Direct payments: the future now

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Direct payments in mental health services have come a long way in the last few years, but are personal budgets and the increasing prominence of social care in policy terms having detrimental effects on their success? While most people agree that direct payments are a good idea, in reality less than five per cent of those eligible to use community care services actually use them. Realising the government's intention of *'prevention, early intervention, enablement, and high quality personally tailored services'* still has a way to go.

Key words: Direct payments; Individual budgets; Independent living; Mental health services; Self-directed support

A few years ago the majority of people using or involved in providing mental health services had either not heard of direct payments, or thought that they were a social services initiative that would, at best, rarely be applicable to people who use mental health services.

Things have changed considerably, though not dramatically, since then. But now there is a real danger that the benefits realised by individuals, and the progress made by organisations, could be adversely affected by two factors, which, in themselves, are to be welcomed: the development of personal budgets (and the remodelling of the social care system that this requires) and the increasing prominence of social care in policy terms. This is of particular concern in mental health services, which, despite the clear intentions of the 1999 Care Programme Approach guidance, have still not become fully integrated, coherent health and social care enterprises.

'The CPA is care management for those of working age in contact with specialist mental health and social care services. It is essential to work towards an integrated approach across health and social care, to minimise the distress and confusion sometimes experienced by people referred to the mental health system and their carers.' (Department of Health, 1999)

Instead of responding to mental health needs holistically – making health and social care support available as best suits the particular needs of individuals – there are growing signs of an even further delineation of 'responsibilities' between local authorities and mental health trusts where direct payments are concerned.

There are two issues at stake here. First, a lack of access to direct payments by mental health service users when joint panel decisions need to be agreed:

'[social care director] is making it virtually impossible (along with [trust social care lead]) to get a direct payment agreed by the panel… Misinformation is still rife at team and higher level about direct payments and although they are putting a training programme in place, this will take time to roll out, and it will be their version of direct payments and how it is being implemented in [local authority] which… [is] not within the "spirit" of how they were intended but more concerned with budgetary constraints.' (Mental health worker, 2007)

'I really do believe there is an underlying boycotting of the direct payment system within the entire NHS and social services network which is continuing to be ignored by those in power. I am not the only one to think this way!' (Carer, 2007)

This is happening at the very time that *Putting people first: a shared vision and commitment to the transformation of adult social care* (HM Government, 2007) has been published *'to set out and support the government's commitment to independent living for all adults'*; a transformation across public services, beginning with social care, in which the increased use of direct payments will be a key feature.

The second issue is that, once direct payments have been agreed, there are reports from some local authority areas that the flexibilities intended by their introduction are being curtailed, and there is a holding back of the commitment to independent living that they are supposed to support:

'now I've got two social workers dictating to me which agency I can or can't use, rewriting my crisis plan so that I have to go into hospital rather than use extra direct payment support at home, and generally taking away a lot of the flexibility that I used to have with my direct payment… because of one recent problem. They seem to prefer me to come partly back within provided services and to take night sedation rather than have "sleep-in" support, when I really don't want either of these.

'There's still things that need resolving, not least where to draw the line in a crisis between when I can be supported at home by direct payments (essentially how much money is available in my budget) and when the purse strings are passed over to the mental health trust. My impression is that social services are trying to redraw that boundary to put more of the onus on health funding. So much for integrated care!' (Direct payments user, 2008)

Background to direct payments and foreground to individual budgets

Direct payments were introduced in April 1997 following a long campaign by disabled people and their allies. The campaign centred on the belief that far better results could be obtained if individuals had control over the resources that were used to provide their support; services that many experienced as restricting or even denying them their individual rights and aspirations.

'The idea that those who oppose current methods of psychiatric "treatment" do not acknowledge the need for services is strange and fantastic to most of us whose experiences have led us to traditional psychiatry. What is different is the existence of choice and freedom in meeting our needs.' (Lindow, 1994)

Direct payments are a means by which people can be given control over the resources that would otherwise have been used to pay for services to be provided to them. To date, tens of thousands of people have benefited from this opportunity to determine how best, in whole or part, to meet their needs through social activity and support. They have provided compelling evidence that support based around the individual is not only effective in meeting support needs, but can actually transform the lives of those who decide for themselves by whom, or by what means, their needs for support should be met, and when, how and where support would suit them best.

'The freedom that direct payment gives me is immeasurable. First and foremost it gives me control… I employ staff of my own choosing, who are available when I need them most. They follow my wishes and are not bound to distant, rigid policies to which I have had no input. And they help me with the areas of life that I see as priorities for me, at that particular time, rather than being restricted in the tasks that they can do.

"The campaign was centred on the belief that far better results could be obtained if individuals had control over the resources that were used to provide their support."

Koula Serle, manager of Re-energize, outside sports centre

Re-energize

'…incentives need to be created for moving resources from day services and repeat "special" college courses into mainstream leisure, cultural, sport and social opportunities, under the disabled person's control' (Prime Minister's Strategy Unit, DWP, DH, DfES, ODPM, 2005).

Re-energize, is a unique fitness and social group run by and for people who use mental health services. The group is about recovery, relapse prevention and social inclusion. It currently has a membership of 20, many of whom are using direct payments in order to access the facilities used and activities undertaken by the group.

We meet three days a week at an Oxford Sports Centre. There, we swim, use the gym, play squash and socialise before and after our activities; plus, week by week the group chooses a social activity to go to, such as the cinema, horticultural visits or art galleries.

The group has been going for several years now. It emerged from the Hub day centre, where there was a sports group that members enjoyed so much that after the Hub closed down they kept it going. Re-energize operates independently and outside of the services, and promotes a group ethos of: health; well-being; moving forward; reclaiming life.

The role that direct payments plays in Re-energize is twofold: people use direct payments to enable them to get to the venue and also to contribute towards the costs of maintaining the group. At the time of writing, the local primary care trust has awarded Re-energize funding to support the group's social activities. This is a tremendous recognition of the value of the group itself and of how its activities provide both health and social benefits for its members.

The contributions to Re-energize from people's direct payments go into a community business account. This goes towards expenses incurred in running the group, such as phone costs, stationery and members attending conferences and giving presentations about Re-energize.

> *'Second, direct payments provides me with the support and confidence to live my life as I wish to live it, rather than being constrained by fear, lack of confidence and low self-esteem. I now live in my own home, hold down regular employment and have friends who do not need to worry about also being my "carers". I go out independently, do voluntary work with people with mental and emotional support needs, and have learned how to trust, albeit a cat!*
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> *'Third, it acts as a form of mental health promotion and maintenance, rather than being part of all too familiar "crisis intervention" process, which, in my experience, has come too late to be a very positive or empowering form of help.'* (Heslop, 2001)

But, however compelling the evidence, the reality is that comparatively few (under five per cent) of those eligible to use community care services use direct payments, and there remain huge variations in access to direct payments, depending on where a person lives and which type of services they use.

Many people are simply not being offered direct payments as an option when they should be, and even when they have been, many people's experiences have been of protracted delays, staff uncertainty or being told that they are not eligible to receive them. For a number of years now, mental health services have been routinely identified by, for example, the Department of Health, the Commission for Social Care Inspection (CSCI) and the Social Exclusion Unit, as failing to give adequate access to direct payments. The latest official figures from CSCI (for 31 March 2007) show that the number of people using direct payments in lieu of learning disability services was three times greater than the number of people using direct payments in lieu of mental health services.

It is both the success of direct payments where they are used and the limitations imposed on access to them within the current community care system, that have led to the current political agenda. This has been informed by bringing together and implementing ideas and evidence as to how the whole care system could be adapted to provide the same maximum level of choice and control to all.

The work on designing a new system (generally known as 'self-directed support') has been led by In Control since 2003 and given further impetus by the 13 pilot individual budget sites funded by the Department of Health since 2006 (www.individualbudgets.csip.org.uk). Two recent developments are of particular interest: the publication by In Control of a discussion paper on mental health and self-directed support, *A choice and a voice* (Brewis, 2007), and the publication of *Putting people first: a shared vision and commitment to the transformation of Adult Social Care* (HM Government, 2007).

Direct payments (as we currently define them) are not being replaced, as has been supposed, but will remain as one way of receiving an individual budget. Effectively, the system is being remodelled to reflect the aspirations of those who campaigned for so long to bring direct payments into being:

Hazel

'Family members and carers to be treated as experts and care partners.' (HM Government, 2007)

'It took a year from the time I alerted the trust to my son's urgent need for the 12 hours he was assessed as needing, to being offered direct payments for just six of those hours.

'We had been seriously misinformed about direct payments over a protracted period of time. Having been initially told that direct payments were not applicable, we persisted as we had information to the contrary. Twice we were assured that the direct payments were approved, and twice it turned out they were not!

'On the third occasion, we were told that, contrary to previous assurances, our son's level of need was not significant enough for him to be deemed "eligible". At the time, he was virtually a recluse in a bungalow in our garden. Two years earlier, he had started work again on a part-time basis and had begun to rebuild his previously successful career in business.

'The protracted nature of the process, the apparent lack of knowledge by staff and the inconsistent and incorrect information provided were all real problems. The strange phenomenon of needs being agreed as eligible at an assessment, then at a trust panel meeting, but subsequently being declared ineligible by the local authority in a third part of the process, should surely have been of serious concern for senior trust and authority staff. The decision was particularly unexpected given that my son's CPA assessment – used in the direct payments application – was actually graded at "critical", the highest level on the scale.

'However, I challenged and lost the six-hours-per-week decision. My son had deteriorated to such an extent that it seemed pointless trying any longer, and I became resigned to the fact I had lost my long battle. The ordeal my son and I have gone through has made the outcome far worse than could ever have been imagined, and I have regretted ever embarking on my fight for direct payments. I lost faith and hope and, sadly, my son did too. He became a total recluse and wanted nothing to do with anyone, including me.

'I still maintain that it would never have got to this situation had he received the help when I first asked. I watched him deteriorate month by month, and constantly prayed for "intervention" that was not forthcoming. I felt pain and anger, and was disillusioned and dispirited. My son had no will to do anything now other than to breathe, eat, sleep and smoke. I could do no more for him and felt ashamed at admitting defeat and deserting him. I just couldn't achieve what I knew could be achieved, without help – and it just wasn't there.

'Shortly after this, my son was shown a residential home by his social worker. He didn't like what he saw and returned to the bungalow. With considerable difficulty, we eventually recruited a support person for the six hours that were granted. We had a poor response to the advert, but at first it seemed to work. He went bowling and enjoyed it, and even drove my car for about a mile after being advised that his driving licence had been reinstated. But he quickly lost his confidence and is now saying he doesn't like the support worker. His confidence is now letting him down very badly, and he just wants to retreat to his solo world again.

'The sad thing is that if he had received these direct payments a year ago, his confidence probably wouldn't have plummeted as it has done over the months, and he could have been much further advanced by now. Also, if we could have been offered the 12 hours he was originally assessed as needing, we may have been able to attract a wider range of people and found someone he would feel more comfortable with.

'I have sent the records to the Local Government Ombudsman to see if the six hour allowance can be challenged. I will not back down though; we have come too far and fought too many battles to give up now.

'On a brighter note, the new support worker is persevering and, in spite of some minor protests, my son is agreeing to continue. They have just come back from a walk with the dog, the sun is shining, and they have just gone off to the pub for a drink! I never thought I would see the day… watch this space!'

'The time has now come to build on best practice and replace paternalistic, reactive care of variable quality with a mainstream system focused on prevention, early intervention, enablement, and high quality personally tailored services.' (HM Government, 2007)

Unless the scale of the challenge that the required transformation presents to our current mental health services is fully recognised and positively addressed, there is a real danger that some of the significant progress that has been made towards this goal could be jeopardised. This would be a profound disservice to those pioneers who have, often against considerable resistance or outright opposition, created personal support solutions that reflect the ambitions of *Putting people first* and have greatly inspired others.

Recent evidence from the USA supports our view that it is of particular importance that the way in which people can choose to meet their mental health needs, and the balance of health intervention and social activity and support, is optimised by this transformation (Alakeson, 2008). This requires an active engagement with the requirements of *Putting people first*, led by a true partnership approach between health trusts and local authorities, to maximise the flexibilities available to people in meeting their mental health needs:

'This will not require structural changes, but organisations coming together to re-design local systems around the needs of citizens.' (HM Government, 2007)

Direct payments have enabled people to provide us with some encouraging glimpses of the future, now.

Karen

'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.' (Department of Health, 2003)

'Living alone in a rural area and with depression was making me feel worse and more isolated, and I realised that I needed help. I was assessed by the community mental health team and they agreed that I was in need of support to regain my confidence and self-worth.

'They arranged for a community support worker to visit me at home for a couple of hours a week. But this didn't work well... I became more and more anxious knowing a stranger was coming to see me, and that their service was often inflexible and unreliable.

'Things got so bad that I had a meeting with my care co-ordinator and on my request they stopped the service. Then I was informed about direct payments, which gave me choices that met my needs.

'After thinking long and hard about what would reduce my isolation and get me out of myself, I met with my care worker and we discussed my thoughts that my needs could be met by having a dog.

'After a meeting with the direct payment team, and receiving a direct payment, I bought my dog, Jess, through the RSPCA, who were very helpful and gave me the knowledge of how to care for her.

'I've had Jess for sometime now, and everything seems to be working out just fine. I feel less isolated, we go out for long walks and I often chat to people, and of course Jess is a great companion. Things have started to improve for me, and I really feel that I'm on the road to recovery.

'Direct payments gave me the opportunity to buy my social needs. Needs that I never could have received through in-house services.'

From *Direct payments and mental health*, CSIP North East, Yorkshire and Humber Development Centre/Rotherham MBC 2007.

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Pauline Heslop has been using direct payments to support her mental health needs for eight years.

Koula Serle manages Re-energize and has experienced mental illness for six years.

Hazel March is full-time carer to her 38-year-old son who developed schizophrenia five years ago. He has significant ongoing problems and is severely disabled by his illness.

Karen is a pseudonym. Like Pauline, she has been using direct payments to support her mental health needs. Since the DVD (see above) was made, Karen has stopped using mental health services.

For more information on Re-energize contact Antony Thorn, Direct Payments Development Officer, Oxfordshire County Council at antony.thorn@oxfordshire.gov.uk

For information about the Wilby Campaign to promote the importance of dogs in recovery, and for the recognition of their status as 'assistance dogs' contact Christine Mcdonald at christine.mcdonald@nest-network.co.uk

For a copy of the DVD that features Karen's story and four others contact call Jacqui White on 01206 287579; email: Jacqui.white@csip.org.uk