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Personalisation of care: A wicked problem or a wicked solution?

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Introduction

The personalised provision of equitable and effective social care to the marginalized and oppressed represents both a wicked problem (Churchman 1967) and a wicked solution. Western policy makers, economists and social care professionals struggle to address the costs and resources associated with the provision of quality social care. Limited outcomes of social services in addressing the changing and complex needs of the most excluded groups of people in countries of the global north is of ongoing concern to politicians policy makers and professionals. On the other hand, countries of the global south, such as Indian and China, are only just coming to terms with the question of universal social care service provision on a scale not previously negotiated and the concept of personalisation at this stage may appear as a distant pipe dream.

Equitable and effective social care remains an intractable problem. Personalisation of service delivery appears as both a vision and strategy in response to the issues involved. People with disabilities indeed have individualised and diverse needs. Some would (Rittel and Webber 1973) would have us believe that personalisation is the preferred solution to the inadequacies

traditional models of welfare delivery. International evidence does suggest that personalisation may well contribute to a radical transformation of social care however, the costs and complexities of implementing products such as personal budgets alongside traditional resource allocation systems, service provision and culture presents major challenges. Personalisation is potentially a wicked solution giving power and control back to the recipients of social care. Yet, the initial enthusiasm for radical social care reform has somewhat waned in light of the complex reality. Issues around the provision of personal payments continue to generate considerable debate and discussion amongst the multiple stakeholders including people with disabilities, professionals, politicians, policy makers and academics (Scourfield 2005). A critique of personalisation and its inadequacies to address the ineffectiveness and inequity of traditional welfare delivery modes is therefore warranted, and in the process, an understanding as to why personalisation has not reached its potential maybe provided.

The concept of 'personalisation' first emerged in the early 1990s, initially for people with learning disabilities as a means of achieving increased levels of choice and control in tailoring solutions to individual need through direct management of the care budget. Its subsequent introduction across social policy for adults also came with the anticipation that it would deliver much hoped for, but far less prominently advertised, cash savings in the welfare bill of adult social care support. However, the term personalisation is in a contentious and troublesome term. Divergent policy trajectories of personalisation across the UK, Europe and internationally has resulted in it being implemented and perceived in a variety of ways. It has become associated with a range of products; for example direct payments (DPs); personal budgets (PBs); individual budgets (IBs); and self-directed support (SDS). Personalisation appears to reflect the provision

of welfare services from a ground up approach, but exactly who sets the agenda and models of care provision represents a very much top down approach dictated by economists and policy makers (Anand et al. 2012).

In order to examine the impact or lack of impact of personalisation a rapid systematic literature review of the experiences and outcomes of personalisation for people with disabilities occurring across different jurisdictions, namely the UK, ROI, Netherlands, USA and Australia. The international evidence is summarised and critiqued in response to a series of wicked questions relating to the promotion of social equity and human rights in relation to personalisation.

What are personal budgets?

Personal budgets involve an individualised system of funding, based on assessments of need of individuals, and of their changing needs over time (Anand et al. 2014). A personal budget is an amount of funding allocated to a service user to enable them to determine which services they wish to purchase to meet their expressed needs. The money provided should follow the needs of service users. There are a range of different models but usually needs are assessed by health and social care professionals, in partnership with the service user. This assessment provides the basis for the personal budget. The idea is that the individual then has some flexibility to meet the needs for which the budget is granted in ways, which they choose, giving them greater control over their own social care provision.

A personal budget may be paid directly to a service user in the form of a direct payment, or paid indirectly, through another person, broker or agency, or a combination of both. Personal budget schemes vary considerably but often share common characteristics. Internationally there is a variety of funding models for the provision of personal budgets, such as ‘direct payments’ in the United Kingdom (Rabbie et al. 2009; Spandler and Vick 2006), ‘consumer directed care’ or ‘self-directed care’ in states of Australia (Fisher et. al. 2010), and ‘cash and counselling schemes’ in the USA (Dale and Brown 2006). A range of models has been generated, including, at the one end of a continuum, large scale national programmes, such as the Netherlands model with its links to the national insurance system, and at other end, regional or small scale community based programmes, such as those being developed in states and provinces of Australia and Canada.

In principle, personal budgets may be used irrespective of the person’s age (e.g. older adults, working aged adults, young adults, or children) or disability i.e. illness, chronic health conditions, intellectual disability, mental health conditions, sensory impairment, and physical disability, but in reality there availability is limited to certain age groups, disabilities or geographical areas i.e. urban rather than rural areas. The implementation of personal budgets aims to promote personal responsibility, independence, capability and resilience through the delivery of cost effective and innovative services chosen by the service user.

Personal budgets and human rights

The principle of self-determination for all people is enshrined in the Universal Declaration of Human Rights. The International Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly (2006), included the general principle, ‘Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices and independences of persons’ (Article 3). One of the claims made is that personal budgets facilitate opportunities for personal development and greater independence for people with disabilities through increased responsibility, flexibility and choice (Egan 2008). However, there are concerns that complicated personal budget schemes can reduce control and oversight for some service user groups (Ungerson 2004).

Some UK user groups have criticised government plans to introduce personal budgets into healthcare as being too restrictive and bureaucratic in administration. Galpin and Bates (2009) point out that there are “winners and losers” in every model of social care provision, with service users who lack the essential attributes and support to make rational and strategic choices, being less able to benefit from personal budgets compared to other groups. Those without the ability or capacity to manage personal budgets may be excluded from access to this type of funding, unless support (such as advocacy, financial assistance and protective policy/legislation) is in place to facilitate their participation. Personal budgets provide opportunities to enable people with significant cognitive disabilities to exercise their preferences, but they may also present unique challenges for supporting and communicating decision making.

The successful introduction of personal budgets depends on the positive response of existing disability services to adopt new care philosophies. This requires not only moving from

professionally driven (case management) to person-centred (service user directed) models of provision, but also the emergence of new types of services and categories of service providers that can respond to the demands of service users. In order to take control of budgets, service users may require a range of advocacy, brokerage, planning, administrative and independent living support services, depending on their individual needs.

The introduction of personal budgets can have the effect of helping to create new services and means of support, effectively breaking down the near monopoly of existing home-care organisations (Timonen et al. 2006). The introduction of personal budgets can increase the demand for personal assistants (Spandler 2004), a human resource which may or may not exist in local communities. In some cases personal assistants may be drawn from informal support networks such as family members and significant others, but the use of paid, informal personal carers has implications for the standard of care provided and raises issues of regulation and accountability.

Existing service providers may find the introduction of new market models and the prospect of having to 'sell' their care services somewhat challenging. For example, service providers in Australia have criticised their Government for wanting control of agencies, but distancing themselves from the risks and responsibilities of care provision (Aged and Community Services, 2008). Promoting the 'growth' of new support services and a flexible care workforce involves developing a culture of collaboration between government and service providers.

Public bodies are obliged to ensure that public funds are fully accounted for, and used by people with disabilities and organisations for the purposes intended (Egan 2008). Personal budgets are thought, by some, to have the potential to increase opportunities for the misuse of funding or budget allocation difficulties. However, it also has the potential for cost saving and greater flexibility to respond to the needs of people with disabilities, and to prevent inappropriate institutionalisation and hospital admission.

Methodology

A critique of personal budgets was undertaken using the following methods (Anand et al., 2014). Key jurisdictions were selected to illustrate and compare a range of models of personal budget frameworks. The United Kingdom (including England and Wales, Scotland, Northern Ireland), the United States of America (Washington, Arkansas), Canada (Ontario) and the Netherlands were included because they have personal budget programmes in place. For this review a Rapid Evidence Assessment (REA) was undertaken. REAs provide more thorough syntheses than narrative reviews, and are valuable where a robust mix of evidence is required, but the time or resources for a full systematic review are not available. The reviewers develop and then specify search strategies and each study is quality assessed using standardised instruments. Only studies that provided directly relevant data were included. The majority of studies include small sample sizes which may limit the generalisability to the population of people with disabilities. Reliable evidence on long-term social care costs and implication was at the time not available. The result of the review are outlines in response to critical questions as to the effectiveness of personalisation to deliver rights and equity.

What are the outcomes for service users and carers?

Service users' responses to the introduction of personal budgets vary according to scheme and service user group. Overall, the evidence suggests that personal budgets outperform traditional services in meeting service users' needs, given the right kind and level of information and support.

The UK National Personal Budget Survey (Hatton and Waters, 2011) found that service users reported more positive outcomes if they were themselves managing their personal budget, although there have been exceptions regarding older people (Poll and Duffy, 2008). Sikma and Young (2003) US study reported high levels of satisfaction with personalised budgets, emphasising freedom and the opportunity to take control of important aspects of life and daily care. Glendinning et al. (2008)'s evaluation of the Individual Budgets pilot in England reported that generally service users reported improvements in quality of life, care and control although there were differences between groups as will be further discussed below. Likewise, Laragy and Ottmann's (2011) small scale Australian study reported that the self-esteem of the five participant families was enhanced because they were no longer reliant on a case manager. However, the families in this study also reported a need for more information and support than was available. Ensuring service users are well informed of their financial allocations and providing them with adequate support to implement care plans and services were identified as critical factors in this study. A large survey of over 1,700 people in the USA found that the ability to employ paid personal assistants was highly valued by service users (Foster et al. 2003).

In Australian study different forms of employment options are available to service users included hiring through a company, association or cooperative; or directly. Different employment models suit individuals at different points in time. Services users require knowledge and information to support informed decisions as to what model suits them at a particular time, and to support the transition between arrangements as required or desired.

A Scottish study on dementia patients, involving 28 Local Authorities) (Innes et al. 2011) found that payments were used for personal care, social/recreational activities, domestic tasks and respite. In this study, personal budget recipients used their payments more often to employ personal assistants than to purchase services. It also indicated perceived benefits to be tailored outcomes; improved value for money; improved quality of care; and improved health outcomes. Considerable work has also been done by **In Control** (Hatton and Waters 2011) on the impact of personal budgets for carers. Most carers reported a positive impact of the personal budgets on their quality of life and physical and mental health. Carers reported that the receipt of personal budgets by the person they cared for had no impact on their own capacity to get and keep a paid job. However, they did express concerns about other aspects of the personal budget process - particularly the stress and worry associated with personal budgets. For the family carers of older service users, the impact of personal budgets was less positive. The impact on carers appears to be linked to factors such as whether the carer is living in the same house as the service user, and how much care and support the carer is providing. The critical factor for in achieving positive outcomes for service users managing their own personal budgets appears to be the availability of adequate information and support. Of course these findings raise further questions as to what is meant by adequate support for whom and by whom?

Are issues of equity and diversity addressed?

There has been an assumption that personal budgets will improve choice and control for all people with disabilities. However, recent UK research has failed to yield significant findings on the implications of individual budget schemes for members of minority groups (SCIE 2011). In fact there is a suggestion that the introduction of personal budgets may result in further inequalities, such as a two-tiered system of service provision, in which some (the majority community) are able to avail of personal budgets; and others (minority groups) are not (Galpin and Bates 2009; Bloche 2000). Not only do different service user groups report different levels of outcomes but there appears to be significant variations in access to personalisation. Groups that face inequity of access to personalisation include older people, people with a mental health diagnosis.

Glendinning et al. (2008,2) reported that “mental health service users reported a significantly higher quality of life; adults with physical disabilities reported receiving higher-quality care; people with learning disabilities were more likely to feel they had control over their daily lives; and older people reported lower psychological wellbeing, possibly because they felt that the processes of planning and managing their own support were burdens”.

The evidence suggest that up-take of personal budgets in the UK remains highly variable between countries, across local authorities within countries, and between different groups of social care service users. For example, rates of uptake are highest in England and lowest in

Northern Ireland, and the up-take of direct payments by people with physical and intellectual disabilities is highest in areas with lower population density (Fernandez et al., 2007). People with physical and sensory impairments have had consistently higher rates of up-take, while older people, people with intellectual disabilities and people with mental health problems have had much lower average take-up rates (Riddell et al. 2005; Priestley et al. 2006; Davey et al. 2007). In a national Australian study (Fisher et al. 2010), it was found that individual funding is more likely to be used by people of working age with low support needs, by male and non-Indigenous service users, by people with a single impairment, and by people across all disabilities without informal care networks.

Older people and people with complex needs require greater time and support to help them get the most from personal budget schemes. Alzheimer Scotland (2011) identified that the main barriers to take up of personal budgets for older people included the need for an appropriate person to manage the direct payment as the illness (dementia) progressed. Many of those interviewed acknowledged the issue of not being able to get a direct payment unless the person with dementia had the capacity to consent or the family carer had appropriate legal powers in place.

People with mental health problems also face considerable inequities as to access. Not all local authorities extend personal budget schemes to all health services. UK research suggests that some practitioners may perceive some groups as 'risky', particularly people with mental health problems, and limit their access to personal budgets (Taylor 2008). One study found that people

with mental health problems were more likely to receive a personal budget if they had family or a 'significant other' to help manage it (Spandler and Vick 2001).

One of the challenges to the implementation of personal budgets is that some models appear to work well for some categories of service users and not for others. It is therefore important to attempt to address these different needs, whilst preventing the fragmentation of service provision. Service providers need support to negotiate personal budgets because of possible barriers including complexity of needs, geographic distance, racial and ethnic bias, cultural barriers, mental capacity issues and discriminatory attitudes. Information and support, clear policy guidance, legislation and advice on decision making capacity are all key issues for the equitable provision of personal budgets.

Will personal budgets improve health outcomes?

Evidence as to personalisation resulting in improved health outcomes is again tenuous. Findings from the evaluation of Cash and Counselling schemes in the USA suggest that people in receipt of a personal budget may be more likely to use health services (Robert Johnson Wood Foundation 2007). This could be due to the improved identification of health needs arising from the assessment process and the greater availability of funding which, in the context of the USA, may address some of the financial barriers to accessing health care. In the same study, recipients employing their own personal assistants were more likely to experience positive health outcomes, such as a reduction in falls and bedsores due to personal care provided. Alakeson (2008), in a discussion of the USA and UK systems, compared self-directed care with the

traditional system and found that people using the former make greater use of routine services, and that there is a shift towards prevention and early intervention. This can lead to efficiency gains by avoiding costly acute interventions. The Australian Government's (Fisher et al. 2010) evaluation found that most service users using individual funding experienced personal wellbeing and physical and mental health at levels similar to the Australian general population norm, and participants attributed these positive results to their increased control over the organisation of their disability support.

Are personal budgets cost-effective?

The introduction of personal budgets is based on the assumption that they should be at least cost neutral. However the variation in models and service users makes it difficult almost impossible to compare costs. Small-scale studies in the UK by Jones et al. (2011) and Stainton et al. (2009), indicate that personal budget schemes were cheaper than services delivered by the local authority, and relatively cost neutral when compared with independent sector provision. However, both research teams warn of the need to adequately budget for start-up costs.

Potential cost savings have been suggested through the stimulation of business processes such managing access to services, auditing and IT systems, together with reduction in waste, overhead cost reduction and greater value for money (SCIE 2011). Stainton et al. (2009) conclude that there is some evidence to suggest that direct payments are cheaper than traditional in-house service provision and relatively cost neutral when compared with independent sector provision. The Individual Budgets Evaluation Network (IBSEN) evaluation of the individual budget pilots in 13 local authorities, Glendinning et al. (2008) reported that there appears to be a small cost-

effectiveness advantage over standard support arrangements for younger people with a physical disability and people with mental health problems. However, there is virtually no reliable evidence on the long-term social care costs and outcomes of personal budgets in England (SCIE, 2011). In the Australian context, individual funding has not resulted in an increase in the total specialist disability support cost to government (Fisher et al. 2010). In their US study, Dale and Brown (2006) report that the additional costs involved in the provision of personal budgets could be offset by the associated prevention of the need for some nursing home places. Based on a scan of the relevant research, the Health Foundation concluded that “There is limited information about value for money, largely because there are few rigorous effectiveness studies and the costs of traditional care and personal budgets tend to be underestimated” (2010, 3) .

In the Netherlands, the estimated state expenditure on personal budgets in 2007 was considerably less than the budgets for nursing homes or residential care services, and equivalent to home care services (Kremer 2007). However, van Ginneken et al. (2012) cite the Dutch Ministry of Health reporting that personal budgets had become unsustainable. “Between 2002 and 2010 the number of personal budget holders increased 10-fold, and spending increased on average by 23% a year, a rate that was much faster than for those without budgets”.

What are the perceptions of frontline staff?

The attitudes of professional service providers who gate keep access to personal budgets was highlighted in many of the reports reviewed. Splander and Vick (2004) discovered early in their pilot research that, in order for it to be successful, local authority senior managers, practitioners

and care co-coordinators, had themselves to be willing and able proactively to support direct payment implementation. The reluctance of front-line staff to offer direct payments is evident in several research studies. As early as 2006, Kremer highlighted that training for frontline staff and first-line managers is pivotal to the successful implementation of personal budget schemes. Training is needed to manage change, improve knowledge and assessment practice and promote equality and diversity awareness (Glendinning et al. 2008). It is also needed in order to challenge erroneous perceptions about risk for certain groups (particularly older people, people with mental health problems and/or severe intellectual disabilities) whom professionals might assume are not able to benefit from a personal budget. Tyson (2009) in a study of the introduction of personal budgets in Hartlepool between 2006 and 2009 reported that “there are four areas which must be addressed in the early days: leadership; legitimacy (shared understanding and ownership); a system for resource allocation; and a system for support planning and brokerage” (p. 4). Evidence suggest that the adoption of the philosophy of personalisation and person centred approaches is critical for the implementation of personal budgets.

What are the implications for the availability and quality of support infrastructure?

The availability of qualified support workers for disability support and of new types of support services is fundamental for implementing of personal budgets (Timonen et al. 2006). The experience in the Netherlands was that the growth of the care market has been slower than originally anticipated (Kremer 2006). In the Australian context, particular supply issues for personal budget users living in rural areas have been a challenge (Laragy and Ottmann 2007).

As for the nature and quality of care, evidence suggests that personal assistants employed by budget holders regard themselves able to provide a better care than is possible when employed by a care organisation, and service users are more satisfied with their support than with traditional personal assistance programmes (Kremer 2006; Hatton and Waters 2011). Personal assistants tend to be either known to the service user through family or social networks. Kremer observes that personal assistants “employed via direct payments sometimes feel obliged, like unpaid family carers, to undertake certain tasks or duties which may be beyond their skills or which may go against their professional standards”, because “clients did not always understand their role as employers” (Kremer 2006, 394).

Concerns that personal budgets may undermine the professionalism of care are valid. For example the lack of opportunities for professional development for personal assistants, who cannot consult other professionals or train and educate themselves, and the lack of control over “development of professional knowledge” (Kremer 2006, 395). One potential problem that may arise from informal care giving is that caregivers may feel reluctant to exercise their social rights such as taking the annual leave to which they are entitled. The emergence of an unregulated market of personal assistants may present concerns about not only the quality assurance of care, but also the employment conditions, training and low wages of care providers. Kremer (2006) reported that, in the Netherlands, the state no longer regulates domiciliary care, with half of the caregivers in this study saying they were overburdened because of living in the same house with the care receiver.

The Dutch government is increasingly wary of the ‘monetisation’ of informal care, because, in some cases, people are being paid in circumstances where they would provide care without payment. The debate around payment for previously unpaid, informal carers is complex, and involves ethical, budgetary and social rights issues. The availability of sufficient high quality, trained and skilled personal assistants who are able to offer the type of choice required by personal budget employers, presented challenges in most of the programmes reviewed.

Personalisation as a wicked solution to welfare rights and equity

In conclusion, any opportunities that promote the equity and rights of people requiring support and care must be considered in light of the complexity of welfare provision and the multiple interests involved. Good intentions and ideas should always be subject to critique, especially at the interface where technical solutions to welfare provision intersect with professional norms, service providers cultures and service users responses (Head and Alford 2013). Contrary to policy claims, the evidence base for personalisation, identified in this paper, is limited and so it is difficult to draw strong conclusions about the implementation, management and impact of personal budgets. However, it can be said, that qualitative findings from service users tend to be positive. The introduction of personal budgets provides an opportunity to promote a greater level of choice and control services and facilitate peoples’ inclusion in society (Spandler and Vick 2004). Personalisation should be prefaced with an acknowledgement that people with disabilities have individualised and diverse needs and that the age old tenant that a ‘one model fits all’ approach is unlikely to be adequate to address complex social welfare problems. Evidence suggests that personal budgets are not appropriate for everyone with disabilities and there is a

need for a range of service delivery options responsive to the needs of people with physical, sensory, mental health and/or intellectual disabilities (Anand et al., 2014). Personal budgets are not appropriate for everyone with disabilities and there is a need for a range of service delivery options responsive to the needs of people with physical, sensory, mental health and/or intellectual disabilities. The unbridled acceptance of personalisation as the solution to welfare ills may unintentionally reproducing the deficiencies of past welfare delivery. Just who gains or who loses in the personalisation stakes of social care is still a matter of considerable debate. Developing individually tailored and accessible support arrangements should not detract from necessary investment in improving directly provided state welfare services for those who still want and/or need them.

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