

Health & Social Services Committee

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Date: Wednesday 5 October 2005

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

Purpose

1. The Committee is invited to approve the final draft report at Annex 1. The earlier draft was considered by the Committee on 22 June and has been amended to incorporate the suggested addition to para 3.8.

Committee Service

September 2005

Annex 1

National Assembly for Wales

Health and Social Services Committee

Report on the Review of the National Service Framework for Mental Health - Standard 2: User and Carer Participation

Foreword by the Chair of the Committee

In May 2002, the Welsh Assembly Government published a National Service Framework (NSF) for adult mental health services. The principal aim of the NSF is to drive up quality and reduce unacceptable variations in health and social services provision.

Services for the mentally ill are a high priority in the Committee's strategic forward work programme, and funding for the implementation of the Mental Health NSF had been identified as a priority when the Committee considered its budget priorities for 2005-06. It was therefore agreed that the Committee

would undertake a broad review of Standard 2 of the National Service Framework for Mental Health - User and Carer Empowerment.

During the Committee's public consultation period the Welsh Assembly Government published "Stronger in Partnership", its guidance on involving service users and carers in the design, planning, delivery and evaluation of mental health services in Wales. The Committee takes the view that implementation of the guidance will enhance the health and quality of care for both service users and carers.

I was pleased that the Committee was able to take evidence from service users as well as front line health and social care providers. Much of the evidence the Committee received was from either end of the spectrum. We heard from those who were already committed to making the care planning approach a reality, but also from users whose experience was that care planning was, at best, tokenistic. However, the Committee was encouraged by the examples of good practice that were cited and felt that these provided a firm foundation for the future.

The Committee was once again most ably served by its Secretariat and staff of the Members' Research Service.

On behalf of the Committee I should like to commend the dedication and commitment of the people working in the statutory and voluntary sectors under what are often challenging and difficult pressures, and to thank all those who gave their time in providing written and oral evidence.

David Melding AM

1. Introduction

1.1. On 14 July 2004 the Health and Social Services Committee agreed to undertake a broad review of Standard 2 of the National Service Framework for Mental Health. A copy of Standard 2 is at Annex 1. The terms of reference for the review were:

"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."

1.2. During the summer of 2004 the Committee consulted the key statutory and voluntary organisations in the sector. The Committee invited 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. Examples of good practice in encouraging full and genuine participation by users and carers in all aspects of mental health services.
6. Whether people with mental health problems feel stigmatised, and if so what should be done to eliminate it.

1.3. Fifty one responses were received. A list of those who responded is at Annex 2

1.4. The Committee took oral evidence at four meetings between November 2004 and March 2005.

Summary of Conclusions and Recommendations

1.5. The Committee noted that in September 2004 the Welsh Assembly Government had published "Stronger in Partnership", its guidance on involving service users and carers in the design, planning, delivery and evaluation of mental health services in Wales. This was during the consultation period on the Committee's review and therefore did not have a significant influence on the responses received.

1.6. The Committee commends "Stronger in Partnership" as being a comprehensive and practical tool for service providers, users and carers. The Committee recognises that implementing the guidance will place demands on service providers' time and other resources. However, the evidence suggests that where there is already engagement with users and carers there are considerable benefits to the health and care of the patient. The guidance should provide a benchmark against which implementation is evaluated so that best practice can be identified and shared.

1.7. At the strategic level "Stronger in Partnership" and the complementary documents (Footnote "Promoting Partnership in Care – Commissioning across Health and Social Services" and "Planning and Commissioning NHS Services") focus on the commissioning of services. The Committee takes the view that a more integrated approach with users, carers and the voluntary sector being involved in the initial

strategic planning of services would be beneficial.

1.8. Much of the evidence the Committee received was from either end of the spectrum. We heard from those who were already committed to making the care planning approach a reality, but at the other end of the spectrum we heard from users whose experience was that care planning is, at best, tokenistic.

1.9. Recommendations

- i. Local health boards and trusts should have a training strategy for identifying the training needs of all staff in relation to user and carer participation, including those in primary care, and delivering training.
- ii. User involvement development officers should be appointed. They should be independent of the statutory agencies. They should be appointed jointly by LHBs, Trusts and LAs. Their role should include training individual users and carers to participate in planning, commissioning, monitoring and evaluating services. It should also include cascading information and guidance and helping user and carer organisations to work with the statutory bodies.
- iii. "Stronger in Partnership" should be reviewed with a view to giving more emphasis to the involvement of users, carers and the voluntary sector in the initial strategic planning of services.
- iv. All individual care plans should be "signed off" formally by the service user and the appropriate health care professional and copies given to the user and / or any carer.
- v. When a service user is not at a crisis point, he or she should be invited to agree that their carer should be involved in care planning at times of crisis.
- vi. The Welsh Assembly Government should take urgent steps to ensure that children and young people are treated in an appropriate environment.
- vii. All staff involved in care planning should be trained to recognise the special cultural needs of some black and minority ethnic groups, and to know where to seek advice on how to respond to such needs.
- viii. All staff involved in care planning for the elderly should be trained to recognise and respond to the special needs of vulnerable elderly people and their carers.
- ix. The six sectors listed in paragraph 2.4 should have regard to the points set out in that paragraph when improving service planning and commissioning and for improving individual care planning.
- x. With appropriate training, service users should be involved in the recruitment of staff at all levels.
- xi. The Welsh Assembly Government should ensure that there is a mechanism for disseminating good practice in Wales and from other countries.
- xii. The Committee endorses the Welsh Assembly Government's proposal for an action plan for mental health awareness to address stigma. It recommends that Health Promotion Wales consider an award scheme that would celebrate and publicise cases where people have successfully overcome mental illness.

2. The Main Themes of the Evidence

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

2.1.1. There was general consensus among those who provided evidence that this should mean that services are 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 could be achieved in a number of ways, through small user groups or larger meetings. Equality requires mutual listening and dialogue.

2.1.2. A number of witnesses said that 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 and where they are involved in the recruitment of staff their involvement should be meaningful. In planning meetings it is important that the needs of service users and carers are taken into account as well as those of professionals. For example some medication affects people's ability to concentrate early in the day and carers may have difficulty attending meetings because of work or family commitments.

2.1.3. The N W Wales NHS Trust acknowledged the need for the carer to be involved in the assessment process to help achieve a full understanding of the patient's situation. This involvement should also benefit the carer.

2.1.4. Several witnesses recommended the Tidal Model, which offers a patient centred approach.

2.1.5. 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.

2.1.6. 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. However, the survey identified four examples of good practice. The common factor in these was that the individual had been involved in joint working and felt valued.

2.1.7. 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.

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

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

i. Individual care plans

2.2.1. Responses to consultation indicated that 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 to train staff.

2.2.2. Many respondents suggested that the attitude of health care professionals creates barriers. There is 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.

2.2.3. Needs that cannot be met are not be recorded in the care plan.

2.2.4. Users and carers may be hindered 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.

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

2.2.6. Mencap pointed out that people with learning difficulties often were not able to access mainstream health services. Many professionals had not received training in communicating with people with learning difficulties. It was felt that they missed some treatable illnesses because they assumed that any problem related to the learning difficulty. 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. Both primary and secondary healthcare providers needed more information on the mental health and behavioural problems that could prevent such people accessing services.

2.2.7. 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.

2.2.8. 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.

2.2.9. 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 those of others.

2.2.10. 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

2.2.11. 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 the user's expectations may be unrealistic or in conflict with the professional's assessment of need.

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

2.2.13. 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.

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

2.2.15. The needs of carers are not necessarily the same as those of users. Several of those who gave evidence said that there may be conflict between the interests of carers and service users.

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

2.2.17. Rhondda Cynon Taf User Network reminded the Committee that carers often knew the patient better than the professionals and many service users preferred their carer to make representations on their behalf. While the service user was in the community the role of the carer was valued, but when the user was admitted to hospital the carer could be marginalised. Stephen Pearce of Newport Council supported the view that the carer could be marginalised at times of crisis, often because of the issue of patient confidentiality. He suggested that a solution might be to obtain the agreement of the user to the involvement of the carer when the user was not in crisis.

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

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

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

2.2.20. 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.

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

2.2.22. 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.

2.2.23. 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; and
- although user groups exist, many are not well publicised and are poorly attended.

2.2.24. 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.

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

2.3.1. 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"

2.3.2. Service Planners and Providers

- There should be commitment to the process at all levels within the organisation.
- Staff need more time and smaller caseloads to engage with users effectively.
- More training is needed 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 suggested 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.
- Patient councils and other user groups should be established, 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.

2.3.3. Service Users and Carers

Individual care planning

- Processes should be clear and transparent. Users and carers should agree the plan, have a copy, regular reviews and, where services identified as needed cannot be provided this should be recorded.
- The process should be more flexible, with out-of-hours access to health and care professionals.
- Venues for meetings should be appropriate for the service user and carer.
- Advocacy should be available.
- Mentor support and expert patient programme should be developed.
- More information is needed 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.
- There should be a career structure and training, with recognised NVQs, for people who have had experience of mental health services to help support user participation.
- Training should be available in confidence building, assertiveness skills, working in committees and the service planning system.
- Advocacy and support should be available 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 should be set up to gather the views of their constituency.
- Service users and carers should be reimbursed 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.

2.4. 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

2.4.1. 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.

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

i. The Local Health Board should

- 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; and
- provide briefings and papers in accessible formats.

ii. NHS Trusts should

- 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; and
- provide briefings and papers in accessible formats

iii. The Primary Care Team should

- 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 stigmatisation;
- encourage user involvement in health promotion;
- joined-up working between GPs, dentists and nurses; and
- should be aware of the physical health needs of mental health patients.

iv The Voluntary Sector should

- provide information, training, support and advocacy to users /carers;
- provide a lead in training on participation at national level;
- help users / carers express their views;
- be 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; and
- organise self help groups, campaigns, pressure groups.

v. The Local Authority should

- work in partnership with other sectors to develop consistency in the area;
- implement and monitor user / carer policy;

- use its experience of user / carer participation to lead on work locally;
- allocate resources;
- encourage local councillors to lobby on behalf of their constituents;
- engage as equal partners in consultation; and
- include education on mental health issues in secondary schools.

vi. The Users and Carers should

- Try not to let bad experiences in the past prevent a more positive attitude to participation;
- participate in planning and service development;
- share expertise;
- provide peer support;
- represent the range of views, not just own perspective; and
- have reasonable expectations and commitment to working towards agreed joint consultation process.

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

2.5.1. 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.

2.5.2. 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.

2.5.3. 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.

2.5.4. 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. In Rhondda Cynon Taff, users are involved in the recruitment of staff at all levels. This gives the message that to prospective staff that service users were integral to service planning and delivery. Bro Taf Voluntary Sector Mental Health Network and S Wales Mental Health Advocacy also referred to this pilot.

2.5.5. 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.

2.5.6. 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.

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

2.5.8. 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.

2.5.9. 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.

2.5.10. 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.

2.5.11. 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 commended 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.

2.5.12. 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.

2.5.13. 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.

2.5.14. 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.

2.5.15. 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.

2.5.16. Gofal Cymru's supports users in drawing up Individual Support Plans. These are led by the user, but the support worker helps the user to achieve his / her 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.

2.5.17. 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.

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

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

2.6.2. 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 set up by the Welsh Assembly Government that had recommended that the Assembly Government should run an anti-stigma campaign.

2.6.3. 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.

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

2.6.5. There is also stigmatism 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 a history of mental illness.

2.6.6. 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.

3. Conclusions and Recommendations

3.1. The Committee notes the perception expressed by Mencap that people with learning difficulties have difficulty accessing services and recommends that Welsh Assembly Government considers the need to improve information and training given to professionals to enable them to communicate effectively with, and understand the needs of, people in the sector.

3.2. It is important that staff and service users and carers are trained and skilled to playing their part in service planning, commissioning and evaluation. Professional staff should try to see the problems and issues from the perspective of the service user or carer. The involvement of service users and carers in training staff would help to achieve this. LHBs and trusts should have a training strategy for identifying the training needs of all staff, including those in primary care, and delivering training.

3.3. A wide range of consultation methods are required for effective participation to be achieved. It is not sufficient to rely on formal meetings even when they are well run and properly resourced and supported. Where meetings are used care should be taken to put users and carers at their ease, so that they are not overwhelmed by jargon and their input is valued for the expertise they bring from their experience. The statutory agencies should be sensitive to the problems that the voluntary sector and individuals may have in attending meetings or otherwise engaging in planning services. They may need help with the cost and or provision of respite care or transport, especially in rural areas. The work that is being done by the Rhondda Cynon Taff User Network, the Brighter Futures Project in Wrexham and Meeting of Minds in Carmarthen are good models.

3.4. People who have been service users, but who have recovered and are in a stable position, and people who have been carers may have much to offer the service planning process from their experience and should be encouraged and trained to contribute. Subject to their having received training, service users should be involved in the recruitment of staff at all levels

3.5. The Committee endorses the suggestion that user involvement development officers should be appointed and that they should be independent of the statutory agencies. The Committee recommends that they be appointed jointly by LHBs Trusts and LAs. Their role should include training individual users and carers to participate in planning, commissioning, monitoring and evaluating services. They should also cascade information and guidance and help user and carer organisations to work with the statutory agencies.

3.6. The Committee received anecdotal evidence that users and carer involvement in care planning was often tokenistic. The Committee noted the survey by Mind Cymru which found that some users and carers did not have care plans. While it may be that some care plans are prepared informally, the Committee takes the view that all care plans should be signed off formally by the service user and the appropriate health care professional and copies given to the user and / or any carer.

3.7. The involvement of carers needs sensitive handling and the Committee commends that procedures

are put in place to secure the consent of the user to carer involvement at a time when the user is stable. The needs of the carer should not be overlooked, even though they may conflict with the needs of the service user. Carers' assessments should always be offered. The Committee notes that there could also be a conflict of interest which would adversely affect the service user where the carer is a statutory body which also provides the service. Children who are looked after by the local authority may be an example.

3.8. Some witnesses referred to the pressure under which staff were working and the time and resources needed to undertake care planning properly. The Committee takes the view that care planning and commissioning is a vital element of producing effective care and it has to be reflected in the staff complement.

3.9. The Committee was particularly disturbed to hear the experiences of the young people from the Barnardo's project. The support and care given to children and young people with mental illness is crucial to their development into healthy adults. The involvement of the young person and their carers is central to the success of their treatment. The Committee recommends that the Welsh Assembly Government takes urgent steps to ensure that children and young people are treated in an appropriate environment.

3.10. The special cultural needs of some black and minority ethnic minority groups should be recognised in both individual care planning and service planning, design and commissioning. As a minimum all staff involved in the process should be able to recognise and know where to seek advice on how to respond to such needs.

3.11. The elderly and their carers are another of group of vulnerable people who may have special needs requiring a different and sensitive approach.

3.12. Many service users felt that their needs were not addressed until they reached a crisis point. The Committee takes the view that if the care planning approach is applied effectively it will ensure that people who have chronic problems will receive appropriate and timely support, measures and therapies that will prevent relapse or deterioration wherever possible without the need for drugs or intensive treatment. (Paragraph 3.7 above also refers.)

3.13. The evidence summarised at paragraph 2.4.2 above comprehensively lists the key roles for the five different provider sectors and the service users and carers. The Committee recommends that they be taken by the Welsh Assembly Government as a guide to the mechanisms for improving service planning and commissioning and for improving individual care planning. The Committee expressed the view that in referring to the statutory sectors, the roles should permeate the individual professions and disciplines that make up the whole care team. With regard to local government, it is felt that the key for elected members is to champion the cause of care planning within the authority's overall programmes.

3.14. The Committee was very encouraged by the examples of good practice that were cited. It

concludes that these, and the many others that have not been mentioned, are a firm foundation for the future. The Committee recommends that the Welsh Assembly Government disseminate these examples across Wales, along with any examples from other countries.

3.15. Despite the progress that is being made through user participation to recognise the expertise of people who are suffering, or who have suffered, mental illness, a significant number of those who responded felt that such people were still stigmatised. This stigma may be based on people's fear of mental illness. The NHS Confederation recognises the need to be promote positive images of mental health. Twenty five per cent of the population suffer mental illness at some stage in their life, yet stigma may prevent some people coming forward for treatment of their problems at an early stage before crisis point is reached. The Committee noted that the Welsh Assembly Government proposes to develop an action plan this year for mental health awareness that will be directed at all sectors of the public. The Committee endorses this approach. It also recommends that Health Promotion Wales considers sponsoring an award scheme that would celebrate and publicise cases where people have successfully overcome a mental illness.

Annex 1

Standard 2

User and Carer Empowerment

Aim

To encourage full and genuine participation by users and carers in all aspects of mental health services including planning and commissioning.

Key Action 4

Over the next two years, authorities and agencies will develop arrangements to ensure that users and carers constructively participate in the development of plan to meet their individual needs, as identified in the 1996 guidance issued by the Welsh Office (See also key action 34)

Responsibility for Implementing:	NHS including Community Mental Health Teams (CMHTs) in partnership with the voluntary sector, LAs
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Performance target	All users and carers to have been involved in the development of their individual care plans and to have or have been offered a copy of their written care plan within the context of existing quality and performance management systems, by end June, 2003.
Monitoring information	Return on Welsh Health Statistics data set supplemented by local audit by users and carers with appropriate support.

Key Action 5

By the end of December 2002, service users and carers should have timely access to comprehensive, clear, appropriate and helpful information, in a range of appropriate formats and languages. This will include information in minority languages as well as English and Welsh and on tapes with access to interpreters or people who can use British Sign Language if required. There should be accurate information on facilities available across the area for providers especially those in primary care as well as users and carers. There may need to be local updated directories of services but organisations such as CALL and NHS Direct Cymru may be able to collate such information. Full use should be made of all existing sources to avoid unnecessary work or duplication.

Responsibility for Implementation	NHS Commissioning Trusts, LAs, LHBs
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Performance Targets	Comprehensive information available e.g. in libraries, GP surgeries or on the internet. Spot check system to be in place by end December 2002
Monitoring Information	Audit data

Key Action 6

A range of appropriate independent, trained, dedicated advocacy services should be available and promoted across Wales accessible in the community by end December 2005 and at in-patient sites by end-December 2002.

Responsibility for Implementation	Trusts, LHBs and LAs
Performance Target	100% of areas have access to a range of advocacy services by 2005
Monitoring Information	Audit data.

Key Action 7

By the end of December 2003, the NHS and local authorities will have introduced arrangements to ensure constructive user and carer participation in the

- planning
- design
- delivery and
- monitoring and evaluation of mental health services.

Responsibility for Implementing	LHBs, NHS commissioning Trusts in partnership with the voluntary sector, LAs
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Performance Target	Expenditure on travelling expenses, administrative costs and training for users & carers, respite payments for carers
Monitoring Information	Audit, SSIW inspections, complaint procedures audit in place. Annual report to be published describing selection and training systems for users and carers.

Key Action 8

Carers have a right to their own assessment and if assessed as eligible for support, a written care plan. The special needs of young carers must be taken into account.

Responsibility for Implementing	Local Authorities
Performance Target	100% of carers of individuals subject to CPA who have requested an assessment have been assessed by end December 2002
Monitoring Information	Survey returns locally and nationally. Local Authorities should produce a gap analysis of unmet need identified by the assessments.

Consultation Responses

1. Working Futures
2. Pontypridd & Rhondda NHS Trust - Mental Health Directorate
3. US (User and Survivor) Network
4. David Pugsley, Coity Clinic Day Hospital Manager, Bro Morgannwg NHS Trust
5. Anheddau Outdoors
6. Gogledd Gwynedd CHC
7. Conwy & Denbighshire NHS Trust
8. Moonflower Enterprises
9. 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