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Exercising Choice and Control: Independent Living, Direct Payments and Self-Harm

Helen Spandler and Pauline Heslop

Introduction

It is clear from other chapters in this book how crucial the exercise of power and control is to people who self-harm. For example, young people have been very clear that any support should respect their autonomy and not undermine their sense of control (Spandler, 1996). A consistent theme has been: how we develop responses which support young people to remain in control whilst not merely condoning self-harm and effectively ignoring their pain and distress? One of the ways that self-harm survivors have begun to address this themselves is through direct payments, a funding mechanism based on the key tenets of choice and control. In the previous chapter Louise Pembroke argues that more mechanisms need to be developed which support survivors to work within their own understandings and frames of reference so they are able to *direct* their own support. The organisation Survivors Speak Out is one of the few mental health organisations to have explicitly endorsed the expansion of direct payments to people who use mental health services. Therefore, this chapter explores the possibilities and limitations of using direct payments to facilitate greater choice and control, in relation to support around self-harm.

The Independent Living Movement and Direct Payments

The 'direct payments' discussed here are *not* social security benefits paid straight into a person's bank account, but an alternative means of purchasing community care support. The idea of direct payments can be traced back to the early 1970s when young disabled people in the US forced their local authorities to give them the money that had been used to keep them in residential institutions (Glasby & Littlechild, 2002). With this money they employed their own personal assistants to support them to live their own lives outside of the institution and go to college. Such action by disabled people laid the groundwork for the International Independent Living Movement (see Barnes, 1992; Kestenbaum, 1996; Hasler et al., 1999; Charlton, 1998).

The right to have individualised funding or direct payments to purchase one's own support and assistance is central to the Independent Living philosophy and has been campaigned for vigorously by disabled people (Campbell, 1998; Glasby & Littlechild, 2002; Hasler, 1999; Stainton & Boyce, 2002; Zarb & Evans, 1998; Evans, 2003). To the Independent Living Movement, independent living is not about people living alone and doing everything for themselves unless that is their choice. Rather, it is about having choice about the personal support needed to ensure citizenship and social inclusion, with the support funded and provided in such a way that the individual, as far as possible, remains in control.

The 1996 Community Care (Direct Payments) Act (DoH, 1996) meant that service users assessed as eligible for statutory community care services (due to a range of disabilities including physical impairment, learning difficulties, and mental health support needs) can receive direct payments or individualised funding. This is a way of giving service users more control over their support arrangements by giving them the money with which to plan and purchase the support they think they need to meet their assessed social care needs. This enabled local authorities in England and Wales to offer adults receiving community care between the ages of 18–65 years the option of receiving the money instead of some, or all, of their support.

Since April 2003, it became mandatory for Local Authorities in England to offer direct payments as an option to everyone assessed as needing, or in receipt of, community care services. Direct payments have also been extended to 16–17 year olds (as well as older people and carers). The rationale for dropping the age limit was to gradually enable disabled young people to make more choices in their transition to adulthood (Morris, 1999). Although social services departments have a number of concerns about how younger people would manage direct payments, young people should not have to do this alone. It should be possible to utilise various supported decision initiatives pioneered in the learning disabilities field, such as user controlled trusts and circles of support (Heslop et al., 2001; Heslop, 2005). These are designated groups of people that the service user trusts to make decisions on their behalf, if they lack capacity, or feel unable to do so. They can include friends, family, advocates and/or workers. A Circle of Support is a non-professional group of supporters who have a strong commitment to an individual and helps them achieve their goals. A User Controlled Trust or Independent Living Trust is a more formal and legally binding groups of trustees who act on behalf of an individual or group of individuals.

So how might direct payments work in the mental health field? Currently the service user's 'care co-ordinator' (often a community psychiatric nurse or social worker in a Community Mental Health Team) carries out a community care assessment of need. Once assessed as needing a community care

service, the service user should be offered the option of having some or all of their needs met using direct payments. With the resources paid directly to them, the service user can decide how they actually want to meet their assessed needs. To be able to negotiate and direct their own support and make decisions about what they need at a particular time has profound implications for people.

Such opportunities have led to recent initiatives promoting the use of direct payments in mental health (Davidson & Luckhurst, 2002, Heslop 2001; Ridley and Jones, 2002). In 2001, a National Pilot scheme was set up to increase awareness and take-up of direct payments by mental health service users across five local authority sites in England. The evaluation of this pilot scheme identified service users who were using direct payments to meet their mental health needs in a variety of creative and flexible ways outside the usual boundaries of service provision (Spandler & Vick, 2004). Follow-up work from the national pilot scheme has focused on enabling wider access to direct payments, including people from black and minoritised ethnic communities who are often believed to be underrepresented in take-up (Lowe & Newbigging, 2004).

Although there has been some concern that ‘independent living’ may be a Western concept which is alien to many cultures, this is often because of the misconception that it means living alone without support from family and community (Hasler et al., 1999). Others have argued that it is precisely because people can choose their own carers, which makes it particularly suitable for many people from marginalised communities (Begum, 1995). This is especially the case given that service users should be able to choose to employ members of their own family or community (DoH, 2003). Of course it also enables people *not* to employ staff from within their own communities. It is often another assumption that people from minoritised communities always want workers that ‘match’ their ethnicity or cultural background, as if this were possible or necessarily desirable (Chantler et al., 2001).

For the purposes of this chapter we focus on a small, but significant number of women who were using their payments to meet needs associated with self-harm. Although people may choose to meet their needs in a variety of ways through direct payments, employing and directing support workers or ‘Personal Assistants’ (PAs) has always been at the heart of independent living (Campbell, 1998; Glasby & Littlechild, 2002). For these women, using direct payments in this way has offered them a different perspective of choice and control than they might previously have encountered from mental health professionals.

Using Direct Payments

The concept of ‘user control’ might seem like a contradiction when considering meeting needs associated with self-harm. However many young people report that they use self-harm as a way of coping with intolerable distress when other coping mechanisms are beyond their control. By providing the person with the control to adopt other coping mechanisms, direct payments can, in effect, help the person control their self-harm. We offer some tentative examples to illustrate this point:

Janet,¹ for example, used direct payments to employ someone to stay with her during the night. Workers employed via direct payments are usually referred to as ‘personal assistants’ (PAs). Janet employed a worker for two waking night-sits per week when she felt she needed it most (for example at weekends). Janet had ongoing serious and escalating self-harm and suicide attempts, difficulties sleeping and would often feel acutely unsafe and vulnerable at night. Her PA would either help out with household chores while Janet slept, or sit up with her if she couldn’t sleep.

It’s very flexible. She comes in the evening and we have a drink and chat and take the dog for a walk sometimes and then I’ll go to bed at whatever time and she might do some cleaning for me or whatever ... then she sits up all night and when I get up during the night, I have got someone to talk to. That just gives me a chance to get some sleep, because I don’t sleep very well, and I self-harm quite a lot ... Just knowing that somebody is going to come in and spend the night and it gives me a bit of a break, somebody to talk to and I know I can phone her up too.

According to both Janet and her social worker, this arrangement helped reduce the severity and amount of self-harm. In addition, she has had fewer hospital admissions; the admissions she had needed were voluntary, not compulsory, as had usually been the case; and when she had gone into hospital, she had been discharged sooner than previously because she had her support arrangements already in place. Janet managed to have an arrangement whereby her worker visited her in hospital and supported her on discharge.

[before this] I was spending a lot of time in hospital, I was in hospital for nearly half a year, every year, sometimes more ... It’s reduced it quite a lot. My PA comes to see me on the ward,

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she phoned a lot and kept in contact on the phone, she kept in contact with me, so the night I came home, she came that night too.

In this way, direct payments were acting as a source of mental health maintenance and promotion to Janet, rather than merely being part of a crisis intervention process with a revolving door of entry to services. Susan was looking at formalising a longstanding supportive relationship with a friend who she knew had sufficient knowledge and understanding about her situation and her self-harm.

I would say one of the biggest needs is to have someone understand why you are self-harming ... If they know how that works they can also help you not do those things, or they can support you if you do in a way that's not patronising ... To have someone that understands the reasons behind the self-harming, that makes a difference ... Recently I self-harmed on my stomach and basically I didn't want to tell anybody and I ended up telling her and I had to go and see the doctor and then I had to go and see the nurse and I had lots of appointments, lots of dressings and she supported me all through that. She came with me to see the nurse, if the dressing fell off she learnt how to put the dressing on, she didn't criticise me or anything for what I had done to myself.

For Susan, choosing a PA who understands self-harm and reacts to it in an acceptable way was crucial:

It would be awful to have someone as a personal assistant who said 'Don't do it', 'Why do you do it?' or 'That was a silly thing to do' you know those kinds of comments. She understand the reasons behind it and can talk about it afterwards, instead of criticising, we can have a sensible conversation afterwards. That does make a difference, because in the past I have had CPNs where I've just had loads of comments, you get that from the hospital anyway when you go and have stitches.

Accounts by people who self-harm highlight the need for responses that are flexible, negotiable and open to change according to their varying needs at different times. This type of arrangement allows the service user to decide not only who, but also what, when and how they want to be supported and facilitates a more genuinely 'user-centred' approach. With this kind of arrangement the service user can draw up a contract with their PA identifying how they would like them to react and respond to their self-harm. For example, they may want to instigate a trial no-cutting rule at particular times with a view to finding alternative coping mechanisms, or they may wish to hold onto the option of self-

harm whilst having the necessary support to enable them to continue to live their chosen lives. As Janet explained:

I've rung her before when I was thinking about [self-harming] and also afterwards. When I rang her afterwards she has come to be with me until I have gone to sleep, kept me safe ... On the other hand I've rung her before and said I really feel like it and she has come round and we have talked things out and I didn't harm myself. It depends on how you feel, what's happened in the day, on the circumstances really.

This whole process can give a whole new meaning to the term 'contracts'. People who self-harm frequently object to the setting of contracts which have been initiated by mental health professionals. In this arrangement, it is possible for the individual to draw up a contract with their PA on their own terms, either informally (verbally) or formally (written in job description or work guidelines). For example Janet wrote a contract with her PA that she would not harm herself in her PA's presence, or during a specific period before or after her visit:

I don't do it while they are there, I wouldn't or I wouldn't normally do it before they come, and the day they come in either. I wouldn't do it in the morning if I knew they were going to come. Me and [social worker] come up with this together. If I feel like harming myself and she is due to come round then I'd tell her and talk to her about it instead. Sometimes I still feel like doing it but I can always talk to her about it.

Such contracts are very similar to forward planning tools such as 'Advanced Directives', sometimes called advanced statements or living wills (see Amering et al., 2005). These help ensure that during a mental health crisis, service users retain control and choice. For example Linda recalled how she set out specific guidance to her PAs outlining how she wanted them to respond in a mental health crisis. She knew that when she was feeling extremely distressed and suicidal she would often refuse help, even when she desperately needed it. With this in mind she developed explicit guidance describing her personal signs of crisis (for example refusing to answer the door) and outlining what the PA should do in such a situation. Advanced directives can also involve specific requests for help or 'advanced refusals' such as not wanting particular interventions or certain relatives to be informed.

Of course the PA would have to agree to these guidelines and should be able to discuss with the person concerned any problems with their implementation in practice. The whole process can help develop a useful dialogue between the service user and the PA as they negotiate their way through

this. The kinds of arrangements described here, in order to work, may require a high level of self-knowledge and understanding. It is clearly not a particularly simple or straightforward process and requires careful consideration and the thinking through of any possible consequences. However, in doing this it is possible for the person who self-harms to retain a greater level of control and can also help them to take on a greater level of responsibility over their behaviour and its emotional impact on others.

Such strategies build on important work carried out by survivor organisations. They are a development from crisis cards and other survivor led initiatives which have been advocated by organisations such as the Manic Depression Fellowship and Survivors Speak Out. In addition, they build on work done specifically by self-harm organisations. For example the National Self Harm Network produced an information sheet designed for people who have self-harmed to use when attending an Accident and Emergency department. The information sheet provides a very practical set of questions that the person can respond to in advance about their injuries and how, specifically, they would (or would not) like to be treated. This was developed so that service users can, as far as possible, remain in control and retain their dignity and self-respect.

Using direct payments should not rule out the option of alternative approaches either instead of, or in conjunction with direct payments e.g. more specifically psychotherapeutic interventions. Indeed, by providing them with the additional social support they require, some service users reported that direct payments could actually enable them to access and use psychotherapy. In this way, they could direct and manage their own support in ways that were consistent with and complimented their therapy.

Some mental health service users also wanted to be able to use direct payments to purchase particular alternative therapies that are either unavailable on the NHS or deemed to be 'unsuitable' for their particular needs or diagnosis. At the moment direct payments can only be used for 'social' not 'health' care. Because these therapies are viewed as health interventions, it is not usually possible to purchase them with direct payments. However, this is currently being challenged by many advocates of independent living who want to see a wider variety of options available for service users seeking more holistic support.

Tensions and Difficulties

Although direct payments offer a number of opportunities for service users who self-harm, it is certainly not the case of ‘one size fits all’; directly provided services have their place too. In reality, direct payments, as with any other service provision, can raise a whole new set of tensions and dilemmas, some of which are highlighted here.²

Firstly, choice and control are nebulous concepts and their exercise is limited by the personal, social, environmental and political contexts in which they operate. Many service users’ capacity for exercising choice and control has been undermined by their experience of mental distress and long-term use of mental health services. It might be a long and difficult learning process both for professionals, in giving up, and service users in taking on, more control. Not surprisingly, such difficulties can emerge most acutely when actually employing people. Then choices have to be made about who to employ, how and when a PA could best support the individual, and what guidelines the PA should be following. Greater ‘choice’ is often accompanied by responsibilities, constraints and consequences. The responsibility of being a ‘good employer’ and thinking through issues such as contracts, pay, insurance and back-up arrangements can be overwhelming—although every Local Authority should fund a support service whose role is to help service users with all of these issues.

Secondly, the use of direct payments may be constrained by the choices actually available and possible in a given social context. Service users need to be able to access direct payments in the first place. There is currently a high eligibility criteria for community care services, meaning that only people with ‘severe and enduring’ assessed mental health needs requiring statutory service intervention are likely to be able to access direct payments. Many people, especially young people, and people from black and minoritised ethnic communities may not use statutory mental health services, preferring voluntary community projects, precisely to avoid getting caught up in the statutory ‘system’. During the National Pilot, it was evident that very few young people under 25 were accessing direct payments. Ideally, assessments should be needs-led and informed by self-assessment. However, in practice there are tensions between definitions and understandings of need, the assessment of which does not ultimately rest with the service user.

A further constraint is the quality of support possible through direct payments. If employing PAs, their ability to exercise choice and control relies heavily on the availability of workers willing to work for the relatively low wages that can be offered and prepared to work in often quite isolated conditions. The degree of flexible support possible can be dependent on finding people able to work at times necessary (often evenings and weekends) and usually for only a small number of hours each week. It

also requires being able to find people willing and able to work and negotiate relationships in the ways that service users require. Self-harm can be very distressing both for the people harming themselves and for the people supporting them. The variety and complexity of tasks undertaken by PAs and their need to negotiate new ways of working requires a depth of responsibility and associated stress which should result in greater levels of pay, supervision and training than are generally provided for by direct payments.

There has been little focus on the presumably complex relationships and power dynamics between PAs and direct payment recipients. However, research carried out across disability groups found that despite some problems, such relationships were usually mutually beneficial. Such relationships often made the negotiation of boundaries and responsibilities easier, contained important elements of trust, loyalty and affection and resulted in subtle shifts in power relationships (Glendinning et al., 2000). Despite this, the situation of PAs remains precarious as they often work alone, are low paid, un-unionised and may be dependent on the continued receipt of direct payments by their employer. Although this has been a concern for disability activists (see Ford & Shaw, 1992), it has not driven policy. Further research may be required to look at what support and supervision PAs might need particularly in relation to supporting people who self-harm and/or attempt suicide which, as far as possible, ensures the service user remains in control. It may be possible for service users to direct their PAs to particular training and awareness-raising courses in relation to self-harm like those run by local self-help groups and voluntary agencies such as 42nd Street and the Bristol Crisis Service for Women.

This discussion raises questions about the role of the voluntary sector in general. International research has demonstrated that where governments promote individualised funding without resourcing community support networks in the non-profit sectors, the result can be a highly privatised system which limits the choice and control available to individuals without individualised funding (Lord & Hutchinson, 2003).

Independent living necessitates a shift in values and philosophy towards building greater capacity for choice and control and increasing client autonomy. More generally, it highlights the tension between maximising the potential for individual choice and control whilst maintaining a wider commitment to the collective provision of services. Direct payments have the potential of developing more creative and innovative ways of providing support and assistance (Torjman, 1996). However, people arranging their own support and funding on an individual basis has implications for the funding and availability of other collective support services. Therefore, a strategic approach to service development needs to balance two key elements. The first element is the structures in which individuals can articulate their claims for the support they need, such as advocacy services (Stainton, 2002). The second is the

conditions which will support services that offer highly customised, specialised, publicly accountable and collective service provision and assistance to meet the changing and dynamic needs of groups and communities (O'Brien, 2001).

One way of resolving this tension is through the development of strategies which support the collective pooling of resources, such as the development of co-operatives. Co-operatives could give people more collective power in using direct payments. These could facilitate the expansion of community resources, the development of new communal services or the regeneration of services that have been run down (Ridley & Jones, 2002; Maglajlic et al., 2000). Co-operatives could be developed which to help individuals combine their payments to purchase care collectively and, if necessary, help recipients with employment and administration difficulties as well as providing a collective contingency or emergency fund. In the National Pilot, for example, there was a group of service users who were using direct payments to buy in a creative arts worker (Spandler & Vick, 2004). The development of 'multi stakeholder' co-operatives have also been proposed, which would provide a structure through which direct payments recipients and PAs could openly discuss and negotiate key interests, have a powerful advocacy function, decrease individualisation and maximise the pressure for adequate resources (Lewis, 2002).

Conclusions

Although direct payments are not necessarily the best option for everyone, they do address many of the issues that are at the heart of demands of service users and survivors. Not all people who self-harm would be eligible for direct payments or would want to have them. However, some of the learning from the creative ways in which people are using direct payments could be built into existing service provision, and they do suggest alternative ways of managing the tensions so evident in current professional support for people who self-harm. Direct payments are not the only solution—nor are they a 'cure'. They are only as good as the support arrangements people are able to develop and negotiate. In other words, it is the quality of support possible through direct payments that is crucial rather than direct payments as such. However, the use of direct payments is an important step forward in the provision of support for people who self-harm—provision that is generally not 'evidence-based' but based on past patterns of service provision or assumptions by professionals about what is needed. Service users who have pioneered the use of direct payments to cope with their self-harm have much that we can learn from in our efforts to work in a person-centred way that optimises choice and control.

Finally, we end on a cautionary note. Increasing powers to offer direct payments has been viewed as a victory by the Independent Living Movement. Direct payments are currently being promoted by government ministers and increased take-up is becoming part of the monitoring of individual local authorities' performance targets. This could offer service users increased opportunities for choice and control. However, direct payments must remain not only an option, but a *viable* one. Without investment in a wider supportive infrastructure necessary to enable service users to plan, direct and manage their own support arrangements, the principles of independent living at the heart of demands for direct payments could be compromised.

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FOOTNOTES

1. Names have been altered to preserve anonymity.
2. A more general critical assessment of Direct Payments has been attempted elsewhere (Spandler, 2004).