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Building an Industry of Choice: Service Quality, Workforce Capacity and Consumer-Centred Funding in Disability Care

Final Report for United Voice, Australian Services Union, and
Health and Community Services Union

Natasha Cortis, Gabrielle Meagher, Sharni Chan, Bob Davidson & Toby Fattore

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Introduction

In Australia, the provision of disability services is undergoing large-scale, systemic reform (COAG, 2012). The establishment of the National Disability Insurance Scheme (NDIS) is an important recognition by national and state governments of the essential role that disability services play both in enhancing the wellbeing, independence, and quality of life of people with disabilities, and in assisting family members and other informal carers, whose unpaid work provides the majority of support for people with disabilities (AIHW, 2011; Saraceno, 2010). The NDIS reforms aim to ensure not merely that more services will be available to people with disabilities, but that those services will be high quality, appropriate to each individual's needs, and efficiently run.

In recent years, to improve outcomes for people with disabilities and the efficiency of services at both a user and system level, Commonwealth, State and Territory agencies have developed and trialled a range of market-based funding models within which 'choice' and 'control' are key principles (COAG, 2012; Productivity Commission, 2011). Consumer-centred funding models, including allocations of funds which are portable between providers, and self-managed, personal or individual budgets, are a growing part of the service mix. These models are likely to continue to grow as the Commonwealth expands its activity, and the scale of public funding, in the disability field (COAG, 2012).

This report is concerned with the impact of consumer-centred funding models on disability services workers, with particular focus on their capacity to provide high quality services. Specifically, the report compiles research and evaluation findings about what individualised funding models mean for workers in disability service organisations, and for those whom service users directly employ or contract to provide support. We recognise that disability services include staff in a wide range of occupations and roles. People with disabilities may draw on assistance from nurses, case managers, allied health workers, planners, facilitators, welfare workers, as well as food and transport workers and others who provide personal care and therapy, social and or welfare support, respite care, and domestic assistance. In this report the term 'disability support worker' refers to this wide range of paid workers, while the term 'carer' refers to family, friends, and volunteers who provide informal or unpaid assistance.

QUALITY SERVICES DEPEND ON A QUALITY WORKFORCE

The report is premised on recognition that there are critical challenges confronting disability care and support in Australia, and that a high quality, high capacity and sustainable workforce will be essential to any solution. The Productivity Commission's Inquiry into Disability Care and Support began by stating that disability services in Australia are underfunded, that service provision is inadequate, inequitably distributed, and poorly organised, that there is unmet need for support, and that there 'appears to be a strong link between observed disadvantage [of people with a disability] and a lack of

support services' (Productivity Commission 2011: 112). In the Commission's view, 'people with disabilities and their informal carers bear too much of the costs associated with disability' (2011: 102). The scale of unmet need is significant: the ABS Survey of Disability, Ageing and Carers in 2009 found that more than a third of all Australians with a disability (36 percent) did not have their need for assistance fully met.¹ Further, the extent of support provided by informal carers vastly exceeds that provided in the formal care system, and current arrangements are based on 'an excessive and unfair reliance on the unpaid work of informal carers' (Productivity Commission 2011: 105).

The workforce is central to the way in which services are provided. They are the main determinant of the quality of care and the major cost of service delivery. In turn the outcome of system reform under the NDIS is critically dependent on how effectively the current workforce challenges are addressed. The benefits of supporting a workforce quality workforce, and developing disability services as an industry of choice, will be widespread. For *people with disabilities*, skilled and well-supported workers, employed with decent working conditions and job security, can ensure care is consistent, reliable, and responsive to clients' choices and needs. Skilled and well-supported workers are best placed to build and sustain care relationships; foster capabilities, wellbeing and participation; and assist individuals and their families to take more control in defining and meeting their support needs (Blyth & Gardner, 2007, p. 243; Carmichael & Brown, 2002, p. 805). Good relationships between care workers and service users reinforce users' self-esteem and dignity to make them feel genuinely valued and cared for, while unsatisfactory relationships can erode users' self-esteem, be overly intrusive, and enforce passivity and dependency (Vernon & Qureshi, 2000).

Studies link good quality services to good working conditions. An English survey for example collected information about service quality from 7,935 users of home care services, and found service users perceived service quality to be higher where workers had received a higher number of hours of training, where they had guaranteed working hours and paid travel time, where female wage rates were closer to men's, and where workers had been employed in the same organisation for more than five years (Netten et al., 2007, p. 84).

The quality and sustainability of the paid care workforce is also important for *family members, friends, neighbours* and others providing informal care. Access to a well supported, high quality paid workforce can improve trust in, and access to, the service system and can relieve stress among these carers, to improve their quality of life.

The paid care workforce also matters for *society* more broadly, given the community and national economic benefits from increased health, wellbeing, and participation of people with disabilities, and their informal carers (Productivity Commission, 2011). In turn, the

¹ Authors' calculation based on data in Table 16 of *Disability, Ageing and Carers, Australia: Summary of Findings, 2009*, Cat. 44300D0001_2009.

'enablement' and 'restorative' functions of good quality care have efficiency benefits by assisting some people to be more independent, thereby enabling funded services to be directed to where they are most needed.

The capacity of the service system to implement change, and meet policy goals, depends on a skilled and experienced workforce. In recent years, studies of Australia's disability workforce have contributed compelling evidence that shortages of appropriately skilled staff are likely to constrain the system's capacity to provide quality services in the context of increasing levels of demand, and that without resolving these issues, it will be difficult to promote consumer choice and control and facilitate the introduction of the National Disability Insurance Scheme (NDIS) (NDS, 2011; Productivity Commission, 2011). As noted below, employers currently find it difficult to attract and retain disability support workers. Without substantially improving working conditions and the capacity to recruit and retain skilled staff, there is little prospect that goals of national system expansion will be met. Without appropriate workforce planning, monitoring and regulation, it will be difficult to guarantee appropriate safeguards and standards of care for consumers as the system expands (Productivity Commission, 2011).

AUSTRALIA'S DISABILITY SUPPORT WORKFORCE

Individualised funding models are being introduced in a context in which workforce trends in the disability sector have, for many years, undermined system capacity and sustainability.

As a group, disability support workers are older compared to the rest of the workforce, and the workforce is strongly female dominated. A high proportion of workers have worked in the sector for a long period, and many will retire in the next decade. In addition, qualification and skill levels are relatively low, which affects the quality and variety of services available. A large survey found that nationally, high proportions of disability sector employers reported that their employees are under-skilled (Martin & Healy, 2010, p. 131). More than half of employers (55 percent) reported that *some* of their non-professional employees were under-skilled. Of this group, almost a third (or sixteen percent of all employers) reported that *at least half* their non-professional workforce was under-skilled (Martin & Healy, 2010, p. 132). Further, there is evidence of low levels of organisational support for learning and development beyond mandatory courses and induction, although professional development opportunities appear more common among services with more secure funding (Fattore et al., 2010, p. 107).

These workforce challenges are largely a result of the low levels of government investment in the sector, contributing to low pay, insecure working conditions, and the low status of disability support work.

Wages in the disability sector are low, and, compared with the general workforce, a high proportion of workers depend on industrial awards (Productivity Commission, 2011, pp. 698-699). Mean hourly wage rates have been found to be around 13 percent less in disability services than the average among all female employees, with the lowest wages

concentrated in the non-government sector, reflecting the effects of widespread outsourcing in recent years (Martin & Healy, 2010, p. 119). This is important, given the likely concentration of future employment in disability services in the private, rather than the public, sector.

Casualisation is a major structural feature of the workforce. Martin and Healy showed that among non-professional workers in the disability service sector (a group which includes personal carers, home care workers, community care workers, and disability or residential support workers), almost a third (31 percent) were employed on a casual basis (2010, p. 145), but only half as many preferred this arrangement (2010, p. 144). Among non-professional disability service workers, casual employment contracts were most prevalent in the non-government sector: 35 percent of non-government sector non-professionals worked casually, compared to 11 percent of public sector non-professional disability workers (Martin & Healy, 2010, pp. 112-113). Short shifts were also found to be common, and over a quarter of non-professional workers reported wanting to increase their working hours (Martin & Healy, 2010).

People with disabilities and their carers consider these issues to be significant problems in their lives, especially workers' lack of training, low pay, and inadequate understanding of disability issues (National People with Disabilities and Carer Council, 2009). The consultations to inform the development of a National Disability Strategy, for example, confirmed that people with disabilities want policy makers to recognise the importance of the paid care workforce to meeting their needs, and the need for better employment conditions and rates of pay; education, training, and skills; and career pathways (Maher, 2003; National People with Disabilities and Carer Council, 2009).

THE PURPOSE OF THIS REPORT

The report discusses approaches to consumer-centred funding, and based on a review of the literature, identifies some associated risks. As we show, under various models of consumer-centred funding, payment adequacy interacts with expenditure rules and employment standards to create an array of risk profiles for service users, employers and support workers. As such, the implications for people with disabilities, their support workers, and the quality of care that can be provided depends on the precise structure and context of models adopted.

The report does not aim to provide a full taxonomy of possible funding models and issues. Rather, it identifies the characteristics of models which have been implemented in England and Australia, and explores issues and challenges which have been found to arise for paid workers, and which affect the quality and sustainability of the care they can provide. The models we examine are: Direct Payments and Individualised Budgets in England, and programs in Western Australia and Victoria, which are well-developed in an Australian context (COAG, 2012). The English examples exemplify market-driven approaches which have resulted in largely unregulated markets of personal assistants directly employed or contracted by consumers, and much instability for support workers employed in organisations. Direct payment models, and direct employment, have been more

circumscribed in Australia, although recent reforms in Victoria, and the launch of the National Disability Insurance Scheme, may facilitate rapid growth in direct employment and contracting.

In analysing evidence of the implications of various funding models, we have identified important limitations in the evidence base. Few research and evaluation studies have involved disability support workers themselves, or been designed with methodologies intended to capture their experiences of, or perspectives on, providing quality consumer-centred care. Notwithstanding these limitations, the report identifies a series of issues which may compromise disability support workers' capacity to provide quality services, and the safety and security of people with disabilities, and their carers. These issues relate to workers' job security; income security; opportunities to use, retain and develop skills; health and safety; and access to voice and representation.

Based on the analysis, the concluding section outlines some principles to guide policy and program development in ways that can promote service quality and sustainability in the context of consumer-centred care. The findings suggest standards of care for consumers may be best safeguarded where:

- arrangements that involve both *direct* employment of workers by people with disabilities, and *contracting* (rather than employment) models are carefully managed or avoided;
- overall levels of government funding and payments to consumers and service provider organisations are sufficient to support a decent income and safe working conditions;
- workers are supported to upgrade and develop their skills;
- there is a properly resourced strategy to build workforce capacity and sustainability, resulting from genuine collaboration between government and sector stakeholders.

Models of individualised funding

Individualised funding refers to a range of approaches to implementing personalised, self-directed, or consumer-centred care. Across the various models is a common assumption that consumer choice and control over resources will help overcome welfare paternalism, improve efficiency, and promote the autonomy, independence, inclusion, rights and citizenship of people with a disability (Glendinning, 2008). As such, these models aim to shape service delivery more directly through the market signals arising from consumer demand; to empower people with a disability to develop their own goals and demand higher standards of services; and to stimulate innovation to expand the range of supports available.

Although goals of consumer-centred care can be achieved by increasing the voice of service users within provider organisations or increasing the capacity for organisations to meet service user needs, there has been a recent proliferation in programs providing service users with funds to directly purchase their own care. In the United Kingdom, market models have introduced consumerist principles in long-term care for people with a disability and the elderly, through direct payments and individualised budgets.

In Australia, states and territories have trialled various models under different pilot programs, although direct employment by consumers has so far been more circumscribed than in the United Kingdom. All states and territories have programs incorporating forms of consumer-directed funding in place (COAG, 2012). However, Western Australia is the most advanced in enabling clients to control service delivery, while Victoria has taken a more strongly market-oriented approach, including through the state-wide roll out of direct employment (COAG, 2012; Fattore et al., 2010).

Although models of individualised funding have mutual priorities of facilitating consumer choice and control and obtaining cost efficiencies, there is much variation in approach (Carr & Robbins, 2009). This variation reflects the inconsistent way individualised funding policies have spread internationally. As Boxall et al (2010) point out, rather than being adopted according to a coherent set of ideas, rational accumulation of evidence, and assessment of relevance to local circumstances, these policies have tended to spread by bureaucrats adopting selected ideas, with positive case studies diverting attention from the potential problems, and strategies for resolving them (Boxall et al., 2009, pp. 507-508).

As such, models of direct funding have differed significantly in terms of their aims and structure, and the context in which they were introduced. Models have different rules about who is eligible; who can hold and manage the funds; the forms of support that funding can be used for; how providers are regulated; whether and under what conditions recipients can directly employ staff; whether they can purchase services from family members; and the role of intermediary organisations in managing funds and/or giving support and advice to users (COAG, 2012; Fisher et al., 2010). Models also differ in terms of

the existence and extent of workforce planning and development in the broader policy framework.

Alongside these dimensions, the adequacy of individualised payments – the extent to which the size of payments enable recipients to fully meet their needs – is also an essential and variable feature of the design and operation of these schemes. Where payments are inadequate, recipients who purchase labour for intensive forms of support, such as personal assistance or attendant care, may face trade-offs between the rate of pay they can offer, the number of hours of support they can purchase, and the quality of the support worker (in terms of skills and experience) they can afford to engage. Payment adequacy interacts with expenditure rules and employment standards to create an array of risk profiles for service users and support workers. Where expenditure rules and employment standards are weak, and payments low, support workers can be at risk of exploitation.

Here we analyse models of funding in England, and in two Australian states, with a focus on these issues, both in terms of how the programs have been designed and how they have been actually used by recipients. First, we examine the system of direct payments in place in England between 1997 and 2006, and the trial and implementation of individual, or personal budgets that followed. We then outline two models of consumer-centred care in Australia, examining arrangements in Western Australia and Victoria, the states with the most extensive experience of individualised approaches (COAG, 2012).

INDIVIDUALISED FUNDING IN ENGLAND

The development of individualised funding

In the United Kingdom, demands for cash payments arose from a number of sources, notably from philosophies of self-determination and independent living, especially among people with physical and sensory disabilities; from social (rather than medical) models of disability²; and from the convergence between welfare service users' critique of inadequate services and the politics of the new right's attempts to dismantle state provision (Spandler, 2004). Cash payments to support individuals with disabilities living at home were first made under the Independent Living Fund established in 1988, but direct payment programs have expanded most rapidly in the last decade, especially after policy made it mandatory for local authorities to offer direct payments to eligible consumers from 2003 (Riddell et al., 2005).

Individual Budgets were made available from 2006, combining a series of funding programs into one, and relaxing rules about how funds could be spent. Across this period,

² Social models relate disability to barriers to inclusion, rather than individual impairment, and emphasise the supports people with disabilities require in order to live on more equal terms with non-disabled people (Boxall et al., 2009).

individualised payments have been offered to an increasing number of groups of social service users, in what has been described as a 'wholesale implementation' with 'no international precedent' (Boxall et al., 2009).

Workforce planning and strategy and the English reform agenda

In the roll out of policies in England, the adult social care workforce has had status on the national agenda, with a series of national policy documents articulating the importance of workforce planning and development to achieving the goals of personalisation. England's strategy for increasing users' choice and control in adult social care for example, incorporated a workforce strategy: 'Working to Put People First: The Strategy for the Adult Social Care Workforce in England' (Department of Health, 2009). This document set a vision of "a confident, enabled and equipped social care workforce" which supported the cultural shift associated with the personalisation agenda (Department of Health, 2009, p. 17), and articulated priorities around workforce planning, promoting recruitment, retention and career pathways, remodelling the workforce around personalised services, developing the skills and diversity of the workforce, promoting integrated working, and regulating for quality standards and safety. Through Skills for Care, the UK government has also established a workforce development strategy for adult social care (Skills for Care, 2011) and a personal assistant framework and implementation plan (Skills for Care, 2012), as well as good practice case studies and other resources. However, as the discussion below shows, outcomes for workers appear to be more strongly shaped by the processes of marketisation associated with funding reforms than the aspirational goals of these policy initiatives.

DIRECT PAYMENTS

Background and Context

Direct payments were introduced in England, Wales and Scotland in legislation that took effect in 1997, and a year later in Northern Ireland. This gave local authorities discretionary power to offer adults with a disability who were eligible for social care the option to access means-tested cash payments in lieu of services. These payments could be used to purchase services from the private or voluntary sector to meet assessed needs, and were intended to give service users choice and control over how their needs were met.

Direct Payments: Who accessed the funds?

Under direct payments from 1997, local authorities could offer cash payments to adults aged 18-65 with a sensory impairment, physical or learning disabilities and some people with mental health problems. Eligibility was also expanded to include people aged over 65 (in 2000), young people aged 16 and 17 with a disability and parents of disabled children (in 2001). In 2003 new regulations came into force that removed local authority discretion

and made it mandatory for councils to offer direct payments to all people using community care.

Take-up was lower than expected, and there was much variation between regions, and among groups with different needs (Davey et al., 2007; Priestley et al., 2007). Those with conditions which were stable over time, such as physical and sensory impairments for example, were found most likely to take up a direct payment, and to use the payment successfully, while uptake was lower, and more difficult among people with mental health problems, and the elderly (Davey et al., 2007; Land & Himmelweit, 2010; Riddell et al., 2005).

How direct payments could be spent

Direct payments could be used to purchase care services from personal assistants (workers providing one-to-one support, under the direction of the consumer), or from private or voluntary sector providers, but *not* from municipal social service departments. Most often, direct payments were used to directly employ personal assistants. Initially, direct payments could not be used to employ a family member. However, in 2003, policy changed to allow direct payment holders to employ non-resident family members, although conditions for doing so varied between local authority. One study based on a sample survey of 526 Direct Payment employers of personal assistants in 16 local authorities in 2007 found that close to half employed people they already knew. Of these, around a third employed family or friends (31 percent), and around a fifth employed persons who had assisted them before they received a Direct Payment (20 percent) (Adams & Godwin, 2008; Manthorpe et al., 2011).

Adequacy of payments

Consumers employing personal assistants directly have reported that the total amount of money received through direct money was insufficient to meet their support needs. Adams and Godwin (2008, p. 47) reported that 43 percent of employers felt the local authority assessment underestimated the amount of assistance they required. The majority (64 percent) believed their needs were underestimated by under ten hours a week. However, a significant proportion (15 percent) reported a shortfall of more than 20 hours. This shortfall had implications for the hourly wage rates offered to personal assistants (Adams & Godwin, 2008, p. 47). The funding shortfall also had implications for training. Indeed, the most frequent reason that recipients of direct payments reported being unwilling to pay for external training for the personal assistants they employed was that they could not spare the money, suggesting low payment rates undermined skill development (Adams & Godwin, 2008, p. 105).

INDIVIDUALISED BUDGETS

Background and context

In 2006, the UK government piloted an Individual Budget scheme, built on the direct payments system and a model previously developed by the social enterprise 'In Control' (Glendinning et al., 2008). The idea behind Individual Budgets was to give an allocation of resources to service users in lieu of care, from which they could meet their self-assessed needs. In the process, individualised budgets also pooled previously separate streams of health and social services funding to which individuals were entitled (Carr & Robbins, 2009). Overall, the intention was that budget holders would shape social care markets through their purchasing decisions, and would access more integrated services, and a wider range of services.

In 2010, the UK government (Department of Health, 2010) sought to expand the availability of individual budgets (also called personal budgets), setting the target that by April 2013, all councils would provide personal budgets for eligible adult social care users.

Individualised Budgets: Who accesses and manages the funds?

Budgets can be taken as cash payments to individuals, or held and deployed by care managers, a trust, or a service provider or another third party (Carr & Robbins, 2009). If direct payments are used, not all the budget is necessarily taken in this way. Individual consumers are required to develop plans as to how they will meet personal outcomes, and can purchase support to meet these needs from private or voluntary sector services, or friends or family members. Support in planning and brokering supports comes from care managers, social workers, other agencies, or informal carers. As of March 2011, one third of local authority supported service users received an Individual Budget, and plans were in place for every service user to have a budget by 2013, with most growth expected among people receiving budgets managed by councils, rather than by individuals (Wilberforce et al., 2012).

How Individualised Budgets can be spent

Individual Budgets went further than Direct Payments in facilitating personalisation, in that holders could use the cash payments to purchase *any* goods or services that could be shown to meet their assessed needs. As well as hiring personal assistants or purchasing other domestic assistance, funds could be used for leisure and social activities, and service users could select providers other than those engaged in contracts with local authorities (Wilberforce et al., 2011). Social care professionals have a clear role in assisting service users to make decisions, to support them to assess their needs, or have their needs assessed, to help allocate resources, to manage risks in service users lives, and to support planning and brokerage.

Adequacy of payments

The evaluation of the pilots of Individual Budgets found that for older people at least, the funding available was only enough to meet basic functional needs. As such, older people spent their payments predominantly on personal care, with little money leftover for social or leisure activities. As such, the funding continued to be spent on direct care, and often on maintaining pre-existing arrangements, rather than purchasing goods and services from outside the sector (Moran et al., 2012).

INDIVIDUALISED FUNDING IN AUSTRALIA

In Australia, individualised funding has been implemented in various ways in most of the states and territories, and while many programs have been small-scale trials (Productivity Commission, 2011), they are rapidly expanding. Implementation of personalised planning and individualised funding is most developed in Western Australia, where direct payments to some people with a disability have been available for more than twenty years, although the emphasis has been on facilitating control over service planning and delivery, rather than facilitating direct employment. Recognising the State's established arrangements for self-directed disability support, the Productivity Commission (2011) recommended that the National Disability Insurance Scheme incorporate elements of that state's system, although key structural elements of the NDIS are yet to be determined (COAG, 2012). In the last few years, Victoria has also led the states in trialling direct payments (Fisher et al, 2010; Productivity Commission, 2011, p. D.4; COAG, 2012), and since December 2012, these payments have been allowed to be spent on directly employing support staff (COAG, 2012). The following sections explore the model of individualised funding in these two states.

WESTERN AUSTRALIA

Background and Context

Western Australian disability services have a well established focus on promoting consumers' abilities to make decisions about how funding is directed. There are two main programs.

One, the Local Area Coordination (LAC) program, has operated across Western Australia since 1988, in part because the small population spread over vast distance was perceived to make provision of standard services impossible (Disability Services Commission, 2003). Under this program, local area coordinators work with family members and others to assist people with a disability to plan and organise their services and to participate in the community (DPRWG, 2011). A small minority of LAC program recipients (around 18 percent in 2009) receive a direct payment with which they purchase support services, rather than relying on the coordination, advocacy and community participation that were the goals of the scheme (Productivity Commission, 2011, p. D6-D7).

Under the second, main program, since 2005 the Disability Services Commission (DSC) has provided 'individually tied funding' to all people with a disability to meet their needs for most specialised disability services, including accommodation support. In this program, funding is based on individual assessment and planning, and funding is portable between service providers. Local Area Coordinators play a key role in coordinating services purchased under the main DSC individual budget program, including providing support in applying for funds.

Service users develop a funding plan, in collaboration with an agency they have selected. The Disability Services Commission provides this organisation with a loading of between 15 and 21 percent above the direct care funding amount to support this administrative function (Fattore et al., 2010, p. 39; Productivity Commission, 2011, p. D.6). This has been perceived to guarantee a level of service capacity, which is necessary for developing workforce (Fattore et al., 2010).

Portability is underwritten by government, to secure the viability of service provision (Fattore et al., 2010). In accommodation support for example, where service users move between providers, the Disability Services Commission considers the viability of remaining funding of other residents, and funding can be increased to maintain service continuity. In addition, some training costs are paid for by the Disability Services Commission, with service establishment funding provided to cover orientation and induction (Fattore et al., 2010, pp. 52-53).

It is important to note that in 2011-12 nearly one third of operational expenditure by the DSC was internal, with the remaining two thirds disbursed to disability services organisations. Further, two thirds of people receiving some DSC funded services received some (34 percent) or all (28 percent) of those services from the commission itself. Less than two fifths (38 percent) received all their services from a disability sector organisation. These latter figures do not take into account service intensity, as the DSC's annual report notes when reporting them. But they give some sense of the quite significant extent to which users will continue to rely on careworkers employed by organisations and the possible scale of resources that will need to be organised on a consumer-directed basis.

Who accesses and manages the funds?

Individually tied funding can be allocated by the Disability Services Commission to people with intellectual, psychiatric, cognitive, neurological, sensory, or physical impairment that manifest before they are 65 years old (Disability Services Commission, 2012, p. 6-7). Rather than a direct *payment*, there is a notional allocation of funding for an individual; the primary goal of the program is that individuals should be able to direct *spending* to meet their assessed needs (COAG, 2012, p. 20). Accordingly, all arrangements for managing individually tied funding involve an intermediary organisation, with management of funds on a continuum in which service users can choose to have more control to one in which they select an agency to receive the budget and deliver the service (Productivity Commission 2011, p. D4).

Service users who want significant involvement in directing the spending of individually tied funding allocated to them, for example, can opt for 'shared management'. Under this arrangement, their chosen service provider takes on administrative responsibilities, thereby reducing the burden of fully arranging and managing their own care (Fisher et al., 2010; Productivity Commission, 2011, p. D.5). Shared management is argued to give people with a disability scope to design and control their own services, but with the support of organisations engaged to ensure legal requirements are met, including paying care workers and paying tax, arranging insurance, workers compensation, and paying superannuation. Agency-management or shared management is considered appropriate for the most complex self-managed clients (Productivity Commission, 2011, p. D. 7).

How individualised budgets can be spent

Regardless of whether consumers fully manage their funds or have a service provider manage them, Western Australian policy intends that the consumer will control how the funding is spent. Direct employment of support workers is allowed, under the Local Area Coordination program, but as noted above, this option is used by only small proportion of the LAC service users. Consumers must take on all the legal responsibilities of an employer, and meet accountability requirements (Productivity Commission, 2010, p. D.7). Levels of compliance with these requirements are at present unclear.

Only in exceptional circumstances can family members be employed as paid support workers. Western Australia has a well-reasoned formal policy which allows consumers to employ family members only where alternative supports are unavailable (discussed in more detail below). This may include situations where the person with a disability has cultural requirements that formal services cannot meet; where they live in an isolated or remote location with no alternative supports available; and/or where there are not other suitable alternative when all other options have been considered (Disability Services Commission, 2012b).

The role of intermediaries in facilitating choice and control

Intermediary organisations are available to support clients to exercise choice and control, and where they choose to be direct employers, they gain assistance in this role. These agencies can help clients set up legal entities to employ and pay staff, who could include a neighbour or somebody else chosen by the person. In addition, they can help recruit, train and pay staff on consumers' behalf. This assistance is offered by the organisation 'My Place', for example.

Employment and contracting models in the WA system

There is a range of employment and contracting models through which support workers can be engaged by people with disabilities in Western Australia, with assistance from an intermediary organisation. 'My Place' lists these options on their website, which is our

source here.³ One option is for the person with a disability (or a family member) to become the legal employer of the support worker(s). Further, as the 'My Place' website states:

“An advantage of people with disability (or a family member) being the employer is that, under certain conditions, carers can be employed under 'private and domestic' arrangements which offers greater flexibility in carer pay levels, conditions and hours of work as the carer is not deemed to be an 'employee' in the traditional legal sense.”

People who receive individual budgets can also engage support workers as 'independent contractors', on the basis that these arrangements may enable people with disabilities to form flexible arrangements with their carers, while minimising their legal responsibilities (Productivity Commission, 2011, p. D.5).⁴

Alternatively, the client can defer all service coordination, financial and administrative functions to the intermediary organisation, or all of these tasks plus service delivery and design (PC, 2011: D.5-6). As such, support workers can be employed by intermediary organisations rather than directly by service users.

Recent developments

In November 2012, Western Australia started 'My Way', a three year program established in four locations. In these four areas, all people with a disability in will be eligible for funding and support, which will involve developing individual plans to identify, select and design their own supports and services. This approach, which enhances features of the LAC program, was recommended by the WA State Government Economic Audit Committee in its 2009 report (Economic Audit Committee, 2009). My Way Coordinators perform a similar function as Local Area Coordinators in other sites, but are based in the non-government as well as government sectors, and have a lower client load, to increase capacity to plan individualised responses (Disability Services Commission, undated). My Way also provides more opportunities for consumers to actively manage their spending, with a continuum offered from self-management to complete agency management (Disability Services Commission, undated). Evidence as to the impact of My Way is not yet available.

Adequacy of payments

We are not aware of any studies about the adequacy of payments for disability support in Western Australia. The DSC's annual report for 2011-12 reports average per-person cost in

³ See <http://www.myplace.org.au/services/index.html>

⁴ Note however, that where the work that disability support workers do is controlled by their employer, and where they work the hours told by their employer, arrangements may be illegal 'sham' contracts (Fair Work Ombudsman, undated). Neither the extent of contracting, nor the extent of sham contracting, are evident.

several program areas (Disability Services Commission, 2012a). Although total spending is rising quickly, there is no right to a service and there is some evidence of rationing of funds. Information for potential applicants includes the warning 'Only applications indicating the most critical need are likely to be supported'.⁵ The DSC annual report for 2011-12 reported that of 595 applicants for funding under the accommodation support funding stream 207, or 35 percent, were successful. Application numbers and success rates in other funding streams were not reported. It remains an open question whether those who receive an allocation are adequately funded. Interestingly, one of the human interest 'case studies' presented in the report describes how a family with a child with a disability found funds for a wheelchair accessible vehicle largely from community fundraising (a 'monster garage sale'), and private donations. Of the \$50,000 raised, a maximum of \$7,500 came from the DSC itself, via the Independent Living Centre it funds (2012, p. 32). In this way, the sense that charity still has an essential role in funding supports for people with disabilities is clearly communicated.

VICTORIA

Background and Context

Victoria's Disability State Plan 2002-2012 emphasised the development and expansion of self-directed approaches. Early examples of flexible funding packages were available in the early 1990s, but Individual Support Packages (ISPs) were first offered in 2003, under the 'Support and Choice' program which provided flexible funding for families with a child with a disability. Administered by the Department of Human Services, ISPs have since been expanded to provide flexible funding to a wider range of service users. As of mid-2012, over 14000 people accessed individualised funding in Victoria, and in late 2012, 30 per cent of Victoria's total disability budget was spent as individualised funding (COAG, 2012).

Who accesses and manages the funds?

Currently, ISPs are available to people with long-term sensory, physical or neurological impairments; intellectual disabilities or developmental delays. ISPs are intended to give consumers control over budgets to meet their needs and goals. At present, those receiving ISPs have a number of options. They can receive direct payments in a separate bank account, from which they pay invoices; or the ISP can be held by a government-contracted financial intermediary, which pays invoices and keeps records on behalf of the client; or a registered disability service provider can hold the funds, maintain records, provide the bulk of services, and act as an agent to purchase services from other agencies (Productivity Commission, 2011, p. D.9). People who use intermediaries or service providers can move between them, but a period of notice, set by the provider, must be given. This period of

⁵ See

[http://www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/combined_application_process_brochure_-_english_\(id_372_ver_2.0.0\).pdf](http://www.disability.wa.gov.au/Global/Publications/Services%20supports%20and%20eligibility/Funding/combined_application_process_brochure_-_english_(id_372_ver_2.0.0).pdf)

notice allows organisations time to adjust, to find new service users, and manage funding and rostering, to protect service continuity and employment standards.

How individualised budgets can be spent

In Victoria, the ISPs cannot be used for entertainment or other things normally purchased from income, except where they are necessary for social, health or wellbeing outcomes, and where they can be provided more cheaply by a mainstream service than by a specialised disability service (Productivity Commission, 2011, p. D.9). Until December 2012, direct employment was not allowed: staff needed to be employed by service providers. Non-resident family members, or staff recruited through informal networks, could be used. However, these workers needed to be employed through accredited disability agencies, who took on responsibility for ensuring all training, safety and occupational health and safety requirements were met, and that all entitlements were paid, as for other employees (Laragy & Ottmann, 2011; Productivity Commission, 2011, p. D.9).

Adequacy of payments

There is no clear evidence as to the adequacy of payments, although the adequacy of unit prices has previously been a contentious issue in the sector, with some service providers struggling to offer services within the unit cost parameters (Victorian Auditor-General, 2011). Current unit prices paid by the Department of Human Services for commonly used Individual Support Package services are published on the DHS website, including (from 1 December 2012) \$38.82 per hour for in home one to one personal support, \$51.57 per hour for complex case management. For therapy services, the unit price ranged from \$33.01 for therapy with an unqualified assistant, to \$37.04 for a qualified assistant, and \$71.59 per hour for a professional therapeutic service. Current unit costs include provision for training (Department of Human Services, 2011).

Recent developments in Victoria: The expansion of Direct Employment

Since December 2012, ISP recipients across Victoria have been allowed to use funds to directly employ their own support staff. The Victorian Department of Human Services announced the expansion of direct employment following a small-scale trial of direct employment, and its evaluation (Department of Human Services, 2011; HDG Consulting, 2010). Under this new system, ISP recipients can choose who to employ, and as employers, they carry legal, financial and human resource management obligations, including for recruiting staff, negotiating conditions, training workers, paying workers, paying for insurance and taxation, and handling performance issues. As such, this model differs from the alternatives of engaging staff as contractors, using support staff employed by host agencies, and establishing separate legal entities, such as companies or cooperatives to act as employer (HDG Consulting, 2010).

The Department of Human Services has created a 'direct employment resource guide' to assist ISP recipients who elect to employ their own support workers, which outlines their obligations and responsibilities with respect to recruitment processes, pre-employment

checks, pay and conditions, taxation, insurance, occupational health and safety, anti-discrimination legislation, termination of employment, and record keeping. Among the resources are a sample application form, contract of employment, position description and a summary of the minimum pay and conditions under the Social, Community, Home Care and Disability Services Industry Award 2010 (Department of Human Services, 2012).

Evidence as to the impact of the state-wide roll-out of direct employment is not yet available. However, the evaluation of the trial which (upon which expansion of the model was based) found it was successful for service users and workers. However, this involved interviews with only a small number of self-selecting participants: eleven ISP recipients, and seven support staff (HDG Consulting Group, 2010). Further, it should be recognised that participants in the trial appear to have been among the best positioned to benefit from direct employment, in that all reported having previous professional or other experience, such as bookkeeping, accounting, or business ownership, that helped them to perform the employer role effectively (HDG Consulting, 2010, p. 25).

Concerns are emerging about developments in Victoria. In a forum regarding service provision to children with disabilities and their families held in November 2012, a range of important specific risks of individualised funding and support were raised. These included the loss of coherence and collaboration that could arise when ‘a plethora of individual therapists’ work with a child, without collegial and professional coordination {NDS, 2012 #192}.

Transition planning and workforce strategy

Recognising the workforce challenges likely to be raised with the introduction of the National Disability Insurance Scheme, National Disability Services Victoria developed a Workforce Strategy, as part of the Victorian Disability Services Transition Plan (NDS, 2011). This outlines the importance of training and capacity building to ensure the skills, knowledge and behaviours of support workers are consistent with self-directed approaches; of ensuring policy and regulatory settings facilitate attractive jobs and a workforce that is responsive but not insecure; and ensuring the sector can maintain and strengthen its commitment to skill development under the NDIS (NDS, 2011).

Summary

The above analysis has provided some examples of how models of consumer-centred care can be structured. In England, market-based funding models for adult social care have been pursued in an advanced way. Despite formal recognition of the importance of the workforce to service quality (Department of Health, 2009; Skills for Care, 2011), consumer-centred funding models have contributed to the development of a poorly regulated market for personal assistants. The implications of this are discussed in the following sections.

Within Australia, the Western Australian and Victorian models are considered most well developed. Neither approach has so far resulted in the level of marketisation evident in England, although evidence as to the impact of both systems is lacking. In Western

Australia, the emphasis of personalisation appears to be on planning and designing services, and exercising choice and control through a notional allocation of funds that is portable between services, rather than seeking to facilitate direct employment. Western Australia also has a funding base to support organisational capacity, which may help mitigate risks for workers employed in organisations. In addition, Western Australian policy restricts the employment of family members to exceptional circumstances only. However, the possibility of using 'private and domestic' arrangements to engage support workers outside regular workplace relations safeguards presents substantial risk. In Victoria, individual packages are accounting for a significant proportion of disability spending. However, not all these funds are direct payments, some are held by service providers or other intermediaries. Significant features of Victorian arrangements include the radical state-wide expansion of direct employment, predicated on very limited evidence of positive outcomes for either service users or support workers. To support sector capacity in the transition to person-centred care, the state-wide transition plan includes a workforce strategy (NDS, 2011).

Workforce implications of individualised funding

In this section we examine evidence of how individualised funding has impacted on the disability services workforce, and support workers' capacity to offer consumers high quality care. As outlined in the previous section, models of individualised funding vary in terms of a number of factors, including which groups of consumers are eligible, how payments can be used, and whether they can be used to directly employ staff. As such, the impact of individualised funding could be expected to be different in different contexts, with a specific set of issues and challenges arising where workers are directly employed or contracted by consumers.

LIMITATIONS IN THE EVIDENCE BASE

Evidence about the implications of individualised funding for workers is limited, as most research in the area has focused primarily on outcomes for users and their families, and few studies have involved and captured the perspectives of care workers (Christensen, 2012; Glendinning, 2012; Manthorpe et al., 2011; Spandler, 2004). Further, much of the evidence about workforce implications comes from research and evaluation studies conducted prior to, during, or soon after implementation, and as such, may not clearly distinguish anticipated, transitional or longer-term problems. Further, questions of workforce implications, and methods which include frontline workers, have been low priorities for research.

Empirical evidence about workforce issues is thus limited to studies focused primarily on the experiences of service users and their families, or which capture issues for workers from the perspectives of service managers or policy officials. In conducting a scoping study of direct employment by adults with disabilities and long-term health conditions, for example, Manthorpe et al. (2011: 202) captured many of the problems of the UK evidence base:

“few studies looked in depth at the employment relationship from the perspective of care and support workers, especially where the employee was a family member... At best, employment relationships and the significance of them were marginal considerations in many studies and reports; others had small samples or were unclear about their sources of evidence. Furthermore, there was some difficulty in establishing whether some authors meant family members giving informal care, or paid care and support workers, when using the term ‘carer’” (Manthorpe et al., 2011, p. 202)

Our review confirmed that these problems are also evident in the small number of Australian studies in the field. Ottman, Laragy and Haddon (2009) for example captured the experiences of directly employing support staff, but the study included only 12 families caring for a child or an adult son or daughter with a disability living at home. Fisher and

colleagues (2010) captured some perceived workforce challenges associated with direct funding, but this was based on the issues anticipated in interviews with a small number of policy makers in some states. The evaluation of the direct employment trial in Victoria (HDG, 2010), which the Victorian government has used to rapidly facilitate direct employment of support staff (Department of Human Services, 2011) included the perspectives of only seven workers, and eleven consumers.

Recognising that there are profound limitations in the evidence base, this section analyses the best available information about the impact of individualised funding on the workforce. First, we examine evidence as to the implications for workers employed in service provider organisations. Many of the risks for organisationally employed workers arise from the challenges facing employer organisations in the context of consumer choice and control, in particular, increasingly unpredictable patterns of demand, demands for more flexible services, and increasing administrative and transaction costs. In the absence of adequate funding, employers may attempt to pass the costs and risks they face onto workers, resulting in lower pay, reduced hours and job security, inadequate training, and health and safety risks. Second, we examine the implications of individualised funding on workers directly employed or contracted by consumers, including where assistance is purchased from family and friends. However, in examining the risks for workers employed by organisations and those employed by consumers separately, we recognise these groups are not mutually exclusive, as staff may move between consumer and agency employment, or may simultaneously work for consumers and organisations.

WORKERS IN ORGANISATIONS

Literature from England highlights how individualised funding, both in the direct payments and individual budgets models, can result in the shifting of risk from employers to workers.

Pressures on Service Provider Organisations

In large, these risks and challenges have been perceived to arise from pressures on organisations, including compromises to viability and stability resulting from changing and uncertain patterns of demand for their services, and the costs associated with increased administration (Baxter, Wilberforce, et al., 2011). In turn this has led to greater financial and operational uncertainty and a lower capacity to plan, including planning for recruitment and training needs (Baxter, Wilberforce, et al., 2011).

- *Uncertainty about demand for services from organisations*

In the UK, prior to the direct payment system, block funding from local authorities specified the amount of services to be delivered to multiple users over a given period, and so provided organisations with a level of security that allowed them to employ staff in the longer term, and invest in training and workforce development (Baxter, Glendinning, et al., 2011). Service providers largely expected the shift to cash payments to undermine their

viability and sustainability, by reducing demand for the formal care services they provide, which would increase their unit costs, as the economies of scale associated with large government contracts would be lost (Glendinning, 2012:296). Service commissioners and managers expected demand for some services, such as day centre services, to drop substantially, as service users instead opted to use their funding to hire personal assistants, or to participate in other activities. Similarly, in Australia, government officials in Victoria anticipated that in the expansion of self-directed funding, consumers would choose to shift portable funds away from disability service providers, and use them to access mainstream services, such as a local gym (Fisher et al, 2010).

Evidence to substantiate concerns about falling demand for formal care services in the United Kingdom has been mixed (Wilberforce et al., 2011). The evaluation of the Individual Budget pilots found, for example, that take-up of personal budgets by some groups was low, with older people the least likely to ask for changes in their services. For these groups, care organisations retained significant roles as service providers (Baxter et al., 2010; Wilberforce et al., 2011). Where individual budget holders continued with pre-existing service arrangements, services needed to adapt only by invoicing service users rather than local authorities (Wilberforce et al., 2011). As such, there was little effect on the workforce. On the other hand, service providers which did experience a loss of service users found it frustrating as they had invested in recruiting and training service delivery staff, who were no longer required (Wilberforce et al., 2011). This last effect, of course, is likely to have wider negative impact, in that loss of investment can act as a disincentive to further investment in staff. A lack of investment in training may reinforce perceptions of disability support work as short term, irregular or appropriate for those 'in between' other jobs or who have few alternatives, undermining potential workforce quality.

- *Increased demand for care at short notice*

As well as potentially decreasing demand for formal care services and increasing the vulnerability of organisations to fluctuations in consumer demand, a further impact of individualised funding has been that service providers have needed to respond to requests made by consumers at short notice and at peak times (Wilberforce et al., 2011). While increasing choice and flexibility is a goal of individualised funding, this could be problematic for organisations where consumers are allowed to request or cancel services with little notice, or to bank their support hours for later use. Increased demand for care at short notice could result in the increased use of casual, contract and part-time labour, contributing to worker vulnerability and lower levels of commitment between workers and organisations.

- *Increased administrative burden and higher transaction costs*

UK research has also identified that service provider organisations have faced new cost pressures, largely related to the increased administrative requirements associated with individualised funding. The evaluation of the Individual Budget pilots found, for example, that individualised funding increased the administration required by service providers,

who needed to negotiate and manage a large number of individual contracts with service users, rather than a single block grant with local authorities (Wilberforce et al., 2012; Wilberforce et al., 2011). High costs were associated with customising plans and administering budgets for low-hours clients in particular (Wilberforce et al., 2011). Overall, the administration associated with serving clients receiving an individualised payment was found to be costly for organisations, resulting in increases in administrative staff and investment in IT systems, and increased efforts in chasing up clients for unpaid bills (Wilberforce et al., 2011).

Research based on interviews with commissioning managers suggested that larger agencies appeared, in the process of implementation, to be better protected against the financial risks associated with personal budgets, as they had more capacity to manage risks of non-payment of bills by clients, and to respond to demands for flexibility (Baxter et al., 2008).

It is important to note that a number of these effects on providers – especially in regard to reduced certainty and stability - are precisely what would be predicted – and *intended* – in service delivery models such as individualised funding that are based on the concept of consumer sovereignty. However, they are likely to have adverse effects on workers, and many of the costs and risks will be passed on.

Pressures on Workers

These pressures on service provider organisations have been found to have a substantial impact on workers in terms of reductions in pay, hours, and security of tenure, together with changes in the pattern of skills and training required.

- *Lower pay*

The financial pressures on service providers noted above have been found to be frequently passed onto workers, through cost cutting by organisations, including through paying piece rates, or eliminating payments for meetings, training and travel between clients, making it difficult for staff to work enough paid hours to make a living wage (Rubery & Urwin, 2010).

- *Outsourcing*

Financial pressures on service provider organisations may also contribute to further outsourcing. Contracting rather than directly employing labour provides opportunities for organisations to manage risks by shifting costs onto workers (operating as contractors). This can lower hourly rates, and enable the supply of care without basic employment protections (Rubery & Urwin, 2010).

- *Reduced hours and security of tenure*

In the UK case, it appears the costs of increased flexibility have been shifted onto employees, resulting in workers being offered unsteady or unpredictable hours, and lower

pay (Cunningham & Nickson, 2010; Wilberforce et al., 2011). Unsurprisingly, widespread concerns about job security arising from personalisation were observed among front-line employees (Cunningham & Nickson, 2010).

In addition, managers in the UK expected increased demand for care at short-notice, and at anti-social times of the day, as a result of individual budgets. Regardless of whether it eventuated, managers were observed to put plans in place for defensive strategies to alter the way staffing was organised in their agencies, often by offering zero hours contracts⁶ to ensure a supply of staff available to work 'on-call' (Baxter, Wilberforce, et al., 2011; Cunningham & Nickson, 2010; Rubery & Urwin, 2010; Wilberforce et al., 2011).

- *Skills and training*

In addition to requiring a more flexible workforce, individualised funding in the UK was also perceived to change the mix of skills required from frontline workers. This has included requirements for higher level health skills in the direct care workforce; more multi-skilling across health, housing, leisure and employment issues among those in frontline roles; and a downgrading of trained and qualified social care practice to focus on personal advocacy, brokerage, risk assessment and navigating among multiple through the service system (Cunningham & Nickson, 2010, p. 7; Glendinning, 2012, p. 294; UNISON, undated). This has been widely expected to require retraining workers, but also a consultation and planning process to establish what staff need to be trained in (Cunningham & Nickson, 2010, p. 7; Wilberforce et al., 2011, p. 609). In Australia, consumer-centred approaches have been expected to require higher levels of skills, particularly in communication and negotiation to support people with a disability to exert choice and control (Adams & Godwin, 2008; Precision Consulting, 2011). However, while on one hand, individualised service models may require staff to be trained in new roles and service delivery approaches, on the other, funding models may place training at risk. On-the-job training and experience may be seen as more important to support roles than formal qualifications, and training initiatives may be limited to skilling workers according to individual clients' priorities rather than a more comprehensive suite of transferable skills consistent with the professionalization of care work.

- *Health and Safety*

High job stress is a feature of work in disability and aged care, and the wider community services sector. Nationally, the health and community services sector makes up around 10 percent of the Australian workforce yet it has the highest percentage of workers compensation claims for psychological distress, comprising 20 percent of claims (Blewett

⁶ Zero-hours contracts do not guarantee how many hours a worker will be allocated, nor the pattern of hours, so leave workers vulnerable to working fragmented or anti-social hours, holding multiple jobs, and accepting excessive or inconvenient shifts due to fear about being disadvantaged in future rosters.

et al., 2006, p. 12). Additional risks may arise under consumer-directed care where consumers request tasks which challenge the boundaries of OH&S practices, or are not anticipated by existing health and safety policies. In addition, casualisation has been found to increase health and safety risks, as contingent workers have been found to be more likely to miss out on OH&S training, and to lack sufficient knowledge about how to report risks, or to be too concerned about job security to report problems (Aronsson, 1999).

WORKERS IN DIRECT EMPLOYMENT

Some individualised funding models allow recipients to use personal budgets to directly employ or contract their own support staff, such as a personal assistant or attendant, and some have allowed direct employment of family members or friends already providing unpaid care. Research and evaluation studies about the impact of these practices have had mixed findings.

Direct Employment and Service Users

For service users, directly employing or contracting support workers has been found to facilitate greater autonomy, enabling the development of better personal relationships, and better communication (Leece & Peace, 2010). One English study (Adams & Godwin, 2008) found consumers using direct payments to employ personal assistants were more positive about them than the care they had previously received through their local authority. In particular, they were more likely to agree they felt listened to, treated with respect, and that they completely trusted their support worker (Adams & Godwin, 2008). Consumers also reported a lower incidence of problems such as lateness, unexplained absence, neglect of duties or tasks, and poor quality care or support.

The small-scale evaluation of Victoria's direct employment trial also reported that service users were able to more finely tailor their support arrangements, and to design and adjust shifts to meet their needs, and that they experienced better communication with their support workers (HDG Consulting, 2010). The small number of service users in this study (eleven) considered direct employment to be preferable to receiving assistance from staff employed in organisations (HDG, 2010). However, this is unsurprising, as many participants opted into the trial due to dissatisfaction with the support they were receiving from agencies, including perceptions agency staff had been unsuitable, that they lacked flexibility, and had been difficult to retain (HDG Consulting, 2010, p 28-9).

While direct employment can benefit service users, it has also been found to be difficult and burdensome, as the English research shows. The requirement for consumers to fulfil formal obligations as employers can be difficult for some, although most programs appear to have supports in place to assist. In Adams and Godwin's (2008) study of employment under direct payments in England, over a quarter (27 percent) of consumers who employed support workers agreed they found being an employer daunting, although this feeling appeared to dissipate over time. UNISON (undated) has also noted it can be

problematic for consumers to fulfil the employer role, pointing to a lack of knowledge about employment rights, health and safety and training requirements. The Wiltshire Best Value Direct Payments review for example found consumers ill-prepared or supported for their employer role, and that they were sometimes unable to pay staff or paid staff late (Carmichael & Brown, 2002:803). Glendinning et al (2000) found users of direct payments were keen to be good employers overall, but funding levels made it difficult to offer good terms of employment, as they needed to bear costs and risks themselves.

It may be that some service users can perform the role effectively. In the Victorian trial of direct employment, for example, all participants who opted into the trial and the evaluation reported having previous professional or other experience, such as bookkeeping, accounting, or business ownership, that were perceived to have helped them perform the employer role effectively (HDG Consulting, 2010: 25).

Implications of direct employment for care workers

In some studies, care workers have been reported to prefer, or benefit from, working directly for, and with, service users. Compared with working for an organisation for example, time may be less rationed, and so staff may be less rushed when working directly for a service user, and able to benefit from better communication and closer relationships with employers (Leece & Peace, 2010). Based on interviews with a small number of service managers in Victoria, Laragy and Ottman (2011) reported that some support workers preferred to negotiate their conditions and hours directly with their employers.

However, the literature also points to a set of risks where support workers are engaged directly by service users, either as employees or as independent contractors. As discussed below, offering work through contracting arrangements alleviates consumers' responsibilities as employers, and removes the protections of the employment relationship. In addition, non-existent or ambiguous employment contracts and job descriptions can informalise care work, and heighten vulnerability to exploitation; pay and conditions can be undermined, especially where funding is inadequate; working hours can be short or unpredictable; and training and professional development may not be supported. Health and safety standards and access to representation may also be undermined. These risks are discussed below.

- *Outsourcing*

As discussed above, organisations may respond to financial pressures by supplying labour through contracting rather than employment relationships. Service users wishing to use their funding allocation to engage their own staff may also find that engaging an independent contractor, rather than directly employing labour, reduces costs and removes the responsibilities of the employer role. However, this removes the employment protections available to support workers, and may not comply with laws on sham contracting (Fair Work Ombudsman, undated).

- *Contracts and informal employment*

In England, much personal assistant employment is not governed by clear employment contracts and conditions. A survey of consumers employing staff with direct payments found that between 59 and 63 percent of employers did not issue a job description (Adams & Godwin, 2008; Glendinning, 2012; Manthorpe et al., 2011). As Glendinning et al (2000) pointed out, the absence of formal agreements about obligations and entitlements can exacerbate the vulnerability of personal assistants to exploitation.

- *Employment of family members and friends*

Recipients of individualised funding often recruit staff already known to them, with payments often going to those who already provide informal care, but who may have little experience of providing formal care services. In many cases under direct payments in England, consumers employed a personal assistant who was a spouse, partner, relative or friend: 42 percent did so (Adams & Godwin, 2008). Three fifths (61 percent) employed somebody previously known to them (Adams & Godwin, 2008). Other researchers estimated that around half of service users used direct payments to employ family or friends (Manthorpe et al., 2011; Stainton & Boyce, 2004). In any case, clients' use of family and friends, or somebody else known to them, has been considered the norm rather than exception, and a key motivation for taking up direct payments (Blyth & Gardner, 2007; Leece, 2010). This may be, at least in part, because family, friends, neighbours or others could make brief visits to provide flexible care, often at short notice, compared with workers for whom these arrangements may be unattractive (Stainton et al., 2009).

Adams and Godwin (2008) captured some of these issues in their survey of direct payment users and personal assistants in England. They found that around three fifths of employers had used direct payments to employ at least one person previously known to them, and at the time of the study, 42 percent of employers employed at least one personal assistant who was a partner, relative or friend. This was higher among black and Asian employers (page 49). In most cases, partners, relatives or friends were the preferred care workers, however, employing family or friends was used in 9 percent of cases as a temporary measure, for example, when it was difficult to recruit somebody more suitable (Adams & Godwin, 2008).

Adams and Godwin found that people using Direct Payments to employ personal assistants have a preference for hiring someone they know, or that is known by someone they know (page 50). This is understandable, given the relational and intimate nature of much personal support work. However, there are good reasons why directly employing family members and close friends or neighbours may not be ideal. Many of these reasons are outlined clearly in the Western Australian Government's Family Members as Paid Support Workers Policy (Disability Services Commission, 2012b).

The policy makes a clear distinction between carers (those who provide ongoing care and assistance and may receive income support under Commonwealth Carer Payment and Carer Allowance programs), and support workers, who may be paid under a variety of employment/contractual relations. The policy states that Disability Services Commission

funding should 'enhance and supplement informal networks rather than replace them' (Disability Services Commission, 2012b, p. 3). More importantly, the policy outlines a range of ways in which employing family members may increase the vulnerability of the person with a disability. These include their capacity to exercise genuine choice and have an independent voice in relation to their care arrangements, the risk of dependency on the family 'to fulfil all roles and tasks', the risk of the family member being dependent on the person with a disability for an income, lack of respite for the family member taking on the role of support worker, and problems with monitoring the extent of support supplied, with risks of over-servicing at the family support worker's expense or under-servicing, at risk to the person with a disability's welfare (Disability Services Commission, 2012b, p. 3). It is notable that this policy recognises the problems that close emotional attachment can engender when personal and employment relationships become blurred.

Indeed, this arrangement may be less than ideal if being a family member or friend makes it difficult for care workers to leave their role, and if future job prospects are damaged where providing familial care is not recognised as valid employment experience (Leece, 2004; Ungerson, 2004).

- *Pay and conditions*

In England, working as a personal assistant generates a low income (Adams & Godwin, 2008, p. 87). Rates of pay are constrained by the amount of government funding received by consumers. As Leece (2010, p. 197) found, payment amounts did not allow for travel time, pension payments and some forms of leave. Rates of pay offered to personal assistants in the UK were also found not to properly account for the complexity of tasks performed, nor the flexible, unsocial or extended hours of assistance required by some people with disabilities, causing some directly employed workers to feel exploited (Glendinning et al., 2000). Some also avoided obligations to pay national insurance by engaging personal assistants for a small number of hours (Land & Himmelweit, 2010).

Australian evidence is more limited. In Australian pilots, Fisher et al (2010) found workers' pay and conditions tended to be poorly protected, with fieldworkers observing some service users were concerned to get the most hours of support possible, by employing staff willing to work for below-award rates. The rationale was that funding was insufficient to meet their care needs (Fisher et al., 2010). On the other hand, the evaluation of the Victorian trial found direct employment increased income for half of support workers, through above award rates or increased hours of work (HDG Consulting, 2010: 43).

- *Working hours*

In-home, community support and respite work involve volatile and unpredictable hours, including short shifts in peak periods, seven days a week, and split shifts. In the United Kingdom, personal assistants have been found to work very short hours. Adams and Godwin (2008) found that under direct payments, 38 percent of personal assistants worked fewer than eight hours per week, and 27 percent worked 8 to 16 hours a week.

Unsurprisingly 43 percent had other paid employment. Less than half (44 percent) worked fixed hours, while 29 percent worked hours which were always variable (Adams & Godwin, 2008, p. 83).

Leece (2010) found personal assistants were often called in at short notice by employers. Whereas consumers' emergency or short notice requests would otherwise be mediated by agencies, direct employees were contacted directly by employers. Workers felt responsible for clients, and lacked access to substitute staff, so tended to respond to consumer demands. As such, personal assistant work has been observed to encroach on home life more than home care work for an agency (Leece, 2010, pp. 201-202).

- *Training and professional development*

In the UK, there is no requirement for personal assistants to have minimum qualifications, nor do individual budgets cover training and development (Glendinning, 2012, p. 297; UNISON, undated). Holders of personal budgets were observed to place low priority on previous experience or training, but instead emphasised the importance of on-the-job training (Glendinning, 2012, p. 297; Glendinning et al, 2000, p. 207). Adams and Godwin (2008, p. 105) report that some consumers directly employing personal assistants with direct payments do not see it as their responsibility to train and develop personal assistants' skills, especially where work is considered casual and informal. However, the most common reason employers were unwilling to pay for training was a lack of finance to do so.

Personal assistants have been found to report wanting more opportunities for training, and to obtain formal qualifications. Further, as support workers can be asked to do any tasks requested by their employers, including basic domestic tasks, it may be difficult for those workers with higher level skills to exercise and maintain them (Wilberforce et al, 2011).

In Australia, access to training has also been identified as a problem associated with direct employment. In the Victorian evaluation, support workers reported having less access to formal training under direct employment, compared with being employed in an organisation (HDG Consulting, 2010). Analysis of financial data for the trial showed no expenditure at all on training. Some service users reported that support staff also worked for service provider organisations, and expected staff to receive training through them, or independently (HDG Consulting, 2010: 44-45).

- *Health and Safety*

Working on their own in private homes raises challenges for worker health and safety, as workers may be asked to perform tasks that go outside what would be acceptable OH&S practice within an organisation. These risks could be exacerbated where consumers have very complex needs (for example mental health needs) which raise risks for workers; where employment contracts and job descriptions are lacking, or do not govern the pace or content of work tasks; or if budget holders' demands place pressure on workers to perform tasks they consider unreasonable, or which are illegal (Manthorpe et al., 2011, p. 200).

Relationships may become abusive or otherwise distressing and can be difficult to handle when isolated from the professional, managerial and collegial supports or organisational employment, and where personal assistants are migrant care workers, and isolated from support networks (Land & Himmelweit, 2010, p. 34). In the complete absence of an OH&S framework, consumer-driven preferences for lifting and caring techniques may also expose workers to increased musculoskeletal injury (Dellve et al., 2003).

- *Discrimination*

As consumers tend to hire people who share ethnic or other characteristics with them, when service users recruit their own staff, racism and other prejudices may play a role in hiring and firing decisions (Stevens et al, 2012). The risks are greater where employers are poorly informed and supported to fulfil their responsibilities as employers.

- *Representation*

Where individual support workers perform their work in the homes of their employers, directly employed support workers are isolated from other workers, and studies have shown they express desires for more contact with colleagues (Glendinning, 2000:207). In private homes, unions' right of entry may not be straightforward. Isolation mean workers are difficult for unions to access, undermining knowledge of rights, and capacity to organise for better conditions. Thus, at the same time that workers have a greater need for representation given the new risks they face in relation to working conditions, they are less likely to be able to obtain it.

Summary

In general the evidence indicates that individualised funding schemes create a number of risks and uncertainties for workers. For those who are employed by organisations, there is evidence that organisations have passed many of the risks associated with increased flexibility onto workers, responding, for example, to increases in short notice requests with a casualised, on-call workforce, for whom there appear few offsetting benefits.

Where service users engage staff through direct employment or contracting arrangements, some studies have emphasised benefits in that some workers may feel less rushed than when time is rationed by an agency, and that workers sometimes appreciate the directly negotiating hours and other conditions with consumers. However, as the evidence outlined shows, the risks associated with contracting and direct employment are substantial, and these outweigh the limited benefits for some. In the next section, we summarise the risks which emerged from our analysis.

Summary of employment risks

The capacity of the service system to foster the capabilities, wellbeing and participation of people with disabilities; and to assist them to take more control in defining and meeting their own support needs, depends on a high capacity and skilled workforce. Yet work in disability services is characterised by low pay and insecurity. As the previous sections have shown, unless carefully designed and implemented, individualised funding may exacerbate these problems, bringing further risks to service quality and the continuity of care. This section summarises the risks identified for disability support workers employed by organisations or consumers, or those engaged through contracting arrangements. In doing so, we identify the main risks for working conditions, and the capacity for the service system to provide quality care in the context of individualised funding. These risks relate to job security; income security; opportunities to gain, use and retain skills; access to healthy and safe work environments; and rights to voice and representation.

SERVICE CONTINUITY AND JOB SECURITY

Issues for workers in organisations:

- Job loss as service users opt out of organisationally provided services
- Loss of direct care functions if organisations redirect resources to non-direct care functions such as administration and planning and managing funds
- Increased casual employment in response to fluctuations in consumer demand
- Increase in unsteady, unpredictable, anti-social hours as services respond to increases in short notice requests and consumer banking of hours
- May lack a formal employment contract or have a non-existent or changing job description, especially in small organisations

Issues for contractors

- No employment contract
- Job description may be non-existent or changing
- No guarantee of regular hours or ongoing work
- Lack of access to severance pay

Issues for workers in direct employment:

- No formal employment contracts
- Non-existent or changing job description
- Employer discrimination, including racism, in hiring and firing decisions
- Lack of access to severance pay
- May be difficult for employed family members to leave

INCOME SECURITY

Issues for workers in organisations:

- Low wages
- Threat of further reductions in wages and other payments, including through the use of piece rates, and the loss of payments for meetings and travel
- Unpredictable pay where hours fluctuate
- Loss of income if consumer is hospitalised or dies, especially in small organisations

Issues for contractors

- Pay and conditions may fall below award levels
- Unpredictable hours and pay
- Inability to achieve a decent wage, especially if hours available are very short
- Increased responsibility for individually negotiating conditions
- Increased personal responsibility for financial management, including invoicing clients and recovering debt
- Risk of underpayment or late payment
- No paid leave
- Loss of income if client is hospitalised or dies
- Personal responsibility for managing multiple contracting arrangements and clients
- May be difficult to ensure compliance with sham contracting laws

Issues for workers in direct employment:

- Low wages, especially where government funding provided to consumers is inadequate
- Increased responsibility for individually negotiating conditions with no increase in bargaining power
- Increased personal responsibility for financial management, including recovering unpaid wages
- Attempts to employ staff at below-award rates and conditions
- Inability to achieve a decent wage if hours available are very short
- Underpayment or late payment of wages
- Difficult to use leave without access to substitute staff
- Loss of income if employer is hospitalised or dies
- Multiple job holding, and the need to manage multiple employers, employment arrangements and conditions

OPPORTUNITIES TO GAIN, USE AND RETAIN SKILLS

Issues for workers in organisations:

- Need for higher level skills, and multi-skilling in some aspects of the work
- Downgrading of direct care practice where work refocuses on brokerage, assessment and navigating the service system
- Limited access to non-mandatory training
- Growth in lower skill positions
- Turnover may provide a disincentive for organisations to invest in training

Issues for contractors

- Responsible for own training

- Skills developed through on-the-job, consumer-specific training only, rather than formal training
- May be difficult to access opportunities to perform tasks that maintain higher level skills
- Future employers may not recognise providing care for family members to be valid experience
- Lack of access to professional supervision
- Lack of access to learn from colleagues

Issues for workers in direct employment:

- No budget for training
- Emphasis on on-the-job, consumer-specific training rather than formal training
- May be difficult to access opportunities to perform tasks that maintain higher level skills
- Future employers may not recognise providing care for family members to be valid experience

A HEALTHY AND SAFE WORK ENVIRONMENT

Issues for workers in organisations:

- Increased pressure to perform tasks as directed by clients, some of which may not be in accordance with health and safety requirements
- Increased pace and intensity of work
- Over-work
- Poor work-life balance

Issues for contractors

- No OH&S framework to guide practice
- Increased pressure to perform tasks as directed by clients, some of which may not be in accordance with health and safety requirements

- Undermining of health and safety where employers do not understand or respect responsibilities and legal obligations
- No professional supervision
- Over-work
- Poor work-life balance
- Lack of access to social support from colleagues

Issues for workers in direct employment:

- No OH&S framework to guide practice
- Increased pressure to perform tasks as directed by clients, some of which may not be in accordance with health and safety requirements
- Undermining of health and safety where employers do not understand or respect responsibilities and legal obligations
- No professional supervision
- Over work
- Poor work-life balance
- Risk of bullying and abuse
- Family members providing paid care may be at risk of over-servicing, and may lack access to respite

RIGHTS TO VOICE AND REPRESENTATION

Issues for workers in organisations:

- Diminished voice and workplace power through casualisation
- Isolation of workers
- Difficult to inform workers of rights as workforce dispersed

Issues for contractors

- Isolation of workers

Issues for workers in direct employment:

- Isolation of workers
- Difficult to inform workers of rights as workforce dispersed

Promoting service quality and workforce capacity

As the section above summarised, individualised funding models present risks to employment standards and workers' rights, and compromises the continuity and quality of care. This section draws together the findings from the review to suggest some policy objectives, and associated strategies, for protecting against these threats, and promoting employment standards and standards of service quality in the context of individualised funding.

IMPROVING GOVERNMENT FUNDING

The effectiveness of disability support policies depends as much on the *level* of resources available to fund support measures as it does on the *design* of those measures themselves. With the introduction of the National Disability Insurance Scheme requiring an increase in the size of the disability workforce, levels of funding that cover the full cost of service provision are required, including decent wages, and the costs of training, recruitment, leave, and superannuation. These are necessary to ensure a flow of workers can be pulled into the industry, and the existing workforce can be retained.

ENSURING THE SUSTAINABILITY OF SERVICE PROVIDER ORGANISATIONS

If service users could access care from funded organisations that better met and responded to their needs, fewer would perceive cash payments, and direct employment or contracted care, to be necessary. As such, support to maintain the sustainability of service provider organisations, and their capacity to achieve outcomes for service users can help keep jobs in organisations.

A key goal should be to avoid the development of a market consisting of a multitude of atomised and inexperienced employers, which would be extremely costly to monitor and regulate. Government funding to ensure basic infrastructure and administrative capacity of service provider organisations would help them remain sustainable, and to properly fulfil their roles as responsible and compliant employers.

MINIMISING THE ROLE OF CASH PAYMENTS

The approaches to personalisation examined indicate that goals of consumer choice and control can be achieved through other models, including through user-centred planning, notional funding allocations and other alternatives which minimise the role of direct cash

payments and direct employment, and which maintain organisational capacity to respond to, and advocate for, consumer need.

AVOIDING & MANAGING DIRECT EMPLOYMENT

Many of the risks identified in the literature would be managed by altogether avoiding the model of direct employment, that is, by facilitating consumer choice and control while maintaining employment of support staff in organisations. Where direct employment is allowed, the capacity of consumers to be employers, and the working conditions that can be offered, should be carefully regulated. Significant resources are required to ensure employers understand their responsibilities as employers around wages, leave, health, and safety, and to monitor and ensure compliance. Initiatives could include compulsory induction and training before commencing as an employer, and ongoing support. Where direct employment is allowed, workers will need access to information, complaint mechanisms, and union representation.

Alternative organisational models, such as localised cooperatives, may also provide a ways to mediate some of the negative implications individualised funding for workers, for example, by providing access to leave cover, training and support, and to living wages and leave (Myers & Cato, 2011). In the United Kingdom however, without infrastructure support, social care cooperatives have required additional funding from clients, and volunteer labour, as direct payment rates have not fully covered costs (Fisher et al., 2011).

AVOIDING & MANAGING CONTRACTING ARRANGEMENTS

Consumer-centred funding may facilitate an increase in the contracting of support workers, either by organisations or consumers. These arrangements offer consumers and service providers opportunities to manage risk, minimise costs and achieve flexibility. However, they place workers outside the employment protection frameworks, and are likely to undermine workforce investment, and the continuity and quality of care. In some cases, contracting arrangements may be inappropriate and illegal, and monitoring compliance with independent contracting laws is likely to be extremely costly. Ensuring adequate government funding will help ensure the costs of decent employment conditions can be covered, and reduce the pressure on organisations and consumers to contract for care.

AVOIDING EMPLOYMENT OF FAMILY MEMBERS

Employment of family and friends can be a key motivation for taking up direct payments (Blyth & Gardner, 2007; Leece, 2010), and this is understandable, given the relational and intimate nature of much personal support work. However, there are good reasons why directly employing family members and close friends or neighbours may not be ideal.

These arrangements may displace unpaid assistance and result in less care overall (Productivity Commission, 2011, p. G.9). Employing family members may also compromise the capacity of consumers to freely and independently exercise choice and voice, and risk the family member depending on the person with a disability for income, with limited access to respite. Arrangements may also be difficult for paid workers to leave, and future job prospects could be damaged if the work is not recognised as valid experience (Leece, 2004; Ungerson, 2004).

MANAGING DEMANDS FOR FLEXIBILITY

Where organisations and individuals must respond to fluctuations in consumer demand, such as requests made by consumers at short notice or at peak times, funding should allow that providers charge a premium for meeting these needs, to ensure workers can be paid penalty rates. Organisations should also be properly resourced in ways that allow them to respond to fluctuating levels of demand in ways that do not rely on casual staff.

WORKFORCE PLANNING AND DEVELOPMENT

The introduction of the National Disability Insurance Scheme should be introduced with a coherent national workforce planning and development strategy, developed collaboratively with workers and their representatives, government agencies, employers, and service users. This should also include monitoring of workforce capacity and change. Indeed, COAG (2012, p 34) has identified the need to progress a national workforce strategy for disability services.

BUILDING ALLIANCES WITH SERVICE USERS AND PROVIDERS

Workers' rights could be promoted by emphasising the links between working conditions and care quality for service users, and strengthening alliances with service users, service provider organisations, and their peak bodies. Although their interests may not always align, care workers and care recipients share a common interest in quality of care, and therefore in the way care markets, and the care workforce, are managed. Commonalities may be strengthened if threats to the workforce are framed as threats to service quality.

INVOLVING SUPPORT WORKERS IN RESEARCH AND EVALUATION

Research and evaluation studies have focused primarily on service users' experiences, and the outcomes of individualised funding in empowering consumers. Where care workers' perspectives have been explored, it has often been through managers' or policy officials' perspectives, rather than those of care workers themselves. Better monitoring of the

workforce in the context of individualised funding would improve capacity to develop appropriate models.

CONCLUSION

It is clear that sufficient – and significant – resources will need to be devoted to the task of meeting the stated aims of disability policy in Australia in a way that maintains the independence and dignity of people with disabilities, their families and paid workers who provide support.

The National Disability Insurance Scheme is being introduced in a context in which there is already strong evidence of recruitment and retention difficulties stemming from decades of under-investment, low pay, and insecure working conditions. Without recognition of the role of the workforce in a quality service system and initiatives to ensure workforce planning and appropriate models of regulation, it is unlikely that either goals of national system expansion, or standards of service continuity and quality for consumers, will be met.

People with disabilities rightly expect support services to meet their needs flexibly, respectfully, and in ways that fundamentally attend to their individuality. Controlling an amount of money is one way of providing access to such services – a way with considerable risks for both the person needing services and the people providing them. Voice and choice for people with disabilities can be developed in collaborative arrangements *within* service organisations that, by enabling the sharing of skills, resources, and infrastructure, can provide high quality individualised support along with the high quality jobs that underpin that support.

Overall, this report recommends what has been called a ‘high road’ strategy for care work reform (Folbre, 2006). Such a strategy may involve some higher costs in the short term, but in the intermediate and longer terms will lead to more sustainable and higher quality service delivery, better outcomes for people with disabilities, and a more efficient and cost-effective system of care.

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