



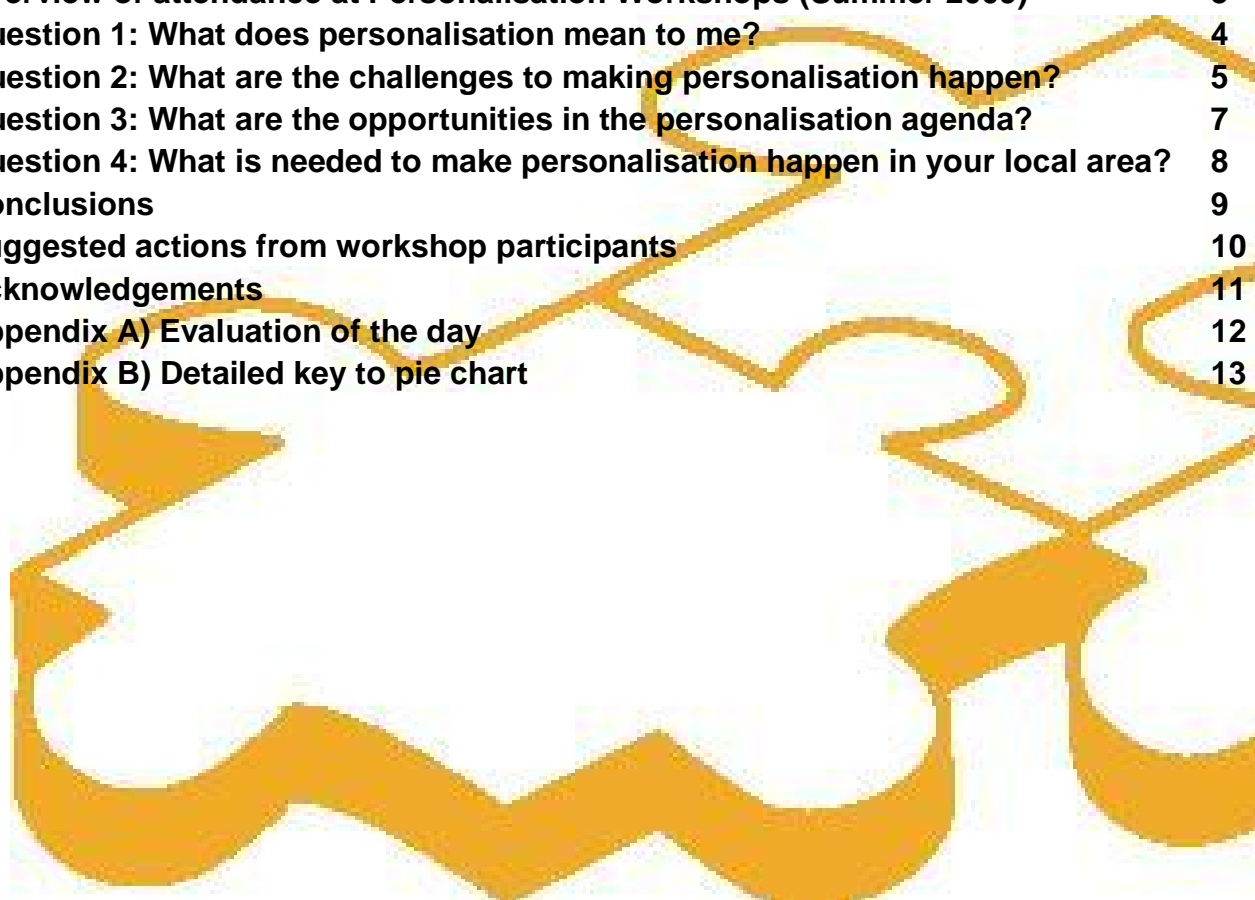
## Mental Health Personalisation Workshops London, June and July 2009.

In June and July, the Social Perspectives Network held five workshops across London. The following report is a summary of the key themes that emerged.

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## Context.

Personalisation is the key driver for reform of the health and social care systems including mental health. The IBSEN study<sup>1</sup> was the first major evaluation of Individual Budgets (IB), which form a major part of personalised approaches. The IBSEN study findings need to be treated with some caution due to sample size and the short time span in which outcomes were measured. Nevertheless, the report comes to three key conclusions with respect to uptake and outcomes for mental health service users who used IB

- a. the uptake of IB was much lower for mental health service users than for the other groups in receipt of IB. These groups included people with physical disabilities, older people and people with learning disabilities
- b. mental health service users in receipt of Individual Budgets experienced better social care and better psychological outcomes and reported higher quality of life than the control group not in receipt of IB
- c. the mental health sample in receipt of IB used less money per head than the sample group of mental health service users not on IB as well as the other user group categories in receipt of IB

So, why the anomaly of low uptake despite demonstrable benefit to mental health service users and cost savings to the system?

Social Perspectives Network (SPN)<sup>2</sup> in conjunction with Commissioning Support for London (CSL)<sup>3</sup> and the Department of Health London Region wanted to explore where people were with the personalisation in mental health agenda in London, what the barriers were to rolling out personalisation in mental health and how these might be overcome. We felt that the best way to explore this was to facilitate better dialogue between the full range of stakeholders involved in personalisation in mental health across London, including service users, carers, mental health workers in the statutory and voluntary sectors and commissioners.

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<sup>1</sup> Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. and Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*, Social Policy Research Unit, University of York, York

<sup>2</sup> Social Perspectives Network is an independent membership based national charity that aims to put social perspectives at the heart of mental health policy, practice, research and legislation. <http://www.spn.org.uk/>

<sup>3</sup> NHS Commissioning Support for London was created on 1 April 2009 to provide clinical and business support to London's NHS. <http://www.csl.nhs.uk>

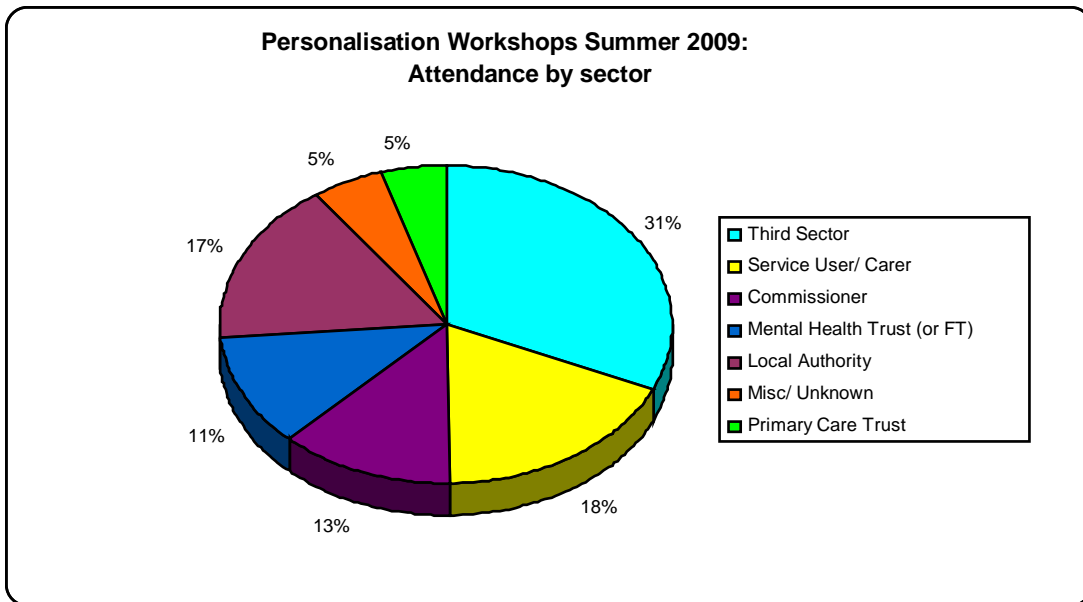


## The workshops.

A series of five workshops were held on a London sub-regional level to develop the personalisation agenda in mental health across London. This report is a summary of the main themes that emerged from the workshops. In all, three hundred people participated in this series of events, the vast majority from within the Greater London area.

The workshops consisted of plenary speakers and discussion groups. The discussion groups focused on four questions. The first three questions were discussed by stakeholder specific groups, i.e. service users and carers, statutory providers, voluntary providers and commissioners from health and social care. This was not entirely straightforward, as some people fell into more than one category, e.g. service user and voluntary provider. However, it proved to be a good way to start the dialogue, as delegates generally found it easier to begin talking with other people from similar backgrounds. For the fourth question, the groups were based on local area (usually borough) and had members drawn from all the stakeholder groups.

### Overview of attendance at Personalisation Workshops (Summer 2009)<sup>4</sup>



<sup>4</sup> For a more detailed explanation of the different sectors please see appendix B, page 15.



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This is an overall summary of the views of delegates across the five workshops in response to the four questions asked of them in the round table discussion groups. It summarises a range of views discussed at the workshop.

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## **Question 1: What does personalisation mean to me?**

*'I was gobsmacked to hear about the options potentially available to service users'*

**Service user delegate**

### **All stakeholder groups**

- § Personalisation is about giving service users more choice and control.
- § It is a major cultural change and a shift of power from services to service users.
- § It is not just about delivery mechanisms like personal budgets, but should be seen in the broader context of recovery and social inclusion.

### **Commissioners**

- § Personalisation is about services and support becoming more person-centred.
- § Commissioners, particularly from social care, emphasised their support but some felt NHS commissioners needed to be more on board.
- § Implementation in mental health is behind learning disabilities and older people.

### **Service Users**

- § Personalisation is about greater equality and a shift from medical to social models of mental health.
- § It allows greater creativity in choice of services and support.
- § Specific examples of personalised services and support include personal assistants (PAs), and education and training opportunities

### **Statutory Services**

- § Personalisation is a change of focus from service users passively receiving charity and gifts to actively exercising their rights as citizens and risk enablement.
- § Personalisation entails a major rethink of professional attitudes, skills and roles

### **Third Sector**

- § Personalisation is about service users driving services.
- § It will result in change, expansion and diversification for the third sector.
- § It creates more opportunities but there is concern at the potential loss of some third sector services.



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## Question 2: What are the challenges to making personalisation happen?

*'We need to reframe risk control as risk enablement'*

### Statutory sector delegate

A number of overarching themes emerged which are outlined below

#### Fears about transition to a more diversified market

- § **Commissioners** felt that the transition to personalisation could be long and messy.
- § **Statutory providers** thought services and support for which there is not sufficient demand within the personalised economy would have to be gradually decommissioned, so there was no sudden removal of services, bearing in mind that there are still going to be some service users who are reliant on them.
- § **Third sector providers** were worried about the potential loss of services and jobs in which they have invested (e.g. through staff training). They wanted some central funding to kick start some services.

#### Services should stop trying to control service users

- § **All stakeholder groups** thought personalisation entailed deep seated changes in culture and attitudes.
- § **Commissioners** said the system needed to stop trying to control service users.
- § **Service users and carers** feared their choices being restricted, e.g. limiting a PA to doing cleaning, as well as inflexibility around exit and access criteria which ignored the varying nature of mental health problems. They felt disempowered by services, and sometimes found it difficult to start exercising rights and make active choices due to previous disempowerment by the system. They felt stereotyped by services. They believed that one of the reasons services don't let go is because of their perception of risk.
- § **Statutory service providers** are conscious of being constrained by risk but acknowledged they needed to focus more on risk enablement rather than avoidance, although they did worry about some service users making unwise choices.
- § **Third sector providers** were concerned over potential exploitation of the system.

#### Lack of information slowing down the agenda

- § **All stakeholders** believed more good quality advocacy and brokerage is needed to help overcome the lack of information.
- § **Commissioners** acknowledged that even they weren't always up to speed. Advocacy and brokerage needed to be better aligned to support and planning.
- § **Service users and carers** were simply unaware that they were entitled to more choice and control because of the lack of information and signposting.
- § **Statutory service providers** said they needed to know more in order to make personalisation happen, but didn't want to wait until a commissioning strategy came out before acting.



### **Better joint working and pooling of resources**

- § **Commissioners and statutory services** highlighted the need to improve the health/social care interface in order to make the service user's personalised journey more effective, through, for example, pooling together diverse funding streams – not only health and social care, but also Supporting People and Independent Living Fund resources. Social care is more engaged with the personalisation agenda than health.

### **Assessments aren't holistic**

- § **Service users** said assessments ignored the bigger picture and weren't holistic or recovery focused
- § **Statutory providers** said there needed to be new types of assessment.

### **Financial concerns**

- § **All stakeholder groups** were concerned that there was under investment in existing mental health provision. Switching to a more personalised system would not do anything to resolve this. In fact, under investment might effectively restrict the roll out of personalisation and service users' ability to exercise choice in their treatment and support.
- § **Commissioners** were concerned about how personalisation would be funded,
- § **Statutory providers** were concerned about potentially having to run day centres for some service users, and giving others Personal Budgets on top of this.
- § **Third sector providers** were worried at the costs of training up staff and then having to cut a service. They wanted funding to set up services to offset any potential losses which they can't bear alone.

### **Diversity and social inequality are not acknowledged**

- § **Service users** felt personalisation wouldn't deal with existing inequalities of race, gender, sexual orientation, ageism and so forth. They also feared inequality of access, with personalisation favouring the articulate and well presented middle classes.

### **Lack of evidence base for effective outcomes**

- § **Commissioners** emphasised the need to develop the evidence base for effective outcomes on which they can commission services and support. They acknowledged the need to become smarter at assessing the capabilities of new providers. On a more fundamental level, they asked who would determine the outcomes?

### **Other issues that were raised**

- § Will Foundation Trusts be blockers or levers for change?
- § Some people are concerned that personalisation is based on an expressly consumerist philosophy.



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### Question 3: What are the opportunities in the personalisation agenda?

*'Personalisation gives us a mechanism for doing what we always wanted to do'*

**Voluntary sector delegate**

#### Linking the Care Programme Approach (CPA) to Budgets

- § Statutory providers, service users and carers highlighted the importance of linking personalisation and CPA

#### More joined up working between agencies

- § Voluntary providers and commissioners felt that personalisation could encourage more joined up working between good providers, including local authorities, voluntary organisations and health.

#### Challenging low expectations of service users

- § Service users and third sector providers said low expectations of service users needed to be challenged

#### More flexibility, choice and control

- § Service users and carers felt personalisation could give more choice and control and challenge paternalism within services. This would enable people to have their recovery and social inclusion supported, giving more benefit at less cost, and enabling them to get help with specific things like home help and education and training through PA support. Personalisation was felt to offer more scope for creativity in choosing the kinds of support that helped people.
- § Commissioners said personalisation allowed them greater flexibility by letting them commission based on outcomes

#### Promoting best practice

- § Statutory services felt that personalisation would support existing best practice in support plans and extend best practice.
- § Third sector providers said personalisation gave them a mechanism for doing what they always wanted to do.

#### Creating new business opportunities

- § Voluntary sector providers emphasised personalisation creating new business opportunities as a real possibility for their sector.

#### Bringing together different funding streams

- § Commissioners said bringing together different funding streams would give service users a really meaningful pot of money with which to do things.



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## Question 4: What is needed to make personalisation happen in your local area?

*'Remember that personalisation is old wine in new bottles'*

Commissioner

*'Is personalisation new wine in old bottles?'*

Mental health activist

Mixed stakeholder groups discussed what is needed to make personalisation happen on a local area level and made the following suggestions:

### Better information and support

- § through ongoing events like the workshops, promoting best practice, using Facebook and an online moderated discussion forum, more advocates to signpost and a buddying' system for service users led by service users who have taken up personalised choices

### Better leadership

- § through supporting and developing 'trail blazers' to demonstrate 'how to' achieve whole systems change. This must involve PCTs and NHS trusts as well as local authorities and voluntary organisations. Appointment of a personalisation lead to join up processes across trusts and have transparent criteria and timescales for all boroughs

### Better joint working

- § between all stakeholder groups in health, social care and commissioning. As well as the local authority and voluntary sector, this must include PCT commissioners, NHS trusts and specific vocational groups such as doctors, clinical directors, consultant psychiatrists and community mental health teams

### Greater choice

- § through commissioners becoming more responsive to service user preferences and through having a personalisation. Suggestions for an 'Oystercard' system entitling holders to access services and support across all London boroughs and developing co-production

### Improved process of getting personalised care

- § by reducing bureaucracy for taking up Personal Budgets or Direct Payments addressing Fair Access to Care Services, making assessments more holistic and recovery focused, clarifying eligibility criteria and enabling individuals to feedback on outcomes

### Improved financial aspects of transforming the system

- § by having one Resource Allocation System (RAS), unbundling Payment by Results (PbR) and emphasising cost effectiveness in pilots



## Simplified terminology

- § of personalisation and make it more 'user friendly'

## Move away from risk aversion to risk enablement

- § needs and organisational culture shift

## More holistic assessment to drive the priorities of commissioners

## Listen to service users and carers

- § especially during assessments

## Stop focus on buildings based services

- § to increase flexibility of options

## Develop a common outcomes framework

- § to effectively compare areas

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## Conclusions.

Participants saw the potential of personalisation to help shift power from services to service users and to produce better mental health outcomes. However, the sheer scale of the system change that is needed means that personalisation will have a long and rocky road to travel to realisation. Drawing on participants' own suggestions to the questions above the following changes were identified as needing to happen to develop personalisation in mental health more effectively across London:

### Cultural change

#### Professionals

- § Professionals need to critically reflect on their attitudes, skills and roles and how these may need to change. This includes challenging low expectations of service users and being less risk averse. Professionals will continue to be gatekeepers to financial resources, so this attitudinal change is vital

#### Service users

- § Service users need to be helped to challenge their low expectations of themselves. This is needed given the history of disempowerment of service users by the mental health system

#### Providers (including the third sector)

- § Providers of services need to positively accept the risks of the market economy brought about by personalisation. They need to be prepared to innovate and develop successful services but also to cut unpopular services. This may be difficult for smaller organisations whose risk has not paid off. This will also be disadvantageous to service users who like 'unpopular' services

As well as embedding these cultural changes, there are a number of specific actions that were identified which would help roll out personalisation:



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## **Suggested actions from workshop participants.**

### **More events to promote personalisation**

- § to engage all the stakeholders – service users, carers, mental health workers in all sectors and commissioners, especially on a local borough level.

### **Develop personalisation champions**

- § to promote personalisation.

### **Reduce bureaucracy and clarify jargon around being able to get budgets**

- § to encourage greater take up

### **Increase cross sector collaboration**

- § between the NHS, Social Care and the Third Sector to facilitate the journeys of service users who cross these ‘boundaries’

### **Pool funding pots**

- § Pool health, social care funding and any other funding, into one resource that service users could use to purchase something that could make a real difference. Think service user, not organisational bureaucracy.

### **Improve financial aspects of transforming the system**

- § by having one Resource Allocation System (RAS) , unbundling Payments by Result (PbR) and emphasising cost effectiveness of budgets (the IBSEN study already showed a modest cost saving for people to took up Individual Budgets including for mental health)

### **Make assessments more holistic and recovery focused**

- § for services and support that can only be accessed after assessment

### **Develop the evidence base**

- § to enable commissioning of non mainstream services and support
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## **Acknowledgements.**

SPN would like to thank the following for chairing workshops:

**Dr Adi Cooper**

Strategic Director for Adult Social Services and Housing, London Borough of Sutton,

**Paul Kelly**

Transformation Programme Co-ordinator, Social Care & Partnerships, Department of Health - London Region,

**Sean McLaughlin,**

London Borough Islington/Islington PCT Director of Social Services,

**Paul Najsarek**

Chair, Corporate Director, Adult & Housing Services, London Borough of Harrow.

## **SPN would like to thank the following plenary speakers for their contributions:**

**Terry Bamford**, Trustee SPN,

**Amber Chidakashi**, Service user,

**Caroline Glendinning**, Professor of Social Policy, University of York,

**Rebecca Harrington**, Assistant Director, Strategic Planning and Joint Commissioning, Camden Council and Camden PCT,

**Kevin Lewis**, Personalisation Lead, National Mental Health Development Unit,

**Bob Marshall**, Personalisation Lead, Lincolnshire Partnership NHS Foundation Trust and

**Neil Nerva**, London Social Care Transformation Programme Manager.

We are very grateful to [Commissioning Support for London](#) for their administration support and for their funding of the workshops. We thank [Alison Mohammed of Rethink](#) for her help in the planning of this event and her feedback into the draft for this summary. SPN acknowledge the role played by Terry Bamford, who as then SPN Director was responsible for developing the idea of the workshops. Finally, we would like to give a heartfelt thanks to all the participants who actively debated the issues during the workshops.



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## Appendix.

### A) Evaluation of the day

Delegates were asked the question:

**“Has the workshop made you more feel confident about the personalisation agenda in mental health?”**

Across the five workshops, an average of 78% of participants said **Yes**.

The following is a selection of quotes from the evaluation forms:

*‘The workshops increased my determination to promote [personalisation] and work with local mental health user groups to empower users to demand their right to self assessment.’*

*‘It was reassuring that commissioners were confused too!’*

*‘I [now] feel I can begin a debate with local partners.’*

*‘[The workshop] helped me feel I could take more control over my life.’*

*‘It helped me unravel the complexity of the agenda.’*

*‘[The workshop was] a reminder that staff have to be taken on the journey.’*

*‘I feel able to discuss more confidently and explore potential market expansion.’*

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## Appendix

### B) Key to attendance pie chart (shown on page 3)

|  |   |
|--|---|
| <b>Service Users and Carers</b>              | Service Users and Carers  |
| <b>Commissioners</b>                         | Commissioners - PCT (often joint commissioners with local authorities)  |
| <b>Mental Health Trust (or FT)</b>           | Providers, mostly in the form of Mental Health Trusts/ Foundation trusts.   |
| <b>Third Sector</b>                          | Third Sector, these were charities such as Mind but also those providing particular services, such as housing or local support groups.  |
| <b>Local Authorities (not commissioners)</b> | Often local authority service managers. Joint commissioners were included under the term commissioners  |
| <b>PCT (not commissioners)</b>               | Also in attendance were other professionals from PCTs who weren't commissioners, such as service managers and the odd clinician.  |
| <b>Misc/ Unknown</b>                         | There were also a few people whose origins are not clear. More often than not, it is likely that these were service users/ carers/ third sector as part of the reason for their unknown status was their reluctance to provide us with an email address and job description. There were a few people with national roles and a university lecturer. |

