning difficulties often were not able to access mainstream health services.
9. The Mental Health Foundation considered that users could be e involved in controlling or leading research.
10. In their written evidence Mind Cymru expressed concern about the lack of knowledge and clarity among professionals about who should be involved in care planning. They had carried out an extensive survey of service users, carers and groups and based their evidence on the 40 written responses and oral evidence from 44 people. The majority did not have a care plan and those who did had little or no input.
11. There were however four examples of good practice. The common factor in these four was that the individual had been involved and felt valued.
12. Children in Wales said that participation for children and young people was defined in Funky Dragon's "Breathing Fire" guide. Young people from the Barnardo's Young People's Crisis Service contrasted experiences at the project, where staff mixed well with the young people and made them feel responsible and relaxed, and their experience at the Adolescent Unit at Whitchurch Hospital, where their education and support needs often were not met.

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

- a) the development of individual care plans; and
- b) in the planning, design, commissioning, delivery, monitoring and evaluation of mental health services?

a. Individual care plans

13. Responses indicated that the many of the barriers relate to people's attitudes, but there are also issues about communication, and the time and resources needed to engage the parties properly and train staff.
14. Many respondents suggested that the attitudes of health care professionals put up barriers. There was a tendency for professionals to take over responsibility and power when people were ill and not give it back as part of the recovery process. Some professionals still have the attitude that they know best what is appropriate for the user and do not recognise the expertise the patient or carer has acquired. Jargon is often used and professionals assume that the user / carer has understood all that is said.
15. Needs that cannot be met may not be recorded in the care plan.
16. Users and carers may be handicapped by a lack of information on treatment, drugs, options etc and understanding of what a care plan should be. They may not understand the implications of proposed

actions. Because of the nature of the illness it is not easy to engage with some users to agree and implement a plan.

17. Users and carers may be reluctant to criticise or to become involved because they feel stigmatised and lack self confidence.

18. The provisions of the Mental Health Act do not require the patient's agreement to the care plan, and the threat of forcible detention and medication does not encourage participation.

19. There may be conflict between the interests of carers and service users.

20. Lack of respite or alternative care, transport problems, and expense can be a barrier to carer involvement.

21. Mencap said that professional staff were not always trained and skilled in communicating with people with learning difficulties. In oral evidence they said that their report "Treat Me Right" found that in a number of cases carers felt that there would have been a different outcome had their views been listened to. They also said that the mental health problems of someone with learning difficulties were assumed to be related to those difficulties.

22. Children in Wales said that time was not always available to build up the trust that was needed to engage with children and young people. The format for obtaining feedback from them could be unsuitable and heighten distress. Young people might also be inhibited by previous bad experiences.

23. Mind's Survey indicated that professionals often do not attend meetings, and that there may be significant delays in waiting for appointments. The shortage of psychiatrists and high turnover of staff make it difficult to develop an effective relationship. In oral evidence they said that the six monthly turnover of senior house officers and pressure on their time, meant that the doctor was not always able to read the patient's notes before the consultation and valuable consultation was lost in rehearsing the case history. They also suggested that lack of communication might be due to reluctance by professionals to share information.

24. Meeting of Minds, Carmarthen said that there was an issue around the prioritisation of services, where a person may feel worthless because their needs are not valued as highly as others'.

25. The Brighter Futures Project, Wrexham, submitted that the individual may feel outnumbered and led by professionals; may not know their rights and may not have prepared for a meeting. Users may find the plan too document-based

26. Bro Morgannwg NHS Trust referred to the need for families to understand the nature of the illness. Lack of information and understanding, especially in the early days of the illness may affect the way users and carers engage. Sometimes families do not understand that the problem may be long term and

recurrent. The trust also said that users' expectations may be unrealistic or in conflict with the professionals' assessment of need.

27. The All Wales User Survival Network advised the Committee that they had found evidence of professionals bullying patients into agreeing inadequate care plans.

28. Hafal drew the Committee's attention to the needs of black and ethnic minority groups. Professionals did not always take account of different cultures.

29. Lorraine Best, a service user, told the Committee that when someone with a history of mental illness became unwell again, doctors often prescribed drugs without attempting to find the root of the problem.

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

30. Generally there was agreement among respondents on the main barriers. As with individual care plans, many of these related to attitudes and resources.

31. There is a lack of resources for training service users and carers about planning structures and processes.

32. Staff were not skilled or trained to facilitate involvement and to work in an empowering manner. Users and carers need to know where decisions are made and how they can influence them.

33. The financial cost of participation, transport etc, without remuneration could deter people. Where carers are involved alternative arrangements may require funding.

34. Service users are also deterred from taking part because:

- they feel their input is tokenistic;
- they feel intimidated and lack self confidence and do not feel that they can make an impact in a meeting;
- difficulty of making an impact as a minority in the decision making culture;
- they may have difficulty in articulating their views and in consequence their views may be disregarded;
- there is too much jargon and use of acronyms;
- dates and times of meetings may make attendance difficult;
- once a user feels confident to contribute they may wish to move on and put their experience behind them; and
- use of e-mail for communication may exclude many people.

35. Other factors raised include:

- mental health services are complex and difficult to plan and deliver - no individual can adequately represent a range of users' interests;
- there is an assumption that "a seat at the table" is the only valid means of participation;
- there needs to be a balance of input between people with short term, milder needs and those with longer term more intensive needs;
- the pressure of other demands on professional service planners and commissioners precludes them from spending the time needed to develop participation;
- similarly service users need time to prepare for meetings etc;
- although user groups exist, many are not well publicised and are poorly attended.

36. The Mental Health Foundation's (MHF) Guiding Lights project in Wales found a number of barriers and obstacles including unstable short term funding; lack of willingness to take risks and give service users responsibility; and "us and them" staff attitudes.

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

37. Some respondents referred to the need for the Welsh Assembly Government to take a lead in demonstrating commitment and issuing guidance. Reference was made to the document "Service User and Carer Participation Charter"

38. The main themes running through the responses were as follows

Service Planners and Providers

- There should be commitment to the process at all levels within the organisation.
- Staff needs more time and smaller caseloads to engage with users effectively.
- Need more training to recognise the expertise of users and carers, to hand back personal responsibility to the user.
- Staff should receive equality training.
- Rhondda Cynon Taff User Network had found that joint training for staff and service users had been successful in changing staff attitudes.
- Service users should be involved in the recruitment and training of staff.
- Service users' input should be valued and users treated with respect and dignity.
- The Brighter Futures project in Wrexham suggests that Mental Health students should have a placement with user-led organisations
- At strategic planning level there should be a strategy for the recruitment, engagement and continuing support for users and carers adopted by all the partner agencies.
- Establish patient Councils and other user groups. A range of views and experiences are needed.

- Better communication and information - Language should be clear and free of jargon. One organisation provides information packs for users.
- Service users / carers should be provided with briefing and information ahead of a meeting to make them less intimidating.
- People chairing planning meetings should be trained in how to engage the input of the users / carers.
- User / carer input should be documented and tracked as evidence that their views have been heard and acted upon.
- Appointment of a user involvement development officer in every trust area, to support users and work with the statutory sector. The post should be independent of service providers
- Meeting of Minds, Carmarthen suggests a consultation register of groups for early receipt of consultation documents.

Service Users and Carers

Individual care planning

- Clear and transparent processes – users and carers to agree plan, have a copy, regular review, and where services identified as needed cannot be provided this should be recorded.
- Process should be more flexible, with out-of-hours access to health and care professionals.
- Appropriate venues for meetings
- Provision of advocacy.
- Development of mentor support and expert patient programme
- More information about the rights of users and carers.

Planning design, commissioning, delivery, monitoring and evaluation of services.

- Service users should be canvassed to establish what they find confusing, the information they need, and how they want to be involved.
- Training for users with recognised NVQs.
- Training on confidence building, assertiveness skills, working in committees and the service planning system.
- A career structure for people who have had experience of mental health services to help support

user participation.

- Advocacy and support to help users express their views.
- Users should receive clear and unambiguous feedback.
- Meeting of Minds, Carmarthen, recommends independent mediation where users and carers feel that their views are being ignored.
- In Caerphilly "ForUs" is establishing a Mental Health Users' Council with approval of statutory partners. They plan to employ a full time advocate and to involve Managers and service planners in their meetings.
- In Rhondda Cynon Taff a range of mechanisms are used to gathering views on service planning. They suggest encouraging service users and carers to visit other areas to find out about good practice and to feed information into the planning process.
- Local groups which enable user and carer participants to gather the views of their constituency.
- Service users and carers should be re-imbursed expenses and some suggest that they should be remunerated.
- Gofal Cymru recommend that the NHS develop a culture which involves users more effectively in monitoring services.

4. The role of:

- i. the LHB;
- ii. the NHS Trust;
- iii. the Primary Care Team.
- iv. the voluntary sector;
- v. the local authority; .and
- vi. the service user / carer

39. Several respondents referred to roles that are common to all or most of the above. These include:

- working together in a framework with clearly defined goals;
- sharing information;
- promoting and encouraging participation

- Local health boards, trusts and local authorities should fund and support user / carer organisations. In turn those organisations should build their membership, communicate with it and work with the statutory organisations in the planning and development process.
- There should be a multi-agency approach with central funding targeted at empowerment and developing local arrangements for effective participation.

40. The key roles identified by respondents for the different sectors include:

i. The Local Health Board

- Show commitment and provide a lead.
- Be a driver for change.
- Disseminate good practice
- Ensure service users' / carers' policy in place and monitor progress.
- Provide funding for staff training, user / carer training and remuneration, advocacy, patient participation posts and initiatives.
- Set minimum requirements for involvement in planning structures.
- Facilitate consultation and action on response.
- Encourage bottom-up strategies.
- Involve users / carers in all stages of the commissioning cycle.
- Commission services more specifically to meet individual needs.
- Provide briefings and papers in accessible formats

ii. NHS Trusts

- Show commitment.
- Implement and monitor user / carer policy.
- Facilitate high quality services.
- Recruit, and train staff with right attitude and skills, and monitor performance.
- Motivate staff
- Move from a medical model to social model of care
- Provide adequate number of patient participation officers to meet need.
- Develop mechanisms for user feedback.
- Ensure mechanisms are in place to support user networks and involvement.
- Provide training for users / carers on consultation.
- Consult early on proposed changes.
- Ensure staff have sufficient time with each patient on their care plan.
- Provide briefings and papers in accessible formats

i. The Primary Care Team

- Reinforce values
- Set standards;
- Engage with other sectors.
- Recruit and train staff with right attitudes, and monitor performance.
- Train users / carers and advocates.
- Encourage user involvement in their own care as well as service planning and delivery.
- Consider using vacant posts as employment opportunities to develop user participation;
- Raise awareness of mental health issues, with outreach to a broad cross-section of the public.
- Seek to eliminate stigmatism
- Encourage user involvement in health promotion.

- Joined-up working between GPs, dentists and nurses.
- Should be aware of the physical health needs of mental health patients

iv The Voluntary Sector

- Provide information, training, support and advocacy to users /carers.
- At national level provide a lead in training on participation.
- Help users / carers express their views.
- An independent forum for statutory agency consultation
- Provide befriending, drop-in advocacy and other services that complement and enhance core statutory services.
- Work in partnership with statutory sector and give constructive criticism.
- Organise self help groups, campaigns, pressure groups.

v. The Local Authority

- Work in partnership with other sectors to develop consistency in the area.
- Implement and monitor user / carer policy.
- Use their experience of user / carer participation to lead on work locally.
- Allocate resources.
- Local councillors to lobby on behalf of their constituents.
- Engage as equal partners in consultation.
- Include education on mental health issues in secondary schools.

v. The Users and Carers

- Forget bad experiences and cultivate a positive attitude to participation.
- Participate in planning and service development.
- Share expertise.
- Provide peer support.
- Represent the range of views, not just own perspective.
- Have reasonable expectations and commitment to working towards agreed joint consultation process.

1. Examples of good practice in encouraging full and genuine participation by users and carers in all aspects of mental health services

41. The Rhondda Cynon Taff User Network, the Pembrokeshire and Derwen NHS Trust and Newport City Council (Community Care and Adult Services) spoke of the benefits of the Tidal Model when they gave oral evidence to the Committee on 12 January and 2 March. This is a person-centred approach to mental health that places individual experience at the centre of the therapeutic process. It emphasises the role of the nurse as a "helper", enabling people with a

mental health crisis to use their own resources to achieve recovery. Evaluation has indicated a more effective therapeutic experience for patients and improved staff motivation and morale.

42. Other examples of good practice cited in written and oral evidence follow.

43. Conwy and Denbighshire NHS Trust involves users and carers in their Clinical Advisory Groups on Learning Disability, Adult Mental Health and Older People's Mental Health. The groups advise the Divisional Management Team on strategic and operational matters.

44. ForUs, Caerphilly (a user-led initiative) has piloted a user self evaluation tool which encourages people to reflect on their problems and the impact they have on their daily lives; to identify what they themselves can do and what help they need from the statutory agencies. One of the advantages is that it allows users to present with a summary of their needs as a basis for dialogue and decision making.

45. Merthyr Tydfil and Rhondda Cynon Taff were two of four pilot areas that received Assembly Government funding for User Involvement Development projects. The posts funded have been invaluable in enabling and sustaining the involvement of service users and carers. Bro Taf Voluntary Sector Mental Health Network and S Wales Mental Health Advocacy also referred to this pilot.

46. Rhondda Cynon Taff has published a User and Carer Engagement Consultation Framework for the years 2004-07. Each head of service is required to produce an action plan to dovetail into their business plan. One heading is the recording of unmet need.

47. Swansea LHB mentioned the Sainsbury Centre for Mental Health's "Quality Improvement Programme" which was used at Cefn Coed Hospital in 2001. The user focussed monitoring study recruited and trained service users as researchers and interviewers.

48. Pembrokeshire and Dewen NHS Trust involved users in the development of the Bro Cerwyn site which subsequently won a design award.

49. Depression Alliance Cymru commended work done by the Patient's Resource Centre, Whitchurch Hospital and the Occupational Planning Group at Hafan Dawel Penarth which involve users and carers from an early stage in planning vocational activities to assist recovery.

50. Hafal's Recovery / Empowerment Programme and its Partnership Compact encourage and support people in making decisions about their lives and recovery and also to engage in advising on wider issues.

51. The Mental Health Foundation visited some 18 projects around Wales, all of which demonstrate good practice in encouraging full and genuine participation. They also referred to the

Caterpillar Group, formed by a group of young people involved in the Youth Crisis Project. The group aims to give young people a voice about mental health services for their age group.

52. The College of Occupational Therapists commended the Pathways Back to Care Course in Gwent. Users are able to plan and discuss the way they wish to be treated if they become ill again. The college also uses the use of vocational rehabilitation profiles in Cardiff. These are patient held plans for returning to work. They give clear goals for the patient and a profile of the user's commitment and skills for future employers.

53. Bridgend LHB cited some nine schemes in its area, which focus on user involvement, addressing different aspects of service provision and the needs of mental health patients.

54. Pembrokeshire LHB also cited a number of schemes it considers to comprise good practice. One of these Pontydd (Dyfed Powys Mental Health Service Users Training Consortium), is a service user group that is used to conduct audits of statutory services, demonstrating that users can deliver relevant work. The group is able to access information that the statutory organisations cannot. Other respondents referred to Pontydd's involvement in training.

55. The Chartermark awarded to the Forge Centre in Port Talbot recognised the high Level of service user and voluntary sector in the activities and functions of the Centre

56. Among the examples mentioned by Meeting of Minds, Carmarthen are the Expert Patient training (SCVS Swansea) where service user trainers are paid, and service user involvement in mental health first aid training in Scotland.

57. Gofal Cymru's supports users in drawing up Individual Support Plans. With These are led by the user, but the support worker works with the user to help him / her achieve their goals. While this may take time it benefits the user. One of the user groups Gofal Cymru has set up across Wales is drafting a service user handbook, which they hope to roll out across their organisation.

58. Advance Brighter Futures Wrexham has three components: providing a user service representative group; independent advocacy; and a drop in resource centre providing out-of-hours service every day of the year.

1. Evidence on whether people with mental health problems feel stigmatised, and if so what should be done to eliminate it.

59. Nearly two thirds of all respondents felt that people with mental health problems were stigmatised. The remainder did not comment.

60. Public education was widely recommended as the means of addressing the problem. Several respondents suggested that more should be done in schools and one referred to a project, no longer

running, where service users and carers went into schools to stimulate discussion about the issues. There was reference to a committee of stakeholders that had recommended to the Welsh Assembly Government that it should run an anti-stigma campaign.

61. Many felt that more needed to be done to educate the press to stop them using derogatory language and the Welsh NHS Confederation suggested that the health service could do more to promote positive mental health stories, rather than reacting to the negative.

62. The way in which services are provided can lead to stigmatisation. One NHS Trust that has sited a mental health unit on a district general hospital campus reports improvement in attitudes.

63. There is also stigmatisation in employment. . Depression Alliance Cymru is working with Unison and other organisations to develop employment retention services. Intensive support, early in the incidence of ill health, can help to keep a patient in work. More supported employment opportunities are needed and it was suggested that the health service and local authorities could take the lead in employing people with problems.

64. Finally, several respondents referred to the negative impact of the draft Mental Health Bill that was published by the last Government. This is felt to reinforce the view that people with mental health problems are a threat.