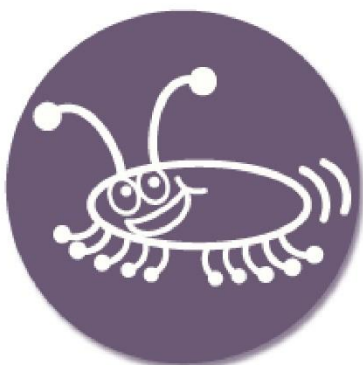


# **Self directed support** **A Survey**



**carried out by BUG**  
**Brent Mental Health User Group**

**Commissioned by Healthwatch Brent**

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## INTRODUCTION

## EXECUTIVE SUMMARY

### Use of self-directed support by people using mental health services in Brent

Healthwatch Brent's Community Chest funding to enable local community organisations to undertake research has presented this opportunity as anecdotal evidence has indicated that individuals using services in Brent to deal with mental health issues are both utilising and benefiting from their use of self-directed support in a range of creative and imaginative ways to meet their social care needs. As highlighted by the National Audit Office indicators specific to personalised commissioning in the DH's Social Care Outcomes Framework measure take-up rather than user outcomes and there has been little systematic analysis to date of the relationship between use and benefits for individuals using direct payments.

While this research report for Healthwatch Brent includes a summary of feedback from individuals using self-directed support in Brent who responded to the survey carried out by Brent Mental Health User Group and brief information about the analysis of people's use of self-directed support between 2013 and January 2016 via Brent's mental health services, full detail is included in *Report on use of self-directed support by people using services to deal with mental health issues, BUG, August 2016*. Information from interviews with key staff is incorporated throughout.

### Progress in relation to use of self-directed support by people using mental health services

Evaluations carried out since the introduction of direct payments highlighting that individuals using mental health services were making significantly less use of direct payments than other groups have resulted in a number of pieces of work to increase uptake. Both experience to date in Brent, including that incorporated in this research report, have highlighted continuing barriers which need to be addressed to embed systematic use of direct payments to meet the social care needs of individuals using mental health services. Addressing key issues and recommendations made – incorporating the views of individuals using services and staff in service providers – will facilitate improvement in future. Learning from existing projects and work to facilitate use of personalisation and self-directed support will strengthen use.

### Brent's Health and Wellbeing Board achieving its strategic objectives

Systematically facilitating use of self-directed support by individuals using services to deal with mental health issues will significantly contribute to Brent's Health and Wellbeing Board achieving its strategic and key objectives. This is the case particularly in relation to improving mental wellbeing – including for people with a serious mental illness – and working together to support the most vulnerable adults in the community, including by facilitating individuals' developing their own self-management in the community. Embedding use of self-directed support by people using services to deal with mental health issues will also facilitate improving integration of health and social care services and greater focus on identifying and meeting individuals' social care needs, including via robust and ongoing assessment.

Use of self-directed support facilitates both meeting individuals' social care needs and addressing the social determinants of health. Information included in this research presents an opportunity for partners included in Brent's Health and Wellbeing Board to provide leadership

locally, giving strong messages and support to – and involving – both commissioners and service providers as well as people using services and carers.

### **Transformation of health and social care services**

Use of self-directed support is part of the transformation of health and social care services – incorporating personalisation, prevention and self-management. Inclusion in local Transformation and Sustainability Plans required by The Five Year Forward Plan presents an opportunity to give a profile to and clear messages about the expectation that use of self-directed support by people using services to deal with mental health issues is systematically embedded locally.

### **Focus on outcomes**

The current mental health strategy and outcomes frameworks for health, social care and public health all highlight the expectation of both commissioning organisations and service providers that staff enable individuals to identify the outcomes they want to achieve from using services – and facilitate their achieving them. Use of self-directed support by individuals using services to deal with mental health issues is an integral part of this approach to meet people’s social care needs and enable them to improve different aspects of their wellbeing – the principle on which the Care Act is based.

### **Expectations of secondary specialist mental health services**

Focus on transformation of health and social care services, including via the requirement placed by commissioners on statutory service providers to create service development and improvement plans (SDIPs), creates an opportunity to embed and measure use of self-directed support for people using services to deal with mental health issues in staff’s practice.

### **Shifting the culture in specialist mental health services and shifting settings of care**

Specialist health and social care services need to replace the traditional, chronicity approach with a wellbeing and recovery approach of which use of self-directed support is an integral part. Senior management needs to have a clear vision and strategy to achieve this significant change, give clear messages and provide strong leadership to ensure that staff are aware of expectations. Recent redesign of community mental health services provides an opportunity, including to give clear information to individuals using services and carers about ways that staff will work with them to enable them to utilise specialist services and move away from them having achieved the outcomes they want to – so shifting settings of care.

Partner organisations need to adopt a clear process and provide information, including about the facts about self-directed support to both all staff and people using services and carers. Comprehensive training needs to be provided to all staff and use of self-directed support needs to be incorporated in supervision and team and reflective practice meetings as well as facilitating staff sharing examples while avoiding creating a ‘menu’ in order to maintain creativity and imagination. Staff also need to incorporate use of self-directed support in comprehensive health and social care assessments and care planning on an ongoing basis. Ways of systematically embedding feedback from both people using services and staff about outcomes of using self-directed support need also to be created. Services need to engage with barriers experienced

particularly by people using mental health services, including by utilising work already carried out to address risk and safeguarding in relation to personalisation<sup>1,2</sup>.

Use of self-directed support also has the capacity to challenge inequalities and stigma, normalising and engaging with individuals' own motivations, not least because such a high proportion of people from black and minority ethnic communities have accessed direct payments locally which has often not been the case in other areas. Recent work has highlighted that individuals often experience greater satisfaction with services and improved wellbeing when using direct payments.

### **Effective use of resources**

Self-directed support can often make more effective use of reducing resources as solutions are most often low cost with high impact as well as enabling individuals to reduce their use of and reliance on secondary, specialist mental health services, including by enabling people to leave hospital, re-engage with their communities and rebuild their lives.

### **Co-production with individuals using services and independent evaluation**

Co-production has been a strong feature of facilitating use of self-directed support by people using services in Brent to deal with mental health issues and this needs to continue. Utilising expertise of user groups and enabling individuals using direct payments to be actively involved in showcasing their experience and benefits needs to be incorporated locally. Facilitating individuals to support and share information with each other enables others to take positive risks and so overcome barriers. Building on the evidence base created by this work, independent evaluation including the views of both individuals using services to deal with mental health issues and staff needs to be actively facilitated.

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<sup>1</sup> Mitchell W and Glendinning C (2007) A review of the research evidence surrounding risk perceptions, risk management strategies and their consequences in adult social care services for different groups of service users, University of York Social Policy Research Unit

<sup>2</sup> SCIE Report 36: Enabling risk, ensuring safety: Self-directed support and personal budgets (Sarah Carr, SCIE, Nov 2010)

## METHODOLOGY

BUG produced a questionnaire, incorporating both information about the research and a monitoring form to see whether individuals of different age groups, ethnicities, genders, sexualities, those with physical and/or learning disabilities were accessing self-directed support, had different experiences and/or ideas for improvement. This is included as Appendix 1.

This survey was circulated on behalf of BUG by Brent's Personalisation Peer Support Worker to all those who had made successful applications for self-directed support between 2013 and January 2016. People could complete and return a survey anonymously, talk to a member of BUG staff or be visited at home together with staff – though speaking separately and confidentially. Five people completed and returned surveys while two contacted BUG saying they were not aware they were using direct payments<sup>3</sup>.

BUG's Director interviewed key staff in Brent's mental health services – provided by a partnership between Central and North West London (CNWL) Foundation Trust and Brent council – as well as offering staff across the service the opportunity to give their input – and Brent council. Staff from two agencies which provide a significant number of personal assistants as well as the independent organisation that provides practical support to individuals employing their own personal assistants were also interviewed<sup>4</sup>.

A further opportunity to enable individuals who have accessed self-directed support to make their input was created via a drop-in session at Patidar House. Two people gave their input via phone and three people came to the drop-in session<sup>5</sup>.

Additionally, BUG analysed anonymised information about all applications made to Brent's Self-Directed Support Panel between 2013 and January 2016<sup>6</sup>. A summary of information is included about how 247 individuals have utilised – and benefited from – their use of self-directed support as well as about their identities while full detail is included in the separate, more detailed report produced for slightly different audiences by BUG<sup>7</sup>.

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<sup>3</sup> Surveys completed and returned to BUG and phone calls received, February 2016

<sup>4</sup> Interviews carried out by BUG with key staff from different organisations, June 2016

<sup>5</sup> Input given by individuals using services via phone and drop-in session, June 2016

<sup>6</sup> Analysis of information about applications made to Brent's Self-Directed Support Panel between 2013 and January 2016, May 2016

<sup>7</sup> Report on use of self-directed support by people using services in Brent to deal with mental health issues, BUG, August 2016

## BACKGROUND

### Aims of the Research

This research has been carried out by Brent Mental Health User Group (BUG) on behalf of Healthwatch Brent as part of its Community Chest scheme that enables community groups to apply for funding to carry out research locally. The aims of the research were to:

- gather information from individuals about how they have benefited from use of self-directed support, any difficulties they encountered and their ideas for improvement in future
- gather information from relevant staff about their experiences of self-directed support, any difficulties and ideas to resolve issues raised
- present an overview of how individuals using secondary specialist mental health services in Brent have utilised self-directed support between 2103 and January 2016 and how they have benefited
- raise key issues and make recommendations for the future based on information gathered and other knowledge

### Who Carried Out the Research

Brent Mental Health User Group (BUG) is one of the oldest independent user groups in the country, set up by local people from different communities using mental health services. All staff have experience of using services in a range of ways to deal with mental health issues. The organisation works with individuals from different communities using services to enable them to get actively involved in their own recovery – including via developing their knowledge and self-management – and to access peer support both directly via staff as well as taking part in regular events and workshops. BUG also enables individuals to get involved in designing and improving health and social care services in a range of ways.

BUG works strategically and operationally with staff in Brent's health and social care services in order to improve different aspects based on the aspirations, experiences of and involvement of individuals as well as providing wellbeing and recovery training to staff. BUG also facilitates individuals' involvement in local commissioning by working with both NHS Brent Clinical Commissioning Group (CCG) and Brent council.

### About self-directed support and work to increase the uptake of direct payments

Self-directed support is the generic term<sup>8</sup> used to describe the different approaches used to meet individuals' social care needs in different local authority areas in England, incorporating a personalisation approach. What is common, however, is that self-directed support is paid as 'direct payments' and this is therefore the term that has been used in legislation, projects to increase uptake, research and targets.

### History of direct payments legislation and work to increase uptake

Brief details are included below about the history of legislation that introduced use of direct payments and work since to increase their uptake by different groups of people as well as to

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<sup>8</sup> Think Local, Act Personal (30 national partners committed to change in social care working with NHS England) 2011



introduce the personalisation agenda. More detail is included in *Report on use of self-directed support by people using services in Brent to deal with mental health issues, BUG, August 2016*.

- 1997 Direct payments introduced (*Community Care (Direct Payments) Act 1996*)  
Local authorities given a power, rather than duty, to make payments for working age disabled people to have more control and choice in meeting their social care needs.
- 2000/2001 Use of direct payments extended to older people and in 2001 to parents of disabled children and carers<sup>9</sup>.
- 2003 The *Health and Social Care Act 2001* made it mandatory for local authorities to make direct payments to individuals who wanted to and were able to manage them with or without support<sup>10</sup>.
- 2004 Comprehensive evaluation carried out by HASCAS into use and benefits of direct payments in five national mental health pilot sites as part of the National Social Inclusion Programme, Direct Payments<sup>11</sup>.
- 2005 Joseph Rowntree Foundation's New Directions Project had discussions with over 250 individuals using mental health services and staff working in integrated mental health and social care organisations to build on the research undertaken by HASCAS. Its main aim<sup>12</sup> was to identify and address common concerns in order to identify what needed to happen for direct payments to be successfully implemented for this group.
- 2005/2006/2007 Legislation introduced to take forward the personalisation agenda and transform adult social care<sup>13</sup>
- 2006 Since experience – and research – was highlighting that individuals using services to deal with mental health issues were not accessing direct payments, their consistent use was incorporated in *Ten High Impact Changes for Mental Health Services*<sup>14</sup>.
- 2006 Specific project introduced by CSIP<sup>15</sup> alongside that to increase the use of direct payments by people with learning disabilities together with the charity In Control.
- 2009 Provision extended to enable both people who were considered to lack 'mental capacity' to have someone appointed to receive direct payments on their behalf as well as those subject to mental health legislation to access direct payments<sup>16</sup>.

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<sup>9</sup> Carers and Disabled Children Act 2000 which inserted new section 17A into the Children Act 1989

<sup>10</sup> Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003 since replaced by the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009

<sup>11</sup> Evaluation of 5 mental health pilot sites, Spandler and Vick, Health and Social Care Advisory Service (HASCAS), 2004 on behalf of National Social Inclusion Programme Direct Payments, Care Services Improvement Partnership (CSIP)

<sup>12</sup> New Directions, Joseph Rowntree Foundation, 2005

<sup>13</sup> Independence, Wellbeing and Choice, Department of Health, 2005; Our health, our care, our say, Department of Health, 2006 and Putting People First: A shared vision and commitment to the transformation of adult social care, DH, 2007

<sup>14</sup> Ten High Impact Changes for Mental Health Services, Department of Health, CSIP, 2006

<sup>15</sup> Direct payments for people with mental health problems: A guide to action, CSIP, 2006

<sup>16</sup> Community Care, Services for Carers and Children's Services (Direct Payments)(England) Regulations 2009

- 2012 MP Norman Lamb, Care Services Minister – in relation to reform of health and social care integration – which gave a deadline of April 2013 for local councils to have offered personal budgets to all eligible users of social care services was quoted as saying: *‘I don’t want to see any evidence of [care] plans being signed off by the service user and described then as a personal budget if they haven’t had any real involvement in it. I don’t want a target achieved that turns out to be meaningless. I want real empowerment for people’*.<sup>17</sup>
- 2014 Care Act<sup>18</sup> introduced. Its ‘wellbeing principle’ aims to put individuals’ wellbeing at the centre of provision, facilitate greater choice and focus to a greater extent on prevention rather than crisis. Carers can now also access self-directed support to meet their identified social care needs. New criteria introduced against which individuals’ identified social care needs are assessed to ensure eligibility. Duty placed on local authorities to offer personal budgets.
- 2014 Use of personal health care budgets has been developed to facilitate a personalisation approach in health provision. Work has been done to develop use of personal health care budgets and integrated health and social care budgets, including by the Integrated Personal Commissioning (IPC) Programme<sup>19</sup>.
- 2016 National Audit Office research<sup>20</sup> highlights that indicators specific to personalised commissioning in the Department of Health’s Adult Social Care Outcomes Framework measure take-up rather than user outcomes. From December 2015 the Health and Social Care Information Centre has published a more detailed dataset that facilitates some analysis of this relationship.

### Approach to self-directed support

In some areas local authorities created a Resource Allocation System (RAS) which assigns ‘points’, based on assessing individuals’ social care needs – incorporating self-assessment – to create an annual ‘indicative budget’. Individuals can either use the budget in its entirety in the ways that they feel will meet their social care needs, use existing provision or a combination. Utilising this approach, individuals have access to ‘personal social budgets’, paid as ‘direct payments’. Individuals’ needs were also assessed against local authorities’ different Fair Access to Services (FACs) criteria based on the organisations’ resources. Local authorities are responsible for carrying out financial assessment for any sums above £500 to ascertain whether individuals need to contribute to the cost if they have savings, for example.

When payments are made as direct payments, individuals are responsible for managing and making payments, often via use of a pre-paid card loaded up with agreed funding by the local authority and used to make payments as well as for recordkeeping and feeding back.

Where individuals are employing personal assistants (PAs) they become employers and so responsible for all aspects of employment. Individuals can employ friends or family as their PAs – though not their partners – as long as they do not live with them, or via agencies or direct

<sup>17</sup> Interview with David Brindle, The Guardian, Wednesday 24<sup>th</sup> October 2012

<sup>18</sup> Care Act (England) 2014

<sup>19</sup> Getting serious about personalisation in the NHS, Think Local, Act Personal, September 2014

<sup>20</sup> Personalised commissioning in adult social care, National Audit Office, March 2016

recruitment. Where individuals directly employ PAs they can use independent organisations to, for example, run payroll, organise appropriate insurance, help to manage the relationship and resolve any difficulties. Costs charged by these organisations need to be incorporated in the cost of the personal social care budget and any application. Clearly, where individuals are using PAs via agencies, these organisations charge an hourly rate and manage all aspects of employment.

### Ethos of self-directed support

The aim of self-directed support is that it should enable individuals to meet their social care needs in creative and imaginative ways, based on their aspirations and what motivates them, as opposed to staff's opinions about what will improve different aspects of their wellbeing. As a result, there is no menu but instead individuals should be enabled to design their own support, based on what they feel will improve their lives and their wellbeing and move towards recovery. It is intended to be driven by individuals as opposed to being service-driven - *'As a general principle, local councils should aim to leave choice in the hands of the individual by allowing people to address their own needs as they consider best, whilst satisfying themselves that the agreed outcomes are being achieved.'* **Direct payments for people with mental health problems: A guide to action, Department of Health, 2006**

### Approach taken in Brent

In common with other areas, the resources for self-directed support are held by the local authority. While Brent council social services directly facilitates access to self-directed support for older people and people with learning disabilities, responsibility for facilitating access by individuals using services to deal with mental health issues is devolved to Brent's mental health services provided by Central and North West London (CNWL) Foundation Trust.

Brent council did significant work to create a resource allocation system but abandoned it some years ago. As a result, indicative budgets are not created though direct payments for older people and people with learning disabilities are facilitated via assessment and creation of a care plan with a social worker. Once the system has been put in place there is no further involvement of staff until an annual review is triggered, there are difficulties or individuals' needs change, though Brent council is currently considering more regular reviews. Self-directed support paid as direct payments up to £250 a week – using pre-payment cards – is approved by team managers.

### Approach taken in Brent in relation to individuals using services to deal with mental health issues

In recognition of the fact that there are significant barriers to individuals using services to deal with mental health issues utilising self-directed support, in 2012 Brent's Head of Mental Health Services set up a Self-Directed Support Panel. BUG's Director was involved both to incorporate co-production with individuals using services to deal with mental health issues as well as their significant knowledge and expertise about self-directed support.

This panel met every two weeks and created the system for applications for self-directed support to be made by any staff in Brent's mental health services on behalf of people using services, having developed them together. The panel's terms of reference included ensuring the ethos of

self-directed support, providing advice and information to staff, working with staff to develop applications within the ethos of self-directed support and reviewing individuals' use of and benefit gained based on the outcomes they had identified they wanted to achieve. The panel also worked with staff to facilitate their ensuring that dependency was not created but instead that use of PAs, for example, enabled individuals to develop their skills in different ways to enable them to move away from services as well as that applications were based on what motivates individuals themselves as opposed to what staff thought they should be addressing.

The panel, chaired by the lead occupational therapist for Brent working in the acute service, also included BUG's Director and service managers from both Brent's recovery and rehabilitation teams. Individuals were welcome to come to panel meetings together with staff to make their case as well as to share how they felt they had benefited which a number chose to do. Initially administrative support was provided by an administrator in the rehab service.

Following restructure within CNWL in 2013, the new Peer Support Worker for Personalisation based in the recovery team worked with some individuals to develop their applications – including by using the self-assessment tool developed by Brent council when working towards use of a resource allocation tool (RAS) – booking in staff to make applications to each meeting and ensuring reviews took place. While one administrator took notes and updated the database, another was responsible for progressing payments using Brent council's systems.

Following review in January 2014 by senior managers from CNWL and Brent council, it was decided the panel would continue to deal with and review applications up to £250 a week, above which applications would be made to a newly-created social care panel. It was also intended to include team managers from across the service in the panel to facilitate their involvement. During 2015 the chair of the panel was replaced by Brent's lead social worker, the two community mental health team service managers alternated at panel meetings and BUG's Director continued as part of the panel. While involvement of the Peer Support Worker for Personalisation continued, an administrator was responsible for processing payments.

While direct payments should ideally be paid direct to individuals using services, in some cases this represented a barrier for people using services to deal with mental health issues. As a result, the panel took a pragmatic approach – enabling payments to be made direct to providers on presentation of invoices though one-off purchases were always made using pre-paid cards. However, a recent project by Brent council to ensure that direct payment targets are being met has highlighted that only use of pre-paid cards contributes. As a result, successful applications for self-directed support have not been logged in this way by the local authority as pre-paid cards had not been used. The local authority is therefore aiming to replace existing systems with use of pre-paid cards for all individuals accessing self-directed support.

The Self-Directed Support Panel was disbanded by Brent council in May 2016. BUG's Director is no longer involved and applications up to £250 a week are approved by team managers while those above this sum go to the social needs panel.

## FINDINGS

The 12 individuals who responded via phone, completing and returning surveys or who came to the drop-in session gave a range of responses. Individuals are of a range of age groups, genders and ethnicities with the majority being from black and minority ethnic communities. The majority of people have used services for a significant number of years and had heard about use of self-directed support largely from staff who worked with them on an ongoing basis. While some people felt that staff had taken control and made specific suggestions about how they might use self-directed support, they did not necessarily disagree with their suggestions. Others felt that staff had worked with them to enable them to think about how use of self-directed support could meet their social needs and about what motivated them and a number of people talked particularly about how useful it had been working with the Peer Support Worker for Personalisation.

People were clear about what they wanted to achieve from their use of self-directed support and felt that they had achieved what they wanted to overall, though one wasn't sure why their gym membership had been stopped and two were having difficulties with delays and lack of information about what was happening with other applications they had made. People talked about feeling that they had achieved more than they had expected to, including regaining their sense of identity, building their confidence, seeing that they are capable individuals and feeling more motivated and that they are spending their time in ways they enjoy, motivating them to look after themselves better as well as to take positive risks to try new things. People felt that individuals' experiences of using self-directed support would be improved if staff worked with them in relation to what motivates them, the process was clear and effective and staff kept in touch to let them know about progress.

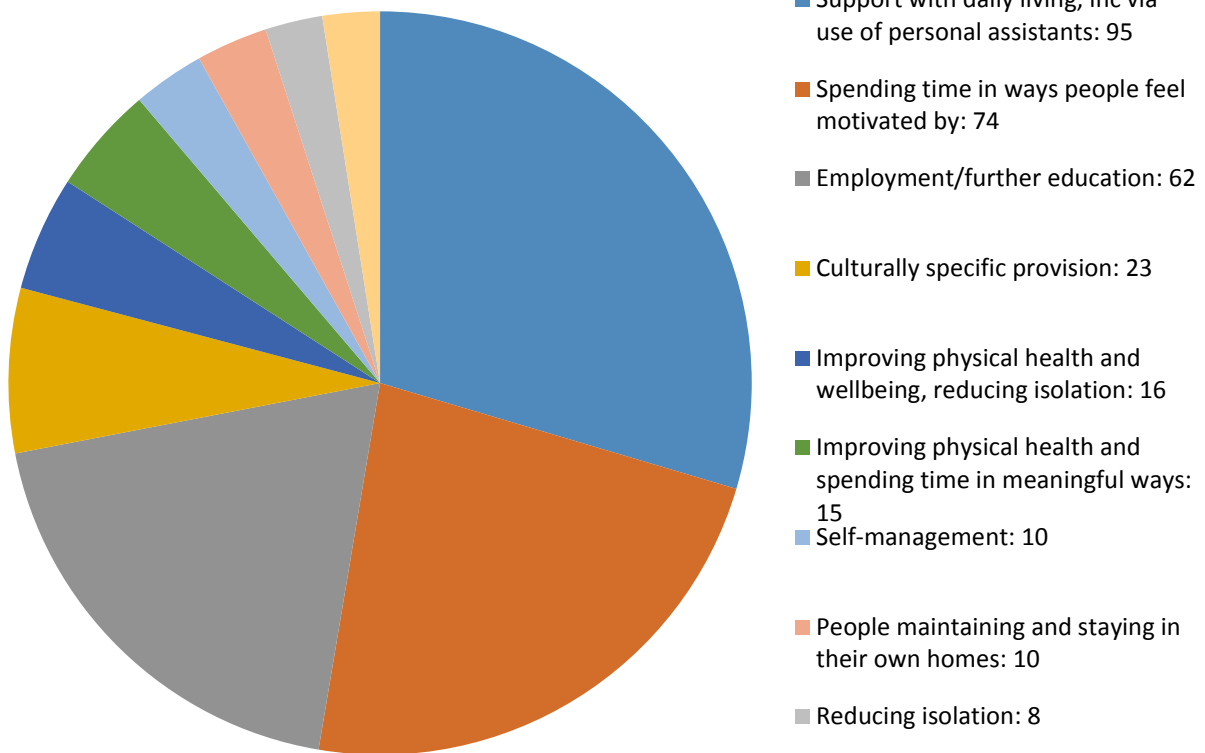
## ANALYSIS

The following information is based on anonymised detail in the database used by Brent's Self-Directed Support Panel. A total of 357 applications for self-directed support were made during this period. While 335 applications were agreed – including by 14 people who made more than one, one-off application – 22 were refused on the basis of lack of information, not being appropriate for self-directed support as their focus was health provision, what people needed eg cookers and fridges being accessed via other means or not appropriately meeting individuals' social care needs and three were not progressed as people's circumstances changed, for instance, because they had gone into hospital.

Of the total of 335 applications agreed, 175 were one-off and 160 for ongoing provision. Of those who made one-off applications, one person additionally has learning disabilities.

Of those who made applications for ongoing provision, 10 people are additionally living with physical health conditions such as diabetes, difficulties with memory, arthritis and hyperthyroidism; 8 have physical disabilities – including two who were disabled short-term by accidents; 7 are older – two of whom have been diagnosed with dementia – four are living with a range of physical health conditions while four people additionally have learning disabilities. Examples are given below of how self-directed support has been utilised by individuals.

### How people have used self-directed support



#### Identities of these individuals

Since 298 of those included here are from a range of black and minority ethnic communities, this indicates that individuals of a range of ethnicities are accessing self-directed support which is very positive. People are of a range of age groups. More men than women are using self-directed support and information was not systematically included about individuals’ physical and/or learning disabilities or sexualities.

#### RECOMMENDATIONS

Key issues and recommendations incorporated here are based on experience to date, analysis of anonymised information provided about applications made between 2013 and January 2016, feedback from individuals who gave their views as part of this survey and particular staff from Brent’s mental health services, Brent council, agencies providing personal assistants to individuals and local organisation that provides practical help to people using direct payments.

#### Who Has Accessed Self-Directed Support to Date

It is clear from the anonymised data about individuals who have made successful applications between 2013 and January 2016 that self-directed support is being accessed by people of a range of ages, ethnicities and genders, faiths and by those with physical disabilities. Since lack of access to direct payments by people from black and minority ethnic communities has

consistently been highlighted in different pieces of research, it is particularly positive that so many people who have traditionally been excluded are using them.

People who also have learning disabilities – and dementia – are also utilising self-directed support. It does seem, however, that a significantly larger number of men have utilised self-directed support. In addition, information included raises questions about whether lesbians and gay men and those who identify as transgender are accessing self-directed support.

1. Attention needs to be paid by staff to ensure that individuals of all genders and sexualities in particular are accessing self-directed support.

### **How Self-Directed Support Has Been Used**

Again, from the information included about how people have utilised – and are utilising – self-directed support it is clear that it is being used to enable people to get back into education; into employment; to develop their social lives and social networks; to improve their physical health and wellbeing; to help manage physical disabilities and illnesses; to develop their daily living skills and maintain and/or stay in their own homes; to spend their time in ways that feel meaningful for them as well as to reduce isolation; to re-engage with their families and friends and cultures; and to develop their self-management.

People are being enabled to particularly make one-off applications to spend their time in creative and imaginative ways which enable them to move towards recovery and improve their sense of wellbeing in a range of ways.

1. Ensure that staff maintain the ethos of self-directed support, enabling individuals to use direct payments in ways that they feel will meet their social care needs.

### **Use of Personal Assistants**

A significant number of people are using personal assistants (PAs) though the majority are provided via agencies. While this has some advantages for individuals – it can represent a barrier to appropriate matching and to their being or feeling in control of the relationship which is the intention.

1. Individuals need to have more choice about their personal assistants (PAs) and staff need to work with them to ensure they feel in control of the relationship. People need to be enabled to use guidelines to consider when employing personal assistants produced with individuals using services to facilitate greater control over their relationships with PAs.

In Brent, a PA Finder database of people who want to work as PAs is being developed by the organisation funded to support individuals to employ PAs directly and to manage their direct payments generally.

2. Attention needs to be paid to ensure this meets individuals' needs.

PAs are currently largely enabling people to manage at home – doing laundry, cleaning, shopping and looking after themselves – while fewer are using PAs to develop their social lives and social networks; to spend their time in ways that feel meaningful to them; and to get involved in the community.

3. Staff need to work with individuals to enable them to identify and utilise PAs to do what they feel motivates them as opposed to what staff think will motivate people.

Individuals' use of PAs has been set up during this period with the intention that the number of hours they have worked each week has reduced as people have developed their confidence and abilities – and/or wanted to spend their time in other ways, including in order to avoid creating dependence.

4. Individuals need to be actively involved in measuring their progress, reducing the number of hours that PAs support them in order to avoid creating dependency as they develop their confidence, ensuring their needs continue to be met. Flexibility to meet individuals' changing needs also needs to be incorporated.

Experience has indicated that mental health service staff can struggle with the notion that PAs role is not intended to be either an extension or duplication of theirs.

5. The role of PAs needs to be distinct from that of staff in specialist mental health services as opposed to duplicating it. Individuals need to be the drivers of their relationship with PAs.

The relationship between individuals, PAs employed by agencies and staff in mental health services is complex.

6. Where individuals are using PAs via agencies, the role of these agencies needs to be very clear. Individuals' control of the relationship with their PAs needs to incorporate control of information that PAs have and with whom they are comfortable this is shared. Staff in mental health services need to be clear they are not the employer but have facilitated the provision and need to ensure that individuals have identified the outcomes they want to achieve and that use of PAs is enabling them to do so, systematically reviewing this.

### **How People Have Benefited From Use of Self-Directed Support**

While considerable information was included in the anonymised data provided to BUG as well as gathered from individuals and specific staff who took part in the survey about how people have benefited from use of self-directed support, information has not been routinely gathered from individuals.



1. Make it a requirement that both individuals utilising self-directed support and staff systematically feedback on how people have benefited from use of direct payments in future. Staff need to work with people to enable them to identify the outcomes they want to achieve via use of direct payments and to be actively involved in ensuring they are meeting these outcomes.

It is very clear that people have significantly benefited from their use of self-directed support, including in ways they had not anticipated. People have increased their confidence in their own abilities as well as developed their ability to manage and improve their lives and take risks to try new things and recognise their potential.

People have also been spending their time in ways they enjoy and feel motivated by, so improving their sense of wellbeing, and often motivating them to manage other aspects of their lives. While some individuals using direct payments have done so in order to develop their self-management which has been successful, use of self-directed support in different ways has achieved this outcome for others too.

A significant number of people have both taken part in further education courses as well as been able to move towards and gained employment.

A number of people have also been enabled to leave the mental health unit, including after quite long stays, and to rebuild their lives via use of particularly PAs. However, this is also a function of Brent Council's Reablement Team.

2. Access to Brent Council's Reablement Team by people using mental health services needs to be clarified.

### **Gathering and Analysing Qualitative and Quantitative Information**

While information included in this survey has focused to a greater extent on qualitative information which is very useful to develop a picture of individuals' use and experience of using direct payments, it would also be useful to regularly analyse quantitative data. In order to do so both hard and soft targets need to be measured, so, for example, individuals' reduced use of or reliance on any aspects of mental health services.

1. Creation of a system to enable and analyse the relationship between use of and benefit to individuals of direct payments – incorporating recommendations from the National Audit Office's recent research – needs to be prioritised locally, including via co-production with individuals using services to deal with mental health issues and their user groups.

### **Individuals and Staff Reporting How People Have Benefited From Use of Direct Payments**

The fact that so few individuals – and staff in Brent's mental health services – responded to BUG's invitation to share their experiences of use of self-directed support and ideas for

improvement in future is of considerable concern. While it can be difficult to extrapolate the reasons for this, it is worth considering the possibilities that individuals are not aware that they are using self-directed support, have not been sufficiently involved in discussions or are worried that they may lose this resource if they give their input.

It is also the case that BUG surveys have consistently shown that individuals are not used to measuring their progress or what they have changed or achieved as a result of using services which needs to be addressed, including since this is an expectation of services of NHS England, Public Health England and the National Institute of Clinical Excellence (NICE).

1. Staff need to recognise the importance of feeding back on their own and individuals' experiences of using direct payments. This needs to be built into staff's practice in future, not least to ensure that individuals are both identifying and then achieving the outcomes of using services that they want to.

### **Systematically Facilitating Access to Direct Payments**

Everyone who uses services to deal with mental health issues should have access to direct payments to meet their social care needs.

1. Staff need to recognise the importance of their facilitating individuals' access to self-directed support. Staff have a crucial role to play in championing use of self-directed support, sharing examples and information about benefits with each other as this will help practitioners see the value of giving control to individuals using services and to take a pragmatic approach to risk-taking, comprehensive crisis planning and developing positive risk-taking plans, incorporating use of advance statements.

### **Addressing Barriers to People Being Enabled to Utilise Self-Directed Support**

The fact that take-up of direct payments by people using mental health services has been consistently lower than other groups of people who can also utilise self-directed support has been addressed in a range of ways over the years by strategic statutory organisations. This includes the Department of Health in its cross cutting outcomes mental health strategy for people of all ages and associated outcomes frameworks including that in relation specifically to meeting individuals' social care needs which aims to enable local authorities in particular to measure progress achieving its outcomes.

There are a significant number of barriers to individuals using services to deal with mental health issues accessing direct payments which have been recognised over the years by, for example, the Department of Health. Some of the issues raised here are reflective of the national position.

### **Lack of Focus on Individuals' Social Care Needs**

While mental health services have comprised integrated health and social care for some years, the fact that individuals' experience is that these services continue to have a tendency to focus on health to a greater extent has been consistently raised in BUG surveys.

1. Staff need to ensure that they carry out comprehensive health and social care needs assessments on an ongoing basis.

### **Staff's Beliefs about People's Abilities**

Where mental health services continue to use the traditional, chronicity approach, staff can struggle to believe that individuals using those services are capable of deciding for themselves their needs and how they can utilise self-directed support to meet those needs. This has been raised as an issue by staff themselves, for example, in wellbeing and recovery training and workshops in relation to self-directed support and needs to be addressed.

1. Staff need to challenge their assumptions about individuals' abilities and enable them to develop their use of direct payments using reframing skills and positive risk-taking.

### **People's Own Beliefs about Their Abilities**

Individuals using services have also expressed a lack of belief in themselves during workshops designed to facilitate people gaining information about and developing use of self-directed support.

1. Workshops need to continue to be provided – including individuals talking about their experiences of using self-directed support and how they have benefited as hearing from their peers could facilitate people developing their confidence and feeling more prepared to take a risk themselves. Staff also have an important role to play in instilling confidence in as well as sharing information with people using mental health services.

### **Individuals' Concerns about the System**

People have expressed concerns about using pre-paid cards as this is unfamiliar and requires their being actively involved in making payments and recordkeeping.

1. Individuals need to be given clear information about and provided with support to use pre-paid cards.

### **Staff Wanting a Menu from Which to Select**

Staff are most used to using specific interventions when working with individuals using services to deal with mental health issues. Conversely, direct payments are intended to be driven by individuals themselves, based on what they feel motivates them and outcomes they want to achieve to meet their social care needs. Staff need to bear this in mind when working with people to develop their individual use of direct payments.

1. In order to be creative and imaginative, staff need to share examples and information with individuals about how others have used direct payments while avoiding creating a 'menu' from which people are supposed to select.

### **Staff's Approach to Individuals' Use of Self-Directed Support**

Staff continue not to routinely enable individuals to access direct payments.

1. It needs to be made clear to staff that individuals using services to deal with mental health issues not only have a right to access direct payments but that enabling people to do so is part of staff discharging their duty in relation to social care defined by the Care Act. Staff need to talk about use of direct payments on an ongoing basis – throughout the time people are using specialist mental health services – incorporating its use in care planning. The Trust needs to address the fact that it may help if this is linked into its information system.

### **Myths about Self-Directed Support**

Despite detailed information having been produced by Brent's Self-Directed Panel in relation to use of self-directed support - circulated to all teams and discussed at team meetings – myths about individuals' eligibility, how self-directed support can be utilised and use of self-directed support generally have continued.

1. Clear messages need to be given by commissioners to service providers and by providers to staff about the use of self-directed support by individuals using services to deal with mental health issues.

### **Difficulties with Brent Council's Systems**

Staff working in mental health services, those from agencies providing PAs to individuals and people themselves raised concerns about considerable, ongoing difficulties with payments being made – initially as well as ongoing. As well as a number of individuals having missed the opportunity to take part in further education courses, agencies are having to continue paying PAs they employ to ensure that they continue working with individuals.

1. Brent Council's systems need to be clear, function effectively and staff in Brent's mental health services and Brent council need to both recognise the importance of and be enabled to process payments immediately in order to avoid delays. As well as a need for a clear process that is communicated, the system needs to build in flexibility so people can easily change how they use direct payments based on their needs, so, banking hours when they use fewer PA hours to enable them to use more when necessary, avoiding a protracted process. This approach with other groups of people needs to be replicated with people using mental health services.

An issue currently being addressed is that there is no system to enable people using pre-payment cards who have been overpaid by the system to repay funds.

2. The system needs to be as flexible as necessary to meet individuals' needs using direct payments as opposed to individuals meeting the system's needs.

### **Acknowledging People's Changing Needs**

Experience to date has indicated that, where individuals have used mental health services, there is an assumption that only staff from these services will provide assessment, for example.

1. Individuals not being able to access specialist assessments in relation to physical and/or learning disabilities needs to be addressed. Additionally, the fact that people's primary needs may no longer be in relation to mental health needs to be recognised.

### **Changing the Culture**

While some progress towards change has been made, mental health services do continue to use the traditional, chronicity approach – characterised by staff 'managing risk and care'. This represents a barrier to achieving consistent use of self-directed support by individuals using services to deal with mental health issues.

1. Service providers need to replace this approach with all elements of a wellbeing and recovery and personalisation approach which is consistent with national expectations of services.

Staff need to be provided with comprehensive wellbeing and recovery training such as that designed and run successfully by BUG for some years, based on the approach developed together with people using services, carers and clinicians from a range of disciplines by National Institute for Mental Health England (NIMHE). Staff need to work with people as unique individuals in the context of their lives, in equal partnership, facilitating their identifying what they feel will enable them to improve all aspects of their wellbeing and move towards recovery. Staff's practice needs to incorporate a strengths-based approach – recognising and building on people's strengths and engaging with their intrinsic motivations as opposed to trying to create artificial motivations. As well as using reframing skills to challenge negative assumptions about individuals and turn them into opportunities to get to know and work with them as individuals, staff also need to use a positive risk-taking approach, enabling individuals to stretch themselves and try new things in order to achieve their potential.

Use of self-directed support needs to be incorporated, including to facilitate a personalisation approach, enable individuals to address all aspects of their wellbeing, develop their self-management and utilise community resources. Individuals who took part

in the survey talked about how use of self-directed support had enabled them to regain their loss of identity as well as having developed a sense of purpose in life.

### **Focus on Meeting Individuals' Social Care Needs**

Staff in mental health services do not focus sufficiently on people's social care needs.

1. Staff need to focus to a greater extent on enabling individuals to both identify and meet their social care needs, utilising self-directed support. Service providers need to use this approach in order to meet their duties under the Care Act. Focus on identifying and achieving outcomes of using services – including to achieve the ambition that all eligible users have a personal budget – is incorporated in the adult social care outcomes framework utilised alongside the frameworks for both the NHS and public health. The 2015-16 version outlines its future development, in particular considering the implications of the Care Act and measures included are used to monitor the Department's progress in meeting its equality objectives.

### **Enabling Individuals to Identify and Achieve Outcomes**

Staff are not used to focusing on outcomes.

1. Staff need to focus on enabling individuals to identify outcomes they want to achieve from using services – and achieve their goals, including via use of self-directed support. This is an expectation of services incorporated in NHS England's broad strategy for health and care improvement, detailed recommendations on how to deliver this within the London context as well as the independent Mental Health Taskforce report in which 20,000 people took part of create a 10-year implementation plan for this strategy to transform mental health and social care services. This implementation strategy in particular highlights the need to increase the uptake of direct payments by people using mental health services.

### **Strategically Addressing Difficulties and Barriers**

Experience to date has indicated significant difficulties strategically addressing barriers on an ongoing basis.

1. Identified barriers need to be systematically strategically addressed.

### **Clear Strategy and Messages from Senior Management and Co-production**

Use of self-directed support has little profile in Brent's mental health services.

1. Senior management in CNWL as well as well as Brent's mental health services need to give a high profile to and prioritise use of direct payments. They also need to develop a clear strategy and implementation plan for as well as give clear messages to all staff about the expectation that they facilitate individuals' access to and use of direct payments. Co-

production with people using services – and organisations’ representing them – those involved in their support network – and their representative organisation needs to be central to this work.

### **Information and Workshops for Staff and People Using Services**

Information produced and circulated has not necessarily been engaged with by staff – or passed onto individuals using services.

1. Clear information needs to be circulated amongst staff about use of self-directed support, including the process used, and their understanding regularly checked. The factsheet already produced could continue to be utilised here. Written information needs to be supported by provision of workshops for staff.

Similarly, information needs to be routinely given to individuals using services about use of self-directed support – including about the process to get access. Workshops also need to be provided to individuals.

### **Ensuring all Staff Enable People to Utilise Self-Directed Support**

While a few staff working in CNWL’s rehabilitation service and in acute services have enabled people to access self-directed support, the majority are from the community teams.

1. All staff working in Brent’s mental health services need to recognise that they have a role in facilitating individuals’ access to and use of direct payments.

### **Building Use of Self-Directed Support into Staff’s Practice**

Use of self-directed support is not routinely incorporated in staff’s practice.

1. All staff need to recognise that individuals can utilise self-directed support. Team managers need to incorporate discussion of progress in managerial supervision, team meetings and reflective practice groups. This will enable staff to share information and examples with each other, building their knowledge and confidence and challenging negative assumptions and misinformation. Recent redesign of Brent’s community mental health services presents an opportunity to build in discussion and facilitation of use of direct payments in regular contacts with care coordinators.

### **Enabling Individuals to Routinely Meet with the Personalisation Peer Support Worker**

Access to the Peer Support Worker for Personalisation based in one of the community mental health teams is limited.

1. Learning from experience of the benefits of individuals meeting with Brent’s personalisation peer support worker to develop use of direct payments – including to

identify what they feel motivated by – people should routinely be enabled to meet with this member of staff when they start to use mental health services as well as ongoing.

### **Individuals Being Actively Involved in Their Use of Self-Directed Support**

People's response to this research has indicated that they are often not aware they are using self-directed support.

1. Experience to date has indicated the importance of people using services leading to a greater extent as opposed to staff deciding what will motivate them. People also need to be actively involved in their use of self-directed support.

### **Creating Opportunities for Individuals to Meet Each Other**

People do not have many opportunities to meet each other.

1. Opportunities need to be created for individuals using direct payments to meet and gain peer support from each other, sharing their experiences and finding ways of resolving any difficulties.

### **Cost of Self-Directed Support**

There is often an assumption that use of self-directed support is more costly, the opposite is true, particularly where this replaces other provision.

1. Cost benefit analysis of direct payments, including based on savings as a result of individuals having been enabled to stay out of hospital or reduce their reliance on secondary specialist mental health services needs to be carried out.

### **Developing the Local Evidence Base**

Evidence of benefit and outcomes achieved has not been gathered until now.

1. Developing a system to routinely gather information about individuals' use of direct payments, experiences and benefits from both staff and people using services will facilitate the development of this local evidence base. The National Audit Office's recent research highlighted this need as information gathered on outcomes has focused on meeting targets as opposed to qualitative information and any analysis of the relationship between use and benefits of direct payments. It also highlighted the fact that local surveys have more usually gathered information about people's negative experiences and generally not used surveys such as those produced by the In Control charity. Qualitative information should also be gathered by independent user groups.

### **Developing Use of Personal Health Budgets and Integrated Health and Social Care Budgets**

There has been little progress locally in developing use of these personal budgets.



1. Health and social care commissioners and partners involved in developing personalised commissioning and use of self-directed support in its broadest sense need to incorporate learning from these pilots locally and take risks to develop this approach.

### Shifting Settings of Care

While the aim is to enable individuals to utilise specialist mental health services for the shortest possible time, there is a belief that individuals' use of self-directed support can represent a barrier to 'discharging' people from these services. At the same time, individuals often either have continuing social care needs when they move away from specialist mental health services or have social care needs when using primary care services.

1. These issues need to be addressed.

### Commissioning and Accountability

As mentioned previously, use and benefits of using self-directed support for individuals using services to deal with mental health issues currently have a low profile in Brent.

1. There are a number of ways in which accountability either does or could apply to use of direct payments as well as opportunities to strengthen their use. The recently formed Mental Health Strategic Partnership Board, chaired by Brent council, should incorporate use of direct payments in its work and any workstreams, including co-production with people using services to deal with mental health services and their user groups.

Brent council's Overview and Scrutiny Committee could also be utilised to ensure that service providers are enabling individuals using services to deal with mental health issues are routinely accessing direct payments.

The same applies to Brent's Health and Wellbeing Board to which the Mental Health and Wellbeing Transformation – and Implementation Boards – report, including in relation to the North West London LikeMinded Mental Health and Wellbeing Strategy and work to transform mental health services. The LikeMinded team incorporates co-production with Mad Alliance – an independent group of individuals using services to deal with mental health issues and carers. The North West London Mental Health and Wellbeing Transformation Board has a particular remit to strengthen mental health services addressing individuals' social care needs and social determinants of health.

It is also reasonable to expect that NHS Brent CCG's Local Sustainability and Transformation Plan incorporates use of personal social care budgets, health budgets and integrated health and social care budgets.

### Learning from Relevant Work

Opportunities to learn from relevant work is sometimes not taken advantage of.

1. Healthy London Partnership – comprised of 32 London CCGs and NHS England – is working on enabling people using self-directed support in different ways to manage this using online tools as well as doing considerable work in relation to social prescribing to facilitate commissioners utilising this personalisation approach, including to enable individuals to avoid having to use statutory provision to meet their needs. Brent’s health and social care commissioners and partners involved in developing use of direct payments need to link in with this project, both in order to influence and utilise it – and incorporating co-production with people using services and their independent user groups and carers and their representative organisations.

## **CONCLUSION**

Both information included in this report and the process of carrying out the research indicates that considerable attention needs to be paid locally to enabling people using services to deal with mental health issues to access and utilise self-directed support. It is very clear that people have considerably benefited from their use of self-directed support and this needs to be built on locally.

This applies to service providers and commissioners and partners will need to work effectively together – including with individuals using services and carers – and their organisations to address key issues and implement recommendations in the report.

## **ACKNOWLEDGEMENTS**

As ever, our thanks go to those individuals using self-directed support who have taken the time to give their input as part of this survey. Similarly, thanks to the staff who took part in order to improve both take-up of self-directed support as well as the experiences of both individuals using services and staff in future

## APPENDIX

### Survey about Experiences of Using Self-Directed Support in Brent

#### About this survey and whose views we want to gather

This survey is being carried out to find out about the experiences of people who have made successful applications for self-directed support in Brent.

So you might have been able to get money to buy a piece of equipment – like a musical instrument or laptop – go to the gym, do a course, spend your time in ways you enjoy... or maybe you have a personal assistant who supports you with your daily living and/or to develop your social life. It doesn't matter what you use this money for, we really want to hear your views.

And we want to hear what you thought both about the information you got from staff and of the process of making the application – both good and bad – as well as how it felt to work with staff to make your application. Very importantly, we really want to hear what you think would improve the experience in future.

#### How can you give your views

You can complete and return this questionnaire without putting your name on it. You don't need to put a stamp on the envelope if you return it to BUG's Freepost address at: **Brent Mental Health User Group, Freepost RTRT-EHCH-BJBC, Dephna House, 7 Coronation Road, London NW10 7PQ**. Or you can get a Word or pdf version to complete by e-mailing BUG on [info@brentusergroup.com](mailto:info@brentusergroup.com).

If you would like to go through the questionnaire with a member of BUG staff, you can do this either on the phone (we can call you back so you don't pay for the call) or face-to-face. Just ring Lynn at BUG on 020 8964 8650 to organise a time to talk or meet.

We are also happy to come and visit you with any member of staff who comes to see you at home. We just need to know the name of this member of staff so we can organise it with them. Of course, if we did come to see you at home we would make sure that we talked privately – rather than in front of the member of staff, if this is something that is important to you.

We are more than happy to talk to you on the phone using Typetalk if you are Deaf or have a hearing impairment. Or we can organise a British Sign Language (BSL) interpreter if you want to go through the questionnaire face-to-face.

If you want to talk to us using your first language we can organise an interpreter using LanguageLine on the phone. You just need to phone and tell us which language you want to use.

Or maybe you would like to get together with others who also use self-directed support to give your views. If you do, then just ring BUG on the phone number above or e-mail us on [info@brentusergroup.com](mailto:info@brentusergroup.com). If there are a number of people who would like to do this we can organise it. We need your completed questionnaire back by: **Thursday 11<sup>th</sup> February 2016**.

Don't forget to also complete the attached monitoring form so that we can see whether people of different ethnicities, genders, sexualities, age groups, faiths and who have physical and/or learning disabilities have had differing experiences or ideas for improvement as well as to make sure that we have gathered the views of different groups of people using self-directed support.

We have also included a contact sheet at the end of the questionnaire to enable you to get feedback about this survey and/or would like to be added to BUG's mailing list in order to get involved in future or take advantage of other services offered. We really want to hear about your experiences and ideas for improvement in future.

#### **What will happen to the information you give us**

Information you give us will be separated from any personal information you give us such as your name and contact details and used only in the ways you have asked us to. Your views will be combined with others in a report and will be used to improve how self-directed support is accessed by individuals using services to deal with mental health issues in future.

So nothing you say will be attached to you personally. You can feel free to say what you want about your experience. This is too good an opportunity to really make a difference and make sure your voice is heard so don't miss out!

#### **Survey about experiences of using self-directed support in Brent**

As well as lots of space to tell us both about your experiences to date and ideas for improvement, we have also included some options for you to select – so the questionnaire shouldn't take too long to complete.

#### **About your use of services to deal with mental health issues**

1. Roughly how long have you been using mental health services? (please tick below)

- 6 months to a year
- 1-2 years
- 2-5 years
- 5-10 years
- more than 10 years (please give details)

#### **About which staff in Brent's mental health services told you about self-directed support**

2. Could you tell us which staff talked to you about self-directed support?  
(Some options are included from which to select as many as you want)

- staff at Park Royal Centre for Mental Health (*on Shore, Pond or Pine wards or Caspian or Tasman wards – please circle which ward/s*)
- staff in Brent’s Home Treatment Team (*that enables people to stay out of hospital and/or to leave hospital more quickly*)
- staff in the Early Intervention Service
- staff in the Assertive Outreach Team
- staff in the community team (*which includes care coordinators; welfare and employment workers; occupational therapists that work with people to develop daily living skills; peer support worker...*)
- staff in the rehabilitation service (*rehab houses where staff provide support in your shared house*)
- other (*please give details*):

### Information about self-directed support

3. Where did you hear about self-directed support?

*(some options are given below from which to select as many as you want)*

- from staff in Brent’s mental health services who work with you on an ongoing basis, for example, care coordinator or mental health support worker
- from Brent’s peer support worker in the community team
- from Brent Mental Health User Group (BUG) – for example, from going to a workshop or a BUG Information and Participation Day
- other (*please give details*):

4. How did you hear about being able to use self-directed support?

*(some options are given below from which to select as many as you want)*

- staff in Brent’s mental health services told you about it
- from a BUG workshop and/or Information and Participation Day
- from an information sheet produced by BUG on behalf of Brent’s Self-Directed Support Panel
- from someone else using services who has accessed self-directed support
- other (*please give details*):

5. Could you give us a sense of what information you were given about self-directed support and how you could use it? *(some options are given below to select as many as you want)*

- staff told you that you could use it in a particular way (*could you give details?*):
- staff worked with you to find out what you need and how you could use self-directed support to meet those needs
- staff talked to you about what you feel motivates you and then how you
- could use self-directed support in the way/s you wanted to

other (*please give details*):

6. Could you tell us what you felt about how staff worked with you to develop your application?

*(some options are included below for you to select as many as you feel apply to you)*

- you felt staff had particular ideas about how you could use self-directed support
- you agreed with staff's suggestions *or*
- you weren't sure you agreed with staff's suggestions
- you talked with staff about what you need and staff made suggestions *or*
- you talked with staff about what you need and you decided how you wanted to use self-directed support
- you felt that your application for self-directed support was developed with you at the centre – with staff being imaginative and creative
- you were invited to the Brent Self-Directed Support Panel to talk about your application *or*
- you were told you had to go the panel meeting to talk about your application
- you felt staff told you about what was available and you chose which service you wanted to use – using self-directed support
- you were involved in doing research, for example, about model of laptop or where to buy particular equipment – or a particular service you might want to use
- other (*could you tell us more?*):

7. Could you tell us about your experience of using self-directed support?

*(some options are given below for you to select as many as you want but do add your own information too)*

- staff supported you to use the money in the ways you wanted to
- staff checked with you to make sure that you were getting what you wanted from self-directed support
- staff enabled you to think about how you were benefiting from use of your original application and think about how you could develop use of self-directed support in future
- staff didn't really seem to know much about it
- staff took control
- staff enabled you to access another service such as Penderel's if you are employing your own personal assistant – rather than employing a personal assistant via an agency (*could you tell us about your experience if you have used Penderel's?*):
- other (*could you tell us more?*):

8. Could you tell us what you felt about how staff worked with you to develop your application?

*(some options are included below for you to select as many as you feel apply to you)*

- you felt staff had particular ideas about how you could use self-directed support
- you agreed with staff's suggestions *or*

- you weren't sure you agreed with staff's suggestions
- you talked with staff about what you need and staff made suggestions *or*
- you talked with staff about what you need and you decided how you wanted to use self-directed support
- you felt that your application for self-directed support was developed with you at the centre – with staff being imaginative and creative
- you were invited to the Brent Self-Directed Support Panel to talk about your application *or*
- you were told you had to go the panel meeting to talk about your application
- you felt staff told you about what was available and you chose which service you wanted to use – using self-directed support
- you were involved in doing research, for example, about model of laptop or where to buy particular equipment – or a particular service you might want to use
- other (*could you tell us more?*):

9. Could you tell us about your experience of using self-directed support?  
(*some options are given below for you to select as many as you want but do add your own information too*)

- staff supported you to use the money in the ways you wanted to
- staff checked with you to make sure that you were getting what you wanted from self-directed support
- staff enabled you to think about how you were benefiting from use of your original application and think about how you could develop use of self-directed support in future
- staff didn't really seem to know much about it
- staff took control
- staff enabled you to access another service such as Penderel's if you are employing your own personal assistant – rather than employing a personal assistant via an agency (*could you tell us about your experience if you have used Penderel's?*):
- other (*could you tell us more?*):

What you wanted to achieve by using self-directed support

10. Could you tell us what you feel you wanted use of self-directed support to enable you to do?  
(*please tick as many as you feel apply to you*)

- stay out of hospital
- reduce contact with staff in mental health services generally
- avoid use of drugs and/or alcohol
- reduce isolation
- stay in contact with family and friends
- develop your social life and social network
- take part in daily activities that enable you to move towards recovery and improve your sense of wellbeing
- get involved in activities which connect you to your culture

- support you in your first language
- spend time in ways that feel meaningful for you and that you enjoy
- get back into work
- get back into education
- live independently, including by managing physical disabilities or illnesses
- maintain your home or tenancy
- manage your life, including carrying out practical tasks
- improve your physical health
- lessen feelings or symptoms such as thoughts or feelings that are intrusive
- maintain your motivation
- develop your coping strategies and self-management, for example, by going to self-help groups

Please tell us about anything else that you wanted to achieve from using self-directed support:

11. Do you feel you have achieved what you wanted to?

- Yes
- no
- to an extent

Could you tell us more?

### Achieving what you wanted to via use of self-directed support

12. Could you tell us what you applied for to enable you to achieve your goals?

(some examples are given below for you to select as many as you want to but do add your own information too)

- equipment eg laptop, camera, musical instrument...
- materials
- further education course
- anything that enables you to move towards employment (could you give details?):
- going to the gym
- help to maintain your home
- help with practical, daily tasks in order to manage your life
- funding to enable you to spend your time in ways that are meaningful to you and enable you to improve your wellbeing and move towards recovery (could you give details?):
- funding to enable you to take part in daily activities to improve your social life (could you give details?):
- funding to enable you to develop your life, including by linking into cultural activities (could you give details?):



- employed a personal assistant to help you manage your life in different ways (either through an agency or directly employing someone) (could you give details?):
- develop your coping strategies and self-management

Please add anything else that you want to about what you applied for:

### Improvements to your life

13. Could you tell us how you feel use of self-directed support has enabled you to improve your life?  
(a few examples are included below for you to select as many as you want to but do please add your own information too)

- you have been able to develop your skills and abilities
- you have developed confidence in your own abilities
- you have developed your communication and relationships with others
- you feel you have greater control of your own life
- you have been able to try new things
- you have recognised what you are able to do, so, recognised your potential
- you are able to live independently
- you have been able to improve your sense of wellbeing
- you have been able to develop your own management of your mental health issues and your life generally
- you have been able to improve different aspects of your life

Could you tell us more here about how using self-directed support has helped?

Could you tell us about any other ways you feel your life has improved, including anything you didn't expect?

### About the process of making your application for self-directed support

14. Could you tell us what you felt about the process of making your application for self-directed support?  
(some options are included below for you to select as many as you want to and do add your own information too)

- it felt clear
- you felt involved
- the member of staff you worked with kept you up to date with progress
- you felt you had to wait ages for your application to go to the Self-Directed Support Panel
- once your application was agreed it seemed to take ages to receive the money

- there were problems with you receiving the money
- other (could you tell us more here?):

If you did have problems with receiving the money, could you tell us about them here?

### Improving experience of self-directed support

15. Could you tell us what you feel would improve experiences of self-directed support in future?

(some options are included below for you to select as many as you want and do add your own information too)

- everyone being told about self-directed support when they start to use mental health services
- everyone using services being able to meet with a peer support worker to develop use of self-directed support
- staff knowing more about the process of making an application for self-directed support
- staff being able to give clear information about the aims of self-directed support, for example, that it is intended to be personalised to individuals and enable you to achieve what you want to – and be creative and imaginative
- staff being more creative and imaginative
- staff being able to offer examples and suggestions – based on what you feel you need
- staff being more confident about self-directed support
- having clear information about use of self-directed support
- having information about how others have used self-directed support
- use of self-directed support being discussed each time your care plan is reviewed
- use of self-directed support being talked about constantly
- being able to meet with others who are also using self-directed support
- being kept informed throughout the process
- being able to sort out any problems with receiving money once the application has been agreed

Could you tell us what else you think would improve the experience of using self-directed support?

### Any other comments

Please make any other comments that you would like to about your use of self-directed support

Thanks a lot for completing this survey. Don't forget to also fill in the monitoring form attached and return your questionnaire by Thursday 11th February 2016 to BUG's Freepost address on the covering information sheet.

**Monitoring Form**

Thanks for filling in this monitoring form too – so that we can see whether women and men, people of different ethnicities, people with physical and/or learning disabilities, of different age groups – or who are lesbian or gay, bisexual or transgender – have different experiences of using self-directed support now – or want different things in future. Please circle or tick your chosen answers below. And you can tick more than one box – and add your own information if you would like to.

Age group:                    under 18                    18-25                    26-34  
    35-44                    45-54                    55-64                    65+

**Gender**

                                Woman                    Man                                  Transgender

You could give information here about any other way you identify your gender, if you want to:

Do you have a physical disability and/or learning disability?

                                Yes    No

(If yes, please tick the box/es below that you feel apply to you)

- Deaf or have a hearing impairment
- blind or have a sight impairment
- have mobility disabilities
- have learning disability/ies

**Sexuality**

Do you identify as:

- lesbian or gay
- bisexual
- heterosexual

Please add anything you want to about how you describe your sexuality:

How you describe your ethnic origin

(Please tick the box/es below that you feel apply to you. The list below is just examples and is not intended to include a complete list of every community in this country – so do add your own information)

- Asian (eg Pakistani, Bangladeshi, Indian, Sri Lankan)

- South East Asian (eg Chinese, Vietnamese, Malaysian, Thai)
- Asian British
- Middle Eastern
- Black Caribbean
- Black African
- Black British
- Turkish
- Greek
- White European
- Eastern European
- White British
- Irish
- Jewish
- Mixed race

Please use this space to tell us how you describe your ethnicity, if you want to:

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#### Faith

A few examples of different faiths are included here so please tick which is appropriate to you – though do add your own information if you want to:

- Agnostic
- Atheist
- Buddhist
- Christian
- Hindu
- Jewish
- Muslim
- Rastafarian
- other (please give information):

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#### Life experiences you have had to deal with

We have given a few examples below but it would be useful if you could give some idea here of particular life experiences you have had to deal with which you feel have contributed to your mental health issues, eg:

- racial abuse or harassment
- homophobic abuse or harassment

- abuse of any kind (including as a child)
  - anti-woman abuse
  - domestic violence
  - homelessness (including as a result of lack of safety where you live)
  - using drugs and/or alcohol
  - other (please say what):
- 
- 

### Contact sheet for individuals

Information you give here will be separated from the detail you have given in your completed form and used only to send you feedback from the completed survey – or to contact you in the way that you have said you want to be contacted.

Name:

Contact details:

(you could give your address and/or e-mail address, depending on how you would prefer to be forwarded feedback from this survey – and contacted in future)

E-mail address:

Please tick below as appropriate

- I would like a copy of the completed survey
- I would like to be added to BUG's mailing list