Key Findings - May 2013
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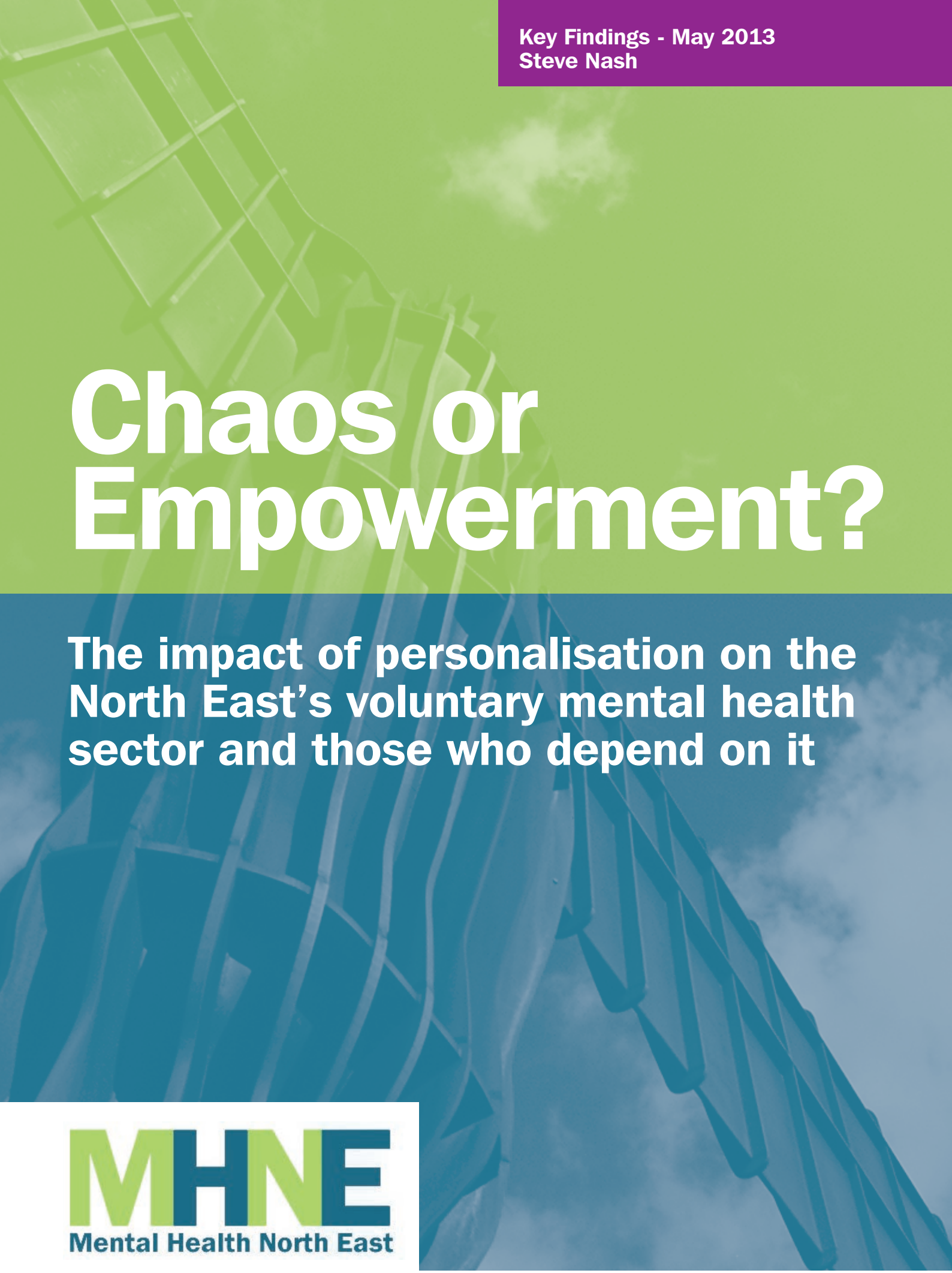
# Chaos or Empowerment?

## The impact of personalisation on the North East's voluntary mental health sector and those who depend on it



MHNE
Mental Health North East

# Introduction

Personalisation is a key government policy for public services, especially in social care and health, where 'self directed support' is being introduced in order to increase choice and control for people with support needs. As an ethos personalisation is informed by concepts of co-production and citizenship. A core element is the allocation of a 'personal budget', a cash sum that the person uses to purchase the help and care they need, and which can be taken as a 'direct payment'.

This paper summarises the findings of the Chaos or Empowerment? project, which focused on the introduction and impact of personalisation and personal budgets in the North East, especially from the perspective of the mental health voluntary and community sector (MH VCS), and its beneficiaries.

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# Key points: implementation

1. At the end of 2007, the Government published *Putting people first: a shared vision and commitment to the transformation of adult social care*,[1] setting out a major programme of change for social care, and including the introduction of personalisation and personal budgets. In 2009, *Personal Health Budgets: first steps*[2] announced the intention to extend personal budgets and direct payments to the NHS.
2. In March 12 in England 52.8% of those eligible for social care received some or all of this as a personal budget or 432,349 out of 818,700 people. This includes over 51,000 carers. The number of people receiving their personal budget as a direct payment (which it is argued offers the most choice and control), has stalled compared to those on council managed personal budgets. In October 2012 the government revised its April 2013 implementation target from 100% to 70%.
3. Implementation in social care continues to be slower for older people and those with mental health problems when compared to other groups. This mirrors levels of take up of the 'old style' direct payments that were available from 1997.
4. In November 2012, following positive evaluation of pilot projects, NHS personal health budgets were given the go ahead. These are currently only available to people with mental health problems in twenty pilot sites.
5. Studies suggest there are significant cultural barriers in NHS mental health services with most professionals not ready for personalisation. There are also fears that there will be parallel systems for personal budgets in social care, and personal health budgets in the NHS, creating additional complexity and duplication for service users and carers.[4]
6. In the North East, in 2012, around 1000 people with mental health problems (or 15% of those eligible), received personal budgets from social care, although there is widespread variation between individual local authorities. This variable picture is repeated across England. None of the mental health pilots of personal health budgets took place in the North East, so these are currently not available for this client group in this region, but should be by 2014.

# Key points: impact

In 2008, it was not difficult to get the impression that the policy of personalisation would bring about a revolution in social care. Councils would soon enable people with support needs to exercise unprecedented levels of choice and control, stimulating change and innovation in the social care market and radically altering the relationship between service users and service providers. Voluntary organisations and charities were warned that in order to realise the potential opportunities presented by this agenda, they must become much more businesslike - or face the risk of closure. Nearly five years later, in 2013, the actual impact on mental health voluntary and community sector providers (MH VCS) in the North East has been rather less dramatic.

1. In order to maximise the potential opportunities and minimise the risks, many VCS MH providers embarked on a major process of organisational development that included reviewing their financial, marketing and workforce systems. The resource and time investment has been significant.
2. Persistent difficulties remain in making personal budgets and direct payments accessible to the majority of people with mental health problems - even those who are already receiving support from social care. This is not confined to the North East.
3. Positive examples of self directed support do exist in mental health services, but they are still few and far between, and all too frequently the process of getting and managing a personal budget is fraught with frustration and bureaucracy.
4. Many MH VCS providers spend extensive amounts of time and energy offering informal advice, support and brokerage in relation to the process of accessing and managing a personal budget.
5. There is evidence that MH VCS providers in the North East are beginning to realise income from people using personal budgets and direct payments, but the number gaining significant income in this way is still extremely small.
6. The current toxic mix of economic recession, Government public sector cuts and controversial reductions to work, disability and housing benefits has had a negative impact on progressing the personalisation agenda, especially in North East, where:
    a. Levels of mental ill health are higher than in other regions, and some respects, they are the highest in the country.
    b. High levels of unemployment, physical ill health, social deprivation and dependency on benefits mean that there is a greater demand for mental health support.
    c. Department of Health figures show that per capita investment in mental health services has for several years been the lowest (or second lowest) of any English region.[5]
    d. The VCS is smaller, less well established and more dependent on public sector grants than in other regions – leaving it more exposed to spending cuts.
    e. Government public sector cuts and welfare reforms are having a disproportionate impact compared to other regions, reducing councils' capacity to invest in further implementation support.
7. NHS Personal Health Budgets are not yet available in the North East for people using mental health services. It is not clear what impact they will have on the implementation of personal budgets in social care. It remains to be seen whether personalisation will become integrated across health and social care - or whether there will be parallel systems.

[1] Putting people first: a shared vision and commitment to the transformation of adult social care, HM Government 2007

[2] Personal health budgets: first steps, Department of Health, 2009

[3] ADASS Personal Budgets Survey March 2012

[4] Facing up to the challenge of personal health budgets, The view of frontline professionals, NHS Confederation, 2011

[5] 2011/12 National Survey of Investment in Adult Mental Health Services, Department of Health, August 2012

# Personalisation policy in social care

Personalisation is a key overarching driver for reform across the public sector in England, especially within health and social care. It is also being introduced, albeit in different forms, in other countries such as Holland, Australia and parts of the United States. The idea that people with support needs should have greater choice and control over the care they receive can be traced back to the Civil Rights movement of the 1960s and the Social Model of Disability (1970s), through to *The Community Care (Direct Payments) Act, 1996,* and *Improving the Life Chances of Disabled People, 2005*, which introduced the idea of individual budgets. It is strongly supported in the Government's mental health strategy:

> *4.13 Personalisation is about respecting a person's human rights, dignity and autonomy, and their right to shape and determine the way they lead their life... This is of critical importance for people with mental health problems – we know that feeling in control leads to better mental health. Choice and control over their support services is just as important for ex-offenders, drug users and other socially excluded groups.*
>
> *No Health Without Mental Health, 2011*[6]

*Putting People First (2007)* and *Transforming Adult Social Care (2008)*[7] set out an extensive agenda of reform for local authorities, especially the implementation of more personalised approaches to providing assessment, advice, help and care. Self directed support (SDS) was introduced as the mechanism that had to be put in place to deliver personalisation and personal budgets. These developments were informed by the findings of the *Individual Budgets Pilot Programme (2008)*[8] and the ongoing work of *In Control.*[9]

## Table 1. **Personalisation - some key terms**

**Direct payment** - one way to get a personal budget. Money is paid directly to the person, who has to account for it. Alternatives include managed budgets by councils or where a third party manages the budget for the person.

**FACS (Fair Access to Care Services)** - the system that decides how much support people with social care needs get, to help them cope and keep them fit and well. It includes a financial assessment.[10]

**Individual budgets** - piloted in 13 local authorities in 2007 and included funding combined from social care and other sources. They are currently no longer available.

**Personal budget** - money allocated to meet a person's assessed social care needs. Only those who are eligible under FACS are able to access social care.

**Personal health budget** - money allocated to meet a person's assessed health care needs.

**Personalisation** - a broad concept whereby individuals choose and control the services and supports they need, as opposed to having to fit into whatever service is available.

**RAS (Resource Allocation System)** - translates a person's support needs into a cash sum. Each LA has had to develop its own approach.

**Self directed support** - the process by which councils are delivering personalisation and personal budgets, featuring an 'up front' allocation of funds.

6 No health without mental health: a cross-government mental health outcomes strategy for people of all ages, HM Government, 2011

7 LAC (DH)(2008)1: Transforming adult social care, Department of Health, 2008

8 Evaluation of the Individual Budgets pilot programme: final report, IBSEN, SPRU, University of York, 2008

9 http://www.in-control.org.uk/

10 Facts about FACS 2010: A guide to Fair Access to Care Services, Social Care Institute for Excellence

Table 2.

## The seven step model, developed by In Control, outlines the key steps at the heart of the self directed support process

| | |
|---|---|
| **1. Set personal budget** | The person is supported to carry out a self assessment. This enables them to find out how much funding they will be entitled to. Needs are translated into cash via a Resource Allocation System |
| **2. Plan support** | 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 |
| **3. Agree the plan** | The person agrees their assessment and support plan with their care manager/local authority |
| **4. Manage personalised budget** | The person decides on the best way to manage their personalised budget - manage it themselves (via a direct payment), or continue with the council managing it for them, set up a trust, pay an independent broker, use the care manager or a service provider |
| **5. Organise support** | The person is supported to organise the housing, help, activities, equipment or other kinds of things they want |
| **6. Live life** | 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 |
| **7. Review and learn** | The person, along with care manager checks how things are going and makes changes if needed |

In 2010 *Think Local, Act Personal (TLAP)*[11], a national, cross sector leadership partnership, took over the task of driving forward work on personalisation in community-based social care. It brings together people who use services and family carers with central and local government, major providers from the private, third and voluntary sector and other key groups.

In 2011 TLAP published *Making it Real: Marking progress towards personalised, community based support*. It sets out six headline progress markers that describe in simple terms what people should expect to see and experience if support services are truly personalised. The markers have been written by real people and families, and organisations can use them to check how they are transforming adult social care. The Association of Directors of Adult Social Services (ADASS) actively promotes the use of these markers as indicators of good practice, but sign up and adoption is voluntary, and as yet not all councils have agreed to use them. TLAP set the agenda for the next steps in terms of implementing self-directed support by requiring Councils to provide everyone eligible for social care with a personal budget by April 2013. This target has since been adjusted to 70%.[12]

In 2012 TLAP said that direct payments should be the default way to receive a personal budget, as this provides the highest degree of choice, control and service user/carer satisfaction. Whilst it is the case that direct payments can offer the most flexibility, they also demand higher levels of confidence and accountability, and this means that they may not be ideal for some people using mental health services, especially given the lack of support and advice that is often available. For this reason many feel that personal budgets that are managed by the council or another third party must continue to be an option.

[11] http://www.thinklocalactpersonal.org.uk/

[12] Lamb scraps 100% personal budgets target, communitycare.co.uk, 26th October 2012

# Implementing personalisation in social care

Between 2008 and 2011 councils shared £520m to transform social care, including implementing personalisation and the systems to support it. In March 2011, they duly reported that 30% of those eligible for social care were now receiving this as a personal budget, although implementation varied widely for different groups and in different parts of the country.

In July 2012 ADASS announced that 52% of people receiving adult social care had accessed some or all of this via a personal budget – a four-fold increase on the 2009 figure.[13] A more detailed breakdown of the data (and confusingly, a different total figure of 43%) is shown in Table 3. As a region the North East occupies a 'mid table' position – a significant improvement on its early performance, when only the South West had reported lower rates of take up. There are now fears that progress has become overly focused on overly bureaucratic processes around accessing the actual budget, and that the cultural shift required to deliver meaningful choice and control is not being given sufficient attention or energy.[14]

In early 2013, *The Barriers to Choice Review (David Boyle)* identified that there are still major problems for many people, especially in terms of information, access and effective systems that genuinely support meaningful choice and control.

Since the publication of the David Boyle report', a group of prominent organisations has subsequently written an open letter to Norman Lamb, The Care Minister, expressing their concerns[15].

Specific points include:

- financial threats to current levels of support
- assessment that is too late and too deficit based
- unsuitable resource allocation systems
- burdensome support planning approaches not controlled by people themselves
- rigid rules on spend, with social workers not trusted to make judgements
- people left without information advice and advocacy
- under-developed markets and restrictive preferred provider lists

The authors argue that if local authorities do not manage to shift and share power with the users of public services, *'one of the biggest ideas and potential drivers for positive public service reform in a generation'* will be put at severe risk. They argue that councils should implement Boyle's recommendations including:

- entitlement to an asset-based assessment
- phasing out the use of preferred provider lists
- giving local authorities a duty to signpost social care users to where they can access independent advice and support
- support for community enterprise – services run by local people for local people
- more intermediary organisations that can help people to employ personal assistants.
- a wider range of services available for people on direct payments
- more informal or mutual services, like time banks or help to pool budgets

These points, and the reasoning behind them, are as relevant to the North East as they are other parts of the country. However, at a time of austerity and recession, when councils are narrowing eligibility thresholds for access to social care, and imposing widespread cuts to service provision; and when the effectiveness of personal budgets is being undermined by the introduction of caps and ever increasing personal contributions, the gap between the promise of personalisation and the reality seems to be growing daily. In such a climate the likelihood of successfully reasserting these fundamental principles seems increasingly remote.

[13] ADASS Personal Budgets Survey March 2012

[14] Report 55: People not processes: the future of personalisation and independent living, SCIE, March 2012

[15] Personalisation: how to avoid snatching defeat from the jaws of success An open letter in support of key Boyle Report recommendations. In Control, Shared Lives Plus, Community Catalysts, Inclusive Neighbourhoods, Inclusion North, March 2013.

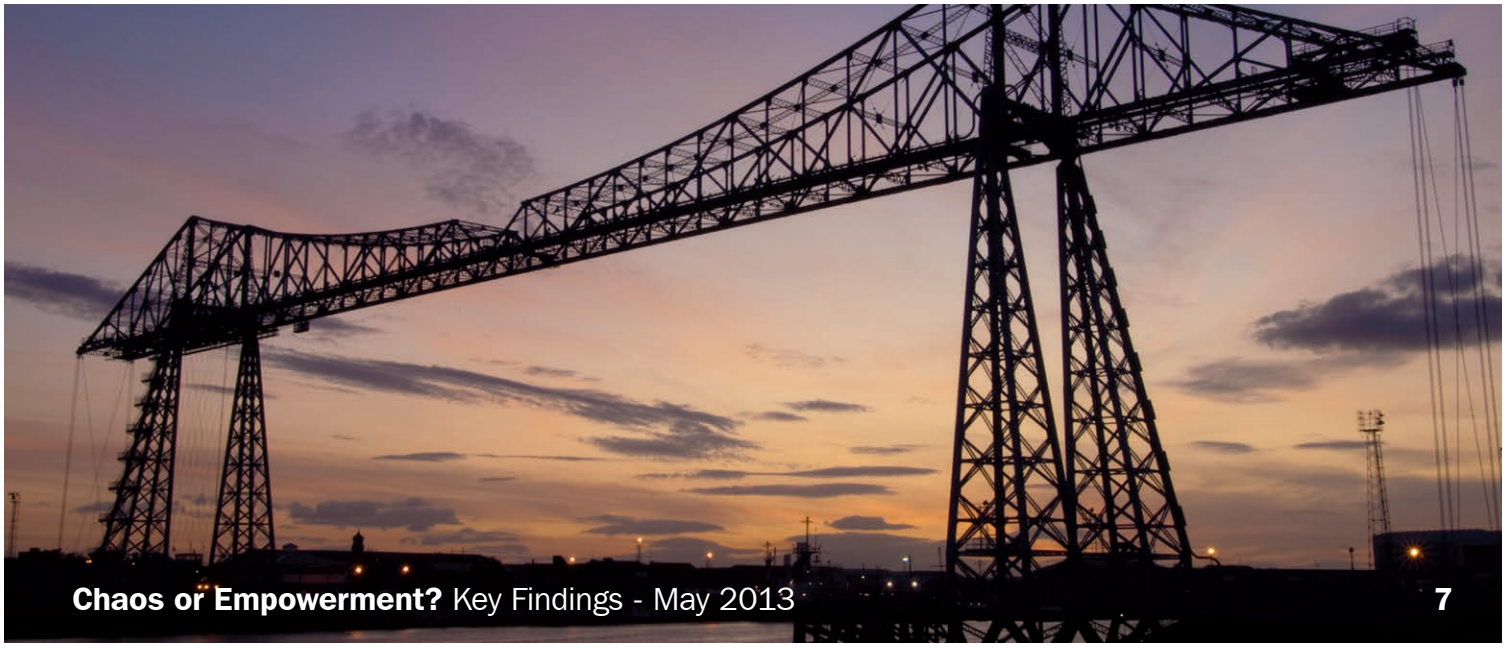
Table 3.

## Numbers of people in the North East receiving self directed support for their mental health problems

(Figures from the Adult Social Care Outcomes Framework - England, 2011-12, Final, Feb 15th 2013, The Health and Social Care Information Centre)

| *Local Authority or area* | *Receiving Community Support as SDS (18+)* | *Receiving SDS (18+)* | *% who receive CS as SDS* | *18 - 64s receiving CS for MH* | *18 - 64s receiving CS for MH as SDS* | *% 18 – 64s receiving CS for MH as SDS* |
|---|---|---|---|---|---|---|
| Darlington | 3520 | 1495 | 42.5 | 395 | 70 | 19 |
| Durham | 19540 | 10460 | 53.5 | 1380 | 150 | 10.7 |
| Gateshead | 5460 | 2385 | 43.7 | 250 | 105 | 41.3 |
| Hartlepool | 5730 | 1880 | 32.8 | 400 | 150 | 36.9 |
| Middlesbrough | 7500 | 1735 | 23.1 | 1105 | 60 | 5.5 |
| Newcastle | 9480 | 4070 | 42.9 | 575 | 145 | 25.2 |
| North Tyneside | 3840 | 2605 | 67.8 | 450 | 50 | 11.1 |
| Northumberland | 8635 | 3890 | 45.0 | 665 | 30 | 4.7 |
| Redcar & Cleveland | 6435 | 1520 | 23.6 | 345 | 50 | 14.1 |
| South Tyneside | 5745 | 3505 | 61.0 | 260 | 80 | 31.8 |
| Stockton on Tees | 6905 | 1280 | 18.5 | 405 | 30 | 7.7 |
| Sunderland | 6320 | 4025 | 64.6 | 320 | 75 | 24.1 |
| Northeast (12) | 89,025 | 38,855 | 43.6 | 6525 | 995 | 15.3 |
| England(152) | 1,407, 190 | 605,425 | 43.0 | 144030 | 21050 | 14.6 |

As the table above clearly demonstrates, with the exception of Gateshead and Hartlepool, self directed support (including personal budgets and direct payments) is being implemented much more slowly for people with mental health problems than for other groups, with 8 out of 12 local authorities yet to reach 20%. However, as the figures for England show, the North East is marginally ahead of the rest of the country in delivering personalisation to this group. These figures should be viewed with caution for a number of reasons. For example, an individual might receive more than one direct payment in the period, in which case they may be counted more than once. Also it is not clear that all local authorities use the same method for calculating the number of people receiving social support for mental health reasons. For example, according to these figures, the total number of people receiving MH support from social care in Middlesbrough is three times that of other areas with a similar total population, such as Redcar and Cleveland, and South Tyneside.



# Personal health budgets

Personal health budgets, and direct payments from NHS funds, were piloted between 2009 and 2012 in around sixty sites including Tees PCT. About twenty of these pilots focused on people using NHS mental health services. An in depth evaluation of twenty personal health budget pilot sites was published in November 2012.[16] As a result of its positive findings, by April 2014 up to 50,000 people receiving continuing healthcare support from the NHS will have the right to ask for a personal health budget. It is the intention to widen the coverage of these budgets to other services in future years. However, research by the NHS Confederation indicates that there is still a long way to go before mental health staff feel comfortable and confident with the concept of personal health budgets and direct payments in the NHS, and there are concerns that this cultural barrier will impede implementation.[17]

There are other issues to be considered - for example, critics of the Coalition Government's *Health and Social Care Act 2012* have expressed concern that personal health budgets and especially direct payments represent another aspect of privatisation of the NHS, and there are fears that they open the door to fees and top up charges.[18] The transition to Clinical Commissioning Groups may also cause delays and further barriers, given both the structural upheaval involved and the fact that the Royal College of General Practice's Position Statement (June 2012) expressed concerns about personal health budgets in terms of clinical effectiveness, quality of services, cost, sustainability of NHS services, and the danger of creating new health inequalities.[19]

The NHS Confederation has suggested a *'dual carriageway'* approach in response to fears that personalisation will become overly complicated when both personal budgets (in social care) and personal health budgets (in the NHS) are available. Whether this next phase of personalisation will act as a driver for integration in mental health services, or create further complexity and dislocation between health and social care very much remains to be seen.[20]

Given that none of the mental health pilot sites were based in the region, the North East could find itself lagging behind other areas when it comes to offering personal health budgets to people using mental health services.

## Personalisation and Mental Health Payment by Results

In the NHS A Mental Health Payment by Results (MH PbR) model is being introduced and there are fears about how well it fits with the personalisation ethos. Critics argue that integration between health and social care is suffering as a consequence of implementing this at the same time as personalisation, and there are fears of increasing complexity and duplication for service users and staff alike.[21] In parts of the North East mental health social workers have reduced their direct involvement with Community Mental Health Teams in order to concentrate more on delivering self directed support. Elsewhere, early experiments to bring the two emerging approaches together have had limited success and it seems likely that meaningful integration of personalisation and MH PbR is still some way off.[22] At the very least, this presents another complicating factor when it comes to implementing personalisation for people with mental health problems.

[16] Evaluation of the personal health budget pilot programme, University of Kent, November 2012

[17] Facing up to the challenge of personal health budgets, NHS Confederation, March 2011

[18] http://www.redpepper.org.uk/the-end-of-the-nhs-as-we-know-it/

[19] RGCP Position Statement June 2012, Personal Health Budgets

[20] Joint personal budgets: a new solution to the problem of integrated care? NHS Confederation, October 2012

[21] Getting it together for mental health care: Payment by Results, personalisation and whole system working' National Development Team for Inclusion, January 2012

[22] hIntegrating Mental Health Funding' The Centre for Welfare Reform, 2011

# Personalisation research

*The Evaluation of the Individual Budgets Pilot Programme (2006 -07)* showed that people with mental health needs can and do benefit significantly from having greater control over their support, in some cases reporting higher levels of satisfaction than other client groups. The evaluation also found that there appears to be a small cost-effectiveness advantage over standard support arrangements for younger physically disabled people and people with mental health problems. Despite this, concerns continue to be expressed about the relatively slow manner and pace at which personalisation is being introduced in mental health services.[23 24 25]

In 2009 Mind published '*Personalisation in Mental Health, A review of the evidence*' as part of its '*Putting Us First*' campaign. This highlighted a number of earlier studies that showed that:

- In 2001 the number of direct payment recipients with a mental health problem was 50; in 2008 it was 3373. (It is currently 20,580).
- On the whole, given sufficient support, people with mental health needs use DPs imaginatively and effectively.
- The longer people are working to a model of self-directed support the better the outcomes, suggesting that benefits should increase over time.
- Given that mental health services are often concerned with the management and control of 'risky behaviour', there are particular worries about the management of risk for people choosing to opt for a PB.
- Better targeted training and support for frontline staff is needed to encourage a higher level of take up of DPs and PBs.
- There are a number of systems-level developments that are needed, including better streamlining of the Care Programme Approach with the personalisation approach, and clarity in the application, eligibility and assessment processes.

The *Personal Health Budgets Evidence Scan (Health Foundation, 2010)* summarised a number of useful findings:

- A review of PBs in social care found that almost all schemes in the EU have underestimated implementation costs, perhaps partly due to unpredicted demand and unmet needs. This means that sometimes evaluations use underestimates when calculating cost effectiveness, making it even more difficult to draw conclusions.
- Despite these caveats, there are some positive trends. In Germany, it has been suggested that people receiving long-term care spend 50% less with PBs than they would with traditional care, and in the Netherlands some suggest spending is 30% less.
- Most of the international evidence about improved outcomes comes from the US and suggests some improvements are possible, but the literature is far from conclusive and studies are small and open to challenge.
- International studies suggest that personal budgets do help to improve patient centred care and control, and can help people feel more empowered and confident about their care. Some similar UK research is also available.

In 2011 two national studies in the UK found that increasing numbers of people are now enjoying the benefits of greater control and choice as a consequence of having a personal budget and/or a direct payment. Outcomes are generally improved for all groups in most domains (more for some than others and there is huge variability across councils) and there are high levels of satisfaction. However, many issues remain, with the level of bureaucracy involved, the lack of support for the overall process, and limited flexibility in how money can be spent. The relatively small rise in direct payments also led to concerns that 'managed personal budgets' are seen as the easy option for councils, leading to calls for direct payments to become the default method for receiving a personal budget.[26 27]

[23] Getting Personal: Making personal budgets work in local authorities, Rethink Mental Illness, 2011

[24] Financial management of personal budgets, Audit Commission, 2010

[25] Getting Personal: Making personal budgets work in local authorities, Rethink Mental Illness, 2011

[26] National Personal Budget Survey of service users and carers, Think Local, Act Personal, June 2011

[27] ADASS Personal Budget Survey, March 2011

In November 2012 the final report of the evaluation of 20 personal health budget pilot sites in England found that

- PHBs were cost effective and thus wider roll out is supported.
- High-value PHBs were most cost-effective, suggesting they should be initially targeted at people with greater need, as substitute for conventional service delivery.
- PHBs were cost-effective for people with mental health problems and those receiving NHS continuing healthcare but the analyses for other health conditions were inconclusive due to small sub-samples sizes.
- Budget-holders emphasised the value of information and guidance about their budgets, including what services were covered.
- The use of PHBs is likely to result in greater use of 'non-conventional' providers.[28]

# Personalisation and mental health

Progress with implementation continues to vary widely in different parts of the country but also for clients with different kinds of needs. According to the 2011/12 figures on the Health and Social Care Information website, across all English local authorities, the average for learning disability is at 58.8%, physical disability 47.9% and older people at 45.2%; with mental health at only 14.6%.[29] (Also see page 7).

The low numbers of people using personal budgets for mental health reasons show that whilst it is still being implemented in social care, and whilst there are exceptions, personalisation is far from being seen as part of the overall culture in all mental health services. There are a number of critical factors:

- The drive to implement personalisation has since 2008 been in social care. However 80% (or more) of the mental health services budget sits with the NHS, where personalisation has not been seen as a priority in the North East.
- Social care assessment for those with mental health needs still tends to be accessed via 'health' gateways' (eg GP referral to CMHT, then possible referral to mental health social worker). This adds layers of time and complexity to the process of accessing a personal budget.
- Continued lack of knowledge and confidence amongst mental health professionals about self directed support, personal budgets and direct payments.
- Limited and patchy access to the support a person (and their carer) needs in order to understand and make meaningful use of a personal budget - especially those who most dependent on the psychiatric system.
- The fluctuating nature of many mental health conditions, resulting in changing support needs can be problematic.
- Stereotypical, limiting attitudes about people's capacity for self-determination still exist.
- The absence of simple distinctions between what is health and what is social care in mental health services - with ongoing debates about who pays for what.
- Lack of knowledge and information for service users and carers, including limited access to positive peer stories and local expertise.

The importance of these barriers has been acknowledged for some time, but tackling them continues to pose a difficult challenge to implementation.[30] [31]

[28] Evaluation of the personal health budget pilot programme, University of Kent, November 2012

[29] Adult Social Care Outcomes Framework - England, 2011 - 12, Final, Feb 15th 2013, The Health and Social Care Information Centre

[30] A Voice and a Choice: Self Directed Support by people with mental health problems, A Discussion Paper In Control, September 2007

[31] Personalisation in mental health: Breaking down the barriers, A guide for care coordinators, Mind, 2009

# Additional challenges in the North East

## 1. Levels of mental ill health

The connection between rates of mental illness and levels of poverty, unemployment and social isolation is well established. Indicators designed to estimate likely rates of mental health problems in the population suggest that the North East has higher than the national average rates of both common mental health problems and severe mental illness. The region has the lowest percentage of people with a mental health problem in employment and the highest claimant rate for incapacity benefits for mental and behavioural disorders (396 per 100,000 compared to 263 per 100,000 for England).

Employment can protect mental health by boosting confidence and self-esteem and people with mental health problems can be particularly sensitive to the negative effects of unemployment. Amongst working age adults in this region the being out of work rate is 71.8 per 1,000 population, compared to 59.4 in England as a whole (2010/11). The number of young people not in education, employment or training (NEET) is also high - (8.8% compared to 6.2% England average).

The general health of people in the North East tends to be worse than that of England as a whole; the region has the highest percentage of adults with a life limiting long term illness (21.5% compared to 16.9%). Levels of deprivation are high; in 2010 32% of the relevant population were living in the 20% most deprived areas in England, compared to 9.8% for the rest of the country. Life expectancy for both men and women is consequently lower than the England average.

### Table 4. **Mental ill health** - the North East has:

- One of the highest percentages of people over 18 using specialist mental health services (3.2 - 3.4%, England average is 2.5%)
- Significantly more than the average number of people on a Care Programme Approach (9.7 per 1,000 population, compared to 6.4 England average)
- 310 in-year bed days for mental health per 1,000 population (England average is 193)
- Significantly higher than England average rates of depression (15.60 per 1000 as opposed to 11.68)
- The highest percentage of common mental disorders amongst women (26%)
- More women with two or more psychiatric conditions than any other region
- The highest levels of self harm amongst both men and women in England, including the highest age standardised rates of hospital admission for self harm and for drug overdose (353 per 1000 compared to an average of 207)
- The second highest level of suicide (8.5 per 100,000 of the population)
- The greatest percentage of women with alcohol dependency and the second highest level of male and female alcohol related deaths
- 30.9 per 1000 hospital admissions for alcohol related conditions (compared to 22.1 across England)
- 0.62 % of adults (18+) with dementia (compared to 0.53 for England)

**Sources:** Community Mental Health Profile NEPHO 2013; Indications of Public Health in the English Regions 7, Mental Health; North East Regional Summary, Health Profile 2010, Association of Public Health Observatories; Patterns of Mental health Service Usage in England, Centre for Regional and Local Statistics, 2010; Adult Psychiatric Morbidity in England, Results of a Household Survey, NHS Information Centre; North East Regional Suicide Prevention Steering Group, A Five Year Strategy, 2010; Alcohol Related Deaths in the UK, 2000 - 2009, Office for National Statistics, 2011.

# 2. The North East's Mental Health Voluntary Sector

Since 2008, a combination of global recession, Coalition Government austerity measures (in particular the programme of cuts to local authorities), and a revisioning of 'Civil Society' has resulted in a dramatic recasting of the relationship between the state and the voluntary sector that was forged over the previous decade.

Since 2011 various regional health and social care development agencies have closed, and local authorities are drastically cutting budgets. Sources of statutory sector grant funding for voluntary and community groups have therefore significantly reduced, and this trend looks set to continue as a consequence of Government policy. At the same time there has been a move towards tendering and procurement processes, with bigger and bigger contracts that tend to exclude smaller service providers. Payment by Results systems, and the shift towards Social Investment (ie loan based models of funding) have further changed the financial landscape in the past two or three years. In this new world, smaller mental health charities and VCS infrastructure bodies are especially vulnerable.

Around £800k per annum was lost when the North East Mental Health Development Unit closed in September 2011, much of which was invested in research, consultation and development work critical to the mental health VCS, and service user and carer groups. In addition to the loss of funding opportunities from the statutory sector, there has also been a reduction in the availability of charitable grants. For example, in 2011 the Northern Rock Foundation's grant programme, already much less than it had been a few years before, was reduced by a further third to £8m. The January 2012 sale of Northern Rock plc to Virgin Money means that even the current levels of grant making are not guaranteed beyond 2014.

Many mental health VCS organisations are therefore faced with downsizing and letting staff go. At the same time there are increasing demands on their services, as unemployment increases, poverty deepens, and public services are diminished. Service providers find themselves having to ration or reduce support and care to people in increasing need, and the sector's longstanding tradition of dissent and protest has to some extent softened, as an agenda for survival has taken over, and agencies increasingly compete for ever diminishing funding opportunities.

## Table 5.
## The 'State of the Sector' Update, VONNE 2011

- There are 4760 general charities in the North East, around one fifth of which work in health and social care. There is a much larger number (about 10,000) community groups that are described as 'under the radar'.
- Across the sector as a whole, income is estimated to be £1.54bn. Compared to the rest of the country however, average income per organisation is considerably less (£153,400 in the North East compared to £207, 500 nationally).
- The third sector in the North East is more reliant on public sector funding (49% compared to 38% for the UK nationally); making it more susceptible to ongoing cuts in public sector funding.
- 73% of organisations had experienced cuts to funding, and 40% had lost staff. Roughly, one quarter was considering cutting services or closing altogether. Despite these reductions in capacity, 59% had witnessed an increase in demand for advice and support.

# 3. The Cuts and the North East

***The Tipping Point: the human and economic costs of cutting disabled people's support, The Hardest Hit, October 2012***

*Across the UK 3.6 million people claiming disability benefits will be £9 billion worse off from 2010 to 2015, with an estimated 500,000 disabled people expected to lose out when DLA becomes Personal Independence Payment (PIP) in April 2013. Around 450,000 disabled households are set to lose out under the new Universal Credit (UC) system, including 100,000 families with disabled children that stand to lose up to £28 a week. Disabled people are already twice as likely to live in poverty and even a small loss of income can tip them into greater dependence on health and social care services, or friends and family.*

In 2009, the Royal College of Psychiatrists stated that it was entirely predictable that reduced health and social care, increased unemployment and financial hardship would lead to raised levels of emotional distress and mental ill health in individuals, families, and communities.[32] In common with many other organisations that advocate on behalf of vulnerable people, The Centre for Welfare Reform has set out a detailed analysis of the way that Coalition Government cuts have since then unfairly targeted people in poverty, disabled people and their families.[33]

Higher levels of poor health (including mental illness), unemployment and reliance on certain benefits in the North East mean that all of these effects will be felt disproportionately in this region. This is very well set out in another recent report: *The Impact of Austerity Measures on Women in the North East of England. The Women's Resource Centre, October 2012.*

Other worrying factors were set out in *'Well North of Fair'*[34] the IPPR's response to the Coalition Government's 2010 Comprehensive Spending Review, which shows that:

- Cuts and welfare reforms will negatively affect more people.
- There is greater competition for job vacancies than anywhere outside of London.
- There is the highest proportion of working age adults claiming out of work benefits.
- There has been significantly lower levels of investment in transport, technology and science in recent years than the average for the country as a whole.
- The greatest number of public and private sector jobs has been lost as a consequence of cuts to public spending.

[32] Mental Health and the economic downturn, RCPsych, NHS Confederation & LSE, November 2009

[33] Campaign for a Fair Society, www.centreforwelfarereform.org/

[34] Well North of Fair, The implications of the spending review for the north of England, Cox and Schmueker, IPPR , 2010

MHNE has looked closely at the impact of Work Capability Assessments and Employment Support Allowance on people with mental health problems. The inadequacies and insensitivity of the process, the high levels of people found to be fit for work in spite of serious health conditions (69%), and the high percentage of decisions that are reversed on appeal (40%) have led to many calls for the government to stop and review this process.[35] [36] Given that about 1m people receiving Incapacity Benefit do so for mental health reasons,[37] this is a major issue and an additional source of stress for people in the mental health system, and just one example that the Coalition Government's approach to managing the deficit is impacting very specifically on people with mental health needs.

There is a growing and deeply concerning body of evidence that shows quite clearly the way that government policy is having an unfair and uneven impact in some parts of the country when compared to others. In 2012 The Institute for Fiscal Studies calculated that at an average of 13%, North East local authorities are suffering the highest level of cuts[38]. The measures that are being introduced will have an increasingly detrimental effect on vulnerable people in the North East with mental health problems, and the resources that are available to support them.

In a recent survey (Personalisation Revisited, October 2012) MHNE's members identified financial pressures due to reduced LA funding and fees as the biggest challenge they are currently facing. along with increased bureaucracy resulting from the shift to contracts, and changes relating personalisation - specifically providing support to clients to get a personal budget and attracting new/enough service users.

The combined effect of all the above factors is especially worrying in a region where the Department of Health's own figures show that investment in adult mental health services has been consistently less than it has been in other parts of the country.[39]

Against this backdrop, it is not surprising that dealing with budget and service cuts has increasingly become much more of a priority than implementing personalisation.

*'The loss in 'Spending power' equates to a reduction of £80.21 per head of population in the North East compared to the England average loss of £49.30 per head and the South East reduction of £21 per head. The Association has highlighted that some of the technical measures employed by the Government, appear to have had the effect of reducing allocations to areas with higher levels of deprivation, such as the North East. In addition, the loss of Working Neighbourhoods Fund means that the North East will lose a further £73m. This fund targeted areas with higher levels of deprivation and aimed to support local communities into employment opportunities and its loss will mean that support in this area will be reduced.'*

Response to proposals for a Review of Local Government Finance, Association of North East Councils, 2010

[35] Early Motion 435, ATOS, The Work Capability Assessment and Mental Health, www.parliament.co.uk

[36] GPs call for Work Capacity Assessment to be scrapped, Guardian Society, 23rd May 2012

[37] Mental Health and the UK Economy, Oxford Economics, 2007

[38] The IFS Green Budget February 2012, Chapter 6, The Institute for Fiscal Studies

[39] 2011/12 National Survey of Investment in Adult Mental Health Services, Department of Health, August 2012

# Personalisation and the North East's Mental Health VCS

*"I have learned about it, discussed it and went to more meetings than I wish I had. I have discussed unit costing, creating a new business model and considered developing a new finance system. I took the view that it was better to wait and see rather than go through a range of expensive changes (that also drain human capacity) without knowing where this is all really going"*

Personalisation Revisited Survey
MHNE October 2012

## In the beginning

When the concept of personalisation and the policy of self directed support was first introduced in 2008, voluntary sector social care organisations were initially presented with a mixed agenda of risks and opportunities. These included:

- Announcements by local authorities that there would be a major shift in funding as block contracts would soon end, and individuals would purchase support via personal budgets and direct payments.
- A shift in the relationship with beneficiaries as 'service users' become 'citizens' responsible for their own choice and control.
- The need for service providers to embrace business change and alternative financial models.
- Possibilities of developing a new offer and attracting new business.
- Fears that there would be 'losers' as service users exercised their consumer power and market forces took their toll.

## Business change

Encouraged by numerous readiness toolkits and preparation events, the most proactive and innovative agencies responded by investing considerable amounts of time and energy into organisational development that focused on four key areas:

- **Finance** - calculating unit costs based on full cost recovery, in order to determine what charges to make to individuals.
- **Staff** - reviewing HR policies and workforce contracts to ensure that maximum flexibility is offered.
- **Outcomes** - putting in place systems to demonstrate impact.
- **Marketing** - initiating effective strategies - 'selling not just telling'.

## Operational challenges

Throughout the life of the project, a number of 'sticky' issues have challenged implementation from the sector's perspective, and to some extent they continue to do so:

- **Access** - many people relying on voluntary sector mental health services have considerable support needs that nonetheless do not meet FACS criteria for social care - or the entry criteria for specialist mental health services. They cannot access personal budgets to pay for their support, but on the other hand there is a declining amount of 'open' or universal services for them to use
- **Narrowing eligibility** - this issue is worsening as a result of pressure on local authority budgets and the consequent narrowing of previous eligibility criteria

- **Preventive services** - many of MHNE's members offer activities and resources that are 'open' to anyone who needs them. Historically these have been funded in two common ways:
  - o local authority grants - which have now drastically reduced, as a result of the move to contracts, the shift to personal budgets, and more recently by reductions in LA funding.
  - o charitable grants - in recent years these have also reduced, resulting in increased competition.
- **Multiple funding streams** - some providers are considering mixed models where support is offered on different terms for different people. So for example, an individual's attendance at the same group activity may be variously funded by personal budget (if they have one), by charitable grant (if they are vulnerable but do not meet the threshold for care) or if they can afford it, they may be self funding.
- **Introduction/extension of charges/ budgets not covering the cost of existing care packages** - pressure on social care funding has led to more and more people with mental health problems being required to contribute financially to the cost of their care. This has caused some to stop using services contracted by the local authority. This creates a complex set of issues for VCS providers; they may be in the position of enforcing payment of council charges, but with no financial gain from the fees themselves.
- **Inadequate care planning processes** - service providers have been excluded from care planning even when direct payments have been set up to fund participation in that provider's activities. This has created worrying scenarios including people simply turning up and attempting to pay for activities or support using cash, without any prior planning or notice.
- **Lack of monitoring and scrutiny** - care manager support has sometimes been withdrawn at the point that a direct payment has been set up leaving the individual without guidance and advice.
- **Advice and information** - MHNE's members are spending increasing amounts of time advising and supporting the people they work with about the personal budget process and this is having an increasing demand on staff time.
- **Brokerage and signposting** - as above - MHNE's members are increasingly having to offer independent advocacy to personal budget holders as this kind of help is not readily available elsewhere in the system.
- **Absence of clear timescales and transitions** - in many local authorities, implementation timescales (where they have existed) have been constantly revised. This has made it almost impossible for providers to plan for the move to new and alternative business models based on personal budgets and direct payments. In a recent MHNE survey 20% of organisations that responded knew no one in their service who had a personal budget or a direct payment.

*"There has been considerable time slippage which is not helping either service users or providers in making preparations as tangible information on which to make decisions is not being received"*

*"It needs developing and rolling out and not just talking about"*

Personalisation Revisited Survey
MHNE October 2012

## Table 6.
## Personalisation Revisited Survey, October 2012

Over the life of the project three surveys and twelve events for MH VCS providers and other partners were organised. The most recent survey (October 2102), received 33 responses, which is about 10% of MHNE's membership, and not an untypical response rate for this kind of survey. The results offer a useful insight into the MH VCS's current position in relation to personalisation, and the extent to which this policy has had any direct organisational impact. Headline findings include:

- Over one third said they have yet to make any changes in response to the personalisation agenda. However, a similar proportion have calculated unit costs, made changes to staff roles and created new business models (including targeting new client groups and connecting more to mainstream community resources) to reflect the opportunities potentially being offered by personalisation.
- Almost half stated that they have no income from personalisation. This includes two organisations that provide free support, and do not expect to create income from direct payments or personal budgets in the future. The majority of respondents estimated less than 10% of income is generated in this way.
- Three organisations indicated that they now have significant income from personal budgets and direct payments, with the overall percentage income estimated between 40% and 100%. These providers are all in the south of the region, specifically Darlington and Redcar and Cleveland. They estimated that between 50% and 100% of service users pay for their support in this way.
- Only four organisations were optimistic that there would be opportunities to increase income from personal budgets and direct payments over the next year or two.
- The three main sources of information about personalisation are the MHNE Personalisation project, and commissioners and personalisation leads in local authorities, followed by other VCS bodies and colleagues. Over a quarter reported that they still struggle to get information.

# The Critical Friends Project

*Every mental health professional should be aware (of personalisation) so they can advise their clients. If they don't know, they can't tell anyone else. Everyone should know about it. It's not that complicated. It gives you choice around how you want your care to be provided".*

Personal budget holder, MHNE Critical Friends Project, April 2012

Between 2011 and 2012 MHNE was funded by the North East Mental Health Development Unit to develop peer expertise and support around personalisation and direct payments in order to fill a gap that was felt to exist for people using mental health services. The first task was to try and identify a group of 20 people from around the region who were receiving personal budgets for mental health reasons. We began by speaking to service user and carer groups, but were disappointed to find that the majority of people we spoke to had not been given any information about personalisation despite being long term users of mental health services. We consulted a wide range of MH VCS service providers, care managers and personalisation leads, but it was extremely difficult to recruit participants into the project. As a consequence, the six month project was extended into a 15 month piece of work and the focus was shifted from building peer capacity and expertise to simply gathering a selection of experiences of personalisation from a mental health service user perspective.

Five individual stories were successfully gathered. In each case there were clear benefits and positive outcomes associated with having a direct payment, but a common set of difficulties and frustrations with the process was also shared. The final report included an account from a group of people who had all recently been through a very negative personal budget assessment experience leaving them feeling confused, angry and anxious. Findings are summarised in table 7 below.

Table 7: **Problems with personal budgets/direct payments**

| Problems with personal budgets/direct payments |
|---|
| Lack of knowledge and misinformation from key workers and other professionals |
| Direct payments being arranged for very specific activities and needs, but a lack of clarity about the process or how to influence it |
| Not feeling really involved in the process |
| Long waits before decisions were made |
| Confusion about why some things were funded but not others |
| Stress involved with managing the money (especially initially) |
| Feeling very anxious when the six month review comes around |

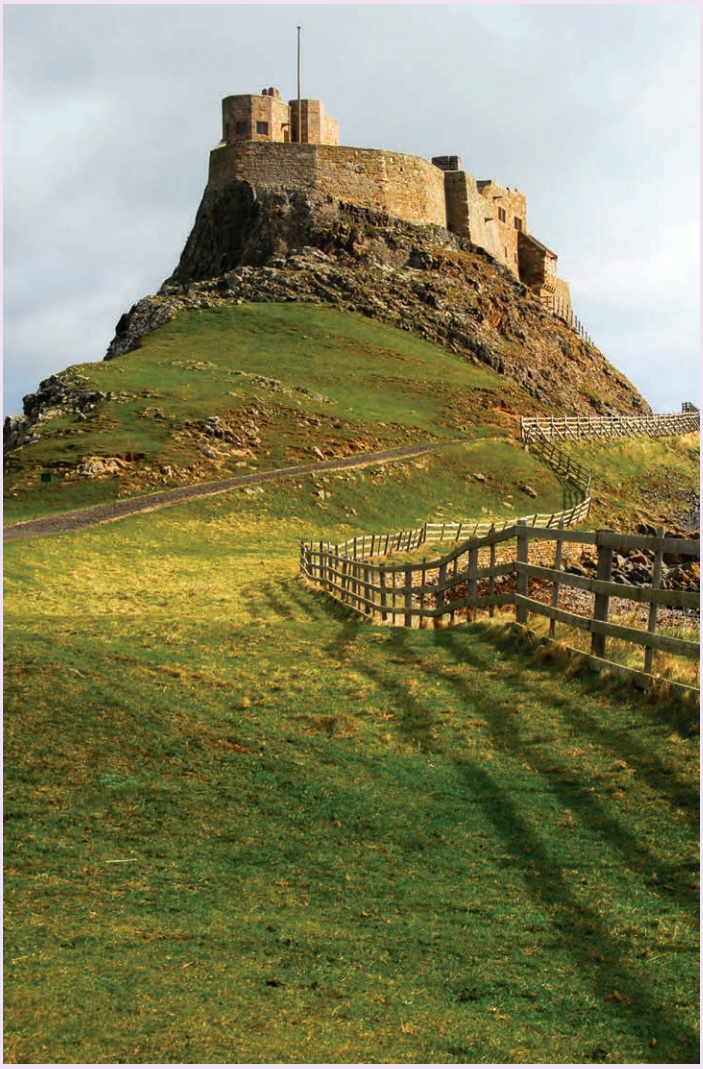
| Benefits and positive outcomes of personal budgets/direct payments |
|---|
| Travel, getting to college |
| Going to the gym and the art studio |
| Paying for course fees |
| Getting out into the world |
| Short breaks |
| Paying a relative to come and provide support |
| Paying for meditation classes and respite |
| Increasing confidence |
| Reduced panic attacks |
| Improved motivation |
| Freedom and security |
| Social contact |
| Learning new skills |
| 'It spurred me on to learn to drive' |

*"Tell the professionals that it is available. It is supposed to be brought up at every new care plan or review but no one ever mentioned it to me in the first five years I was with the mental health service. The numbers that take it up are very poor but that it is because no one knows about it and the service providers do not bring it to your attention".*

Personal budget holder, MHNE Critical Friends Project, April 2012

MHNE's Personalisation Revisited Survey (October 2012) asked members about service users' concerns about personalisation. These are some of the responses:

- *It already seems from those that have been re-assessed in (this area), that some people are coming out with very low scores and hence a reduced budget. Therefore the message coming out is don't volunteer for a budget – wait until you are called for re-assessment.*
- *Service user's fears around re-assessment are tied in with a general suspicion around the review process around Incapacity Benefit, Employment Support Allowance and ATOS. Will the re-assessments for personal budgets work for Mental Health?*
- *How will the assessment process take into account the fluctuating nature of mental health conditions? At what point will a direct payment or personal budget cease upon a condition improving or during a hospital admission?*
- *Is anything being done in order to make the system for application more accessible/ more user friendly/greater support for mental health service users?*
- *Three years down the line there is still a reduced confidence in personal budgets and direct payments amongst mental health service users.*



*"Most clients feel that they have more freedom within their personal budget and it has been positive for many ... we have a client who was over the moon at going to the cinema. He had never been before. Something so small to us, made such a difference to his mental well being"*

Personalisation Revisited Survey, MHNE October 2012

# Chaos or Empowerment? Concluding thoughts

Amongst the half a million or so people currently using personal budgets, there are many examples of success, people who now enjoy greater choice and control over their care and support, and whose wellbeing and quality of life has improved as a result. Equally there is no doubt that large numbers of people experience the processes involved as confusing, rigid and bureaucratic – in other words – as deeply impersonal.

**So has it produced chaos? Or has it been empowering?**

In attempting to answer this question almost five years after the project began, it is first necessary to consider two critical, overarching factors:

1. Personalisation is no longer centre of the policy stage:

a. For MH VCS providers the spotlight is on cuts to local authority social care budgets,[40] and the shift away from grant funding to tendering and contracting processes that tend to exclude smaller providers.

b. For the majority of service users and their families the notion of self directed support has been entirely upstaged by an oppressive regime of welfare cuts and seemingly endless reassessments for out of work and disability benefits.

2. Terms such as 'choice', 'control' and 'personalisation' have become increasingly diluted and difficult to separate from the wider neoliberal political agenda of extending a blatantly consumerist approach into public services.

There is an additional overarching factor from a mental health perspective:

3. Limited progress with implementing personal budgets for people with mental health needs means that most MH VCS providers (and their beneficiaries) have so far experienced very little tangible impact, other than investing in business development and new ways of working with beneficiaries.

Therefore, for MH VCS service providers in the North East, personalisation has arguably produced more chaos than empowerment:

- Slow, incremental implementation creates a kind of limbo for providers. Without a critical mass of personal budget holders the level of income from personalisation is not sufficient to rely on, and the absence of clear timescales makes transition planning almost impossible.
- Personal budgets can be rigid, with no flexibility for the provider to respond quickly to fluctuating need by providing additional support.
- Providers are spending substantial amounts of time helping people with various aspects of personal budgets and direct payments. This is new work often not recognised in contracts.
- Open access 'prevention' based services, often funded by charitable grants, are experiencing increased demand. They frequently support a mix of people who do not meet FACS criteria (so will not get a personal budget) and others who do. This creates an anomalous situation, with some having 'free' access and others having to pay for the same activity.
- Providers that cover more than one local authority area have to manage differences in the way personal budgets are calculated, variations in the level of personal contribution, and inconsistent rules about how they can be spent.
- Developing the 'social care market' is a term that is repeatedly associated with personalisation strategy[41] – and yet to date there has been only limited evidence of this happening in a proactive way that includes the MH VCS.

[40] Cuts hurting personalisation, warn social workers, communitycare.co.uk 5 July 2012

[41] National Market Development Forum, Think Local Act Personal

## Table 7. **Some ongoing implementation issues affecting service providers and individuals**

- **Differences in Resource Allocation Systems** – with some areas having a separate system for people with mental health needs.
- **Care packages reduced** – councils re-assess people as part of the self directed support process, and it is not unusual for the resulting personal budget to be less than the cost of the person's existing care package.
- **Squeezing of budgets** – the effectiveness of a personal budget can be limited by tighter eligibility criteria, increased charges and personal financial contributions, and the introduction of caps or ceilings to the cost of support packages.
- **Financial variations between councils** – including different hourly rates paid for specific activities eg domiciliary care; and different approaches to charging and personal contributions for social care.
- **Using a Personal Assistant** – this is a popular way of using a direct payment but problems continue eg checking self employment status, covering pension contributions, redundancy payments, sickness and holiday cover, CRB (DBS) checks, and whether a PA can also be a relative or live in the same house – with neighbouring councils adopting different policies.
- **Access to advice, brokerage and signposting** – huge variations in the level of guidance and support that is available and how this is resourced mean that some don't get the help they need to exercise meaningful choice and control.
- **Scrutiny and accountability** – some councils have adopted a very risk averse, bureaucratic approach, requiring onerous levels of record keeping and reporting by the direct payment holder whilst limiting how the budget can be spent. Others appear to leave the person to get on with it with very little oversight.
- **Section 117** – despite a change in legislation (2009) to allow people on Section 117 of the Mental Health Act (1983) to access direct payments, there is still great variation in practice around the region.
- **Introduction of personal health budgets** – these have not been piloted for people using mental health services in the North East. In pilot sites elsewhere PHBs have been used by mental health service users to buy items and support that are identical to that purchased by people using social care personal budgets. Without a careful and proactive strategic approach, there is considerable risk of disputes about who should be paying for what, greater complexity, and increased bureaucracy when personal health budgets are rolled out in mental health services.

**Has personalisation been empowering for people needing support for their mental health needs?**

**From a mental health service user and carer perspective, there is more of a mixed picture associated with personalisation.**

The *Critical Friends* project (see page 18) demonstrated that however distressing the process of getting a personal budget or direct payment is, there are people in the North East who have experienced positive benefit. Given that this is usually associated with greater choice and control, it is reasonable to assume that there is some degree of empowerment.

However, as with organisations, individuals frequently find that personalisation brings a variety of problems that can make the experience confusing - and chaotic:

- Many mental health staff, especially in areas where teams are not integrated with social care, still know very little about personalisation and can only offer limited help and advice.
- Even when staff are confident about self directed support and the process locally, they may not have the time to properly support a person (or several people on their case load) to make meaningful choices.
- For some the personal budget process results in their care package being reduced and having to pay charges for the first time. Some have opted out of services as a consequence.
- Some very vulnerable people who use mental health services struggle to take up the offer of 'choice and control'. This might be a consequence of depression, psychiatric medication or a history of disempowerment and institutionalisation. The time and support needed to help them exercise meaningful choice and control is not always readily available.
- This situation will become more problematic if TLAP continues to insist that direct payments are to be valued above council-managed personal budgets as the default option.[42]
- The introduction of personal health budgets could bring additional complexity and possibly duplication for service users and carers.[43]

Overall, for people using mental health services, personalisation – especially in the form of personal budgets and direct payments, presents a mixed picture, with some people benefiting, some struggling with it, and the majority still not having the opportunity to try it out.

# Recommendations

The original aim of personalisation – that help and care should be tailored to fit the person's individual needs and circumstances – is in danger of being lost. It is perhaps not surprising that councils are finding it harder than anticipated to truly empower people with support needs. This is especially true in mental health services, where after five years take up in most parts of the country remains low. For people with mental health needs, personalisation remains very much a work in progress.

Mental Health North East therefore makes the following recommendations to everyone involved in the attempt to make personalisation work as an effectively and meaningfully as possible:

1. If personalisation is to be successfully implemented in mental health services, there needs to be a much more apparent and concerted effort made by councils working together with the NHS. This needs to take into account the Care Programme Approach, and Mental Health Payment by Results. There are real fears that without such a concerted effort, personalisation for people with mental health problems will fall further and further behind other groups.

[42] Transforming Adult Social Care through Direct Payments, Think Local Act Personal, Event Resources, 2011/12

[43] Psychiatrists and adult care directors pledge more joint care for people with mental health problems, ADASS and Royal College of Psychiatrists joint press release, March 2013

2. This also needs to include a genuinely integrated approach to the introduction of personal health budgets, with joint proactive work to ensure that assessment, allocation and monitoring of health and social care personal budgets does not result in greater duplication and complexity for the service user.

3. The North East's MH VCS now has a great deal of expertise around personalisation, personal budgets and direct payments. Councils (and going forward, health commissioners) should recognise and make better use of this knowledge and resource to assist implementation.

4. Whilst it may not ultimately be suitable for everyone, there are still plenty of people with mental health problems who could benefit from having a personal budget but despite being eligible have yet to be offered one. Enabling these people to have greater choice and control should now be a priority for personalisation managers and leads.

5. It should be accepted that some people in the mental health system who are eligible for a personal budget will require significant amounts of help and support to enable them to understand, make use of and benefit from personalisation. This needs to be resourced.

6. Managed budgets must continue to be an option for those that want it.

7. Some experts have started to question whether the self directed support model is the best (or indeed the only) way to deliver personalisation and personal budgets.[44] Given the ongoing difficulties in delivering self directed support for people with mental health needs, councils and their partners should be prepared to consider alternative methodologies for delivering personalisation, including direct payments.

8. Advocacy, peer support and peer brokerage have been shown elsewhere to be effective ways of increasing uptake of personal budgets and direct payments. These need to be encouraged and developed in the North East.

9. The MH VCS has a crucial role to play in ensuring that personalisation is implemented effectively and meaningfully. MHNE (and its members) should continue to act as advocates and catalysts for good practice across the North East and to be a source of up to date information about personalisation in mental health.

## Acknowledgements

This publication would not have been possible without the help and support of many people from mental health services around the region and nationally. This includes colleagues in social care, voluntary sector organisations, service user and carer groups, NHS Foundation Trusts, commissioners and personalisation leads, who with great energy and dedication, work hard to make sense of personalisation; and who everyday strive to minimise chaos and maximise empowerment for people with mental health problems and their families. I am also immensely grateful to my friends at Mental Health North East and the Millfield House Foundation for their guidance and encouragement over the past five years.

Steve Nash

[44] How self-directed support is failing to deliver personal budgets and personalisation, Slasberg, Beresford and Schofieldl, Research Policy and Planning, The Journal of the Social Services Research Group, (2012) 29(3)

## About the project - *Chaos or Empowerment?*

In 2007, the Government set out a major programme of change for social care, including the introduction of personalisation and personal budgets. In 2009 the government indicated its intention to extend personal budgets and direct payments to the NHS. MHNE's members rightly saw these changes as a radical shift in the way people with support needs would access help and care, and in the way that service providers would be funded. Between 2008 and 2012, Millfield House Foundation supported MHNE to explore the impact and implications of the personalisation agenda for voluntary mental health agencies in the North East, and for the people it supports. The project's title 'Chaos or Empowerment?' reflects the scale of innovation and uncertainty that continues to be associated with this policy and its implementation. You can access all of the project's reports on personalisation and related matters at www.mhne.co.uk/personalisation

## About the author

Steve Nash was Personalisation lead for Mental Health North East between 2008 - 2012. He is a qualified occupational therapist and dramatherapist with thirty years experience in mental health services and other parts of the public sector. He has worked as an independent consultant and facilitator since 2006. Steve is a founder member of Playback Theatre York, offering creative, drama based ways of working with communities, groups and teams. He currently chairs and coordinates VOLSAG, the voluntary sector mental health network for Newcastle.

## About Millfield House Foundation

Millfield House Foundation

The Chaos or Empowerment? Project was funded by Millfield House Foundation. MHF's Trustees seek to use the Foundation's resources to help build a better society, one more equal and less divided. The current priority is to promote social change by funding projects that inform discussion and influence public policy and attitudes, with the aim of diminishing social deprivation and empowering communities, in the first instance in the Foundation's own home conurbation and region. www.mhfdn.org.uk/

## About Mental Health North East

MHNE Mental Health North East

Mental Health North East leads a consortium of Voluntary Sector organisations supporting people to improve their mental health and wellbeing. MHNE's remit is to work with all sectors involved in social care, health and wellbeing (voluntary, statutory and private) in order to improve services to people with mental health issues, their families and carers. Visit www.mhne.co.uk in order to find out more about the range of campaigns and activities MHNE is undertaking, and to sign up for their regular bulletin.

For further copies of this report, to get in touch with the author, or to find out about MHNE's other work and how to become a member, please contact:

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