



National Mental Health
Development Unit

PATHS TO PERSONALISATION IN MENTAL HEALTH

A whole system, whole life framework

New Horizons
A shared vision for mental health



DH INFORMATION READER BOX	
Policy	Estates
HR / Workforce Management	Commissioning
Planning / Clinical	IM & T
	Finance
	Social Care / Partnership Working
Document Purpose	Best Practice Guidance
Gateway Reference	13316
Title	Paths to Personalisation - A whole system, whole life framework
Author	National Mental Health Development Unit
Publication Date	16 Mar 2010
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Chairs, NHS Trust Board Chairs, Directors of Finance, Allied Health Professionals, Communications Leads, Directors of Children's SSs, Voluntary organisations
Circulation List	
Description	Paths to Personalisation is a framework to help all those involved in developing personalised services and approaches for people with mental health needs implement the necessary whole system changes effectively.
Cross Ref	N/A
Superseded Docs	

Action Required	N/A
Timing	N/A
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For Recipient's Use	

NOTE ABOUT TERMINOLOGY

Ideally we would like to avoid labels altogether, but sometimes specific references are needed to focus on what is relevant for particular people.

Across the whole system different terms are used for different purposes. On a personal level people may prefer to use different words, words may have a different cultural significance or may unintentionally exclude people. For example, someone who has an unpaid caring role may be a family member, but they may be a friend or neighbour. From their point of view the term *family carers*, or *families* might seem to exclude them as carers. With regard to mental health, different terms are used legally or medically, or are preferred by different individuals or groups.

We have therefore tried to use terms reflected in current policy where consultation has taken place, but acknowledge and respect that there may be different views about terminology.

THE NATIONAL MENTAL HEALTH DEVELOPMENT UNIT

The National Mental Health Development Unit (NMH DU) is the agency charged with supporting the implementation of mental health policy in England by the Department of Health in collaboration with the NHS, Local Authorities and other major stakeholders. Further information about the NMH DU and its programmes of work is available at www.nmhd u.org.uk

NEW HORIZONS

Paths to Personalisation is aligned with the vision and recommendations of New Horizons, a cross government mental health strategy, published in December 2009. New Horizons is a comprehensive programme of action for improving the mental well-being of the population and the services that care for people with poor mental health. It brings together organisations across national and local Government, voluntary and statutory agencies, as well as local communities and individuals to work towards a society that values mental well-being as much as physical health. Further information is available at www.newhorizons.dh.gov.uk

DEPARTMENT OF HEALTH PERSONAL HEALTH BUDGETS PILOT PROGRAMME

The Department of Health's personal health budgets team works with 73 PCTs, in 66 sites, who have provisional pilot status as part of the programme. Twenty of these sites have been selected for an in-depth study, as part of a wider evaluation exploring the potential of personal health budgets to benefit different groups of people and how PCTs can make them work. The pilot programme will run until 2012. Further information is available at www.personalhealthbudgets.org.uk

DEPARTMENT OF HEALTH PUTTING PEOPLE FIRST NATIONAL DELIVERY PROGRAMME

The Department of Health's Putting People First national delivery programme works with key stakeholders across local government, NHS, the third sector and professional and regulatory organisations, to support the implementation of the shared vision of Putting People First (DH, 2007), through a radical reform of public services enabling people to live their own lives as they wish, confident that services are of high quality, safe and promote their own individual needs for wellbeing and dignity. Further information is available at www.dhcarenetworks.org.uk/Personalisation

THE NATIONAL DEVELOPMENT TEAM ON INCLUSION (NDTI)

The National Development Team for Inclusion is a not for profit organisation concerned with promoting inclusion and equality for people who risk exclusion and who need support to lead a full life. We have a particular interest in issues around age, disability and mental health. The NDTi was commissioned to write this framework on behalf of the Department of Health and the NMH DU. Further information is available at www.ndti.org.uk

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INTRODUCTION

WHO AND WHAT IS THIS FRAMEWORK FOR?

This guide has been produced to help all those involved understand how things will need to be done differently to make personalisation a reality for people with mental health needs. This is a whole system guide, so hopefully it will give some information, guidance and signposts for people, whoever and wherever they are. The guide provides information about what personalisation means for mental health services and supports, offers examples of what needs to be in place to make things work, and provides pointers to good practice and sources of advice and information.

There should be something of interest or useful links to be followed up, for example for people with mental health needs and carers (particularly if they are in expert partner roles) – health and social care commissioners, providers, practitioners, care co-ordinators and staff from all sectors – universal services – community groups – senior managers – board and elected members – enthusiasts, advocates and leaders. It is also intended to help people look across the system to recognise all the things that need to fit well together in partnership for a personalised approach.

The framework has been developed and tested with the help of an expert group, including people who use or have used mental health services. It starts from the point of view and perspective of someone with mental health needs and considers the range and nature of things that need to be in place. The first person statements, formed with the help of the group, are designed to consider the question '*What helps to make this happen?*' The group felt that this approach would help focus attention on what needs to be in place to achieve the right outcomes for people, and on people's real experiences of systems and services. These statements also provide a whole system quality checklist for personalisation (See *Appendix 1*).

The '**Signposts**' part of each section provides links to further reading, websites, examples and further resources.

WHAT IS PERSONALISATION?

There has been a gathering policy momentum leading to local authority and health service reform. A fundamental re-think of the relationship between citizens and public services runs through, for example, *Improving the Life Chances of Disabled People*¹, *Our Health, Our Care, Our Say*², *Putting People First*³, and *NHS Next Stage Review*⁴.

The main messages are very clear. We should expect a personalised approach, which means a relationship with public services which ensures that:

- We are empowered to have more say and control in all aspects of public life and participate as active and equal citizens
- We have maximum control of our own lives, including control of our own health and health care
- We are supported to live independently, stay healthy and recover quickly
- We have choice and control so that any support we may need fits the way we wish to live our lives.

One way of giving us more control over the support we may need is to allocate an amount of money (a personal or individual budget or direct payment) so that we can decide ourselves how it can best be used. (For more information about personal budgets see *Section 3*). Having access to personal budgets has undoubtedly led to very positive outcomes for some people. An Individual Budgets Pilot Programme (IBSEN) took place in England in 13 local authorities and has now been evaluated. The evaluation report⁵ found that having an individual budget was associated with better outcomes and higher perceived levels of control and people had more positive aspirations for their lives. Specific benefits for people with mental health needs were reported. However, the report also highlighted major barriers to take up for people with mental health needs. Research on Direct Payments also shows that they are least commonly provided to people with mental health needs⁶.

*Direct payments for people with mental health problems: A guide to action*⁷ sets out good practice in making direct payments more accessible to people with mental health needs. This guide follows on and places personal budgets in a wider context.

Money by itself does not guarantee choice or control. It is clear that if opportunities are to be more generally available to people with mental health needs and not just a battle won here and there (relying on good luck and a few right thinking people) there need to be radical changes that will place personal budgets in the wider context of personalisation.

Personalisation means recognising and respecting us as individual citizens, family members and members of our community with the informal networks that provide most of our support, most of the time. It cannot be achieved without an energetic and effective partnership approach between and beyond health and social care. It requires partnership that concerns itself with improving the life and health of all citizens, and removing barriers so that there is access for all to activities, services and opportunities. This is an approach requiring comprehensive cultural and organisational changes to encourage creativity, innovation, positive risk taking and to change the balance of power between citizens and public services. The IBSEN evaluation reported cultural and organisational barriers in these areas, particularly in mental health, that will need to be addressed to make any real impact on the way many people with mental health needs currently experience public services.

'Personalisation? I know this is happening when I am treated with warmth, respect and honesty – when people listen to me, treat me as an equal, and support me – and when I don't have to fight all the time to get what I want to help me recover and live my life the way I choose to'.

– Mental health expert by experience

A WHOLE SYSTEM, WHOLE LIFE FRAMEWORK FOR PERSONALISATION IN MENTAL HEALTH

This guide describes the wide range of things that need to be in place for a personalisation approach to be a common experience, not an exceptional one, for people with mental health needs. It proposes a whole system approach, looking at the way different elements and strands of activity work together and impact on one another to achieve better outcomes for people.

What people know and feel to be right sometimes gets lost in translation when filtered through the systems set up, in good faith, to provide help and support. However, it has always been the case that determined individuals, staff and people using services, have managed to just get on and make the right things happen. This often involves working round processes and systems and the prevailing culture in order to do something different that meets an individual's unique and particular needs.

A whole system approach, looking at all the things that need to be in place, does not mean that people should stop driving ahead for individual successes while they wait for everything to be fixed. It simply acknowledges that we can only get so far, for a limited number of people, if we do not make progress on all the cultural and organisational changes that need to take place so that everyone can benefit as a matter of right and common practice.

This framework is only a guide and is not comprehensive. Like most frameworks, there is not a perfect fit for all the sections, they are all connected and there are overlaps. The aim of this framework is to provide a tool to start checking what needs to be in place for personalisation in mental health, and planning what action can be taken to ensure that it is. It highlights the need for refreshed and energetic partnership and collaboration across the whole system. The framework will be further developed to take account of learning from the experience of implementing personalisation as it progresses.

Anita Cameron

I am in control of the support I need to live my life the way I want to.

What helps to make this happen?

A whole system framework for personalisation in Mental Health

Information and advice,
personal motivation and
self-help

I have opportunities for self-help and taking control.
I have the information and advice I need to feel
empowered and make choices

Create Commissioning

There is opportunity, choice and innovation in what
is available to support me and give me a good quality
of life.

Workforce and
organisation development

The people who are paid to provide me with support
and treatment have the right skills and approach, and
are available when I need them.

Prevention and
early intervention

I get help and advice about how to stay well. Support
and help are available to me and my family at an early
stage if I begin to feel unwell or things go wrong.

Helpful, person-centred
systems and approaches

The systems I use support me to make my own decisions.
People listen to me and treat me with respect.

All the things are in place that can help
me comfortably manage the resources
allocated to me, in a way that suits me.

Support for managing
personal budgets.

My needs are met in a way that is easy for
me. I get the support I need to participate
as a citizen and take advantage of the
things available to all.

Partnership for inclusion

I can have a leadership role and there is
good leadership wherever it is needed.

Good leadership for all

Opportunities are available to me without
discrimination or unfairness.

Fair access and equality

I get the support I need to carry out my
caring role, stay well and live my own life.

Support for carers



SECTION 1

HELPFUL, PERSON-CENTRED SYSTEMS AND APPROACHES

From the very first contact – by phone, on line, personal visit, or meeting – the messages that individuals or their friends or family members receive will have an impact on the way they feel about themselves and on the way they engage with organisations and professionals. A personalised approach will be evident in the language, attitudes and behaviour on initial contact and in all the processes that people go through. The simple test for this is to ask *'How would I feel if this was what I, or a member of my family, experienced?'*

Person centred approaches were promoted through *Valuing People* (DH, 2001)⁴³ for people with learning disabilities. The guidance produced to support the development of person centred approaches defines the term as: *'activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society... Person centred planning is a process for continual listening and learning, focusing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends.'* (DH, 2001)⁴³.

*Putting People First*³ highlights the intention for these approaches to be used across the board and for *'Person centred planning and self directed support to become mainstream.'*

I have a good experience when I first seek information, help or support.

I am treated in a respectful way that leads to the right outcomes for me.

People have a sense of being respected if they experience:

- A recovery approach that treats people as equal partners with the hope and expectation of a fulfilled life
- Assessment and self-assessment that is a set of personalisation principles, not just a document, and takes account of varied experiences, backgrounds and complexity of need
- Assessment that focuses on what matters to people and what works or does not work for them

- Co-production as the everyday approach: this means people working in partnership with their family, carers and professionals to plan, develop, arrange or purchase the services and support that are appropriate to them
- Person centred planning and reviews that put people in control and equip and empower them to make decisions about their own support and recovery
- People who genuinely listen and go at a pace that suits the person they are supporting: this will be reflected in outcomes and how close they are to what people want for themselves
- An integrated system that responds to people's diverse roles and needs (e.g. health, family, parenting, relationships, housing, employment, leisure, education) and does not only focus on times when people are unwell (*For more detail see under Partnership section 7*)
- The right and appropriate support to help people be prepared and ready to take control and to plan for their own recovery.

People I come into contact with have the right approach and skills to treat me respectfully, help me recover and live my life the way I choose to.

Examples of what needs to be in place to support this:

- A culture that systematically promotes and nurtures the right approaches and skills – with all new staff routinely inducted into person-centred approaches and person centred thinking
- Senior management commitment and enthusiasm to get the culture right
- Clarity about resources for training in person-centred systems, approaches and person centred thinking (including for senior managers) and for developing good information and communications
- Learning and problem solving encouraged and built in to systems
- Clear local and government support for innovation and creative use of processes, practice and resources – so that staff are confident that this is a recognised and endorsed way of working (*See also Workforce and Organisation Development section 10*).

THE SYSTEMS I USE
SUPPORT ME TO MAKE
MY OWN DECISIONS.

PEOPLE LISTEN TO ME AND
TREAT ME WITH RESPECT

WHAT HELPS TO MAKE
THIS HAPPEN?

There is a planned and balanced approach to crisis and risk that I feel confident in and that does not undermine my sense of being in control of my life and recovery.

Getting the balance right between creativity, personal control, aspiration and positive risk management is a key challenge to address for personalisation. Risk is something we all live with every day and is an important part of opportunity and change but responses to this in services can sometimes result in over-restrictive practices. On the other hand, significant risk, for example of self-harm or harm to others, needs to be acknowledged and worked with in a responsible way.

Although the IBSEN evaluation⁵ of the Individual Budget Pilots did not demonstrate any increased risk to or by people using individual budgets, it did report concerns raised by care, social work and adult safeguarding staff around 'the possible risks of financial abuse, neglect and physical harm'. Balanced against this is the evidence of people with mental health needs using individual budgets reporting 'a higher quality of life and a possible tendency towards better psychological wellbeing' (SCIE, March 2009)⁸ and evidence from international research that 'people using self-directed support instead of traditional services are generally more likely to report improved outcomes and satisfaction' (SCIE, March 2009)⁸.

Examples of things that will help achieve this balance:

- Advance directive and crisis planning and day to day person-centred risk management that is taken seriously – so that people are confident that action will be taken with due regard to their plans and wishes
- Recognition that people's needs are not constant and any risk agreements should be regularly reviewed and subject to change
- Activity that promotes a positive risk taking culture in organisations, for example: involving people in developing a Choice, Empowerment and Risk policy, training for all, and support from senior managers so that staff feel confident about this approach
- Self-regulation, with investment in resources to offer peer support and share feedback about, for example, people's experiences of providers and personal assistants
- Involvement of people in setting up and carrying out quality assurance activities
- Sufficient time spent with people to help them design support that will be based on their choices and wishes, whilst recognising those risks that can be reduced
- Acknowledgement of carers needs and wishes and the sensitive balance of support for the rights of all involved.

SIGNPOSTS

Care Programme Approach and Assessment

1. *Wellness Recovery and Action Plan*, A practical approach to recovery. www.workingtogetherforrecovery.co.uk/Documents/Wellness%20Recovery%20Action%20Plan.pdf
2. *3 Keys to a Shared Approach in mental health assessment*, CSIP/NIMHE, 2008 www.3keys.org.uk
3. *Re-focusing the Care Programme Approach: Policy and Positive Practice Guidance*, DH, March 2008. www.dh.gov.uk/publications
4. *Effective Care Co-ordination in Mental Health services: Modernising the CPA: A policy booklet (DH, 2000)* www.dh.gov.uk/publications

Positive Risk Taking and Risk Management

5. DH, *Independence, Choice and risk: a guide to best practice in supported decision making* DH, 2007 Best practice guide, learning and development materials, supported decision making tool, leaflet for people using services. <http://socialcare.csip.org.uk/index.cfm?pid=6>
6. *Person centred risk* A course for senior managers, first line managers, family members and carers and support workers. www.helensandersonassociates.co.uk
7. *Risk enablement and personalisation project*. DH Social Inclusion Programme. info@tonyryan.org
8. *Positive Risk Taking Policy*. Gateshead Council's Community Based Services An example of a policy that has been developed to ensure that there is a consistent approach to the identification, assessment and management of risk across services. www.scie-socialcareonline.org.uk/profile.asp?guid=4225c224-60eb-48fe-837b-c6c44172cb80
9. *Clinical Risk Management: A clinical and practitioner manual*, Steve Morgan, Sainsbury Centre for Mental Health, 200. www.scmh.org.uk/pdfs/clinical_risk_management.pdfwebsite

Person-centred approaches

10. *Person-centred thinking with people who use mental health services*, Helen Sanderson Associates with David Coyle, University of Chester (2005). www.helensandersonassociates.co.uk/PDFs/MHminibookweb.pdf
11. *Our choices in mental health*, CSIP A framework for providers to extend choices and practical support. www.mhchoice.csip.org.uk
12. *Supporting People with Long Term Conditions* (Re: Statement of values and principles of care planning. P12). www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4100252
13. *Co-production: an emerging evidence base for adult social care transformation: SCIE Research Briefing 31, 2009*. www.scie.org.uk/publications/briefings/briefing31/index.asp
14. Website with support planning resources. www.supportplanning.org/MentalHealth/

SECTION 2

INFORMATION AND ADVICE, PERSONAL MOTIVATION AND SELF-HELP

I HAVE OPPORTUNITIES FOR SELF-HELP AND TAKING CONTROL

I HAVE THE INFORMATION I NEED TO FEEL EMPOWERED AND MAKE CHOICES

WHAT HELPS TO MAKE THIS HAPPEN?

I have the opportunity to improve my knowledge of my mental health and self care options.

Self care means having the opportunity to be responsible for your own health and to make the most of life and feel fulfilled.

Examples of things that help with this:

- Access to local Expert Patient Programmes. These are self-management courses giving people the confidence, skills and knowledge to manage their condition and be more in control of their lives
- Support to develop a personalised self-care plan or support plan
- Information about, and access to, tools and assistive technology (such as touch sensors) that could help people self manage
- Health and social care policies and staff guides about self-care
- Promotion of the role that pharmacies can have in providing self-care support with managing symptoms and medication
- Accessible information about mental health diagnoses and treatment options is available and offered to all
- Information about mainstream activities in the community is made available at the same time as information about more specialist supports and services.

I can easily find the information I need about a wide range of things that are available in my locality.

Some people will already be clear what they want to help them live their lives and know where to find it. Other people will need different kinds of help and information to see what opportunities there are and what options they might have beyond their immediate knowledge of services. This might be about where to get help or to take up activities in the wider community (such as leisure activities, employment, or learning). The power to change things can be limited by lack of information. Even if you are clear about what you want, it can be very time consuming and exhausting searching for how and where to find it. This is particularly difficult for anyone who does not speak English, or who has

communication or literacy difficulties (*for more information see section on Fairness and Equality section 5*) Anyone working with people to help them put together support plans will also need reliable, easy to get at, information.

Examples of things that help with this:

- Partnership work within local authorities, across library and information services and social care services, to plan for and manage the information needs of all
- Websites designed specifically to provide information for people putting together support plans
- Access to information technology and specific training and support to use it
- Dedicated staff who are trained and available to help people use computers and access the internet
- Support for local networks and peer groups for the informal exchange of information
- Meetings and discussion groups on a planned and continuous basis – not just one-off opportunities – so that there is a regular opportunity for people to ask questions and be given up to date information
- Use of local radio, community broadcasting and satellite channels that are designed for different communities and audiences
- Information available very locally e.g in local shops, pubs and GP surgeries
- Information related to times in people's lives when help is needed
- Involving people with mental health needs in the design, implementation and evaluation of information services
- Making sure that providers are clear about their responsibility to provide information
- Undertaking research into what really gets information to people
- Co-coordinating and managing information and knowledge that is held by service users, staff, organisations and communities.

There are people around who really want to help me fulfil my dreams and potential.

Examples of things that help with this:

- Enthusiasts, supporters and advocates who are positive and have high expectations and encourage people to be hopeful and see a positive future
- Inspirational figures, community entrepreneurs, mentors or leaders who work actively in their communities and organisations to promote mental health self-care and recovery
- Systematic organisation development programmes to promote a culture of positive approaches to mental health.

SIGNPOSTS

Self care and self help

1. *Self Care Connect*. A website with information on courses and materials, facts and figures and a support network. www.self-careconnect.co.uk
2. For research evidence on self care. www.dh.gov.uk/selfcare
3. *Common core principles to support self care: a guide to support implementation*, Skills for Care/Skills for Health, 2008. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084505
4. Department of Health, *Self Care – A real Choice: Self-care support – A Practical Option* (2005) Practical ideas and action on how to support self care. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4100717
5. *The self care challenge: A strategy for pharmacists in England* The Royal Pharmaceutical Society of Great Britain (2006). www.rpsgb.org.uk
6. Information about the Expert Patients Programme. www.expertpatients.nhs.uk
7. Self care training for people with bipolar disorder www.mdf.org.uk. A peer led self care training programme to help people learn to take action to prevent or reduce the severity of an episode.
8. *HealthSpace* is a free, secure online personal health organiser. It provides information to help people to manage their own health, store important health information securely, or find out about local NHS services. www.healthspace.nhs.uk/visitor/default.aspx
9. HUBB (Barking and Havering and Brentwood Mental Health User Group) have developed Recovery Plan and Well Being Plan booklets and Recovery courses in partnership with the local PCT. info@hubb.eclipse.co.uk
10. A voice and a choice: *Self directed support by people with mental health problems: A discussion paper* Rita K Brewis, In Control, 2007. www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=331&cc=GB
11. *Self-directed support for mental health service users in West Sussex: Project Evaluation Report*, Rogers R , 2007 West Sussex County Council/West Sussex PCT. www.communitycare.co.uk/Articles/2008/06/26/108631/personalisation-self-directed-support-in-west-sussex.html
12. *Mental Health and Personalisation Agenda: Chaos or empowerment* A project to keep people informed and influence the way change towards personalisation happens in the North East. This website also has links to a range of resources about personalisation. www.mhne.co.uk/pge.asp?id=40

Enthusiasts and advocates

13. *The National Advocacy Qualification* is a qualification that has been funded and developed by the Department of Health, together with advocacy organisations and commissioners over the past two years. The introduction of two forms of statutory advocacy, Independent Mental Capacity Advocates (IMCAs) and Independent Mental Health Advocates (IMHAs) led to the recognition of the need for greater focus on quality and consistency across the advocacy sector. www.nmhd.org.uk/our-work/improving-mental-health-care-pathways/independent-mental-health-advocacy
14. *Transforming adult social care: access to information, advice and advocacy*, IdEA, 2009. www.idea.gov.uk/idk/core/page.do?pageid=9454439
15. A lesbian and gay, bisexual and transgender mental health advocacy service. www.pacehealth.org.uk/mental_health_advocacy/
16. *Independent mental health advocacy: Guidance for commissioners* NIMHE, 2008. This guide outlines the statutory independent mental health advocacy role and discusses good practice for IMHA services and recommended commissioning processes. www.mhact.csip.org.uk/silo/files/imha-guidance-for-commissioners.pdf
17. *Mental health advocacy for black and ethnic minority mental health users and carers*, 2002, Joseph Rowntree Foundation. www.jrf.org.uk/publications/mental-health-advocacy-black-and-minority-ethnic-users-and-carers

One stop shop and on-line information

18. Leicestershire County Council provides a website giving information to help people be independent and make their own decisions. The service includes a team to provide support and training for people with little or no previous experience or particular difficulties in using a computer. www.leicscareonline.org.uk
19. Shop4Support is a website that provides information for people developing their own support plans and for those managing their own budgets. It is an internet market place with information about support providers and services with a quality rating and feedback facility for people using them. It also provides ready made systems for managing budgets etc. www.shop4support.com

Accessible information

20. The Association of Social Care Communicators aims to develop and improve communication practice. It has a useful website with practical information, regional groups, networks, and a newsletter and runs conferences. www.ascc.me.uk

TV, video and roadshows

21. *Southwark TV*: Web based community media for all – including mental health groups. www.southwark.tv
22. *Community TV*: Trust Offers consultation, training, facilitation and production. www.communitytvtrust.org
23. *Social care TV*: A broadband service on the SCIE website called Social Care TV, that has short videos relating to e.g. personalisation, dementia, mental health. www.scie-sctv.org.uk
24. NHS South East Coast regional roadshows. www.southeastcoast.nhs.uk/news/Makingchoicespersonalisingcare.asp

SECTION 3

SUPPORT FOR MANAGING PERSONAL BUDGETS

ALL THE THINGS ARE IN PLACE THAT CAN HELP ME COMFORTABLY MANAGE THE RESOURCES ALLOCATED TO ME, IN A WAY THAT SUITS ME
WHAT HELPS TO MAKE THIS HAPPEN?

A personal budget can come in different forms and be managed in different ways. It can be a cash, direct payment or notional budget. Someone can manage a budget themselves, and employ their own staff and directly purchase what they need, or someone else (for example an individual, agency, trust or provider) can do this on their behalf. A personal budget may be funded solely from a local authority or from a combination of sources such as the Independent Living Fund or Supporting People. The NHS can also allocate a notional personal health budget, which, with changes in legislation, may in the future also come as a cash payment. However people choose to manage their personal budget, the idea is that they are encouraged to put together a support plan to meet the personal outcomes they want in their lives, and have maximum control over how the plan is put into action.

I get clear information that tells me what a personal budget is and the different ways of using it.

I get support to decide which is the best option for me.

Lack of information, or confusing information, can stop people taking advantage of opportunities for greater control. For example:

- People are concerned because they believe that having a personal budget means that they have to take on responsibility for employing staff and managing money and they are therefore reluctant to take up the offer
- People are anxious that the change to a personal budget will upset the arrangements they already have that are working well and valued by them
- Language or cultural differences are not taken into account and this leads to misunderstandings.

Examples of things that help with this:

- Clear information that is made available in ways and in places that suit different people
- Information and communication that makes clear:
 - the different ways in which it is possible for people to take control over decisions about how money that is allocated to them is managed and spent
 - that they do not have to directly manage the money themselves or employ staff if they do not want to and that other people can do this on their behalf
- Training and organisational culture which ensures that care co-coordinators and staff are well informed, supportive, positive and hopeful about what people can do and achieve in their lives
- A partnership between mental health services, the Direct Payments or Individual Budgets team and learning providers to actively promote and support the uptake of personal budgets
- Training courses for people with mental health needs that helps them to understand what is on offer with personal budgets, prepare and gain confidence to use them.

I get help with support planning if I want it and this includes support with positive risk taking.

I get the support I need to turn the plan into reality.

When the money has been allocated and people have decided on a way to manage it that suits them, the next stage is to explore how to make best use of it to achieve what they want in their lives. Some people will want to design their own support plans without help. For others, getting the right kind of support to explore options, risks and make decisions will be a vital factor in achieving positive outcomes. Some people will be able to put their plans together quickly and some may want longer to explore options. Support for planning, and for sorting out the things that will make it happen (sometimes called 'brokerage') can come from a range of people, for example, from family or friends, care co-ordinators, advocates, providers, independent brokers, or voluntary agencies. *(for more information about positive risk taking section 1)*

Examples of things that help with this:

- Resources that are earmarked and allocated to support planning and brokerage, for example, to make sure information, advice and training is available for people in support planning and brokerage roles
- Capacity for support planning so that people can have a choice of who assists them
- There are a range of options available so that people can choose a way to take control that suits them, and can choose who they want help from
- User-led organisations are developed as an option to provide information, advice, guidance and support
- People are willing to learn from experience how to get the right balance between level of detail and time taken to develop a support plan
- In thinking about how to put a support plan together, people are encouraged to do as much for themselves as possible and to take account of their existing networks of friends and relatives
- There is good communication when the support plan is complete about what people should expect to happen next, and how long it will take.

I can use the money allocated to me in new and creative ways

The IBSEN report⁵ highlighted questions raised in the Individual Budget pilots about what was an acceptable use of resources. The DH response to these questions was:

'As long as authorities ensure that what they are doing is safe and legal and meets the person's needs, taking account of the risks to the individual and the authority, that is legitimate. In this way individuals have been encouraged to develop their own creative solutions to meeting their needs' (DH, 2008)¹⁷.

Personalisation means supporting people to be more in control over decisions about what will help them recover, stay healthy and have a fulfilled life. Sometimes they will benefit, in thinking about this, from the help of their family and friends or an advocate and advice and support from health professionals. Personal budgets provide an opportunity to spend money on things that are unique, personal, creative and custom built. The exercise becomes frustrating and pointless if, at the end of the process, people (individuals and staff) are told *'I'm sorry but you can't use the resources for that'*

Examples of things that help with this:

- Support plans that look as people want them to, rather than need to be in a format that an organization insists people use
- Culture and training that supports care co-ordinators and staff to feel confident about supporting people to come up with creative ways of using resources
- Senior management support for this approach and clear messages for staff
- Access to stories that show how things can be done differently and uniquely
- Focusing on what is important to the person
- Outcome based support planning that helps people be clear about what is important to them. This helps focus on a simple test for the plan: *'Will this (whatever it is) help me recover, stay healthy and have a fulfilled life?'* Focusing on outcomes will also provide essential clinical audit and monitoring information
- Resources for peer support to enable people to benefit from other people's experiences.
- Wide ranging information about what is available in someone's locality, beyond health and social care (See *information and advice section 2*)

- Being supported to look beyond health and social care services to understand positive health and social care outcomes from things like being part of a community, employment, leisure, education, faith and culture
- Support for community participation.

Information, support and training is available to help me be a good employer and understand fully what is involved as a personal budget holder I know where to go to get help and advice when I need it as an employer and budget holder and if problems arise.

Some people who opt to manage their own budgets and employ their own staff are able and prepared to do so and just want the opportunity to get on with it. Others will need different kinds of help and support to do this confidently and safely

Examples of things that help with this:

- Access to information (see *Information and Advice section 2*)
- Access to legal advice
- Local user led organisations that can provide information, peer support and a 'problem solving' service
- Specific training, workshops, factsheets and sample documents on e.g. advertising, recruitment, making an offer, contracts etc
- Resources planned and available for this kind of help and support
- A person centred culture and the use of person centred thinking tools.

SIGNPOSTS

1. *Putting us First*: A project about direct payments and individual budgets for people who use mental health services. Norah Fry Research Centre University of Bristol Contact: val.williams@bris.ac.uk / pauline.heslop@bris.ac.uk 0117 331 0982
2. Mersey Care NHS Trust *Individual Recovery Budgets Project*. This project was established in Early Intervention Services in Liverpool and Sefton, offering a virtual budget to support individuals to secure items and services that enable people achieve recovery outcomes. Contact: Carey Bamber, NW Joint Improvement Partnership: carey.bamber@northwestjip.nhs.uk or Jenny Robb, Associate Director of Social Care, Mersey Care NHS Trust: jenny.robb@merseycare.nhs.uk

Training

3. *A Learning journey to Direct Payments as part of self-directed support: Is it for me?* Information and resources for trainers and people in a position to make Direct Payments more accessible for people with mental health needs. Includes workshops to give people the information they need to assess whether or not they want to take up the opportunity and how to prepare themselves if they do. Also training the trainers for people who want to run these courses. NIACE (National Institute of Adult and Continuing Education) Contact: susan.rees@niace.org.uk 0116 204 4256

Support for managing personal budgets

4. Practical info and publications on National Centre for Independent Living website www.ncil.org.uk re: employing people, using Direct Payments
5. In Control website – for information on employing staff, and for stories www.in-control.org.uk
6. *Managing the Money: Resource Development options for personal budgets* (DH, 2008) Part of the *Personalisation Toolkit* Also contains information on User led organisations (In Appendix 1) www.toolkit.personalisation.org.uk
7. *Good practice in support planning and brokerage* (DH 2008) Part of the *Personalisation Toolkit* www.toolkit.personalisation.org.uk

8. *Direct Payments for people with mental health problems: A guide to action* (DH) CSIP 2006 Contact: www.socialinclusion.org.uk/publications/Direct_Payments_web.pdf
9. Barnsley Metropolitan Borough Council have developed a useful guide to help people put together their own support plan. www.barnsley.gov.uk/bguk/docs/Social%20Services/Individual%20Budgets/Support%20planning%20guide%20version%203%202002.07.2007.pdf
10. Outcome focused reviews: A practical guide, DH, May 2009 www.dhcarenetworks.org.uk/_library/Resources/Personalisation/Personalisation_advice/OutcomeFocusedReviews2.pdf
11. *The independent broker role and training requirements: Summary report*, Skills for Care, 2009 www.dhcarenetworks.org.uk/_library/Resources/Personalisation/Personalisation_advice/SfC_ISB.pdf

Research

12. The implementation of individual budget schemes in adult social care (2009) *Research Briefing 20* Carr, S and Robbins, D Social Care Institute for Excellence www.scie.org.uk

Positive Risk Taking and Risk Management

(See section 1 *Helpful person-centred systems*).

More information on DH's personal health budgets pilot programme can be found at www.dh.gov.uk/en/Healthcare/Highqualitycareforall/Personalhealthbudgets/index.htm

SECTION 4

SUPPORT FOR CARERS

I GET THE SUPPORT I NEED TO CARRY OUT MY CARING ROLE, STAY WELL AND LIVE MY OWN LIFE

WHAT HELPS TO MAKE THIS HAPPEN?

When someone becomes unwell it is very often their immediate family or friends who provide much of the care that helps them to recover, or who support them through recurrences of mental illness throughout their life. Anyone could become a carer at any time during their life.

The National Carers Strategy stresses the importance of support based on personalisation principles and approaches. The strategy defines a carer as someone who *'spends a significant proportion of their life providing unpaid support... This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems'* (DH, 2008)³⁸.

Many people do not think of themselves as carers and therefore do not seek support or are unaware of the support they are entitled to, including financial support. Carers themselves are twice as likely to have mental health needs if they provide substantial care (Singleton et al, 202)³⁶ (Hirst, 2004)³⁹ An estimated 6,000 to 17,000 children and young people care for an adult with mental health needs (Aldridge and Becker, 2003)³⁷. Those providing 35 hours or more of care a week and those in receipt of Carer's Allowance are more likely to be in the second lowest and middle income bands than the general population and working carers are more likely to be unqualified and less likely to hold university degrees than other people in employment (DH, 2008)³⁸.

The evaluation of the Individual Budgets Pilot reported that: 'individual budgets were significantly associated with positive impacts on carers' quality of life' (SPRU, 2008)⁵.

There is information relevant to carers throughout this document, but this section tries to look specifically from a carer's perspective.

I have easy access to information and advice to help and support me as a carer.

Examples of things that help with this:

- Information available very locally e.g. in local shops, pubs and GP surgeries
- Websites designed for carer information and support and access to the internet (and if needed, training and support to use information technology)
- Local networks and peer groups for support and exchange of information
- Well informed staff who can give me the right information and advice, or direct me to other sources
- Health and social care telephone systems that are warm and responsive and can answer my questions or quickly direct me to the right place.

(See also *Information and advice* section 2)

If I have to go through an assessment or self-assessment process it is easy to access and sensitive to my needs and wishes. If I am eligible, assessment leads to the support I want in a way that suits me.

The contribution I make, and the informal family and friendship networks that support me and the person I care for, are recognised in assessment and support planning.

It is clear what can reasonably be expected from me as a caregiver and I have choices about how and when I provide care.

The processes I go through recognise that I can have a life of my own outside of my caring role.

Examples of things that help with this:

- Assessment systems and processes that are based on a set of personalisation principles, not just a document
- Person-centred tools and approaches that put people in control, recognise and respect the significant role of carer and acknowledge the support of family members and friends
- Being treated as an equal partner to develop support plans and find support

- Being supported to look beyond health and social care to consider things like being part of a community, leisure, education, employment, faith and culture
- Support for community participation

(See also *Helpful, person-centred systems section 1 and Partnerships section 7*).

I get help and support when I need it and at times of crisis.

Examples of things that help with this:

- Advance directive and crisis planning according to people's wishes, that people are confident will be carried out
- Acknowledgement of carers needs and wishes and the sensitive balance of support for the rights of all involved
- Creative commissioning that allows for flexibility and choice
- Carers control over how money allocated for their support is spent

(See also *Creative Commissioning section 6 and Helpful, person-centred systems section 1*).

I am given information about personal budgets. I get the support that I need, and that suits me, if I take on the management of a personal budget.

I am not put under pressure to take on management of a personal budget if I do not feel comfortable with this.

Examples of things that help with this:

- Clear, accessible information in ways and places that suit different people
- Clarity about the choices in managing a personal budget or having it managed on your behalf
- Well informed, positive staff who are sensitive to the right kind and level of support needed to help people take control

- Support for person centred care planning and finding what is wanted, if this is needed
- Support and training as a personal budget holder e.g. as an employer, managing the money, finding the right support

(See also *Support for Managing personal budgets section 3*).

I can get breaks from caring when I need them and in a way that suits me.

In the consultation for the National Carers Strategy, carers made it clear that the provision of breaks and replacement care were among their highest priorities. Carers who do not have breaks from caring are far more likely to have mental health needs (Hirst, 2004)³⁹.

Examples of things that help with this:

- Senior management support for innovation to develop ways of providing breaks in ways and at times that suit people
- Programmes that actively promote information about breaks, in ways that will reach people whoever, or wherever they are
- Expert carer commissioners and consultation that impacts on the way short breaks are provided and made available
- Resources that local and health authorities, in partnership, can invest in a range of ways to meet everyone's short break needs, in response to expert advice from carers
- Personal budgets for carers to decide on and arrange their own ways of taking breaks
- Investment in assistive technology such as Telecare (e.g. sensors placed around the home that trigger alarms connected to help at the sign of unusual activity such as front doors opening at night).

I am not forced into financial hardship as a direct result of having a caring role.

Examples of things that help with this:

- Information about benefits that carers are entitled to is easily available and there are programmes, campaigns and strategies to make sure that information reaches people
- Employers put into practice the requirements of the Work and Families Act 2006 for flexible working for employees who care for an adult
- Improving information about flexible job vacancies via Jobcentre Plus
- Specialist training for Jobcentre Plus Advisers and for health and social care staff
- Funding for replacement care that will allow people to take part in training and employment programmes
- Return to work support
- Information and support for employers to promote the positive benefits of employing carers.

I can continue my learning and personal development.

Examples of things that help with this:

- Replacement care that people are confident in and feel comfortable with, so that they can participate in training and personal development opportunities
- Training and further education opportunities that are designed to be flexible and fit in with caring responsibilities
- Careers guidance and advice services to help carers progress back to learning and work through skills and confidence building.

I am able to stay well as a carer

Examples of things that help with this:

- Regular breaks, a decent place to live and financial security
- Annual health checks for carers
- National and local projects providing emotional support for carers
- Training and guidance for General Practitioners to help them better understand the needs of carers
- Making sure carers can easily access information relevant to the needs of the person they are caring for – and training to help them in their caring role, if appropriate.
- Peer support in the form of local groups and networks and the opportunity to meet new people
- Prevention and early intervention initiatives (perhaps through Local Area Agreements) to reach carers who may not be aware of what is available to support them in their caring role
- Providing replacement care and finance for 'caring for carers' programmes – local and health authorities in partnership with the voluntary sector and local shops and services (e.g. relaxation, therapy and exercise services, drop in centres, meals out, carers cards that give concessionary rates in shops, leisure services and for transport etc).

As a child, I am protected from inappropriate caring and have the support I need to learn, thrive and have a positive childhood.

Examples of things that help with this:

- Dedicated Young Carers projects that provide, for example, evening clubs, weekends away, days out, holidays, someone to talk to, information and advice

- High quality targeted support for young carers
- Support to have the time and space to learn and have friends
- Training and awareness raising initiatives for general practitioners and teachers
- Whole family approaches to support.

I am respected by professionals as an expert partner.

Examples of things that help with this:

- Support for involvement in consultation, including replacement care
- Flexible and innovative ways of including carers in consultation and planning
- Experts by experience paid as advisers and commissioners - in local and wider strategic planning and decision making, inspection and service design
- Carers are able to explore and discuss their concerns in an atmosphere of trust and:
 - given general factual information
 - helped to understand issues of confidentiality and any restrictions requested by the person they are caring for and how to access help
 - offered a chance to see a professional on their own
 - given confidence to voice their views
 - encouraged to feel a valued member of the care team
 - offered an assessment of their own needs.

(See also under Creative Commissioning section 6).

SIGNPOSTS

Information and websites

1. A list of local carer support groups, and links to their websites can be found on: www.mentalhealthcare.org.uk/carersupport/?id=158#Avon
2. There are many good local websites for mental health carers. An example is the website for mental health carers in the Bolton area. www.mentalhealthcarers.org
3. Princess Royal Trust website for young carers: www.youngcarers.net/who_can_help_me/86/92
4. *MIND Carers Factsheet* gives information about the help and services that are available for carers of people with mental health needs. For more information on the emotional aspects of the caring role, see Mind's booklet *How to cope as a carer*. www.mind.org.uk/Information/Factsheets/Carers/
5. *Carers Direct* A website giving information, support and advice for carers. Also gives information about local mental health services. www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx
6. Carers UK is a membership organisation of carers that campaigns on behalf of carers and provides information, support and advice. www.carersuk.org/Aboutus/Howwehelp
7. Facts and statistics about carers. www.carersuk.org/Policyandpractice/PolicyResources/Policybriefings/FactsaboutcarersJanuary2009.pdf
8. Information about financial support for carers can be found on: www.carersuk.org/Information/Financialhelp
9. Information about breaks for carers can be found on: www.carersuk.org/Information/Helpwithcaring/Takingabreak
10. *Carers and confidentiality in mental health: issues involved in information-sharing* A leaflet produced by the Royal College of Psychiatrists and The Princess Royal Trust for Carers www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf

Policy and guidance

11. *SCIE Guide 9: Implementing the Carers (Equal opportunities) Act 2004*, SCIE, 2007. Gives quick and easy access to information that aids the implementation of the act, including research, practice examples and further information. www.scie.org.uk/publications/guides/guide09/files/guide09.pdf

12. *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own* Department of Health, 2007. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345
13. *Department of Health website: Carers* This section of the DH website is aimed at health and social care professionals in the statutory and independent sectors who work with carers. It contains information on Government guidance and regulations affecting carers, details of the current carers grant and other relevant information on carers' policy. www.dh.gov.uk/en/SocialCare/Carers/index.htm
14. Frequently asked questions about the Work and Families Act 2006 can be found on: www.carersuk.org/Newsandcampaigns/makeWORKwork/WorkandFamiliesActFAQ

Projects

15. *Partners in Care* Partnership between The Royal College of Psychiatrists and The Princess Royal Trust for Carers to highlight the problems faced by carers of people with different mental health needs and learning disabilities, and encourage partnerships between carers, patients and professionals. www.carers.org/articles/partners-in-care,264,CA.html
16. *My care* A project for young carers of parents with mental health needs. Mental Health Foundation and The Princess Trust for Carers. www.mentalhealth.org.uk/our-work/children-and-young-people/mycare/?locale=en
17. *Employers for Carers* is relaunching as a membership forum for employers, offering a range of support from information on good practice to training and consultancy. www.employersforcarers.org/Home

Training courses for carers

18. *Caring with confidence* A programme that provides training for carers, empowering and enabling them. It informs people of their rights, the services available to them and develops their advocacy skills and their ability to network with other carers to support their needs. www.dh.gov.uk/en/SocialCare/Carers/DH_075475

SECTION 5

FAIR ACCESS AND EQUALITY

There have been some positive developments in ensuring equality and fair access in health and social care services, supported by legislation, but recent evidence shows that we still have some way to go. Some examples of health and social care inequalities have been evidenced for black and ethnic minorities (DH, 2007⁹ DH, 2008¹⁰) lesbian, gay and bisexual people (CSCI, 2008)¹², disabled people (CSCI, 2009)¹³. and people with mental health needs and/or learning disabilities (Mencap, 2008)¹⁴, (Disability Rights Commission, 2006)¹⁵ Some of the barriers to equality that these studies identify are, for example, physical access, communication, stigma, and low expectations. People with mental health needs are also likely to experience higher levels of deprivation and poverty (Thorncroft, 1991)¹⁶ and have a very high risk of failing to find and retain employment (Office for National Statistics, 2003)¹⁹. All aspects of the framework outlined in this guide would need to be in place in order to ensure fair access and equality and improve opportunities and outcomes for people with mental health needs, but this section deals with some specific equality issues.

My cultural background and communication needs are taken into account in assessment and self assessment and support planning.

Enough time is given to me so that I can explain my needs properly, or for a family member or advocate to explain them on my behalf.

There is continuity in the contact I have with professionals and I don't have to keep explaining things over and over again.

OPPORTUNITIES ARE
AVAILABLE TO ME
WITHOUT DISCRIMINATION
OR UNFAIRNESS

WHAT HELPS TO MAKE
THIS HAPPEN?

Examples of things that help with this:

- In health and social care assessments a whole life approach is taken, which includes, for example, taking into account the importance of culture, faith, relationships, family, caring responsibilities, a decent place to live, finance and employment, social and leisure activities
- There is a streamlined approach to person centred information that means people do not have to keep telling their stories over and over again
- Availability of interpreters, guides and advocates, including dedicated time slots where interpreters are on hand
- Flexibility in appointment systems to reflect an understanding that things may take longer if there are language or communication differences or if people have difficulty in speaking or expressing themselves
- Opportunities for people to find out about and easily access *English for speakers of other languages* courses
- Dedicated training for professionals in working with language and communication differences and working with interpreters
- Drop in facilities where people can get information in a range of formats and languages and check information they have received.

There are no barriers to access and the quality of the services I am offered is the same for me as for everyone else.

There is a good choice of opportunities and services that take account of my particular needs.

Examples of things that help with this:

- Information in different forms and from different sources (*more in info section 2*)
- Dedicated teams, and voluntary groups that speak a range of languages and actively work locally to improve access and outcomes (for example to employment and financial advice) and also work with health and other staff to increase awareness and understanding of cultural and other differences

- Access to an employment adviser and to schemes like Pathways to Work (*more info on partnership section 7*)
- Anyone who is eligible for access to public funding for services is offered the opportunity to have a personal budget
- Promotion of information about personal budgets through local radio, community broadcasting and satellite channels that are designed for different communities and audiences
- Access to information technology and specific training and support to use it
- Availability of specialists with training and understanding of special needs
- Local organisations working with prisoners with mental health needs - for example, providing the opportunity to access training to talk about their experiences, so that professionals and services can have a better understanding and be more responsive
- Innovative approaches to involving people in planning and development, designed by people who use or have used services – for example, community events run by local people
- The involvement of mental health service user experts in the commissioning, contracting and procurement process
- Good, relevant data collection to inform commissioning, including what is working and what is not working for people
- Specific equality targets in commissioning and contracting, including equality principles as part of the criteria for evaluating tenders.
- Support and development of user led services (*more info in the creative commissioning section 6*)
- Dedicated action in helping people to recruit personal assistants who can meet cultural, linguistic and religious requirements – for example, advertising campaigns via local and community specific media

- Flexibility in the limitation in Direct Payments of payment to relatives (but ensuring that assumptions are not made that this might be the only option for some people)
- PCTs working with local authorities through local strategic partnerships and local area agreements to tackle wider social issues impacting on health and well being such as housing and employment as addressed within PSA 16.

I get a fair choice and opportunities are available to me even though I live in a rural area.

About 9.5 million people live in rural areas in England and this is a growing number. There are particular difficulties for people living in rural areas, such as variability in provision, stigmatisation and isolation, rural racism poor transport and housing poverty (SCIE, 2007)²⁰.

Personal budgets could provide an answer to some of the difficulties that people who live in rural areas have in finding the right help and support to live their lives. However, there needs to be a recognition that health and social care policies and programmes must '*recognise and address rural circumstances*' and '*ensure equitable outcomes in rural areas*' (Commission for Rural Communities, 2008)²¹.

Examples of things that help with this:

- Geographical and community specific promotion of personal budgets, and the provision of the right advice, advocacy and support to take advantage of them
- Information made available locally – for example, in local shops, GP practices, or via church and parish magazines
- Good consultation and direction from people in rural areas about what is needed and what will work
- Community development and practical support for the development of local clubs and activities
- Community transport schemes

- Creative use of mobile services (e.g. mobile libraries) and of local venues (e.g. lunch clubs in local pubs)
- Market development and support for small, local voluntary groups and social enterprises
- Systems and services that can be flexible and adapt to local circumstances
- Good contingency planning for the management of crisis and if things go wrong.

SIGNPOSTS

Equality in health and social care and beyond

1. *Will community-based support services make direct payments a viable option for black and minority ethnic service users and carers?* Dr Ossie Stuart, Social Care Institute for Excellence, 2006, London. www.scie.org.uk
2. *Delivering Racial Equality* website: In January 2005, the Department of Health published a five-year action plan, Delivering Race Equality (DRE) in Mental Health Care. DRE aims to help mental health services provide care that fully meets the needs of BME patients and build stronger links with diverse communities. www.actiondre.org.uk
3. Lakhani, M (2008) *No Patient Left Behind: how can we ensure world class primary care for black and minority ethnic people?* London: Department of Health. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084971?IdcService=GET_FILE&dID=165661&Rendition=Web
4. Race for Health (2006) *Towards Race Equality in Health: a guide to policy and good practice for Commissioning Services*. Manchester: Race for Health www.raceforhealth.org/storage/files/Race_for_Health_Commissioning_Guide.pdf
5. MIND website with information about mental health discrimination and how to challenge it. www.open-up.org.uk/resources
6. *Vision and progress: Social inclusion and mental health*. www.socialinclusion.org.uk/publications/NSIP_Vision_and_Progress.pdf

Local services

7. Health and Advice Links services based in GP surgeries in Tower Hamlets and Hackney – offer advice on a wide range of issues such as housing, debt, and employment.

The services are managed by Social Action for Health, a community development charity that works alongside marginalised local people and their communities. It operates mainly in East London with staff recruited from local people trained to work with their community in their mother tongue. www.safh.org.uk/safh_php/networks.php?gi_session_name=gi_session_49d0e28dbc3af

8. Sharing Voices in Bradford (SVB) A community development charity that works with black and ethnic minority communities to provide culturally sensitive mental health services. www.sharingvoices.org.uk
9. Rural Emotional Support (REST) service, Staffordshire. This is a service run by a voluntary organisation providing emotional support and practical help for people living in agricultural communities. www.staffordshirementalhealth.info/details.asp?CourseID=104

Access

10. Department of Health *Equal Access Framework* Part of the Personalisation Toolkit. www.toolkit.personalisation.org.uk
11. Information about rights to access, treatment and support. www.equalityhumanrights.com/en/yourrights/rightsindifferentsettings/Healthandsocialcare/Pages/Accessstoservice.aspx#Mental%20health
12. Newman J, Hughes M (2007) *Modernising Adult Social Care – What's working?* London DH. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076203

Rurality

13. Manthorpe J, Stevens M (2008) The personalisation of adult social care in rural areas, Cheltenham: Commission for Rural Communities. www.ruralcommunities.gov.uk/files/CRC%2078%20Adult%20Social%20Care.pdf
14. Bowden C and Mosley M (2006) *The quality and accessibility of services in rural England: a survey of the perspectives of disadvantaged residents* Wolverhampton, ADAS. www.defra.gov.uk/rural/pdfs/research/quality-accessibility-services-rural-eng-report.pdf
15. Rural Emotional Support (REST) service, Staffordshire. This is a service run by a voluntary organisation providing emotional support and practical help for people living in agricultural communities. www.staffordshirementalhealth.info/details.asp?CourseID=104

SECTION 6

CREATIVE COMMISSIONING

THERE IS OPPORTUNITY, CHOICE AND INNOVATION IN WHAT IS AVAILABLE TO SUPPORT ME TO HAVE A GOOD QUALITY OF LIFE

WHAT HELPS TO MAKE THIS HAPPEN?

Commissioning is at the heart of developing personalised approaches and services. Getting it right has a significant impact on the quality of people's lives and experiences. Commissioning also has some challenges for radically changing systems, processes and attitudes and for changing the balance of power to give people who use services the opportunity to set the agenda.

Commissioners will need to be willing to think imaginatively, innovate and take positive risks, working with people as equal partners to look beyond traditional health and social care services. They need to be fully supported by their organisations to ensure that people can direct their own support, and to develop co-production in commissioning in strategic locality based, area wide or regional commissioning. One of the key principles for personalisation is partnership – with individuals and their families, communities, commissioners and providers. *(There is more detail on partnership working in the section on Partnership section 7).*

I can influence strategic planning of services as part of consultation or as a paid worker and as an equal partner.

The decisions and choices that I, and other people with mental health needs, make is captured and reflected in strategic planning.

Examples of things that help with this:

- When consulting:
 - Ensure and demonstrate that strategies for involving people who use services and public consultation impact on the way services are designed
 - Seek people's views on the best way to consult
 - Make sure everyone is engaged – e.g. people with complex needs or who have difficulty expressing themselves, people with different ethnic or cultural backgrounds or language differences, travelling communities, gay and lesbian citizens

- Engage people from the start before any plans are written, and then throughout the implementation, monitoring and evaluation processes
- Ensure that consultation is imaginative and sensitive to different situations, locations and cultures
- Always complete the circle and let people know the outcome of consultations, monitoring and evaluation.
- Commissioners work with partners to identify people's real needs and don't develop the market in a vacuum and for its own sake
- Commissioning is co-produced with people who use services and family and carers
- There is a system in place to ensure that what people have identified in their support plans is captured and used to ensure that the right supply of local services is available
- Experts by experience are members of planning boards and forums, locally, regionally and nationally – and they have the personal support (financial or other) they need to be effective contributors
- Training is available to give people the knowledge and skills needed to influence decision making and policy making
- Training is available for all board and forum members on disability, mental health and diversity
- Expert commissioners and advisors are employed
- People who use or have used mental health services are engaged as expert commissioners
- Patient advisors are engaged to help re-design services, influence change and bring about local improvements
- Strategic plans are supported by action plans and financial plans and there is honesty about available resources and realistic timescales

- Commissioners plan with people for services they need over the course of their whole lives – and that all citizens will use, or potentially use, at some point
- Commissioners consider the needs of people that services are not currently meeting, for example, younger people and those from different cultural backgrounds.

I am supported to take control, live more independently and have more choice through well supported self care.

Self care means having the opportunity to be responsible for your own health and to make the most of life and feel fulfilled. In order to support self-care approaches, commissioners and providers need to work in partnership with people to achieve the best possible outcomes. (*For more detail see under Information, Self-help and Advice section 2*).

I have the opportunity to be in control of health resources for my recovery and well being.

Personal health budgets are a way of giving people more control over how money is spent on their health care. Primary Care Trusts already have powers to offer personal health budgets, either as a notional budget or held by a third party. However, as yet there has been a very limited use of these powers. A DH pilot programme is underway to enable PCTs and their partners to be innovative and explore opportunities offered by personal health budgets (DH 2009)¹⁸. As part of the pilot programme once regulations are in place, pilot sites will be able to offer direct payments for health care, where individuals are given the money.

Examples of things that help with this:

- Commissioners and providers:
 - who are enthusiastic and motivated to support people to take up the opportunity for personal health budgets
 - who experiment and are innovative and also look outside the scope of traditional NHS commissioning practice
 - use learning from the personal health budgets pilot programme that is being set up by the Department of Health

- work together positively to focus on outcomes for people (not just on processes and inputs)
- have arrangements and contracts which allow for flexibility to respond to what people want.
- Innovation and improvement in service design, with the full involvement of people with mental health needs
- Support and leadership from senior managers and clinicians to give commissioners and providers the confidence to boldly innovate
- Commissioners Learning Networks to share ideas, experiences and solutions to difficulties
- Personal health budgets seen as embodied in the context of practice based commissioning and world class commissioning – not as a separate initiative.

There is a wide range of things available so that I can make real choices and barriers to access are removed.

(*For more detail on a partnership approach to broader commissioning see Partnership section 7*)

Examples of things that help with this:

- Commissioning for the whole community. This means local authorities commissioning for the well being of communities with an integrated approach to commissioning universal services (such as housing, transport, leisure, culture, adult learning, employment services etc) and care and support services – and taking action on how barriers to universal services can be overcome so that they are accessible and available to all
- Co-produced commissioning strategies, ensuring that people are able to directly influence what is commissioned
- Support for smaller providers and micro enterprises as a vital part of choice in a managed market. Support services and projects to offer advice, networking and marketing support to small providers to ensure that they can offer a viable alternative to larger providers

- Services directly provided by health and local authorities have strategic development plans to ensure that they have personalised approaches and are of good quality
- Joint commissioning
 - a joint strategic assessment of future needs with full community engagement - actively engaging with local communities, patients, people using services, carers and providers to develop a full understanding of needs to feed into commissioning
 - integrated local authority commissioning (universal and care and support services) and health commissioning
 - health and social care commissioners take the opportunity for a more personalised approach, working together in response to the Improving Access to Psychological Therapies programme (see link in Signposts below)
 - full advantage is taken of mechanisms for joint planning such as Local Area Agreements and Joint Strategic Partnerships (see link in Signposts section under Local Planning for further information)
- Ensuring that people still have the choice of group solutions e.g. in housing, social contact and activities, if that is what they want
- A sustainable financial model for a personalised service
- Using practice based commissioning creatively – so that teams can work with people as partners to design personalised support, improve the effectiveness of prevention and early intervention services, develop a wider range of local services being delivered at times that are convenient, and supporting people to manage and protect their own health and well-being to help avoid unnecessary admissions to hospital
- Voluntary organisations coming together to pool expertise and offer a whole system approach – so people can move flexibly between or through services

- Commissioners ensuring that they are planning for the needs of groups who are currently not well served, for example younger people and black and ethnic minorities with mental health needs.

I have an opportunity to choose a user led service or be involved in running one.

A User-led organisation is one in which the people who the organisation represents or provides a service to, have the balance of power on the Management Committee or Board and are accountable to members and service users. User led organisations provide a range of services, for example, training, information and advice advocacy and peer support, support in using personal budgets, support to recruit and employ personal assistants, but their full potential is still being explored.

'A key recommendation in the Improving Life Chances report (p91) states that: "By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing CILs". DH established in 2006 the ULO project to address this recommendation. The organisations envisaged by this recommendation are seen as one of the key mechanisms for encouraging the participation of disabled people, carers and other people who use support in the design, delivery and monitoring of resources and services designed to support independent living.' (DH, 2007)³⁴.

Putting People First outlines the aim for local authorities to *'support at least one local user led organization and mainstream mechanisms to develop networks which ensure people using services and their families have a collective voice, influencing policy and provision'*¹³.

Examples of things that help with this:

- Commissioners, with the support of senior managers, who want to promote and encourage the development of user led organisations

- User led organisations as a clear part of commissioning strategies and plans for the development of the market
- Networks of user led organisations and those representing different groups of people that can support one another, share information and experience, collaborate in change and develop new ways of doing things
- Personal support, if needed, for people to be employed by or participate in user led organisations.

I can see that services that I and my peers report are not good or not running in an appropriate style are supported to change, or are de-commissioned.

I can see that commissioners have listened to people reporting gaps in service provision and these are planned for.

People with mental health needs often find it frustrating that they have to use and put up with services that they do not find useful and which do not behave in ways that treat them with respect. This presents significant difficulties for people when no new resources are available for alternatives or to fill identified gaps.

Examples of things that help with this:

- Regular feedback from people with mental health needs through, for example, marketplace internet sites where people can rate services that they experience
- Involvement of people with mental health needs in designing and carrying out quality assurance activities (including inspection and service review), in a consultation role and as paid workers
- Inclusion of the involvement of people with mental health needs as a quality measure in inspection and audit

- Key individuals (such as clinicians, senior managers and commissioners) should check for themselves what it is like, as a human experience, to get information, help or support from the organisations they work in and the systems they are responsible for. They should also routinely get feedback from people using those systems (service users and staff) about the nature of that experience and what changes could be made to improve it. This does not mean just dealing with complaints – but pro-actively seeking to improve the experiences people have by making the right changes
- Frameworks for measuring success that are designed to look at **outcomes** for people, not just outputs (e.g. not just the number of people with personal budgets)
- Using feedback to take action to improve or remove
- Data that is routinely collected and analysed to create an evidence base for successful provision that leads to the right outcomes for people and for decommissioning provision that does not
- There is a strategic understanding of gaps in services.

SIGNPOSTS

Projects and programmes

1. *Personal Health Budgets: first steps* Department of Health, 2009 Information about personal health budgets and a pilot to try them out. Contact: Personal Health Budgets Team personalhealthbudgets@dh.gsi.gov.uk
2. *Improving Access to Psychological Therapies Programme* National programme to provide improved access to psychological therapies for people with mental health needs. It also responds to service user's requests for more personalised services. <http://mhchoice.csip.org.uk/psychological-therapies.html>

Mental health: commissioning vision

3. *A new vision for mental health: Discussion Paper* The Future Vision Coalition 2008 www.newvisionformentalhealth.org.uk *The Future of Mental Health: A vision for 2015* The Sainsbury Centre for Mental Health 2006
4. www.scmh.org.uk *Mental health into the mainstream* ADASS 2008 Mental health, drugs and alcohol network. www.adss.org.uk/images/stories/Publications/Guidance/MHintoMainstream.pdf
5. *Services for people with learning disabilities and challenging behaviour or mental health needs* Guidance: Department of Health 2007 Mansell Report (rev ed) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129
6. *Green Light Toolkit – for improving mental health support services for people with learning disabilities.* www.learningdisabilities.org.uk/EasysiteWeb/getresource.axd?AssetID=14930&type=Full&servicetype=Attachment
7. *From segregation to inclusion: Commissioning guidance on day services for people with mental health problems* CSIP, DH 2006. www.socialinclusion.org.uk/publications/Day_Services_web.pdf

Involving people in commissioning

People who use services and carers

8. *Working together for change: Using person-centred information for commissioning*, Department of Health, 2009. Looking at how commissioning can be co-produced at a strategic level and using aggregated information from person-centred reviews. www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/General/?parent=2734&child=5802

9. *Involving people who use services in the commissioning process, Commissioning eBook* Department of Health (2006). www.dhcarenetworks.org.uk/_library/Resources/BetterCommissioning/BetterCommissioning_advice/Chap3NWalker2.pdf
10. *Having your say* Tameside MBC has a Service User Involvement Team and a website that tells people how they can be involved and make their views known. www.tameside.gov.uk/tmbc2/haveyoursay.htm
11. Surrey Users' Network (SUN) have produced '*Involving Service Users and Carers in Local Services: guidelines for social services departments and others*'. www.suntimes.btinternet.co.uk/info/invurcer.htm

Clinicians

12. *Clinical leadership for NHS Commissioning: Exploring how allied health and other health professionals lead change through and beyond commissioning for a patient led NHS*, NHS Alliance, 2007. www.baat.org/Clinical_leadership_AHP_Nov07.pdf

The Community

13. *Community Engagement to improve health: NICE Public Health Guidance 9*, NICE, 2008. www.nice.org.uk/nicemedia/pdf/PH009Guidance.pdf
14. *Community engagement and community cohesion*, Geraldine Blake, John Diamond, Jane Foot, Ben Gidley, Marjorie Mayo, Kalbir Shukra and Martin Yarnit, Joseph Rowntree Foundation, 2008. An exploration of the challenges of community engagement. www.jrf.org.uk/sites/files/jrf/2227-governance-community-engagement.pdf
15. *Chapter 1: Community Engagement in Vision and Progress: Social inclusion and mental health.* www.socialinclusion.org.uk/publications/NSIP_Vision_and_Progress.pdf

Commissioning and market management

16. *Relentless Optimism: Creative Commissioning for Personalised Care* CSIP, 2006
17. *Commissioning for personalisation: A framework for Local Authority commissioners* Department of Health, 2008 and *Commissioning for Support Planning and Brokerage*. Part of Putting People First Personalisation Toolkit. www.toolkit.personalisation.org.uk

18. *Self-directed support: Financial sustainability model* Part of the Personalisation Toolkit. *Commissioning Framework for health and well being* Department of Health, 2007. www.commissioning.csip.org
19. *Market Management: A guide for Local Authorities on creating a local system of self-directed support* In Control: Part of Guides to Self-Directed Support series. www.in-control.org.uk
20. *Joint Strategic Assessment*, Department of Health, 2007 Guidance and tools for local partners. www.dh.gov.uk/en/Publicationsandstatistics/Publications/
21. *About time: Commissioning to transform day and vocational services* Lockett H, Seymour L, Pozner A Sainsbury Centre for Mental Health (2008). www.scmh.org.uk/publications/about_time.aspx?ID=580

Networking and action learning sets

22. *North West Commissioning Road Map* and joint commissioning development programme – to support personalisation and promote and link commissioners across the region. The website has some helpful general information and models to learn from. www.northwestroadmap.org.uk
23. *The Commissioning e Book*. Written by people who are actively involved in commissioning and want to share their knowledge and experience. Contributions reflect real challenges and concerns as well as exploring good practice in different aspects of the commissioning process. www.dhcarenetworks.org.uk/BetterCommissioning/Commissioning-e-book
24. *IDea Better Outcomes Community of Practice*: Information about and support for outcomes based commissioning. www.communities.idea.gov.uk/comm/community-search.do?queryText=Better+Outcomes&x=30&y=12
25. *Answering the 'So What?' question. Monitoring the outcomes for users of mental health service users* Commissioning eBook, DH, 2006. www.dhcarenetworks.org.uk/BetterCommissioning/Commissioning-e-book/Chapter10MonitoringandImprovement/10.21AnsweringtheSoWhatquestionMonitoringoutcomesforusersofmentalhealthservices/?parent=2963&child=3009

Supporting smaller providers

26. *NAAPS Micro Markets Project*. Piloting a local agency model of support for existing and new micro markets in Oldham and Kent. Also a practical guide to be published on how to set up an agency to support micro providers. Contact Sian Lockwood, NAAPS Chief Executive www.naaps.org.uk

User led organisations

27. *What is a user led organisation?* Department of Health link: www.dh.gov.uk/en/SocialCare/Socialcarereform/Userledorganisations/DH_079592

28. *Disability connects* This is a network of disability related organisations in the London Borough of Ealing, including organisations for people with mental health needs that works together to share information and experience and create change. www.ecil.org/index.asp?pageID=58
29. *User led organisations project policy*, Department of Health, 2007. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078804

World class commissioning

30. The World Class Commissioning programme is designed to transform the way in which services are commissioned in health services – with a focus on personalisation and improving outcomes. www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm
31. *World class mental health commissioning: From vision to practice*, Humana, 2008. www.commissioning-circle.co.uk/wpcontent/uploads/2008/08/mentalhealthwhitepaper.pdf

Inspection

32. *Experts by Experience: The benefit of experience: involving people who use services in inspections* CSCI (2009). [www.cqc.org.uk/_db/_documents/20080930%20ex%20by%20ex%20booklet%20final\[1\].pdf](http://www.cqc.org.uk/_db/_documents/20080930%20ex%20by%20ex%20booklet%20final[1].pdf)

Local planning

33. Department of Health link to information about Local Area Agreements and Local Public Service Agreements. www.dh.gov.uk/en/SocialCare/Socialcarereform/Localareaagreements/DH_086691
34. IDeA website link to information about Local Area Agreements. www.idea.gov.uk/idk/core/page.do?pageId=7532066

SECTION 7

PARTNERSHIP FOR INCLUSION

MY NEEDS ARE MET IN A WAY THAT IS EASY FOR ME. I GET THE SUPPORT I NEED TO PARTICIPATE AS A CITIZEN AND TAKE ADVANTAGE OF THE THINGS AVAILABLE TO ALL

WHAT HELPS TO MAKE THIS HAPPEN?

Partnership is the oxygen needed to give life to personalisation. Checking the strength and breadth of the partnerships an organisation sustains is a good indicator of how successful they are likely to be in implementing personalisation. There are some excellent examples of joint working between health and social care. Generally speaking, however, history demonstrates continuous and only partially successful government strategies and attempts to improve health and social care partnerships and make them work to achieve better outcomes for people.

(Glendinning, Hudson and Means, 2005)²². Personalisation challenges health and social care services to more energetically and reliably improve their partnership but also:

- to embrace citizens as equal partners, so that they have more control over decisions in public services, and for their own care and support
- and
- to reach beyond health and social care to forge and support strong partnerships with other agencies, communities and local groups.

The Health and Social Care Act (UK, 2001)²³ paved the way for the integration of health and social care professionals into integrated mental health teams within one organisation. The aim of this was to streamline processes and to have a more holistic approach to mental health practice. A report drawing on nine research projects carried out between 2003 and 2007 concluded that, in spite of a period of integration, '*On balance... at the time of this investigation FACS implementation has revealed and reinforced a growing separation rather than an integration of mental health and social care ideas and practices*'. (Newman J, Hughes M, 2007)²⁴ The report also highlighted differences in culture, priorities and budgetary considerations as ongoing problems. Any real progress towards personalisation requires a concerted effort from both agencies to finally address these challenges. A shift in power and control through the active participation of citizens with mental health needs will be one of the levers that is needed to break free from these organisational tensions and barriers.

Partnership working is particularly vital for people with complex needs who require a range of services from a range of professionals and agencies. As well as working across and beyond traditional agency and professional boundaries, successful personalisation also requires working across and beyond the traditional single categories that people have been funneled into. This requires '*sophisticated partnership working to ensure that the experience of people using services is one of coherence and integration*' (CSCI, 2009)²⁵.

I am an equal partner in any health or social care assessment process, and it looks at my whole life, not just at problems and times when I am unwell.

Examples of things that help with this:

- A person-centred and whole life approach, taking into account, for example, people's natural supports and the importance of culture, faith, relationships, family, caring responsibilities, a decent place to live, finance and employment, social and leisure activities (*see also Helpful person-centred approaches section 1*).
- A recovery approach that treats people as an equal partner with the hope and expectation of a fulfilled life
- Integrated care pathway approaches
- Investment in support for self-assessment and self-care
- Care co-ordinators who are knowledgeable about the range of opportunities available to people

I have good information and real choices so that I can recover and live life the way I want to.

Examples of things that help with this:

- Promotion of, and support for, personal budgets for health and social care for people with mental health needs
- A focus on wider partnerships and collaborations
- Support for projects that bring together opportunities, activities and information (the Bromley by Bow Centre is an example of this, see *Information and References section 12*)

- Commissioning that is led by information from people's real experiences and preferences, and that impacts on the way services are provided (*for more info see section 6 on Creative Commissioning*)
- Involvement of Experts by Experience as commissioners
- Active input using the skills, expertise and mutual support of citizens (sometimes known as co-production) to build trust, peer support and social activism within communities
- Support for people to become more active citizens and volunteers
- Empowerment of local care managers, clinicians and teams to work more creatively and to innovate
- Senior management support for this approach which gives staff the confidence to do things differently and do different things
- Good, easily accessible, information for staff and people with mental health needs about local life opportunities and options for support (*see also Information section 2*)
- Support for people to choose to run their own services and support each other.

I can get the support I need to live where and how I want to.

'Good-quality, affordable, safe housing is essential to our wellbeing. Poor housing or homelessness can contribute to mental ill health or can make an episode of mental distress more difficult to manage. This may also be compounded by the fact that poor housing and homelessness are often linked to other forms of social exclusion, such as poverty. The housing charity Shelter has found links between overcrowded family housing and depression, anxiety, sleep problems and strained relationships'

MIND website information on housing and mental health

'People who are homeless or living in temporary accommodation are more likely to suffer from poor physical, mental and emotional health than the general population, and ill health is often associated with poverty and homelessness... Drug and alcohol misuse and mental health problems are also prevalent amongst the homeless population, and many rough sleepers have multiple needs (e.g. a mental health problem plus one or more other issues, such as alcohol or drug misuse).' (Communities and Local Government, 2005)⁴¹.

The accumulation of rent arrears and lack of communication between housing, care and benefits staff or an unexpected hospital admission can be the cause of housing problems for people with mental health needs.

Ensuring that people's housing needs are taken into account and choices offered that suit where people want to live and the way they want to live their lives, is vital for recovery and staying well.

Examples of things that help with this:

- Person-centred CPA and support planning that looks at people's whole lives and support networks
- Mental health housing strategies based on partnership working and informed by good consultation, information from support plans and the views of experts by experience
- Partnership work to implement strategies that lead to the expansion of housing, care and support options
- Partnership and joint systems to ensure that care and support is co-ordinate from admission to hospital onwards
- Accurate mapping of needs and available supplies of housing and support services for people with mental health needs carried out in each locality
- Regional or sub-regional support to address shortages in specialist provision
- Shared approaches to assessing needs and collecting and sharing information

- Partnership, co-ordination and joint pathways across health, housing and homelessness services
- Support for innovation
- Guidance to housing authorities on lettings and stability for people with mental health needs
- Advice for social housing services on rent arrears management
- Improved access for all to advice and information about housing and support options
- Training for, health, social care and housing professionals to improve understanding of mental health and housing issues
- Feeling secure that your housing arrangements will not be threatened by any periods of being unwell, or financial difficulty
- Housing that takes account of family life.

I have the opportunity and support to develop my interests and learning and participate in cultural, creative, sports, leisure and community activity.

The Report of the Review of Arts and Health Working Group (DH, 2007)²⁷ concludes that *'There is a large amount of evidence and good practice both from the UK and internationally that demonstrates the value of arts and health'* and that *'spending on arts and health is and should be seen as a legitimate, integral part of good health care and good staff management, and entirely appropriate for NHS activity and investment'*.

An outcomes study, as part of work on mental health and arts commissioned by the Department for Culture, Media and Sport and the Department of Health (DH, 2007)²⁸ has demonstrated that for people involved in arts activities:

- There were significant improvements in empowerment, mental health and social inclusion

- There was a significant decrease in the proportion of participants identified as frequent or regular service users
- Arts projects can benefit people with a range of mental health needs, including those with significant mental health difficulties.

There is also evidence (Department of Health, 2004)³⁰ that *'Physical activity is effective in the treatment of clinical depression and can be as successful as psychotherapy or medication, particularly in the longer term'* and *'It may also help people with generalized anxiety disorder, phobias, panic attacks and stress disorders and can have a positive effect on psychological well-being in people with schizophrenia'*

Examples of things that help with this:

- Support from the Department of Health for arts and health by:
 - making clear statements and including arts and health in policies
 - creating an environment in which it is considered to be good practice to invest in arts and health
 - promoting the substantial evidence base for arts and health
 - forming partnerships with other Government Departments and other organisations to expand the contribution of arts and health.
- Local authority and PCT support for local arts and health by:
 - having a clear arts and health strategy
 - commissioning projects and investing in arts and health organisations
 - having a dedicated 'arts co-coordinator' to raise awareness and funding and engage with artists and arts organisations
 - providing good information about local arts activities and projects.

- Partnerships between Primary Care Trusts, local authorities and sports and leisure organisations and providers to create innovative projects and opportunities for people to improve their health through sport and leisure
- Strategies and action through Local Area Agreements and Local Strategic Partnerships that focus on opportunities for all to improve mental health and stay healthy.

I am supported and encouraged to prepare for employment, find work and stay employed.

I can gain the qualifications, skills and training I need to improve my employability and help me progress in my career.

People with mental health needs have one of the lowest employment rates in the UK even though consultations and research repeatedly report that the majority of people with mental health needs want to work (Secker, Grove and Seebom, 2001)²⁹. Where people are properly supported into work, and to continue working, the impact on their recovery can be very significant. Professor Robert Drake, who helped to develop an individual placement and support approach in America, said in speech at the Sainsbury Centre:

'In following people for 30 years and then following patients who are in dozens and dozens of research studies that are sent around, it's totally clear to me at this point that there's nothing... that we study that helps people to recover in the same way that supported employment does. That doesn't mean that we've had success with everybody... but it does mean that for a significant portion of people we've had tremendous success in the sense of helping them to get out of the mental patient role and recover meaningful lives.' (Drake, 2008)²⁶.

One key barrier to employability for people with mental health needs is poor access to further education and training due to stigma and discrimination, low expectations by others about what people can achieve and contribute and lack of support for achievement and success (Social Exclusion Unit, 2004)³¹.

Examples of things that help with this:

- Individual placement and support schemes that focus on finding paid employment of an individual's choice that matches their skills and interests
- Responding to people who say they want to work and are ready for it, rather than subjecting them to lengthy 'job readiness' assessment processes or eligibility criteria
- A partnership approach that brings together mental health clinical expertise and vocational and welfare benefits advice to support people to find work and stay employed
- Support that is not time limited and can continue once the person gets a job, and if necessary through their employment career
- Support for individuals to decide for themselves whether to disclose their mental health needs to employers
- Support for employers if this is required and in line with the person's wishes
- Programmes promoting positive attitudes and dispelling myths and misunderstandings among employers and their staff
- Local reviews of the current investment in mental health day services to ensure that there is sufficient investment in vocational services that support people into work and while they are working, social enterprise and services that can provide evidence of success
- Strategies and policies for inclusive learning, including building capacity in the further education system, encouraging and supporting people to access learning opportunities, ensuring equality of provision and raising the achievement levels of learners with mental health difficulties
- Support and resources for teachers and trainers to practice and promote inclusive learning.

I can influence strategic planning of services as part of consultation or as a paid adviser or commissioner (See section 6 on Creative Commissioning).

SIGNPOSTS

Arts and health

1. *A prospectus for arts and health*, Department of Health with Arts Council England, 2007. This prospectus produced jointly by the Department of Health and Arts Council England celebrates and promotes the benefits of the arts in improving everyone's wellbeing, health and healthcare, and its role in supporting those who work in and with the National Health Service. The prospectus shows that the arts can, and do, make a major contribution to key health and wider community issues. This prospectus stems from the recommendations of the Review of Arts and Health Working Group, commissioned by the Department of Health. (DH, 2007)²⁷. www.artscouncil.org.uk/publications/publication_detail.php?browse=recent&id=581
2. Norfolk Arts and Health Strategy. www.artsandhealthnorfolk.org.uk/consumption/groups/public/documents/article/ncc064231.pdf
3. ARC (Arts for Recovery in the Community). An organization working with people who are experiencing emotional or psychological distress to give them opportunities to explore art, find hope of a new beginning and move on with confidence to achieve their life goals. www.artsforrecovery.com
4. Start. An arts and mental health project in Manchester Mental Health NHS and Social Care Trust for people recovering from a period of serious and long term mental ill health. www.startmc.org.uk/index.php
5. *Mental health, social inclusion and arts: Developing the evidence base* The Anglian Ruskin/UCLan Research Team, DH 2007. www.socialinclusion.org.uk/publications/MHSArts.pdf

Employment and adult learning

6. *Meaningful lives: Supporting young people with psychosis in education, training and employment*. This statement was launched in London at an event organised by the World Health Organisation and the Department of Health to mark World Mental Health Day 2008. Its promotion aims to increase the focus on the area of functional recovery in early psychosis and bring it to be seen as being equally important as symptomatic recovery in the approach to treating early psychosis. www.iris-initiative.org.uk/silo/files/meaningful-lives-poster.pdf
7. *Doing what works: Individual placement and support into employment: Briefing 37* Sainsbury Centre for Mental Health (2009). www.scmh.org.uk/pdfs/briefing37_Doing_what_works.pdf

8. *Pathways to work* provides a single gateway to financial, employment and health support for people claiming incapacity benefits and Employment and Support Allowance. dwp.gov.uk/welfarereform/pathways.asp
9. *About time: commissioning to transform day and vocational services* Sainsbury Centre for Mental Health, 2008. www.scmh.org.uk
10. *Vocational services for people with severe mental health problems: commissioning guidance* Department of Health 2006. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4131059
11. *Improving services for people with mental health difficulties* Learning and Skills Council, August 2006. <http://readingroom.lsc.gov.uk/lsc/2006/learningopportunities/promotion/nat-improvingservicesforpeoplewithmentalhealthdifficulties-ps-aug2006.pdf>
12. *Strategies for Creating Inclusive Programmes of Study (SCIPS)* is a website that provides resources and strategies for teachers and trainers to promote inclusive teaching, learning and assessment. www.scips.worc.ac.uk
13. Lancashire Community Management Programme brings together healthcare professionals and Job Centre Plus. It is a 13 week self-help based project. Individuals work with a case manager to look at barriers to work and plan action to overcome them. www.lancscmp.nhs.uk
14. *Employers for Carers* is relaunching as a membership forum for employers, offering a range of support from information on good practice to training and consultancy. www.employersforcarers.org/Home
15. *Managing mental health and employment: DWP Research Report 537*, Annie Irvine SPRU, DWP 2008.
16. Findings of a research project exploring what helps people with mental health needs to manage in work and to retain employment. www.dwp.gov.uk/asd/asd5/rports2007-2008/rrep537.pdf
17. SCIE Knowledge Review 21: Supporting People in accessing meaningful work: Recovery approaches in Community Based Adult Health Services, 2008. www.scie.org.uk:80/publications/knowledgereviews/kr21.asp
18. National Social Inclusion Programme Employment Project for people with mental health needs. www.socialinclusion.org.uk/work_areas/index.php?subid=12

19. PSA Delivery Agreement 16. A Public Service Agreement (PSA) to support adults who are at risk of social exclusion. www.cabinetoffice.gov.uk/media/cabinetoffice/social_exclusion_task_force/assets/chronic_exclusion/psa_da_16.pdf

Co-production and whole life approaches

20. *Co-production: an emerging evidence base for adult social care transformation* SCIE Research Briefing 31 (2009) SCIE, London. www.scie.org.uk/publications/briefings/briefing31/index.asp
21. *Whole Life Workbook: Change the thinking, change the practice, change the system* Eastern Development Centre (2009) www.wholelife.org.uk
22. *Partners in Policymaking* A leadership training course for disabled adults and parents of disabled children. Designed to give participants the knowledge and skills they need to influence decision making and policy making. www.partnersinpolicymaking.co.uk/partners-policy-making.php
23. National Social Inclusion Programme interactive database of bridge building projects to help people with mental health needs actively participate in their communities. Builds on the work done by the National Development Team (now NDTi) for the Making Inclusion Work Project. Includes a section on housing. www.socialinclusion.org.uk/good_practice/?subid=78

Housing and housing support

24. *Department of Health website: Housing* Useful information and links. www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Housing/DH_083237
25. *Choice based letting for people with mental health problems* NSIP briefing, 2006. www.socialinclusion.org.uk/publications/NSIP_CBL_briefing.pdf
26. *Improving the Effectiveness of Rent Arrears Management for People with Mental Health Problem* NSIP Briefing 2006. www.socialinclusion.org.uk/publications/Rentarrearsbriefing.pdf
27. *Sustainable communities; settled homes; changing lives* Communities and Local Government, 2005 Sets out the Government's homelessness strategy. www.communities.gov.uk/publications/housing/sustainablecommunitiessettled2
28. *Bringing it all back home: mental health and housing* Housing, Care and Support Vol 113/No 2008 pp 30-35. This article calls for better co-operation and co-ordination between mental health and housing support services, and greater recognition of the important role of social housing in community mental health care.

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30. Camden Extra Care Housing for people with mental health needs. www.dhcarenetworks.org.uk/Prevention/MakingItHappen/PracticeExamples/AvoidingInstitutionalism/?parent=3940&child=4019
31. Department of Health Care Network. Information on housing and mental health. www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/Topics/browse/MentalHealth/
32. *Rethink* factsheet on housing options for people with mental health needs. www.mentalhealthshop.org/products/rethink_publications/housing_options_for.html
33. *Mental health and the experience of housing problems involving rights* Pleasance P, Balmer N, University College London, 2007. http://extra.shu.ac.uk/ppp-online/issue_1_300108/documents/mental_health_housing_problems_rights.pdf
34. *Getting a move on: addressing the housing and support needs of people with mental health needs: Briefing Paper 25* Sainsbury Centre for Mental Health, 2004. www.scmh.org.uk/pdfs/briefing+25.pdf
35. *The Department of Health Housing Learning and Improvement Network* Promotes new ideas and supports change. www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing
36. *The Housing and Support Partnership (H&SP)* is a housing and social care consultancy specialising in consultancy, training, development and research in housing where there is a connection with social care and health. www.housingandsupport.co.uk/about.html
37. MIND website page on housing and mental health. www.mind.org.uk/Information/Factsheets/Crisis+services/Housing+and+mental+health.htm#_ftnref2
38. National Social Inclusion Programme Housing Project for people with mental health needs. www.socialinclusion.org.uk/work_areas/index.php?subid=14. PSA Delivery Agreement 16: Increase the proportion of socially excluded adults in settled accommodation and employment, education or training Cabinet Office 2007. www.cabinetoffice.gov.uk/media/cabinetoffice/social_exclusion_task_force/assets/chronic_exclusion/psa_da_16.pdf

39. "Care Programme Approach (CPA) care coordinators should have a strong focus on ensuring that employment and housing needs are identified, considered and effectively met as part of individual care plans." PSA Delivery Agreement 16: Increase the proportion of socially excluded adults in settled accommodation and employment, education or training Cabinet Office, 2007. www.cabinetoffice.gov.uk/media/cabinetoffice/social_exclusion_task_force/assets/chronic_exclusion/psa_da_16.pdf

Sport , leisure and other universal services

40. Heywood, Middleton and Rochdale PCT have joined forces with Sport England and the Big Lottery Fund to regenerate sports facilities in the community as part of a prevention programme. It has also employed dedicated community workers to develop services the local population want to encourage healthy lifestyles and improve public health. www.hmrpct.nhs.uk
41. *At least five a week: evidence on the impact of physical activity and its relationship to health* Department of Health. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4080994
42. Open to all: Social inclusion and mental health awareness training for museums and galleries. www.socialinclusion.org.uk/work_areas/index.php?subid=109

Supporting the voluntary and community sector and wider partnerships

43. The *Compact* is an agreement between Government and the voluntary and community sector in England. It recognises shared values, principles and commitments and sets out guidelines for how both parties should work together. www.thecompact.org.uk. This website explores the **Compact** and the **five Codes of Practice** which underpin it.
44. *Volunteering for all*, a programme to tackle barriers in volunteering, so that people can have an equal opportunity to take part in voluntary activity. www.cabinetoffice.gov.uk/third_sector/volunteering/volunteering_for_all.aspx
45. *Communities in control: Real people, real power* Communities and Local Government, 2008. www.communities.gov.uk/publications/communities/communitiesincontrol
46. *Bromley by Bow Centre*. A partnership between private, public and voluntary sectors with a range of arts, garden and community projects in a well designed building, reflecting the ethnicity of the local community. There is also welfare benefits and employment advice available on the site. www.bbbc.org.uk

47. *Creating strong, safe and prosperous communities : Statutory Guidance* Communities and Local Government, 2008. www.communities.gov.uk

48. *Local Strategic Partnerships* are multi-agency partnerships that bring together the public, private, community and voluntary sectors. *Local Area Agreements* focus on a set of outcomes that are agreed by all as key priorities, such as PSA 16 to improve employment and housing outcomes for people in contact with secondary mental health services. People decide locally how to achieve outcomes by working together. www.neighbourhood.gov.uk/page.asp?id=531
49. *NICE public health guidance 9: Community engagement to improve health* (NICE, 2008). www.nice.org.uk/nicemedia/pdf/PH009Guidance.pdf
50. *Putting Partnerships into Practice* Learning from the Southwark experience of the partnership between Making Space and Southwark team for early intervention (STEP). www.mentalhealth.org.uk/our-work/all-adults/putting-partnerships-into-practice/?locale=en
51. National Development Team website on community inclusion. www.ndti.org.uk/what-we-do/work-themes/community-inclusion.aspx

Partnership working (general)

52. *Supporting people for better health: A guide to partnership* Department for Communities and Local Government , 2006. A guide that draws attention to key issues that need to be considered when setting up services designed to cross organisational boundaries - gives practice examples. www.dhcarenetworks.org.uk/_library/Supporting_people_for_better_health.pdf
53. *Making ends meet: Partnership* Audit Commission website giving information, examples and resources about partnership working. www.joint-reviews.gov.uk/money/partnerships/3-22.html#3-221
54. *Making partnerships work: Examples of good practice*, Department of Health, 2007. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072998
55. *Making partnerships work for patients, carers and service users: A strategic agreement between the Department of Health, the NHS the voluntary and community sector*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089515

SECTION 8

PREVENTION AND EARLY INTERVENTION

I GET HELP AND ADVICE
ABOUT HOW TO STAY WELL

SUPPORT AND HELP ARE
AVAILABLE TO ME AND MY
FAMILY AT AN EARLY STAGE IF
I BEGIN TO FEEL UNWELL OR
THINGS GO WRONG

WHAT HELPS TO MAKE
THIS HAPPEN?

Putting People First (HM Government, 2007)³ is clear that it expects public services to make 'a strategic shift towards early intervention and prevention' Prevention can be difficult to define because it embraces a wide continuum from intermediate care to supporting social inclusion (Hudson and Henwood, 2008)³² and Putting People First therefore offers a broad framework to help in planning the shift to prevention (Department of Health, 2008)³³.

It suggests three categories:

- Primary prevention/promoting wellbeing aimed at people who have little or no particular social care needs or symptoms
- Secondary prevention/early intervention that aims to identify people at risk and to halt or slow down any deterioration and actively seek to improve their situation
- Tertiary prevention aimed at minimizing disability or deterioration from established health conditions or complex social care needs.

Activity and interventions would need to be planned across all three of these categories to achieve wellbeing outcomes that would meet the needs of all.

Getting help early on can be crucial (Marshall et al, 2005)³⁵ as the first few years of severe mental ill health carry the highest risk of serious physical, social and legal harm.

As a citizen I have access to services that promote well being.

Examples of things that help with this:

- Partnerships (for example between leisure services, community development, supporting people programme, public health, community safety partnerships, housing, employers and employment services, fire service and community safety programmes, health and social care) that work with individuals and communities to provide:
 - Activities to address social isolation
 - Practical help, if I need it, to run my home and keep it safe

- Health living advice and support and access to local activities and opportunities that promote health
- Community safety initiatives that tackle some of the things locally that may be causing anxiety and stress (e.g fire safety, crime prevention)
- Housing choices and improvements
- Transport options.
- Investment in employee health.

I get help when I ask for it, even if I do not meet eligibility criteria.

I get help before a crisis occurs.

Examples of things that help with this:

- Pro-active work to identify people who could benefit from access to information and support e.g. older people at risk of developing mental health needs
- Information and support for people to access universal or voluntary sector services, such as 'navigator' services for signposting and self-help websites
- Community involvement projects that include funding for well being projects
- Support teams and programmes for those at risk of admission to hospital or to facilitate discharge from hospital.

SIGNPOSTS

Older people and mental health

1. Bradford and Airedale Older People's Health in Mind project. A programme to help older people with mental health needs and carers to improve their quality of life and stay independent and healthy. www.bradfordhealthinmind.nhs.uk
2. *Health in Mind Evaluation*, University of Bradford, 2008. www.bradfordhealthinmind.nhs.uk/NR/rdonlyres/716D7346-C3CE-44CD-8999-E06191D03DDF/65015/Bradford_HealthinMindEvaluation_FinalReport_300608.pdf
3. *Camden Networkers*. The Camden Networkers promote information on healthy living, mental health and social care issues to their peers. The project is also creating a database of specialist Mental Health Networkers who will undertake additional healthy living programmes, be informed of wider health prevention services available, act as sign-posters, and establish links/choices with older mental health users, mental health professionals, health agencies, community centres and associations through information sharing. www.dhcarenetworks.org.uk/Prevention/MakingItHappen/PracticeExamples/Access/?parent=3939&child=4004
4. Practicalities and possibilities. Information and stories. www.helensandersonassociates.co.uk/Reading_Room/Who/Older_People.html

Information and programmes

4. *Improving mental health care pathways*: National Mental Health Development Unit. This programme has an emphasis on prevention, early intervention and the support of personalised and socially inclusive care at all stages of a person's experience of mental distress. The programme works to demonstrate that it is age inclusive, gender and culturally sensitive. The focus in 2009/10 is to embed a recovery oriented approach. www.nmhd.org.uk/our-work/improving-mental-health-care-pathways/?keywords=Early+intervention
5. *A window of opportunity: A practical guide for developing early intervention in psychosis services: Briefing 23* The Sainsbury Centre for Mental Health, 2003. www.scmh.org.uk/pdfs/briefing+23.pdf
6. *Rethink website: information about early intervention*. www.rethink.org/about_mental_illness/early_intervention/index.html

7. *All stages diversion: a model for the future*, Sainsbury Centre for Mental Health, 2008. Describes a diversion model for people with mental health needs who enter, or are at risk of entering, the criminal justice system. www.scmh.org.uk/pdfs/all_stages_diversion_model.pdf

Resources for early intervention

8. *Social Care Reform Grant* – providing additional resources for public services to make the shift to prevention. Details in LC(DH)(2008) *Transforming adult social care*. www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_081934
9. *Care Services Efficiency Delivery* CSED helps councils to identify and develop more efficient ways of delivering adult social care. The programme is currently focusing on mental health, physical and learning disability needs. www.csed.csip.org.uk

Housing

10. Camden Extra Care Housing for people with mental health needs. www.dhcarenetworks.org.uk/Prevention/MakingItHappen/PracticeExamples/AvoidingInstitutionalism/?parent=3940&child=4019
11. Housing for older people. www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/Topics/browse/HousingOlderPeople/

Home support and mental health

12. East Sussex Mental Health Care Home Support Service. www.dhcarenetworks.org.uk/Prevention/MakingItHappen/PracticeExamples/Reablement/?parent=3945&child=4059
13. For other examples of prevention partnerships and projects see Prevention section on the DH Carenetworks website: www.dhcarenetworks.org.uk/Prevention/MakingItHappen/PracticeExamples/Access/

Health at work

14. *Health, Work and Well-being* is a Government-led initiative to protect and improve the health and well-being of working age people. www.workingforhealth.gov.uk
15. *Improving health and work: Changing lives: The Government's response to Dame Carol Black's review of the health of Britain's working age population*, The Stationery Office, 2008. www.workingforhealth.gov.uk/documents/improving-health-and-work-changing-lives.pdf

SECTION 9

LEADERSHIP FOR ALL

Leadership is another essential ingredient in implementing personalisation. Service user participation and leadership is a key factor in culture and service change. Good leaders can, for example, bring clarity, create the right culture, encourage enthusiasm, increase trust by being open, keep the momentum for change going, make connections, bring people together, explore opportunities and encourage innovation, creativity and leadership in others. They will also encourage learning from experience in a risk aware (rather than averse) culture and be active in developing a service user led culture. Good leadership and good leaders should be found everywhere – for example, people with mental health needs, carers, elected members, board members, senior managers and executive teams, local managers and staff, professionals from all areas, clinicians, care co-ordinators, advocates, community and faith groups and individual citizens.

Working to put people first: the strategy for the adult social care workforce (DH, 2009)⁴². Identifies leadership as one of the key priorities in bringing about the changes needed to deliver Putting People First. 'Leadership, effective management and commissioning skills are crucial to transforming adult social care. Leaders will need to work together across sectors (adults and children, social and health care, housing, leisure, transport) to drive change, supporting and involving local communities... User-led organisations and networks will grow and provide strong voices for people seeking support and using services to help change the way services are delivered'.

The Darzi Report on the future of the NHS also emphasises that *'Making change actually happen takes leadership. It is central to our expectations of the healthcare profession tomorrow'* (DH, 2008)⁴ and *Personal Health Budgets: First Steps* (DH, 2009)¹⁸ is clear that *'Strong leadership is crucial, including from the most senior levels of the lead PCT and its key partners. Only then will individuals be supported to make different and innovative choices that meet needs in the most appropriate way'.*

I can have a leadership role and there is good leadership wherever it is needed.

Examples of things that help with this:

- Expert by experience consultants and advisers with leadership roles in organisations
- User led organisations and networks that provide strong voices
- Leaders in key roles acting as role models in their behaviour and attitudes and keeping in regular direct contact with people who use services, carers and staff
- Leadership programmes for all (e.g. people with mental health needs, carers, elected members, board members, senior managers and executive teams, local managers and staff, professionals from all areas, clinicians, care co-ordinators, advocates, community groups and individual citizens), delivered in a variety of accessible ways
- Leadership training for people who use services and carers to help them develop confidence as equal partners with policy makers, commissioners and providers
- Mentoring and peer support programmes to encourage and support people in their leadership roles and bring about change
- Equality and diversity leadership
- Publicly visible support for leadership capacity development from government, local politicians, and executive boards and teams in health and social care organisations in the public and independent sector
- Developing the leadership role of commissioners (for example, training, mentoring, learning networks, information about good practice etc)
- Recognition of the need to support smaller organisations to access leadership and management courses
- A vigorous partnership approach (see *Partnership section 7*).

I CAN HAVE A LEADERSHIP
ROLE AND THERE IS GOOD
LEADERSHIP WHEREVER IT
IS NEEDED

WHAT HELPS TO MAKE
THIS HAPPEN?

(SEE ALSO WORKFORCE
AND ORGANISATION
DEVELOPMENT: SECTION 10)

- Clarity of vision for future development and direction (see *Creative Commissioning section 6*)
- Celebration of excellence in examples of good leadership, by internal rewards and acknowledgement, and external accreditation schemes
- Further research to demonstrate the link between good leadership and high quality health and social care, and to develop good models
- Leadership from government on arts and health, to create an environment in which it is legitimate and considered to be good practice to invest in arts and health.

SIGNPOSTS

Service users and carers as leaders

1. *The NHS Confederation* is an independent membership body for a range of NHS organisations and independent health care providers. The *NHS Confederation Mental Health Network* is for mental health and learning disability organisations and has a range of programmes and service groups. It has employed 2 *Service User Consultants*. www.nhsconfed.org/Networks/MentalHealth/AboutTheMentalHealthNetwork/Pages/AboutTheMHNetwork.aspx
2. *Leadership and empowerment in mental health* A programme for people who have used mental health services and wish to develop the skills and knowledge to lead change and make a contribution to service development Liverpool John Moores University. www.ljmu.ac.uk/courses/cpd/75219.htm
3. *Partners in Policymaking* A leadership course for disabled adults, carers and parents of disabled children. www.partnersinpolicymaking.co.uk. North West ROLE Group: contact: paul.greenwood@northwest.nhs.uk. Citizen Leaders programmes in the regions contact: [Tricia Nicoll tricia@tricianicoll.com](mailto:Tricia.Nicoll@tricianicoll.com)

Leadership development

4. *SCIE Social Care Leadership Development Programme* The Social Care Leadership Development Programme for senior leaders in children's and adults' social care in England, run in conjunction with Birmingham University, the Tavistock Centre and the Kings Fund. The first programme has been completed and a new, expanded programme will start in 2008. www.scie.org.uk/workforce/ldp.asp
5. *Leading Practice: A development programme for first line managers*. www.scie.org.uk/publications/guides/guide27/index.asp
6. RCN Clinical leadership programme. www.rcn.org.uk/development/practice/leadership
7. NHS Institute for Innovation and Improvement. This site has information about programmes and projects for developing leadership skills and capacity in the NHS. www.institute.nhs.uk/building_capability/general/leadership_home.html
8. A leadership development programme developed through an alliance of health and social care organisations in the NW. www.cflg.manchester.ac.uk/downloads/social_care_programme_brochure.pdf

Department of health commitment to leadership development

9. The Department of Health is:
 - working with the NHS Leadership Academy to see where there can be an increasing focus on joint leadership initiatives between health and social care
 - identifying 'workforce champions'
 - considering what needs to be done to develop future leaders and grow talent

See Chapter 3, *Leadership in: Working to put people first: The strategy for the adult social care workforce in England*, Department of Health, 2009. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098481

Research

10. SCIE Knowledge Review 17. *Developing Social Care: Service users driving culture change*, SCIE, 2007
Report on research of current literature and practice around service user involvement, the extent to which service user involvement has brought improvements to social work and social care and where the change has become established practice. www.scie.org.uk/publications/knowledgereviews/kr17.pdf
11. Employer led leadership and management training in the social care sector: A report by the National Care Forum, 2009. www.nationalcareforum.org.uk/content/NCF%20Social%20Care%20Leadership%20and%20Management%20Report.pdf

SECTION 10

WORKFORCE AND ORGANISATION DEVELOPMENT

Personalisation requires a fundamental culture shift across the whole system, new skills and knowledge, new roles and responsibilities and a different way of working, thinking and behaving. There are already some good building blocks for this change, such as the development of personal budgets, person-centred thinking and planning and recovery approaches, innovative commissioning and community projects, but much remains to be done. Skilled and experienced specialist professionals, who are valued and have a vital role in helping people recover and stay healthy, are facing the challenge of changes in their approaches and practice, and in overcoming barriers to making partnership right across the system work. At the same time professionals and staff in universal services (e.g. libraries, sports and leisure, culture, education, employment) have the challenge of making services accessible and available to all citizens and working in partnership to encourage innovation.

Some of the challenges are:

- Individual citizens are developing a different relationship with public services that empowers them to have more say and control
- For social workers there is a shift to be more focused on '*advocacy and brokerage rather than assessment and gatekeeping*' (DH, 2008)⁴⁰ and an increased drive to improve partnership working
- In the health service personal health budgets and the shift to more choice and control has significant implications
- As experts by experience become more commonplace in all areas their influence increases and brings about changes in attitude, relationships and approaches
- As former service users become employers of care staff (to varying degrees) or are involved in the development and running of user led organisations, there is a major shift in roles and relationships and in personal and skills development needs

THE PEOPLE WHO ARE PAID TO PROVIDE ME WITH SUPPORT AND TREATMENT HAVE THE RIGHT SKILLS AND APPROACH, AND ARE AVAILABLE WHEN I NEED THEM

WHAT HELPS TO MAKE THIS HAPPEN?

(SEE ALSO LEADERSHIP: SECTION 9)

- The growth of personal assistants raises issues and challenges, for example, about supply, training, qualifications and quality monitoring, isolation, risk, terms and conditions and career development
- Staff involved in commissioning and contracting will need to re-think current ways of operating to accommodate a personalised approach, with more effective and dynamic consultation and user involvement, and a diverse market with more micro commissioning
- Health, education, housing and social care providers have to address the challenge of flexibility in providing personal services through more individualised approaches and contracts
- Communities and community groups have a new challenge for inclusivity, innovation and leadership
- Senior and local managers have the challenge of inspiring, leading change and encouraging leadership in others throughout the system
- Board members and trustees, elected members, local authorities and local health authorities, regional government offices and national government need to embrace the full range and impact of these changes and provide clear leadership and action for change.

All of these changes have a system wide impact on workforce and organisation development and rely on good leadership to inspire and guide change.

I have a good and positive experience of people involved in my treatment and support.

Staff I come into contact with in organisations are helpful, treat me with respect and help me take control.

Examples of things that help with this:

- Active promotion of personalisation and training that inspires staff
- Good leadership that ensures staff are clear about their job and how it should be done and are supported to take calculated risks
- Removal of unnecessarily complicated bureaucratic systems and processes

- Staff that have been given the time, space and expert input to acquire the right skills and are themselves respected, valued and empowered
- Staff who have been encouraged see themselves as partners in better care and support
- Staff who are respected, encouraged, praised and properly rewarded when they get things right
- Staff with high expectations of what people can achieve and contribute
- Experts by experience employed in all areas to influence and inspire new ways of working
- Staff across the system who have terms of employment that are reasonable, legal and fair
- Staff and unions involved in the process of developing personal budgets and of associated training programmes
- Job satisfaction as a result of these approaches.

I can get all the different treatment, information, advice and support I need smoothly and easily, no matter how complex my needs and situation are.

People I rely on and respect for their specialist knowledge, skills and expertise are there for me when I need them

Examples of things that help with this:

- Clear terms of reference for partnership working and partnership arrangements that all concerned have been involved in drawing up
- Training, job descriptions, policies, systems and performance management overhauled and revitalised so that they reflect new roles and responsibilities and new ways of working
- Addressing fears of losing specialisation and professional identity by recognising people's specialist skills and expertise and giving time and space for people to use them but also

- Being clear about the need for willingness and openness to cross professional boundaries and act and collaborate beyond specialisms to solve problems together and achieve the right outcomes for people (rather than passing people around the system)
- Collaboration and partnership beyond health and social care
- Good information systems that can provide information and advice for all aspects of people's lives, and for people who may not be eligible for publicly funded support and services
- Investment in active development work with communities and community groups
- Central and local government leaders and policy makers willing to address differences in eligibility criteria, priorities, performance indicators, referral systems, professional and organizational cultures
- A positive approach to risk taking and risk management.

(For more information see Partnership section 7).

I am trusted to make good decisions.

People who are involved in giving treatment, information, advice and support and in commissioning and managing services are trusted to make good decisions.

Examples of things that help with this:

- Senior managers, boards and elected members who rise to the challenge of personalisation and support an organisational approach based on trust – of staff in their judgments and of citizens in their choices and decisions
- Leadership styles based on trust and collaboration that empower people and allow them to learn from mistakes
- Recognising and supporting professionals as leaders and innovators, not as a barrier to progress

- Supporting people to identify their own learning and training needs
- The development of a different, more open and trusting, relationship between central and local government, between managers and professionals and between professionals and individual citizens
- People who are involved in my treatment and support in health and social care services have the right approaches and skills
- People I come into contact with in the community as part of my support plan have the right attitudes and approaches.

Examples of things that help with this:

- Professional and work based skills training that builds on person-centred approaches, respect, flexibility, enabling and empowering and cultural competence
- Access to knowledge of new ways of working
- Shared practice networks that give people an opportunity to tap into ideas and information
- Organisation development programmes that encourage and support culture change
- Information and training that is available in different forms and at different times (e.g e-learning courses)
- Leadership from health and social care organisations in community development and positive promotion of inclusion
- Access to a structured programme of continuous development and support that builds on existing knowledge and expertise
- Service users and carers involved throughout the design, delivery and evaluation of all relevant education and training.

It is easy for me to find or purchase all the things I need in my personal support plan

Examples of things that help with this:

- Creative, outcomes based, commissioning and contracting (See *Creative Commissioning section 6*)
- Employing *Expert by Experience* Commissioners
- Excellent partnership working (See *Partnership section 7*)
- Good, accessible information (See *information section 2*).

SIGNPOSTS

Policy guidance

1. *Working to put people first: The strategy for the adult social care workforce in England*, Department of Health, 2009. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098481
2. *Options for Excellence: Building the Social Care Workforce of the Future*, DH/DfES, 2006. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139958

Training and consultancy

3. *Working to Recovery* offer training and consultancy to deliver recovery-based services. www.workingto_recovery.co.uk/Default.aspx?tabid=1128
4. City University scoping exercise for a mental health carer support curriculum. www.city.ac.uk/sonm/research/projects/Mental%20health%20and%20learning%20disabilities/alan%20simpson%201.html
5. An example of personalised e-learning can be found on: www.embrace-learning.co.uk
6. Training to support closer work between voluntary and statutory sectors CSIP esvsproject@gy mind.org.uk
7. *The ten essential shared capabilities: A framework for the whole of the mental health workforce*, Hope R, Department of Health 2004. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4087169

Research

8. *Personalisation of Health and Social Services: Leadership challenges and workforce development needs of the mental health voluntary sector in Leeds* Loul B, Crawshaw G, Volition 2008. www.volition.org.uk/documents/VolitionsummaryreportpersonalisationandworkforcedevSept08.pdf
9. Service user and carer led research. <http://hesas.glam.ac.uk/news/en/2009/apr/08/first-all-wales-mental-health-research-group-estab/>

Partnership working

10. Luton Centre of Excellence A resource with an integrated team of social care staff and Community Psychiatric Nurses offering a range of services and therapies, information and advice. www.dhcarenetworks.org.uk/Prevention/MakingItHappen/PracticeExamples/CommunitySupport/?parent=3942&child=4043

Recognition and Accreditation

11. *Practice development* is a person-centred framework that enables the development of creativity and innovation in practice. It facilitates practice that is leading edge and evidence based, and harbours a “bottom up” approach to improving care where any individual, regardless of their place in the organisation, can be instrumental in taking good ideas forward. The University of Leeds have an accreditation scheme. www.cdhpp.leeds.ac.uk/services/practice2.php
12. Recognition and reward for innovation www.hee.org.uk

Building capability

13. *Capabilities for Inclusive Practice*, CSIP/NSIP/DH, 2007 Builds on *The 10 Essential Shared Capabilities* to look at values, characteristics and skills needed in a workforce capable of delivering inclusive opportunities for people with mental health needs. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078095

Personal health budgets: understanding the implications for staff

14. Department of Health 2010 www.dhcarenetworks.org.uk/PHBLN/Topics/latest/Resource/?cid=7346

SECTION 11

STORIES AND PERSONAL ACCOUNTS

I HAVE OPPORTUNITIES
FOR SELF-HELP AND
TAKING CONTROL

I HAVE THE INFORMATION
I NEED TO FEEL EMPOWERED
AND MAKE CHOICES

WHAT HELPS TO MAKE
THIS HAPPEN?

Personal stories of how personalisation has made a positive difference in people's lives are very helpful in demonstrating what it means in practice.

The following websites have examples of personal accounts and stories:

- www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/MentalHealth/?parent=2737&child=5126
- www.in-control.org.uk/site/INCO/Templates/SectionHome.aspx?pageid=5&cc=GB
- www.dhcarenetworks.org.uk/Personalisation/Stories/index.cfm
- www.northamptonshire.gov.uk/en/councilservices/asc/pay/pb/Pages/pbdvd.aspx
- www.changeagentteam.org.uk/_library/Case%20Examples.doc
- www.supportplanning.org/MentalHealth/
- www.helensandersonassociates.co.uk/Reading_Room/Who/Older_People.html

SECTION 12

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3. *Putting People First: A shared vision and commitment to the transformation of adult social care* H M Government, 2007. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118
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SECTION 13

OUTCOMES AND QUALITY FRAMEWORK

1. HELPFUL, PERSON CENTRED SYSTEMS AND APPROACHES

The systems I use support me to make my own decisions. People listen to me with respect.

- I have a good experience when I first seek information, help or support
- People I come into contact with have the right approach and skills
- There is a planned and balanced approach to crisis and risk that I feel confident in and that does not undermine my sense of being in control of my life and recovery.

2. INFORMATION ADVICE, PERSONAL MOTIVATION AND SELF-HELP

I have opportunities for self-help and taking control. I have the information and advice I need to feel empowered and make choices.

- I have the opportunity to improve my knowledge of my mental health and self care options
- I can easily find the information I need about a wide range of things that are available in my locality
- There are people around who really want to help me fulfil my dreams and potential.

3. SUPPORT FOR MANAGING PERSONAL BUDGETS

All the things are in place that can help me comfortably manage the resources allocated to me, in a way that suits me.

- I get clear information that tells me what a personal budget is and the different ways of using it
- I get support to decide which is the best option for me
- I get help with support planning if I want it and this includes support with positive risk taking
- I get the support I need to turn the plan into reality
- I can use the money allocated to me in new and creative ways
- Information, support and training is available to help me be a good employer and understand what is involved as a personal budget holder
- I know where to go to get help and advice when I need it as an employer and budget holder and if problems arise.

4. SUPPORT FOR CARERS

I get the support I need to carry out my caring role, stay well and live my own life.

- I have easy access to information and advice to help and support me as a carer
- If I have to go through an assessment or self-assessment process it is easy to access and sensitive to my needs and wishes
- If I am eligible, assessment leads to the support I want in a way that suits me
- The contribution I make, and the informal family and friendship networks that support me and the person I care for, are recognised in assessment and support planning
- It is clear what can reasonably be expected from me as a caregiver and I have choices about how and when I provide care
- The processes I go through recognise that I can have a life of my own outside of my caring role
- I get help and support when I need it and at times of crisis
- I am given information about personal budgets
- I get the support I need, and that suits me, if I take on the management of a personal budget
- I am not put under pressure to take on management of a personal budget if I do not feel comfortable with this
- I can get breaks from caring when I need them and in a way that suits me
- I am not forced into financial hardship as a direct result of having a caring role
- I can continue my learning and development
- I am able to stay well as a carer
- As a child, I am protected from inappropriate caring and have the support I need to learn, thrive and have a positive childhood
- I am respected by professionals as an expert partner.

5. FAIR ACCESS AND EQUALITY

Opportunities are available to me without discrimination or unfairness.

- My cultural background and communication needs are taken into account in assessment and self assessment and support planning
- Enough time is given to me so that I can explain my needs properly, or for a family member or advocate to explain them on my behalf
- There is continuity in the contact I have with professionals and I don't have to keep explaining things over and over again
- There are no barriers to access and the quality of services I am offered is the same for me as for everyone else
- There is a good choice of opportunities that take account of my particular needs
- I get a fair choice and opportunities are available to me even though I live in a rural area.

6. CREATIVE COMMISSIONING

There is opportunity, choice and innovation in what is available to support me and give me a good quality of life.

- I can influence strategic planning of services as part of consultation or as a paid worker and as an equal partner
- The decisions and choices that I, and other people with mental health needs, make is captured and reflected in strategic planning
- I am supported to take control, live more independently and have more choice through well supported self care
- I have the opportunity to be in control of health resources for my recovery and well being
- There is a wide range of things available so that I can make real choices and barriers to access are removed
- I have an opportunity to choose a user led service or be involved in running one
- I can see that services that I and my peers report are not good, or not running in a appropriate style, are supported to change or are de-commissioned
- I can see that commissioners have listened to people reporting gaps in service provision – and these are planned for.

7. PARTNERSHIP

My needs are met in a way that is easy for me. I get the support I need to participate as a citizen and take advantage of the things available to all.

- I am an equal partner in any health or social care assessment process, and it looks at my whole life, not just at problems and times when I am unwell
- I have good information and real choices so that I can recover and live life the way I want to
- I can get the support I need to live where and how I want to
- I have the opportunity and support to develop my interests and learning and participate in cultural, creative, sports, leisure and community activity
- I am supported and encouraged to prepare for employment, find work and stay employed
- I can gain the qualifications, skills and training I need to improve my employability and help me progress my career
- I can influence strategic planning of services as part of consultation or as a paid adviser or commissioner.

8. PREVENTION AND EARLY INTERVENTION

I can get help and advice about how to stay well. Support and help are available to me at an early stage if I begin to feel unwell or things go wrong.

- As a citizen I have access to services that promote well being
- I get help when I ask for it, even if I do not meet eligibility criteria
- I get help before a crisis occurs.

9. GOOD LEADERSHIP

I can have a leadership role and there is good leadership wherever it is needed

- I can have a leadership role and there is good leadership wherever it is needed.

10. WORKFORCE AND ORGANISATION DEVELOPMENT

The people who are paid to provide me with support and treatment have the right skills and approach and are available when I need them.

- I have a good and positive experience of people involved in my treatment and support
- Staff I come into contact with in organisations are helpful, treat me with respect and help me take control
- I can get all the different treatment, information, advice and support I need smoothly and easily, no matter how complex my needs and situation are
- People I rely on and respect for their specialist knowledge, skills and expertise are there for me when I need them
- People who are involved in giving me treatment, information, advice and support and commissioning and managing services, are trusted to make good decisions
- People who are involved in my treatment and support in health and social care services have the right approach and skills
- People I come into contact with in the community as part of my support plan have the right attitudes and approaches
- It is easy for me to find or purchase all the things I need in my personal support plan.

