

Evaluate the assertion that current policies regarding health and social support services not only fail to provide disabled people with the necessary services to live independently within the community, but also deny them the dignity of independence in personal relationships and in their own homes.

Introduction

To answer this question it is first necessary to examine what is meant by living independently in the community and exercising independence in personal relationships and at home. This will provide a yardstick against which social services and health services can be evaluated, to determine the extent to which the support provided is, or is not, failing to enable disabled people to exercise independence within the community, personal relationships and at home. The evaluation will necessarily be selective, given the breadth of the topic, and will focus primarily on the achievement of independence by disabled people in the UK.

The concept of independent living

Defining what is meant by 'independent living' is key to any discussion around the adequacy of health and social care services to enable independence for disabled people. In the field of disability studies, within the disabled people's movement and here, the term 'independent living' has a very particular meaning; it was originally defined by disabled people themselves but has increasingly been adopted by policy-makers, although the extent to which this applies to policy-makers across the whole of government has recently been questioned by Sue Bott of the National Centre of Independent Living, in her evidence to the Parliamentary Joint Committee on Human Rights:

'We feel that where the Government are at the moment is that independent living is often considered to be a matter for one particular department or another, whereas we contend that independent living should concern the whole of Government.' (JCHR, 2011 p 4)

In society in general, most people are interdependent rather than totally self-sufficient, and at different times in our lives and in different contexts we may be more or less dependent on other people. However, the greater need of disabled people for the assistance of others can lead to inequality and imbalance in relationships, with the one providing the assistance having more power and exerting control over the one needing the assistance. This may be the case whether the person providing assistance is paid to do this, as their job, or is assisting as a 'family carer'. The reality of this inequality of power and control is graphically illustrated by the example of a frail older person being bathed by a carer; the fact that the older person is of necessity naked heightens his or her vulnerability (Twigg 2000, cited by Morris 2005). A key aim of enabling independent living is to remove that imbalance of power – to empower and give control to disabled people.

For disabled people, independent living does not mean doing everything without assistance. If it did, most disabled people would never be able to aspire to living independently. Instead, independent living means '*...disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community*' (Barnes and Mercer 2006, p 33). Importantly, this means that the disabled person should be in control of what personal assistance they receive, when they receive it and who provides it.

The independent living movement in the UK originally began among disabled people living in residential institutions (notably the Le Court Cheshire Home in Hampshire), who were looking for an alternative to the

'benevolent paternalism' (Morris 1993, p 17, quoted in Beresford 2011, p 44) of residential care and wanted to move into the community. Jenny Morris lists four key beliefs of the independent living movement:

- *'That all human life is of value;*
- *That anyone, whatever their impairment, is capable of exerting choices;*
- *That people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to exert control over their lives;*
- *That disabled people have the right to participate fully in society.'* (Morris 1993, p 21, quoted in Beresford 2011, p 44)

The concept of independent living as espoused by the independent living movement is rights-based and is a natural evolution of the social model of disability, which draws a distinction between a person's impairment, a personal attribute of body or mind, and disability, a consequence of living in a society that does not accommodate the needs of people with impairments. Support to enable independent living is seen as a disabled person's human right, and as such is enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (the Disability Rights Convention), which was ratified by the UK Government in 2009. For the independent living movement, independent living is a holistic concept, encompassing all aspects of life, including:

'....not only the right to have to have control over basic daily living tasks - such as when to get up, go to bed, go to the toilet, when and what to eat - but also the right to have personal relationships, to be a parent, to have equal access to education, training, employment and leisure activities and the right to participate in the life of the community. The development of the Independent Living Movement is inseparable from that of the disabled peoples' Civil Rights movement.' (Evans 1995 p 2)

Thus, while this essay examines the adequacy of health and social care services to enable independent living, true independence requires a great deal more than the provision of health and social care support. In 1985 the Derbyshire Centre for Integrated Living developed a list of seven requirements for independent living, to which four more were later added, in 1989, by the Hampshire Coalition of Disabled People. This produced the following list of eleven basic pre-requisites for independent living: information; counselling and peer support; housing; aids and equipment; personal assistance; transport; physical access; employment; education and training; income and benefits; advocacy (Barnes and Mercer, 2006). Out of this list, health and social care services would be expected to be the primary providers of personal assistance (the exact meaning of which is explained below), aids and equipment and information and advocacy in relation to health and social care. Whilst adequate health and social care services are clearly **necessary** to facilitate independent living, they are by no means **sufficient**; the achievement of independent living is dependent on a wide range of services and facilities across all aspects of modern life, in addition to the removal of economic, social and physical barriers to participation.

To promote independent living, health and social care services should provide support and empowerment, which enables disabled people to exercise autonomy and choice, rather than 'care', which creates and perpetuates dependence. In relation to living in the community, services should enable disabled people to choose support to enable them get into and out of bed, wash, dress, shave or apply make-up, go to work, shop for and prepare food, wash their clothes, maintain their home, facilitate leisure and a social life and maintain their health and well-being.

In relation to family relationships and home life, health and social care services should support disabled people to fulfil their roles as spouses/partners, mothers, fathers, siblings, grandparents etc. This would include, for example, a parent having support to feed and bath a baby, take a child to school, participate in play activities, supervise homework, cook family meals, purchase appropriate clothing and provide emotional support. If independent living support is not provided, disabled people are often not able to participate and contribute; rather than look after themselves and their families they may instead be inappropriately dependent on a child or a spouse for care or unable to live in their own homes and forced to go into residential care. Above all, achieving independence in personal relationships implies that disabled people can enjoy balanced personal relationships, freed from the imbalances of power and responsibilities that often arise when one person in a relationship has greater needs than another and those needs are not met in an empowering and enabling way.

Recent developments in health and social care services

Until the 1970's, most health and social care services (apart from some provision of home helps in the 1950's and 60's) were provided on a residential basis in asylums, hospitals, workhouses or residential care homes. One of the most significant changes in the way both health and social care services are provided has been the shift from residential provision to provision in the community (Beresford et al 2011) – in other words, social care in people's own homes ('domiciliary care') and health care in primary care settings or on an outpatient basis. In relation to social care services, a greater emphasis on support in the community was the objective of the Chronically Sick and Disabled Persons Act 1970 which, however, did not fundamentally change the perception that disabled people needed to be 'cared for' rather than enabled to live independent lives. This assumption, coupled with inadequate funding, meant that disabled people did not actually achieve independent living.

'..... disabled people who were dependent on local domiciliary services often declared that they were 'isolated' or effectively 'institutionalised' in their own homes, without the chance of leading an outside social life or developing social relationships beyond their family members.' (Barnes and Mercer, 2006)

The independent living movement, described earlier, was partially successful in transforming the lives of disabled people, particularly those with physical impairments, as individual local authorities and later central government adopted the independent living ethos, to a degree, by providing disabled people with direct payments, or cash, instead of services. This alternative to the provision of traditional services was formalised and legalised by the Community Care (Direct Payments) Act 1996, which enabled local authorities to make direct payments to disabled people to employ their own personal assistants, as an alternative to providing traditional care services.

More recently, governments across the political spectrum have promoted the concept of 'personalisation' and person-centred support, achieved mainly through the use of personal budgets. Service models such as direct payments and personal budgets that allow service users to choose how their support is provided are collectively referred to as 'self-directed support'. There are now also moves towards 'personal health budgets', which seek to provide greater choice and control over health care services. The extent to which direct payments, personal budgets, traditional social care services and health services promote independent living, as defined by disabled people, is discussed below.

The role of direct payments in enabling disabled people to live independently

It is worth looking in some detail at direct payments, pioneered by disabled people themselves as explained above, because they are arguably the most effective method of delivering social support in a way that promotes independent living. People with physical impairments, in particular, have been able to lead fulfilled, active lives that would have been impossible even thirty years ago. The key has been their ability to use direct payments to employ personal assistants of their own choosing to provide support and assistance how and when they want it. Research has shown that disabled people who are enabled to use direct payments successfully find the ability to employ their own personal assistants much more satisfactory than receiving traditional services (Barnes and Mercer 2006).

There are many ways in which the ability to employ their own staff has revolutionised the lives of disabled people by addressing specific daily living challenges. For example, disabled people of working age who need assistance to get up, wash and dress stand a much better chance of securing paid employment if they can employ personal assistants to provide the assistance in a manner and at a time which allows them to travel to work for the start of the working day. Another example is that visually impaired people can have more control over their own affairs if they can employ trusted personal assistants to help them read their post and deal with paperwork on a confidential basis.

Importantly, disabled people can employ personal assistants to undertake intimate tasks rather than rely inappropriately on their partner to provide such care, which risks creating imbalance and strains in the relationship. Baroness Jane Campbell illustrates this well when she explains the tensions that affect her marriage and home life when her PA support breaks down:

‘What sparks tension between me and my husband, is when we are thrown together for two or three weeks because my PAs have all gone sick at once. He has to leave work and therefore gets behind and I have to put up with his way of doing what I consider to be my own domain.... It is the situation that causes the tension not anything to do with our relationship, which with social care support is dynamic and equitable, when we both regain the right balance of control over our lives.’ (Campbell, 2008)

The above vignette demonstrates very clearly how direct payments can enable disabled people to exercise independence in personal and family relationships and to organise their home lives as they wish.

However, it would be a mistake to give the impression that the introduction of direct payments has secured independent living for all, or even most, disabled people, or that the roll-out and continuation of direct payments have been straightforward. A number of studies of ‘cash for care’ schemes in western countries (collated by Arksey and Kemp 2008) have highlighted barriers to successful take-up of direct payments, often disadvantaging certain groups of service users more than others.

‘In particular, older people, mental health service users, people with learning difficulties and people from black and minority ethnic communities, have all been shown to experience additional difficulties in accessing direct payments’ (Beresford et al 2011, p18-19, referencing Clark et al, 2004).

Some of the barriers to accessing direct payments relate to the unwillingness of social workers/care managers to relinquish control of budgets and support services, which may be exacerbated by doubts about a service user’s capacity to give consent and/or to manage direct payments. As a result

'...practitioners may be selective in terms of the clients to whom they offer cash payments, which in England and elsewhere can impact particularly on opportunities for people with cognitive impairments, including persons with mental health problems, dementia or learning difficulties' (Arksey and Kemp 2008, citing Clark et al., 2004; Priestley et al., 2006; Tilly and Weiner, 2001).

Other difficulties relate to practical issues inherent in the direct payments model. The need for the service user to recruit and train staff, keep records, manage money and wages and comply with employment law is a very real barrier to the take-up of direct payments, particularly for some older people and people with cognitive impairments, although support organisations, particularly those controlled by disabled people, provide invaluable support (Barnes and Mercer 2006). Some service users have difficulty in recruiting suitable personal assistants (Arksey and Kemp 2008), although others find benefit in the ability to pay friends to support them (Arksey and Kemp 2008, citing Tilly and Wiener 2001 and Foster et al 2003). For older service users in particular, direct payments can sometimes work better if they are managed by a family carer (or other person) on behalf of a service user (Timonen et al 2006, cited in Arksey and Kemp 2008). However, this can restrict the service user's choice and control over their support, with the family carer choosing how the direct payment is spent (Clark and Spafford 2001, cited in Arksey and Kemp 2008), compromising independence.

Thus whilst some groups of disabled people have not derived as much choice and control from direct payments as others, certain groups, particularly younger physically disabled people, have successfully used direct payments to achieve vastly more independence, both in the community and in the context of personal relationships and home life.

'[Direct payment] schemes have helped disabled people move away from their lives being dominated by the medical profession and the negative dependency and restrictive practices of the medical model of disability, into the more vibrant, realistic and dynamic mode of the social model reflecting the true values of the world we live in.' (Evans, 1995)

Do 'traditional' social care services promote independent living?

Many service users, especially older people, who have been unable or unwilling to access direct payments or other self-directed support schemes, continue to receive 'traditional' social care services in the community. The bedrock of traditional services is home ('domiciliary') care, which may be supplemented by day centres, meals on wheels and similar one-size-fits-all services provided by or on behalf of the local authority. In common with many state-funded services, there has been a move away from direct service provision to 'contracted out' services; in domiciliary care this has meant that care workers are almost always employed by private agencies under contract to local authorities rather than by local authorities themselves.

The predominant model of domiciliary care provision is for agency carers to visit people in their homes for, say, 30 or 45 minutes per visit, to undertake such tasks as washing, dressing, assisting with using the toilet and meal preparation. It is apparent that this model of provision cannot deliver independent living as, typically, the service user has little or no choice or control over the identity of the care worker provided or the timing of the visits; the worker usually works to a care plan drawn up by the local authority following an assessment. The visits tend to be purely practical in nature, with workers visiting a number of service users in succession, delivering task-orientated care; the provision of 'social interaction' is not usually a specified requirement of the visits:

'I get sick of the in-out business [from care agencies]. Come in, get up, go away, come back, put to bed, gone again. If you want a drink at night, tough.' (Beresford et al 2005, p 7)

The impersonal nature of the visits and the lack of choice around the identity of the worker is a big issue for many service users, who have a *'succession of strangers'* (Beresford et al 2011, p 41) coming into their homes. This impersonal aspect of agency care is expressed by a service user as follows: *'Any Tom, Dick or Harry coming into the house. You don't know who they are'* (Beresford et al 2005 p 7).

Thus traditional social care services offer little choice or control for the service user and cannot be said to enable independent living in the sense that disabled people define it. However, some service users, particularly older people, see traditional services as a *'least-worst option'* as they require no effort on the part of the service user to decide what they want or manage their support; they see self-directed support options as being too much trouble to organise (Barnes 1997). For these service users, traditional services can at least offer them greater independence than living in residential institutions, but this is a long way from truly independent living.

Personalisation, person-centred support and personal budgets

Although many service users still receive traditional services, as described above, both the New Labour government, prior to May 2010, and the Coalition government, since May 2010, have encouraged local authorities to roll out personal budgets to all eligible service users within a very few years. This *'transformation'* process is supposed to reflect a commitment to greater *'personalisation'* of support, but the move also reflects the rise of consumerism and the increasing marketisation of public services under Conservative, New Labour and Conservative/Liberal Democrat Coalition governments over the past 30 years (Beresford et al 2011).

Whilst the concept of independent living was developed by disabled people themselves, as a reaction against the institutionalisation and dependency-creating culture of residential care, current policies around personalisation and person-centred support derive, at least in part, from the concept of person-centred planning, which was initially developed by professionals in relation to services for people with learning difficulties. The aim of person-centred planning is to enable disabled people to live *'ordinary lives'* in mainstream society rather than simply living in a care *'system'* (Beresford et al 2011).

'Person centred planning is a process that finds out what an individual wants to do with his/her life, helps the person decide on goals and then plans what action needs to be taken to achieve those goals' (Cole et al 2000, p 30, quoted in Beresford et al 2011, p 43).

A key practical emphasis of services developed under this model is on assisting, or supporting, service users to undertake tasks themselves, rather than undertaking those tasks for them (Beresford et al 2011). It is perhaps notable that the approach here appears to be centred on achieving change in the skills and abilities of service users, especially those with learning difficulties, to enable them to fit into mainstream society, rather than seeking societal change to facilitate inclusion.

Current social care policy, being rolled out by local authorities under the banner of *'transforming social care'* and focusing on personalisation, draws from both the concept of independent living, developed by disabled people, and the concept of person-centred planning, developed by professionals and policy-makers. The basis of personalisation is that services should be tailored around a person's needs, rather than trying to fit a

person's needs to the service; in practice this is achieved principally through the use of personal budgets, although there is also a strong emphasis on prevention and 'reablement', which seeks to provide targeted support in the first few weeks following an illness, accident or hospitalisation, to minimise the need for ongoing support.

Personal budgets share some similarities with direct payments but there are some important distinctions. A personal budget is an allocation of money to pay for support to meet the assessed needs of a service user. It may be taken as a direct (cash) payment or as a virtual budget, where the money is held by the local authority and used to purchase services for the service user. In theory, personal budgets can be spent on any service or support that achieves the outcomes identified in the service user's support plan. The support plan explains what is important to the service user and how the personal budget will be used to meet his or her needs, and is normally written by the service user and agreed with the social worker/care manager.

The rhetoric around personal budgets has emphasised the choice and control they provide for service users. The information provided to service users by local authorities explains that personal budgets can be spent on anything, apart from something illegal or something that doesn't improve the service user's life. They can be used to purchase or pay for services other than conventional social care services, including universal services such as adult education or gym membership, or equipment such as adaptive technology, in addition to employing personal assistants. In theory at least, this gives service users more choice in how their needs are met (Royal Borough of Kingston 2009).

The limited research evidence available suggests that, in general, personal budgets have been a positive development for disabled people. For example:

'... the great majority of people see themselves benefitting significantly through having a personal budget and that this applies to all groups of personal budget holders and carers, though there remain some differences across groups' (Hatton and Waters 2011, p 4)

Anecdotal evidence suggests that the scope for service users to identify creative ways of meeting their needs has the potential to lead to outstandingly positive outcomes, as evidenced by the following testimonial from a young woman with mental health difficulties:

'The advantage of having a [personal budget provided as a] direct payment was that instead of my social worker trying to figure out what would work for me, I was given responsibility for finding something that worked... Arranging my kickboxing myself...worked out very well... I was [previously] considered to be at a high risk of crisis but.... My prognosis is [now] 100% better, I'm happy and enjoying my life. I have lost 8 stones in weight so my health is much better and I am developing a skill that will hopefully one day provide me with a career... There is no quick fix to my health issues but... they no longer control my life....' (Kingston Centre for Independent Living 2011)

Whilst the personal budget model has the potential to promote independent living, the extent to which this is achieved depends on a number of aspects of its implementation. The size of the budget depends on the needs assessment undertaken by the local authority and the 'resource allocation system' used to determine the indicative budget; service users then need information, advice and support to choose and purchase services to achieve independent living; a range of suitable services need to be available to be purchased. In addition, as outcomes for service users with council-managed budgets are not as positive as for those who

take their budgets as a direct payment (Hatton and Waters 2011), much depends on the extent to which the problems inherent in direct payments, described earlier, can be overcome. In addition, despite the rhetoric promising choice and control, many service users are finding that in practice they face considerable restrictions on how they are allowed to use their personal budgets (Pitt 2011).

The impact of funding issues on social care services

Despite the empowering potential of direct payments and personal budgets, arguably the most significant determinant of the adequacy of social care services to promote independence in the community and in personal relationships and home life is the availability of funding. Social care, unlike health care, has never been free at the point of need, and a lack of resources has always restricted the amount of support available. This problem is now exacerbated by the combination of increasing demand for social care (for a variety of reasons including the increasing incidence of age and lifestyle-related conditions and improvements in healthcare which mean that both children and adults are more likely to survive serious conditions and injuries resulting in chronic impairments) and a significant lack of funding due to the government's debt problems and the Coalition government's response of imposing major cuts in the funding for public services since the May 2010 election (Beresford et al 2011).

There are two principal methods by which local authorities can ration services to save money. The first is by restricting eligibility for social care services to those with the highest level of need and meeting only people's 'eligible needs'; this means that disabled people with lower level needs are not eligible for support and that disabled people who are eligible only receive help with their most basic needs, which in practice often include only essential personal care and managing medication. Most councils have tightened eligibility criteria in this way over the past few years.

Secondly, local authorities can increase charges to disabled people for the services they receive. The Department of Health produces guidance for councils to follow in deciding how to charge for social care services but individual councils are free to use this guidance to levy charges at a level they see fit (Department of Health 2003 and 2010). Most councils have charging regimes that, typically, take up to 100% of disabled people's available income (after allowances and deductions made following the Department of Health guidance) and charge those with more than a modest level of savings the full cost of their services.

Both these methods of containing costs restrict the extent to which social care services promote independent living. For example, a young disabled person who needs local authority support to live independently may be unable to save to buy a home as he or she may be charged the full cost of their support once they have saved enough for a deposit. Or a severely disabled person may receive sufficient support to meet their personal care needs but not to take part in normal social activities, resulting in social isolation and lack of independence. Whilst the issue of funding has attracted a great deal of attention from politicians and policy-makers in recent years and the Commission on Funding of Care and Support has produced some helpful proposals (2011), there is a wide gap between the wishes of service users, most of whom would support social care being funded from taxation in the same way as health care, and the mainstream political parties who consider this to be too great a burden for the taxpayer (Beresford 2010).

A related reason for the failure of social care services, including self-directed support, to enable independent living, is that support is funded and provided locally. If a disabled person moves from one local authority area to another, they cannot take their support package with them and typically receive inadequate support

until their needs are re-assessed by their new local authority. There is no certainty that their new local authority, with its own eligibility criteria and charging policy, will provide the same level of support, so disabled people are effectively deterred from moving elsewhere in the country, for example to take up employment or to live closer to family members. Although many policy-makers have expressed their understanding of the difficulties inherent in this system, a solution has not yet been found to make support packages 'portable'.

Family carers

Over the last 30 years or more, successive governments have placed increasing reliance on informal, voluntary care provided by family members to save money (Beresford et al 2011). This has led to increasing demands for support for family carers; for example, voluntary sector organisations have started to provide specific support for 'young carers'- children who have to play a major part in caring for a parent or other family member. However, the pressures on family carers and the need to support them are not inevitable but are the consequence of failing to provide adequate support for disabled people to live independently and to exercise their natural role within the family. In the case of young carers, self-directed support services for disabled parents to enable them to fulfil their role as parents are a much better way of ensuring that such families are able to enjoy healthy, balanced relationships and that children do not have their life chances compromised by playing an inappropriate caring role.

The problem of family carers can be analysed by addressing confusion in the use of the word 'care'. Jenny Morris points out that when used in the context of informal family carers, the word 'care'

... does not mean to 'care about' someone, in the sense of loving them. Rather it means to 'care for' someone, in the sense of taking responsibility, taking charge of them... We need to reclaim the words 'care' and 'caring' to mean 'love' to mean 'caring about' someone rather than 'caring for', with its custodial overtones (Morris 1993 pp 150 and 174, cited in Beresford et al 2011, p 151)

Care by family members '*limits the autonomy of both the service user and the carer*' (Beresford et al 2011, p 151) and alters the balance in family relationships; viewing the disabled person as dependent on the non-disabled family member ignores the reality that disabled people themselves have caring responsibilities, for example as parents. In addition, the tendency of family carers to 'speak for' those they support is a serious barrier to the ability of disabled people to make their own choices, and gives rise to the need, for some groups more than others, for access to advocacy services to enable disabled people to realise their aspirations.

Reliance on informal carers both undermines independent living for disabled people and restricts the opportunities and quality of life of family members providing care. However, given the paucity of funding allocated to independent living support for disabled people across all age groups and impairment types, it seems fair to say that governments of both the left and the right are more likely to promote support services for family carers than to enable independent living to those they care for.

Dependence, independence and health care services

Whilst to a certain extent social care services have adopted the definition of independent living promoted by the independent living movement, health services generally take an individualist view of disability, using society's accepted definition of independence to mean people being able to do everything themselves. Thus:

'Health and welfare professionals usually work to a definition of disability... which focuses on functional deficits in the individual.... disabled people are dependent because their bodies, senses or minds are somehow 'defective' and don't allow them to function independently. In short, they are 'not normal'...' (Goble 2004, p 42)

This leads to an approach by the medical profession that focuses almost solely on improving the functioning of disabled people's bodies and/or minds:

'The role of professional support and services is to mitigate the effects of the functional deficits faced by disabled people in order to help them to achieve greater normality and personal functional independence.' (Goble 2004, p 42)

In the field of medical rehabilitation in particular, unreasonable efforts to achieve greater 'normality' can compromise disabled people's well-being and independence. Vic Finkelstein's experience was of spending 'endless soul-destroying hours at Stoke Mandeville Hospital trying to approximate to able-bodied standards by "walking" with callipers and crutches' (Oliver 1996b cited in Borsay 2005 p 60), rather than being empowered by the provision of a suitable wheelchair.

Even when health care provision is appropriate, the lack of flexibility in its delivery is often a barrier to independent living, as illustrated by the following quote from Baroness Jane Campbell's contribution to the House of Lords debate on the Health Bill in 2009:

'I am currently in contact with a young disabled woman who requires personal assistance throughout the day. That assistance is funded through a direct payment and an ILF (Independent Living Fund) grant. She also needs regular physiotherapy, but that is designated as healthcare. She finds it very difficult to access a service that fits into her working life. She would like to purchase a service that is flexible enough to come to her place of work in the lunch hour, but no service is flexible enough to do that, so there is no physiotherapy' (Hansard 2009)

Some policy-makers have been keen to try to replicate the benefits of self-directed social care support by the use of personal health budgets to give disabled people greater control over certain health care services. The Health Act 2009 legalised direct payments within the NHS and personal health budgets are currently being piloted in a number of areas. Early evaluation suggests that whilst there are a number of difficulties, such as the management of risk and changing the culture of health services, and the progress of the pilots has been slowed due to the Coalition government's NHS reorganisation, personal health budgets have the potential to improve health care for people with long term conditions. For example:

'[The personal health budget process] can have a huge impact on mental or psychological health and I think that it will have an impact on keeping people healthy rather than this kind of dependency that people can get when they sit back and aren't involved [in their care]. Giving them [the budget holder] the control and making them the person managing their health rather than being managed is quite a big win here' (Jones et al 2010)

However, there may be more fundamental difficulties associated with personal health budgets. Peter Beresford has argued that great care should be taken in adopting a model from social care, which has never been provided free of charge, into a universal healthcare system where most services are free at the point of delivery:

'... how [do] we square the circle of a universalist NHS, still in many ways free at the point of delivery, with a model of cash payments or allowances borrowed from a selective social care system... What will be included as part of people's individual health budget, and what will continue to be part of their core NHS entitlement? What will stop the latter being eaten away? How will lines be drawn, and who will draw them? What will happen to such individual budgets if governments or economic circumstances get harsher?' (Beresford 2008)

Thus it is too early for any firm conclusions to be drawn on the extent to which personal health budgets will succeed in giving disabled people more independence, or on the effect they will have on the NHS as a whole.

Conclusion

It is clear that some 30 years after the birth of the independent living movement, the view that disabled people are dependent and need to be 'looked after' or 'cared for' is still deeply embedded in health and social support services, which are provided following assessment of an individual's functional limitation. Self-directed support has the potential to deliver independent living, but increasing scarcity of resources means budgets are insufficient to enable disabled people to purchase the support they need to live independently. Disabled people have to rely on informal care, which prevents them from enjoying balanced personal relationships, and the services they do receive do not enable them to live independently in the community as they are insufficient to meet any more than their most basic needs. The lack of any entitlement to independent living significantly undermines disabled people's striving for equality, civil rights and full citizenship in 21st century society.

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