

SPECIAL ISSUE

Individual Funding for Disability Support: What are the Implications for Accountability?

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A range of different countries have experimented with the concept of individualised funding and self-directed support, particularly for long term care. With the introduction of the National Disability Insurance Scheme, individual funding looks set to be an area of future development in Australia. Individual funding is concerned with making the financial aspects of care more explicit at the level of the individual. Supporters suggest that it has the potential to transform paternalistic and inflexible systems into ones that grant greater power to individuals. The introduction of individualised funding also poses a number of interesting questions about accountability. The paper considers these accountability dilemmas and provides evidence from different national settings to illustrate how these accountabilities may manifest in an Australian context. The paper concludes by setting out a framework of accountability bringing together these different dilemmas to think about provision of care as a whole.

Key words: *individual funding, accountability, social policy*

In recent years a number of different countries have experimented with the concept of individualised funding and self-directed support, particularly for long term care. The aims of these sorts of approaches are to give individuals more choice and control over how their care is provided and in the process enhance citizenship. Although these experiments have, to date, been limited in an Australian context, the introduction of The National Disability Insurance Scheme (NDIS) will mean that there is much more of a focus on individual funding. DisabilityCare Australia has recently been established with a remit of delivering the

NDIS, however, much of the detail of how systems of individual funding will be delivered is unclear and the launch sites are grappling with a range of difficult issues. Duffy (2013) believes there are a number of inherent dangers within the design of the NDIS and that it does not sufficiently 'reflect international or Australian learning about best practice in individualised funding systems' (10). This paper seeks to draw on select theoretical discussions and international evidence to explore a number of the dilemmas that the introduction of individualised funding brings in terms of issues of accountability.

We start by setting out a brief overview of the concept of individual funding and some of the ways it has been developed in different national settings. We then move on to set out some of the accountability dilemmas that individual funding might raise. Given the constraints of the paper this is clearly not an exhaustive list and we are aware of important debates about issues such as the specification and monitoring of outcomes and how to operate performance management in these systems. Many of these debates are widely rehearsed in Australia given trends towards outsourcing (e.g. Meagher and Healey 2003) and we have chosen not to revisit these here and instead focus on others which are unique to individual funding policies. We draw on theoretical framings of ‘care’ and ‘choice’ to suggest alternatives ways of viewing issues of accountability. We do not presume to resolve the many challenges of accountability that individual funding poses – this is a complex process that should involve the negotiation of a range of different stakeholders. Instead, our aim is to draw attention to these issues and to suggest that by employing different logics of public service provision we may conceive of accountability in different ways than the public sector has done traditionally. We propose that a comprehensive framework for assessing accountability is required in order to properly appreciate the potential and limitations of individual funding.

Individual Care Funding

In recent years a range of care systems have experimented with the idea of individual funding for disability support. Terms such as personalisation, person-centred support, consumer-directed care, self-directed care, cash for care, case and counselling, personalised allocations and individualised funding have all been used to refer to this concept (see Needham 2011 for overview of these and their differences). Whilst these terms each have a slightly different focus, all are ultimately concerned with making the financial aspects of health and social care more explicit at the level of the individual (Dickinson and Glasby 2010). The assumption is that

specifying an individual’s budget and allowing the individual to decide how this is spent should enhance control, choice and flexibility. Supporters suggest that it has the potential to transform what have often been considered paternalistic and inflexible systems into ones that grant greater power to individuals (Duffy 2010; Bartnik 2010). Rather than individuals being forced into traditional patterns of services, this model gives power to the individual who can choose how and when to spend this money and in a way that best suits how he or she lives his or her life.

It is well recognised that the systems for supporting people with disabilities are in need of improvement. As the Productivity Commission concluded ‘the current disability support system is underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community’ (Australian Government Productivity Commission 2011: 3). The NDIS was established ostensibly to address these challenges and to provide all Australians with a significant and ongoing disability funding for high quality long-term care and support. One of the features of the NDIS is that it affords people with disabilities greater control over their care, whether this is in terms of choosing the providers of their care or cashing out their package and opting to self-direct the funding they are entitled to. DisabilityCare Australia is the organisation that will deliver the NDIS and the 2013/14 Commonwealth budget committed to provide \$19.3 billion over seven years from 2012–23 to roll out this scheme across the country, although with a change of government this may be under threat. DisabilityCare Australia will initially be launched in a number of pilot sites before the full scheme is progressively rolled out from July 2016. Individual funding policies for disability services are not completely new to Australia as Purcal et al. (2014) illustrate, yet, there are significant disparities across the country. At this stage much of the detail of how individual funding will operate through the NDIS is unclear and a range of difficult issues are being grappled with by the launch sites as they develop these systems.

Outside of Australia a number of other countries have a more significant history of individual funding systems. The United States, offers examples of cash and counselling and empowerment initiatives (Alakeson 2007). The UK has had a system of Direct Payments for social care since 1997 and has since developed a range of different forms of individualised funding for those eligible for social care funding and has piloted the use of personal budgets in health (Glasby and Littlechild 2009). Schemes have also been developed in the Netherlands, Canada, Belgium, France, Austria, Finland, Sweden and Germany (e.g. Alakeson 2010; Gadsby 2013) adopting a variety of different approaches. Given the constraints of the article we are unable to provide a systematic review of these (Ungerson and Yeandle 2007). Whilst these initiatives typically have similar sorts of aims, they vary significantly in the detail of how individual funding is implemented and the degree of control and power that individuals are afforded. However, they provide a wealth of data to draw on in thinking about the potential application and impact of individual funding in an Australian context including highlighting a number of potential accountability dilemmas.

Accountability Dilemmas

The implementation of individual funding is a challenging and complex process as it often requires substantial changes across a wide range of different service systems and institutional boundaries. The introduction of these initiatives involves changes to the activities and roles of professionals, the kinds of values and beliefs intrinsic to care systems, the role and power of individuals receiving care services and the purpose and functions of public service organisations. As suggested above, many of those who advocate individual funding models see them as a way to transform traditional, patriarchal services into ones which are citizen-driven and empower individuals (e.g. Duffy 2013). Yet, if this transformation is to be realised, it will involve significant changes to a range of

structures, values and practices in addition to some resolution of the accountability dilemmas this paper focuses on.

Giddens states that ‘to be accountable for one’s activities is to explicate the reasons for them and supply the normative grounds whereby they may be justified’ (1984: 30). This points to the relational nature of accountability – it is a two-way exchange of giving and holding to account. In the context of public services, accountability is a public matter where the giving of and holding to account is often done in public, through formal reports and/or meetings, and via external scrutiny by expert peers (Mulgan 2000) or an engaged citizenry (Beetham 1996). Public accountability is also both ‘explanatory and amendatory’, requiring provision for redress and sanction should performance have fallen below agreed standards (Oliver 1991).

In hierarchical governing and public service institutions, accountability is secured through the construction of vertical authority relationships. The emergence of markets and networks challenged these established institutions and academics began exploring the possibility of horizontal accountability relationships to mirror the new institutional arrangements. In place of formal rules, a focus on actors and routines or practices emerged as the new sources of horizontal accountability (e.g. Considine 2002; Sullivan 2003). This focus on actors and agency aligns well with the arguments of supporters of individual funding who see the latter as affording a new relationship between the citizen and the state, in which the transparency of the funding arrangements enables greater effectiveness of resource use and citizen responsibility (Duffy 2010). However, it also poses the question of whether, as care becomes personalised or individualised, so too does accountability, and what the implications of this might be for ‘public’ performance and scrutiny. A number of potential accountability dilemmas arise in relation to this, each of which reflect on ideas about ‘the public’ nature of accountability in the context of public service outcomes, the use of public resources, and the impact on public service workers.

Who is Accountable for Outcomes?

If individuals are to become more involved in making decisions about the services that they receive then this raises interesting questions about who should be accountable for the outcomes of that care. As any funds received through the NDIS will come from the public purse does this make government responsible for outcomes delivered, even if they have not actually had a role in designing or delivering services?

In an English context there has been no change in legal accountabilities for outcomes of care with the introduction of new forms of individual funding. However, some local governments appear to have become confused by the legal situation, assuming that the introduction of these mechanisms absolves them of responsibility for individual outcomes provided the right sorts of processes have been followed (Clements 2008). The uncertain chains of accountability within this new context may create particular anxieties for social workers and other frontline staff who are encouraging users of services to exercise more choice and control but may be exposed to blame if citizens make bad or inappropriate choices (Ferguson 2007).

If states are stepping back from accountability for outcomes, this shifts more responsibility onto the users of services to bear the risks of their own choices. For some on the right of the political spectrum this can be seen as an extension of consumer responsiveness, giving people an incentive to make good care choices. However, for those on the left of the spectrum, who have championed self-directed support as a way to enhance citizen rights for individuals with disabilities, this risk-transfer is problematic. Beresford and Jones (2008) warn that the introduction of individual funding might essentially involve simply transferring risk from the state to the individual; 'it carries the dangers of just passing on to disabled people the requirement and responsibility to be the restrictors of their own ambitions' (3). Under these circumstances if individuals fail to manage their own care and aspirations then they might be blamed or held accountable for this. Whilst in some

cases this may be correct, in others this may be due to issues outside of their own control.

The capacity to act as an expert consumer will be unequally distributed between people with disabilities, and concerns about the potential for self-directed support to magnify existing inequalities have been expressed (Slasberg and Hatton 2011). Research from the UK suggests that younger adults with physical disabilities and (to an extent) learning disabilities have more warmly welcomed and benefitted from individual funding whilst this is much less so for older adults (Glendinning et al. 2008; Daly and Roebuck 2009). Older adult groups seem to be less able to realise their citizen rights within this system, suggesting that there may still be an important role for the state here. There are also geographic issues which may play a major role in explaining quality differences. Recent experience from an English context suggests that access to good quality care for the self-directing citizen may be more or less easy depending on the local context. If there is a range of providers with the capacity to offer good quality care then it may be easier for individuals to get access to the care and ultimately the outcomes that they are aiming for. People in rural areas, for example, may find it harder to access diverse and affordable services compared to people living in more urban environments (Baxter et al. 2013).

How can we Ensure the Accountable Use of Public Money?

Individual funding schemes offer people with disabilities a greater say in how they spend the money to which they are entitled. This may happen by giving the cash equivalent of a care package to an individual and allowing them to spend it in the most appropriate way for them, or the public sector or a broker may hold funds but give individuals a bigger say in how this money is spent. Public money is still being spent although not necessarily with the involvement of public service professionals. This raises important questions about how we are able to ensure that public money is used in an accountable way. What happens if people spend their money on the "wrong" things?

Individual funding systems have varied approaches to this issue. Some countries do not actually allow individuals to spend their budgets on whatever individuals deem appropriate. For example, Finland restricts choice to lists of approved providers and France to specific care packages. England, the Netherlands and the US theoretically allow individuals to spend budgets more freely, but in practice this can be restricted by linking spend of money to specifically identified outcomes or lists of approved services or goods. Sweden, Austria and Germany have few restrictions on how money is spent, allowing much more autonomy to individuals (which is similar to Victoria's Individual Support Packages). In these cases, restrictions typically only extend to those things that are legal and often prohibit things like debt repayment, gambling or the purchase of alcohol or tobacco.

In the UK, there were some early media stories that direct payments in social care were being spent on football match tickets and trips to the pub. Although some of this may have been apocryphal, it highlighted the tensions that exist when citizens rather than professionals make judgements about what sorts of spending will best improve their wellbeing. Purchases such as a walk-in bath have an obvious link to care, but spending on a family holiday, a TV sports package, a laptop or a massage may expose service users and spending departments to critical media scrutiny (Needham 2011).

Who is Accountable for the Welfare of Care Workers?

Whilst individual funding might hold the potential for profound changes for how individual care recipients and the state interact, there is also the possibility of changes to the sorts of roles that care workers undertake. Many of those who receive a cash equivalent for their care may wish to use this to employ a care worker (often known as a personal assistant) to care for them personally. The value of these individuals is that they are able to provide activities of daily living for an individual and this may range from domestic chores to physical mobility and therapeutic care. Like many aspects of individual funding systems the

arrangements for personal care assistants vary. Some are highly regulated and ensure that employees receive, for example, holiday pay, sick pay, regular work, training and stipulated working conditions. Others are less regulated and there is little monitoring of spend of this money to the extent that 'illegal and/or undocumented labour is not explicitly forbidden or sanctioned' (Ungerson 2004: 190). In those less regulated systems where employees are not entitled to the kinds of labour protections that they would likely be afforded if working in public organisations this raises important questions about who should be responsible for the welfare of care workers.

In another important dimension to this debate, some individual funding systems allow individuals to employ a relative as their carer (e.g. Netherlands) but others forbid the employment of spouses or resident relations (e.g. UK). The regulation of care workers in this way sets the parameters about who is allowed to care and has implications for informal or migrant workers to be used. Employing relatives gives some compensation for individuals who may already be doing these sorts of roles formally, although there is a debate over whether this is a step forward for these individuals or justifies the low-pay and low-status attached to these roles. These kinds of roles tend to be filled primarily, although not exclusively, by women raising a gendered aspect to this debate. Where relatives cannot be used, individuals may employ recent migrants or in some cases undocumented workers as they may be willing to work for lower wages and have fewer expectations over the conditions of their employment. Clearly there are important ethical implications that follow from these forms of employment.

Clare Ungerson (1997) refers to the phenomenon of 'informal care' becoming state subsidised by having cash attached to it as the 'commodification' of care. In a later paper Ungerson (2004) sets out five possible variants of commodified care from empirical research from across Europe. These forms vary to the degree to which labour markets are regulated or not and the degree to which care is provided informally or fully funded. Ungerson argues that governments need to think carefully about how

the use of individual funding initiatives may impact on the empowerment and independence of not just care-users, but also care-givers. Care workers are often a precarious workforce, even when employed directly by the state or by contracted agencies. The shift to more personal assistants which may accompany the move to more self-directed support may bring some advantages for this workforce. A study of personal assistants in the UK found that they had higher job satisfaction than agency care workers. However, they were also likely to have less job security, less training and were more likely to work unsocial hours than agency staff (IFF Research 2008). The implications of self-directed support for the care workforce need to be considered within broader discussions of how to improve the status and working conditions of those who provide care.

A Comprehensive Framework for Accountability

The accountability dilemmas highlighted above are likely to emerge in any system engaged in reform of this kind and the discussion of each provides some indication of how these dilemmas may be addressed individually. However, what is missing from the above discussion, and indeed from many discussions of the implications of individual funding, is a comprehensive assessment of these dilemmas that sees each as part of a whole.

Annemarie Mol (2008) offers another way of thinking about the nature of public service provision and its relationship to various publics – users, community members, and worker – that provides a helpful framework for assessing public accountability and individual funding. Drawing on research in health care she contrasts what she terms has become a dominant logic – the ‘logic of choice’ – with an alternative logic – ‘the logic of care’. The ‘logic of choice’ is popular with many across the political spectrum as it is suggestive of autonomous consumers exercising individual judgements over possible service options with professionals providing the relevant information and the market making different options available. The wider

community is engaged in this logic only in so far as it judges public money to be well spent or not. It fits well with the preferences of many centre-right political parties for consumer rights, personalisation and marketisation.

However, Mol argues that in the context of health services this analysis is flawed and that the ‘logic of care’ offers a more apposite mode of understanding health service practices (and arguably many other public services). The ‘logic of care’ begins from a position that we do not act as autonomous rational individuals, but are always situated in collectives (or communities) of one form or another that influence how we perceive ourselves and our options. In health care patients are not necessarily passive but exist in interdependent and collaborative relationships with professionals. Between them they are engaged in an ongoing relationship in which judgements are regularly made and re-made to attune knowledge and technologies to their complex lives. Adaptation and tinkering are expected and encouraged in order to ensure that the patient receives the best care. The ‘logic of care’ offers a more meaningful way of expressing what is being sought and offered on the part of patients and providers including those interactions that are not calculable but are central to the experience of giving and receiving care. In this logic the wider community are engaged as actors who also may be engaged in acts of adaptation and tinkering in their relationships with service users, and who regard themselves also as beneficiaries of a wider system of care. Applying the ‘logic of care’ to public services more widely offers a different way of appraising service provision and deciding what should be provided, in what way and by whom.

What is particularly helpful about Mol’s logics is that both can be applied to individual funding but with rather different implications for how public accountability is conceived and practiced (Figure 1). Under a ‘logic of choice’ the individual budget holder is afforded considerable autonomy and freedom to act. Accountability is correspondingly individualised and public accountability restricted to those areas where there may be legal requirements in relation to how society wishes

Figure 1. Designing Accountability using Logics of Choice and Care

Accountability for...	Logic of Choice	Logic of Care
Outcomes	Accountability rests with individual budget holders who may take advice from professional advisors but are free to determine priorities and activities.	Government, professional advisors and individual budget holders share accountability. Outcomes determined and activities agreed jointly led by wishes of budget holder. Government maintains responsibility for providing commissioning and regulatory framework that reflects public priorities for care quality.
Public Money	Individual budget holders are accountable for ensuring funds used responsibly. Likely to be some requirement for a regulator to monitor this. Tax payers likely to press government to intervene should scandals occur.	Government, professional advisors and individual budget holders share accountability for decisions about spend priorities and preferences. Government retains overall responsibility for ensuring value for money of self directed care within a flexible framework.
Care Workers	Individual budget holders are accountable for the conditions of service of those who provide care as they make bespoke arrangements with workers or service providing organisations if services are commissioned this way. Government responsible for legal frameworks for minimum wage and conditions.	Government, service providing organisations and individual budget holders share accountability for appointment of care workers according to the agreed needs and preferences of individual budget holders. Government has overall responsibility for legal frameworks for minimum wages and conditions and standards regulator.

to regulate employment conditions for example. Ostensibly individual budget holders are solely accountable for the outcomes of their funding use, although this may be challenged should there be concern about how public money is being spent. The limitation of the ‘logic of choice’ in the context of our accountability dilemmas is that the boundaries between the private and the public can always be breached where public money is being spent.

By contrast under a ‘logic of care’ the individual budget holder is always considered to be in a relationship with some manifestation of ‘the public’, in the form of government bureaucrats, professional advisors, other individual budget holders, or the wider community. Freedom to act then becomes necessarily circumscribed by the need to take account of others’ views, whether they be expert perspectives or societal expectations., The limitation to the ‘logic of care’ is that it does not allow for an easy separation of public and individual accountabilities as it sees actors as inextricably linked to one another through ongoing relationships and interactions. Such an approach might give a more nuanced perspective of the com-

plex webs involved in the provision of care but these kinds of accounts are rarely the definitive sort that politicians (and others) seek (Sullivan 2011).

Concluding Discussion

Proponents of individual funding argue that this provides the opportunity for significant changes in the ways that individuals with disabilities are able to live their lives. Through the NDIS Australia is currently in the early stages of a journey towards more self-directed care that Government and others hope will produce a fairer and supportive care system, with more choice and control for individuals with disabilities. However, individual funding raises a set of dilemmas about lines of accountability and how these might change within this new system. These dilemmas cannot easily be resolved, but they can be surfaced and discussed rather than ignored. It may be, for example, that a weakening of accountability for public money is an appropriate trade off for greater user choice and control. However, such trade

offs should be the subject of open debate. Otherwise there is a danger it will take a tragic news story about care failure before questions about where accountability lies in a system of self-directed support are seriously addressed.

Two steps in particular need to be taken as Australia makes the transition to self-directed support. The first is for accountability to become part of the conversations between commissioners, frontline staff, service users and workers, rather than leave such issues as silences in an increasingly complex chain of relationships. The second is to consider what mechanisms could be put in place to better secure accountability, such as preferred provider lists of care organisations which meet certain minimum standards and required minimum training standards for care workers. These are not without their problems – both act as constraint on user choice – but they may be a way to maintain accountability for the provision of publicly funded care for people with disabilities.

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