

# **Right to Control Consultation**

## **Who are we?**

Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We help over 48,000 people each year through our services and support groups and by providing information on mental health problems. Our website receives almost 300,000 visitors every year.

Our aim is to make a practical and positive difference by providing hope and empowerment through effective services and support to all those who need us. We believe that people who experience severe mental illness are entitled to be treated with respect and as equal citizens. We actively campaign for change through greater awareness and understanding and we are dedicated to creating a world where prejudice and discrimination are eliminated.

As a membership organization and a service provider we are in a key position to comment on the Right to Control, as it will directly affect our members and our services.

## **RESPONSE**

Rethink believes that the personalisation of services and individual budgets will provide better outcomes for people with mental illness. However, Rethink believes that the Right to Control will pose particular challenges for individuals, local authorities, commissioners and service providers, particularly where it concerns people with mental illness. These challenges will need to be managed sensitively and with understanding, and not merely ignored because they are 'too hard'.

## Issues for Individuals

There is still a great lack of awareness among individuals about individual budgets and direct payments, along with confusion and misunderstanding about what is possible. People feel daunted by the prospect of it, with one respondent in a Rethink focus group commenting ‘sounds impossible. Count me out’<sup>1</sup>.

## Support and Brokerage

The transition to a new system always involves confusion and complication. The Commission for Social Care Inspection (CSCI) identified lack of information and inadequate and patchy support services as key barriers to the uptake of direct payments, along with unnecessary and bureaucratic paperwork<sup>2</sup>. Indeed, our services in the south-west have noticed that since Dorset County Council simplified its Direct Payments paperwork, the uptake of direct payments increased significantly. In order to keep this to a minimum, all people accessing the Right to Control will need one-to-one support in identifying needs, what they are entitled to, and what support would be appropriate. This should be made as easy as possible.

The CSCI also found that the quality of support provided has a significant impact on the experience of using direct payments. People said they preferred an independent body to provide the support service.<sup>3</sup> Rethink believes that organizations in the third sector who represent service user interests are in a unique position to offer information and advice on personalisation and direct payments. They have specialist knowledge of the needs of the people who are affected by certain disabilities and will be able to provide advice about services in the local area, and could also provide brokerage. It is

---

<sup>1</sup> The Use of Direct Payments for People Experiencing Mental Health Problems, Living in County Durham: Overcoming the barriers and recommendations to improve the up-take of direct payments within mental health services (2006)

<sup>2</sup> Direct Payments. What are the barriers? Commission for Social Care Inspection. August 2004.

<sup>3</sup> Ibid

important that whichever organization provides a brokerage service has an in-depth knowledge of services that are available, as service users rely on these organizations to advise them of all the options available to them. Where one organization has a contract covering brokerage for all client groups, there can be a tendency for the support brokers to recommend only one or two options, relying on one or two agencies, because the sheer number of referrals does not allow time to specialise.

### **Case study – Rethink Brokerage in Southampton**

Southampton Local Authority established a system where an individual broker was provided for each client group. Rethink has the responsibility for brokerage for mental health. This allows us to provide an informed and specialist service, handling direct payments, and recommending services based on specialist knowledge of the needs of people with mental illness.

There will need to be funding provided for support, advice and brokerage services.

### **Collective Personalisation**

There is some concern that personalisation, if badly managed, could lead to greater isolation of people with mental health problems. Those who are able to manage their condition well enough to remain out of hospital, but who are not well enough to work or volunteer are often left behind, a 'forgotten generation'<sup>4</sup>. Rethink estimates that there may be more than 50,000 people with severe mental illness living in the community with little or no support from services.<sup>5</sup> Personalisation could either reach out to engage with these people, or leave them to be isolated further. As a membership organisation, Rethink and others in the third sector is able to support communities of service users and carers. Rethink can offer a collective service that is tailor made to the individual.

---

<sup>4</sup> Lost and Found: Voices from the Forgotten Generation. Rethink 2004

<sup>5</sup> Action Stations: The Way out for the Forgotten Generation Rethink 2005

There will need to be funding provided for support for service users to use direct payments creatively.

### **Case study – Dorchester Creative Writing Workshop**

Several users of Rethink services already had access to direct payments, but didn't know how to go about purchasing the sort of service they wanted. Rethink brokered an arrangement for them to pool their direct payments to purchase the services of a creative writing tutor to teach them as a group. Rethink arranges these sessions, but did not receive payment for this intervention. While this raised awareness in service users of the potential of direct payments, and the fact they can be pooled to give a collective service, this is not currently a workable business model for a service and income will need to be provided by local authorities.

### **Fluctuating Conditions**

It is essential that people with mental health problems are well supported to identify outcomes and assess their own support requirements. Social services and other staff providing this support must have an understanding of mental illness, which can be complex and fluctuating. Mental Health Carers in particular show great concern that systems will not be in place to support the person they care for, particularly around managing money when they are not well, and it will be left to the carer to manage the situation if problems occur.

Support staff helping people managing Individual Budgets, who are not familiar with mental illness will need training in the common issues which may arise. All staff will also need training in the use of advance statements, which can be used by service users to try to ensure that appropriate arrangements of their choice are put in place should they experience a period of mental incapacity.

## **Case study – Information from National Information and Advice Service**

Rethink's National Advice and Information Service has produced information on Direct Payments and mental health as part of a project funded by the Department of Health. This includes leaflets and factsheets on advanced statements and on lasting power of attorney, which carers can use to manage money on someone else's behalf.

### **Disability benefits**

Rethink received numerous spontaneous responses to the suggestion in the Social Care Green Paper that Disability Living Allowance (DLA) and Attendance Allowance (AA) would be included in funding the wider social care system. The responses indicated that these benefits should definitely remain unchanged and should not be incorporated into a general funding stream. Mental Health service users indicated that they used benefits for the spontaneous needs caused by their fluctuating conditions, such as taxi fares to remove a person from a stressful situation when a panic attack occurs.

“Being able to spend money flexibly as my condition fluctuates is vital. I can save it for when I need it. My experience of personalised budgets is that you have to agree how and when you spend in advance. That would be a disaster for me.”

– Email to Rethink from a Service User concerned about the Social Care Green Paper

### **Issues for Services**

Right to Control will pose challenges to services, who will bridge the gap between Local Authorities and Commissioners and the individuals who will receive Direct Payments. There is much that can be done to ease the transition into personalised services.

## **Adaptation and Provision of Different Services**

There should be help available for services to develop service options which are tailored to fit with direct payments. Many services have rightly focused their energy on the provision of good services and may not have the business development knowledge to know how to adapt their service to allow them to be accessed by service users with direct payments.

## **Publicity and Marketing for Services**

Service providers will also be in the new situation of having to promote their services to individuals, rather than just accepting referrals. This is a new area for many who are skilled in providing services, but not in marketing and public relations. There should be help available for services to develop ways of communicating with service users and connecting services to people in a manner which is appropriate. This will be particularly crucial in extending new services to people who may have been isolated for some time.

It is also true that many care co-ordinators are unsure as to what services can be paid for by Direct Payments. In the experience of Rethink services, care co-ordinators and service users who think creatively about how assessed needs can be met, access more funding.

## **'Payment Gap' in funding**

For many services, it is possible that there will be a payment 'gap' – a period of time when services may not be commissioned by traditional means, but has not yet build up enough service users on direct payments who want to use the service. In Rethink's experience, in some cases this discourages care co-ordinators from recommending a direct payment because of this 'gap'. They argue that the service user can access an existing service immediately instead of having to wait for a direct payment, which take some months to set up. While some agencies provide a service immediately in the expectation that

Direct Payments will be back dated, there is much confusion which results in lower uptake.

### **Case study – Bridges**

'Bridges' is a Community Resource Centre based in Norfolk. It runs many successful programmes, including art, sports, and a creative writing group along with other structured recovery and self management groups. When funding was threatened, Service Users from Bridges applied for direct payments so they could jointly fund the service through their own payments. However, there remained a 'gap' in funding whilst applications were processed.

The transition between the old system and the new system will have to be carefully managed, with funding available to services to cover the difficult interim period.

### **Maintaining Quality**

It is also possible that, despite efforts to the contrary, the introduction of Individual Budgets will produce a drive towards economy rather than value for money. The cheapest services will be able to maintain themselves on lower amounts of money, while higher quality services have greater overheads. This has been raised in terms of support staff leaving to become personal assistants, but the issue is wider than this.

It is not clear what regulation there will be for services funded by Direct Payments and how vulnerable adults will be safeguarded. For example, it is essential that staff quality is maintained. Many new organizations are setting up services funded by Direct Payments who employ staff who have not gone through a recruitment process, beyond a CRB check. These organizations are able to respond more quickly to need, as they do not have a complicated recruitment procedure, but the quality of their staff is not monitored. There currently seems to be little or no monitoring of such organizations, and the quality of the service they provide or the staff they employ.

## Supporting People

Including the Supporting People funding stream in the Right to Control would have a huge impact on housing services, particularly for those with mental illness. Housing provision for this vulnerable group can be key to recovering a better quality of life. Specialist housing can be essential when someone is first discharged from hospital, or when someone has severe ongoing needs. When specialist housing is not available, Rethink members have experience of very poor housing, in areas where people with mental illness can be a particular target for crime. The link between mental illness and homelessness is also well established. A survey of one of St Mungo's street-facing hostels found up to 85 per cent of clients with personality disorders; around 40 per cent with anxiety disorder; and around 25 per cent each with depressive disorder or post-traumatic stress disorder.<sup>6</sup>

It is a PSA 16 objective to ensure that the most socially excluded adults are offered the chance to get back on a path to a more successful life by increasing the proportion of at-risk individuals in settled accommodation. If Supporting People funding is included in the Right to Control, care must also be taken that essential services, such as supported housing, are still available for people with fluctuating conditions when they are in crisis regardless of the number of service users pooling Individual Budgets. Supported housing services cost more to run than a service which supports someone in their own home, as they provide a much higher level of care and are unlikely to be commissioned in the first instance by a group of service users pooling their Individual Budgets.

While including Supporting People within the funding streams for Right to Control would in theory allow people choice over their housing support, it is essential that the variety of housing remains available in this field and that specialist services are maintained.

---

<sup>6</sup> Homelessness: It Makes you sick St Mungos 2008

## **Issues for Local Authorities and Commissioners**

### **Local Authority Engagement**

Despite having been shown to have the best outcomes from a system of Individual Budgets, people with mental health problems have had the lowest uptake rate.<sup>7</sup> Rethink's National Information and Advice service were commissioned by the Department of Health to look into barriers to uptake and one of the key areas they have identified has been lack of awareness that Direct Payments were available at all. Figures show great variation between Local Authorities in engaging with Direct Payments for people with mental health problems.<sup>8</sup> It may also be possible that it seems 'too hard' for many in Local Authorities to engage with the complex issues which surround supporting someone with mental health problems to take up Direct Payments.

Local Authorities should be required to report on outcomes for people from different disability groups, in order to monitor the outcomes for these groups.

### **Right to Control and the Engagement with Health Services**

The distinction between social care and health services is often unhelpful, and it is possible that this has also meant slower uptake of direct payments in the past for people with mental health problems. The Ibsen review particularly highlighted this for mental health and continuing care funding.<sup>9</sup>

Informal research by our National Information and Advice service for the Department of Health also suggested that while people with other disabilities had a care co-ordinator based within Social Care services, people with mental health problems under the Care Programme

---

<sup>7</sup> Evaluation of the Individual Budgets Pilots Programme: Final Report 2008  
IBSEN

<sup>8</sup> See appendix 1 provided to Rethink's National Information and Advice Service

<sup>9</sup> Evaluation of the Individual Budgets Pilots Programme: Final Report 2008  
IBSEN

Approach (CPA) had their care co-ordinator based within a health service (for example a Community Psychiatric Nurse, or another part of a Community Mental Health Team)<sup>10</sup>. Many of these professionals have not been well informed about elements of social care, and may not see their role as encouraging Direct Payments. They may be unclear as to whether they can recommend Direct Payments and what the payments can be used for. The National Information and Advice Service also heard that care co-ordinators can be actively hostile towards Individual Budgets, fearing the threat this may pose to their own service and their own jobs.

As care co-ordinators are the ones who are best placed to advise on what care may be needed, the Right to Control must actively engage care co-ordinators from health services.

---

<sup>10</sup> Section 64 Funded Project: Direct Payments Take Up Campaign Rethink Unpublished

## Appendix 1

March 31<sup>st</sup> 2008 direct payments in England for Mental Health

Region	Council	payment on direct services MH who use	estimate popn 2007	Number per 100,000 popn
SE	Slough	44.0	120,076	36.64346
SE	Bracknell Forest	41.0	113,549	36.10776
SE	Windsor & Maidenhead	48.0	140,994	34.044
SE	Buckinghamshire	159.0	490,620	32.40797
E	Norfolk	229.0	840,656	27.24063
L	Kensington & Chelsea	46.0	178,643	25.74968
L	City of London	2.0	7,983	25.05324
L	Kingston upon Thames	36.0	157,923	22.79592
NEYH	Rotherham	51.0	253,416	20.12501
L	Bexley	42.0	222,131	18.90776
NEYH	South Tyneside	27.0	150,987	17.88233
NEYH	Stockton-on-Tees	33.0	190,248	17.34578
SE	West Berkshire	25.0	150,684	16.59101
NEYH	North East Lincolnshire	26.0	158,356	16.4187
NEYH	Hartlepool	15.0	91,391	16.41299
NEYH	Barnsley	35.0	224,641	15.58041
NEYH	Middlesbrough	21.0	138,686	15.14212
WM	Shropshire	44.0	290,882	15.12641
SE	Oxfordshire	96.0	635,512	15.10593
L	Westminster	33.0	234,131	14.09467
NW	Cheshire	92.0	688,747	13.35759
WM	Stoke-on-Trent	31.0	238,976	12.97201
L	Wandsworth	36.0	281,845	12.77298
L	Barnet	41.0	329,683	12.43619
L	Merton	24.0	199,276	12.0436

WM	Telford & the Wrekin	19.0	161,669	11.75241
WM	Warwickshire	59.0	526,683	11.20218
SE	Portsmouth	22.0	197,740	11.12572
WM	Staffordshire	89.0	825,818	10.77719
SE	Southampton	23.0	231,195	9.948312
NW	Wigan	30.0	305,598	9.816818
E	Bedfordshire	39.0	406,989	9.582569
WM	Sandwell	27.0	287,494	9.3915
SE	Surrey	100.0	1,098,233	9.105536
L	Barking & Dagenham	15.0	166,938	8.985372
WM	Herefordshire	16.0	178,429	8.967152
E	Hertfordshire	95.0	1,066,122	8.9108
E	Essex	120.0	1,376,439	8.718149
NEYH	Redcar & Cleveland	12.0	139,361	8.61073
L	Croydon	29.0	339,531	8.541194
L	Hounslow	18.0	220,629	8.158492
NW	Cumbria	40.0	496,942	8.049229
L	Tower Hamlets	17.0	215,317	7.895336
L	Redbridge	20.0	254,373	7.86247
SE	Kent	109.0	1,394,733	7.815116
SE	East Sussex	38.0	508,274	7.476282
SW	Swindon	14.0	189,479	7.388682
L	Hillingdon	18.0	250,675	7.180612
EM	Derby	17.0	237,892	7.1461
NW	Salford	15.0	219,178	6.843753
L	Richmond upon Thames	12.0	179,952	6.668445
NW	Liverpool	29.0	435,488	6.659196
EM	Leicestershire	42.0	640,981	6.552456
NW	Wirral	20.0	310,155	6.448389
NEYH	Sunderland	18.0	280,272	6.422333
SW	Dorset	26.0	406,847	6.390609
NEYH	North Tyneside	12.0	195,961	6.123667
NEYH	East Riding of Yorkshire	20.0	332,977	6.006421

NW	Lancashire	69.0	1,168,086	5.907099
L	Waltham Forest	13.0	222,309	5.847716
NW	Manchester	26.0	458,136	5.675171
EM	Lincolnshire	39.0	692,758	5.629672
L	Islington	10.0	187,835	5.323821
SW	Torbay	7.0	134,187	5.216601
E	Suffolk	37.0	709,409	5.215609
NW	Trafford	11.0	212,799	5.169197
NEYH	Newcastle upon Tyne	14.0	271,614	5.154373
SW	Bath and North East Somerset	9.0	178,250	5.049088
NW	Halton	6.0	119,541	5.019198
SE	Isle of Wight	7.0	139,482	5.018569
NW	Oldham	11.0	219,477	5.011915
NW	Stockport	14.0	280,948	4.983129
NW	Bolton	13.0	262,300	4.956157
SW	Bristol	20.0	416,352	4.803628
L	Hackney	10.0	209,656	4.769718
NEYH	Kirklees	19.0	400,989	4.738285
NEYH	Gateshead	9.0	190,499	4.724434
NEYH	Durham	23.0	504,865	4.555673
NEYH	Bradford	22.0	497,379	4.423186
NW	Sefton	12.0	276,213	4.344473
WM	Dudley	13.0	305,419	4.256448
L	Enfield	12.0	285,105	4.208976
NW	Tameside	9.0	214,364	4.198466
SE	Reading	6.0	143,744	4.174087
SW	Plymouth	10.0	250,675	3.989229
SE	Wokingham	6.0	156,619	3.830953
NW	Bury	7.0	183,335	3.818147
EM	Nottingham	11.0	288,661	3.810698
WM	Worcestershire	21.0	555,435	3.78082
L	Brent	10.0	269,969	3.704129
L	Lambeth	10.0	273,249	3.659666
WM	Coventry	11.0	306,726	3.586263

SW	North Somerset	7.0	204,666	3.420207
WM	Wolverhampton	8.0	235,995	3.389902
NW	Knowsley	5.0	150,889	3.313694
NEYH	Leeds	25.0	761,124	3.284616
NEYH	Sheffield	17.0	530,329	3.205557
SW	South Gloucestershire	8.0	256,516	3.118714
SW	Bournemouth	5.0	163,166	3.064364
NEYH	Darlington	3.0	99,983	3.00051
SE	West Sussex	23.0	776,274	2.962871
NW	Rochdale	6.0	206,054	2.911858
L	Newham	7.0	249,614	2.80433
SE	Medway	7.0	252,215	2.77541
NEYH	Kingston upon Hull	7.0	256,977	2.723979
EM	Rutland	1.0	38,430	2.602134
L	Camden	6.0	231,909	2.587222
NEYH	Northumberland	8.0	310,619	2.575502
E	Southend-on-Sea	4.0	161,952	2.469868
SW	Devon	18.0	750,105	2.399664
WM	Walsall	6.0	254,473	2.357814
NEYH	North Yorkshire	14.0	595,537	2.35082
E	Cambridgeshire	14.0	597,363	2.343634
EM	Nottinghamshire	18.0	771,865	2.332014
L	Southwark	6.0	274,391	2.186661
WM	Birmingham	22.0	1,010,247	2.177685
SW	Poole	3.0	138,067	2.172858
L	Sutton	4.0	185,894	2.151764
NW	Warrington	4.0	195,238	2.048781
EM	Derbyshire	15.0	758,153	1.978492
EM	Northamptonshire	13.0	678,296	1.916567
SW	Gloucestershire	11.0	582,595	1.888104
L	Greenwich	4.0	223,148	1.792532
L	Haringey	4.0	224,717	1.780017
SE	Milton Keynes	4.0	228,447	1.750953
L	Havering	4.0	228,448	1.750946
EM	Leicester	5.0	292,601	1.708812

SW	Cornwall	9.0	529,545	1.699572
NW	St Helens	3.0	177,447	1.690646
SE	Brighton & Hove	4.0	253,492	1.577959
SE	Hampshire	20.0	1,276,767	1.566457
NEYH	Wakefield	5.0	321,617	1.554644
E	Thurrock	2.0	150,018	1.333173
L	Ealing	4.0	305,283	1.31026
NEYH	North Lincolnshire	2.0	159,393	1.25476
L	Hammersmith & Fulham	2.0	172,531	1.159212
SW	Somerset	6.0	522,790	1.147688
SW	Wiltshire	5.0	452,612	1.104699
E	Luton	2.0	188,791	1.059373
WM	Solihull	2.0	203,599	0.982323
NW	Blackburn with Darwen	1.0	140,852	0.709965
L	Bromley	2.0	300,719	0.665073
E	Peterborough	1.0	163,295	0.612389
NEYH	Calderdale	1.0	200,124	0.49969
L	Harrow	1.0	214,625	0.465929
L	Lewisham	1.0	258,498	0.38685
NW	Blackpool	0.0	142,488	0
NEYH	Doncaster	0.0	291,052	0
SW	Isles of Scilly	0.0	2,105	0
NEYH	York	0.0	193,307	0