E Impacts of self-directed funding

Many countries and local areas have implemented or trialed forms of self-directed funding, and have attempted to assess its impacts. In general, the picture that emerges is a positive one compared with more traditional models in which block funded service providers make the decisions about who gets what. This appendix sets out the key evidence. It does so against the background of significant methodological challenges for assessing the impacts of self-directed funding, and a literature that, in many cases, relies strongly on small samples of people and qualitative analysis. In that context, the appendix concentrates on studies that tend to take a more quantitative approach.

E.1 Impacts on people with disability and carers

There is good evidence from many studies that self-directed funding has significant overall positive benefits for people with disability and their families.[1] It is typically associated with greater satisfaction levels, perceptions of greater power and control over life decisions, without adverse effects on health.

The United Kingdom

There have been a host of largely qualitative studies of self-directed funding in the UK — generally revealing highly positive views about the impacts of self-directed funding, but few are as rigorous as the US evidence discussed later.[2] However,

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[1] Ottmann, Allen and Feldman (2009) provides a meta-study of the self-directed funding literature in the UK, US and Australia. The study is oriented to outcomes for older people, but the literature covered typically relates to people with disability generally. While much of that literature is of low or medium quality, nevertheless, there is sufficient evidence from higher quality studies to confirm generally positive outcomes.

[2] The studies have not generally used methods that compare outcomes of a group being offered self-directed funding against a group not offered it (the 'treatment-control' method). Instead, most of the results are based on people's perceptions about the impacts of self-directed funding compared with a previous period when they were not accessing the program. As well as being subject to recall bias, this method does not indicate the impacts of self-directed funding on the whole population of people with disability. In particular, it omits the possible effects on people who are offered self-directed funding, but elect not to take it up. They could, in theory,

more compelling evidence is from three tranches of research assessments of outcomes for people and carers:

- the Individual Budgets Pilot study (IBSEN) (Glenndinning et al. 2008), the most thorough assessment of self-directed funding in the UK
- three phases of research evaluating *In Control* pilot sites in English local authorities (2006–2009)
- a research study into the outcomes for people who became employers under self-directed funding (Adams and Godwin 2008)

Most research in the United Kingdom has focused on direct payments and individual budgets, which, while giving people considerable choice about the direction of services, still involves considerable oversights and limits on allowable spending. Curiously, there has been very little analysis of a 'pure' form of self-directed funding available to all qualifying people with disability — the Disability Living Allowance.

The Individual Budgets (IB) Pilot study

Individual budgets are a particular form of self-directed funding implemented in some pilot sites in England in 2005-06. They allowed people to bundle and direct funds from a wide range of disability services, but with a variety of options for people about how they wish to manage the funds (including 'contracting out' the management of funding and services). People knew how much they would get and what services would cost before they planned how they would allocate their funds.

The IB Pilot (Glendenning et al. 2008) was based on a randomised control trial in which people were randomly allocated to the IB program (the 'recipient' group) or to standard social care support (the control).[3] Unlike many other UK studies, it involved a reasonably large sample of respondents (959 service users).[4] The

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experience positive benefits (the option of choice, or changes in the behaviour of traditional service providers who are having to compete more to keep customers) or negative ones (an exodus of quality support workers to flexible employment arrangements with those who do take up self-directed funding). Either way, given that the bulk of people do not actually take up self-directed funding, the aggregate impact on all people with disability is considerably less than the benefits experienced by the relatively small groups of people who do use it.

[3] Despite the sophistication of the design, it nevertheless had some drawbacks. The period of assessment was short (six months follow-up after commencement, and many commenced late), the local authorities volunteered to participate in the pilots and may have been different from other authorities to which the pilot might later be extended, and staff overseeing may have been more motivated given the media and political attention devoted to the pilots.

[4] Actual samples for individual questions could be smaller than this.

impacts of IB were assessed by comparing the outcomes for control and recipient groups.

Based on the analysis of outcomes, the study found:

- 47 per cent of the recipient group were very or extremely satisfied with the support planning process underpinning IBs and just under half were similarly satisfied with the financial arrangements. (The comparable shares of people who were dissatisfied in any way were 16 and 12 per cent respectively, pp. 66–67.)
- the aspirations of people who accepted an IB[5] appeared to have increased substantially, with 52 per cent of people with a disability aged under 65 years saying that the IB process had changed their view of what could be achieved in their lives ‘a lot’, 20 per cent ‘a little’ and 27 per cent ‘not at all’ (p. 67)
- 49 percent of people assigned to the IB group were either extremely or very satisfied with the help they received (compared with 43 per cent for the control group). 11 per cent of the IB group were dissatisfied and 16 per cent of the control
- people in the IB group had modestly better perceptions about the quality of their care (p. 80). For example, 64 per cent of the IB group said that their care workers always do the things that I want, compared with 59 per cent of the control group
- at six months after initial consent to join IB, people in the IB group had their needs better met (a modest, but statistically significant effect); felt much greater sense of control over their lives (a big and statistically significant effect) had better psychological health (a small and not significant effect) and expressed greater satisfaction than the control group (a large and statistically significant effect) (pp. 81–86).[6] (The study found some adverse effects for the psychological impacts of IB for older people, but this group is outside the scope of this inquiry.)
- across all disability groups, IBs appeared to generate better overall social care outcomes for given expenditure (a measure of cost effectiveness) than ordinary service provision arrangements, but there was no advantage in relation to psychological well-being, and seemingly a negative one for people with learning disabilities (p. 111). Cost-effectiveness appears to be greatest for mental health users

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[5] These are people who were assigned to the recipient group and accepted taking on an IB.

[6] These results control for covariates, such as age. The Adult Social Care Outcome Toolkit (ASCOT) was used to measure of the extent to which people’s needs were met, while the 12-item version of the General Health Questionnaire (GHQ-12) measured psychological wellbeing.

- there was large variations in outcomes for different groups. So while on average people with disability had better outcomes on most dimensions of wellbeing, there was, nevertheless, a sizeable share who actually faced adverse impacts

Notwithstanding the sophisticated design, the slow implementation of IB meant that many people in the recipient group had not really participated in self-directed funding at the six month point, and indeed only around one third had working IB arrangements in place for more than one month at the time of testing. Second, some critical outcome measures were not collected prior to commencement of IB, so that there was no reliable baseline against which to measure progress. Finally, the results from the study include people whose take-up of IB was motivated by acquiescence to the preferences of their social worker, which may skew results (p. 72).[7]

Outcomes from the In Control pilot sites

In Control is an independent English charity that has promoted and used a particular model for self-directed funding in various UK sites. The experiences of self-directed funding in those sites have been examined over three successive periods:

In the 2003–2005 report (Poll et al. 2006), data were collected for 31 people both before and after the introduction of self-directed funding. While the sample is small, the results point to the benefits of greater power. No one was 'really happy' with their level of control over their life before self-directed funding, compared with more than 50 per cent after its introduction. There was a similar pattern for the overall happiness with support services (3 per cent 'really happy' before and around 60 per cent after). People tended to shift from residential care to tenancies, the number of co-tenants fell by 50 per cent and people were happier with their home situation. People were much more likely to be 'really happy' with their relationships (25 per cent before, 67 per cent afterwards). There was little change in some other areas. For example, there was no increase in employment.

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[7] It is also important to note that the 'treatment' group were people randomly assigned to be *offered* IB, and therefore included people who refused IB and took standard care arrangements. This is the Intention to Treat (ITT) experimental design, and it means that what is being tested is not the impact of self-directed funding per se, but a policy of offering self-directed funding and providing it to those who accept. This indicates the effect of introducing self-directed funding on the entire population of people with disability, but it will probably underestimate the benefits for those who want self-directed funding, but who have not been able to get it. To test that effect rigorously, people would need to be asked whether they wanted to access self-directed funding, and of those saying yes, there would be a lottery to determine who would get it. Outcomes would then be compared for the two 'yes' groups.

Based on self-reported outcomes of 196 people before and after their use of self-directed funding, the 2005–2007 evaluation found that self-directed funding mainly had no or positive impacts own people's lives, with very few adverse effects (table E.1 and Duffy and Waters 2008). Most people used self-directed funding to make purchases different from those made under traditional service arrangements.

The third phase from 2007–2009 (Tyson et al. 2010) presented aggregated results for phase one and two respondents (shown as the results for 2005–2009 in table E.1).

Table E.1 **Self-reported impacts of self-directed funding in the UK**

2005–2007 and 2005–2009[a]

Outcomes[b]	*Improved*		*Same*		*Worse*	
	2005-2007	2005-2009	2005-2007	2005-2009	2005-2007	2005-2009
	%	%	%	%	%	%
General health & wellbeing	47	51	49	44	5	4
Spending time with people you like	55	58	42	40	3	2
Quality of life	77	69	23	30	1	2
Taking part in the community	63	58	34	39	2	3
Choice and control	72	67	27	32	1	1
Safe and secure at home	29	40	71	58	1	2
Personal dignity	59	52	41	48	0	1
Economic wellbeing	36	40	60	52	5	7

[a] The results for 2005–2009 were estimated from a graph as exact figures were not disclosed. The sample sizes for the answers varied as not all respondents answered all questions. For instance, the number of respondents for the combined phases varied from 385 to 528. [b] It should be emphasised that the studies on which these results are based were authored by strong advocates for self-directed funding, rather than by impartial evaluators. As an illustration, the phase three report argued that local authorities should not 'obsess' about any one set of issues about implementing self-directed funding, and 'leaders must lead from the front, showing a relentless commitment to the vision' (Tyson et al. 2010, p. 30). The partisan nature of the studies need not affect the objectivity of the results actually reported in the study, but it may affect the methods used to assess outcomes and the extent to which the authors actively sought to find problems that might affect self-directed funding. Ottmann et al. (2009) has made the same criticism.

Source: Tyson et al. (2010); Hatton and Waters (2008); and Duffy and Waters (2008).

The results imply that later cohorts of users of self-directed funding had much the same beneficial outcomes. However, there was a higher likelihood that later cohorts perceived greater improvements in safety, and lower improvements in the quality of life and dignity of support from self-directed funding. A subsample of users suggested that — as in phase two — self-directed funding had a negligible impact on paid work by people with disability (p. 148). The third phase also examined carers' experiences with self-directed funding, finding large benefits, particularly in perceptions of being an equal partner in planning, the support to carry on caring and remain well, and quality of life. The poorest outcomes related to the capacity to undertake paid work, with just over 20 per cent of carers considering that this had improved since commencing self-directed funding and just less than 20 per cent considering that this had worsened. Most professionals involved in implementing personal budgets also tended to be highly positive about the impacts of self-directed funding, particularly in perceptions that it allowed people with disabilities to plan creatively, tailor their supports, acquire power and to get positive outcomes in their lives. While overall outcomes were still positive, around one in five professionals considered that their own work motivation and capacity to help people in a timely way had worsened.

Outcomes from the Employer study

Adams and Godwin (2008) is one of the largest and most through examinations of self-directed funding in the UK. It collected information from 526 people with disability and carers hiring support workers (the employers) and 486 personal assistants (with more detailed follow up involving 100 respondents). The aspects of the survey relating to the experiences of personal assistants are described in section E.4.

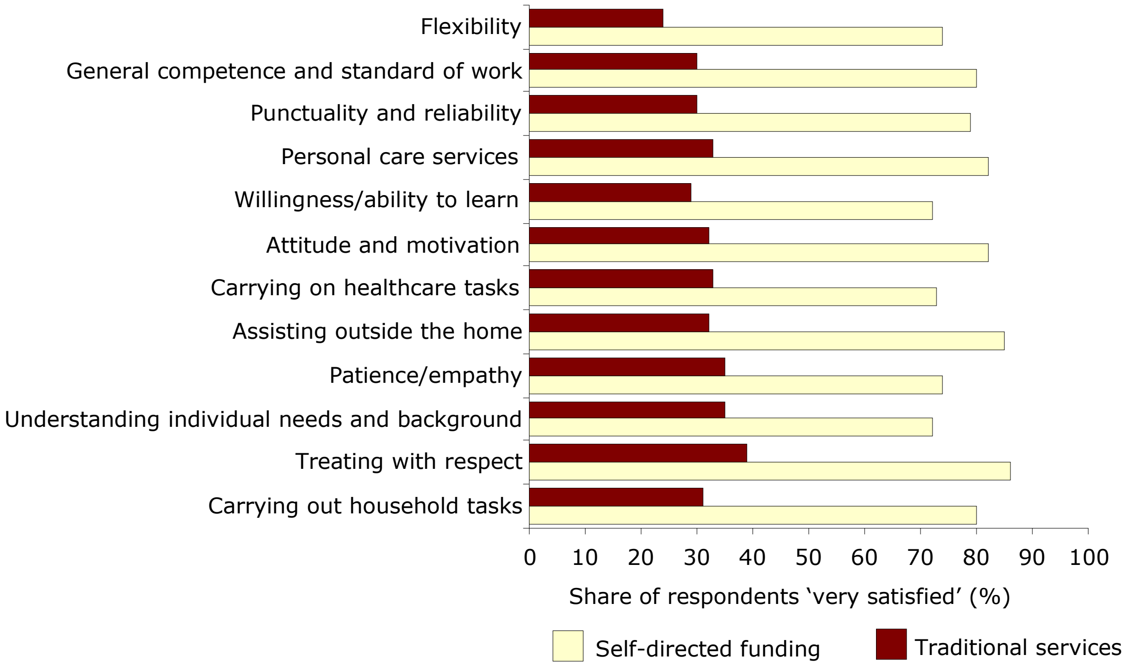
Overall, people were much more likely to be satisfied with care and support provided by directly employed personal assistants than those provided by the local authority. 79 per cent of people were very satisfied (6 per cent very dissatisfied) with support under self-directed funding compared with only 26 per cent (27 per cent very dissatisfied) for traditional services. Similar patterns were apparent for the varying aspects of personal services (figure E.1). People found that they were more bale to get services that would not have been provided by a traditional service and that they were able to rely less on families/friends and to gain greater independence (pp. 39-42).

Employers were also much more likely to encounter problems with personal assistants under traditional service arrangements than self-directed funding (IFF 2008, p. 32). This included lateness (36 per cent cf 6 per cent); not turning up at all without telling the person (31% cf 5%); poor quality of care (34% cf 2%); and insensitivity in the way they dealt with issues of personal hygiene and waste (21% cf 1%). These problems can undermine the capacity for maximising independence, for example, by never being sure that an outside appointment can be kept.

(Inadequate care of the kind described above also have devastating consequences for the dignity of a person with disability. One of the participants in this inquiry described how her son had not been toileted or fed properly while in respite care (Lesley Baker, sub. 188, p. 5).)

Figure E.1 Perceptions of the quality of personal services under self-directed versus traditional service models

People who are 'very satisfied', United Kingdom



Data source: Adams and Godwin (2008, p. 29).

Take-up of self-directed funding in the United Kingdom

The take-up of self-directed funding across the UK generally and by various groups of people who use services has been described as 'disappointing' and 'slow, patchy and sometimes inequitable'. In part this is symptomatic of the staggered implementation of the policy across user groups and regions (Davey et al. 2007, p. 16, pp. 25–31). The Royal Society for the Blind SA (sub. 511, p. 13) said that it had received feedback from counterparts in the UK that many blind people did not get access to direct payments.

Concern about managing direct payments among consumers and resistance to their adoption among social workers and unions has also contributed to slower than ideal take up (Davey et al. 2007, p. 103; Riddell et al. 2005).

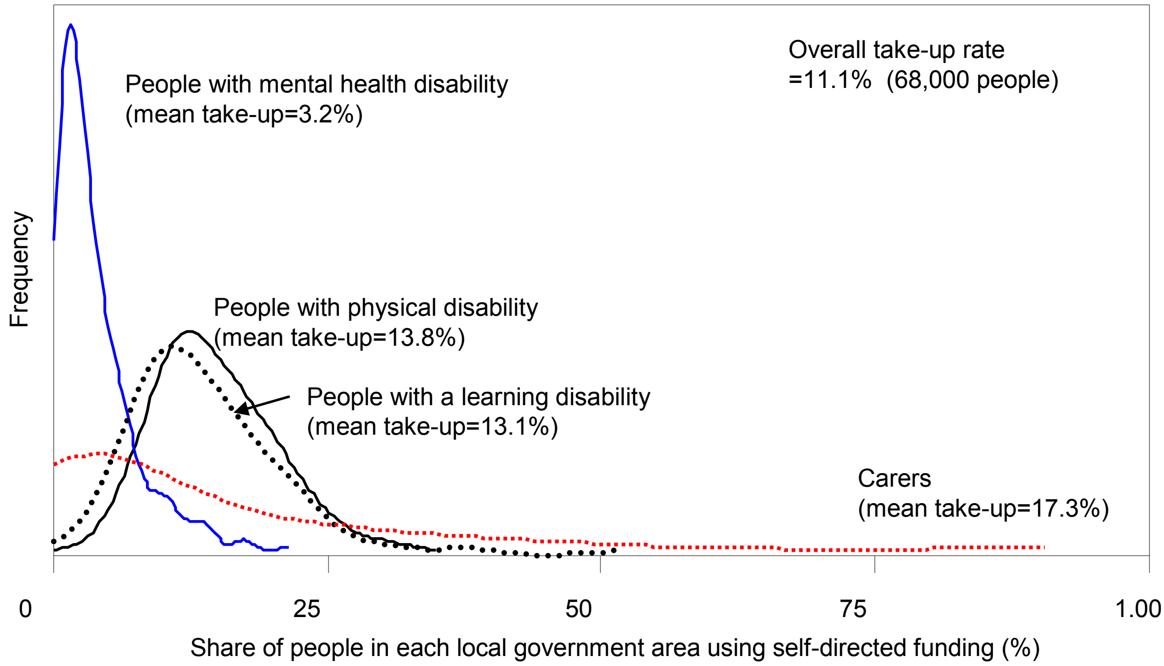
England has around double the take-up of the other countries making up the UK, but overall take-up in England was still only around 11 per cent of people aged less than 65 years eligible for disability social services in 2008-09 despite its availability for social care services in all local authorities. (Take-up was lowest among people with mental health problems and highest among carers of people with disability.)

However, in the UK, people's use of direct payments has been growing rapidly. For instance, the trend growth rate in England of all direct disability payments to adults was 37 per cent per annum from 2000-01 to 2008-09, and while growth rates are abating, they still remain above 25 per cent. Gross spending on direct payments for adults aged less than 65 years rose from just over 1 per cent in 2000-01 to 6.8 per cent by 2008-09. Expansion in direct payments over this period has also been accompanied by a consistent reduction in the average size of payments per person — with the orientation of self-directed funding shifting outside its original focus on people with the most intense needs. Accordingly, in the UK, a much larger share of people may access direct payments in the future.

The UK experience with self-directed funding also reveals significant variations in the take-up in different local government areas — shown by the distributions in figure E.2.

Figure E.2 **Take-up of self-directed funding by people aged less than 65 years in England, 2008-09**

People aged under 65 years, distribution of take-up across local authorities[a]



[a] The densities were estimated by the PC using Gaussian kernel density estimation based on individual local government records. The overall take-up rate excludes 'vulnerable people' and those experiencing substance abuse. The take-up rate is measured as those using direct payments (and individual budgets) as a share of total service users.

Data source: Health and Social Care Information Centre (2010a).

The spatial differences are too large to be attributed wholly to chance. Not only is there large disparities in take-up spatially across England, take-up in the rest of the

United Kingdom is significantly lower (Priestley et al. 2007). It appears that differences in the attitudes and support given by local authorities, varying animosity from public sector unions, and variations in voluntary sector advocacy for direct payments can significantly affect the adoption of consumer-directed payments (Hasler and Stewart 2004, Rankin 2005, Riddell et al. 2005, Glasby and Littlechild 2009, pp. 47ff, Davey et al. 2007).

The United States

The most sophisticated international assessments of the effects of self-directed funding have been undertaken in the United States. Many of these assessments were part of large demonstration programs that allowed people to take the funding from traditional agency care and to spend it on what they needed. The evaluations were often strengthened by adoption of a random-assignment experimental design to test the impacts self-directed funding against a control group of people getting traditional agency care (Doty et al. 2007; Brown and Dale 2007).[8] Moreover, the capacity to extract Medicaid claims data in many of the evaluations enabled an accurate assessment of service usage for the different groups — which helped accurately determine certain outcomes (hospitalisation) and relative costs (section E.3). (One of the advantages of a coherent insurance-like approach to disability service provision in Australia is that systematic ongoing data analysis of the kind used in the US evaluations could be routinely undertaken.)

The Commission examined 27 US studies into self-directed funding, spanning the last 25 years. The evaluations consistently found that self-directed funding provides significant benefits to people with disability and their families compared with traditional agency-based services (table E.2). Positive results were found for those with physical, intellectual and mental health disabilities, and for the non-elderly and elderly.

An exemplar is a study of self-determination in Michigan. This found that those using self-directed funding exerted much greater control over their lives (Head and Conroy 2005, p. 230) after introduction of a pilot program. People much more often hired and fired staff; selected their preferred agency, agency support person and case manager; chose the people they lived with; and chose whether they lived in an apartment or house. There were many gains in control over the small aspects of life too, like what to have for meals, when to get up or go to bed, and who to go out

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[8] As in the UK study by Glendinning et al. (2008), the evaluations undertaken using the US *Cash and Counselling* demonstrations used an Intention to Treat methodology (so that the 'treatment' group would include people who elected not to manage their own funds).

with. Having greater choice had positive impacts on outcomes.[9] People had more outings (an average of 35 per month compared with a baseline of 25), a higher quality of life (from 69 to 81 points on a scale of 0–100 as measured by an instrument examining 15 dimensions of quality of life), and more satisfaction (a 0.25 points increase on a scale from 1–5). All 15 dimensions of the Quality of Life Changes Scale showed increases, particularly happiness, getting out and about, overall quality of life, socialising and privacy.

Longitudinal studies have confirmed the persistence of the benefits. A nine-year longitudinal study in the United States found that by the ninth year families gaining access to an individualised funding had fewer unmet needs and higher service satisfaction than did families on the waiting list who did not get such funding (Caldwell and Heller 2007).

While not valid statistically, detailed case studies based on experiences in the US *Cash and Counseling* scheme suggest that the benefits of self-directed funding often arise from the capacity of people to tailor services to their own very specific needs (Antonio et al. 2007). For example:

- under agency provision of services, support workers would arrive at 8 am, although Mary (the person with disability) only got up at 10 am. Mary had to deal with many workers (once a different worker every day for two weeks). Using self-directed funding, Mary hired a single reliable support worker for the hours she wanted. The support worker also valued the set routine and her close personal association with Mary
- before self-directed funding, workers followed agency practices by expecting to dictate the tasks and schedule for a woman with a severe degenerative condition (Angela), and doing a range of motion exercises the way the agency trained them to do so, rather than follow the client's directions. Under self-directed funding, Angela hired caregivers without much experience so she could train them herself to provide care the way she wanted.

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[9] All were highly statistically significant. A possible limitation of the study methodology was that it examined outcomes before and after program implementation only for those people who participated, and not for a control group of non-participants. This would only make a difference to the estimated impacts of self-directed funding if some of the improved outcomes reflected a general improvement in services over time for all people. Head and Conroy (2005) note that similarly positive results were found in a complementary study in another state that did account for non-participants, so the study methodology probably produces reliable results.

Table E.2 Summary of impacts of self-directed funding

Summary impacts of 27 empirical studies in the United States

	Person with disability	*Family members*
Consumer and family benefits		
Met individual needs	Up	..
Satisfaction with care	Up	Up
Sense of control over life/ empowerment	Up	
Community interaction (circles of friends)	Up	
Quality of care/ confidence in care	Up	Up
Abuse and neglect	Down	..
Satisfaction with life	Up	Up
Culturally and linguistically appropriate care	Up	..
Providing care during non-business hours	Up	..
Continuity of care	Up	..
Employment and productivity gains	Up	
Use of preventative care	Up	
Use of hospital, other health services & residential care	Down	
Financial strain	..	Down
Health status	Up or no change	Up
More aids & appliances and home/vehicle modifications	Up	

Sources: Based on Commission analysis of Kemper (2007); Prince et al. (1995); Conroy and Yuskauskas (1996); Richmond et al. (1997); Beatty, Adams and O'Day (1998); Beatty et al. (1998); Feinberg and Whitlatch (1998), Benjamin et al. (2000); Conroy et al. (2002); Foster et al. (2003); Matthias and Benjamin (2003); Dale et al. (2005); Hagglund et al. (2004); Schore and Phillips (2004), Head and Conroy (2005); Heller and Caldwell (2005); Kim et al. (2006); Caldwell and Heller (2007); Carlson et al. (2007); Dale and Brown (2007); Foster et al. (2007); Schore et al. (2007); Texas Health and Human Services Commission (2007); Shen et al. (2008), Applebaum and Nelson (2009), Norstrand et al. (2009); and Alakeson (2010).

Australia

Apart from Western Australia, most Australian jurisdictions have yet to develop arrangements in which self-directed funding is the default model for delivery of services (appendix D). Reflecting this, no large-scale evaluations akin to the US Cash and Counseling State demonstration evaluations have been undertaken. Nevertheless, the available (weak) evidence does suggest positive outcomes.

Western Australian Local Area Coordination

The Western Australian models of person-centred support appear to have yielded positive outcomes, based on a meta-study of 17 evaluations of the Local Area Coordination (LAC) program (cited in Laragy and Naughtin 2009). That said, satisfaction levels for the LAC appeared to have declined over time (appendix D). However, LACs are not the only vehicle for self-directed funding in Western Australia.

The NSW Community Participation Program (CPP)

The evaluation of the (small-scale) CPP for young people with disability found high levels of satisfaction with self-direction (ARTD Consultants 2009). People said the CPP gave them greater control, choice and flexibility, such as being able to hire the workers they wanted — including siblings and friends. Some participants struggled with the responsibilities they had under the model and would have liked more support.

The NSW Attendant Care (Direct Funding) program (ACDFP)

The evaluation found an 'overwhelmingly positive response' by participants to the pilot scheme (Fisher and Campbell-McLean 2008). Nearly all outcomes were positive compared with the period prior to enrolment in the program (table E.3), which was supported by qualitative evidence from participants about a sense of greater control, better consistency and quality of care, and flexibility. For instance, one person was able to get care for half an hour when they returned from work, because they were able to hire someone who lived nearby.

Table E.3 **Impacts of the NSW Attendant Care (Direct Funding) Program**

Outcome	*Mean (baseline)*	*Mean (Follow-up)*	*Treatment effect*[a]	*Control group mean*	*Selection bias*[b]	*Spurious treatment effect*[c]
Personal wellbeing index	83	86	3	71	12	15
Life as a whole	82	89	7	69	13	20
Standard of living	79	88	9	75	4	13
Health as a whole	81	82	1	63	18	19
Achievements	83	87	4	71	12	16
Personal relationships	87	88	1	69	18	19
Safety	88	83	-5	77	11	6
Feeling part of the community	83	84	1	72	11	12
Future security	80	84	4	72	8	12

[a] The treatment effect is the difference between the follow-up outcome (after the intervention) and the baseline outcome (before the intervention). [b] The difference in outcomes between the control group and the treatment group *prior to treatment* is a measure of selection bias, since without such bias, the control group should have matching outcomes. [c] Many studies (but not this one) measure the treatment effect as the difference between the treatment and the control groups. When the groups are identical, this is a sound methodology, but as shown here, this indicator can provide very poor guidance about real program effects when there is significant selection bias.

Source: Fisher and Campbell-McLean (2008).

The results also show significantly better results compared with a 'control' group of people not using self-directed funding (table E.3, last column). However, that difference appears to be mainly spurious, reflecting the differences in the underlying characteristics of the control and treatment groups — an issue acknowledged in this study.

While the overall results are highly suggestive of benefits from self-directed funding for those who take it up, the pilot is so small in scale that it cannot provide reliable evidence about the effects of rolling out a bigger scheme. Only 10 people took part in the trial, and there were only 26 people in the (flawed) control group.

Evaluation of various individualised funding arrangements across Australia

A qualitative study of individualised funding arrangements across Australia found typically favourable outcomes, and few risks (table E.4). The study was based on face-to-face interviews and questionnaires with people with disability, families, service providers and officials.

Support and Choice, Victoria

This was a precursor to full direct payments. The funding was not held by the person, but by a fund holder who was responsive to a plan drawn up by a facilitator with the person. The (qualitative) evaluation was mainly focused on what processes and structures worked well, rather than on the impacts on people (LIME Management Group 2005). However, the evaluation found that S&C worked best for people moving from shared supported accommodation and for families with children under 16 years old. Of the latter, 80 per cent considered that the program had improved the quality of their life (compared with 57 per cent of all participants in the program). People were able to exercise greater control, take up more creative activities, and use mainstream services more often. There were considerable frustrations about the way planning was done, particularly with delays in approving plans. The evaluation recommended the trial of a full direct payments program.

The Victorian Direct Payments program

The evaluation of the program found it had met all its objectives by giving people more effective choice, control and flexibility, and in developing the policies, tools and processes for running a direct payments system (LDC Group 2007).

Table E.4 **Impacts of self-directed funding in Australia**

Perceptions of self-directed funding	*Share in category (%)*
Service providers	A lot or very much
Driven by client's wishes	100
Facilitates the type, quality and quantity of support the client wants	68.4
Accountability and planning protects the client and provider	89.5
Support workers conditions are protected	77.8
Improves availability of qualified workers	33.3
Funding used in flexible & creative way (a lot/very much)	78.9
	Better/much better compared with agency-type services
Community participation	72.2
Social benefits	70.6
Access to relevant services	64.7
General wellbeing	66.6
Mental health	66.7
Physical health	53
Achieving social inclusion	63.1
Views of people with disability[a]	Happy/very happy
Provides choice about service provider, workers and support services (share saying yes)	92.4
Satisfaction with help choosing support (share happy/very happy)	81.2
Share saying support is better/much better than before	71.4
Share saying support is worse than before	0
Share saying can change services when needed (often/always)	61.7
Share happy/very happy with types of support used	86.5
Subjective personal wellbeing compared with	

[a] The study also included a comparison of various personal wellbeing measures of those using self-directed funding with a broad group of people in Victoria with an intellectual disability. The comparison has some drawbacks given the self-directed funding users include all disability types, whereas the control group does not. Moreover, the comparisons do not match for other individual traits of the treatment versus control group, and do not take account of the selection biases that would lead some people to enrol in self-directed funding. Nevertheless, there were no substantive differences in wellbeing, except that people using self-directed funding had much lower sense of future security — perhaps reflecting uncertainty about the continuation of self-directed funding.

Source: Fisher et al. (2010).

Most participants in the trial reported more favourable outcomes than under previous arrangements, with:

- 70 per cent agreeing that they were more able to participate in the life of their family, friends, and the wider community
- 70 per cent stating that they were more confident in their ability to negotiate the support they needed
- 80 per cent saying that they were more in control of their lives

- 70 per cent saying that they were better able to determine and choose the supports needed
- all users continuing their use of direct payments after completion of the trial period.

The most useful aspect of trials of these kinds is learning how to administer such schemes and identifying the practical issues that would need to be resolved when they are scaled up. The very small numbers of people participating in the trial — 10 people (as in the NSW ACDFP) — means that outcome measures are of very limited empirical reliability. However, the results all point to benefits from self-directed funding, and are consistent with the findings of bigger scale evaluations abroad.

The Victorian Uniting Care Community Options Directed Care Pilot program

This self-directed funding program was set up by a service provider — with the support of the Victorian Department of Human Services — after requests from families. The pilot involved 15 families, and, uniquely, gave considerable control by families over both their funding and the governance of the pilot (Ottmann et al. 2009). The evaluation focused on how processes worked within the pilot, rather than outcomes per se for participants. The pilot revealed that most people did not want to take on the administration of the packages (paying 10 per cent for a third party to do this), and that around half did not want to relinquish external support through case management. The 'self-governing' aspect of the pilot proved ultimately to be unstable and in its absence, substantial internal communications problems and lack of coordination emerged. The drawbacks in the self-governing aspects of the pilot did not necessarily reflect an intrinsic fault in this approach — but factors like ongoing resourcing for that role.

Personalised Lifestyle Assistance (PLA) Victoria

PLA is a not-for-profit organisation formed in 2003 as an experimental project with a non-recurrent grant from Disability Services Division of the Victorian DHS. PLA is not itself a self-directed funding program, rather than a process for encouraging self-directed care, whatever the funding sources and resources. In that sense, the project still sheds some light on the impacts of self-directed funding.

PLA aims to increase self-determination among people with disability by providing information to families (and groups of families) and helping them organise resources (in many cases private and community ones, rather than just government) and new arrangements for managing their support. A particular aspect has been on assisting families to form collectives, funded through individual support packages and private resourcing. [10]

The (qualitative) evaluation of the program indicated that there was a 'very high satisfaction with PLA from individuals, family members and service providers involved' (Fyffe 2008).[11]

However, unlike some examples that fall under the banner of self-determination, PLA has a set of principles that exclude some options that people might want — for example, combining traditional services and more flexible arrangements, or sharing a house with another person with disability. The evaluation of the program notes that, given these principles, PLA is not suited to all people wanting to pursue individualised approaches, and it appears that it suited people with more resources and energy. This was not seen as a flaw.

Notwithstanding the qualitative and non-independent nature of the evaluations, its findings of improved outcomes experienced by families seeking individualised approaches over traditional ones are consistent with most other studies.

Queensland

The Commission is not aware of any completed evaluations of self-directed funding pilots in Queensland. However, Queensland Disability and Community Care Services have commissioned a major evaluation of the Self-Directed Support Pilot, which covers children and young adults with a disability (Gendera et al. 2010). The (longitudinal) evaluation intends to compare outcomes and costs of self-directed funding with baseline outcomes under standard service arrangements. It is due to be completed in early 2012.

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[10] One by One provides an illustration of such a collective — and shares many of the aspects of self-directed funding apparent in traditional self-directed funding arrangements. It includes a capacity for each person to influence the allocation of their funding and other resources to meet their aspirations. One by One employs a host agency to take care of legal and financial requirements while delegating necessary authority to individuals and families to create their own arrangements and lifestyles. Governance is by the families in One by One and not by the host organisation.

[11] The evaluation was commissioned by the PLA and its hosting organisation, and was therefore not independent.

Other countries

Many other countries have self-directed funding arrangements in place. These include Austria, Belgium, Canada, Denmark, Finland, France, Germany, Italy, Ireland, the Netherlands, Slovakia, and Sweden (Arksey and Kemp 2008; Townsley et al. 2010).

In the main there appears to be little rigorous evidence about their impacts. However, the evidence that does exist suggests similar benefits to those identified for the UK and the US:

- Survey analysis in Ontario (Canada) found that people using self-directed funding 'experienced positive outcomes', including obtaining greater independence in their lives and moving away from the family home; gaining employment or volunteer work; getting out and about; expanded personal networks; and recreation and leisure activities reliant on mainstream, rather than the specialist 'segregated' provision of services (Lord and Hutchison 2008, p. 44, p. 49; Lord et al. 2006). The study also revealed that some of the accompanying features of self-directed funding — particularly the role of facilitators in helping families make self-directed funding plans — were important ingredients in achieving good outcomes.
- Qualitative analysis of the Canadian *Individualised Residential Model* (which gave people much greater choice about how to organise their accommodation options) found people felt much more in control of their lives and were able to make choices that met their needs better. For example, one participant noted 'For the people supporting us, for health and safety reasons, they "bubble wrap" us. But we have to take the layers off. What if I wrap you and you can't do what you want to do — you don't get bruised, but you can't handle your shopping, handle money. you have to let us be independent and have experience.'(Jenny Carver and Associates 2009).
- An evaluation of self-directed funding in the Netherlands found that around 80 per cent of disabled and elderly participants who opted for a personal budget had a positive assessment of the services they received compared with less than 40 per cent among those receiving traditional agency-based services (Alakeson 2010, p. 4).

E.2 Compliance and red-tape effects

While the quantitative and qualitative evidence suggests strong overall positive benefits of self-directed funding on people with disability and their families, people also identified drawbacks. These mainly related to the administrative aspects of self-directed funding. Several international studies have found that people with disability regard the record-keeping requirements for hiring support workers to be 'overly bureaucratic and burdensome' (as reported by Arksey and Kemp 2008, p. 10; Chenoweth and Clements 2009, p. 19; Commission for Social Care Inspection 2008, p. 5, p. 13). Many people have overcome these difficulties by outsourcing administrative tasks to intermediaries (an option that is available in Western Australia self-directed funding arrangements).

Specific studies have revealed some of the detailed issues and specific groups finding the administrative tasks difficult:

- in a Canadian study, people were frustrated with the procedures of self-directed funding, the deadlines required by officials, forming contracts with support workers and the need to re-apply each year for continued funding (Lord and Hutchison 2008, p. 49)
- in a detailed UK study of the experiences of people with disability who hired personal assistants, people experienced a variety of administrative and compliance burdens, such as poor information about direct payments, recruitment difficulties, tax issues, filing accounts and paperwork (Adams and Godwin 2008, p. 45). However, while overall around 40 per cent expressed at least one such problem, a relatively small share of employers experienced any specific problem (the maximum for a given problem was just 8 per cent). More generally, there were mixed attitudes regarding the administrative and paperwork burdens associated with self-directed funding in the UK (Glendinning et al. 2008). The burdens were greater for parents of people with intellectual disability, who had to assume all of the support planning on top of their caring responsibilities (p. 161).
- In the US Cash and Counselling program, older people tended to find it hard doing the 'math and paperwork necessary for developing spending plans', even when helped by the program coordinators (Brown et al. 2007, p. 32)
- The evaluation of the NSW Attendant Care Pilot reported some concerns about paperwork requirements, indicating they could not be 'bothered' or lacked the skills. However, this only appeared to be an issue for some people (Fisher and Campbell-McLean 2008, p. 17).

E.3 Effects of self-directed funding on costs

A key policy concern is whether self-directed funding costs more or less to meet people's needs than traditional forms of care.

The evidence is of variable quality. Few studies considered the overall costs of self-directed funding compared with agency-based provision. These costs comprise annual direct expenditure by people with disability on services, support provided by case managers and others for families using self-directed funding, and the annuity value of implementation costs. Most studies focused on the first (and most prominent) cost. Relatively few studies used large samples or made rigorous comparisons between the 'treatment' group enrolled in self-directed funding and the 'control' group enrolled in traditional agency-based services. It is sometimes also important to consider the appropriate reference cost. For example, Stainton et al. (2009) found self-directed funding was lower-cost than local authority provided supports, but not *always* lower cost than the independent sector.[12]

The most rigorous evidence is from the United States, where proper treatment-control comparisons were carefully built into trials and where sample sizes are comparatively large (Kemper 2007, Doty et al. 2007). Unfortunately, in some of the US studies, people in the control group did not get the services authorised for them (for example, due to labour shortages affecting formal support workers), whereas the treatment group did get the authorised services because they were able to pay family members (Dale et al. 2004; Dale and Brown 2007). Consequently, the findings in these studies that self-directed funding were more costly was an artefact of effective rationing for people using traditional agency care services.

Nevertheless, there is enough evidence from diverse sources to suggest that self-directed funding is likely to be less costly than alternative service models (table E.5). While the evidence mainly relates to ongoing costs of personal care, the relatively low magnitude of additional support costs and amortised implementation costs associated with self-directed funding suggests that this result would apply to overall costs too. As noted in chapter 8, in Australia there is greater concern about the risks of excessive costs when self-directed funding includes a capacity to pay family members (Kerr et al. 2009).

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[12] Staintin, T., Boyce, S. and Phillips, C. 2009 'Independence pays: a cost and resource analysis of direct payments in two local authorities', *Disability & Society*, vol. 24, no. 2, pp. 161–172.

Table E.5 **Evidence on the cost impacts of self-directed funding**

Source	*Location*	*Cost findings*[a]
Zarb and Nadash 1994	UK	Self-directed funding 39.2% less
Prince et al. 1995	Colorado and Boston, US	Self-directed funding 14.6% less
Conroy and Yuskauskas 1996	New Hamsphire US	Self-directed funding 12.4%–15.5% less
Ladd and Associates 2000	Washington and Oregon US	Cost per hour around 50% less
Dawson 2000	UK	Direct payments were a cheaper alternative than direct service provision or contracted agency service and become cheaper still comparatively over time.
Bradley et al. 2001	19 states US	Higher system overhead costs (eg coordination, sophisticated management information systems), but may be offset by lower costs generally
Conroy et al. 2002	Michigan, US	Self-directed funding 6.7% less
Conroy et al. 2002	Califonia US	Half the rate of growth of costs compared with agency services
Stainton & Boyce 2001	Wales UK	Positive savings
Dale et al. 2004	Arkansas US	Higher, but because control group did not get the amount of care authorised for them (eg. due to labour shortages). The treatment group had savings on long-term care and hospital in-patient services. Other than this rationing effect, the experiment was designed to be at least cost neutral.
Head and Conroy 2005	Michigan US	Self-directed funding 16% less
Robertson et al. 2005	UK	2.2% (statistically insignificant) increase in per annum costs, but there were one-off implementation costs
Heller & Caldwell 2005	Home-Based Support Services Program US	Significant cost savings by delaying residential care
London Borough of Richmond upon Thames 2005	UK Richmond	The unit cost of direct payments is on average sufficiently lower (by 17%) than the equivalent unit cost of providing direct services, enabling the support service to be met from the difference
Kim et al. 2006	Kansas US	Self-directed funding 3% less (not statistically significant)
UK Audit Commission 2006	UK	The cost per user of *implementing* direct payments varied from under £200 to about £1800 per council. Some councils have cashed out at a lower rate than local authority organised care — with net savings.
Poll et al. 2006	5 English authorities, UK	Self-directed funding 12%–45% less
Texas Health and Human Services Commission 2007	Texas US	In aggregate, self-directed funding was 9.2% less than the agency model. Waiver services were 9.2% higher, but acute care services and prescription drug costs were 39.5 and 34.1% lower respectively.
Crosby and Fulton 2007	UK 'Dynamite' program for young people	Families using self-directed funding tended to 'under-assess' needs, compared with professionals who tended to 'over-assess', implying lower cost outcomes
Davey et al. 2007	UK survey	Average cost of *support* for direct payment person was £734

Table E.5 **Continued**

Source	*Location*	*Cost findings*[a]
Dale and Brown 2007	Arkansas, Florida and New Jersey, US	In year 2, for non-elderly Arkansan 4.2%, Florida 13.5%, New Jersey 13.4% and Florida young adults 8.4% more costly due to under-entitlement of control group. Higher costs in personal care, but saved resources in long-term care
Duffy and Waters 2008	UK	Costs fell by 9 per cent for those who moved from traditional social care services to self-directed funding (p. 47), but these data are preliminary and reflect a sample biased towards higher-than-average costs.
Glendinning et al. 2008	UK	Self-directed funding around 10% less than the control (p.98) (not statistically robust). Greater health care costs. Small possible gains in cost effectiveness for some groups.
Peak and Waters 2008	City of London, UK	Of the people taking part in the survey, 70 per cent had previously received a service, and the total costs of these exceeded the total costs of all the people receiving self-directed funding (p. 5)
Fisher and Campbell-McLean 2008	Australia (Attendant Care program)	No greater, after full administrative costs, and considerable savings carried forward to next year — so possibly bigger long-run cost savings
Leadbetter et al. 2008	UK	Self-directed funding 10.3% less
Stainton, Boyce & Phillips 2009	Two Welsh authorities, UK	Direct payments significantly less than authority services and cheaper than the independent sector for all but the lowest wage rate independent sector services
Alakeson 2010	Netherlands	17% of total funds allocated to individual budgets went unspent in 2005
Townsley et al. 2010	Sweden	Lowered costs (p. 44)
Fisher & Campbell-McLean 2008	NSW, Australia	Described as ‘cost-effective’. Costs similar to alternative models; users had surpluses from funds
Fisher et al. 2010	Australia	Qualitative research based on officials’ views showed no consistent judgment about the net costs of self-directed funding. Some cost concerns related to implementation of a new system, rather than to ongoing costs.
Kerr et al. 2009	Australia	Small-scale quantitative study of TAC clients paying family members for attendant care (*not* self-directed funding as a whole). The study found much lower use of group homes among people paying family members, but overall costs of claimants paying family carers were greater

[a] Cost relate to those borne by government, and not any contributions by people with disability and their families (for example, through non-reimbursed administrative costs). Some studies did not examine the annual ongoing costs of self-directed funding, but rather the implementation and support costs of self-directed funding for people with disability and their families. By their nature, these costs are greater than related expenditures for traditional agency-based care, but they do not indicate the net cost outcomes.

Some studies have probed why cost reductions are realised. In one Michigan study, which found a 16 per cent cost saving from self-directed funding , the anecdotal evidence suggested this reflected that people:

- were not compelled by outside parties, such as a specialist provider or professionals, to use unwanted services. (This was a point also made in this inquiry by the Julia Farr Association, which argued that under self-directed funding people 'stop buying the wrong things'; sub. 494, p. 67.)

- chose supports that matched their needs better
- negotiated lower prices.
- hired their own staff, taking responsibility for the administrative costs themselves, lowering budgeted costs per hour (Head and Conroy 2005).

In this inquiry, several participants indicated that flexible employment arrangements under self-directed funding would often entail lower costs and better quality than traditional agency-based approaches:

> … there's something called Commonwealth Emergency Respite Service, or something. My son wakes repeatedly through the night, I get to the point from time to time where I can't go on. .... They got on to an agency who sent someone [at a cost of] $897.40… That is absurd. You could give me $160 directly and I could employ someone, instead of the … person who turned up from the agency who couldn't even speak English, who couldn't understand my son, who my son couldn't understand, and who ended up having to wake me five times in the night to tell him what my son was saying. So the inefficiencies are just boundless (Ms O'Reilly, trans. p. 878)

> Experience in WA, where several thousand people with disability and their families have had ongoing access to Individualised Funding (ranging from several hundreds to tens of thousands of dollars per year) are more proficient than formal services providers (government and non-government) in procuring needed services in an efficient and cost-effective manner. They see the Individualised Funding they receive as a finite and precious resource and are loathe to spend it wastefully. (My Place, sub. 217, p. 7)

While not always measured, some studies also identified savings in the health system from self-directed funding. As an illustration, in one US study, people with major spinal cord injuries using self-directed funding had fewer re-hospitalisations and diminished preventable complications because of the better quality of personal care (Prince et al. 1995). (High quality home care can avoid bedsores that lead to hospitalisation.) Other studies have corroborated savings in health care (Beatty, Adams and O'Day 1998; Kim et al. 2006).

Another reason for the promising cost results is that governments have often designed self-directed funding schemes to be at least cost neutral and sometimes to save costs. In the United States, the Office of management and Budget has required that the Medicaid-waiver trials of self-directed funding be budget-neutral to the federal government (Doty et al. 2007). In Germany, *Cash Allowance for Care* payments to families are 50 per cent of the amount that would be used to fund agency-based services, but still had very high take-up rates (Arntz and Thomsen 2010 and Lundsgaard 2005).[13]

There may be some potential offsetting costs associated with self-directed funding, to the extent that the exodus of clients from traditional specialist disability services adversely affects non-users. Some have conjectured that the scale-economies of traditional services may be lost, leading to higher costs in these services, or even their closure (Lyon 2005, Land and Himmelweit 2010, pp. 27–28). For instance, in Northumberland in the United Kingdom, the council decided to close seven day-care centres, citing underuse linked to the introduction of personal budgets.

However, scale economies within an enterprise are not a benefit in their own right, but one of a variety of considerations underlying the costs and attractiveness of an enterprise to consumers. Market structures reflect the tradeoffs people make between proximity, flexibility, price and other aspects of services. That some enterprises may relinquish some economies of scale or close when exit barriers to new (micro) entrants are relaxed suggests that the optimum scale in personal services may often be smaller. The fact that some consumers lose from removing an industry's barriers to entry is not a convincing policy argument against self-directed funding.

Moreover, the most important function of specialist disability services is the provision of accessible attendant care in local areas, which limits the potential for scale economies. The most important source of economies of scale in specialist disability services are likely to arise because larger suppliers can spread the fixed costs of regulatory burdens over a greater client base (and more diverse services), and as they have more scope to provide services during awkward times. That said, micro-suppliers — friends, neighbours and family members — are ideally placed to provide the latter flexible service, despite being single employee 'enterprises'. In any case, the available Australian evidence suggests that, all other things being equal, there are limited differences in the costs of large versus small disability services (Fisher et al. 2009). In addition, given the evidence on the likely take-up of self-directed funding and that a new disability system will address the current

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[13] The detailed design matters. In Germany, people could choose between cash benefits (cash benefits (Pflegegeld) and agency services (Sachleistung), with the cash-equivalent entitlement of the latter double that of the former. In recent years, Germany has trialed an intermediate form of budget, the so-called personal budget (Pflegebudget), which allows people to have the same budget as the Sachleistung, but with more flexibility. Given the flexibility of the Pflegebudget, this raised cost pressures because people shifted from Pflegegeld to the Pflegebudget. (Arntz, M. & Thomsen, S. 2010, 'The social long-term care insurance: a frail pillar of the German social insurance system', Forum, CESifo, DICE Report, 2/1010, p. 29–34).

significant shortfall in disability funding, most service providers are unlikely to contract by much, if at all.

E.4 Impacts on disability support and other workers

As noted in chapter 15, there are shortages of specialist disability workers, with these expected to grow strongly over the next 50 years. Self-directed funding and personal planning may at least partly address these shortages by:

- drawing the so-called 'grey' market of family, friends and neighbours into the pool of people who can provide support services to people (Kodner 2003, p. 2), reflecting the relatively simple character of many disability services. The US Cash and Counseling Trials showed that the capacity to pay family members appeared to have alleviated a shortage of agency workers, particularly in one of the trial states experiencing the most labour market pressures (Kemper 2007, p. 580). The issue of whether families *should* be paid is discussed in chapter 8.
- reducing the number of administrators responsible for contracting and managing frontline workers by shifting that responsibility to people with disability and their families
- shifting away from specialist services (for example, an outing organised by a specialist day care centre) to mainstream services (for example, joining a local scouts group or a gym).

Impacts on existing employees in social care

There are varying views about the impacts of self-directed funding on support workers and case managers.

Some identify problems

Some commentators see risks of low pay, disenfranchisement and abuse for personal assistants (those providing daily care needs for people with disability).

As an illustration, the Liquor, Hospitality and Miscellaneous Union in Western Australia indicated that given their employment status, people engaged as 'domestics' under self-directed funding failed to get certain protections under the industrial relations legislation in that state, and were often not eligible for superannuation contributions. They also pointed to instances where people were paid at rates well below the standard wage rate in the disability sector and indeed, below the minimum wage (trans., p. 888).

Similar concerns emerged in the United Kingdom. A detailed report prepared for the public service union, UNISON (Land and Himmelweit 2010), considered there were some benefits from personalisation for people with disability, but identified some particular problems for support workers. Using secondary sources, they found evidence that workers employed under self-directed funding were paid less, had few training opportunities, lacked job security, lacked knowledge about where to turn to if the relationship with the person with disability becomes difficult, and had a poor knowledge of their rights (in part reflecting that many workers were newly arrived migrants). They argued that:

> Some of the benefits claimed for being a direct payment holder sound like those of a 19th-century factory owner, able to hire and fire at will, secure complete working time flexibility and avoid health and safety risk assessments which other employers have to adopt. (p. 52)

Others argued that people with disability have greater power over personal assistants under self-directed funding than they would under agency-based arrangements (such as an easy ‘hire and fire’ capacity), and that unions could play a useful role in restoring a balance in that power (Leece 2010, Mickel 2009a,b).

The evidence for claims about some of these matters is often not clear. For instance, while a significant body of UK evidence has drawn attention to the potential for lower wages and some other adverse consequences for people employed under self-directed funding, the results are often ambiguous or likely to be unreliable:

- A major survey assessment of the effects on employees of direct payments in the UK found employees perceived some negatives (Adams and Godwin 2008). This included too many hours, endorsed strongly by 5 percent of employees and slightly by 13 per cent and insufficient rates of pay (endorsed strongly by around one in ten employees, and slightly by a further 20 per cent). However, it is not clear whether the latter is a reliable indication of low pay per se, since many people in any industry believe they are underpaid. There were also perceived concerns about the adequacy of training (such as handling medication). On the other hand, the survey found that the ‘vast majority’ of workers hired through self-directed funding were happy in their current working role, with around two-thirds ‘very happy, and around 30 per cent ‘quite happy’. Around 90 per cent felt appreciated by the client most of the time or frequently. Only 6 per cent wished they had a different job to the one they had. Nevertheless, a major methodological caveat about this study is that it relates to the perceived gross impacts of self-directed funding on employees, but not its effects relative to traditional agency-based service models. So, while the study suggests concerns about low pay (but good employment experiences) under self-directed funding, it does not reveal whether they are better or worse than arrangements outside self-directed funding

- Another study found that local authorities tended to fund hiring of workers under self-direction at a lower rate than when services were block funded through agencies. (Frontier Economics 2006, p. 59). However, it is not clear how much this difference is reflected in the actual take home pay of employees, since block funded agencies must receive a premium to meet their overhead costs. Moreover, many of the employees were friends, neighbours or relatives, which may not be the appropriate comparison group to agency staff. The study was also only based on information from ten authorities, of which five paid lesser amounts to people employed under self-directed funding, three paid the same rates and two paid more — so the pattern of 'low' payment is not consistent
- A further study found average wages of £5.16 among people employed under direct payments (which includes friends) and £6.14 for those employed by agencies (Leece 2010).[14] This tends to substantiate a significant wage differential. The study also found that, notwithstanding lower pay rates, those employed under self-directed funding had higher levels of job satisfaction and lower stress. That said, these findings relate to a tiny and unrepresentative group of respondents (eight white employees in each employment category, providing services to those with a physical disability), which is too small to reach reliable inferences about the large population of personal assistants
- A much larger survey (Davey et al. 2007, pp. 61–2) considered the potential wages of people employed under direct payments compared with those employed by agencies. UK local authorities determine direct payments by multiplying the entitlement for hours for personal assistants by an hourly rate. That hourly rate includes amounts to meet the typical statutory obligations of employers, such as national insurance and tax payments. However, in any actual employment contract, a consumer may not need to make these deductions if their employees work below the threshold of hours that trigger these obligations. If a consumer was entitled to a 37 hour weekly package and employed a single assistant for that time, the full statutory obligations would apply, and the potential wage that could be paid would be below the agency rate (albeit by only 2 per cent). However, were consumers to receive the average care package

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[14] This study (Leece, J. 2010, 'Paying the piper and calling the tune: power and the direct payment relationship', *British Journal of Social Work*, vol. 40, pp. 188–206.) has been seen as an important source of information about relative wages, and has been cited by several commentators troubled about pay conditions under self-directed funding, such as Land and Himmelweight (2010) in a paper prepared for the union covering attendant care workers (UNISON) and Mickel (2009).

(typically not involving an entitlement to many hours of assistance), they would be able to offer salaries exceeding the average wage for agency workers.

Other concerns have been raised about the implications of self-directed funding for professionals in the disability sector. For instance, in the UK, some care coordinators thought that the mechanical self-assessment process used by some local authorities under individual budgets (IBs) had automated and undermined their role (Glendinning et al, 2008, pp. 188–189).

Others have found positive, or at least no negative overall impacts

In general, the best empirical evidence suggests that fears about the overall wellbeing of employees are misplaced.

For instance, in the UK, while Glendinning et al. (2008) found some perceptions of negative outcomes for care coordinators (as cited above), other coordinators considered that IBs had revived the skills of social work because of the closer tailoring of services to the individual. A formal analysis of the impacts of IBs on care coordinators using the Karasek Job Content Questionnaire found no substantive or statistically significant difference between those working with IB users and those not. The only exception was that care coordinators working with IB clients had better customer relations (p. 191). Overall job satisfaction was slightly higher for IB care coordinators than non-IB coordinators, but the difference was not statistically significant.

Given its 'treatment-control' experimental design and large samples, the experiences in the US *In-Home Supportive Services* (IHSS) program and the *Cash and Counseling* (C&C) program are likely to provide the most reliable indication of the incremental effects of self-directed funding on employees than most other studies (Benjamin and Mathias 2004; Dale et al. 2005 and Foster et al. 2007).

In the IHSS program in California, wages of non-family members employed under self-directed funding were significantly lower than those for agency workers (a gap of 23 per cent), but in general there were no significant differences in the satisfaction of employees in the two systems (Benjamin and Mathias 2004, p. 483).

In the first period of the Arkansas C&C demonstration, the only significant differences between unrelated people employed under self-directed funding and agency workers was *greater* satisfaction with wages and benefits and the tendency to provide unpaid hours (Dale et al. 2004, p. 590). There were no significant differences in worker welfare.

The most comprehensive study, encompassing all three states in the C&C demonstration and covering a longer period than Dale et al. (2005), found generally positive outcomes for consumer-directed employees. Considering only workers who were unrelated to the person with disability, the results suggest that compared with agency workers, hourly wages were higher (by around 15 per cent across the three states); people were much more satisfied with the wages they got (42.5 per cent compared with 21.3 per cent); and they had equivalent satisfaction with working conditions. People employed under self-directed funding tended to work more unpaid hours (seven hours a week compared with two for agency workers), but clearly without this affecting their positive attitude to their employment conditions. Nearly 30 per cent of people employed under self-directed funding did not receive personal care training compared with only 4 per cent of agency workers, but a greater share of those employed under self-directed funding felt well informed about care needs (casting doubt about the actual returns from the training provided to agency workers). As in the other US studies, worker well-being was much the same in the two different employment forms and there was no higher incidence of adverse events or health problems for them.

There is little Australian evidence on the impacts of self-directed funding on employees. However, the evaluation of the NSW Attendant Care (Direct Funding) pilot found that:

> All direct funding participants report an increase in attendant carer satisfaction. They state that attendant carers are happier for reasons discussed above, including pay and conditions and the quality of the relationship. (Fisher and Campbell-McLean 2008, p. 29)

There is, therefore, little systematic evidence of low wages, but reasonably good evidence that wellbeing of employees is typically better, or at least no worse. In that context, even were pay rates lower, that may not be problematic as the outcomes for people with disability and employees are positive.

As discussed in chapter 8 that does not mean that policies should ignore the risks for employees associated with self-directed funding.

Impacts on service providers

As noted by many participants in this inquiry, self-directed funding will have some effects on service providers.[15] It removes some of the certainty that block funding provides and provides people with a greater capacity to shift between service providers (including to mainstream services or to workers employed directly by the

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[15] For example, Northcott Disability Services (sub. 376, p. 14–15).

person). It can also require new administrative arrangements and systems for suppliers, with the transitional costs that these involve.

On the other hand, it can also entail new market opportunities for innovative service providers and the creation of new types of agencies, such as brokering services or intermediaries that take responsibility for the administrative aspects of self-directed funding on behalf of a consumer. In that sense, there should not be a presumption that service providers are hostile to self-directed funding. Many recognise its value (for example, Held and Ottmann 2008). Laragy (sub. 84, p. 5) noted that there will inevitably a process of sorting between agencies able to flourish in the new environment and those who are not:

> Service systems have to change radically, including financial systems which were not designed to provide individual accounts. It seems likely that some established agencies will adjust and flourish while others will disappear.

The extent of structural change in the sector will be limited by the likelihood that many people will continue to purchase all of their services from a single supplier because they are happy with their service quality and because the intangible costs of complete self-directed care are considerable (such as hiring workers). The overseas experiences discussed above support this contention. It is also notable that service provision in Western Australia does not appear to be in crisis, despite the absence of block funding in that state.

In any case, in most markets it is recognised that an industry exists to meet the needs of its consumers, not its own interests, and so the key issue for self-directed funding are its impacts on people with disability, not on suppliers per se (a point made by Adam Johnston, sub. 55). If anything, the imperative to meet the need of the client is greater in disability services, given their relative poverty and vulnerability, and their current lack of empowerment. A strong rationale would be needed to give pre-eminence to the interests of suppliers *where these did not match those of people with disability*.

We examine the effects of self-directed funding on service provision and the policy implications of these in greater detail in chapter 8.

E.5 The links of self-directed funding to person-centred planning

Person-centred planning (PCP) is a collaborative process that helps people with disability to outline their needs and life goals as the basis for support, rather than the professional judgments of specialist providers. PCP is typically an essential component of self-directed funding, though it is possible to have one without the other. For example, a person may collaboratively formulate a life plan, but a service provider may ultimately determine which elements to implement (unlike direct payments). PCP is relevant to the issue of the power of people with disability in two ways:

- The close association of PCP with self-directed funding complicates the assessment of the effectiveness of self-directed funding
- It gives people with disability some power in its own right, as it increases the extent to which decisions about support are influenced by individual preferences.

The evidence on PCP is less developed and sophisticated than that relating to self-directed funding. The most elaborate and quantitative study of its impacts (Robertson et al. 2005) noted that:

> … very few studies have been reported that sought to formally evaluate the impact or outcomes associated with PCP. … research evaluating quality of life outcomes as a result of PCP have tended to employ qualitative research designs. … they cannot be accepted as credible evidence of either efficacy or effectiveness.

Nevertheless, some quantitative evidence favours large benefits from PCP. The Robertson study was a detailed two year longitudinal study of PCP in the UK, involving 93 people with intellectual disability. The study found many benefits including a:

- 52 per cent increase in size of social networks
- 2.4 times greater chance of having active contact with family and a member of family in their social network
- 40 per cent increase in level of contact with friends
- 35 per cent increase in the number of activities and a 24per cent increase in their variety, as measured by the extended version of the Index of Community Involvement (ICI)
- 33 per cent increase in hours per week of scheduled day activities
- 2.8 times greater chance of having more choice.

There was no statistically or economically significant increase in the costs of support to achieve these outcomes. There were however increased problems with hyperactivity as measured by scores on the Strengths and Difficulties Questionnaire hyperactivity subscale, and a 1.5 times greater likelihood of greater perceived risk to be at risk in or out of the home or from traffic (unlike the findings for self-directed funding more generally).

A US longitudinal study examined outcomes for 20 people with intellectual disability using PCP and a matched group of 18 receiving traditional service planning (Holburn et al. 2004). 95 per cent of the person-centred planning participants moved to community living arrangements, compared with just under 30 per cent of the control group. Outcomes were superior for the PCP group, including improvements in autonomy, choice-making, daily activities, relationships, and satisfaction.

Overall, the evidence (as limited as it is) implies that PCP is likely to be one contributor to the success of self-directed funding, suggesting that PCP should be a key aspect of implementing self-directed funding.