G Paying family members

Paying family carers raises many thorny issues. Despite this, government payment for family members to be carers is an increasingly important aspect of self-directed funding arrangements. For example, Flanagan (2001) found 80 per cent of consumer-directed personal assistance programs in the United States in the late 1990s allowed people to hire relatives and friends (but not the parents or spouse of the person with disability). In the UK, an evaluation of self-directed funding found that around 40 per cent of people used funds to get help from people close to them, though this was based on a small sample from one council only (Tyson et al. 2010, p. 147). Payments to family members have been used routinely throughout Europe for a long time (Colombo et al. 2011, Annex 4.A3; Rostgaard et al. 2011; Land and Himmelweit 2010, p. 29; Arksey and Kemp 2008, p. 8; Townsley et al. 2010). For example, in:

- Germany virtually all people receiving cash payments are informal caregivers (Wiener 2007, p. 569)
- Norway, municipalities are obliged to offer a wage to family members who substitute for municipal home care services.[1] The wage is most commonly received by the parents of disabled children
- Denmark, while most support is provided in an in-kind form, local authorities can pay a *Cash Supplement* to someone under age 65 needing substantial amounts of help and support. The cash must be used to employ a carer, who can be a relative. However, the cash supplement is usually available if the local authority cannot provide the necessary care (for example, if the person with a disability lives in a remote rural area) or the person finds the available in-kind services unacceptable. The palliative care for terminally ill people compensates relatives for loss of income experienced while caring. There is also a *citizen-managed personal assistance scheme* for people with major disabilities whose needs cannot be met by conventional personal care. This scheme was modified following the findings of a personal budget pilot project in 2004 and the

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[1] However, there is no entitlement to such payment and eligibility criteria vary widely between municipalities.

employment of a family member was prohibited (though a family member can still be responsible for managing the budget).[2]

- In Bulgaria, only unemployed family members from low income families may be employed (Townsley et al. 2010, p. 36)

While it cannot be characterised as a form of self-directed funding, Australia, among others, already includes a well-entrenched payment to relatives, friends and others for providing care to people with disability — the Carer Payment (box G.1). The Carer Payment and its various predecessors have a history that spans nearly 30 years, with a trend towards liberalisation of its coverage.[3] The advent of self-directed funding has provided an additional potential avenue for such payments. A key difference between Carer Payment and payment of family members under self-directed funding is that the Carer Payment is income and asset-tested and is capped.

Some have supported payment of family members in this inquiry.[4] Others have questioned its appropriateness. The desirability of paying family members for their caring role depends on trading off their various benefits and costs: their consequences for people with disability, their caregivers and families, costs to taxpayers, and for social norms. International evaluations of self-directed funding involving payment of relatives provide an evidence base for weighing up these tradeoffs.[5]

And, while many countries include provision for paying family carers, this not at all universal. For example, under new laws in Finland, family members may not be employed as assistants except in exceptional circumstances. Slovakia has similar restrictions (Rostgaard et al. 2011).

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[2] Information on Denmark and Norway are based on personal communication from Caroline Glendinning (Professor of Social Policy at the University of York and an Associate Director of the NIHR School for Social Care Research).

[3] Appendix E of the Carer Payment (Child) Review Taskforce (2008).

[4] These include Murphy (trans., p. 910); Aiesi (trans., p. 398); the Julia Farr Association (sub. 494, pp. 19–20); Raelene West (sub. 42, p. 13); John Pini (sub. 96, p. 6) and Name withheld (sub. 74, pp. 10–11).

[5] This evidence base draws generally on the experiences of those aged less than 65 years since these are the main target of a national disability insurance scheme. That said, the evidence suggests that the aged share similar experiences from hiring family members under self-directed funding, so the literature relating to older people is still relevant (Benjamin et al. 2000).

Box G.1 **The Carer Payment**

Carer Payment (CP) is made to someone providing constant care at under award wages to a person with a sufficiently severe disability in their home. The carer could be a family member or a friend, and they may or may not normally be resident in the home of the person with disability. CP allows 63 days of respite per year. Constant care is defined as a 'significant period' of the day, typically interpreted by Centrelink as a normal working day, though it may be less if caring is intense. To be categorised as constant, care must severely limit the capacity of the carer to be in paid employment (or education). People are not eligible if working, training or studying for more than 25 hours a week (including travel time). While different criteria apply, CP is available for the care of adults and children. However, as children are typically at school five days a week, CP is rarely paid to carers of children aged less than 16 years old.

Payments for a single carer meeting the assets and income tests were $644.20 per fortnight in August 2010. The corollary of this payment level is that the implicit hourly CP rates are low compared with paying the standard support worker rates that might be paid to family members were self-directed funding to allow this.

- If it is assumed that a normal working week is 35 hours a week, this is around the equivalent of a maximum $9.20 per hour of care. This is around half the rate were the person a paid carer employed by a specialist disability agency and around one quarter of the amount governments would provide to a block funded specialist agency to provide the equivalent services.

CP shares some of the advantages and disadvantages from hiring family members under self-directed funding. On the positive side, it may provide the financial capacity for some people to stay at home to provide high quality care for a partner, friend or child. (Or, as may often be the case under the current system, where a person must exercise the caring responsibility because they cannot access sufficient alternative specialist disability services, it at least provides income support.) On the adverse side, it is hard to verify the actual hours of support provided and it creates some incentives for dependence. Whether these incentives are greater or smaller than hiring family members under self-directed funding is not clear-cut:

- As noted above, the financial amounts offered under CP could be much less than some arrangements for hiring family members under self-directed funding — and in that sense, create fewer incentives for long-run dependence
- On the other hand, the taper rate on CP once income exceeds a relatively low threshold is 50 per cent, which with other aspects of the tax and social welfare system, creates very high effective marginal tax rates associated with additional employment income — encouraging welfare dependence. In this regard, a notable difference between CP and hiring family members under self-directed funding is that if a carer works (much) under the former, all CP benefits are lost, whereas if a carer works in outside employment under the latter, the person with a disability (or proxy) still gets access to self-directed funding to allocate in other ways.
- Activities such as volunteering or education may disqualify someone from eligibility for CP, while not necessarily doing so under self-directed funding arrangements

Were there to be a capacity to hire family members, this would be likely to reduce the uptake of CP (with a budget saving). This would reflect the income test in CP and the fact that it would be harder to meet the 'constant care' test.

Source: Centrelink (2010abc), Australian Government (2010).

Dependence and quality concerns?

A major concern is that family carers paid for care may become financially dependent on cash payments — relying on it, for example, to meet mortgage commitments. Given such income dependence, paid caring might:

- place financial pressures on carers to persist with caring arrangements that are not generating high quality care for the person with disability
- compel families to continue a caring role that is progressively socially isolating and stressful for themselves, but that they cannot relinquish for economic reasons (what some have called the 'wear and tear' hypothesis of caregiving)
- create the perverse incentive that the more successful is a paid parent or partner in reducing disability and encouraging independent living, the more they face financial stress.

Anecdotally, the Commission has heard of instances where payments to family members have frustrated the goal of independent living for both the family and the person with disability. Qualitative evidence from a study of Transport Accident Commission claimants found that there were four instances reported by formal carers or treating therapists where paid family members were seen to have hindered progress and eight other instances where there was concern that family carers might affect the quality of care (Kerr et al. 2009, pp. 23–4).[6] However, the quantitative evidence from the study found no difference 'between the two groups across any of these independence measures'.

Overall there is little evidence on the extent to which paying family members may frustrate independence and the circumstances where it would most likely arise — a matter that would be considered as part of the Commission's proposed trial in this area.

On the other hand, the other side of the risk of dependence is a sufficient amount of wages for family members to be able to afford to provide care to the extent desired by (or sufficient for the wellbeing of) the person with disability. As one participant noted, paying primary carers and family members 'would provide family carers with a real choice of providing care or undertaking paid employment elsewhere' (name withheld, sub. 74, p. 10).

There may be benefits to people with disability if there is a capacity to employ family members suited to them. Such family carers will often know the needs and

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[6] However, the latter including family members making complaints about the skill and quality of support by external agency staff, which may have been appropriate, and might increase care quality. The capacity for such complaints is a feature of the Commission's proposed NDIS.

preferences of relatives with disability well, and share an emotional rapport. One participant noted:

> … family and friends should be able to provide for instance paid respite, so that family bonds become closer and part of the family gets to know the client better. Everyone will benefit from this in the long term, especially when there will be a support network available after parents pass away. (Name withheld, sub. 424, p. 1)

In contrast, unrelated paid carers are less likely to know the person with disability well, exacerbated by the likelihood of short tenures in the job. People sometimes complain about the ‘railway station’ aspect of formal care intermediated through service providers — with various support workers coming and going during the week and changing periodically given staff turnover.

Glendinning et al. (2008 p. 54) noted:

> The opportunity to pay an informal carer was felt to be a major advantage of Individual Budgets for those who refused to be cared for by non-family members. For example, one carer [from a black and minority group] reported that her mother depended on her 24 hours a day, seven days a week and would not let anybody else look after her. The carer felt that the IB would provide some recognition of her caring duties and could help her to organise more activities for her mother.

The evaluations of California’s In-Home Supportive Services program found that family members and friends ‘are simply more reliable than strangers’ (Barnes and Sutherland, 1995). Another study of the same program found that self-directed funding had improved safety, reduced unmet needs and increased people’s satisfaction, and these benefits rose when services were provided by paid family members (Benjamin et al. 2000). In an Australian survey, two of the major concerns about formal support workers expressed by families and friends providing informal care were the trustworthiness and quality of respite carers/services, and the unwillingness of the care recipient to accept another carer or someone in the home (Orima Research 2008). The capacity to hire family members may provide a partial solution to this.

And, while financial dependence may theoretically risk adverse personal consequences for carers, the flipside is that paid care may sometimes provide better financial security to a family, relief of the stress associated with alternative low paid or precarious employment, and partly mitigate the tensions of two competing roles (unpaid care and an outside job). US evidence, drawing on a rigorous experimental design, suggests significant benefits for paid family support workers:

> Our assessment of the effects of payment on caregiver outcomes suggests that primary informal caregivers who became paid workers derived substantial benefit from their change in status, even though they were paid for only a fraction (12 to 17 per cent) of the hours they worked. Most notably, paid treatment group caregivers in all three states

> were about 20 percentage points more likely than control group caregivers to be very satisfied with their own lives at the time they were interviewed. (Foster et al. 2005, p. 46)

On the other hand, a longitudinal study of a small group (12) of Australian families found that carers may experience an increased sense of isolation and lack of support if they participate in self-directed funding (Ottman et al. 2009). While carers were not paid under such arrangements, it nevertheless points to the risks likely to be encountered by some families in which carers are paid.

Vulnerability and powerlessness?

Hiring relatives could also heighten the vulnerability of some people with disability. A person with disability may not be able to exercise genuine choice about their carer once having entering into such an arrangement. As staff members of local authorities put it:

> It’s not had much of an impact as we all feel a bit uncomfortable with it as the boundaries are not particularly clear…It’s a nightmare, I think it is a really bad idea. How do you sack your mum? (cited in Vick et al. 2006. p. 37)
>
> I think a more general point, both around direct payments and by implication IB as well, [is] in those situations where a service user employs a friend or family member … you are talking about relationships that go beyond, ‘I pay you’, personal relationships. And I think we may have to consider that phenomena like domestic abuse could play a part in choosing to pay a family member. The danger doing this job is that you have a fairly jaundiced view of humanity really. (words from an Adult Protection Lead officer, cited in Glendinning et al. 2008, p. 174)

However, while this dilemma may sometimes arise, in many other instances, people with disability would be readily able to shape the arrangements they have with their families — including ‘sacking’ them or altering the employment arrangements. Providing people with the freedom to hire relatives is consistent with the notion of self-determination and sovereignty for people with disability (and by inference, some people might see a blanket prohibition as paternalistic). In a large US study, around 85 per cent of people wanted to be allowed to pay family members (Dale et al. 2004, p. 55). A similar study of the Cash and Counselling program found that the capacity to hire family members was an important reason why people with disability were interested in self-directed funding in the first place (Mahoney et al. 2004, p. 660). And as noted above, people with disability report greater benefits from self-directed funding when they hire family members, which is not consistent with systemic vulnerability under such arrangements.

When probed, the actual incidence of cases of exploitation or severe problems associated with hiring family members appears exaggerated. One US study noted:

> In addition, respondents generally focused upon the problem case that created a lasting fear. One agency administrator's explanation typified many respondents: "When the situation works well, it works well, but the few times problems occur they are 'horrible?" When asked about the frequency of major problems, this respondent estimated two cases out of five thousand. (Simon-Rusinowitz 1998)

A large-scale US quantitative assessment of people's sense of security and the incidence of physical and psychological abuse revealed that self-directed funding arrangements involving paid family members reduced risks significantly compared with self-directed funding arrangements involving non-family providers (Matthias and Benjamin 2003).

That said, there are grounds for case managers to support people to change family employment arrangements that are not working well and to particularly monitor risks for people with disability who hire family members. This would be an important role for such managers were hiring relatives permitted.

Accountability issues?

Hiring relatives raises monitoring problems, as it may be hard to confirm that resident unsupervised family members have genuinely provided services for the paid hours. This poses risks for subverting the assessment process by exaggerating the severity of disability to get greater family benefits, explicit fraud and for underservicing the needs of the person with disability. In contrast, people with disability and informal carers purchasing services from outside providers have strong incentives to get the services they have paid for, and a limited scope for fraud.

While not providing systematic evidence, a manager of a large community (aged) care program in Illinois (US) observed that 'paid family caregiving can be the best of care and, unfortunately, the worst of care' (Blaser 2001, p. 278), citing examples where:

- families wishing to benefit from cash payments fabricated a disability and 'hired' a family member as a way of laundering the money
- family members continuing to receive cash payments for caring for people who had died or moved interstate
- family members underprovided services or chose times of care that suited the caregiver not the client ('the most common form of abuse')
- coercion through intimidation of a client to sign a receipt for services apparently provided by a paid family carer.

Similar examples have arisen with the Carer Payment in Australia (Advocare 2003, p. 34 and Office of the Public Advocate 2005, p. 41ff). While these experiences relate to aged care, it is likely that similar problems would arise for the non-elderly.

More subtly, hiring family members, particularly resident ones, may remove one avenue for cost savings for governments from self-directed funding. People hiring non-family members will often only want to buy the services they want. They often do not want strangers in their house for longer than they need. However, with the monitoring difficulties above, that constraint is weakened in the case of hiring resident family members, creating cost-padding incentives.

Several potential factors suggest that the above risks may not be large or that the government could manage them:

- cases of inappropriate payment due to fraud, negligent claims, or changes in circumstances are inevitable when there are hundreds of thousands of customers. From a policy perspective, the key issue is the rate of such problems among beneficiaries of paid family carers using self-directed funding, about which little is known. However, to put the risks in context, in 2008–09, the Commonwealth Director of Public Prosecutions prosecuted around 3400 people for Centrelink fraud (for *all* Centrelink payments) out of a caseload of around 6.8 million customers — or a fraud rate of 0.05 per cent (Centrelink 2009, p. 11 and Centrelink 2010d). Mistaken payments due to error and changes in circumstances for Carer Allowance and Carer Payment accounted for 1.6 and 2.6 per cent respectively of the relevant caseloads (FaHCSIA 2009, p. 287). In the United Kingdom, the estimated expenditure costs of fraud with the Disability Living Allowance (effectively an unhypothecated form of self-directed funding) was 1.9 per cent (NAO 2006, p. 66). More disturbingly, random response surveys in the Netherlands suggested that between 12 and 16 per cent of Disability and Old Age (income) benefit claimants did not notify authorities about an improvement in health (NAO 2006, p. 46)
- while there are exceptions, families are usually strongly motivated to support a family member with disability, and not to exploit them. In addition, genuine exploitation would arise when a family member was paid for hours not actually provided to a person. Given that most family members will continue to provide some unpaid hours, it is unlikely that this circumstance would arise very often.[7] That said, any process for paying family members would have to assess the capacity of a family to genuinely and responsibly provide paid caring services

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[7] For instance, under *Cash and Counseling* in the United States, paid family members were paid for an average 17 hours and provided an additional 34 unpaid hours (Foster et al. 2007, p. 527).

- fraud and risk management — as already systematically employed by Commonwealth agencies — may reduce the problems
- reducing the value of the self-directed funding care package when it includes payment of a resident family member would offset cost-padding incentives.

Displacement?

Hiring relatives may displace unpaid hours previously provided by those family members, while simultaneously relinquishing the hours of paid formal care provided by specialist providers. In that instance, the capacity to hire might actually reduce overall hours of personal support. This could exacerbate unmet need, or require additional taxpayer funding to achieve desired levels of support, affecting the sustainability of an insurance scheme. A small-scale study of Transport Accident Commission claimants conjectured that one reason for the greater provision of paid attendant care hours when payment of family members occurred was the displacement of gratuitous care. However, while a reasonable conjecture, it was not substantiated (Kerr et al. 2009, p. 16).

The most rigorous international trial of self-directed funding (the United States Cash and Counselling program[8]) found compelling evidence of aggregate displacement, with people shifting from unpaid to paid hours of personal care, with the net effect of slightly lower *overall* hours of personal care compared with a control group not assigned to self-directed funding (Carlson et al. 2007).

Of course, at the individual level, self-directed funding might elicit more hours of care for the same costs, reflecting lower wages, reduced administrative costs and the fact that labour shortages affecting specialist disability providers are less likely to affect the capacity to provide support from family members. Hiring family members was seen as one way to tackle the difficulty in recruitment affecting particular communities in the UK, such as sparsely populated rural areas (Riddell et al. 2006 p. 8). Difficulties in recruiting support workers was one reason given in the UK for supporting employment of relatives

Moreover, care from hired relatives may be more efficient than paid formal care, and more flexibly and efficiently directed at the key areas where people need support. In that case, the *effective* extent of care may be greater for any given number of hours. These benefits may also have the long-run effect of relieving pressures on families, allowing them to provide support over longer periods (and saving government resources). Empirical evidence favours these effects. The Cash

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[8] This program had a strong bias to provision of services by family members (Schore et al. 2007, pp. 457–8 and Dale et al. 2003, p. 569).

and Counselling program found that, notwithstanding slightly reduced aggregate hours of care, unmet needs fell by between 10 and 40 per cent, and was accompanied by significantly improved satisfaction with services, especially among the non-elderly (Carlson et al. 2007). That study concluded:

> Consumers' high level of satisfaction under Cash and Counseling may have been mainly due to their receiving paid care from someone close to them rather than from strangers. However, it is unlikely that all of the positive outcomes that consumers experienced were attributable to the familiarity of their paid caregiver. Rather, the reduction in unmet needs and in adverse events that consumers experienced under Cash and Counseling suggests that the paid care provided by these family members and friends was of higher quality than agency care. (p. 481)

This underlies the point that unmet need should not be equated with hours of care.

A broader concern is that hiring family members may undermine social 'efficiency'. Paying for what was formerly unpaid care may potentially create family tensions about appropriate familial roles and, more generally, undermine the social norm in families and the wider community of voluntarily providing unpaid support to those who need it (a form of social capital). However,

- the evidence from the US trials of self-directed funding suggest that it had positive or no adverse impacts on relationships between caregivers and care recipients (Foster et al. 2005)
- the risk of eroding social capital would also apply to paying non-family members for work once performed solely by unpaid family and community members. Yet, government payments for services that were once the sole responsibility of families — disability, aged and child care — are now commonplace in all western countries, and could not realistically (or desirably) be wound back
- existing Australian Government payments to families for caring roles, particularly the Carer Payment, have been in place for a long time, without systemic evidence that these have adversely affected social capital.

The 'woodwork' effect

Governments have sometimes expressed concern about the fiscal implications of hiring family members because unpaid caregivers previously invisible to the system come out of the 'woodwork' because of the attractiveness of a cash option (Simon-Rusinowitz 1998; Doti et al. 2007). If there were no woodwork effect, governments could estimate the total cost of self-directed funding as the number of people originally seeking services times the cost difference between agency-based and self-directed funding (which appears to yield a cost saving). However, the woodwork effect introduces a new group of service users, and their additional costs may overwhelm any savings from self-directed funding.

The evidence is mixed on the strength of the woodwork effect and depends strongly on the policy context. In the United States, the effect in the Cash and Counseling programs was reduced through several means — such as restrictions on enrolees who were not previously recipients of Medicaid funding (Doti et al. 2007). In interpreting European and Japanese long-term care systems, Gleckman (2010) contends that it is unclear whether the issue is a serious concern.

Regardless, the size of the effect could be limited through various other strategies:

- the resource allocation method used to determine the budget for self-directed funding would take account of the existing capacity of family members and the community to provide unpaid support, so that payments are not made for support that would reasonably be provided for free by a family. For example, in Australia, the woodwork' effect associated with the Carer Allowance for children is partly constrained by restricting it to cases where there is a significant carer load from caring for a child with disability[9]
- the government could reduce the value of the cash option when family members are paid
- case managers could monitor self-directed funding arrangements involving paid family carers, and avoiding open-ended arrangements that resemble income support.

Of course, it is not clear that the woodwork effect is always a bad one. The role of insurance is to spread the financial and other implications of costly events. Some families bear all of the costs of disability privately because of the barriers posed by long waiting lists and their concerns about receiving services from formal support workers unknown to them. Self-directed funding and a capacity to hire family members may remove those barriers, creating the woodwork effect, but meeting the social goal of insurance.

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[9] In fact, the Australian Government has not sought to rigorously control the woodwork effect, because it allows an exemption from the care burden test for most disabling conditions.