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Individualised Funding, Social Inclusion and the Politics of Mental Health

Helen Spandler

Abstract

This paper explores how the changing nature of welfare provision can open up, or close down, opportunities for people with mental health needs to organise their own lives and develop their own communities. In particular it focuses on the rise of individualised funding or direct payments, where individuals can receive money instead of services in order to plan, purchase and direct their own support arrangements.

Introduction

The changing nature of welfare provision presents us with a number of dilemmas in forging a progressive politics of mental health. This situation simultaneously opens up and closes down opportunities for people who have been psychiatrised to exercise greater self determination, organise their own lives and develop their own communities. This article considers the particular opportunities and constraints offered by the rise of individualised funding or direct payments.

Ian Parker argues in this edition that there is 'nothing so practical as a good theory and nothing so theoretical as a good practice' (Parker 2005). A critical analysis of individualised funding poses a number of questions in relation to the theory and practice of a politics of mental health. For example, while it offers service users the opportunity to develop their own individually tailored 'practice' in response to their assessed social care needs, can it facilitate the

articulation of service user's own 'theory' (or new understandings, meanings and concepts)? Can such developments help generate spaces for the production and circulation of 'counter knowledges' (Cornett 2005) in the service of those subjected to psychiatric discourse and practices? Likewise could they support the development of politicised alternative and self help organisations such as networks of people who hear voices, experience paranoia or self harm (Jacobson and Zavos 2005; Cresswell 2005).

The politics of individual choice, culminating in demands for individualised funding mechanisms, represents a wider international trend towards service users having money in lieu of social care services in order to plan, purchase and direct their own support arrangements (Glasby and Littlechild 2002). The 'theory' impetus underlying this development (at least as far as disability activists are concerned) has been the 'social model of disability' which was developed by activists during early 1970's and later given academic credibility (Shakespeare and Watson 2002; Campbell and Oliver 1996). This has been seen as a modernist project built on historical materialist, structuralist Marxist foundations (Shakespeare and Watson 2002) and which could be construed as based on Badiou's 'democratic materialism' (Parker 2005).

A more theoretically complex notion of a 'materialist dialectic' would, Parker tells us, imbue us to consider 'subjects', rather than 'individuals' and interrogate 'truths' rather than 'communities'. This means that a truth becomes a subject which 'subtracts itself from every community and destroys every individuation' (Parker 1995). Might this short statement be calling for the reversal of years of campaigning by disabled people, their allies and now increasingly mental health service users and survivors, for greater *self* determination and social *inclusion*? We need to be careful about sweeping claims regarding the shortcomings of particular ideas and practices especially (like the social model of disability) which have served as a sound basis for activism and struggle without offering acceptable and practical alternatives (Light 2000). However, we also need to be aware of their theoretical (and therefore practice) limitations in terms of forging a progressive politic which

offers a space for multi perspectives, conflict and diversity (Gabel and Peters 2004; Shakespeare and Watson 2002).

Context of Emergence

Policy and practice simultaneously expresses and constitutes contradictory demands and outcomes. To understand the rise of individualised funding we must first understand the context of its emergence which includes the philosophy of independent living, the social model of disability and critiques of the medical model (Pearson 2000; Spandler 2004). This context influences its impact but does not necessarily determine the progressive (or reactionary) ways that such policies can be implemented or used. Ironically perhaps (if we view individualised funding as being rooted in the radical materialist social model of disability) both the New Right and New Labour projects have endorsed this policy initiative. During the 1990's various political influences converged to form a new consensus about the importance of the individual consumer-citizen and this unholy alliance ushered in initiatives like direct payments.

In the UK individualised funding was legalised by the Conservative Government in 1996 as 'direct payments' (DoH 1996). Before this, there were a number of 'informal' or indirect payments, most notably, where disabled people pressurised their local authorities to free up money to pay for alternative support arrangements via a third party. For the New Right, direct payments fitted with emphasis on individual choice, privatisation and market forces. Direct payments are now being thoroughly endorsed by New Labour and since 2003 the Government have insisted that local authorities have to offer it as an option to all social care users (DoH 2003). For New Labour, individualised funding fits with their emphasis on citizenship, social inclusion, choice and responsibility and getting people off incapacity benefit and back into 'meaningful work'.

However, the most important strand is the demand right to have individualised funding from disabled people themselves, and increasingly mental health

system survivors. The legalisation and endorsement of direct payments is seen by many as an important stage in the achievements of a civil rights movement. Typically, Morris claims that the 'struggle for direct payments has been a struggle against segregation' (1997: 58). The independent living movement has similar roots to many other progressive social movements and can be traced back to the early 1970's in the US when disabled young people pressurising their local authorities to free up the money which was effectively used to incarcerate them in residential homes and day centres to provide themselves with the support they needed to live independently: to travel, study and, in some cases, go on to become the disability activists and theorists of our generation. In the early days, Jane Campbell compared the first people who demanded direct payments, with Rosa Parks refusing to give up her seat to a white man, an act which is widely reported as kick-starting the Black Civil Rights Movement in the US (Campbell 1998; Morris, 1997).

Whilst progressive initiatives usually happen at the margins of acceptable or mainstream practice, direct payments are becoming mainstreamed, increasingly acceptable and promoted by central government and local authorities. For example whilst the 1996 legislation stressed the ability and 'capacity' of service users to manage direct payments, recent guidance states that people's capacity should be assumed and local authorities should find appropriate ways to support them to receive and use direct payments, if they so wish (DoH, 2003). Furthermore, from April 2003, all local authorities in England are required to offer anyone assessed as needing community care services the opportunity of having all, or part, of their support via direct payments (DoH, 2003). Numbers of social care users on direct payments are now part of local authority's 'performance indicators', which in turn helps determine their 'star' ratings. Despite this, promotion and take up of direct payments amongst people with mental health needs continues to lag behind, and this has led to a growing recognition of the need to promote direct payments in mental health (Glasby and Littlechild 2002; Maglajlic et al. 2000; Ridley and Jones 2002).

Opportunities

Despite initial attempts to exclude people with mental health needs from the original direct payments legislation in England (Beresford 1996) its expansion offers opportunities for mental health system survivors to challenge responses to their distress and set up alternative support arrangements which validate their own accounts and perceptions. Direct payments are part of a growing number of initiatives which attempt to de-centre professional expertise in terms of decision making, challenge the privilege of professional knowledge and promote more user-centred knowledge, definitions and alternatives (Faulkner and Layzell 2000).

Whilst a person's 'social care needs' have to be assessed by a mental health professional, the way they decide to meet these needs should (in theory) be up to them. This allows them to decide not only who, but also what, when and how they want to be supported. Although accessing direct payments is far from easy, those who have been able to access them for all (or part of) their support arrangements are beginning to use them in a variety of challenging and creative ways. Some of these potentially challenge accepted notions community, work and family and can result in individuals determining the support necessary for them to lead their lives outside dominant definitions of 'health' and 'normality'. For people who have been in the psychiatric system, being able to define the kinds of lives they want to lead is extremely important because their lives and choices are frequently pathologised (Cornett 2005; Jacobson and Zavos 2005; Cresswell 2005).

For example people have been able to employed friends, fellow mental health survivors (and even family members) as their support workers (or personal assistants). As a possible way round the difficulties of individualisation some individuals have collectively pooled their payments to meet the needs of self defined groups and communities (Spandler and Vick 2004). Furthermore, in the light of how service user's experiences and responses are too readily problematised and medicalised it may be possible for, them to negotiate and direct specific responses to particular pathologised experiences like self harm. Given the complex and paradoxical experiences which underlie self harm this

strategy might enable survivors to facilitate and direct their own responses, which might even attend to both the 'silence' and the 'scream' of self harm (Cresswell 2005). For example, survivors are able to draw up contracts with their worker identifying how they would like them to react and respond to their self harm, rather than having specific rules or contracts to 'not self harm' imposed by professionals. Such negotiations can be helped with the use of 'advanced directives' which have been endorsed by many in the survivors movement (Amering et al. 2005; Thomas and Cahill 2004) In the age of risk obsession and management (Berke 2003; Furedi 1997; Laurance 2003) this is a profoundly risk taking proposition.

Furthermore, users of direct payments frequently report greater levels of satisfaction in comparison to conventional services (Witcher et al. 2000; Stainton and Boyce, 2002; Spandler and Vick 2004) and many even speak of their experience using increasingly emancipatory language (Stainton, 2002). It has been suggested that a corresponding growth in users' confidence and assertion may also lead to demands for increased civil rights and the greater ability to participate in community and political forums (Witcher et al. 2000).

However, notwithstanding the importance of peoples positive experiences of receiving direct payments, a simple narrative of a 'march of progress' towards the adoption of progressive social policy is perhaps questionable. I have attempted a more general overview of a critique of direct payments elsewhere (Spandler 2004) but in the following section draw out some salient points in relation to mental health.

Difficulties

Firstly, I wish to attend to 'social inclusion', a notion which is very high up the New Labour political agenda and a key impetus and justification for policies such as direct payments. New Labour is promoting direct payments as one important means through which users of welfare services can be more included in mainstream society rather than be confined within specific disability or mental health services. Social inclusion and direct payments also

both relate to the Government's interest in ensuring that people do not become 'dependent' on welfare services and are encouraged to work and become responsible active citizens in their local communities (Marinetti 2003). Projects of 'social inclusion' often attempt to simultaneously fuse the identification of social exclusion with attempts to make life easier and more socially harmonious and cohesive for both the 'socially excluded' and the rest of us.

However, the social inclusion agenda has moved unproblematically from a discussion about social exclusion (or oppression and discrimination) to imperatives to 'include' in mainstream community settings which we are all assumed to want (or need) to be part of. While social exclusion and discrimination has a negative impact on health and well-being, it is not clear that 'inclusion' in the wider community is necessarily good for our mental health (Angus 2002). Such assumptions rarely consider structural inequalities e.g. race and gender (Bates and Davis 2004) or its impact on those who do not want to live within (or are oppressed by) conventional approximations of 'community, work and family.' For example, as Cornett points out in this volume (Cornett 2005), personal narratives of paranoia and conspiracies can actually serve to reconfigure community, family and/or work as the site of exclusionary practices. Understanding narratives of exclusion means we may have to question the existence of a benign, unitary and benevolent community rather than assume that 'everyone can feel at home in mainstream society' (Bates and Davis 2004: 199)?

Some commentators have described how many new progressive initiatives encourage participants to engage in activities which merely mitigate the perceptions marginalised people have of their own exclusion (Merli 2000). In this way, initiatives like direct payments may actually encourage a minority of social care users to find individual solutions to the effects of social exclusion rather than address the fundamental divisions which cause exclusionary practices (Lyons 2005). These concerns relate to some disquiet amongst service users and survivors about the social inclusion agenda who have

expressed concern about the imperative to be 'socially included' (Wallcraft 2001).

The option of direct payments doesn't have to mean people choosing to be socially included in such mainstream and potentially damaging social settings. Rather it could facilitate the individual being part of alternative communities of their own choosing and thereby engage in other ways of living their lives further away from the gaze and scrutiny of professionals. However, can individualised funding strategies can secure opportunities to build larger alternative communities and political networks through which more fundamental social changes can happen which challenge dominant ideas about mental health and illness? Instead could they circumvent the process necessary to develop new collective responses, including self help initiatives? The individual nature of direct payments could remove those most likely to initiate new challenges, especially dissatisfied people with seemingly 'marginalised' needs who might otherwise be able to voice and address new collective responses. Moreover, rather than 'freeing up' pathologised experiences so their meaning becomes 'set adrift' from its specific individualised associations (Cornett 2005), could initiatives such as direct payments be viewed as just another means of individualising and privatising distress, experience and thereby limit a wider politics of experience or subjectivity (Torjman 1996)? Moreover could such progressive initiatives take the 'wind out the sail' of welfare user movements by co-opting their more political activists and advocates?

Another concern is the way that progressive innovative ideas become 'watered down', 'downgraded' and made 'more comfortable' through the process of implementation (Dowson 2002). Elsewhere it has been tentatively suggested that care co-ordinators (the gate-keepers to direct payments in mental health) might merely re-insert notions like 'independent living' or individualised funding into their dominant understandings, frameworks and funding mechanisms so that doesn't pose too much of a challenge (Spandler and Vick 2005). More generally, Dowson predicted that mechanisms such as individualised funding could ultimately become (another) professionalised

technology which ultimately gets rested away from the very people who demanded it. He warned against the rise of 'experts' seeking to devise more sophisticated ways of deciding who should be allowed access. Indeed, particularly given the increasing demand of direct payments and corresponding resource constraints, professionals will increasingly be forced to police access and determine what they can (and can't) be used for.

Ultimately, ideas about 'choice and control' which are so central to individualised funding do not operate in a vacuum but in a wider social context of constraints, conflicts and competing ideologies (Pearson 2000). For example, the choice and control agenda is particularly problematic in mental health services as it conflicts with other government policies which increase the focus on risk and control, regulation and standardisation. In this context it may become another means of monitoring and managing clients for example by ensuring they take their medication and overseeing their support arrangements (Spandler and Vick 2005). Thus rather than delivering 'empowerment' such initiatives might be used to covertly control or manage by being reduced to a therapeutic tool or used as a means of clients 'taking responsibility', reducing 'dependency' and being less 'resistant' to mental health care. Moreover it could introduce a two tier system of those who wish to be 'independent', 'included' and/or seek individual solutions versus those who wish to rely on state provided services (Lyons 2005). This situation could result in the latter group becoming even more marginalised and excluded, not only by wider society but by an implicit hierarchy within groups of users of welfare services (Lyons 2005).

There are further ideological constraints regarding the continued and disputed nature of mental health and illness. Thus direct payments are only available for 'social' not 'health' care and this in itself reinforces the social/individual/biology split which has particularly profound implications for mental health system survivors. Many survivors would argue that their needs are primarily social, not medical and require social, relational and personal support, not medical (primarily pharmaceutical) intervention (Bracken and Thomas 2001). If direct payments are not available for 'health' care then

it may be hard for individuals to exercise choice and control in relation to alternatives to medication and other more medicalised and clinical interventions. Although social workers (often the profession who gatekeep access to direct payments) are viewed as potentially putting into practice a more 'social model of disability' (Stainton 2002), some have argued that they have been heavily influenced by the psychiatric and psychological industry to such a degree that they are as likely to medicalise personal and social problems and police the boundaries of 'health' and lifestyle decisions (Gambrill 2003; McCormick 1996).

In addition, O'Brien argues that whilst the image of the 'paying customer' may inspire people who are dissatisfied by the current welfare system, the 'metaphors that excite enthusiasm' need careful scrutiny (O'Brien, 2001: 2). The discourse of consumerism may be seductive particularly because paying customers hold a more valued role in consumer society than do beneficiaries of welfare services. Consumers can be seen as providing the 'heat that paying customers can apply to unfreeze a system stuck in controlling people' (O'Brien, 2001: 2). However, despite the official endorsement of concepts such as individual choice and person centeredness, it is questionable whether this necessarily results in a wider power shift. Moreover, initiatives such as direct payments could be viewed as another means through which individuals are effectively duped into believing in illusory notions of self determination (this time as 'consumers') by actually participating in more insidious means of self regulation which ultimately forms part of wider social processes of modern de-centralised, diffused (and increasingly self) 'governance' (Rose 1996; Marinetto 2003). As a result, participants may be less inclined to rebel and more inclined to feel part of, included in and less antagonistic to the systems of social care. Encouraging active citizenship, participation and responsibility promotes particular forms of personal morality and life decisions for individuals, communities and governments (Marinetto 2003). Like 'community participation', it can become part of the efficient and effective management of 'deviant' populations which seek to integrate welfare beneficiaries into political, economic and ideological structures over which they ultimately have little control (Rose 1996; Marinetto 2003; Henkel and Stirrat 2001). Thus as

we have seen, the power and control offered to individuals in terms of accessing direct payments has to be granted by the state via care managers working for the local authority. In doing this service users must still, to some degree, participate in wider practices of psychiatric diagnosis and pathologisation, even if it is now caged in terms of the mantra 'severe and enduring mental health problems'.

Conclusion

In many ways both the opportunities and potential problems with individualised funding or direct payments are equally compelling. It is clear that such initiatives are an important part of an ongoing struggle for a progressive politics of welfare and mental health. Not only do they open up possibilities for greater self determination, they also offer a new and unique opportunity of understanding modern forms of care, control and governance. Any analysis of the social care system needs to take into consideration both the wider political, economic and ideological context and perhaps more importantly, the strength and abilities of progressive social movements. Social movements can help sustain or reinvigorate the more radical intent of initiatives like direct payments, challenge the prevailing culture and help to forge more collective solutions.

It remains to be seen whether initiatives such as direct payments might actually help to generate alternative communities of interest, not bound to place, diagnosis or 'use of' services, but more based on relations of resistance, struggle and solidarity. While today this struggle may take the form of demanding individualised funding, tomorrow it may be through new forms of struggle (Basaglia 1987). Without such critical analysis the rush to provide short term tactical resolutions may mean that, rather than functioning as 'one means to re-shape our world' (O'Brien, 2001: 15), today's 'solutions' may become tomorrow's problem.

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