



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Adult Mental Health Services

STRONGER IN PARTNERSHIP

Involving Service Users and Carers in the
design, planning, delivery and evaluation
of mental health services in Wales

Policy Implementation Guidance

September 2004

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Adult Mental Health Services in Wales

Stronger in Partnership

1. Aim

The aim of this guidance is to provide advice and information on how to effectively involve people who use mental health services and their carers in the design, planning, delivery and evaluation of those services. The guidance is for all those concerned with mental health services including people in the statutory and voluntary sectors, commissioners and providers, and service users and carers.

It can be used as a framework to support a consistent and co-ordinated approach to what is broadly referred to as 'service user and carer involvement'. Reference to 'involvement' in this guidance is meant in its broadest sense, and should be taken to mean to include, to concern and to surround.

The Assembly Government's aim is for people with mental health difficulties and their carers to be genuinely and constructively involved in all aspects of mental health services, and this is a fundamental principal of our adult mental health strategy, 'Equity, Empowerment, Effectiveness, Efficiency' published in 2001.

We do not consider service user and carer involvement to be a one-off intervention or a discrete piece of work. Rather, we believe it is a far broader and more empowering way of working that should be an integral part of every aspect of mental health design, commissioning and provision.

2. Introduction

The concepts of user involvement and empowerment are complex and have been widely debated and contested over many years. They are concepts that have been regularly discussed within health and social care services and particularly within mental health. Unfortunately there is no universally accepted definition for these terms that are often used to encapsulate a wide range of different ideas and activities.

There are varying degrees of involvement that can range from basic information giving and consultation on a one to one basis, through to formal partnerships being established between professionals and users and/or user-led services.

Standard Two of the National Service Framework (NSF) for working age adults, published by the Assembly Government in 2002, relates to service user and carer involvement and empowerment. It requires services to develop arrangements to ensure service users and carers constructively participate in the development of their own personal plans as well in the design, planning, delivery, monitoring and evaluation of mental health services generally.

The Assembly Government has published generic guidance relating to the involvement of people using health and social care services in Wales, and this includes:

2.1 Signposts

‘Signposts – a practical guide to public and patient involvement in Wales’ was published in 2001 and was the result of a joint initiative between the Assembly and the Office for Public Management. It provides information and advice to NHS organisations about how to develop work in public and patient involvement (PPI). The guide focuses on both the strategic and operational aspects of PPI and provides information on how to successfully implement PPI initiatives.

‘Signposts Two – Putting Public and Patient Involvement into Practice’ was published in 2003, and aims to tackle the challenges of developing PPI practice further into a more mature form. It provides practical pointers for Trusts and Local Health Boards (LHBs) about how to plan for a more sustained and inclusive approach towards implementing PPI, as well as contact details to encourage the sharing of lessons learnt and experiences. The guide identifies the importance of engaging staff to improve PPI capacity, and how to monitor and evaluate PPI to gauge the impact it has made. Both guides can be accessed at:

<http://www.wales.gov.uk/subihealth/content/nhs/signposts/signposts-e.pdf>

<http://www.wales.gov.uk/subihealth/content/nhs/signposts/signposts2-e.pdf>

2.2 Health and Social Care Guide for Wales

This guide sets out what service users can expect from service providers both now and in the future as improvements to services are made. It is for everyone who uses health and social care services, and applies equally to those receiving mental health services. It can be accessed at:

<http://www.wales.nhs.uk/documents/4dech&SCareGuide.pdf>

2.3 Guidance on Planning for Social Services

This guidance is for local authority members, management bodies of partner agencies, corporate local authority managers and social services managers. It states that ‘arrangements must be in place to include users and carers views and perspectives in the planning function’. The guidance can be accessed at:

http://www.wales.gov.uk/subisocialpolicy/content/pdf/guid_plan_e.pdf

2.4 Commissioning guidance

Two sets of generic guidance have been issued relating to the commissioning of services. ‘Promoting Partnership In Care - Commissioning across Health and Social Services’ is primarily for councils with social services responsibilities and concerned with the practical and more detailed aspects of commissioning. It needs to be read alongside guidance on managerial arrangements for health commissioning given in ‘Planning and Commissioning NHS Services: Guidance’. Both pieces of guidance stress the need to involve patients, users and carers in the planning and design of services. In addition specific guidance has been issued on commissioning mental health services. All of the commissioning guidance can be accessed at:

<http://www.wales.gov.uk/subisocialpolicy/content/guidance/partnership-care-e.pdf>

<http://www.wales.gov.uk/subihealth/content/consultations/commissioning/commissioning-guide.pdf>

<http://www.wales.gov.uk/subihealth/content/consultations/commissioning/commissioning-adult-mh.pdf>

2.5 Service and Financial Framework (SaFF)

The priorities and requirements for the NHS in Wales for 2004-05 are set out in the Assembly Government's 'Annual Priorities and Planning Guidance for the Service and Financial Framework 2004-05' document. Under the heading 'Involving People' one of the main priorities includes the following target:

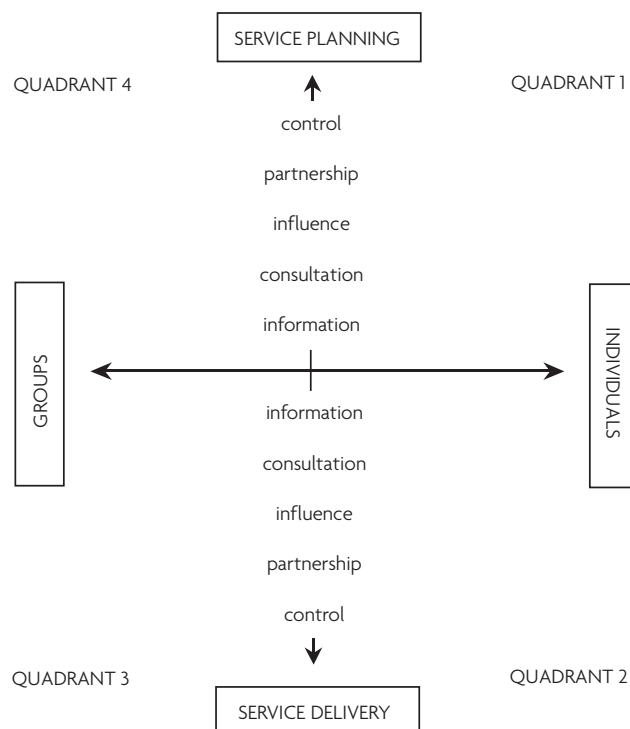
'All Trusts, LHBs to have introduced by March 2005 arrangements to ensure constructive service user and carer participation in the planning, design, delivery, monitoring and evaluation of mental health services'.

3. Key issues around service user involvement

The National Institute for Mental Health in England (NIMHE) has produced a useful summary of the key issues around user involvement as part of its 'Cases for Change' series of booklets (*Cases for Change – A Review of the Foundations of Mental Health Policy & Practice 1997-2002*).

It quotes a useful model (Hogget, 1992, p19) for encapsulating the complexity of this issue. See figure 1 below.

Figure 1



Referring to the model, 'Cases for Change' points out that this seeks to distinguish between the degree of participation/control available and whether the user is involved as an individual or via collective action. For example:

- Is the user involved in decisions about their own care or service plan (quadrant 1)?
- Does the user have any influence over the way that these services are then delivered (quadrant 2)?
- If the user is part of a group that receives a particular service, to what extent is the group able to influence the way in which the service is provided (quadrant 3)?
- The user may be one of many living in the area with similar needs and problems. To what extent is the group involved in the service planning process (quadrant 4)?

4. What is genuine service user involvement?

The Assembly Government endorses the view that genuine user involvement can best be demonstrated when service users and carers believe and perceive they are being involved. This requires not only service users and carers being on planning groups, but also having a genuine influence over how services are planned, developed and delivered as well as over how they can be improved in the future. Genuine involvement requires:

Building of confidence. Service users have unique skills and abilities, and are 'experts' in their own illness and experts by experience. Service providers should recognise and appreciate this and actively seek the opinions, views and feelings of service users.

Providing relevant and timely information. This should include what service facilities are available nationally as well as locally and what alternative types of service exist.

Providing suitable space and time. Time and space for service users and carers to express their views. In addition to meetings and conferences, etc. commissioners and providers should also consider other means of obtaining views such as through letters, via e-mail, questionnaires, etc.

Responding appropriately. Responses from service providers, who are responsible for acting on advice from service users, should be explicit. Feedback should always be given showing how service users' views have been acted upon or an explanation given where they haven't.

Empowerment

The notion of empowerment is closely related to that of user involvement but is difficult to define. At its most basic it involves:

- Professionals recognising that their training, their status as salaried workers, their control of public resources places them in a more powerful position than the service users with whom they work.
- Professionals being prepared to relinquish a degree of their own power and working with service users rather than for them.
- Professionals enabling service users to have a greater choice and control over

their own lives.

- Not only listening to but responding to service users' views.

5. The Expert Patient Programme

The Expert Patient Programme (EPP) is a NHS based training programme. It aims to help people living with a long-term chronic condition develop new skills to manage their own condition better and so improve the quality of day to day living. The courses are delivered within a community setting by volunteers with experience of living with a long-term illness. Pilot studies in Wales have been very well received, with evidence that the EPP has improved the patients' confidence and ability to self-manage, as well as helping people make life changes and feel calmer.

Further details can be found at:

http://www.expertpatients.nhs.uk/about_people.shtml

6. The benefits of service user involvement

It is widely recognised that service user and carer groups have a unique body of knowledge. Trusts, LHBs, local authorities and all other relevant service providers should clarify the purposes of involving users and carers in planning and delivering services.

The range of benefits include:

- Service users are recognised as experts in their experience, with a good knowledge of mental health services and of living with a mental health problem. No one else – no matter how well trained or how qualified – can have had the same experience of the onset of mental illness, the same initial contact with services or the same journey through the mental health system.
- Many service user organisations have developed a range of coping mechanisms and survival strategies that help people manage their mental health problems. Many users can predict when they are about to become unwell and have a plan for coping in place. Service providers can use this expertise.
- Service users bring their own perspective about treatment and care and can prompt service providers and practitioners to re-evaluate their provision of services, challenge traditional assumptions and highlight the key priorities that users would like to see addressed.
- Service user involvement can be seen as providing a personally therapeutic experience and enabling people to feel that they are being listened to and that their contribution is being valued. Working collectively as part of a network of groups can help people increase their confidence and raise self-esteem.

7. Engaging with service users

There are many good examples throughout Wales where service users through well-organised networks and organisations are involved in a wide range of activities and structures. Many

service users are serving on the management committees of local drop-in centres and represent their network/organisation on various strategic planning groups.

The User Survivor (US) Network is the only independent mental health service user led organisation operating on an all Wales basis. It has over 600 members across Wales providing a voice for users and survivors of mental health services.

There are also many regional networks such as the 'Powys User Link' (PUL) and the North Wales 'Mental Health Users' Forum' that are service user led.

These networks are involved in a range of activities including:

- Providing independent information and resource services to network members via telephone, correspondence, newsletters and other publications;
- Facilitating workshops, conferences, training, seminars and other education on mental health issues;
- Providing a focal point for the voluntary and statutory sector and others to liaise and seek the views of service users;
- Encouraging service providers to involve service users in a meaningful and constructive way in the planning, delivery and monitoring of services;
- Working to improve general awareness about mental health matters.

8. The special needs of carers

Carers of people with mental health problems need services too. By carers we mean people who look after a relative or friend who needs support because of their mental illness. Carers are likely to have a special insight into the needs of the person they support and be used to representing their needs. Carers also have a right to their own assessment and, if assessed as eligible for support, a written care plan. Carers are service users in their own right though their needs may not always coincide with the people they care for and there may be times when their respective needs and interests diverge and may conflict.

9. User Involvement Development Officer posts

These posts were established in 2001 as a three-year pilot covering the areas of Cardiff and the Vale and Merthyr Tydfil, and Rhondda Cynon Taff. The project, funded by the Assembly Government, aims to work with service users and mental health agencies to promote good practice in service user involvement.

The project has developed a number of activities that have improved the confidence of service users taking part. These activities have included:

- Delivering recruitment training to service user groups and establishing a trained pool of representatives available for short listing and interviewing;
- Building better relationships with professionals through service user

presentations, visits to services and consultations, etc.;

- Organising a service user 'Open Day' that helped raise awareness and promote the project;
- Facilitating a 'Standing Up - Speaking Out Skills' training course that covered communication skills, assertiveness, working with professionals and meeting skills.

This project is still subject to final evaluation, however the Assembly Government believes this is a worthwhile and constructive way of taking forward service user and carer involvement.

10. The Care Programme Approach

The Care Programme Approach (CPA) is a co-ordinated system of care management that focuses on the needs of the individual, and requires service users, and where appropriate carers, to be fully involved in the formulation of their own care plan. The Care Plan will focus on the service users' strengths as well as their needs, and seek to promote recovery and independence. It should also recognise the diverse needs of service users, reflecting cultural and ethnic background as well as spirituality, gender and sexuality. It will include action and outcomes in all aspects of an individual's life where support is required, e.g. psychological, physical and social function.

Charter for User and Carer Participation

A 'Charter for User and Carer Participation' has been developed by a group of service users and carers in Wales and endorsed by the Assembly Government. The Charter is given at Annex 1. By adopting this Charter service commissioners and providers make a commitment to involving service users and carers in the design, planning, delivery and evaluation of mental health services in Wales.

Good practice checklist

A good practice checklist is given at Annex 2. This can be used as a tool to check progress against Standard Two of the National Service Framework (NSF). This quick self-check is a useful starting point for undertaking any formal review relating to service user involvement and empowerment.

Adult Mental Health Services

Charter for Service User and Carer Participation

Design and Planning of Services

Involving service users and carers in decision-making processes about how services are designed and planned is likely to lead to services that are more responsive to the needs of people who use them.

Personal planning of services

Service users and carers have a right to:

- Be full partners in the planning for their own service needs and in the design and drawing up of their own care plans.
- Have access to independent advocacy.
- Be present when their needs are assessed and their services planned and reviewed.

Joint planning and commissioning of services

Service users and carers have a right to:

- Be treated as full and equal partners within the joint planning process.
- Have effective independent support for involvement during meetings when this need has been identified.
- Have meetings held in an appropriate format, at appropriate times and in appropriate venues.
- Have other mechanisms available for ensuring effective involvement, e.g. representatives of planning groups visiting user and carer meetings to obtain views.
- Be involved in the formal processes for gathering the views of service users and carers separately and seeing them integrated into the planning structure.
- Have effective support for communicating with their respective organisation or forum.
- Receive remuneration of expenses incurred for involvement in planning processes.
- Receive good quality, appropriate and accessible information in good time to enable effective consultation with constituent groups.

- Receive good quality, relevant and appropriately timed training.
- Have clearly agreed roles and responsibilities.
- Be kept informed about how their contributions have influenced planning and service delivery.

Service Delivery and Monitoring

Service user and carer involvement in the delivery and monitoring of services will make services more responsive and increase their appropriateness and therefore their effectiveness. It will help raise standards and build trust and confidence in services.

Service Delivery

Service users and carers have a right to:

- Be treated as full and equal partners and fully involved in the delivery of services.
- Be involved in the selection and recruitment processes of staff who will be delivering services and receive training and support to enable them to do so.
- Be involved in the drawing up of job descriptions for Mental Health professionals in order to ensure the inclusion of qualities deemed essential or desirable by users or carers, e.g. empathy, personal experience of mental health problems etc.
- Be involved in induction training for staff who deliver services and receive support to do so.
- Be offered clear and understandable information about a choice of services appropriate to their expressed need.
- Have their views taken into account and be provided with feedback if they are not satisfied with services offered.
- Be made aware of alternative services where these exist.

Monitoring and Evaluation

It is vital that monitoring is not simply a gathering of statistics and that qualitative as well as quantitative methods are used to monitor services. What is essential is how this information is used to develop and change services appropriately to meet identified needs.

Service users and carers have a right to:

- Be informed of how to make a comment or complaint about the services they receive and be supported in this process in a non-discriminatory way.
- Have a method of commenting on services anonymously and have their responses fed into the monitoring and evaluation process.
- Be given the opportunity to inform service providers whether or not their

identified needs are being met.

- Be involved in the design and collation of monitoring and evaluation procedures and in the compilation of results.
- Be informed of the results of monitoring and evaluation of services.
- Not have their services affected negatively by making comments or complaints.

Good Practice Checklist

Design and Planning of Services

Action	Not Met	Part Met	Met	Action Plan
Service users and carers are made aware of how they can be involved in the design, planning and commissioning of services.				
Service users and carers are asked how they would like to be involved.				
Service users and carers are made aware of service user groups and organisations.				
Service users and carers from all communities are fully included, with outreach work undertaken to ensure participation of people living in rural areas.				
Consideration is given to how to involve people with mental health needs who are not currently engaged with services.				
Copies of the 'Charter for Service User and Carer Participation' and this checklist are made widely available.				
At a personal planning level the Care Programme Approach (CPA) is adopted and service users and carers are fully involved in the development of their own care plan.				

Action	Not Met	Part Met	Met	Action Plan
A wide range of views is sought amongst service user and carer groups and responsibility falling to one or two individuals is avoided.				
Independent advocacy is available to service users.				
<i>Training</i>				
Briefing and support is offered to service users and carers who are considering becoming involved.				
Training is made available to service users and carers as early as possible.				
Training aims to ensure genuine and meaningful service user and carer involvement.				
Training is offered pro actively and without the service user or carer having to request it.				
Training is tailored to meet individual needs, as far as is practical.				
<i>Expenses</i>				
Expenses are reimbursed for service users and carers attending planning meetings, interviews etc.				

Action	Not Met	Part Met	Met	Action Plan
<i>Support for carers</i>				
Respite care is considered to allow carers to attend planning meetings, etc.				
<i>Meetings</i>				
Design and planning of meetings always includes input from service users and carers.				
Service users and carers are given sufficient advance notice to enable them to attend.				
Information, agendas, minutes, etc., is provided in an appropriate format, and in good time to allow consultation with constituent groups.				
Transport is planned carefully with due respect to carers' and users' personal circumstances.				
Meetings are conducted in an informal way with proper respect for all attending.				
Language used at meetings is clear and understandable and use of jargon is avoided.				
There should be a minimum of two service users and carers at meetings.				
Support prior to meetings and after is provided to users and carers to ensure their empowerment to participate.				
There is a nominated person to co-ordinate user and carer involvement.				

Service Delivery and Monitoring

Action	Not Met	Part Met	Met	Action Plan
<i>Recruitment of Staff</i>				
Service users and carers with the appropriate interest and skills are selected to participate in the recruitment and training processes.				
Carers and service users are involved and supported in the recruitment and selection process for all posts.				
Person specifications for all posts include personal experience of mental health services as a desirable.				
<i>Training</i>				
Service users and carers are always involved in the planning and delivery of Induction Training of all staff.				
Service Users and Carers are regularly involved in on-going training for all staff.				
Service Users and Carers are included in 'away days'.				
Service Users and Carers are involved in designing and planning of monitoring techniques e.g. designing monitoring forms, planning focus groups etc.				
Service Users and Carers are involved in the analysis of monitoring information.				
Service users and carers are involved in the dissemination of monitoring information.				
Results of monitoring and evaluation are shared with all stakeholders.				