

**MHNE**  
Mental Health North East

**MHNE**  
Riverside House  
Unit 9 - 10  
Defender Court  
Sunderland Enterprise Park  
Sunderland  
SR5 3PE

Tel: 0191 549 6500  
Fax: 0191 549 8085

[www.mhne.co.uk](http://www.mhne.co.uk)

## Personalisation – chaos or empowerment?

The impact of personalisation, personal budgets and increased direct payments on voluntary sector mental health organisations in the north east of England

Project Report November 09



Social Care



**Millfield House  
Foundation**

## Contents:

<b>Section</b>	<b>Title</b>	<b>page</b>
1	This report	3
	Executive Summary	4
2	Some key concepts and terminology	9
3	The MHNE Personalisation Project - methodology and outputs	11
	a. The case study approach	14
	b. Other project outputs	16
4	Brief overview of personalisation in social care and the NHS	17
5	Personal budgets, direct payments and mental health	21
6	Project findings	23
	a. Personalisation in social care and the NHS in the north east – a snapshot	23
	b. Feedback from initial consultations	28
	c. Findings from the case studies	31
	I. Base line questionnaires	
	II. Case study group consultation	
7	Summary of project findings	36
8	Key recommendations	41
9	Appendices	
	A. Putting People First - key national milestones	44
	B. What can service providers do now?	46
	C. Organisational readiness checklist	47
	D. 'Are you ready' conference programme	48
	E. Selected reading and useful websites	49

## 2. This report

This report has been written at a critical time. General awareness of the so called 'personalisation agenda' has increased noticeably over the past year, most local authorities in the region have now held generic provider events, and some have now made public commitments to a timescale for the phased introduction of personal budgets between now and April 2011. Three PCTs in the region were identified over the summer as DH pilot sites for 'personal health budgets'.

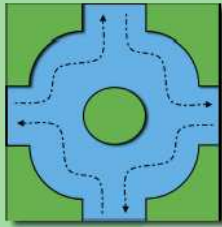
Some believe that the introduction of personalisation into the mental health system, with its emphasis on self directed support and direct payments, is potentially as revolutionary as the changes brought about in the early nineties by Care in the Community, and the closure of so many large asylums. The historical evidence suggests when personal budgets are introduced, 50% of people receiving them opt to keep existing services; 35% make some changes and 15% choose to access totally different sources of support.

Yet at the time of writing this report, very few voluntary sector mental health service providers in the north east have had any detailed discussions with commissioners about how the planned changes will affect them in practice. Service users and carers report similar problems in terms of accessing locally specific information, and a study by the Centre for Disability Research at Lancaster University recently found that 80% of health and social care service users still know little or nothing about personal budgets. Search local authorities' internet websites for 'personal budgets' or 'personalisation' and very variable results are found – whilst some do indeed offer links to useful advice and resources, others give no indication that potentially radical changes are taking place. Some make no reference to direct payments for mental health whatsoever.

Over the past year the MHNE Personalisation Project has worked to explore and clarify the key issues, risks and opportunities that face the sector as a direct consequence of 'Putting People First', the 'Transformation of Adult Social Care', and the resulting 'personalisation agenda. This report summarises this work.

Not surprisingly a huge vote of thanks is necessary – to MHNE member organisations, the MHNE Board, office staff, volunteers, service user and carer representatives, LA Transformation and personalisation leads, and the many colleagues locally and nationally who have shared their time, expertise, and energy in supporting the project, its aims and its author.

Steve Nash,  
Project Consultant  
[steve.nash.mhne@googlemail.com](mailto:steve.nash.mhne@googlemail.com)



**MHNE**  
Mental Health North East

**MHNE**  
Riverside House  
Unit 9 - 10  
Defender Court  
Sunderland Enterprise Park  
Sunderland  
SR5 3PE

Tel: 0191 549 6500  
Fax: 0191 549 8085

[www.mhne.co.uk](http://www.mhne.co.uk)

## **Personalisation – chaos or empowerment?**

### **The impact of personalisation, personal budgets and increased direct payments on voluntary sector mental health organisations in the north east of England**

*Executive Summary November 09*

#### ***The Mental Health North East Personalisation Project***

In November 08 MHNE began a Personalisation Project and the year's work culminated with a major regional conference on October 09. It was funded by a grant from the Millfield House Foundation with additional support from the Transforming Social Care programme at Government Office North East. Its main aims were to:

- *Look at the potential risks and benefits of the 'personalisation agenda' for voluntary sector mental health service providers, service users and carers in the north east*
- *Ensure stakeholders are informed about the changes and able to influence the way they are implemented locally*
- *Provide information and support to help the sector 'prepare for change' in commissioning and service delivery*

An initial period of consultation found a low level of awareness, knowledge and confidence about personalisation amongst service providers, service users and carers, and even amongst many statutory sector managers and commissioners.

Given national timescales and the realities of trying to cover the whole region, it was agreed the project would concentrate mainly on the changes taking place in

adult social care, and do this by using a case study approach, looking at the experiences and concerns of a small number of voluntary sector mental health providers as they prepared for new systems of funding and ways of working.

### ***A brief recent history of personalisation***

In 2007 the government published *Putting People first: A shared vision and commitment to the transformation of adult social care* – a ground-breaking concordat between central government, local government and the social care sector. This officially introduced the idea of a personalised adult social care system, where people have maximum choice and control over the services they receive. The government committed a £520 million ‘Social Reform Grant’ to assist councils in delivering this change between 2008 and 2011. Personalisation is one aspect of a wider package of reforms that include integrated working with the NHS, investment in prevention and early intervention and universal information and advice services for all citizens.

For many people – commissioners, managers, practitioners, service users and carers alike, personalisation will be most acutely realised by the new funding systems designed to enable self directed support. Personal budgets are a transparent sum allocated to anyone eligible for adult social care funding, depending on their assessed needs. The person may decide to continue to get support as they always have done, or they may opt to receive their personal budget as a direct payment, giving them greater flexibility and control to buy their own care and support. Direct payments in social care have been around since 1996, but are now expected to be used by more people. As an alternative, the personal budget could be allocated to a third party (for example a broker or service provider) on the person’s behalf. An individual budget is very similar to a personal budget but it includes money drawn from other funding sources in addition to adult social care.

#### **Personal health budgets**

The decision to pilot personal budgets in the NHS was announced in Lord Darzi’s review in 2008. It was argued that the potential benefits for those receiving social care should also be available for those receiving health care – not least because many people with complicated, long term needs use both health and social services. *‘Personal Health Budgets - First Steps’* was published in early 2009 and PCT pilots were announced later in the summer.

## ***Personalisation and mental health***

In many local authorities, numbers receiving social care funding for mental health problems are relatively small - most of the funding for mental health services sits within the NHS, in specialist mental health services. Department of Health figures for 2005 showed that a quarter of LAs in England were making no direct payments to people in lieu of mental health needs at all, and as a group, people with mental health problems have been low uptakers of direct payments. But between 2007 and 2008, the increase in direct payments to people for MH reasons exceeded that of any other care group; the total number of people in England with direct payments to support their MH needs grew from 50 in 2001 to 3373 in 2008.

The split between health and social care services funding is particularly unhelpful in mental health, where the importance of and interplay between social and health factors is well established. Where they have been available, people have used direct payments to maintain and improve their mental health in a variety of creative and successful ways.

## ***Personalisation in the North East***

- All NE Local Authorities are members of the In Control support and learning network
- Newcastle, Northumberland and Hartlepool Adult social care departments have opted for 'Total Transformation' by April 2011
- Hartlepool, Redcar and Cleveland, Middlesbrough and Stockton on Tees PCTS are piloting personal health budgets in the NHS
- Hartlepool and Stockton on Tees PCTs are to be part of a national evaluation of personal health budgets in the NHS
- Gateshead was one of 13 pilot sites for Individual Budgets

## ***Project Findings***

- Personalisation requires significant organisational development for statutory agencies, with the current emphasis being on major change in adult social care. Much of the focus to date seems to be on the cultural change and internal redesign required to support such a radically different way of working
- There are no examples yet of what happens when a whole locality or social/health care economy – or even an entire client group - has moved across to personal or individual budgets and increased direct payments

- Across the north east, currently less than 10% of people receiving adult social care funding receive this as a direct payment. People on direct payments for mental health reasons make up less than 10% of this figure. Few people who use mental health services know anyone who has a direct payment
- Paradoxically some people have not been able to get advice and help about direct payments when they have requested it from staff
- The numbers of people eligible for adult social care because of mental health needs differs markedly from area to area within the north east and nationally
- Traditional funding mechanism eg 'block contracts' will be significantly reduced. It is frequently stated that 'there will be losers'. This is extremely unsettling for voluntary sector providers. There are fears that the real driver for personalisation is reducing costs - and not improving quality
- Voluntary sector mental health providers – with one or two exceptions - do not yet have any specific, formal, local information about how the changes will affect them, when they will be introduced, or how things will work during and after the transition period
- Whilst there is in the sector positive awareness of and sign up to the fundamental principles of personalisation and self directed support (the destination), a host of questions and concerns remain about how to get there (the journey)
- The personalisation agenda offers opportunities for providers to rethink what they do and how they do it. Increased advice, signposting, support, brokerage and user led input is required and these are positive opportunities for the voluntary sector
- Local authority plans for these functions, and the way that 'markets' will be stimulated and developed, remain unclear. There are fears – and some evidence - that commissioners will turn to large established providers, and the private sector to assist them in implementing the personalisation agenda
- Many have started to take a proactive approach to make themselves more 'commissionable' in the future
- At a local level, and strategically via MHNE, the voluntary sector has much to contribute in terms of successfully implementing personalisation and in influencing positive outcomes for people who use mental health services.

- There is however a sense of frustration in the sector that providers do not feel more involved in designing this early but important and influential stage, and that opportunities to create solutions in partnership with commissioners are being missed

### ***Project Recommendations***

- a. If the national milestones are to be meaningfully achieved for the mental health voluntary sector in the north east, social care and health commissioners should now actively engage the sector, to develop a genuine partnership approach to meeting the challenges that exist
- b. The sector is now keen to address with commissioners and transformation leads the following issues:
  - a. Developing the voluntary sector mental health 'provider market'
  - b. Effective approaches to transitional arrangements
  - c. Sharing resources and expertise to co-create the systems and processes necessary for effective implementation eg
    - i. assuring quality of providers
    - ii. developing an accessible directory of services and supports for service users and carers
    - iii. supporting collaborative approaches and consortia amongst voluntary sector mental health agencies
    - iv. ensuring that the sector has access to appropriate business and change management advice and support
    - v. helping to ensure that service users and carers are aware of and prepared for the move to personal budgets
- c. This engagement needs to happen both at a strategic regional level (for example with the North East Regional Improvement and Efficiency Partnership) and within each locality, at LA and PCT level
- d. Adult social care directors should review the apparently wide variations in access to adult social care across the region by people with mental health problems, and work towards a more equitable approach
- e. MHNE should continue to support its members by prioritising personalisation. However the emphasis should now shift away from simply providing and gathering information to focus on supporting the above recommendations and facilitating the practical steps necessary to carry them out. The personalisation agenda offers a valuable opportunity for the sector to demonstrate its unique contribution to the region

## 2. Some key concepts and terminology

Even in the opening paragraphs above there are references to terms and concepts that may not yet be understood clearly by everyone reading this report. Below is an attempt to provide a quick and early guide to some of the key words and ideas that are central to this subject:

### **Personalisation**

A broad concept whereby public services are designed, delivered and responsive to the needs of individuals, as opposed to individuals having to fit into whatever service is available. It means starting with the individual as a person with strengths and preferences, who may have a network of support and resources, which includes family and friends. It applies to all of the public sector, eg education and housing, and not just health and social care

### **Self directed support**

Whereby individuals are encouraged and actively supported to be in control of the care resources and services they need and receive. This sense of being in control should run through the service user's experience, from the initial stages of (self) assessment through to having the information needed to make an informed choice, and being in charge of how care, support and interventions happen on a day to day basis. It can be seen as a system whereby citizens exercise their rights to the support that they need, as opposed to being passive recipients of care services provided on their behalf

### **Personal budgets**

If a person is potentially eligible for social care, there is an assessment process. A personal budget is the funding that is identified to meet that person's needs as a result of this assessment process. It is a transparent allocation of money that is identified to meet the person's needs, and it comes with the right to choose how this is managed and spent. People will be helped to use their personal budget to purchase support and other resources, in accordance with their care plan.

The support might come from social services, the private sector, voluntary or community groups, or families and friends.

**Local Authorities are expected to provide a personal budget for at least 30% of those eligible for social care funding, by April 2011.**

The person can decide how they want to receive their personal budget. For example they can carry on as they did before, and receive care or services directly – for example continue attending a day centre, or have personal care provided by the same agency. Or they can choose to have a direct payment (see below)

## **Direct payments**

At its most simple level, a direct payment means having the money allocated in a personal budget paid directly to the service user, so they have much more freedom and control about how this is then spent – provided it is still in keeping with the person’s agreed care plan. It is a means tested cash payment made in the place of regular social service provision to an individual who has been assessed as needing support.

It is also possible for a direct payment to be made via a third party, for example, a broker, or an agency, a trust, a carer or care manager. A further emerging model is that of the Individual Service Fund, where the money for a person is paid to the provider but specifically allocated to the individual, giving the person the opportunity to customise their own service. Direct payments do not affect entitlement to state benefits.

**All Local Authorities are expected to increase the number of people who receive their personal budgets as a direct payment.**

However, the key principle remains that they are not compulsory and no-one should feel pressurised to receive a direct payment.

## **Individual budgets**

Individual budgets were piloted in 13 local authorities in 2007 (the evaluation report was published in 2008) but are now being used by a much larger number of LAs. An IB sets an overall budget for a range of services, not just from social care, from which the individual may choose to receive as cash or services or a mixture of both. Currently, an IB can be made up of money from:

- Local authority adult social care
- integrated community equipment services
- Disabled Facilities Grants
- Supporting People for housing-related support
- Access to Work
- Independent Living Fund.

As with personal budgets, IBs can be received directly as a Direct Payment, via a third party, a trust or care manager.

**Individual budgets are best described as an additional option that all Local Authorities can now choose to implement (or not)**

NB Originally, the term personal budget only applied to social care funding, and individual budgets referred to this wider scheme. Now the terms are often (and confusingly) used interchangeably.

## Personal health budgets in the NHS

The formal introduction of personal *health* budgets by health service commissioners, began in early adopter PCTs in August 09, but is not expected to have widespread impact for another 2 – 3 years, and has not in itself been a key focus of this project to date.

### 3. The MHNE Personalisation Project, methodology and outputs

#### Key aims of the project

The MHNE Personalisation Project began in November 08 and the year's work culminated with a major regional conference on October 9<sup>th</sup> 09. It was funded by a grant from the Millfield House Foundation with additional support from the Transforming Social Care programme at Government Office North East.

Its main aims were to:

- *Look at the potential risks and benefits of the 'personalisation agenda' for voluntary sector providers, people who use mental health services, and their carers. (Including: individual budgets, direct payments and personal health budgets) across the North East region*
- *Ensure that voluntary sector mental health agencies, service users, and carers in the north east are informed about these changes and able to influence the way they are implemented locally*
- *Provide information and support that can enable the sector to 'prepare for change' in commissioning and contracting arrangements*
- *Share learning, produce explanatory materials, and hold a regional conference*

#### Project timescale and changes in adult social care

It was originally anticipated that by October 2009, Local Authorities would have made significantly more progress in implementing personalisation, especially in terms of changes to commissioning and contracting voluntary sector mental health services, than has been the case. Similarly, for the vast majority of service users and carers in the North East region who are eligible for social care funding, the concept of

personal budgets, and the opportunity to receive these as a direct payment, is still a rather theoretical and confusing concept. At the time of writing it is predicted that the next 6 – 18 months, leading up to April 2011, will be absolutely critical in terms of the practical and 'felt' introduction of personalisation, and the operational changes required to bring about the '*Transformation of Social Care*', of which personal budgets are a key part. Inevitably this time scale factor has had an important effect on the work of the project.

## Setting the scene

Following the production of a project initiation document in November 08 and the setting out of key deliverables, time was spent visiting voluntary sector mental health networks, service user and carer groups, speaking with key individuals locally and nationally, and doing some background reading.

The themes and perspectives initially captured were gathered and gleaned from 33 meetings, conversations with individuals, and events undertaken in the first four months. The approach was informal and action research based, with the findings providing a useful starting point on which to base further project work.

It was soon clear that:

- There was (and still is) a high degree of confusion amongst service users and carers, practitioners and managers in the mental health community, about what is happening, and how changes will be felt and experienced 'on the ground'
- There was (and still is) considerable scepticism about the government's reasons for making the changes, with some openly claiming that it is all about financial pressures and trying to reduce costs
- Local knowledge about the practical implications of 'the personalisation agenda' and its implementation, at commissioner and service provider, was (and to a large extent still is) very sketchy at best

In terms of the practical scope of the project it also quickly became evident that:

- Each Local Authority in the NE, whilst working to the national guidance set out in *Transforming Adult Social Care*, would be implementing personalisation in a different way according to local needs and processes
- The formal introduction of personal *health* budgets by health service commissioners would not begin in early adopter PCTs until August 09. At the beginning of the project it was not yet clear which NE PCTs would be selected to act as pilots of the personalisation approach in health care

It was also highly relevant to note that National MIND (with whom good links had been established at the outset) was already doing a piece of work that was very similar to the initial idea of the MHNE project, ie to undertake focus groups with service users, and to produce and publish a detailed literature search.

## **Agreeing a project focus**

It was therefore agreed with the MHNE Board that the most productive way of using the limited resources and time at the project's disposal would be to concentrate on the following areas:

- Local Authority implementation of the personalisation agenda (especially the introduction of personal budgets and increased direct payments) as a key aspect of '*Transforming Adult Social Care*'
- Looking at common issues and concerns arising from the impact of this on the mental health voluntary sector across the north east region
- Signposting MHNE members towards sources of information and support
- The production of specific advice and guidance for MHNE members that would enable them to manage the risks and make the most of the opportunities
- Exploring ways that the MHNE and its members can influence this potentially critical development strategically within and across the north east region

Given that it was not possible to work with all MHNE members individually, or even all of the 12 NE LAs, it was further agreed that the project would focus on a small number of individual voluntary sector provider organisations, in order to capture their experiences of preparing for personalisation, and developing ways to share the learning from this process with the wider MHNE membership. This has become known as 'the case study approach' and is described further below.

## **Project organisation and governance**

- The project was overseen on a day to day basis by the director of MHNE and supported by the MHNE office
- There was a Steering Group that functioned as a sub group of the MHNE board. This received project updates on a bi-monthly basis
- The project's main channels of communication and contact were carried out through local voluntary sector mental health networks, service user and carer groups, MHNE events, and the MHNE web portal (see also below)
- Where no such networks existed, attendance to LITs or ad hoc events were two alternatives that were considered

Achieving balance between being a visible resource for the sector on the one hand, and reflecting and reporting findings and producing materials (such as the website) on the other has been a key challenge in the time available.

### 3a Key output - the Case Study Approach

The core idea was to follow and record the experiences of a limited number of voluntary sector mental health agencies as they prepare to meet the changes and challenges imposed by the personalisation agenda, personal budgets and increased direct payments, as follows:

Key aims of the case study approach:

- Set the scene i.e. provide some context and background about the organisation
- Describe the organisation's experience of preparing for personalisation e.g. internal planning, relationships/dialogue with commissioners
- Clarify particular opportunities and risks for that organisation (as defined by them)
- Where possible, include accounts and concerns from a variety of related perspectives that may include some or all of the following:
  - The service provider's staff
  - People who use that service and their carers
  - Commissioners who contract with that specific service
  - Local personalisation/transformation leads
- Capture general themes and learning that can be shared and used to assist other organisations and influence implementation within and beyond the region
- Outputs to include web based and hard copy materials, conference presentations, and articles for publication (possibly!) as well as content for the project's final report

### Which organisations?

The intention was to try and identify a small but representative sample from across the North East region to reflect the range of different services provided, including organisational size, geographical location, and client group(s) served

Realistically it was anticipated that a maximum of 6 - 8 case studies could be created in the available time (see below), but this obviously limited the range of providers included. A list of participants is given below. Some studies would be more in depth (for example incorporating all of the perspectives listed above), and others less comprehensive.

In the first place some 15 organisations were identified in discussion with the MHNE Director. These were approached individually and at the same time some other organisations came forward expressing interest in taking part. This method was chosen over a more lengthy general invitation and application process in order to save time. Some organisations declined to participate as they felt it was not something they had the resources to prioritise. Eventually the following list of organisations agreed to take part:

<b>MHNE Personalisation Project Case Study Participants</b>	
The Artrium	Hartlepool
Crossroads Care	NE Region
The Dementia Care Partnership	Newcastle
Key Enterprises	North Tyneside and Newcastle
Mental Health Care	(Durham)
Mental Health Concern	(South Tyneside)
Mental Health Matters	(Darlington)
North Tyneside Art Studio	North Tyneside
Redcar and Cleveland MIND	Redcar and Cleveland MIND
Stockton International Family Centre	Stockton
Sunderland Counselling Services	Sunderland
Tyneside Women's Health Project	Gateshead and Newcastle

At the point of writing this report, the following activities have been undertaken as part of the case study approach:

- Initial invitation and sign up to the approach
- Design and completion of baseline questionnaire
- Initial meeting with participants and progress update
- Conference breakout session to be led by case study participants

A summary of findings to date from the case study approach are included in section 6c below.

### **Case Studies – stage one**

Write up and disseminate learning so far (ie from the baseline questionnaire and the case study group consultation) in the form of section 6 of this report.

### **Case Studies – stage two**

Further work on the case study approach is contingent on the continuation and agreed priorities and focus of the project for a second year.

### **3b Regional Conference 'Are you ready?'**

The regional conference held 9<sup>th</sup> October 2010 was designed to disseminate, support and further the work of the MHNE Personalisation Project and is written up separately in a companion document to this report. The outline programme can be found at Appendix D.

### **3c Website**

The MHNE web portal ([www.mhne.co.uk](http://www.mhne.co.uk)) now features a personalisation sub section that includes reference and links to useful documents and reports, grouped into service users and carers, providers and commissioners, mental health, evaluation and research, general policy and guidance sections.

### **3d Literature search**

It was agreed at an early stage that rather than spend a lot of time undertaking an academic style literature search, signposting to useful guidance, policy and evaluations would occur on the MHNE personalisation web portal. This was partly in recognition of the fact that MIND nationally were undertaking a similar exercise, now published (*Personalisation and mental health – a review of the evidence, MIND, 2009*).

The complete selected reading list to date is included at the end of this report, with web links, in Appendix E

### **3e Other project outputs**

#### **Project readiness checklist**

This was designed at an early stage as a guide for MHNE members (see Appendix C)

#### **Presentations at MHNE and other events**

The project lead has made a number of presentations about the project and its work at MHNE regional events, regional and local voluntary sector and mental health networks and events, and national conferences.

## Contacts database

An up to date database of personalisation leads, LA and NHS commissioners and other interested parties across all sectors in the region as well as key national contacts has been compiled.

### 4. Brief overview of Personalisation in social care and the NHS

In 2007 the government published *Putting People first: A shared vision and commitment to the transformation of adult social care* – a ground-breaking concordat between central government, local government and the social care sector. This officially introduced the idea of a personalised adult social care system, where people will have maximum choice and control over the services they receive. The government committed a £520 million 'Social Reform Grant' to assist councils in delivering this change between 2008 and 2011.

A number of key results are expected, of which personalisation is but one core element. These deliverables were set out in *Transforming Adult Social Care, Local Authority Circular (2009)*<sup>1</sup> and are summarised as follows:

- Integrated working with the NHS
- Commissioning Strategies, which maximise choice and control whilst balancing investment in prevention and early intervention.
- Universal information and advice services for all citizens
- Proportionate social care assessments processes
- Person centred planning and self-directed support to become mainstream activities with personal budgets which maximise choice and control
- Mechanisms to involve family members and other carers
- A framework which ensures people can exercise choice and control with advocacy and brokerage linked to the building of user-led organisations
- Appropriate safeguarding arrangements
- Effective quality assurance and benchmarking arrangements

These need to be supported with local market development, a workforce strategy and an approach, which demonstrates effective use of resources, including the delivery of 3% efficiencies year-on-year.

The milestones and timescales for bringing about the Transformation of Adult Social Care were set out in a Putting People First paper *Progress*

*Measures for the delivery of transforming adult social care issues* published in October 09 (see Appendix A)

This transformation is essentially a shift from a care management approach to one of self directed support - or from managing to enabling, as it has been described. This is a comprehensive process but for many people – commissioners, managers, practitioners, and clients and carers alike, both within the social care system and the systems of its partners such as the voluntary sector, increased personalisation will be most acutely felt by the introduction (or extension) of the new funding systems and mechanisms that are designed to enable greater choice and higher quality, most especially personal and individual budgets, and direct payments.

Direct payments first became available to disabled adults of working age in England as a result of the *Community Care (Direct Payments) Act 1996*, and have since been extended to other groups. The popularity and success of direct payments (with those people who have used them) has stimulated much of the thinking around individual and personal budgets. As of March 2007, 54,000 people (including parents caring for disabled children and young carers) used direct payments across England. Historically, people with mental health needs have been low up takers of direct payments (*A Voice and a Choice, Rita K Brewis, In Control, 2007*).

## **Future funding of social care**

In 2009 the government began a consultation on the future funding of social care with the publication of the Green Paper *Shaping the future of care together*, which sets out proposals to reform the social care system in England. It is beyond the scope of this report to cover this development in detail; however it is important to refer to the consultation and the pressures on the social care system that have prompted it – the increasing elderly population and the increased demand for social care that will result from this - the so called 'demographic time bomb'. This is because it is anticipated that a more personalised adult social system will also be a more efficient system.

## **Personalisation in the NHS**

The decision to pilot personal budgets in the NHS was first announced in Lord Darzi's review in 2008 (*High Quality Care for All, DH*). This followed some years of lobbying by various groups (including service users), who argued that the potential benefits for those receiving social care should also be available for those receiving health care – not least because many people with complicated, multiple and long term needs use both health and social services, and it was illogical to not to try and develop similar approaches to funding, choice and quality in both health and social care.

The initial thinking was set out in '*Personal Health Budgets - First Steps*' (DH 2009) and PCT pilots were announced in summer 2009. There are three in the north east – see section 6a below.

Some commentators (e.g. Professor Peter Beresford, who supports the philosophy of personalisation but questions how personal budgets can work in NHS, *The Guardian newspaper 16<sup>th</sup> April 2008*; and Karen Jennings, Head of Health, Unison, also in *The Guardian, 16<sup>th</sup> January 2009*) have raised serious concerns about the application of personal budgets to the NHS, where unlike social care, services are universal and free at the point of delivery.

It is true to say that many questions remain about how '**personal health budgets**' will work in practice, although technically it is already possible for NHS patients to receive direct funding for their health care via a payment to a third party such as a trust set up for that purpose. It is intended that the PCT pilots will road test the principles and work through the challenges that exist, including the potential use of direct payments in the NHS. At the same time, the DH is keen to stress that any PCT can begin to experiment with the use of personal health budgets – ie they do not have to be part of the formal pilot process to do this.

## **In Control**

In Control [www.in-control.org.uk](http://www.in-control.org.uk) is a social enterprise that was set up to transform the current social care system into a system of Self-Directed Support.

Its mission is now to create a new welfare system in which everyone is in control of their lives as full citizens. It works at an international level, and in England it works very closely with the Department of Health on the development of the personalisation agenda in social and health care.

Individual councils, and primary care trusts pay an annual fee to be members of the In Control and Staying in Control support programmes and in return they are able to participate in a variety of learning and organisational development activities to assist them in the implementation of the personalisation agenda.

## **The In Control 'model' of self-directed support**

Much attention is understandably focused on the introduction of personal budgets and individual budgets and the planned expansion of direct payments in social care.

But it is essential to bear in mind that these steps are only meaningful if they are implemented as components of a comprehensive self directed

support process. This model has been defined by **In Control** and forms the basis of the way personalisation is being introduced across the country.

The model is summarised in the table below. It is implicit that the person and their carer/s will be provided with all of the information and support they need to understand and confidently carry out each stage of the process, by informed and facilitative staff.

### The seven step In Control model:

<b>1) Set personalised budget</b>	The person is supported to carry out a self assessment. This enables them to find out how much funding they will be entitled to. (This could in the form of a <b>personal budget</b> or an <b>individual budget</b> )
<b>2) Plan support</b>	The person, and their care manager, family, or independent broker, works out how to best use that money to meet their needs in a way that suits them best
<b>3) Agree plan</b>	The person checks out their assessment and support plan with the local authority or any other funding provider
<b>4) Manage personalised budget</b>	The person decides on the best way to manage their personalised budget – manage it themselves (for example via a <b>direct payment</b> ): have a representative; set up a trust; pay an independent broker; use the care manager or direct the service provider
<b>5) Organise support</b>	The person is supported to organise the housing, help, equipment or other kinds of things they want.
<b>6) Live life</b>	The person uses that support in a flexible way with as few restrictions as possible, to live a full life with family and friends in the community
<b>7) Review and learn</b>	The person along with care manager checks how things are going and makes changes if needed

## 5. Personal budgets, direct payments and mental health

The bullet points below are an attempt to summarise the key points in the existing literature on this subject. All of the references are listed in Appendix E with web links.

- Direct payments have historically tended to be used much less by people with mental health problems than other client groups
- The reasons for this are felt to be complex – and to some extent attributed to the attitudes of professionals and commissioners (e.g. lack of awareness and confidence, myths about mental illness)
- Also, users of mental health services are concerned about taking on something that they fear will result in increased stress, or that they will not be able to manage when they are unwell
- In many local authorities, the number of people receiving social care funding for mental health problems is relatively small. Department of Health figures for 2005 showed that a quarter of LAs in England were making no direct payments to people in lieu of mental health needs at all (*Direct payments for people with mental health problems: A guide to action, DH NIMHE 2006*)
- Between 2007 and 2008, the increase in Direct Payments to people for MH reasons exceeded that of any other care group; the total number of people in England with Direct Payments to support their MH needs has grown from 50 in 2001 to 3373 in 2008 (*CSIP statistics quoted in Personalisation, a review of the evidence, MIND, 2009*)
- Most of the funding for mental health services sits within the NHS, in specialist, secondary mental health services
- The split between health and social care services funding is particularly unhelpful in mental health, where the importance of and interplay between both social and health factors is well established
- The 2005 report on *Direct Payments and Mental Health (New Directions)* Joseph Rowntree Foundation, recommended that:
  1. There should be streamlined and straightforward processes for people with mental health problems to have their eligibility for social care assessed
  2. Accurate and accessible information should be available to staff as well as to service users
  3. Mental health advocacy and support to encourage take up is essential
  4. The process needs to fit with the Care Programme Approach

5. Increasing the take up from black and other ethnic minority groups requires a specific approach, which the voluntary sector is well placed to deliver
  6. Significant cultural change in organisations and inspired leadership is required
- The recently published literature review by MIND, *Personalisation in Mental Health, 2009*, reiterates some of the above points but also adds that:
    1. Some general barriers apply including lack of awareness of direct payments by care coordinators, risk aversion and protectionism, especially in relation to safeguarding and vulnerable groups, perceived lack of resources, service led assessments, and concerns over the capacity to consent to a direct payment.
    2. In addition there are some specific barriers in the mental health field: difficulty in deciding which are health and which are social care needs, eligibility issues where needs are fluctuating, the role of care coordinators as gatekeepers, and specific concerns about risk – for example insight
  - There are concerns that an increase in the uptake of direct payments in mental health will lead to a reduction in the direct provision of drop ins and ‘building based’ day services that some people in the mental health system currently depend upon for any sort of social interaction, with a consequent increase in social isolation for some service users
  - The HASCAS national pilot of direct payments in mental health (2001 to 2003), found that approximately half of all direct payment recipients employed a personal assistant (PA) to provide social and personal support – including assisting them with daily activities (shopping, cooking, cleaning), helping them access community and leisure facilities, or providing respite and night sits. DPs were also used for transport, education, short breaks, arts activities and accessing mainstream leisure services (*Spandler and Vick, 2004; 2006, quoted in Personalisation in mental health, a review of the evidence, MIND, 2009*)
  - Where it has been tried the evidence is that it has worked well – people who use mental health services report increased satisfaction and improved self esteem (*ref. Evaluation of the Individual Budgets Pilot Programme, Challis et al, 2008; Direct Payments, Independent Living and Mental Health, HASCAS, Spandler and Vick, 2002*)
  - The general consensus is however that this approach has yet to be fully tested – especially over time - by large numbers of people with mental health problems

## 6. Project findings

### 6a Personalisation in social care and the NHS in the North East – a snapshot

#### A regional perspective

The wide range of different personalisation pilots, programmes and initiatives currently in place across the north east, means that it is difficult, especially from a mental health voluntary sector perspective, to describe any consistent trends across the region as a whole – everywhere is different.

The Association of North East Councils' Efficiency and Improvement Partnership oversees the Joint Improvement Partnership and this in turn has identified personalisation as one of five priorities for the region. There is a dedicated work stream and programme board to support its implementation, especially in terms of the degree of change and reorganisation that adult social care services are undertaking. A State of the Region report was published in October 2008 (<http://www.northeastiep.gov.uk/adult/projects.htm>) which found that there was strong strategic direction and leadership across the north east as a whole, and that the region was generally on track when compared with other parts of the country. However, at the level of local implementation, more collaboration and consistency between and across north east local authorities was felt to be possible.

Perhaps inevitably and unavoidably, each area is developing its own implementation plan for personal budgets and increasing direct payments based on different timescales and different priority groups, within the national timescale of April 2011. Mental health trusts, voluntary sector providers, and user and carer networks alike operate across more than one local authority; individuals may access care and support across local authority boundaries, and it requires quite a determined effort to stay abreast of who is doing what and where.

This picture is further complicated when the piloting of personal health budgets in (some) PCTs is factored in. Access to a personal health budget promises to be very significant for people who use mental health services, because the majority of the funding and commissioning of MH services comes from the NHS (via PCTs), far more than is funded or commissioned by local authorities. A change in law was required in 2009 so that PCTs (initially official DH pilot sites only) can experiment with using health care funding for direct payments.

The table below lists membership of different programmes that the project has been able to establish to date:

<b>Programme or initiative</b>	<b>Participating LAs</b>	<b>Participating PCTs</b>	<b>Client group focus (where known/applicable)</b>
In Control	All 12 NE LAs are paid up members. Three - Northumberland, Newcastle and Hartlepool - are 'super members' committed to 'total transformation' of adult social care	<i>(In control is a LA focused programme – PCT partners can be members via Staying in Control – see below)</i>	
Staying in Control (looking at personal health budgets)	<i>(Staying in control PCTs work closely with their partner LAs on this agenda)</i>	Redcar and Cleveland  Stockton- on Tees Teaching  Hartlepool	Dementia  Long term conditions and mental health
DH Individual Budgets Pilots	Gateshead LA (06/08)		
DH Personal health budgets pilot sites*		Middlesbrough and Redcar & Cleveland	Chronic obstructive pulmonary disease
		Stockton-on-Tees Teaching	NHS continuing healthcare; long term conditions (chronic obstructive disease, coeliac, motor neurone disease)
		Hartlepool	NHS continuing healthcare; long term conditions
DH study to examine benefits of personal health budgets		Hartlepool and Stockton on Tees PCTs jointly	

\*PCTs do not formally have to become pilots in order to begin experimenting with personal health budgets, as the pilot sites will be sharing early learning as it emerges, and the learning from social care is already available

NB In addition to the above, local authorities across the north east have been involved in a number of different pilots historically, stretching back to 2003, when Gateshead was one of the initial In Control pilot sites

## Individual budgets in the north east

As explained in section 2, the term 'individual budgets' usually refers to a particular type of personal budget that includes funding from other sources in addition to adult social care. Despite the national pilot, and an extensive and broadly positive evaluation, a number of concerns remain about the legal framework that supports this type of budget and as a consequence local authorities in the north east are approaching implementation in a variety of ways, as demonstrated in the table below:

<b>NE Local Authority plans to implement individual budgets (August 09)</b>	
Darlington	Unable to say
Durham	Yes but no definite date yet
Gateshead	Using PBs rather than IBs
Hartlepool	Using IBs; 20% received as DP
Middlesbrough	No comment given
Newcastle upon Tyne	Phasing in from Sept 09
North Tyneside	Yes, moving towards
Northumberland	No comment given
Redcar and Cleveland	Yes, currently testing
South Tyneside	All new offered IB from 04/10
Stockton on Tees	Planning to do so
Sunderland	Planning to at some stage

## People receiving adult social care and direct payments in the north east for mental health reasons

Having established that only annually updated figures were available nationally, LA Transformation leads were approached for current figures as follows:

- The total number of people receiving adult social care funding
- The total number of people receiving this for MH reasons
- Total number of adults receiving DPs and IBs
- Total number of adults receiving DPs and IBs for MH reasons

Whilst colleagues were very helpful in providing this information, a number of unintended variables became apparent. For example, some did not initially include over 65s, or carers; also the total over a year is higher than the total on a given date, as an individual may receive a 'one off' direct payment on more than one occasion; calendar year is different from tax year and so on. Despite repeated attempts to ensure consistency, this proved extremely difficult to assure.

Even bearing this caveat in mind, the wide variance from one area to another, especially in terms of the level of investment in adult mental health by different authorities, raises interesting and important questions. The phrase 'post code lottery' may or may not be applicable. It has however been beyond the scope of this project to explore this

further, but it would appear that a person is much more likely to receive social care funding for a mental health problem in some parts of the region than they are in others, let alone a direct payment.

Please see diagram below.

NB A regularly updated table showing the number of people on personal health budgets in each LA across the country is posted by In Control:

<http://www.in-control.org.uk/site/INCO/Templates/GeneralWide.aspx?pageid=691&cc=GB>

Local Authority area	LA Pop (1,000s) 2008	Total adults with social care funding 2008	Adults receiving for MH reasons 2008	% total pop receiving social care for MH reasons 2008	% of total on social care receiving for MH reasons	Notes re total figure	Total adults on DPs and IBs 2008	Adults on DPs or IBs for MH reasons 2008	Adults on DPs for MH reasons 2006
Darlington	100,000	3860	496	0.50%	12.85%	<i>includes dementia</i>	145	5	3
Durham	505,000	10,704	518	0.10%	4.84%		784	172	6
Gateshead	191,000	7500	679	0.36%	9.05%		350	37	16
Hartlepool	91,000	2826	347	0.38%	12.28%	<i>includes all over 18s</i>	1286	69	3
Middlesbrough	139,000	2942	768	0.55%	26.10%		427	42	9
Newcastle upon Tyne	272,000	7352	1618	0.59%	22.01%	<i>includes res care</i>	455	39	7
North Tyneside	196,000	5576	376	0.19%	6.74%		275	15	5
Northumberland	311,000	8602	2724	0.88%	31.67%	<i>over the year 08/09</i>	673	110	0
Redcar and Cleveland	139,000	6102	1013	0.73%	16.60%		397	28	4
South Tyneside	151,000	5000	250	0.17%	5.00%		400	44	7
Stockton on Tees	190,000	5390	911	0.48%	16.90%		329	32	7
Sunderland	280,000	6911	795	0.28%	11.50%	<i>Not res/nurse care or carers</i>	532	30	2
<b>Totals:</b>	<b>2,565,000</b>	<b>72765</b>	<b>10495</b>				<b>6053</b>	<b>623</b>	<b>69</b>

### NE Local Authorities: People receiving adult social care funding, direct payments and individual budgets for mental health reasons

## 6b Feedback from consultations undertaken

An initial series of 33 meetings and conversations was undertaken with stakeholder networks, groups and with key individuals, mostly, but not exclusively within the region. The majority of these took place within the first six months of the project.

It is important to point out that a greater number of consultations and conversations took place in the northern half of the region. This results from the fact that over the past ten years (and more in some cases) several voluntary sector mental health networks have been established in the Tyneside, and Northumberland areas, leading to a number of collaborative approaches and consortia. This level of development is less evident in the south of the region.

A similar picture exists in terms of mental health service user and carer groups and networks. From a consultation perspective, it was more straightforward to access the views of a range of agencies and individuals in the north of the region via the regular mental health forums that are in place. The timescale of the project meant that there was generally not the capacity to visit individual groups or organisations.

Groups consulted frequently comprised of very mixed perspectives – including managers, practitioners, service users, carers, and staff from statutory services. The key themes from these initial meetings were summarised in section 3 above and were used to inform the overall project methodology as described in that section

Given the nature of MHNE's membership, much of the feedback was focused on organisational/provider issues – see SWOT analysis below:

## Voluntary sector perspectives – initial consultations November 08 – March 09

Strengths	Weaknesses
<ul style="list-style-type: none"> <li>• The values and philosophy of personalisation especially self directed support are what we should be providing and how we should be working</li> <li>• Personalisation will help to drive improvement and increase quality – as we will have to get better at meeting service users expressed needs</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of information across the board</li> <li>• Lack of information for providers</li> <li>• Not sure who to go to locally for specific advice</li> <li>• Feels imposed, not much sense of partnership approach so far</li> <li>• Lack of dialogue or communication with funders</li> <li>• Where DPs are in place = more admin but no real change for individual</li> <li>• Different models in different LAs</li> <li>• Will it happen? Many senior staff are doubtful</li> </ul>
Opportunities	Threats
<ul style="list-style-type: none"> <li>• It's a chance for us to review what we do and how we do it</li> <li>• Consult with clients and find out what they really want from us</li> <li>• The potential to offer new services including brokerage, advice, support, signposting; also training and employment of personal assistants</li> <li>• Start working more to an outcomes focus</li> <li>• Evidence locally that advocacy increases uptake by people from BOEM service users</li> <li>• Tenders for new services to support personalisation as above</li> <li>• Possibility that we could help commissioners find answers to some of their questions</li> <li>• Collaboration with other providers</li> </ul>	<ul style="list-style-type: none"> <li>• Some providers already receiving shorter term contracts – has negative impact on grant applications</li> <li>• Not clear if/when we will block contracts</li> <li>• Anxiety about transitional arrangements</li> <li>• Increased admin costs will increase our unit costs - less competitive</li> <li>• How we can sustain a service if funding taken elsewhere via DPs</li> <li>• Harder for providers in rural areas where there is less choice anyway</li> <li>• Pressure on small agencies - no capacity for admin and OD required</li> <li>• Contracts for the new services will go to private sector – three NE LAs already contract out some DP related support services to A4E</li> <li>• Private sector don't refer on as it means they lose income</li> <li>• All the support, brokerage and agency arrangements will end up costing more</li> <li>• There will be losers</li> <li>• This is not really about improving services – it's all about reducing costs</li> </ul>

## **Initial consultations - service user and carer perspectives November 08 – March 09**

A small number of consultations were undertaken with service user and carer groups. Representatives of people with mental health problems, and sometimes carers, were almost always present at the voluntary and community sector networks and groups referred to above. Initial feedback from service users and carers included:

- Widespread confusion and uncertainty about personalisation and what it means
- Do not have the information needed to understand personal budgets and direct payments
- Some would like to know more but feel that their key worker and other professionals are not knowledgeable enough
- Not being offered an assessment despite requesting one
- Concerns about the future of existing services and reduced choice
- Scepticism about the governments true intentions – it's all about money and privatisation
- (Understandable) tendency to focus on direct payments
- Many questions about eligibility and how money could be spent
- Fear of having to manage additional stress, as service user and/or as carer
- Concerns about what happens if client and carer/family disagree about how to spend a direct payment
- Who decides what is appropriate?
- Fear about the challenges and potential risks of becoming an employer of a personal assistant
- Absence of positive real life examples locally; generic examples and even positive stories from other parts of the country do not have a great deal of meaning or even credence
- There is some local evidence (particularly with BAME service users) that uptake is facilitated and increased by advocates and community workers from the voluntary sector

## 6c Initial findings from the case studies

At the time of writing this report, eleven of the twelve case study participants had completed an initial base line questionnaire. Nine subsequently were represented at a consultation meeting held in September 09. The following key themes and issues in the table below were captured as a result of the baseline questionnaires completed between June and August 2009:

<b>Current commissioning arrangements and funding</b>	
Who commissions or funds your service/organisation?	Across the group there are block contracts with LAs and PCTs, Spot Contracts, and various other grants, mainly via SLAs with the funder, although some arrangements directly with individuals. Several providers have multiple contracts with a range of funders and grant making bodies
What is the period covered and review date of your current contract?	One is being reviewed this autumn, most at the end of this financial year; some have a range of review dates due to multiple funding sources; some current SLAs have no specified review date
Do you currently have any service users who have direct payments? If so, how many?	6 clients in total. 3 clients use DPs to attend one of the services. In another one client uses a DP to pay a carer to help him attend. Some services do not know if clients are on DPs as they are not currently required to access the service Total attendees across all participants = 1000 plus
Is any of your current income derived from direct payments by service users?	Only one of the eleven providers currently has any income from DPs
<b>Implementation of personalisation locally</b>	
Please describe any information or advice received from commissioners about personal budgets	In June 2009 4 organisations had attended generic events organised by their LA. Others had received no information although one of these had requested it. No specific advice yet available to any of the participants
Have you been given a timescale for the implementation of any new commissioning arrangements locally?	9 out of 11 organisations not had a timescale in June One given Mar 2011 For another this is not applicable  One of providers has proactively suggested a timescale to commissioners
What sort of help and advice would you like from commissioners?	In June 09 only one of the participants felt they were getting any helpful info from commissioners, but staff were still feeling insecure.  Clarity around timescales, ultimate destination and transitional arrangements is required. Which services might be seen as essential or a basic entitlement and remain block funded? How will it work if some are paying via DPs and others receive 'free' services?  Access to a project team that could offer specific support and advice would be ideal. Better help and information for our members (service users and carers)  We need clarification about preferred provider's lists, but nothing to date. How do we know if care managers will promote our service to their clients?

	<p>We sit on the local personalisation board but still don't know how we move into the 'market place' and 'sell' the services that we provide free now to whoever needs/wants them</p> <p>I have been to more meetings about this than n anything else ever but still don't know if or how it is going to really affect us</p>
<b>Risks and opportunities</b>	
<p>What are your <u>concerns</u> about the way that personalisation and increased direct payments could affect your service/organisation?</p>	<p>Contracts will be reduced  LA will still control the money and thus how often people can attend  How can we achieve full cost recovery?  Will providers 'chase the money'?  Perverse incentives – provider loses income if person improves and leaves  Changes in every aspect of organisation – finance, HR, training, marketing, staff contracts, relationships with clients  More intensive publicity and promotion  Cashflow and predictability  Increased financial complexity  Perceptions of clients who are on DPs vs those who are not  Shift from a 'free' service to one you have to pay for  Managing a new set of attendees – PAs and paid carers  It could end up being an administrative exercise  More meetings, more time promoting what we do  Private sector and fully commissioned services will have the advantage as they are used to charging for what they do</p>
<p>What are the <u>opportunities</u> you see for your service/organisation as a result of personalisation and increased direct payments?</p>	<p>An increased focus on outcomes and meeting the expressed needs of clients  Those who want to can attend more often – at the moment they have to diversify  New business – more flexibility in what we offer. This could be very positive – at the moment our hands are tied by SLAs  Ability to increase membership and take self referrals from other areas  Will change the culture positively – people will understand the cost of activities and be more involved/responsible  The ability to sell our services directly to clients  Service improvement through personalisation of shared services  Potential for service development, project/activity focus  Carer specific budgets  Reduced focus on building based services</p>
<b>Risks and opportunities for your clients/members</b>	
<p>What are your <u>concerns</u> about the way that personalisation and increased direct payments could the people who use your service/organisation?</p>	<p>Not everyone is/will be eligible for social care – how will this affect the support they receive?  Will those with DPs and IBs benefit from MORE choice while others get less?  Lack of understanding of the system and how it will work amongst staff and clients  Increased stress and anxiety for some  Pressure to deal with increased financial responsibility  Personalisation/direct payments – not for everyone  Safeguarding issues  The money PB or DP may not be enough  If someone needs more help with eating does this mean their unit costs are higher?</p>
<p>What are the <u>opportunities</u> you see for the people who use your service/organisation as a result of personalisation and increased direct</p>	<p>Real choice and involvement  More say and influence – could be a radical shift  More flexibility  Greater awareness of cost of activities and resources  Shift of endemic power imbalances in MH  More independence</p>

payments?	Increased self esteem
<b>Readiness of organisation/service for personalisation including increased direct payments</b>	
What progress have you been able to make in calculating unit costs for the service/s you provide?	7 out of 11 participants feel that they have been able to start addressing this, using a variety of approaches: Market research across the NE including private sector Individual daily rates already applied Establishing a membership model with various levels Full financial cost analysis undertaken 07/08 Currently being explored with our finance department Organisational restructure is the first step We have good figures for all running costs
What other steps (if any) have you been able to make in order to prepare for the impact of personalisation and increased direct payments	Set up a new integrated database system Moving towards a three year plan to adopt a fully personalised model Set up a Personalisation working party across the organisation Review of business opportunities and risks Looking at information from similar providers involved in any of the national pilots Making sure we cascade information to all staff; looking at staff training required Involving service users in our decision making – consulting with users and carers Signed up to national initiatives eg In Control and other modernising projects relevant to our field
On a scale of 1 – 10, how ready do you feel your organisation is?	Varies from 1 – 7, with most clustering around 4  (10 = most ready)

## Meeting with case study participants September 09

Eight of the twelve organisations met to give each other an update on progress and explore how the case study approach could be developed and maintained over the coming year.

### Reasons for participating in the MHNE case study approach:

- To hear about what is happening elsewhere in the NE
- Opportunities to collaborate
- Share learning and develop good practice
- Some areas are moving more quickly and it is helpful to take this back
- We want to be more proactive
- Work on practical matters like job descriptions together
- To feel less isolated and overwhelmed – very useful to talk find out what others are doing – it's supportive

The following is a summary of the key themes that emerged from the discussion that took place:

Ongoing concerns		Steps being taken to be ready
Crossroads Care North East England	Work across the NE region now that we have restructured. If you really want to meet individual needs it is going to cost more to train staff to do this	Carried out a lot of research into personalisation – want to move to dedicated care packages for individual needs Looking at ways to tap into local skills. Implementing a new IT based rota and rostering system, individual invoicing and job specs/descriptions. Looking at describing three levels of skills
Dementia Care Partnership (Newcastle)	Now in contact with LA commissioners, and there has been a provider event, and there are 'market readiness meetings' Told that packages of adult care are to be outsourced – with clients offered a choice of domiciliary care provider Not sure how advocacy and support will work yet Biggest challenge – how will supported housing be provided in the future eg if not all in a house are on the same system	Clear that this will make a difference Lobbying externally Restructuring internally to align with city wards Set up project team to 'win business' Investing in a marketing DVD Consulting with staff to help them prepare
Mental Health Care – 24hr Specialist Nursing Services (Durham)	Seems very target driven and tick box It feels like there is pressure, but not much guidance at the moment especially for providers This will be a big change of culture, but it's still not really understood Our clients will possibly get DPs for specific activities Care managers and coordinators not all on board yet	Trying to see how our overall service model fits with the personalisation agenda. Not likely to be a financial issue initially as its NHS continuing care, but want to move to more personalised approach. Looking at this with LA, using the Recovery Star and an outcomes focus. Training our staff and developing the workforce
Mental Health Concern (South Tyneside)	MHC operate across many LAs and they all seem at different stages The service in question has different sources of funding – how do you disentangle health funding from the social care personalisation approach? Commissioners don't seem to know the answers yet Concerned that Shop4Support will be expensive How do 'traditional day services' fit this agenda? Some people will still want/need this	Trying to help staff be positive Senior managers are providing leadership Trying to be very clear about the wants and needs of the particular client group and base models of provision/intervention around that Using the Recovery Star, narrative testimony and key outcomes to focus on outcomes that are realistic for the client group Internally – we are looking at IT and finance in particular eg software to enable us to invoice and set up individual contracts etc
Mental Health Matters (Darlington)	Our SLA with the LA ends in November – at one point we were told this would convert to 50% DPs in March 2009. Things have slowed up a bit	MHM has had a working party for 18 months Try to get national picture as national organisation – there is

	<p>since then – seem to be moving in the right direction, especially in recognising that some people will still want a fairly traditional type of service</p> <p>The LA has 7 workstreams and we are kept informed via a providers meeting and also had a contracts meeting – but still a shortage of locally specific information</p> <p>Take up of DPs is still very low – service users still have a lot of issues</p> <p>Also CMHTs do not seem to be on board, preoccupied with local restructuring</p>	<p>huge disparity</p> <p>Gateshead and Newcastle seem in the lead</p> <p>We have an action plan to look at all aspects of the organisation – it's a big change management issue, trying to keep staff informed</p>
<p><b>Redcar and Cleveland</b> <b>MIIND</b></p>	<p>We sit on the LIT and get info but the goalposts change</p> <p>Is it just for those on CPA? What about the preventative work we do?</p> <p>Specifics still not discussed - we are realistic, we welcome the philosophy but have so many unanswered questions</p>	<p>Proactively driven forward a package of services and costs</p> <p>Working with staff on job descriptions etc</p> <p>We are interested in developing advocacy but LA not outsourcing</p>
<p><b>Sunderland</b> <b>Counselling Service</b></p>	<p>We offer mainly primary care and women's services, and also an advocacy service that is LA funded</p> <p>Agree with the philosophy – it is crucial that advocates understand what is happening – but will advocacy be seen as essential or something to purchase with a DP</p> <p>This will have big implications but so far we are getting nothing specific – our contract ends in 18 months</p> <p>No open events as yet</p>	<p>Really just starting to get our heads around this – being a part of the MHNE project will hopefully help us get ready</p>

## 7. Summary of findings

The findings of the MHNE Personalisation project over the past year, and set out detail in sections 4, 5 and 6 of this report, can be summarised as follows:

### The overall context

- I. The government is committed to delivering more personalised health and social care services. An intensive three year programme to transform adult social care (*Putting People First*) began in April 2008 and NHS PCT pilots for 'personal health budgets' have begun in the north east as in other parts of the country
- II. The underlying philosophies of self directed support and co-production offer the opportunity for a major shift in the way people think about and access health and social care – a move away from a 'professional gift' service based model to a 'citizenship' model based on individual rights, choice and control
- III. All local authorities (LAs) in England are currently involved (some in an integrated approach with the local PCT) in a set of processes to implement personalisation, especially self directed support, personal budgets and increased direct payments, as part of the overall transformation of adult social care
- IV. Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton on Tees are the PCTs testing 'personal health budgets' in the NHS in the north east
- V. This represents a significant programme of organisational and cultural development for these statutory agencies, with the current emphasis being on major change adult social care. The precise nature of implementation (for example timescales and operational plans) varies from LA to LA. Currently much of the emphasis and energy seems to be on the internal development and redesign required to support the shift to such a radically different way of working
- VI. The vast majority of people currently receiving adult social care receive this in the form of traditional service provision. In the north

east, less than 10% of people receiving adult social care funding receive this as a direct payment (DP). People on DPs for mental health reasons make up less than 10% of this figure. Historically, in some parts of the north east, DPs have been comparatively underdeveloped across all groups

- VII. Research has generally suggested that individual budgets and direct payments can have a positive impact on individual wellbeing, whilst improving quality and often reducing costs. However there is also evidence that for some groups (eg older people) negative aspects such as increased stress are more significant
- VIII. Research to date has been based on discrete pilots and small groups. There are no examples yet of what happens when a whole locality or social/health care economy – or even an entire client group has moved across to personal or individual budgets and increased DPs

### **People with mental health problems**

- IX. As in other parts of the country, local authority investment in mental health services in the north east varies from one locality to the next, and the numbers of people eligible for adult social care because of mental health needs differs markedly from area to area
- X. Most of the funding for mental health services is located in the NHS part of the system, despite the significance of social factors on mental health
- XI. People with mental health problems, and their carers, are traditionally low takers of direct payments. This is partly due to the fact that they have tended to have been given less opportunity to participate in schemes that already exist (eg beliefs that they would not be able to cope or be able take more control of their lives)
- XII. In the north east, very few people who use mental health services, or their carers, know anyone who has a direct payment. The concept remains mysterious to the vast majority, and some are concerned that there will be a reduction in familiar services and increased personal stress

- XIII. Many (but not all) people who use mental health services have needs that fluctuate and their need for support may be less predictable than some other groups
- XIV. There is evidence to suggest that where they are given the opportunity, people are very adept at using direct payments to improve their mental health and overall wellbeing
- XV. Paradoxically there is a significant minority of people who have not been able to get advice and help about direct payments when they have requested it from staff
- XVI. Points 1x – xv indicate that there are unique challenges and considerations to be addressed when increasing personalisation and direct payments and for people with mental health problems and their carers. There are many detailed questions about how personal budgets and increased direct payments will work in practice

### **Impact on the voluntary mental health sector**

- XVII. It is expected that traditional funding mechanism eg 'block contracts' will be significantly reduced. This is extremely unsettling for voluntary sector providers
- XVIII. It is also frequently stated (for example at LA provider events) that 'there will be losers' - implying that those who cannot reinvent themselves will not be able to function successfully in the new world. This is increasing the sense of uncertainty and instability that already exists in the sector
- XIX. Provider personalisation events held by local authorities routinely emphasise to the need to reform the way social care is funded in the future; this has increased fears that the real driver for personalisation is reducing costs - and not improving quality
- XX. Staff are feeling uncertain about what the future holds, and some organisations are finding that the lack of clarity about future core funding is having an adverse effect on the willingness of other funders (eg grant making bodies) to give support
- XXI. These tensions have increased over the past 18 months, albeit more explicitly expressed in some parts of the region than others. In the

past four or five months some north east local authorities have invited providers to generic information events. Some have well established personalisation boards and provider forums that include voluntary sector representatives

- XXII. At the time of writing this report, apart from a very small number of isolated examples, voluntary sector mental health providers do not have specific, formal, local information about how the changes will affect them, when they will be introduced, or how things will work during and after the transition period
- XXIII. Whilst there is positive awareness of and sign up to the fundamental principles of personalisation (the destination), a host of questions and concerns remain about how to get there (the journey), and there is a strong desire to work with commissioners to start co-creating the answers now

### **Growing the market**

- XXIV. Voluntary sector agencies are often 'closer' to the communities they work with than larger statutory agencies and able to be more flexible and creative in designing and delivering responses to identify and meet needs
- XXV. The personalisation agenda offers opportunities for providers to rethink what they do and how they do it. There is some evidence that 'non traditional' areas such as arts, leisure, educational and cultural activities are chosen by people using DPs. Considerable new development in terms of advice, signposting, support, brokerage and user led input is required and these can be positive opportunities for the voluntary sector
- XXVI. Local authority plans for these functions, and the way that 'markets' will be stimulated and developed, especially in terms of the third sector, have in most areas not yet been defined or clearly communicated. There are considerable fears that commissioners will find it easier to use larger, well established providers, and in some cases private sector businesses to assist them in implementing the personalisation agenda

## **Readiness of the mental health voluntary sector**

- XXVII. Currently, in the north east, voluntary sector mental health service providers, and many people who use mental health services and their carers, have good basic awareness of the overall philosophy of personalisation and self directed support and the changes taking place in adult social care to support this
- XXVIII. Many have started to take a proactive approach - preparing themselves to operate in a different way and looking at the opportunities that will exist for them in a more personalised health and social care system
- XXIX. There are fears amongst voluntary sector mental health agencies that in this interim, pre-transition period, opportunities to develop a partnership approach with commissioners, to begin to explore joint solutions to the problems that need to be tackled, are being missed, leading to fears that unilateral solutions will be imposed
- XXX. Voluntary sector mental health providers, especially in the form of local networks, and via the strategic regional voice of Mental Health North East, feel that they have much to contribute in terms of developing innovative solutions to the many challenges that exist in successfully implementing personalisation in the north east and in influencing positive outcomes for the sector and the people who value what it provides
- XXXI. The sector is now ready to work in partnership with commissioners both locally and regionally in order to facilitate and support successful implementation of personalisation in mental health
- XXXII. There is to some extent a sense of frustration in the mental health voluntary sector that providers do not feel more involved in the implementation of personalisation in this early but important and influential stage

## 8. Key recommendations and next steps

### Key overarching recommendations:

The recent *Putting People First* milestones (see Appendix A) state:

**By December 2009:**

That the move to personal budgets is well understood and that local service users are contributing to the development of local practice

**By April 10:**

That councils and PCTs have commissioning strategies that address the future needs of their local population and have been subject to development with all stakeholders especially service users and carers; providers and third sector organisations in their areas

**By October 10:**

That providers and third sector organisations are clear on how they can respond to the needs of people using personal budgets. An increase in the range of service choice is evident

### Overarching Recommendation 1

**In order for these milestones to be meaningfully achieved for the mental health voluntary sector in the north east, social care and health commissioners should now actively engage the sector, to develop a genuine partnership approach to meeting the challenges that exist**

### Overarching Recommendation 2

**The sector is now keen to address with commissioners and transformation leads the following issues:**

- a. Working together to develop the voluntary sector mental health 'provider market' - so that in the future there is as much genuine choice as possible for people with mental health problems and their carers
- b. Developing together effective approaches to transitional arrangements that ensure adequate stability whilst at the same time move towards very different business and operational models
- c. Sharing resources and expertise to co-create the systems and processes necessary for effective implementation - for example:
  - I. assuring quality of providers

- II. developing an accessible directory of services and supports for service users and carers
  - III. supporting collaborative approaches and consortia amongst voluntary sector mental health agencies
  - IV. ensuring that the sector has access to appropriate business and change management advice and support
  - V. helping to ensure that service users and carers are aware of and prepared for the move to personal budgets
- d. That at every level those involved with implementing personalisation are closely allied with mental health service users and carers, and always sensitive to the specific challenges that exist in promoting self directed support, personal budgets and especially increasing the uptake of direct payments by people with mental health problems
  - e. That consistent regional solutions are developed wherever possible

### Overarching Recommendation 3

**In order to maximise progress, this engagement needs to happen both at a strategic regional level (for example with the North East Regional Improvement and Efficiency Partnership) and within each locality, at LA and PCT level. MHNE is well placed to represent the sector in this process of engagement.**

### Overarching Recommendation 4

Figures given by north east LAs suggest that the percentage of people accessing adult social care funding for mental health reasons varies from under 5% to over 30% depending on the locality (*see page 22 of this report*). If the figures are accurate, such a high degree of variation arguably undermines the fundamental principles of personalisation, ie that allocation of resources is based on fair and transparent assessment of need

**Work should therefore be undertaken by adult social care directors to review the data, and clarify the reasons for any major differences in access to adult social care across the region by people with mental health problems, and to work towards a more equitable approach across the north east**

## **Additional Next Steps**

- 1. MHNE should continue to support its members by prioritising personalisation. However the emphasis should now shift from simply providing and gathering information to focus on:**
  - a. Using the Personalisation agenda to demonstrate the unique contribution of the mental health voluntary sector to the north east region**
  - b. Working with commissioners to ensure that the overarching recommendations are carried out**
  - c. Working with commissioners and other partners to support the following additional next steps:**
    - I. Ensure that voluntary sector MH providers get business change support to meet the challenges/opportunities in the personalisation agenda
    - II. Ensure that the sector is represented and engaged at all local and regional personalisation boards and forums
    - III. Where mental health voluntary sector networks exist, LA/PCT Personalisation leads and commissioners to attend on a regular basis
    - IV. Support regional service user and carer initiatives (eg MIND's proposal to develop champions or critical friends to support, inform, and influence) so that implementation is tailored to the specific needs of people with mental health problems
    - V. Ensuring that there is adequate focus on MHNE members in the south of the region given the number of LA and PCT personalisation pilots and initiatives taking place and given that there is an absence of established voluntary sector mental health networks in this part of the region
    - VI. Supporting further collaboration with colleagues in related fields eg Learning Disability and Physical Disability in order to share good practice
    - VII. Consider creating a regional voluntary sector mental health 'personalisation board' to ensure that the views and needs of the sector are properly understood and represented to commissioners, and that good practice and innovative ideas can be disseminated
  - d. MHNE should also review the Case Study Approach with the participating organisations and determine the best way to align that aspect of its work with the above recommendations**

## Appendix A - Progress Measures for the delivery of transforming adult social care issues (Putting People First, September 09) – Key Milestones

	<b>April 2010</b>	<b>October 2010</b>	<b>April 2011</b>
<b>Effective partnerships with people using services, carers and other local citizens</b>	<p>That a communication has been made to the public including all current service users and to all local stakeholders about the transformation agenda and its benefits for them.</p> <p>That the move to personal budgets is well understood and that local service users are contributing to the development of local practice. <i>[By Dec 2009]</i></p> <p>That users and carers are involved with and regularly consulted about the councils plans for transformation of adult social care.</p>	<p>That local service users understand the changes to personal budgets and that many are contributing to the development of local practice.</p>	<p>That every council area has at least one user-led organisation who are directly contributing to the transformation to personal budgets. <i>(By December 2010)</i></p>
<b>Self-directed support and personal budgets</b>	<p>That every council has introduced personal budgets, which are being used by existing or new service users/ carers. *</p>	<p>That all <b>new</b> service users / carers (with assessed need for ongoing support) are offered a personal budget. That all service users whose care plans are subject to review are offered a personal budget. **</p>	<p>That at least 30% of eligible service users/carers have a personal budget.</p>
<b>Prevention and cost effective services</b>	<p>That every council has a clear strategy, jointly with health, for how it will shift some investment from reactive provision towards preventative and enabling/ rehabilitative</p>	<p>That processes are in place to monitor across the whole system the impact of this shift in investment towards preventative and enabling services. This will enable efficiency gains to</p>	<p>That there is evidence that cashable savings have been released as a result of the preventative strategies and that overall social care has delivered a minimum of</p>

	interventions for 2010/11. Agreements should be in place with health to share the risks and benefits to the 'whole system'.	be captured and factored into joint investment planning, especially with health.	3% cashable savings. There should also be evidence that joint planning has been able to apportion costs and benefits across the 'whole system'
<b>Information and advice</b>	That every council has a strategy in place to create universal information and advice services.	That the council has put in place arrangements for universal access to information and advice.	That the public are informed about where they can go to get the best information and advice about their care and support needs.
<b>Local commissioning</b>	That councils and PCTs have commissioning strategies that address the future needs of their local population and have been subject to development with all stakeholders especially service users and carers; providers and third sector organisations in their areas. These commissioning strategies take account of the priorities identified through their JSNAs.	That providers and third sector organisations are clear on how they can respond to the needs of people using personal budgets.  An increase in the range of service choice is evident.	That councils have clear plans regarding the required balance of investment to deliver the transformation agenda. That stakeholders are clear on the impact that purchasing by individuals, both publicly (personal budgets) and privately funded, will have on the procurement of councils and PCTs in such a way that will guarantee the right kind of supply of services to meet local care and support needs.

*\* The ADASS/LGA survey showed 8% was already the national average in March 09 (although it also suggested that the majority of authorities were below this average). It is believed that Councils should have reached a 10% minimum target by March 2010, if they are going to guarantee the 30% target for 2011; the survey itself indicated that only around 20 authorities were not expecting to have reached a 10% level by March 2010.*

*\*\* Given the expectation that service users receive reviews at least annually, this milestone may in itself drive an allocation of PBs in excess of the 30% target for April 2011.*

## Appendix B - What can service providers do now?

### From In Control

<http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=839&cc=GB>

In the future service providers should be able to help people make it easier for people to be in control. There are at least 7 smart strategies that service providers could do now:

1. Build Individual Service Funds (ISFs) into current systems - protect people's money and treat it as restricted
2. Start to offer Personal Assistance to people who want choice and control over staff - but don't want to employ people
3. Rethink 'support work' - don't limit yourself to just providing the services of the past - help people to find work, make friends, learn new skills
4. Plan, design and support for free - don't think 'brokerage' is something someone else must do - you should have the skills to help people plan and design their own support
5. Agree a 'transformation contract' - work with local commissioners to create phased transition plans to the new systems
6. Gather outcome data - make sure you understand the impact of these changes - when it works and when it doesn't
7. Try and share your learning - get involved with the growing community of service providers who want to change.

## Appendix C - Organisational readiness checklist

This was developed as a result of the initial consultations carried out in the first few months of the MHNE project:

1. Assemble all the information that you can about your running costs - activities, materials, workforce, training, admin, office, heating, lighting, travel, transport etc and calculate the unit costs of the service/s you provide to an individual person per intervention/session/day
2. Think about what you offer. What groups of people do you aim to attract? How well do you do this?
3. Consult with your service users and their carers about what you currently provide. Work with them to explore new ideas for activities and services, find out what they would choose if they could
4. What opportunities are there to expand what you offer, to make it available to other groups? Alternatively, might it be beneficial to concentrate on a smaller range of services or activities?
5. Consider marketing and publicity – how well do you describe and promote what you do? You may need different approaches for clients and commissioners
6. Workforce – how can you prepare yourself and your staff? What training or new roles might be required? Depending on what services you offer, are there implications for recruitment (for example choice of worker by client)
7. Be proactive with commissioners – try and find out who is leading on this at the PCT or LA, what areas of need are being prioritised, what timescales etc. Make it clear you want to be involved in a dialogue – don't assume that they have all the answers! Some are actively looking for services and clients to try out new mechanisms and processes
8. Think about the work that will need to be done to support increased personalisation in your area e.g. brokerage, advice, training, advocacy – are there opportunities here?
9. Think about and explore possibilities that exist for partnerships with other providers
10. Get up to date information from the MHNE web portal

## Appendix D – Regional conference programme:

### Are You Ready? Personalisation, Mental health and the Voluntary Sector Friday 9<sup>th</sup> October 2009 - Holiday Inn Seaton Burn

- 9.30 Registration & Coffee
- 10.00 Welcome - Brendan Hill, Mental Health Concern
- 10.05 Overview of the Day – Steve Nash, MHNE
- 10.10 Robin Murray-Neil – DH Mental Health & Personalisation Lead (The National Picture)
- 10.35 Caroline Tomlinson – In Control (The service provider’s agenda)
- 11.00 Refreshment Break
- 11.20 Sarah Ward - Hartlepool LA (The approach in one NE LA)
- 11.35 Group work - to generate questions for the panel
- 12.0 Panel Discussion (Including three speakers above, Steve Nash and Alisdair Cameron)
- 12.30 Lunch
- 13.15 Breakout Sessions (sign up for one at lunchtime on the day):
1. Service user perspectives and MIND’s research - Pauline Heslop, MIND
  2. Mutual models for self managed care – a collaborative response to the personalisation agenda (Mick Taylor, Mutual Advantage)
  3. Progress towards providing a personalised approach – Scott Vigurs Mental Health Concern
  4. An integrated LA and PCT approach to personalisation – Peter Smith and Ann Workman, Stockton Borough Council
  5. The training agenda for potential users of DPs – Catina Barrett, NIACE, and George Spoors, Sunderland Training Partnerships
  6. How can providers minimise risks, maximise opportunities and influence local implementation? - Keith Wyatt, Self Direct
- 14.15 The MHNE Personalisation Project – Steve Nash
- 14.30 Summary remarks on the day – Jeannie Molineux, University of Northumbria
- 14.40 Chair’s closing remarks Brendan Hill
- 14.45 Event Closes

(See also separate conference report)

## Appendix E - Selected reading on personalisation

This is not intended to be an exhaustive list, but hopefully it will provide useful links to a range of relevant information. Almost all of the documents referred to are available from the websites that are included at the end – along with many other useful materials and resources.

### Personalisation and Mental Health

*Personalisation in mental health – Breaking down the barriers - a guide for care coordinators, MIND, 2009*

[http://www.mind.org.uk/assets/0000/2166/putting\\_us\\_first\\_overcoming.pdf](http://www.mind.org.uk/assets/0000/2166/putting_us_first_overcoming.pdf)

*A future vision for mental health 2009 - by a coalition of seven national agencies – contains a useful section on 'self determined care'*

<http://www.newvisionformentalhealth.org.uk/>

*Changes to Direct Payments DH – Legal changes eg allowing payments to be made to those on MH Act*

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_107263.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_107263.pdf)

*Individual budgets come under the microscope, Mental Health Today, 2008*

<http://www.sds4me.org.uk/CL%20North%20West%20Feb%202009/MentalHealthTodayDeo8.pdf>

*Direct Payments in Mental Health – A guide to action, CSIP, DH, 2007*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4131060](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4131060)

*A Learning Journey to Direct Payments - Information and resources for trainers and people in a position to make Direct Payments more accessible for people who have mental health difficulties -Is it for me?*

<http://www.livelearnwork.org/files/v5%20new%20personalisation%20form%20eIFM%20information%20pack%206%2010%2008.pdf>

*A voice and a choice, Self directed support by people with mental health problems, Rita Brewis, In Control, 2007*

<http://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=331&cc=GB>

*George's story from the individual budgets pilots*

<http://networks.csip.org.uk/Personalisation/Topics/Browse/MentalHealth/?parent=2737&child=2743>

*Direct payments and mental health, New Directions, Karen Newbigging with Janice Lowe, Joseph Rowntree Foundation, 2005*

<http://www.jrf.org.uk/sites/files/jrf/1841961388.pdf>

## Research and evaluation of personalisation, direct payments and individual budgets in mental health

*Personalisation in mental health – Creating a vision – views of personalisation, from people who use mental health services, MIND, 2009*

[http://www.mind.org.uk/assets/0000/3856/Creating\\_a\\_vision.pdf](http://www.mind.org.uk/assets/0000/3856/Creating_a_vision.pdf)

*Personalisation and mental health – a review of the evidence, MIND, 2009*

[http://www.mind.org.uk/assets/0000/2164/putting\\_us\\_first\\_personalisation.pdf](http://www.mind.org.uk/assets/0000/2164/putting_us_first_personalisation.pdf)

*Implementing direct payments in mental health – Karen Newbigging with Janice Lowe, Joseph Rowntree Foundation, 2005*

<http://www.jrf.org.uk/node/1082>

*Direct payments, independent living and mental health – an evaluation, HASCAS, 2003*

[http://www.hascas.org.uk/pdf\\_files/HASCAS%20Executive%20Summary.pdf](http://www.hascas.org.uk/pdf_files/HASCAS%20Executive%20Summary.pdf)

*Direct what? A study of direct payments to mental health service users – Julie Ridley and Lyn Jones, The Scottish Executive Central Research Unit, 2002*

<http://www.scotland.gov.uk/Resource/Doc/156674/0042103.pdf>

## Information on personalisation and direct payments for service providers

*At your service – navigating the future market in health and social care, DEMOS 2009*

<http://www.demos.co.uk/publications/at-your-service>

*Putting People First – Working together with user led organisations, DH 2009*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_096859](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096859)

*At a glance 12: Personalisation briefing: Implications for advocacy workers, SCIE, 2009*

<http://www.scie.org.uk/publications/ataglance/ataglance12.pdf>

*Personalisation Briefing for home care providers, SCIE 7, 2009*

<http://www.scie.org.uk/publications/ataglance/ataglance07.pdf>

*A new framework for organisational change, SCMh 2009*

[http://www.scmh.org.uk/pdfs/implementing\\_recovery\\_paper.pdf](http://www.scmh.org.uk/pdfs/implementing_recovery_paper.pdf)

*What are we learning about developing Individual Service Funds? Owen Cooper and Helen Sanderson with Ruth Gorman, Michelle Livesley and Terry Keely, IAS services*

[http://www.supportplanning.org/Support\\_Planning\\_Downloads/SP\\_40\\_What\\_are\\_we\\_learning\\_about\\_Individual\\_Service\\_Funds\\_Sept\\_08.pdf](http://www.supportplanning.org/Support_Planning_Downloads/SP_40_What_are_we_learning_about_Individual_Service_Funds_Sept_08.pdf)

*Key Initial Decisions Community Agencies Need To Make If They Are To Individualize Supports Kendrick, Michael J, Frontline Of Learning Disability, Issue Number 72, 2008*

<http://www.kendrickconsulting.org/docs/KeyInitialDecisionsIndividualization.pdf>

*Commissioners and providers together – the citizen at the centre, In Control 2007*

[http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation\\_advice/Commissioners\\_and\\_Providers\\_Together\\_June\\_07\\_Andrew\\_Tyson\\_CSIP.pdf](http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_advice/Commissioners_and_Providers_Together_June_07_Andrew_Tyson_CSIP.pdf)

*The implications of individual budgets for service providers - Report from a workshop, Office of Public Management, 2007*  
<http://networks.csip.org.uk/Personalisation/Topics/Browse/Commissionersandproviders/?parent=2735&child=2690>

*Personal budgets – how should providers prepare (power point presentation) – Support Solutions 2008 (North Tyneside Council)*  
[http://www.northtyneside.gov.uk/pls/portal/NTC\\_PSCM.PSCM\\_Web.download?p\\_ID=30888](http://www.northtyneside.gov.uk/pls/portal/NTC_PSCM.PSCM_Web.download?p_ID=30888)

*Personalisation of health and social care services - leadership challenges and workforce development needs of the mental health voluntary sector in Leeds – Bereket Loul and Gill Crawshaw, Volition, 2008*  
<http://www.volition.org.uk/personalisation.php>

## Personalisation in the North East

*Lessons learned from Personalisation Pilots and Readiness of Local Authorities across the North East, Report to Directors of Adult Social Services, Tricia Nicoll Consulting*  
<http://www.northeastiep.gov.uk/adult/projects.htm>

*Developing direct payments in the North East of England, Joseph Rowntree Foundation, 2005*  
<http://www.jrf.org.uk/sites/files/jrf/624.pdf>

## Information on direct payments and individual budgets for service users

*A guide to receiving direct payments from your local council - A route to independent Living, DH, 2009*  
[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_104894.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_104894.pdf)

*Stories of using individual/personal budgets, Mental Health, DH 2009*  
<http://www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/MentalHealth/?parent=2737&child=5126>

*A guide to receiving direct payments from your council – a route to independent living - DH, 2008*  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083561](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083561)

*An introduction to direct payments in mental health services - information for people eligible to use mental health services and carers, CSIP*  
[http://www.socialinclusion.org.uk/publications/Direct\\_Payments\\_SU\\_Guide.pdf](http://www.socialinclusion.org.uk/publications/Direct_Payments_SU_Guide.pdf)

*SCIE Race equality discussion paper 01: Will community-based support services make direct payments a viable option for black and minority ethnic service users and carers? 2006*  
<http://www.scie.org.uk/publications/raceequalitydiscussionpapers/redpo1.asp>

How does self directed support work – Stockport Council  
[A Guide to The Mental Health Self Directed Support Scheme.pdf](#)

## Information on direct payments and individual budgets for carers

*The Individual Pilots Projects: Impact and outcomes for carers, Glendenning et al, SPRU York, PSSRU Kent, 2009*  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_095420](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_095420)

*Choice or chore? Carers experiences of Direct Payments, Carers UK, 2008*  
<http://www.carersuk.org/Newsandcampaigns/News/1226587666>

## Personalisation and commissioning

*Common resource allocation Framework Oct 09 ADASS*  
[http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation\\_advice/Common\\_resource\\_allocation\\_framework\\_final.pdf](http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_advice/Common_resource_allocation_framework_final.pdf)

*Putting People First - Outcome-focused Reviews - A practical guide*  
*Authors: Tony Bennett, Martin Cattermole, Helen Sanderson*  
[http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation\\_advice/OutcomeFocusedReviews2.pdf](http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_advice/OutcomeFocusedReviews2.pdf)

*Putting People First - Transforming Adult Social Care contracting for personalised outcomes Learning from emerging practice Aug 09*  
[http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation\\_advice/CFPO.pdf](http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_advice/CFPO.pdf)

*Personalisation Briefing for Commissioners, SCIE 06, 2009*  
<http://www.scie.org.uk/publications/ataglance/ataglance06.pdf>

*Putting People First, Working together for change: using person-centred information for commissioning, DH 2009*  
[http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation\\_advice/WTFC\\_Final.pdf](http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_advice/WTFC_Final.pdf)

*Contracting for personalised outcomes - Learning from emerging practice, DH, 2009*  
[http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation\\_advice/CFPO.pdf](http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_advice/CFPO.pdf)

*Smart Commissioning - A paper exploring the impact of personalisation on commissioning. It provides an early framework for commissioners who want to transform their existing contractual structures into a system of Self-Directed Support, S Duffy, 2008*  
<http://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=386&cc=GB>

*Commissioners and Providers Together: the Citizen at the Centre – Andrew Tyson, in Control, 2008*  
<http://networks.csip.org.uk/Personalisation/Topics/Latest/Resource/?cid=2683>

## Policy and general papers on personalisation and personal budgets in social care

*Putting People First - Transforming Adult Social Care Sept 09 – Progress Measures for the Delivery of Transforming Adult Social Care Services*

<http://www.adass.org.uk/images/stories/Milestones%20for%20PPF%20-%20Final%209.9.09.pdf>

*Making progress with Putting People First: Self-directed support, 2009, ADASS, LGA, I&dea*

[http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation\\_advice/Making\\_progress\\_with\\_PPF\\_-\\_self-directed\\_support\\_final.pdf](http://www.dhcarenetworks.org.uk/library/Resources/Personalisation/Personalisation_advice/Making_progress_with_PPF_-_self-directed_support_final.pdf)

*Putting People First – measuring progress, ADASS/LGA 2009*

<http://www.adass.org.uk/images/stories/PPF%20Measuring%20Progress%207%20May%20NA.pdf>

*Transforming Adult Social Care LAC (DH) (2009)1*

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_095813.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_095813.pdf)

*Putting People First - the strategy for the adult social care workforce in England, DH 2009*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_098481](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098481)

*Transforming Adult Social Care, Local Authority Circular, LAC DH, (2008) 1*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH\\_081934](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_081934)

*Personalisation – a rough guide, Sarah Carr, SCIE, 2008*

<http://www.scie.org.uk/publications/reports/report20.asp>

*Why is everybody talking about personalisation? Integrated Care Network, 2008*

[http://networks.csip.org.uk/library/Resources/ICN/ICN\\_advice/An\\_ICN\\_discussion\\_paper\\_-\\_Personalisation.pdf](http://networks.csip.org.uk/library/Resources/ICN/ICN_advice/An_ICN_discussion_paper_-_Personalisation.pdf)

*Putting People First – A shared commitment to the transformation of adult social care, 2007*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_081118](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118)

*Putting Patients in Control, Vidhya Alakeson, Social Market Foundation, 2007*

<http://www.smf.co.uk/putting-patients-in-control-the-case-for-extending-self-direction-into-the-nhs.html>

*Implications of individual Budgets, Simon Duffy, Journal of Integrated Care Volume 14, Issue 2, April 2006*

<http://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=197&cc=GB>

## Policy and general papers on personalisation and personal budgets in the NHS

*Direct Payments For Health Care: A consultation on proposals for regulations and guidance* DH Oct 09

[http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH\\_107425](http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_107425)

*Citizenship in health – Self Direction theory into practice – In Control discussion paper* 2009

<http://www.in-control.org.uk/site/INCO/UploadedResources/Citizenship%20in%20Health%2020090713%20web.pdf>

*Understanding personal health budgets, DH, July 2009*

[http://www.dh.gov.uk/dr\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_101910.pdf](http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101910.pdf)

*Personal Health Budgets – First Steps, DH, 2009*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093842](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093842)

## Critiques and commentaries

*Personal health budgets may spark tension between services, Health Services Journal, January 2009*

<http://www.hsj.co.uk/personal-health-budgets-may-spark-tension-between-services/1968274.article>

*Jon Glasby's addresses some of the arguments people use against personal budgets and direct payments, Community Care, 2009*

<http://www.communitycare.co.uk/Articles/2009/05/22/111636/why-people-disagree-about-direct-payments-and-personal.htm>

## Research and evaluation of direct payments and individual budgets

*Exploring the attitudes of direct payment employers in the West Midlands towards the training and development of Personal Assistants*

<http://d.yimg.com/kq/groups/21614357/1464205169/name/Final%20report%20-%20DP%20Rpt%20Proofs%20LR.pdf>

*The implementation of individual budgets in social care, SCIE 20, 2009 (updated)*

<http://www.scie.org.uk/publications/briefings/files/briefing20.pdf>

*Evaluation of the individual budgets pilot programme – Caroline Glendenning et al, Social Policy Research Unit, University of York 2008*

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_089505](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505)

Co production, an emerging evidence base for transforming adult social care, SCIE 31, 2009 <http://www.scie.org.uk/publications/briefings/files/briefing31.pdf>

A report on In Control's first phase 2003 – 2005 – Carl Poll et al, In Control, 2006  
<http://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=192&cc=GB>

## Some useful websites on personalisation

The In Control website is probably the most comprehensive of all personalisation and self directed care sites. It provides access to many resources including documentation and guidance produced by local authorities and other bodies. Here is a link to its mythbuster page:

<http://www.in-control.org.uk/site/INCO/Templates/General.aspx?pageid=33&cc=GB>

This is the key site for the Dept of Health policy and updates regarding the transformation of adult social care:

<http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm>

This is the DH's main website for the personal health budgets that are being piloted in the NHS via PCTs:

[http://www.dh.gov.uk/en/Healthcare/Highqualitycareforall/DH\\_090018](http://www.dh.gov.uk/en/Healthcare/Highqualitycareforall/DH_090018)

This site has a wealth of examples of practice based documentation on all aspects of implementing personal budgets – see resources

[www.DHcarenetworks.org.uk/Personalisation](http://www.DHcarenetworks.org.uk/Personalisation)

The SCIE website for personalization – contains a number of useful overviews and research briefings:

<http://www.scie.org.uk/adults/personalisation.asp>

### Some other sites:

<http://http://www.socialinclusion.org.uk>

[www.DHcarenetworks.org.uk/ICN](http://www.DHcarenetworks.org.uk/ICN)

For Personal Assistants and their employers

<http://www.panet.org.uk/>

<http://www.ncil.org.uk/media.asp> (The National Centre for Independent Living)

[www.sds4me.org.uk](http://www.sds4me.org.uk) (Shop for Support)