



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Adult Mental Health Services

Stronger in Partnership 2

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

October 2008



ISBN 978 0 7504 4892 5

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CMK-22-12-132

D2990809

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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 term 'carer' is used throughout this guide, and is used to mean people who look after family members or friends who need care, help or support. Carers can be adults caring for other adults, parents caring for ill or disabled children under the age of 18 or young carers aged 18 who care for another family member.

The term carer includes people who may or may not be a relative and who may or may not be living with the person they care for. It does not include volunteers who provide care as part of their work for a voluntary organisation, nor anyone who is paid for what they do.

Reference to 'involvement' in this guidance is meant in its broadest sense. This reflects the concepts of active, ongoing joint working and true and full participation (actively taking part in) or consultation (looked to for information or advice). In essence, 'involvement' means working towards and aspiring to full participation.

1. Background and Introduction

Today, there is more of a recognition and acknowledgement that people experiencing mental distress have the same rights and needs as the rest of society. The Welsh 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 the service.

This has been a policy requirement for many years and there must now be a renewed effort to ensure that service users and carers are listened to and taken seriously, and have a genuine influence over how services are planned, developed, delivered and monitored.

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

It is therefore essential that we adopt a genuine partnership approach to developing and delivering mental health services in Wales, and important to recognise that mental health service users and carers are equal citizens and have a right to be involved in the wider community, identification made where barriers may need to be broken down, and stigma and discrimination challenged.

The Welsh Assembly Government requires planners 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 the Welsh Assembly Government's 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 far more broadly as a more empowering way of working that needs to be an integral part of every aspect of mental health design, commissioning and provision.

The Welsh Assembly Government endorses the view that genuine user and carer involvement can best be demonstrated when service users and carers themselves say they are involved, and there is clear evidence that their views have significant weight.

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, and that we need to improve and develop better services to meet the needs of people who experience mental distress.

Figures from the Office for National Statistics (ONS) show that one in six of the general population experience 'a common mental health problem' at any one time, and 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.

Many people with or recovering from mental distress have been stigmatised and faced discrimination, and because of this have found it extremely difficult to enter or re-enter the workforce or to enjoy the full participation within society that most take for granted. This social exclusion has hampered many peoples' ability to recover from mental illness and their ability to enjoy full citizenship.

Over the last 30 years there has been a move away from an institutionalised system of care and a move towards a more holistic approach, seeking to care for people as individuals and considering their whole needs rather than defining people through a narrow medical model using a collection of diagnostic labels.

2. What this Guide is for and Some Issues to Consider

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

The idea of producing the original guidance, including having a 'Charter' and a 'Checklist', was conceived by a user of mental health services in Wales. The intention was to develop a guide that would 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.

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

As well as providing practical guidance, it gives service planners and providers the opportunity to declare their commitment to ensuring meaningful service user and carer involvement by adopting the Charter and by using 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 provides links to wider generic guidance relating to Patient and Public Involvement (PPI), as well as linking to the wider health and social care strategic agenda, and gives better and more up to date advice on why involving service users is not an option but a requirement.

People who use mental health services are not all part of one homogenous group with a shared identity and shared interests. Service users are individuals, all with unique situations, and needs and service providers should acknowledge this when seeking views and planning and delivering services.

For example, there is a distinction between voluntary service users and people who are detained 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 should also be distinguished from those for whom they care, and there is a specific section on meeting the needs of carers within 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 who are homeless, people who do not want to leave their own home, people who are in pain, people who are refugees and asylum seekers, people from Black and Minority Ethnic (BME) communities and many others may be considered to be more challenging and difficult than involving those people well known as active citizens within their community. However, 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 a wider range of people should become easier and become the norm.¹

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) or people in particular circumstances (for example people in prison) need to be challenged.

It is also important to recognise that there are people experiencing mental distress who are not in contact with, nor wish to be in contact with service user organisations or, in some cases, statutory services.

There is therefore an onus for service providers to place a strong emphasis on providing good quality information through GP surgeries, libraries, community services, etc. and through mental health promotion initiatives and assertive outreach services. This information should be aimed at ensuring that individuals are aware of their rights to involvement, and that details are provided of who can be contacted if support or assistance is required.

Participation and involvement activity should focus on equipping mental health service users and carers with the skills, knowledge and confidence to make active and informed choices about their level of involvement in both mental health services and the wider community, of which they are equal members.

3. Why Involve People?

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 and carer to be heard to facilitate the improvement of mental health services across Wales.

Advantages

Involving mental health service users and carers has advantages for both individuals and service organisations. Service users and carers are recognised as experts in their experience, and often have a good knowledge of services and how the system works.

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 contact with services or the same journey through the mental health system.

Service users and carers 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.

Working collaboratively and collectively can help people feel valued, increase their confidence and raise self-esteem, and help reduce the social exclusion that many people experience. Decisions are more likely to be seen as positive by those who have had a stake in making 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 illness, 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 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 constructive feedback on how staff are performing.

Involving service users and carers also has benefits for service planners, providers and society in general. These include the improved design and delivery of more effective services and better value for money through less waste on ineffective interventions. Higher standards of customer care are also more likely to be met.

Evidence shows that involving people in planning and developing health services contributes to effective changes in the provision of services across a range of different settings.²

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, and from 1st March 2007 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 on all aspects 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 and so on. 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. Service users should always be involved in, be central to, and have the opportunity to influence their own treatment plans.

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 equality and provide advice on how to ensure the legislation is complied with.

The Disability Discrimination Act (DDA) 1995 recognises mental illness as a disability, and one of the requirements of the Act is for services to make reasonable adjustments so that employees or potential service users are not excluded from using or contributing to services.

It is essential that the public in Wales are offered language choice and that service users speaking either English or Welsh should be treated on the basis of equality in order to comply with the Welsh Language Act 1993. It is especially important for mental health service users as they have been identified as a priority group by the Welsh Consumer Council as patients who cannot be treated effectively except in their first language or in both their languages.

It is also a requirement under the Race Relations (Amendment) Act 2000 for public authorities to promote race equality in the delivery of public services. It is also good practice to ensure that the language and cultural needs of people from BME communities are met to ensure that any specific needs are addressed.

4. How to Involve People

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 NHS Trusts and Local Authorities in Wales have introduced initiatives whereby service users sit and have equal responsibility on recruitment panels and in appointing and selecting all posts including clinical and managerial 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.

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 service users and carers in the planning, delivering and monitoring of services.

This requires not only service users being involved in meetings and sitting on various planning groups for example, but also having an actual genuine influence over how services are planned, developed and delivered and how they can be improved in the future.

There are many good examples throughout Wales where service users and carers, through well-organised networks and organisations, are involved in a wide range of activities and structures. Many service users and carers are serving on management boards or committees and represent their network or organisation on various strategic planning groups.

Contact Points for Service User and Carer information

There is an informal network of 'Service User Involvement Development Workers' in Wales. They are able to offer dedicated support to enable service user and in some cases carer, involvement in all aspects of planning, delivering, evaluating and monitoring mental health services in Wales. Contact details for this service are given at Annex 1.

The following pages set out a range of examples of service user and carer involvement initiatives across Wales.

Service User Involvement Development Workers

Support to service users and carers, where appropriate, is provided in the following ways:

- Assisting mental health service users to increase their awareness of their rights, choices and opportunities;
- Working 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);
- Ensuring the necessary support is made available to service users either by directly providing it or by arranging for others to provide it;
- Supporting 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 and conferences); and
- Assisting service users where appropriate to prepare for, attend and participate in meetings with, for example, service providers, commissioners and politicians.

'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, furthermore, service users should be involved in any ongoing evaluation of the status of mental health nurses post registration; and
- 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.

Neath Port Talbot Mental Health Day Service and Rehabilitation Service

This service is very user focused. Service user satisfaction surveys are undertaken on an annual basis. Service users and carers are always involved in the selection process for new staff.

A service user panel has been established for over two years whereby service users evaluate, offer feedback and monitor the services provided. They also contribute to the design of services. All new initiatives within the service are as a direct result of service user involvement and participation.

Throughout the past five years service users have led and been responsible for quality assurance monitoring of the services which have directly improved the services delivered.

Conwy and Denbighshire Adult Mental Health and Social Care Partnership Board

The purpose of the Partnership is to provide a legally binding framework in order to achieve improved Adult Mental Health and social care services for the people of Conwy and Denbighshire through the provision of user/carer-centred health and social care within an integrated mental health service.

Membership of the Partnership Board includes one remunerated carer and two remunerated service user Board members who are active participants and provide an informed service user and carer perspective for Adult Mental Health services in Conwy and Denbighshire.

Service user and carer Board members have been appointed by a process consistent with good practice in recruitment.

Principles of the Partnership 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;
- ensuring user and carer involvement when planning and developing services, utilising the existing experience to influence future plans and strategies for mental health services;
- the inclusion of a service user and carer on all recruitment panels and processes for the employment of ALL staff employed within the mental health partnership;
- service user and carer involvement and participation through an agreed communication network supported by a full time paid administrator; and
- working to an agreed and ratified strategy that supports equity for service users and carers.

ForUs Caerphilly

ForUs is 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 in 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.

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.

5. Levels of Involvement

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 just mean focusing on the need for hot food in inpatient facilities, but also means discussing the strategic need for inpatient facilities in the first place.

Providing suitable space and time; planners and providers should not rely solely on service users and carers attending official meetings, but should also be pro active in attending local venues, service user group meetings or other places where service users are likely to be.

Receiving feedback and responding appropriately; service providers are responsible for acting on advice from service users and providing explicit feedback on action taken. Feedback should be given showing how service users' views have been acted upon or an explanation given where they haven't.

Other ways of involving people, receiving feedback and being available to service users outside of traditional formal meetings include:

- Question and answer forums;
- Questionnaires;
- E-mail and letters;
- Workshops;
- Telephone conversations;
- One to one meetings;
- Blogs;
- Prepaid postcards;
- Informal group activities;
- Social gatherings; and
- Theatre and performance.

Patient councils and independent service user surveys can play an important part in identifying and addressing many issues that are important to the service user and carer experience.

It is important that agendas for meetings reflect the priorities for and contribution of service users and carers, and that the style and format of minutes are in an accessible format for everyone. Minutes should include the contribution of service user and carer members and agreement should be sought as to how contributions should be recorded.

Professional staff should recognise that their training, their status as salaried workers and their control of public resources places them in a more powerful position than the service users and carers with whom they work. Empowering service users and carers involves professionals relinquishing a degree of their own power and enabling service users and carers to have a greater choice and control over their own lives.

A range of ways individuals might be involved (as suggested in 'Researching User Involvement' 1992)³

People might be involved:

- In an assessment process or treatment decision;
- 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.

³ Barnes M & Wistow G, Researching User Involvement, Nuffield Institute for Health studies, University of Leeds, 1992)

Planning and Delivery of Services

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

- Joint planning with key stakeholders from statutory and non-statutory sectors i.e. users and carers working together;
- Full use of Health Act 'Flexibilities' powers, to ensure effective planning and delivery;
- Rigorous processes, infrastructure and funding to ensure that comprehensive services based on locally agreed models of care are available for all those who need them.

Standard 6 of the NSF 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.

Care Planning

The care planning process is where the service user and carer voice is best articulated.

Care planning 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.

Individual Care Planning

Rigorous approaches to assessment, treatment and aftercare must take place to help ensure the medical, physical, psychological and social needs of service users and carers are met.

Communication through services and within services must be robust, with mechanisms in place to ensure people cannot fall between the general service and specialist provision.

All service users with complex and enduring needs must receive a structured formal assessment and should receive care which encourages engagement, anticipates or prevents a crisis and minimises risk.

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 where service users and, where appropriate, carers are fully involved in the formulation of the service users' 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.

Carers

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 Welsh Assembly Government 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 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 are likely to 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 Research and Development (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.⁴ 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 quantitative data is important as well as having qualitative information. This guidance has previously stated that genuine user involvement is best demonstrated when service users themselves say they are being involved and there is evidence to show this.

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.

6. Tools and Links to Wider Initiatives

Tools

Charter for User and Carer Participation

A 'Charter for User and Carer Participation' is included within this Guide at Section 6. 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.

Good Practice Checklist

The Good Practice Checklist given in Section 7 of this Guide can 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 and reviewed.

Health and Social Services Committee Review

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.⁵

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

Annex 2 of this Guide is a Glossary of Terms and Annex 3 is a range of Benefits information and list of useful publications and other information produced by the Task and Finish Group.

Links to wider initiatives

The Expert Patient Programme (EPP) Wales

The NHS Expert Patients Programme (EPP)⁶ helps people with long-term health condition/s to build their confidence and improve the quality of daily life. EPP courses will be offered 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.

⁵ 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

⁶ For further information visit <http://www.eppwales.org> and http://www.expertpatients.nhs.uk/about_people.shtml

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 6 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. The 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 and compliment professional programmes by providing information to support people to help themselves.

Those involved in the delivery of EPP courses have a 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.

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 over the next decade

'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, social justice and efficient in their delivery.

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 Centered' 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;
- **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'⁷ 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'⁸ 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 experience. 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.

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

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

7. Payments and Expenses

Many service users and carers contribute their time and expertise into improving services, and it is essential they are supported in doing this and that their contribution is recognised and valued. Service users and carers need to be fully informed of the consequences of becoming involved in relation to their personal circumstances.

Both Welsh Assembly Government and UK Government policy actively encourages the involvement of service users and carers 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 and carer involvement can be on a voluntary or paid basis. Volunteering is when people give their time and skills for the benefit of society and the community. It is good practice to reimburse volunteers' out of pocket expenses. Service user and carer involvement may also be on a paid basis, particularly for tasks such as being part of 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, is discussed and agreed at the beginning of the process and is made clear to all concerned.

Guidance outlining the principles and practice of reimbursing and paying service users for their involvement is set out in 'Reward and Recognition'⁹. Although aimed at local health and social care organisations in England, it contains helpful principles and guidance that may be useful for services in Wales. The Assembly Government issued a Welsh Health Circular (WHC (2007) 011) highlighting 'Reward and Recognition' as well as 'Recruiting volunteers: a manual of good practice' published by the Wales Council for Voluntary Action.¹⁰

9 'Reward and Recognition' 2nd Edition published by Department of Health, August 2006
<http://195.33.102.76/assetRoot/04/13/85/24/04138524.pdf>

10 www.wcva.org.uk - click on Publications, then select 'Recruiting volunteers: a manual of good practice' dated 15.9.06.

Principles of good practice for payment and reimbursement include:

- Service providers and service users and carers will discuss and agree on the terms of involvement prior to committing to them;
- Service users and carers 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;
- Financial systems may need to be adjusted to enable expenses payments to be made on the day, and for the timely payment of fees to be made to prevent service users and carers being financially disadvantaged;
- 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/ carers home address;
- Service users and carers 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 and carers 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 should be offered for certain levels of involvement, to be agreed between the service user/carer and the service provider;
- A wide range of service users and carers, with different needs and experiences, are encouraged and supported to be involved;
- Service users and carers in receipt of benefits should be provided with the right information and support to help prevent any breaches of benefit conditions;
- Service users and carers are paid according to open and consistent criteria that take into account the level of involvement, the type of work and the skills and expertise required;
- Service users and carers have the choice to receive payments or to undertake work on a voluntary basis. Service providers have a responsibility towards service users who become involved, particularly those people who rely on benefits, and this responsibility is paramount. Further expert advice on the impact on any benefits should always be sought and service users and carers supported to make an informed choice;
- 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/carer, it should be accessible and easy to understand;
- In recognising the contribution that service users and carers 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;
- Levels of expenses should be locally determined and provide equity with staff/board members. There should be parity throughout the organisation;

- 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.

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 the views of service users; 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;
- Informing relevant agencies e.g. Inland Revenue and JobCentre Plus;
- Service Users should be rewarded for their time and knowledge especially when working alongside other paid workers.

Consider whether a fee is appropriate in advance for the following tasks, for example:

- 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.

This is not an exhaustive list.

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. The payment of fees is not always appropriate, e.g. attendance at public meetings. But it is for service providers and service users and carers to determine and agree when payment of a fee will be appropriate.

8. Charter for Participation and Involvement

All of us have a degree of responsibility for maintaining our own health.

By adopting this Charter and by using the Checklist, 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.

Other responsibilities include:

- Feeding back to a wider network;
- Canvassing a wide range of views;
- Being clear when an opinion is personal or representative;
- Adhering to policies, e.g. confidentiality, or declaring a personal or professional interest.

It is essential that expectations for both service providers and service users and carers 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 must:

- 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 strategic planning of services

Service users and carers must:

- 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 reimbursement 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 must:

- 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, receiving 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;
- 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 must:

- 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.

9. Good Practice Checklist and Monitoring Tool

A good practice checklist and monitoring tool has been produced and is shown over the following pages. This 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 starting consider the following:

- Be prepared to commit to user involvement as an integral part of organisational activity rather than an occasional exercise;
- Be prepared to take action as a result of what is learnt;
- Have a clear, written strategy, developed with staff and service users, for involving people;
- Ensure staff and user groups are fully aware of the tool, and that training has been provided;
- Take practical steps to enable people to participate;
- Ensure there are mechanisms to keep participants informed about how their contributions influence planning and service delivery;
- Ensure there is a named lead at a senior level with responsibility for user involvement, and the power to make things happen;
- Ensure there is an adequate budget for the costs of involving people;
- Be clear on whether a personal or representative view is being given;
- Be clear about the requirements for confidentiality and agree to adopt any appropriate confidentiality policies as required;
- Co-ordinate 'user involvement' activities with other departments and organisations;
- Be clear about why people are being involved;
- Ensure there is a means of evaluating the processes of involving people;
- Ensure there is a means of assessing the impact of involving people;
- Know what needs to be achieved;
- Be clear on who will have the final say over decisions. Can what service users and carers want be delivered?

This list looks challenging, however, there is a wealth 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.

Good Practice Checklist and Monitoring Tool

| Action | Not Met | Part Met | Met | Action taken | Monitoring arrangements | Review date |
|--|---------|----------|-----|--------------|-------------------------|-------------|
| Design and Planning of Services | | | | | | |
| 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 while giving due regard to any requirements for confidentiality. | | | | | | |

| Action | Not Met | Part Met | Met | Action taken | Monitoring arrangements | Review date |
|--|---------|----------|-----|--------------|-------------------------|-------------|
| 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. | | | | | | |
| 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. | | | | | | |

| Action | Not Met | Part Met | Met | Action taken | Monitoring arrangements | Review date |
|--|---------|----------|-----|--------------|-------------------------|-------------|
| 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. | | | | | | |
| Delivery of Services | | | | | | |
| Service users and carers are regularly involved in on-going training for all staff. | | | | | | |
| Service users and carers are included in conferences, workshops and seminars. | | | | | | |
| Training | | | | | | |
| 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. | | | | | | |

| Action | Not Met | Part Met | Met | Action taken | Monitoring arrangements | Review date |
|---|---------|----------|-----|--------------|-------------------------|-------------|
| 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 are 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 | Review date |
|---|---------|----------|-----|--------------|-------------------------|-------------|
| Expenses and other payments | | | | | | |
| 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. | | | | | | |
| Support for carers | | | | | | |
| Carers are offered their own assessment. | | | | | | |
| Respite care is available to allow carers to prepare for and attend meetings, reviews, etc. | | | | | | |
| Service users and carers attending meetings | | | | | | |
| The design and planning of meetings includes input from service users and carers. | | | | | | |

| Action | Not Met | Part Met | Met | Action taken | Monitoring arrangements | Review date |
|---|---------|----------|-----|--------------|-------------------------|-------------|
| Service users and carers are given sufficient advance notice of dates and times of meetings to enable them to attend. | | | | | | |
| Information, agendas, minutes and so on are provided in an appropriate format and in good time to allow consultation with constituent groups. | | | | | | |
| Consideration is given as to how service users and carers will access meetings and events where transport is an issue. | | | | | | |
| 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. | | | | | | |

| Action | Not Met | Part Met | Met | Action taken | Monitoring arrangements | Review date |
|---|---------|----------|-----|--------------|-------------------------|-------------|
| Monitoring | | | | | | |
| Service users and carers are involved in designing and planning of monitoring techniques e.g. designing monitoring forms, planning monitoring 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. | | | | | | |
| Evaluation | | | | | | |
| A date is set for an annual review meeting with service users and carers to assess the quality of service delivery. | | | | | | |

Useful Contacts

Annex 1

| | | | | |
|--|---|---|---------------|---|
| Service User Involvement Development Officer | Interlink (serving - Rhondda Cynon Taf and Merthyr Tydfil) | Interlink Maritime Offices Woodland Terrace Pontypridd CF37 1DZ | 01443 485337 | www.interlinkrct.org.uk |
| Service User Involvement Worker | West Wales Action for Mental Health | First Floor Nat West Chambers Sycamore Street Newcastle Emlyn Carmarthenshire | 01239 712811 | wwamh_userinvolvement@yahoo.co.uk www.wwamh.org.uk |
| Service User Involvement Development Worker | Powys Mental Health Alliance | 2nd Floor, Crescent Chambers South Crescent Llandrindod Wells Powys LD1 5DH | 01597 825966 | www.pavo.org.uk |
| Service User Participation Officer | Neath Port Talbot CVS | Ty Margaret House 17-19 Alfred St Neath SA11 1EF | 01639 631387 | info@nptcvs.org.uk www.nptcvs.co.uk |
| Service User Involvement Development Officer | Cardiff and Vale Mental Health Development Project | Unit 11 Williams Court Trade Street, Cardiff and the Vale MHDP CF10 5DQ | 029 2022 2000 | mail@cardiff-vale-mhdp.org.uk www.cvmhdp.org.uk |
| Service User and Carer Liaison Officer | Unllais - Conwy and Denbighshire | Eirianfa Community Centre Factory Place Denbigh LL16 3TS | 01745 818720 | admin@unllais.co.uk www.unllais.co.uk |
| Service User Involvement Development Worker | Unllais - Gwynedd and Ynys Mon | 42 Glanrafon Bangor Gwynedd LL57 1LH | 01248 353777 | admin@unllais.co.uk www.unllais.co.uk |

| | | | | |
|---|---|--|---------------|--|
| Service User Involvement Development Worker | Unllais - Flintshire | 10a Wrexham Street, Mold Flintshire CH7 1ES | 01352 752471 | admin@unllais.co.uk www.unllais.co.uk |
| Partnership Co-ordinator | ForUs - Mental Health Service User Partnership and Recovery network for the Caerphilly County Borough | YMCA Building Aeron Place Gilfach Bargoed CF81 8JA | 01443 875533 | foryou@forus.org.uk www.forus.org.uk |
| Service User and Carer Participation Officer | Hafal | Unit 49 Tondy Enterprise Centre Bryn Road Tondy Bridgend CF32 9BS | 01656 729191 | sucpobridgend@hafal.org www.hafal.org.uk |
| Service User Involvement Worker | GAVO | Ty Derwen Church Road Newport Gwent NP19 7EJ | 01291 673728 | www.gavowales.org.uk |
| Older People's Mental Health Services Carer and User Involvement Development Officers | Cardiff and Vale Mental Health Development Project | Unit 11 Williams Court Trade Street Cardiff CF10 5DQ | 029 2022 2000 | mail@cardiff-vale-mhdp.org.uk www.cvmhdp.org.uk |

Glossary of Terms

- **Carer** - A person who looks after a family member or friend who needs care, help or support. Carers can be adults caring for other adults, parents caring for ill or disabled children under the age of 18 or young carers aged 18 who care for another family member.
- **Expenses** - All out of pocket costs to service users or carers that enable them to undertake duties required or requested of them. 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.
- **Market Rate(s)** - The rate, or rates, generally payable for an equivalent role or set of skills.
- **Parity** - Equality of treatment of mental health service users and carers with mental health professionals and with other health service users.
- **Payment** - A fee or agreed reward to service users for undertaking an agreed task or role.
- **Reimbursement** - Repayment of expenses incurred by service users in fulfilling the duties expected of them.
- **Reward** - A gift to demonstrate appreciation of a service user or carer contribution.
- **Service Provider** - Any organisation providing mental health services, whether in the public sector, private sector, voluntary or charitable sector.
- **Service User** - Any user or carer, past or current, of mental health services.
- **Subsistence** - The cost of meals and/or light refreshments reasonably incurred in fulfilling the duties expected of the service user or carer.
- **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.
- **Volunteers** - Individuals who offer their services with no expectation of payment or reward for those services.

Benefits Information

This section offers some helpful information regarding dealing with the Department for Work and Pensions (DWP). This information does not replace advice provided by the DWP.

Claiming

- Always keep copies of the completed application forms. Ask the staff to do this.
- Always request a receipt for documents handed in or ask DWP staff for confirmation of receipt.
- Be aware of **'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.
- Be aware of extended payments of Housing and other benefits whilst working for up to an extra four weeks. Again, this is dependent on individual circumstances.

Interviews

- At interview, be accompanied by someone in a supportive capacity - a friend or advocate.
- The same applies in relation to a home visit from DWP staff. (This may mean postponing the appointment until someone can be found to provide support.)
- Ask for breaks if needed.

Decisions

- Always challenge a decision if 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 relevant benefit. Ask for a contact 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 dealing with any issues at each stage of the process.
- If all else falls, complain. There is an official complaint form.

Useful contacts:

| | | |
|---|--|---------------|
| Business Eye | www.businesseye.org.uk | 03000 6 03000 |
| Job Centre Plus | www.jobcentreplus.gov.uk | |
| Inland Revenue | www.inlandrevenue.gov.uk | 0845 915 4515 |
| The Princes Trust | www.princes-trust.org.uk | 0800 842 842 |
| Citizen 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.

If considering self employment, a fuller explanation of the type of support offered can be found in **'Ever thought of working for yourself'** (free from the DWP).

The local DWP office and HM Revenue and Customs have a wealth of information, including numerous booklets, free of charge. Copies can be obtained by downloading from the Internet, telephoning or by attending the nearest local 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 SA 11 3BH

The book costs £15 for non-claimants or £7.50 for 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 try to 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.
- **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 Project** This scheme is only available in certain areas. Ask at the JobCentre/ JobCentre Plus Office.
- **Citizens Advice Bureaux** are also useful sources of a wide range of information.