



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Adult Mental Health Services

STRONGER IN PARTNERSHIP 2

Consultation Draft

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

Policy Implementation Guidance

August 2007



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Stronger in Partnership 2

The term 'service user' is used throughout this Guide, and refers to those people who have used or are using mental health services provided by health and social care organisations.

Other terms used to describe this group of people are just as valid, such as 'survivors', 'clients', 'patients' or 'consumers', but for consistency and ease of use the term 'service user' has been used throughout.

The involvement of carers must be equal to the involvement of service users. Wherever the term 'service users' appears in the text, note that this also covers 'carers'.

1. INTRODUCTION

Mental health is now firmly a part of the health and social care service development agenda. Throughout the UK and the rest of the world there is now a better recognition that mental health must be taken more seriously and given a higher priority.

There is also a general acceptance that if we do not improve mental health there is a burden not only on those who are mentally ill, on their families and their communities, but also an economic burden.

Figures from the Office for National Statistics (ONS) show that one in six of the general population has a common mental health condition such as depression, anxiety or other neurosis at any one time.

The World Health Organisation (WHO) has estimated that one person in four will be affected by a mental disorder at some stage of life, and has found that depression is currently the leading cause of disability worldwide.

People with or recovering from mental illness find it extremely difficult to enter or re-enter the workforce or to enjoy the full participation within society that many take for granted.

Socially excluded within communities and frequently living in poverty, debt and poor housing, this hampers many peoples' ability to recover from a mental health problem and their ability to enjoy full citizenship.

Over the last 30 years we have moved away from an institutionalised system of care and adopted a holistic approach that seeks to treat people as individuals and considers their whole needs rather than defining through a narrow medical model using a collection of diagnostic labels.

There is more of a recognition and acknowledgement that people experiencing mental illness have the same rights and needs as the rest of society.

The Assembly Government is determined to ensure that people who use mental health services and their carers are genuinely and constructively involved in all aspects of **their** service, ensuring that patients - service users - are listened to and taken seriously, and that people have choices and a genuine influence over how services are planned, developed and delivered.

While recognising that clinicians give expert professional advice, it is patients, those people who use the service, who are the experts on how they feel and what the aims and ambitions for treatment should be, as well as how they can be improved in the future.

2. What this guide is for, and some issues to consider

This document is a Guide to involving mental health service users and their carers in all aspects of designing, planning, developing, delivering, monitoring and evaluation of mental health services in Wales. It updates the original 'Stronger in Partnership' document published in September 2004.

The original guidance, or SiP1 as it will now be referred to, was an idea conceived by a user of mental health services in Wales. They also suggested a 'Charter' and a 'Checklist' be developed which could help commissioners and providers of mental health services reflect and then improve upon their engagement with people who either currently use or have used mental health services in the past.

SiP1 was designed to provide practical guidance on getting started, as well as giving commissioners and providers the opportunity to declare their commitment to ensuring meaningful service user involvement by adopting the Charter and making use of the Checklist as a tool to assess progress against Standard 2 of the Adult Mental Health National Service Framework (NSF) 'Raising the Standard'.

It also provided links to the wider generic guidance that was available in Wales relating to Patient and Public Involvement (PPI), as well as linking to the wider health and social care strategic agenda including service planning and commissioning guidance.

This Guide updates SiP1 and gives commissioners and providers of mental health services better and more up to date advice on why involving service users is not an option but a requirement. It also provides practical advice and information on how to effectively involve people.

The Guide is for all those concerned with mental health services within the NHS and independent sectors, including commissioners and providers, individual service users and carers, as well as service user and carer groups and networks.

It has drawn extensively on two particular documents:-

- 'Asking The Experts - A Guide to Involving People in Shaping Health and Social Care Services';¹ and
- 'Reward and Recognition'. Guidance issued by the Department of Health for service providers, service users and carers.²

Reference to 'involvement' in this guidance is meant in its broadest sense, and should be taken as meaning to include, to concern and to surround. This reflects the concepts of active, ongoing joint working and true and full 'participation' (taking part

¹ Asking The Experts - A Guide to Involving People in Shaping Health and Social Care Services', developed as part of a Community Care Needs Assessment Project in Humberside;

² 'Reward and Recognition – The principles and practice of service user payment and reimbursement in health and social care; A Guide for service providers, service users and carers'.

in) or 'consultation' (looked to for information or advice). In essence, 'involvement' means working towards and aspiring to full participation.

However, service users are not all part of one homogenous group with a shared identity and shared interests. For example there is a distinction between voluntary and involuntary service users, that is, those who have exercised some degree of choice in seeking help, and those subject to detention and whose treatment is subject to compulsion, often against their will.

There are also differences in individual needs with some people using services on a long term and continuing basis while others may use services on a short term or episodic basis.

The needs and interests of people who care for people with mental illness need also be distinguished from those for whom they care, and there is a particular section on meeting the needs of carers on page 18 of this guidance.

It is important to ensure that people from a wide range of groups are involved not just those who are already actively engaged.

Involving people from diverse groups, often referred to as hard to reach or marginalised, is sometimes considered to be more challenging and difficult than involving those people well known as active citizens within their community.

This should not be the case. By ensuring people know why they are being asked to become involved, by being clear about what difference this will make, and by giving feedback to communities as well as individuals, involving people 'beyond the usual suspects' should be easier and become the norm.³

Barriers that exist to prevent or deter involving people with particular conditions (for example people with dementia) or people from particular groups (for example refugees) need to be broken down and challenged.

It is essential to recognise that legislation is in place to protect people from discrimination on grounds of Race, Gender, Sexual Orientation, Religious Belief, Age and Disability, and organisations must promote equalities and provide advice on how to ensure the legislation is complied with.

³ For information on the Beyond the Usual Suspects Project go to www.shapingourlives.org.uk/

3. Why involve people?

Advantages

Involving mental health service users has advantages to both the individual and the organisation commissioning or providing the service. Service users are recognised as experts in their experience, have a good knowledge of services and how the system works and of living with a mental health problem.

No one else, no matter how well trained or how well 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.

Service users bring their own perspective about treatment and care and can prompt service providers and practitioners to re-evaluate the provision of services, challenge traditional assumptions and highlight the key priorities they would like to see addressed.

Service user involvement can also provide a personally therapeutic experience and enable people to feel they are being listened to and that their contribution is being valued. Working collectively can help people increase their confidence and raise self-esteem. It also has the benefit of reducing social exclusion.

Decisions are more likely to be seen as positive by those who have had a stake in developing them, and sharing the agenda promotes constructive working relationships.

Many people have developed a range of coping mechanisms and survival strategies that help manage their mental health problems, and can predict when they are about to become unwell. This leads to many people developing a plan for coping with their condition, and service providers can draw upon and utilise this expertise.

Genuine service user involvement can help lead to recovery, with people having more control over their own lives, receiving efficient and effective value for money services they want and need. Service providers are better able to identify where standards are not being met and receive positive feedback where staff are performing well.

Involving service users also presents benefits to service commissioners and providers. These include the improved design and delivery of more effective services and better value for money through less waste on ineffective interventions. Customer care standards are also more likely to be met

Statutory Requirement

The NHS has been required to consult and involve people who use its services under section 11 of the Health and Social Care Act 2001. From 1 March 2007 this duty is a requirement under section 183 of the NHS (Wales) Act 2006 and section 242 of the NHS Act 2006.

The overall aim of the legislation is to ensure that service users and the public are involved and consulted from the very beginning of any process to develop health services or change how they operate.

‘Involving and consulting’ has a particular meaning in the context of the legislation. It means discussing with people their ideas, their experiences, why services need to change, what people want from services, how to make the best use of resources, etc.

There is a duty to involve and consult people not only when a major change is proposed, but also in the ongoing planning of services.

Mental Health Services in Wales

In many ways the mental health sector has led the way in developing systems and initiatives to involve people who use services in planning and delivering them. Some Trusts in Wales have introduced initiatives whereby service users sit on selection and recruitment panels for all posts, both clinical and managerial, and have equal responsibility in appointing staff.

Initiatives have also been developed to ensure that service users are involved in training, and of raising awareness for both new and established staff. Evidence shows that involving people in planning and developing health services contributes to changes in the provision of services across a range of different settings.⁴

Policy in Wales

The Assembly Government requires commissioners and providers to ensure that service users and their carers are genuinely, meaningfully and constructively involved in all aspects of mental health services. This is a fundamental principle of our Adult Mental Health strategy published in 2001, and is one of the Standards set out in ‘Raising the Standard’, the revised Adult Mental Health NSF published in 2005.

Service user involvement should not be seen as a one-off intervention or a discrete piece of work; rather, it should be seen as a far broader and more empowering way of working that needs to be an integral part of every aspect of mental health design, commissioning and provision.

The Assembly Government endorses the view that genuine user and carer involvement can best be demonstrated when service users and carers believe and perceive they are being involved.

It is essential that at the start of the process Trusts, LHBs, Local Authorities and any other service providers clarify, agree and understand the purposes of involving users in the planning, delivering and monitoring of services.

⁴ Crawford MJ, Rutter D, Manley C et al. ‘Systematic review of involving patients in the planning and development of health care.’ British Medical Journal 2002; 325: 1263-1265
<http://bmjjournals.com/cgi/reprint/325/7375/1263>

This requires not only service users being involved in meetings and sitting on various planning groups, etc, but also having an actual genuine influence over how services are planned developed and delivered and 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. It is also important to provide support and training to enable service users to understand and analyse the information provided, and on which their views are sought. This helps build confidence in being able to articulate views into planning and commissioning processes.

Providing relevant and timely information; such information should include what service facilities are available nationally as well as locally, and what alternative types of service exist to enable input into strategic vision and not just into operational matters.

For example, meaningful involvement does not mean just focusing on the need for hot food in inpatient facilities, but also involves discussing the need for inpatient facilities in the first place.

Providing suitable space and time; commissioners and providers should go to people's own territory, local venues, service user group meetings, etc. rather than just rely on service users attending official meetings.

Other ways of being available to service users outside of traditional formal meetings includes:-

- website question and answer forums;
- questionnaires; and
- e-mail and letters.

It is important that agendas for meetings reflect priorities for service users as well as facilitating input to and comment on the agenda/priorities of the commissioners and providers.

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.

Minutes from meetings should always reflect the contribution of service user members, even if the views put forward were not the majority view of the meeting. Agreement should be sought as to how contributions will be recorded.

Empowerment

The notion of empowerment is closely related to that of user involvement but is much more 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; and
- not only listening to but responding to service users' views.

Professionals should be prepared to undertake training as a planning or commissioning team on how to appropriately involve service users in their work alongside the service user members of those teams. A good practice example is the Review Team managers within the Health Care Commission who undertook training on full and meaningful involvement of mental health service user reviewers in their teams.

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 individual care plan. These should be formally agreed and signed by the service user and appropriate health care professional and copies given to the service user, and with their agreement to any carer.

The Care Plan should focus on people's strengths as well as their needs, and seek to promote recovery and independence, recognising diverse needs. 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.

4. Levels of involvement

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 management boards or committees, and represent their network or organisation on various strategic planning groups.

There is a wide range of service user groups and networks throughout Wales 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; and
- Working to improve general awareness about mental health matters.

Conwy and Denbighshire Adult Mental Health and Social Care Partnership Board

The purpose of the Partnership is to achieve improved Adult Mental Health and social care services for the people of Conwy and Denbighshire, through the provision of user-centred health and social care.

Principles include:-

- working together across all statutory agencies and voluntary organisations to ensure a better outcome for users;
- closing the 'gap' experienced by users and carers between different areas of service between the two counties and between mental health and social care;
- reducing existing duplication of services; and
- ensuring user and carer involvement when planning and developing services, utilising the existing experience and future plans and strategies of user and carer groups.

Membership of the Partnership Board includes one Carer and two Service User Board members who are active participants and provide a perspective for Adult Mental Health Service Users in Conwy and Denbighshire.

Service user and carer Board members are appointed by a process consistent with good practice in recruitment. The vacancies are advertised via the regional press and local networks. A description of the role, personal qualities and experience has been agreed and applicants submit a CV detailing their relevant experiences and qualifications for the role. Short listing and interviewing takes place, references are taken up followed by appointment. /mentors are selected from the existing Board members to support the service user and carer members in their induction. Service user and carer Board members receive a payment of £3,500 per annum for their commitment in addition to expenses for travel.

ForUs Caerphilly

ForUs are an independent organisation working to promote, support and develop closer involvement of service users in the planning and delivery of mental health services in the Caerphilly County Borough.

It seeks to help those affected by mental health issues to have a voice, give their opinions, share their experiences and in turn effect positive changes to the way mental health services and support systems are developed and delivered.

ForUs has active and positive relationships with statutory bodies such as the Local Health Boards, Social Services, the NHS Trust and the Assembly. ForUs also has close partnerships with other voluntary sector groups and organisations involved in mental health services. It uses these links to bring pressure on those bodies that plan, commission and deliver services.

Using feedback and comments from service users and members of the ForUs forum, it also acts as a channel to inform those same statutory bodies about the quality of the services received and about changes and improvements that need to be made.

A range of ways individuals might be involved (as suggested in 'Researching User Involvement' 1992).

People might be involved:-

- in an assessment process or treatment decision, as individuals;
- as someone contributing their own views and experiences;
- as someone reflecting the voice of a group or community with a particular interest in common, such as use of a particular service, living in a particular area, or having a particular condition such as depression in common; and
- as citizens.

Contributing to:-

- the strategic framework or vision for services;
- identifying and prioritising needs and allocating resources;
- planning and purchasing services;
- developing assessments and providing services and packages of care and support;
- monitoring, reviewing and evaluating services and taking part in inspections and reviews; and
- staff recruitment and selection, training and development.

For the purpose of:-

- Improving the quality of services by making them more sensitive or responsive to the needs of the individuals who use them; and
- participating in decisions about the way services are designed, managed and monitored.⁵

Welsh Consortium for Approved Social Worker Training: Service User Involvement

The policy of the consortium is to include service users in the planning and delivery of the programme in a manner that is meaningful and not tokenistic.

Service Users have been involved in the planning process and contributed to the taught element of the programme for many years. Indeed, the training session facilitated by service users is well received by candidates each year.

In 2006 a further two service users became members of the planning group and agreed to attend some of the taught sessions and provide feedback.

Some of the advantages of involving service users in the planning and monitoring process are:-

- service users helping maintain standards;
- service user experiences remind the professionals of the reality of mental illness and its consequences;
- service user input assists professionals in reflecting on their practice; and
- service users help to keep the focus on real experience should the processes become too academic.

Service User Involvement Development Workers in Wales

‘Service User Involvement Development Workers’ have established their own all Wales network. They represent dedicated capacity to develop service user and carer involvement, usually informal groups, without charitable status, for representation as opposed to service delivery.

Contact details for Service User Involvement Development workers can be found in Annex 1.

⁵ Barnes M & Wistow G, *Researching User Involvement*, Nuffield Institute for Health studies, University of Leeds, 1992)

Service User Involvement Development Workers

Support to service users is provided in the following ways

Assist mental health service users to increase their awareness of their rights, choices and opportunities.

Work with service users to identify their support needs with regard to user involvement – for example training needs (e.g. confidence building, negotiating skills); resources (e.g. travel expenses, access to phones and other equipment, funding); information gaps (e.g. examples of empowering services, accessible information about local and national developments that impact on services).

Ensure that the necessary support is made available to service users either by directly providing it or by arranging for others to provide it.

Support service users to meet, discuss, raise and respond to issues about mental health services (this could involve developing or supporting ongoing forums and groups or organising one off meetings, conferences etc).

Assisting service users as appropriate, to prepare for, attend and participate in meetings with for example service providers, commissioners, Assembly Members.

Planning and Commissioning Services

Standard 5 of the Adult Mental Health NSF 'Raising the Standard' sets out the Standard for ensuring that services are jointly planned commissioned and delivered in an efficient and co-ordinated way.

Commissioning is a broad umbrella term for the process of determining whether services are needed, how they are provided, and whether existing services need to be changed or re-provided or new services developed.

The process of commissioning generally has three main elements:-

Planning:

- Needs Assessment – e.g. obtaining information relating to unmet need, as well as other feedback from service providers, service users and carers, demographic information, etc; and
- comparing options, service models, etc.

Purchasing:

- Clarifying and agreeing service specifications, changes and developments and agreeing how, and by whom, they will be provided; and
- contract/service delivery agreements

Establishment/Implementation:

- Putting service plans and developments into practice, reviewing and monitoring.

Commissioning has been defined as “the process of specifying, securing and monitoring services to meet individuals’ needs both in the short and the long term. As such it covers what might be viewed as the purchasing process as well as a more strategic approach to shaping the market for care to meet the future needs.”⁶

The WAO found in its review that there were local multi agency mental health strategic planning groups in place across all parts of Wales but found that some were better developed and more effective than others.

In 2005 the Assembly’s Health and Social Services Committee conducted a broad review of Standard 2 of the Adult Mental Health NSF ‘Raising the Standard’ focusing on the current arrangements for service user involvement. It consulted with key statutory and voluntary stakeholders, received both verbal and written evidence, and produced a very helpful report setting out its conclusions and recommendations.⁷

The Committee set out what it saw as the key roles for each of the different sectors in planning and commissioning mental health services in Wales. These are:

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 progress;
- 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.

⁶ “Take your Choice a Commissioning Framework for Community Care” Audit Commission 1997

⁷ National Assembly for Wales, Health and Social Services Committee, Review of the National Service Framework for Mental Health, Standard 2: User and Carer Participation. October 2005.

NHS Trusts should:-

- show commitment;
- implement and monitor user/carer policy;
- facilitate high quality services;
- recruit and train staff with the 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.

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 stigmatism;
- 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.

The Voluntary Sector should:-

- provide information, training, support and advocacy;
- 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.

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/care 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.

Service 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.

The Assembly Government endorsed the Committee's report, and accepts that additional emphasis needs to be given to ensuring effective and meaningful involvement of 'users, carers and the voluntary sector in the initial strategic planning of services.'

The Committee's report and recommendations is itself an extremely useful tool, and the Assembly Government has copied its findings widely across the mental health sector in Wales. The report clearly highlighted a lack of resources for training service users about planning structures and processes.

Training needs to be given and awareness raised to ensure that users and carers know where and how decisions are made, and importantly, how they can influence them and become a part of the decision making process.

The 'Good Practice Checklist and Monitoring Tool' included in this guidance gives some good practice tips on how service users can be involved in the planning and commissioning of services, e.g. the 'Terms of Reference' (TOR) for all mental health planning groups should detail the reasons and need for such a role, the advantages this will bring, and clearly specify what the role is.

Delivery of Services

Standard 6 of the Adult Mental Health NSF 'Raising the Standard' states that mental health services should be responsive, effective and offer high quality, evidence based care in an environment and an atmosphere that provides dignity, privacy and support.

A comprehensive range of accessible services should be available 24 hours a day, 365 days a year. It is a requirement that service users are fully involved and have a major say in determining how these services are delivered.

There are already many good examples throughout Wales of service users having an influence on how services are delivered; examples include:-

- service users on the steering group of 'First Access', a primary care mental health team operating in Flintshire and Wrexham;
- members of the User Survivor (US) Network being involved in delivering training and awareness sessions at a GP practice in Llandovery;
- formal user-led service appraisals of Neath Port Talbot mental health day services, and the development of a service user panel;
- service users being involved in all aspects of selection and recruitment of mental health staff; and
- the involvement of service users in the training of mental health nurses.

Redressing the balance

Mind Cymru undertook a project looking at how service users could be involved in an integral way in training mental health nurses in Wales.

Its report, 'Redressing the balance' made four recommendations:-

- Service user involvement throughout the entire training process of mental health nurses is vital if training is to prepare nurses for their role adequately and if mental health services are to improve.
- Involvement must be meaningful and not seen as tokenism.
- Service users should be involved in curriculum planning, recruitment of student nurses, delivery of identified training sessions or modules; and further more, service users should be involved in any ongoing evaluation of the status of mental health nurses post registration.
- The involvement of service users from the beginning of the process is essential in order to avoid tokenism, and to challenge power imbalances.

Involvement in staff selection and recruitment

A successful pilot project across North Glamorgan and Pontypridd & Rhondda NHS Trusts was developed in partnership with other agencies within the area. The initiative was to ensure that service users and carers were meaningfully involved in mental health nursing recruitment and retention.

Feedback from service users in the pilot sites was unequivocal:

'A wonderful experience, I felt really valued and that my opinion really counted for something' - Service User Rhondda Taff Ely Network

'Since becoming involved in the project my confidence has improved so much.... I felt that I had been treated as an equal and that I had contributed to a really important decision which would affect patient care' - Service User Merthyr User Network

'It is so good to be able to give something back to the service....it has made me feel so valued' - Service User Rhondda Taff Ely Network

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.

The Assembly Government's Social Services Inspectorate for Wales issued Guidelines on Carers' Assessments in 2005, as Annex 12 of "Creating a Unified and Fair System for Assessing and Managing Care. It states:-

'Once all the service user's needs have been identified and the process of planning how the needs will be met has begun, it will be appropriate to engage with the carer, as a partner in the process, to identify what part of the care plan they are able and willing to meet ...'

Guidance issued by the Assembly Government relating to people on the Care Programme Approach (CPA) states:-

"The needs of the service user often relate not just to their own lives, but to the lives of their wider family. All individuals who provide 'regular and substantial' care for a person on the Care Programme Approach will be offered:-

an assessment of their caring, physical and mental health needs which will be repeated on an annual basis; or more often as needs dictate;

a written Carers Plan, which is agreed with the carer and relates to their caring, physical and mental health needs.

Carers will receive information about help available to them, the services provided for the person for whom they are caring, and what to do and whom to contact in a crisis. The service users' consent will be sought before disclosure of this information to carers."

Carers have become used to representing those they support, particularly where communication is problematic, and care should be taken not to undermine working partnerships. However, a distinction should be made between users and carers interests that respects their respective roles and perspectives, and allows each to contribute independently.

Evaluation and Learning

Research

The Wales Office of Research and Development for Health and Social Care (WORD) is a Branch of the Strategy Unit in the Health and Social Care Department of the Welsh Assembly Government. The strategic aim of WORD is to ensure that policy and practice in health and social care in Wales are underpinned by evidence, for the benefit of patients and the public.

To meet this aim, WORD develops, in consultation with partners, policy on R&D to reflect the health and social care priorities of the National Assembly for Wales. WORD also commissions and directly funds R&D activity and contract manages projects and initiatives to ensure that the highest standards are met.

There are numerous ways in which service users can be involved in research. This could include identifying and prioritising topics for inquiry, as well as commissioning, designing and managing the research. It could also include analysing and interpreting information obtained, writing up reports, disseminating results and evaluating the process.

Mind Cymru and Hafal are the lead organisations in the user and carer participation project of the mental health Research Network Cymru (MHRN-Cymru) and as part of this have established and are supporting a user and carer reference group and a database of service users and carers who wish to be actively involved in mental health research in Wales. The MHRN-Cymru has an essential criterion that project proposals must clearly demonstrate full user and carer participation from the design stage. Members of the user and carer reference group are part of the selection panel.

In the UK as a whole mental health and learning difficulty service users have led the way in actively participating in research, as well as in service monitoring and evaluation.⁸ It is essential that service users involved in research are adequately trained, supported and paid for their work and expertise.

Monitoring and evaluation

Ensuring sufficient qualitative data is important as well as having quantitative information. This guidance has previously stated that genuine user involvement is best demonstrated when service users themselves believe and perceive they are being involved.

It is therefore important for service providers to ensure there is a process in place for receiving feedback from those individual service users and service user groups that are involved in planning and delivering services.

A 'Charter for User and Carer Participation' is also included within this Guide, previously developed by a group of service users and carers in Wales. By adopting this Charter service commissioners and providers make a commitment to involving service users in the design, planning, delivery and evaluation of mental health services in Wales.

⁸ Asking The Experts - A Guide to Involving People in Shaping Health and Social Care Services', developed as part of a Community Care Needs Assessment Project in Humberside; p.110

The Good Practice Checklist given within this Guide should be used as a tool to assess progress against service user and carer involvement and Standard 2 of the Adult Mental Health NSF 'Raising the Standard'. The Checklist can be used to not only assess what action is being taken but also to identify how future action will be monitored.

5. LINKS TO WIDER INITIATIVES

The Expert Patient Programme (EPP) Wales

The NHS Expert Patients Programme (EPP)⁹ helps people with long-term health condition/s to build their confidence and improve the quality of daily life.

EPP courses are being mainstreamed throughout the NHS in Wales by 2008, so that as many people as possible in communities throughout Wales are able to benefit from self-management training.

EPP is a self-management course for people with any long-term condition. Courses of 8-16 participants with a variety of different conditions meet over six weekly sessions of 2½ hours per week.

They are led through a structured course by two trained lay tutors, who themselves have experience of making life changes as a result of living with long-term health condition/s.

The course builds on the principle that people with long-term health conditions are in the best position to know, what they need, in order to manage their illness better on a day to day basis.

EPP courses provide people with the skills to better manage symptoms such as depression, anxiety, breathlessness and pain, and empowering techniques such as individual goal setting and problem solving which enable them to live fulfilled lives, independently and at home.

Many people who attend an EPP course report a reduction in the severity of their symptoms, and less interference with their lives. They also report improvements in confidence levels and communication with health professionals.

EPP links with Condition Specific Patient Treatment and Education Programmes

EPP courses are designed to run alongside and enhance condition/disease specific patient treatment and education programmes delivered by NHS professionals. EPP courses compliment professional programmes by providing information about how people can help themselves.

Those involved in the delivery of EPP courses have wealth of knowledge about statutory and non-statutory services within their local communities, and routinely signpost people to sources of information, skills training, equipment, and peer networks to enable more or better self-care.

⁹ For further information visit www.eppwales.org/ and <http://www.expertpatients.co.uk/public/default.aspx?load=PublicHome>

Designed for Life

'Designed for Life' was developed to provide strategic direction to health and social care services in Wales through to 2015. Its key aims are to:-

- focus on health and wellbeing, not illness;
- get supply and demand into balance; and
- create sustainable services Wales can be proud of.

'Designed for Life' has 3 fundamental design principles:-

- user-centred services;
- getting the most from resources; and
- targeted continuous performance improvement.

Fulfilled Lives, Supportive Communities: A Strategy for Social Services in Wales

'Fulfilled Lives, Supportive Communities' sets out the vision, key themes and the future direction for social services in Wales. It sets out the principles for better services for citizens in Wales, including:-

- getting straight through to the services you need whatever your starting point;
- different services and different organisations working effectively together to meet your needs;
- much greater say in how services are provided to you;
- services provided in your home where possible or close to where you live;
- best use of technology, to inform you, help you and protect you;
- more reliable protection for vulnerable people;
- services that help you to lead as full a life as possible in your community; and
- clear, simple systems of complaint and redress

Making the Connections

The Assembly Government has a vision of a Welsh Public Service that shares common goals and works across functional and organisational boundaries to ensure services are; more citizen focused, responsive to the needs of communities, driven by a commitment to equality and social justice and to deliver efficiency

Making the Connections outlines four main principles:-

- citizens at the centre: services more responsive to users with people and communities involved in designing the way services are delivered;
- equality and social justice: every person to have the opportunity to contribute and we will reach out to those hardest to reach;
- working together as the Welsh public service: more co-ordination between providers to deliver sustainable, quality and responsive services; and
- value for money: making the most of our resources.

'Making the Connections' contains a framework for the practical implementation of the Assembly Government's vision for 'Citizen Centred' public service delivery.

The dimensions of the framework are:-

- **Democratic accountability** - this is about elected representatives taking forward the views of the citizen and getting services implemented which meet the needs of the citizen;
- **Front-line access and support** - ensuring that all public service bodies provide good customer service;
- **Responsive services** - providing services that are more responsive to the needs of individuals and communities, particularly those who are vulnerable and disadvantaged; and
- **Community participation** - ensuring that people have the opportunity to be involved in the design and running of their public services.

Signposts 1 & 2

'Signposts – a practical Guide to public and patient involvement in Wales'¹⁰ was published in 2001, the result of a joint initiative between the Assembly Government 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), and focuses on both the strategic and operational aspects of PPI.

'Signposts Two – Putting Public and Patient Involvement into Practice'¹¹ 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.

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http://new.wales.gov.uk/about/departments/dhss/publications/health_pub_index/reports/signposts1?lang=en

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http://new.wales.gov.uk/about/departments/dhss/publications/health_pub_index/reports/signposts2?lang=en

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.

Reward and Recognition

Service users contribute their time and expertise into improving services. It is essential that people are supported in doing this and that their contribution is recognised and valued.

Both UK Government and Welsh Assembly Government policy actively encourages the involvement of service users in the development and delivery of local, regional and national services.

The purpose of involvement is to improve service user and carer experience of services and to make services more responsive to people's needs.

Service user involvement can be on a voluntary basis. Volunteering is when people give their time and skills for the benefit of society and the community. It is undertaken freely and by choice, without concern for financial gain. It is good practice to reimburse volunteer's out of pocket expenses.

Service user involvement may also be on a paid basis, particularly for tasks such as sitting on selection and recruitment panels, or being a reviewer as part of an inspection or investigation.

Whether paid or as a volunteer it is essential that the role in which people participate and are involved, and their responsibilities, is discussed and agreed at the beginning of the process and is made clear for all concerned.

'Reward and Recognition'¹² was first published by the Department of Health in England in February 2006 with a second edition published in August 2006.

It was developed in consultation service users, patient and other health and social care organisations, and aims to support those organisations by outlining the principles and practice of reimbursing and paying service users for their involvement.

The guidance also aims to provide some consistency of approach and ensure that service users are treated fairly and appropriately according to their circumstances, so that they are able to make an informed choice about the arrangements concerning their involvement.

'Reward and Recognition' sets out:-

- the principles of best practice for reimbursement and payment for involvement;

¹² 'Reward and Recognition' 2nd Edition published by Department of Health, August 2006
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138523

- the roles and responsibilities for service users and NHS and social care organisations;
- advice on the implications of paying and reimbursing service users who are in receipt of benefits.

The focus of the Guide is on enabling and ensuring equitable access for service users to involvement activities. It is not intended to be a technical or detailed Guide on benefits advice but it does provide information on benefit rules considered to be most relevant.

Therefore, further expert advice on benefits should always be sought whenever necessary. Service providers have a duty of care towards service users who become involved, particularly those people who rely on benefits, and this duty of care is paramount.

The Assembly Government has issued a Welsh Health Circular (WHC (2007) 011) which highlights *'Reward and Recognition'* as well as *'Recruiting volunteers: a manual of good practice'* published by the Wales Council for Voluntary Action.¹³

The principles of good practice for payment and reimbursement for service user involvement set out in *'Reward and Recognition'* are shown in the following table.

Principles of good practice for payment and reimbursement include:-

- service users are not to be left out of pocket or put at risk of being financially worse off as a result of their involvement in service improvement;
- service providers and service users will discuss and agree on the terms of involvement prior to committing to it;
- service users are given the right information at the right time to be able to make an informed choice about how and on what terms they want to be involved;
- the contribution service users make can be recognised and valued in all sorts of ways such as being thanked, positive feedback and acknowledgement, staff time, practical assistance, personal development or seeing the impact of the work and changes made as a result of involvement;
- payments can be offered for certain levels of involvement, to be agreed between the service user and the service provider;
- a wide range of service users, with different needs and experiences are encouraged and supported to be involved;
- service users in receipt of benefits should be provided with the right information and support to prevent a breach of their benefit conditions;

¹³ www.wcva.org.uk/ – click on Publications, then select *'Recruiting volunteers: a manual of good practice'* dated 15.9.06.

- service users are paid according to open and consistent criteria that takes into account the level of involvement, the type of work and the skills and expertise required; and
- paperwork to claim payment and reimbursement is kept to a minimum. Where paperwork is necessary to safeguard both the service provider and the service user, it should be accessible and easy to understand.

Recommendations of Service User Task and Finish Group for Service User Reward and Payment in Mental Health Services

This section of the Guide was produced by a Task and Finish Group of service users originally established as part of the Action in Mental Health (AIM) programme. It gives recommendations and provides advice and good practice for service user payment in mental health services in Wales.

At the end of this Guide is a Glossary of Terms, a Benefits Fact Sheet, a list of useful publications and other information produced by the Task and Finish Group.

Mental health services in Wales were highlighted as a major health priority area by the last Assembly Government, and as a result the Action in Mental Health (AIM) collaborative was developed with the overall aim of achieving a sustainable improvement in Adult Mental Health in Wales.

In consultation with the main stakeholders, including service users and carers, key issues that will need to be addressed to improve services in Adult Mental Health in Wales were identified. The goal and aims were developed to reflect a number of underlying principles. One such principle of the programme being the; 'meaningful engagement of users and carers'.

During the AIM programme the complexity and difficulties experienced locally in payment of service users became apparent. Whilst this is not new, the AIM programme provided the National Leadership and Innovation Agency for Health (NLIAH) with the opportunity to work with service users from mental health services across Wales.

Principles

Social inclusion

Service users involved in the planning, commissioning, development or delivery of services should not be out of pocket or at risk of being financially less well off as a direct result of their involvement.

Choice

Service users have the choice to receive payments or to undertake work on a voluntary basis. To enable real choice that is based on sound individual advice and information. Organisations have a responsibility to firstly tell individuals that they can explore with them possibilities for financial rewards for their involvement and

secondly provide clarity about any possible financial penalties that might be incurred by service users who are in receipt of benefit. The duty of care for the paying organisation should end at this point.

Empowerment

Empowerment should be embodied within all policies, protocols and processes, assisting individuals towards a more meaningful and fulfilling life, encouraging well-being and allowing the voice of the service user to be heard to facilitate the improvement of mental health services across Wales.

Access to information

Service users in receipt of benefit should be provided with the right information to avoid a breach of their benefit conditions.

Parity within payments

In recognising the contribution that service users make to the work of mental health services in Wales, levels of expenses and payments should be equitable and based on parity with other contributors. This will assist in overcoming the barriers of poverty that many service users face.

Systems of payment

Financial systems need to enable expenses payments to be made on the day and timely payment of fees to be made to prevent service users being financially disadvantaged.

Payment of Expenses

In addition to any payment for attendance claim, service users and carers should wherever possible be reimbursed on the day of any meeting for any reasonable expenses.

Consideration should be given to the base for claiming travel expenses which, in the absence of any other established base of work will be regarded as the service users' home address.

There should be a clear distinction between payments and expenses.

Loss of earnings from benefit payments should be considered and the service users in receipt of benefit should be provided with the right information to avoid a breach of their benefit conditions.

Prior agreement should be secured for the items that are to be paid as expenses, which could include:-

- travel – including attending 'forum' events;
- meal allowance/subsistence;

- child care costs;
- support/carers costs;
- car parking;
- stamps;
- phone/internet –allowance;
- stationery;
- accommodation-maximum level/allowance; and
- printing and photocopying.

Some items can be supplied on reimbursement, e.g. postage where not covered by a fee.

Levels of expenses should be locally determined and provide equity with staff/board members. There should be parity throughout the organisation.

Payment of fees

The role of the service user should be agreed prior to any involvement, including:-

- whether they are providing a representative or individual view point;
- time commitment;
- further involvement - e.g. sub groups (chairing or member) collating service users views; and
- background information.

By accepting fees, service users are responsible for:-

- attendance;
- preparation work in relation to their involvement/role;
- dissemination of information;
- contribution;
- accountability; and
- informing relevant agencies e.g. inland revenue, benefits office.

Service Users should be rewarded for their time and knowledge, especially when working alongside other paid workers.

A fee may be considered appropriate for the following tasks:-

- making presentations;
- task and finish/working groups;

- committees/board members;
- recruitment and selection panels;
- individual face to face interviews;
- leading/facilitating half day/whole day seminars;
- training health and social care staff;
- chairing;
- networking panels;
- focus groups – member of/facilitating;
- planning/implementation teams around service development;
- attending training related to role;
- external consultancy and training; and
- leading/facilitating/presentations.

Level of payments should reflect the level of involvement or role of the service user, should reflect the skills and experience required, be paid at the market rate and not be less than the minimum wage.

No fee should be required for attending meetings just to listen or out of choice, for example a public meeting.

Payments Systems

Regardless of existing payment systems, organisations should reimburse expenses on the day, preferably in cash.

Cash payments should be payable on receipt of evidence of expenses incurred and evidence of current entitlement to state benefits, for out-of-pocket expenses.

A nominated individual should be authorised for service user/carer payments within an agreed set of Guidelines.

The service provider for any project involving service user expense reimbursement or payments should agree a financial budget for that involvement and hand over the budget and the authorisation process to the nominated individual.

The nominated individual should keep a record of all payments and be accountable for the budget.

Impact on Benefits

A distinction should be made between payments for activities and out of pocket expenses – which are reasonable and agreed.

A distinction needs to be made between payment for undertaking a 'role' and doing a job. An assumption cannot be made that by a service user or carer taking up a role that they are able to take on regular employment.

Information needs to be provided together with specialist welfare benefits advice on an individual basis.

The welfare benefits advice needs to be accessible from a named person with contact details provided by those arranging the service user's involvement.

The individual would then take responsibility for making a decision to accept payments and declare this to the benefits office.

The Welsh Assembly Government will seek to negotiate with Job Centre Plus staff with a responsibility for policy implementation in Wales to negotiate parity across Wales, and to ensure that regulations are applied consistently and appropriately across Wales.

Options regarding payments need to be set out clearly for all those involved (staff and service users). These include:-

- one off payments;
- payments below the permitted level of weekly earnings;
- break in benefits rule (8 week linking rule) – negotiation to come off benefits for period receiving payment (say 2 week period) and then immediately restart payments after this period with no further assessment;
- opting out and not taking a fee – although there are still implications regarding undertaking a regular activity that could be taken to demonstrate that you are fit to work that need to be explained fully and conveys an understanding of 'notional earnings'; and
- use of therapeutic earnings.

Clarity needs to be sought to provide accurate information in advance such as when establishing paid service user roles that extend beyond 12 months which may reduce entitlement to benefits after a 12 month period in work.

6. CHARTER FOR PARTICIPATION AND INVOLVEMENT

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.

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.

In implementing this Charter it is important to discuss and be clear about the responsibilities that accompany involvement. People using services have a degree of responsibility for maintaining their own health, and specific responsibilities within the framework of a care plan; for instance keeping to appointment times and observing agreed treatment regimes.

For involvement in the planning, delivery and evaluation of services other responsibilities may include:-

- feedback to a wider network;
- canvassing views of other service users and carers;
- being clear when an opinion is personal or representative; and
- adhering to policies, e.g., confidentiality, or declaring a personal or professional interest.

It is essential that expectations for both parties are agreed and clarified at the beginning of the process. This can be either through a formal contract or at least in an agreed written statement.

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; and
- 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, receive training and support to enable them to do so, and be involved in drawing up job descriptions;
- 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; and
- 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, in the compilation of results, and be informed of the results;
- not have their services affected negatively by making comments or complaints.

7. GOOD PRACTICE CHECKLIST AND MONITORING TOOL

A good practice checklist and monitoring tool has been produced and is shown over the following pages. This gives a variety of good practice 'tips', and can be used to monitor and self assess performance and progress against Standard 2 of the Adult Mental Health NSF 'Raising the Standard'.

This quick self-check is a useful starting point for undertaking any formal review relating to service user involvement and empowerment.

Before you start you may want to first ask yourself the following questions:-

- Are you prepared to commit yourself to user involvement as an integrated part of organisational activity rather than an occasional exercise?
- Are you prepared to take action as a result of what you learn?
- Do you have a clear, written strategy, developed with staff and service users, for involving people?
- Are staff and user groups fully aware of it, and has training been provided?
- Are you taking practical steps to enable people to participate?
- Do you have mechanisms to keep participants informed about how their contributions influence planning and service delivery?
- Is there a named lead at a senior level with responsibility for user involvement, and the power to make things happen?
- Is there an adequate budget for the costs of involving people?
- Do you co-ordinate 'user involvement' activities with other departments and organisations?
- Are you clear about why you are involving people?
- Do you have a means of evaluating the processes of involving people?
- Do you have a means of assessing the impact of involving people?
- What do you want to achieve?
- Who will have the final say over decisions? can you deliver what service users want?

This list of issues to consider looks challenging, and it may be that you are not able to answer all of the questions as you develop your plan. There is, however, plenty of evidence that considering these issues, and getting everyone on board before you start, goes a long way toward ensuring that your initiative will be successful.

Before service users and carers start, they should consider the following questions:-

- Service users should be clear whether they are providing a personal or representative view, this should be agreed with the partners prior to any involvement activity.
- If a representative view is required, service users must gather the views of their constituent group and feed back to that group.
- Service users should be clear about their accountability for their actions and comments. the service user and partners must agree how comments will be documented and owned prior to any involvement activity.
- Service users must be clear about the commitment required for participation.
- Service users must be clear about the requirements for confidentiality and agree to adopt any appropriate confidentiality policies required.
- Service users have a role in nurturing and supporting other service users to build their capacity to promote empowerment and involvement

Good Practice Checklist and Monitoring Tool

Action	Not Met	Part Met	Met	Action taken	Monitoring arrangements
<i>Design and Planning of Services</i>					
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 in the design, planning and commissioning of services.					
Service users and carers are made aware of service user groups and other support organisations available in the local area.					
Service users must be clear about the commitment required for their participation					
Service users and partners must agree how contributions are documented and owned prior to their involvement and giving due regard to any requirements for confidentiality					
Service users must be clear whether they are providing a personal or representative view – if the latter then they must gather the views and feed back to the constituent group					
Outreach work is undertaken to ensure the participation of people living in rural areas, and the involvement of all communities.					

Action	Not Met	Part Met	Met	Action taken	Monitoring arrangements
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 in accordance with current CPA guidance.					
A wide range of views is sought amongst service user and carer groups and responsibility falling to one or two individuals is avoided.					
'Terms of Reference' (TOR) for all mental health planning groups details the reasons and need for service user involvement, the advantages this will bring, and specifies what the role is.					
<i>Delivery of Services</i>					
Service users and carers are regularly involved in on-going training for all staff.					
Service users and carers are included if appropriate in conferences, workshops and seminars.					

Action	Not Met	Part Met	Met	Action taken	Monitoring arrangements
<i>Training</i>					
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 proactively and without the service user or carer having to request it.					
Service users and carers receive training relating to planning structures and processes and made aware of decision making processes.					
Service users and carers receive training relating to selection and recruitment processes.					
Training is in place to ensure that staff recognise the cultural needs of people from black and minority ethnic groups, and how to fully involve people from these communities.					
Service users use their experience to nurture and support other service users to build their capacity to enable their involvement.					

Action	Not Met	Part Met	Met	Action taken	Monitoring arrangements
<i>Expenses and other payments</i>					
Issues regarding expenses and other payments are discussed with service users.					
Advice is given to service users in receipt of welfare benefits to either contact DWP or seek specialist welfare benefits advice.					
Out of pocket expenses are reimbursed to service users and carers.					
<i>Support for carers</i>					
Carers are offered their own assessment					
Respite care is available to allow carers to prepare for and attend meetings, reviews, etc.					
<i>Service users and carers attending meetings</i>					
The design and planning of meetings includes input from service users and carers.					
Service users and carers are given sufficient advance notice of dates and times of meetings to enable them to attend.					
Information, agendas, minutes, etc, are provided in an appropriate format, and in good time to allow consultation with constituent groups.					

Action	Not Met	Part Met	Met	Action taken	Monitoring arrangements
Transport is planned carefully with due respect to service users' and carers' personal circumstances.					
Meetings are conducted in a way to meet the needs of service users and carers, and 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 10% service users and carers at meetings.					
There is an identified post to co-ordinate user and carer involvement.					
Monitoring					
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.					

Action	Not Met	Part Met	Met	Action taken	Monitoring arrangements
<i>Evaluation</i>					
A date is set for an annual review meeting with service users and carers to assess the quality of service delivery.					

Annex 1

Service User Involvement Development Workers: Contact Details: March 2007

Name	Job Title	Organisation	Address	Tel. No	Email
Polly Kitzinger	Service User Involvement Development Officer	Interlink, Rhondda Cynon Taf and Merthyr Tydfil	Maritime Offices Woodland Terrace Pontypridd CF37 1DZ	01443 485337	pkitzinger@interlinkrct.org.uk
Andy Fraser	Service User Involvement Development Officer	Bridgend Association of Voluntary Organisations	10 Park Street Bridgend CF31 4AX	01636 651934	andyfraser@bavo.org.uk
TBC	User Development Worker	Powys Agency for Mental Health	Smithfield Centre Smithfield Road Builth Wells Powys LD2 3AN	01982 825593	pul@pavo-pamh.org.uk
Jo Danielli		Powys Mental Health Alliance		01982 552900	As above
Alison Prydie	Mental Health Service User Participation Officer	Neath Port Talbot CVS	Ty Margaret House 17–19 Alfred Street Neath	01639 631387	AllysonP@nptcvs.org.uk

Name	Job Title	Organisation	Address	Tel. No	Email
Daniel Smith	Service User Involvement Development Officer	Cardiff and Vale Mental Health Development Project	Unit 11 Williams Court Trade St., Cardiff and the Vale MHDP CF10 5DQ	029 2022 2000	daniel@cardiff-vale-mhdp.org.uk
Hilary Roberts	PA to the Service User and Carer Board members	Unllais for the Conwy and Denbighshire Integrated Mental Health Partnership	Eirianfa Community Centre Factory Place Denbigh LL16 3TS	01745 818720	pacd@unllais.co.uk
Robyn Williams	Service User Involvement Development Worker	Unllais covering Gwynedd and Ynys Mon	42 Glanrafon Bangor Gwynedd LL57 1LH	01248 353777	suidnw@unllais.co.uk
Karen Gallagher	Service User Involvement Development Worker (including group administration)	Flintshire Representatives Group/Unllais	10a Wrexham Street MOLD Flintshire CH7 1ES	01352 756185	frgroup@tiscali.co.uk
Barbara Parnell	Co-ordinator ForUs	ForUs	YMCA Building Aeron Place Gilfach Bargoed CF81 8JA	01443 875533	barbara@forus.org.uk generic: foryou@forus.org.uk

Name	Job Title	Organisation	Address	Tel. No	Email
Older People's Mental Health Services	Carer and User Involvement Development Officers	Cardiff and Vale Mental Health Development Project	Unit 11, Williams court, Trade St., Cardiff	029 2022 2000	jane@cardiff-vale-mhdp.org.uk (covers Cardiff P/T) matthew@cardiff-vale-mhdp.org.uk (covers Vale of Glamorgan P/T)

Annex 2

Glossary of Terms

- **Service User** - Any user or carer, past or current, of mental health services
- **Service Provider** – Any organisation providing mental health services, whether in the public sector, private sector, voluntary or charitable sector
- **Carer** - A person who provides a level of support to a mental health service user which is recognised by the service provider(s) as being essential or beneficial to the well-being of the service user
- **Volunteer** – An individual who offers their services with no expectation of payment or reward for those services
- **Parity** – Equality of treatment of mental health service users and carers with mental health professionals and with other health service users
- **Expenses** – All out of pocket costs to service users or carers that enable them to undertake duties required or requested of them as service users. Such out of pocket expenses may include travel, subsistence, administration, and the care of a child or dependent adult, including the care by a carer of a mental health service user
- **Travel Expenses** – Expenses incurred in travelling to and from meetings or events – using the most reasonable and economical form of transport available to the service user.
- **Subsistence** – The cost of meals and/or light refreshments reasonably incurred in fulfilling the duties expected of the service user
- **Administration Expenses** – Costs involved in sending or receiving and handling information relevant to the duties expected of the service user
- **Reimbursement** – Repayment of expenses incurred by service users in fulfilling the duties expected of them
- **Payment** – An fee or agreed reward to service users for undertaking an agreed task or role
- **Reward** - A gift to demonstrate appreciation of a service user or carer contribution
- **Market Rate(s)** – The rate, or rates, generally payable for an equivalent role or set of skills

Benefits Factsheet

This section offers some advice on how to overcome some of the barriers faced within the benefits system and place yourself in a more empowered position should you need to access the Department for Work and Pensions (DWP) to get your benefit issues resolved.

Please note that the information is generic rather than specific, and does not claim to meet all needs as individual.

Claiming

- Always keep copies of the completed application forms. You could ask the staff to do this for you as you are a claimant on a low income and cannot meet the costs.
- Always request a receipt for documents that you hand in. DWP staff may 'refuse' so insist on having confirmation that you have handed in a document. Things go missing and you could experience unnecessary distress or even lose benefits.
- **Linking Rules** - These enable the claimant/services user to return to benefits at the same rate they were accessing prior to starting 'work', provided certain conditions apply. These range from 8 weeks to 2 years, depending on individual circumstances.
- **Extended payment/Run Ons** - extended payments of Housing and other benefits whilst working up to four weeks. Again this is dependent on individual circumstances.
- **Tax Credit** – Benefit to meet additional costs being sick/disabled and working.

Interviews

- Always have someone with you in a supportive capacity -friend/advocate.
- The same applies should you have a home visit from DWP staff. (This may mean postponing the appointment until you can find someone to accompany you).
- Ask for breaks if you feel you need one.

Decisions

- Always challenge a decision if you are not happy.
- Request written explanations - this extends the month period, by two weeks.
- If issues are not resolved, ask to speak to the manager of the respect benefit. You should be given a name.

Communication

- Remember to record important information at the time of the conversation including the date/time and significant details of the conversation.
- Remember to ask for the name of the person you are speaking to. They should give it, be it a pseudonym.
- If all else falls, complain. There is an official complaint form.

Useful contacts:

Should you be considering working for yourself: A fuller explanation of the type of support offered can be found in “**Ever thought of working for yourself**” (free from DWP)

Business Link	www.businesslink.gov.uk/	0845 600 9006
Job Centre Plus	www.jobcentreplus.gov.uk/	0845 606 2626
Inland Revenue	www.inlandrevenue.gov.uk/	0845 915 4515
The Prince’s Trust	www.princes-trust.org.uk/	0800 842 842
PRIME	http://www.primeinitiative.org.uk/	0800 783 1904

Citizens Advice Bureaux, Community Advice Centres, Community Law Centres

Benefit Enquiry Line (BEL)	0800 882200
Textphone	0800243355

They offer general advice on benefits for sick/disabled people, their carers and representatives.

Your local DWP office, Inland Revenue, Department of Trade and Industry have a wealth of information, including numerous booklets, free of charge. Copies can be obtained by downloading from the Internet, telephoning or by dropping in to your nearest office. This list is not exhaustive.

Useful publications

‘The Big Book of Benefits and Mental Health’

Neath Income Project, Neath Mind Association, 32 Victoria Gardens,
Neath, SA11 3BH

£15 to non-claimant £7.50 claimants including postage and packaging

‘Moving in to work’ A Disabled Person’s Guide to Social Security and other help available when starting work

Disability Alliance Universal House, 88-94 Wentworth Street, London E1 7SA

www.disabilityalliance.org/ e-mail office.da@dial.pipex.com

Tel: 020 7247 8765

'The Disability Rights Handbook'

A Guide to Benefits and Services for all Disabled People their Families, Carers and Advisers

Publishers as above

'Welfare Benefits and Tax Credits Handbook' Child Poverty Action Group,

94 White Lion Street, London N1 9PF

NB Most publications are available at a reduced price to claimants, where this is not the case, negotiate with the publishers.

Other Information

- There is a **Disability Rights Worker** in each JobCentre Plus Office, however, she/he may be attached to more than one Office.
- **Prescription Pricing Authority** Sandyford House, Archbold Terrace, Jesmond, Newcastle-upon-Tyne NE2 1BD (0191 203 55555) It is possible to get an exception/wavier from paying for your prescription although you may not be in receipt of a Income Support or a qualifying benefit.
- **National Insurance Contributions Office** Inland Revenue Benton Park Road Longbenton Newcastle-upon-Tyne NE98 1ZZ Telephone and Textphone (0191 213 5000)
- **Access to Work-** Through your JobCentre or JobCentre Plus- provides practical advice and support, including grants toward extra employment cost and special aids for equipment for employment.
- **Pathways to Work Pilot.** This scheme is only available in certain areas. Ask at your JobCentre/JobCentre Plus Office.
- **Business Start UP** Help setting up your own Business. Number of these schemes available including New Deal. Run by specialist training providers and organisations. For example, Training Enterprise Councils (TEC), Local Enterprise Companies (LEC), in Scotland, Local Councils, Enterprise Agencies, The Prince's Trust, Chambers of Commerce. Contact your JobCentre Plus and Job Centre.

