

THE UNIVERSITY OF
NEW SOUTH WALES



*ATTENDANT CARE DIRECT FUNDING PILOT
PROJECT EVALUATION*

INTERIM REPORT

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Contents

1	Background	1
1.1	Evaluation Progress	2
2	Participant Outcomes	3
2.1	Characteristics of the Participants.....	3
2.2	Outcomes	4
	Health and wellbeing	5
	Confidence and self-esteem	7
	Family and friends relationships	8
	Community, social and economic participation	9
3	Governance	11
3.1	DADHC Support.....	11
	Payment from DADHC.....	11
3.2	Transition to Direct Funding.....	11
3.3	Implementation	11
	Taxation	12
	Insurance and occupational health and safety	12
3.4	Accountability Requirements.....	12
4	Care Arrangements	13
4.1	Reasons for Choosing Direct Funding	13
	Information about direct funding	13
	Reasons for changing to direct funding	13
	Expectations before and during entering direct funding	14
	Comparison group views about direct funding	14
4.2	Support Received through ACP.....	14
	Types of assistance	15
	Choosing the provider.....	15
4.3	Comparison to Support Received Prior to ACP.....	16
4.4	Quality of Care.....	16
	Reliability, flexibility and choice.....	16
	Satisfaction with the support.....	17
4.5	Management of Attendant Carers	18
	Recruitment and retention of attendant carers.....	19
	Payment and conditions	20
	Support and training.....	21
	Attendant carer satisfaction.....	22
	Problem solving	22
5	Direct Funding Service System	24
5.1	Effective Use of Resources.....	24
	Financial management	24
	Efficiencies in administrative and overhead costs	24
5.2	Impact on ACP Providers and Clients	24
6	Implications for Policy	25
6.1	Continuation of the Pilot.....	25
6.2	Client Capacity	25
7	Conclusion	26
	Appendix A: Methodology	27
	Individual clients.....	27
	References	29

List of tables and figures

Table 2.1: Profile of Participants	3
Table 2.2: Personal Wellbeing Index.....	5
Table 2.3: Health and Wellbeing	6
Table 2.4: Satisfaction with Physical and Mental Health.....	6
Table 4.1: Attendant Care Program Support Profile.....	15
Figure A.1: Evaluation Conceptual Approach.....	27
Table A.1: Samples.....	28

Abbreviations and glossary

ACP	Attendant Care Program
ACP models	Cooperative model – the client is the attendant carers’ employer; the service provider provides administrative and management support. Funds are paid to the service provider and the service provider is accountable to DADHC for the management of funds and reporting. Employer model – the service provider is the attendant carers’ employer; in some organisations, clients can chose to participate in some attendant carer management decisions, such as recruitment. Funds are paid to the service provider and the service provider is accountable to DADHC for the management of funds and reporting. Direct funding – the client is responsible for all attendant carer employment and management decisions. Funds are paid directly to the clients and they are accountable to DADHC for the management of funds and reporting.
CALD	Culturally and linguistically diverse
DADHC	Department of Ageing, Disability and Home Care
GST	Goods and Services Tax
HACC	Home and Community Care
OH&S	Occupational health and safety
PADP	Program of Appliances for Disabled People
PAYG	Pay As You Go
PWI	Personal Wellbeing Index
SMA	Spinal Muscular Atrophy

1 Background

The Department of Ageing, Disability and Home Care (DADHC) is piloting a direct funding project in conjunction with the Attendant Care Program (ACP). The direct funding pilot aims to complement the objectives of the ACP, which provides support to individuals with physical disabilities with a range of tasks and activities to allow them to live and participate in their communities. ACP is funded under the Commonwealth State and Territory Disability Agreement and administered by DADHC.

The report compares three types of ACP funding models, which differ in who employs the attendant carers, who receives the funding from DADHC and who is responsible for management and reporting:

- Cooperative model – the client is the attendant carers' employer; the service provider provides administrative and management support. Funds are paid to the service provider and the service provider is accountable to DADHC for the management of funds and reporting.
- Employer model – the service provider is the attendant carers' employer; in some organisations, clients can choose to participate in some attendant carer management decisions, such as recruitment. Funds are paid to the service provider and the service provider is accountable to DADHC for the management of funds and reporting.
- Direct funding – the client is responsible for all attendant carer employment and management. Funds are paid directly to the client, who is accountable to DADHC for the management of funds and reporting.

The pilot project is providing funds directly to a limited number of current ACP clients for the direct purchase of personal care services. This is intended to provide clients with greater control over the choice and management of the support they receive as well as to promote more flexible and responsive services for clients.

ACP direct funding is aimed at people with physical disabilities with high personal support needs, who have the capacity to directly manage administration of funding. Individuals in receipt of direct funding are responsible for all legal, financial and accountability requirements as well as potentially taking on employer responsibilities for attendant carers including recruitment, training and support; and financial management including wages, superannuation and insurance.

The pilot project builds on the development of similar programs in Australia and internationally and related research on the significance of client control for social inclusion and independence (Spandler 2004; Lord & Hutchinson 2003; Witcher et al 2000). In Western Australia and Queensland, direct funding is an element of local area coordination of services provided to individuals with disabilities and their families. Direct funding has also been developed as elements of disability support services in ACT and Victoria. Many other countries have also developed direct funding programs including England, Scotland, Canada and Sweden (Heggie 2005; Yoshida et al 2004).

Two contextual issues for the project relate to control and funding. The first issue is the commitment to preference for client control, participation and focus in service delivery, reflected in the Disability Services Standards (Hughes 2006; Spandler 2004; Pearson 2000; NCOSS 2006). The second contextual issue is the shortage of funds for attendant care (PDC 2006). This poses difficult policy and service delivery challenges about access, priorities and maximising efficiency.

1.1 Evaluation Progress

The Department commissioned the Social Policy Research Centre and Disability Studies and Research Institute to evaluate the pilot and explore outcomes for stakeholders in order to identify considerations for future funding options. Stakeholders of the pilot include the Government, ACP clients, paid carers and providers of disability support services and disability support groups. Considerations in the review include client outcomes, quality of care, costs, management and risks (Jacobsen 1997; Spandler 2004; Maglajlic et al 2000; Carmichael & Brown 2002). The evaluation plan is summarised in Fisher et al (2007).

The evaluation includes baseline measures April-June; follow-up measures October; and process, outcomes and economic analysis. Data collection is progressing well. To August 2007 data collection for the following activities has been conducted:

- baseline interviews with the people participating in the direct funding pilot (10);
- interviews with a comparison group of people using ACP (26);
- interviews with ACP service provider managers (2);
- progress presentations to the DADHC Disability Expert Advisory Group (2); and
- attendance at teleconference with ACP direct funding participants (1).

This report presents the progress from the data collection to date. It is not a full analysis of the results, which will be available in December 2007.

Section 2 of this report begins by describing the characteristics of the people in the direct funding pilot and a comparison group of people in the main part of ACP. It then presents and discusses the comparative outcomes for the people in the pilot, including changes since entering the pilot and comparison to the people using main program.

Section 3 discusses the governance arrangements for the pilot including support from DADHC, transition to direct funding, implementation and accountability requirements.

Section 4 presents evidence of changes in care arrangements compared to the main ACP and the impact on quality of care.

Section 5 and 6 introduce the topics that will be further discussed in the final report on the impact on the service system and implications for policy development.

2 Participant Outcomes

This section presents information about who is using the direct funding pilot, compared to a group of people in the main part of ACP. It also discusses the outcomes reported by the people in the pilot, in the domains of health and wellbeing; confidence and self-esteem; relationships with family and friends; and community, social and economic participation.

2.1 Characteristics of the Participants

Ten people are in the direct funding pilot. They are compared to a comparison group of 26 people who use ACP services and volunteered to contribute to the research. The report compares the ACP experiences of people in the ACP direct funding pilot and people using main program in the cooperative and employer models.

The people in the direct funding and comparison groups are similar, although they have some differences (sex, location and participation), which are discussed below. The ages of people in both groups are very similar, although the range is slightly narrower for the direct funding group (25-59 years direct funding; 20-65 years comparison; Table 2.1). The youngest person in the comparison group is most similar to the direct funding participants in terms of his expectations about the care needed and participation. He uses the ACP cooperative model. Some comparison participants were unaware that they can continue to access ACP after they turn 65 years.

Table 2.1: Profile of Participants

	Direct funding (10)	Comparison (26)
Age	25-59 years (range) 41 years (mean)	20-65 years (range) 51 years (mean)
Sex	20% women	69% women
Impairment	8 spinal injury 1 cerebral palsy 1 SMA*	15 spinal injury 2 cerebral palsy 1 SMA* 3 multiple sclerosis 2 spina bifida 3 other
Location	70% regional	46% regional
Cultural background	30% CALD**	8% CALD
Family and friends active support	100%	77%
Economic participation	90% paid work/study 10% retired	35% paid work/study 27% retired 38% not in paid work

Notes: *SMA – Spinal Muscular Atrophy

**CALD – Culturally and linguistically diverse

Only two direct funding participants are women, compared to 69 per cent of the comparison group (Table 2.1). This difference probably has implications for other differences between the groups, such as socio-economic circumstances.

The impairments of people in both groups were similar. Differences are that the comparison group included one person with a brain injury and three women had multiple sclerosis. These conditions are more likely to have an impact on their cognitive functioning and emotional wellbeing. All direct funding participants have family, friends or housemates who are active members in their lives. In contrast, 23 per cent of the comparison group did not have that level of informal support, and all of these people were women.

The biggest contrast between the intervention and comparison group is economic participation. All direct funding participants are employed or retired and were in this position when they entered the program. They are either professionals or business owners. In contrast, only 62 per cent of the comparison group participate in these activities. The groups also differ in their involvement in the community and social networks. In the comparison group, at least five people are significantly socially isolated.

These differences between the groups are taken into account in the interpretation of the findings below. For example, they probably have an impact on participation and wellbeing measures and on the funding and management model best suited to their needs.

2.2 Outcomes

The evaluation seeks to find out if direct funding pilot leads to increased wellbeing and enables them to maximise their participation in the community; and whether it leads to increased participant satisfaction levels. Respondents from both groups participated in an interview, which included discussion and standardised questions. The measurement tools are based on instruments used in the evaluation of similar programs nationally (Fisher et al, 2007). The purpose of this approach is to ensure validity and facilitate comparability to similar programs. This is particularly important given the small number of clients in the pilot. The outcomes measured include personal wellbeing (confidence, esteem, physical and mental health); social networks; community and economic participation. Outcomes are analysed by comparing data collected from people in the existing ACP arrangements; and normative data from similar programs and the validated instruments used in the data collection.

Preliminary results are positive. Participants reported improved outcomes in all domains, including satisfaction, participation and wellbeing. As well as discussing their quality of life, they each completed the Personal Wellbeing Index (PWI), an internationally validated instrument (IWG, 2005). These are very small samples so the results should be viewed cautiously. The baseline measure of PWI for direct funding participants is higher in all domains (Table 2.2).

Table 2.2: Personal Wellbeing Index

	Direct funding (10)		Comparison (26)		Australia
	mean	range	mean	range	mean
PWI	83	60-100	71	0-100	75.02
Life as a whole	82	70-100	69	30-100	77.63
Standard of living	79	70-100	75	30-100	77.28
Health as a whole	81	60-100	63	10-100	75.09
Achievements	83	60-100	71	10-100	74.19
Personal relationships	87	70-100	69	20-100	79.81
Safety	88	70-100	77	10-100	77.63
Feeling part of the community	83	60-100	72	0-100	70.52
Future security	81	60-100	72	10-100	70.49

Note: Personal Wellbeing Index (PWI). Scale 0-100 where 0=completely unsatisfied, 100=completely satisfied (IWG 2005)

The lowest score for direct funding participants in any domain is 60. In contrast, some comparison group participants had scores below 50 in all domains. On average, direct funding participants score higher than the Australian average across all domains, although some participants score below the mean. The comparison group means are mainly below the Australian average except in safety, feeling part of the community and future security.

The differences between the groups discussed in this section are probably at least partly due to the difference in their profiles (Table 2.1), rather than the affect of direct funding, ACP cooperative model or ACP employer model. That is, some people have chosen their ACP model because of the characteristics in their profile, rather than the model directly influencing some of these outcomes.

Health and wellbeing

Most of the direct funding participants stated that their health and wellbeing is very good or excellent (60 per cent; Table 2.3). In contrast, most of the comparison group participants felt their health is good or worse (73 per cent). The direct funding group are similar to the Australian population average (58.6 good or excellent; ABS 2006).

Table 2.3: Health and Wellbeing

	Direct funding (10)	Comparison (26)
Poor	-	1
Fair	1	6
Good	3	12
Very good	3	4
Excellent	3	3

Similarly, people in the direct funding group reported higher satisfaction with their physical and mental health than the comparison group (on a scale of 0-100, 76 and 93 for physical and mental health direct funding, compared to 67 and 77 for the comparison group; Table 2.4). The greatest difference is their level of satisfaction with their mental health, which is consistent with differences in confidence and self-esteem discussed below. From their comments, the comparison group participants' quality of health and wellbeing can be grouped in to generally well, some problems and many problems, discussed below.

Table 2.4: Satisfaction with Physical and Mental Health

	Direct funding (10)		Comparison (26)	
	Mean	range	mean	range
Physical health	76	50-100	67	20-100
Mental health	93	80-100	77	30-100

Note: Scale 0-100 where 0=completely unsatisfied, 100=completely satisfied (IWG 2005)

The participants' comments about their health and wellbeing are consistent with these scores. This difference between the groups might also have been their experience before direct funding. However, the direct funding group comments below about the impact of improved quality of care from the direct funding pilot on their health and wellbeing supports the assumption that these higher scores are at least partly due to the control they have from direct funding.

All direct funding participants noted decreased levels of stress. Reasons they discussed were they are not dealing with inflexible service providers. In addition, they reported that they have less conflict with the attendant carers and providers; better attendant carers and quality of care, control of OH&S management; and direct management of attendant carers concerns about pay, conditions and relationships between the attendant carer and the provider. The attendant carers are more reliable, providing better continuity of care. The impact is the participants are less likely to use agency attendant carers so the quality of care is higher. Some comparison participants discussed having the benefit of similar arrangements. They were mainly in the cooperative model. However, some comparison participants in the ACP employer model expressed stress related to poor care arrangements from unresponsive service providers. These problems are discussed later in the report.

Comparison group people who had good health and wellbeing mentioned ACP assisting their mental health, 'I would be insane if I didn't have attendant care.' A number said that ACP had removed their worry about moving into a nursing home.

Nutrition, bladder, bowel management and pressure care have all improved because of the improved quality of care provided through direct funding. One participant said, 'I have experienced a big difference to my control and flexibility in care. For example, bowel problems and infections have decreased.' Another participant said 'Direct funding has had a great impact on my quality of life. My stress levels have reduced significantly and I can sleep better at night.' People in both groups said they used attendant care to do physical exercise.

At least three direct funding participants discussed improvements to pain management. The attendant carers are now more likely to understand their individual needs in relation to managing their pain and comfort. Some comparison participants agreed that pain management is improved when they have a small number of attendant carers providing consistent care.

One comparison participant said attendant care facilitated her access to dental care. Others commented on having regular meals. However, other comparison participants in the ACP employer model commented on the negative impact on their physical and mental health of restrictions in ACP arrangements, such as attendant carers not permitted to do stoma care; patronising attitudes from attendant carers; and fear of retribution if they raise problems with the ACP provider.

Participants in both groups spoke of their experiences of abuse (financial, verbal and physical threats) when they received ACP in the employer model because of poor quality attendant carers. People using the ACP cooperative model and direct funding participants during the pilot have not experienced any abuse.

Confidence and self-esteem

All ten direct funding participants expressed a feeling of empowerment and self reliance, knowing that full control and management is in the client's own hands so they have a vested interest in getting things right. For example they discussed ensuring attendant carers are paid correctly, and feeling an equal and respected partner in the care arrangements. One participant noted that, 'Having had a catastrophic injury, being able to manage your own care increases your confidence and life skills.' In contrast, a comparison person wanted to re-enter the workforce but did not have the confidence to do so yet after her injury.

Direct funding participants said they have more control over their care and therefore over their own lives. One participant said,

... direct funding gives control, flexibility and independence, which in turn creates something in yourself ... hope ... I know my care arrangements are ok and I am not afraid to accept jobs. This has enabled me to build my own consultancy business.

Another person concluded, 'Don't stop the program. It would be a tragedy. It's empowering me and letting me really live my life.'

Comparison participants also commented that having attendant care maximises their independence, choice and gives them an option away from institutional care or less flexible personal care services. They have the confidence to take on more activities and make more social and work arrangements. However, one comparison group participant using the ACP employer model said,

I feel I should be in control of my own care ... I feel very disempowered by the service providers. I feel kept in the dark to make my own decisions because there is no information. It is not clear what I can use the service on.

Family and friends relationships

All direct funding participants have family and friends active in their lives, compared to 77 per cent of the comparison group (Table 2.1). Their satisfaction with their personal relationships is also higher (average satisfaction score of 87 compared to 69 in the comparison group; Table 2.2).

Direct funding participants reported that family relationships have improved since entering the pilot. Attendant carers are in the home of the whole family. Having consistent attendant carers has enhanced the relationship with family members. This is both between the attendant carers and the family and also between the participant and their family members. They said that when care arrangements are working well, they place less strain on the family to perform the tasks of daily living. This is in contrast to both their previous experience and the family arrangements and family breakdown reported by some of the comparison participants.

By changing the caring responsibility of family members, direct funding has improved the quality of their time together. Some comparison participants have the same benefit. One participant said,

Direct funding has had a huge impact on stress for me. I don't get that sinking feeling ... there is less strain on family and friends who don't have to pick up the pieces.

One direct funding participant commented that his four-year old son has been positively affected by improved consistency of attendant carers. He had previously used a HACC provider and said, 'My son was scared not knowing who would come into our home.' Another person said,

There is an issue of privacy. It is really important to have control of who comes in your house, which has a direct impact on your relationships and family life.

Direct funding participants' relationships with friends have also improved because the care is more flexible in time and place. For example, the attendant carer might provide the care at a friend's home or at later hours of the night. Comparison group people who have active relationships tend to be the ones who reported satisfaction with their level of control and flexibility.

Community, social and economic participation

All the direct funding participants are in paid employment, study or active retirement. Occupations include solicitors, doctor, business owners, artist, IT consultant, university study and government. They were in these positions when they entered the program. Direct funding has enabled them to enhance their capacity to participate, for example, travel nationally for their business and attend university lectures. For example, one person is able to work longer hours at the office by employing an attendant carer who also has office duties. One person is gradually increasing his work, 'Since being on the direct finding pilot, I have contacted Spinal Cord Injuries [Australia] looking for further employment options.' He is building up his consultancy work successfully.

Occupations of comparison group participants are similarly skilled, such as business owners, active retirement, government, graphic design, counsellor and studying. Attendant care had facilitated one comparison person to start university. One comparison participant who had used ACP since he was a teenager said, 'Attendant care has allowed me to have a life, not be in an institution and go from studying, to employment, to being self-employed.' Another said, 'I wouldn't give it up for anything; it is unbelievably unique. If I didn't have AC, I wouldn't have achieved what I have in my life.' In fact, he had moved states to retain access to the program. Thirty eight per cent of the comparison group were not engaged in active participation. The direct funding group on average are younger (41 years) compared to the comparison group (51 years), which probably affects their participation in paid employment and study.

The two groups are in different socio-economic circumstances (Table 2.1), which probably affects these outcomes more than the impact of the direct funding pilot. This difference is also reflected in their satisfaction with future security scores (81 compared to 72). Direct funding participants are mostly in paid employment. Few of them spoke about their financial constraints affecting their participation. They did however talk about the cost of disability, for example, purchasing equipment and problems accessing PADP because they are working. Participation of some comparison group participants is also affected by cost of living because they are not in paid employment.

The direct funding participants all report that the benefits of managing their own care have contributed to their lifestyle and participation in community life. They have higher satisfaction scores with feeling part of the community (83 compared to 72; Table 2.2). A number of direct funding participants, who have significant physical support needs, have reported they are going out more regularly, with their attendant carer accompanying them. People in both groups commented that ACP enables them to participate in local community groups, including management committees and recreational pursuits.

Some of the comparison group are very socially isolated and unhappy about it. They said that they would like more support to access the community. For example, they made the following comments, 'I am a loner'; '... its not much fun being a quadriplegic.' 'I would really like to be working'. '... don't go out much a personal choice, I would like to get out more trying to get part time work – I was doing work at AQA but that ran out.' '... never employed but would like to work.'

Access to transport has meant the direct funding participants are more active in the community and doing more with their friends and family. For example, they talked about socialising at night and attending university commitments. It has also helped them travel for work, study, holidays and to visit family in other regions of the state. The attendant carer is able to drive them. This is especially important in regional areas where taxis are not available at night. They have peace of mind knowing they can get back home when they are ready, and they will not be late for their attendant carer. Some comparison participants said they are restricted in ability to travel with their attendant carer nationally and internationally. Other people are clearer about their entitlements and their provider is responsive.

This discussion has two implications about the relationship between direct funding and participation. First, the direct funding participants probably have different characteristics to some people in the comparison group, in terms of employment, social networks and socio-economic circumstances that are independent of the pilot. Second, a number of people in the comparison group identified that if they had the opportunity to use a direct funding type program, they could become more engaged in their community and be more socially active. They reflected that they would welcome such an opportunity to improve their quality of life by improving the control over their care. Their opinions about the circumstances in which they would or would not make that choice to use direct funding are further discussed in Section 4.

3 Governance

The second set of questions for the evaluation is to review whether appropriate and effective governance arrangements are in place to support the establishment and ongoing development of the pilot. Direct funding participants are satisfied with the governance arrangements. Other ACP service providers said the arrangements have not had any impact on their normal operations. The evaluation activities for the final report will include the experience of attendant carers and government officials.

3.1 DADHC Support

All participants are satisfied with the support provided by DADHC, both with the communication with the project officer responsible and the system support that responds to new questions as they arise. They find the internet forum and teleconferences useful. The internet forum might be improved through using a moderator, one participant noted. They noted improvements in the support process as the pilot has progressed, such as initial late payments to some participants as processes were established.

Payment from DADHC

They were happy with the pay arrangements from DADHC, after the delay in the first payments was sorted. The pay is through direct payment into an account. They raised questions about what the payments could cover, for example hiring a hoist for travel, or paying to repair a hoist. They said specific questions like this were sorted out by DADHC as they arise. They were pleased that setup costs and overheads were included.

3.2 Transition to Direct Funding

Most participants experienced a smooth transition from the main ACP to the direct funding pilot. Some people had problems about retrieving and transferring payment for accrued hours before they entered the pilot, where their ACP provider had not kept full records. DADHC is following this up more generally for all ACP models because some providers were failing in their record keeping. It was a reason a number of the participants reported joining the pilot. They commented that if the pilot ends, questions about accrued funds will need to be similarly resolved.

Direct funding participants are interested in exploring whether there should be the option for training and development for participants on administrative responsibilities and managing attendant carers. They see this as a way for others to take advantage of the direct funding model. One person suggested that DADHC could arrange mentors to help new participants transition from ACP to direct funding.

3.3 Implementation

Most participants did not report ongoing difficulty with financial management, tax, superannuation and pay, once they established the appropriate systems. A number of participants are contracting a bookkeeper or administrator to process the payrolls. Some participants are processing the payments themselves through MYOB software or another payroll system.

Taxation

Taxation questions have been resolved, including:

- direct funding does not count as income for the purpose of taxable income or eligibility for income assistance and other forms of support, such as PADP;
- participants pay PAYG and superannuation for the attendant carer; and
- participants are not a business so they cannot claim the GST.

Insurance and occupational health and safety

All participants have taken out insurance coverage as necessary for the caring and employment, for example, domestic workers compensation. All direct funding participants commented that this was reasonable in price (\$27.50 - \$80 per year) and easily arranged. They have established occupational health and safety systems (Section 4.5).

The participants and DADHC are still resolving access to appropriate insurance for client or staff injury. DADHC is investigating legal options to insure against injury to clients caused by their attendant carer.

3.4 Accountability Requirements

Accountability is required through monthly reporting from the participants. This enables analysis of cost variation per participant. Some participants experienced difficulty aligning the monthly report with fortnightly attendant carer pay but these problems are resolved. The final evaluation report will analyse the financial outcomes of the pilot, including the range of participants' experience with managing their care hours, expenses and reporting.

4 Care Arrangements

The interim conclusion from the participants is that the pilot offers greater choice and flexibility of services compared to funding arrangements in either of the existing ACP cooperative or employer models. This section discusses the findings from the participants and contrasts it with their experience before entering the pilot and the experiences of the comparison group. One participant said, 'Direct funding is the best thing that ever happened to me.' Another said, 'There is so much difference. Dead set it has changed my life.' They explained that from direct funding they can build a better relationship with the attendant carers based on mutual trust and respect.

4.1 Reasons for Choosing Direct Funding

Information about direct funding

Some direct funding participants have used ACP for a number of years. They heard about it from a variety of sources. Some people were familiar with developments in ACP through their involvement in disability organisations, research and information. Others heard about the program by word of mouth, referral from interested organisations or direct contact with DADHC. In contrast, many of the comparison group people had not heard about the pilot or the expression of interest process.

The participants said the information provided by DADHC was sufficient. The timeframe between expressing interest and starting the pilot was much longer than they expected, while details were resolved. Detailed information was only available from DADHC central office rather than from the service providers or regional offices. The availability of emailed information and contact was helpful to them.

Reasons for changing to direct funding

All the participants said the primary reason for entering the pilot was that they saw it as a way to enhance their independence, flexibility and control over their life, hours, money and attendant carers conditions. One person reflected that she thought, 'It would be extremely good to have control over my own life.'

The participants who previously used the ACP employer model felt that before the pilot they were not getting the service they wanted from their service providers. They did not like the bureaucracy and felt they were not getting individualised support. They did not want to rely on a 'bureaucratic service provider' (eg. contact, poor support and attendant carers pay and conditions; Section 4.3). One participant described her previous experience as 'hell'. People spoke of their disappointment with the provider, such as lack of assistance with recruitment, as a reason for changing to an alternative model, more suited to their expectations and preferences.

A number of people said they had a high level of involvement anyway, so they might as well have full control. One participant said, 'I was doing all the work. The agency was just collecting the money and getting in the way.'

Two people previously used the cooperative model (Table 4.1). Their intention was to keep the same attendant carers and extend the control and flexibility available to them (eg. training, flexible contracts, freedom of choice of when and where care is provided and more direct relationship with attendant carers). They have experienced these benefits.

Expectations before and during entering direct funding

Before they entered the program a small number of participants were concerned about the risks of liability, insurance, tax, pensions and the scope of the program. They agreed that the program needed to be piloted to sort out the accountability and parameters of the program. Their experience of applying for the pilot was positive. The support from DADHC was thorough and responsive to all their questions. The information was clear and simple. The teleconference and internet forum was useful for clarifying details. The development took a long time. As it was new they were grateful that the details were sorted out before the program started.

Comparison group views about direct funding

Most comparison group participants had not heard of direct funding. Some people were very interested in it and they wanted to find out more information; for example, about responsibilities, financial information, reporting requirements and the experience and success of the pilot participants.

They saw potential benefits from the model and that it could be applied to their situation now and could resolve the problems they were having such as getting the attendant carers they wanted, cutting out the service provider, attracting quality and reliable attendant carers, providing customised training to suit their individual needs and improving pay rates. Some felt they are doing all the management of the care arrangements anyway (eg. rosters, timesheets, negotiation and on the job training) and the provider creates difficulties (eg. OH&S management and recording hours). Some felt that money is wasted in the provider bureaucracy and direct funding might free up some funds to improve pay and conditions for attendant carers, and thereby improve the quality of care. One comparison participant using the ACP employer model said,

Direct funding would be good because it could increase the rates of pay. Trying to cover weekends is horrific. But I don't want to do the paperwork and I would get a broker to do the admin.

Some people said they would not be bothered and did not have the skills to do the management, such as timesheets, payroll and paperwork. They commented that they do not have the time or want the financial responsibility. One said, 'I'd have no respect for the money, I'd just spend it and I wouldn't want the responsibility.' Other risks they thought could be liability, OH&S and tax. Some said their arrangements are good as they are so they would not change and they could not see much difference to their current arrangements. For example, one comparison participant using the ACP cooperative model said,

In terms of direct funding, I have considered it. I like and believe in the concept but the current demands on my time [being a small business owner] wouldn't allow it.

4.2 Support Received through ACP

Most people in both groups receive the maximum hours of support (34 hours plus one hour emergency care) (Table 4.1).

Table 4.1: Attendant Care Program Support Profile

	Direct funding (10)	Comparison (26)
Hours*		
Range	32-34	17-34
Mode	34	34
ACP model	Former	Current
Cooperative	2	12
Employer	8**	14

Notes: *plus one hour per week emergency
** including one person who entered ACP through the direct funding pilot

A higher proportion of the comparison group receive support from the cooperative model than the direct funding participants who formerly received support from that provider. This difference might affect the comments about care arrangements in this section. The comments about the care management experiences of the comparison group cooperative model clients are most similar to the direct funding participants' comments.

Types of assistance

All research participants receive personal care depending on their support needs. In addition, some people receive domestic assistance and cleaning, meal preparation, transport assistance, administration/organisation and shopping. Generally the types of assistance received are similar in both groups. The direct funding participants tend to have more flexibility to change the content and to respond to specific needs such as, employing the attendant carer to help them access education. Direct funding has allowed some participants to employ someone to drive them to work or study. One person also receives a small amount of HACC domestic assistance. All direct funding participants have family members who provide additional support.

People in both groups raised the problem that they were unclear about the degree to which they can be flexible in defining which tasks are included in the categories of types of assistance. For example, some people are unclear about the guidelines on domestic assistance. Purchasing equipment is still a problem for some direct funding participants (3). They must still wait through PADP to purchase a hoist or more suitable wheelchair, or pay with their own savings.

Choosing the provider

Comparison group participants chose their provider based on their disability or their preference for control. For example, some people chose an ACP employer model provider because of the allied health knowledge of particular organisations. Some people chose the ACP cooperative model because it allows greatest choice for the participant. People who had used ACP for a long time did not discuss choosing the provider because fewer providers existed when they began.

Some people had changed providers, which is offered as part of the flexibility of the ACP to better meet their needs. Managers and officials reported that people usually

change providers due to an unresolved conflict or to move to a provider or ACP funding model that allows them to have greater or less involvement in managing their attendant carers. Some comparison group people had changed away from a HACC provider as their ACP provider. The reasons were control, flexibility of service and choice and involvement in staff selection. One comparison participant complained about their current ACP employer model provider, 'If I had a good agency, it would make me a hell of a lot happier.'

4.3 Comparison to Support Received Prior to ACP

Before receiving ACP, most people in the comparison group received HACC services. They changed from HACC providers because of the quality of care; they could not access sufficient hours under the HACC program; the program was inflexible; they had no choice in staff and times or input into staff management; untrained staff; poor professionalism; lack of confidentiality; and they experienced a lack of responsiveness to need for flexibility. One person had eleven HACC staff from one provider coming to his home each week. Another could not work because of unreliability,

[the HACC provider] couldn't guarantee the times they would come to get me out of bed, so I couldn't go to work and hold down a job because I wasn't guaranteed of getting there. (comparison group)

The impact of ACP is that it has allowed him to maintain a fulltime job.

Other people in the comparison group had moved from an institution before using ACP, where they had 24-hour care but were not happy to live in an institution (eg. rehabilitation ward, hospital or nursing home). One commented, 'If it wasn't for attendant care, I wouldn't be here. I'd have to go to a nursing home or group home.' Others concurred with this sentiment. ACP allowed one person to move into transitional accommodation, where she could learn independent living skills, after which she could move into public housing. Another could move into a shared house.

They each sought ACP support when they heard about it from professionals or other people with disability. One person had previously used a brokerage HACC provider but changed to ACP because the hours were insufficient when her condition changed.

4.4 Quality of Care

Direct funding participants reported improved quality of care because they have greater control over their choice of attendant carer, training and support for the attendant carer. This results in better quality care such as consistency. The attendant carers have compatible knowledge, skills and attributes to match the person's needs and preferences.

Reliability, flexibility and choice

All direct funding participants reported improved choice and flexibility. The exception was people who were previously using the cooperative model and already had higher opportunities for choice and flexibility. They also said they experienced improvements in reliability, flexibility and choice in care arrangements.

Participants reported that attendant carers are more reliable. This has a fundamental impact on their daily life because it can mean the difference between being on time for work, quality of physical care, being able to make arrangements and keep them and having a predictable routine. One person said,

If you are independent and flexible, your life can improve ... I have accepted some work as I know my care arrangements are ok and I'm not afraid to accept jobs.

The impact is that the relationships between attendant carers and participants have improved. They have built trust. They report more 'give and take' in the relationship because of that trust. Negotiating changes to usual routine can be done directly and without fuss. Examples given relate to social and work arrangements, such as social, exercise and travel arrangements. One participant said, 'The buck stops with me now. I have noticed subtle shifts in the way they respond to directions.' One person using the ACP cooperative model summarised the benefits,

The best things about direct funding are that you are an equal stakeholder, there are reduced costs, more client control, no middleman and less bureaucracy.

They reported improved choice and control over their care arrangements compared to before entering the pilot. An example is they can change and negotiate the care times if they have social or work arrangements. A comparison person also reported having this control already,

I feel I have more control over my day-to-day life. I think having my own staff who know me is important because of my communication issues. I am able to have personal care at work when I need it and I can choose the times I have support so I can get to work on time. Furthermore, I have the confidence in undertaking my Masters.

Satisfaction with the support

Direct funding and other clients had different levels of satisfaction with the support they received. All people using direct funding are overwhelmingly satisfied with their care. They reported improved consistency of care.

People from both groups reported that they need more hours, whether they are on maximum hours now or not. One person said you need more hours when you are sick or your needs change. Some people suggested that ACP needs to increase the maximum to 40 hours, particularly since more people with disability are ageing.

Several comparison people commented on the high quality of their attendant carers. One person who manages it herself in the ACP employer model, recruits her own attendant carers through word of mouth and advertisements; she uses the provider for training, records and equipment. She questions the bureaucracy of her provider. Another person who uses the ACP cooperative model is very pleased with her provider because 'they do not get involved unless you ask them to.'

In contrast, some people in the comparison group were very dissatisfied (25 per cent). Most people who were dissatisfied use the ACP employer model. The main dissatisfaction about the cooperative model was a lack of an emergency back-up system, discussed below. People who were dissatisfied had a number of problems, including with the quality of the support and the organisation of the support:

- quality – available hours; relationship with attendant carers such as respect, control and degree of assistance; few supported opportunities for control in choosing staff, no support in recruiting staff; poor quality training; quality of staff, such as untrained in physical care skills and unqualified staff; shortage of staff; frequent use of casuals; no differentiation of pay rates so some hours are uncovered; no guaranteed times; and
- organisation – accrual and recording of hours by the provider; responsiveness; communications; availability for contact and discussion with the provider; provider prioritising the attendant carer over the participant; flexibility; bureaucracy in OH&S and structure; reliability of pay to the attendant carer; insufficient coordinators to respond to quality problems; poor quality control systems; fear of litigation; and fear of retribution from the provider if make complaints.

The response by some people is to minimise contact with the provider and maximise their own control of the care arrangements (at least five people). One person expressed his frustration by saying ‘... [they] are putting that many rules on me that I might as well go back into an institution.’ It seems that systems to manage conflict are not effectively preventing the disintegration of some relationships between the client, attendant carers and providers. The service provider managers discussed the ways they actively invest in trying to prevent that breakdown.

Some comparison participants made suggestions to improve their satisfaction with care. They suggested accreditation of staff to improve the standard of care. Providers are currently accredited by the Department and have the responsibility to train staff. Several comparison participants using the cooperative model said they need an emergency back up service to replace staff when attendant carers are sick or shifts cannot be covered. Under the cooperative model this is the clients’ responsibility to arrange; in the employer model it is the service providers’ responsibility. One person suggested that processes to cope when an attendant carer fails to arrive need to be improved. Other people talked about already having this arrangement through their provider.

Some comparison participants commented that they need processes to share attendant care experiences with other clients. In addition, they could learn from each other about access to community activities and support.

4.5 Management of Attendant Carers

The relationship between the [attendant] carers and me has improved because they have direct contact with their boss. There is a smaller circle to deal with because we can cut out the middleman.
(Direct funding participant)

Direct funding participants report having more stable attendant carers, and therefore enhanced consistency of care. They can pay them more which results in better quality of attendant carers, more stability, and better relationships.

Recruitment and retention of attendant carers

Management of attendant carers requires arrangements for recruitment, training and retention of attendant carers. All participants are pleased with the improvements in managing attendant carers. They feel empowered and equal in the process because they have direct control over the management of the attendant carer. They report that recruitment can be quicker because the attendant carer can be available more immediately after the interview.

As ACP participants can only offer a total of 34 hours for their staff and they need a pool of staff, each staff only works a small number of hours. To secure quality attendant carers, being able to offer better rates and conditions, enables them to compete with providers and other employers. One direct funding participant said, 'If you are going to pay somebody \$19 for only 15 hours a week, they're not going to stick around long.' With the flexibility of direct funding, the participants can choose how much to pay each attendant carer to enhance the commitment and availability of staff. This is largely due to better pay and conditions.

Most of the direct funding participants have kept at least some, if not all, of their previous attendant carers. Other attendant carers they have recruited through advertisement (eg. university, newspaper and local hostels) and word of mouth. None had problems recruiting (some have not had to recruit). Some attendant carers resigned from their previous service provider because the conditions under direct funding were better and they wanted a direct relationship with the participant. Some of these attendant carers were looking for work elsewhere because they were dissatisfied with the conditions with provider. One participant said, 'I never found recruiting staff a problem because [the pay for] my 3-hour morning service is equivalent to an 8-hour shift in a nursing home.'

Interestingly, people in regional areas did not find it difficult to recruit staff. In fact, both participants and providers said it is easier to recruit outside the large cities. However, people in small towns do have difficulties recruiting staff, particularly for some shifts. Participants living in regional areas report greater support than they had previously, because they are able to use innovative methods to recruit the attendant carers they need, for example through social, community and business networks. They also report that the job can be packaged to be more attractive both through increased pay, flexible work arrangements and training.

Participants have improved the retention of their attendant carers because the pay, conditions and relationships are better under direct funding. For example, one participant said his attendant carers are now receiving superannuation. For some participants retention is a problem because of the small number of hours the participant can offer. Two participants are using agencies to fill in the odd hours and emergencies. Participants are reporting better control and more choice when using agencies as back up. People who are using agencies for back up care are reporting a positive response from agencies and less miscommunication.

The direct funding participants were previously required to expend considerable effort in managing the care relationship under the other ACP models. They are relieved that this program is less paperwork and administration for them, as well as the attendant carers, because a third party is no longer involved. They report being able to resolve problems promptly and directly for this reason.

Some comparison group participants do not have problems recruiting attendant carers. They do it through word of mouth (eg. people known to existing attendant carers), networks and advertising. Other comparison group participants in the ACP employer model commented that their providers had difficulty recruiting attendant carers. One said, 'The agency has had a lot of problems attracting workers ... The pay rate needs to be increased, need penalty rates and a proper car allowance.' They said that one impact of poor recruitment and retention is they must use casual staff who are not familiar or trained to deal with their needs. Some casual staff are accessed through agencies. They commented that sometimes agency staff do not turn up.

Another impact of poor recruitment and retention reported by comparison group participants is that some ACP employer model providers are arranging times for the attendant carers to attend to their needs at the convenience of the service provider rather than the participants' preference. For example, if more than one person lives in the same suburb, providing care for them sequentially in a run, irrespective of the person's work and social needs.

Some direct funding and comparison participants suggested that family members should be eligible to be backup paid attendant carers. They explained that if the attendant carer was not available their family members did this role. They recognised that it was most feasible if it was for backup and emergencies, for example following social events after midnight when paid attendant carers are not available.

Payment and conditions

The pay rates vary between direct funding participants. All participants have written employment contracts with their staff. Some participants sought advice from a solicitor and accountant in writing these, and a number of participants suggested that DADHC either provide this advice to participants or source a pro bono firm to give the advice to participants who undertake direct funding.

Variable pay rates are also offered by most direct funding participants because they find different shifts harder to cover. For example, in a regional area a participant may live far from other attendant carers, and so pay a higher rate at night time as it is a short shift. Rates also differ for different tasks (transport and meal preparation compared to complex personal care). One participant has created a return shift loading for attendants who undertake a split shift on the same day, and an emergency shift loading. One person offers a 9-month contract to staff, which is then reviewed by her and the attendant carer, taking account of the quality of the relationship and care provided. Most direct funding participants pay the attendant carers directly into their account. This arrangement has worked well. At least one participant has a cheque book as a back up to pay the attendant carers by cheque if the online payroll system goes down. One participant has included Rostered Days Off in the contract and changes shifts when an attendant carer is tired or stressed.

Some direct funding participants commented that they have reduced the difference between the hourly funds paid by DADHC and the amount paid to attendant carers, compared to service providers,

DADHC paid the agency about \$41 for every hour of my care, and the [attendant] carers are paid \$19.80. I couldn't see what they were doing with the rest of the money. With direct funding I can make better use of that \$680 plus a week of *my* funding!

In contrast, some comparison group participants in both cooperative and employer models commented that the quality of their care was compromised by pay rates, no penalty rates with some providers and poor payroll management. They said the impact was that it is hard to attract good attendant carers and attendant carers leave for jobs with better conditions. They also commented that attendant carers should be better valued.

Support and training

Direct funding participants feel they are part of a supportive and equal relationship with the attendant carers. One said 'I'm now not regarded as simply a passive recipient of care, but as active, equal and manager of the process. DADHC's perception of me has also changed.' Some direct funding participants said the service provider's control over the initial relationship undermines the ongoing relationship between client and attendant carer, for example, who is the boss.

One direct funding participant pays a senior attendant carer an extra fee to conduct in-home training, and contracts an occupational therapist to undertake assessments when required. Another participant has instituted paid staff meetings and finds this a valuable tool for information sharing, team building and problem solving, and directly leads to better care and happier attendant carers.

Each direct funding participant has created their own system of information and documentation that suits them and their attendant carers. Examples include a daily diary, routine checklist and logsheets. This is done in consultation with the attendant carers and can be reviewed easily and without delay, as previously experienced when using a service provider. They reported that these systems were bureaucratic and unsystematic, such as unclear policy about client logbooks under the AC program, including questions of where the information is stored, who has access to it and how it is used.

Training in the direct funding pilot has become more efficient according to the participants, because it is customised to suit attendant carer and participant needs. This includes both specialist training by external organisations and on the job training by the participant and the other attendant carers. Training has improved because it is more personalised to the needs of the participant and more relevant and accessible to the attendant carers. For example, rather than group training about managing a particular impairment, the participant can organise training specific to their physical needs and preferences. An example is attendant carers attending the Cerebral Palsy Conference with the participant.

Direct funding attendant carers are accessing local, innovative forms of training, such as first aid training and seminars, and training on specific health conditions (not

impairment). Another example is paying senior attendant carers to conduct on the job training for new attendant carers. This has a significant impact on the subsequent quality of care provided to the participant, including consistency and management of health needs. It also recognises the experience and competence of long-term attendant carers. One of the participants plans to develop and conduct personal attendant carer training for other attendant carers and clients in the future.

Some direct funding participants continue to access general training available to other ACP clients when it is relevant and local. For example, OH&S training through HACC; and courses, manuals and resources through Paraquad. The participants feel an increased responsibility to protect the safety of the attendant carers in direct funding. One said, 'I nag them to continue to be safe, if they forget or get slack.' Another has developed his own checklist of procedures.

A number of direct funding participants discussed problems with training and support before they entered the pilot, which the direct funding pilot has allowed them to address. In the past being in a regional location was a problem because the training is only available in the city and their attendant carers had to travel and it was not timely. It was sometimes inaccessible in terms of public transport access for the attendant carer or participant. Comparison participants commented that for many attendant carers it is their second job so the timing is impossible. In addition, some providers still require compulsory training for people who have vast relevant experience, and have no flexible approach in delivering training.

Comparison group participants commented that ACP training should be broader content in the training than just OH&S, such as mental health, referral to other services and career development. Another issue raised was the lack of training on other conditions, other than spinal injury.

Attendant carer satisfaction

The direct funding participants report an increase in attendant carer satisfaction. They state that attendant carers are happier for reasons discussed above. The arrangements remove the extra relationship with service provider so that communication is more direct. This has improved their relationship with the person for whom they care. It has meant that problems are easier and quicker to resolve. Many of the attendant carers have experienced increased pay and conditions in their new care arrangements. One participant quoted one of his attendant carers as saying, 'The only reason I'm working with you now is that you are on direct funding.'

Interviews with attendant carers will be conducted in the second half of the evaluation to gain their perspective of their new working relationship. The service provider managers pointed to a risk of direct funding that the employment needs of the attendant carers might not be addressed, such as occupational health and safety.

Problem solving

Direct funding participants report that it is easier to sort out problems when less people are involved. One participant said, 'If there are problems it is more direct, you are in control.' Another said, 'If I do the best by them [staff], they will in turn come to work with a smile and do their best for me, so its win-win.' Some comparison participants in both cooperative and employer models commented that they already

have the benefits from good relations with their attendant carers without needing direct funding.

Some direct funding participants have a grievance procedure in the contracts with staff. One person has stated in the contract that, 'If our relationship breaks down then it may not be possible to continue the employment, given the extremely personal nature of the role.'

5 Direct Funding Service System

The final report will address the third evaluation question about whether the pilot provides a more effective and efficient use of resources compared to existing arrangements. From the perspective of the ten participants it is more effective and efficient. Their experience will be compared to the experience of attendant carers and government officials and verified with analysis of the financial data.

5.1 Effective Use of Resources

Economic analysis examines the financial cost to government of direct care funding compared to existing arrangements. Depending on the availability of data, this could include a cost analysis or a cost effectiveness analysis based on client outcomes. We will use methods consistent with existing research to enable comparisons to international and Australian research. The purpose of the analysis is to derive implications and recommendations for future funding options. To August 2007 no financial data has yet been analysed.

Financial management

Monthly reporting includes expenditure, payment and hours of care per participant over the pilot period. Most participants offer different pay rates depending on the time of day, workload involved, covering inconvenient shifts and meeting client needs. In addition, they are reimbursed for related care and administrative costs.

Efficiencies in administrative and overhead costs

Participants have identified that they are experiencing more effective and efficient use of resources. For example, they are able to pay differential rates for less convenient hours; shift hours to meet their changing needs; and minimise administrative costs. The overhead costs are lower.

Most participants report that monthly costs for attendant carers and expenses are less than payments. Some participants' per hour of care cost is more than they are being paid but they are compensating by receiving fewer hours of care. During the pilot, they are not able to receive more hours of care if their hourly cost is less. Additional resources they are using to improve the quality of care, such as training, staff bonuses, infrastructure and consumable equipment.

5.2 Impact on ACP Providers and Clients

No data are yet available about the impact on existing arrangements. This will be analysed in the final report.

6 Implications for Policy

This preliminary data has not been analysed for implications for policy. The final report will include implications for client support, quality of care, attendant carer employment, cost and accountability.

6.1 Continuation of the Pilot

The participants are concerned that the pilot should continue. ‘Overall very happy with it and definitely hoping it continues.’ Their concerns are about both so that they can continue to experience the benefits they have enjoyed during the pilot period, and that other people can also make the choice to self manage their funds. ‘I would like to see this as a full program, not just a trial and provided to others’.

All direct funding participants offered support for further development of the Direct Funding of Attendant Care. They commented that DADHC will need to refine the process if the pilot or rollout continues. They are all willing to be involved in that feedback. They suggested that this role could include providing information to the Department, other participants and service providers, one person said ‘we need to be kept in the loop ... to develop the program ... it’s a brand new way.’ Another supported this by suggesting,

It could be extended to other disabilities, to people who have support needs. I would like to see the trial extended and a manual developed which would outline the procedures for implementing direct funding. I encourage others to manage their own care.

One comparison participant raised the issue of the need to recruit and develop the attendant carer workforce. He also wants an expanded definition of attendant care to include respite and community access.

6.2 Client Capacity

Direct funding participants are using a suite of skills and knowledge including; understanding the way ACP works; negotiation and communication skills; awareness of OH&S requirements, employment responsibilities (payroll, superannuation, tax, insurance, accountability), support and training for employees, knowledge of contract management; how to seek advice; information technology for recording and reporting, managing attendant carers, rostering and conflict resolution.

The participants in both groups and the service provider managers emphasised the need to have the capacity to develop skills in financial and human resource management; as well as a sophisticated understanding of managing attendant carer relationships.

7 Conclusion

The preliminary data show an overwhelmingly positive response to the pilot from the initial participants. The quality, control and flexibility of their care has improved. This has had a positive impact on their quality of life outcomes. The participants are all keen to assist in developing the model and expressed strong support for it to continue. Many comparison participants are also eager to know about its progress and when they can reconsider joining the direct funding option.

Overall the direct funding participants are extremely pleased with the program, as evidenced in this report. None of the participants noted any negative impacts of direct funding. The sentiments of one participant summarises their experiences,

I congratulate and commend DADHC on the direct funding trial.
It's a very, very successful and rewarding program for people with physical ... disability, who can tell people what they want and how they want it, and have control over their own life.

The elements reported as contributing to improved care arrangements are:

- attendant carer quality – because the pay and conditions are better, so they are more likely to be skilled, knowledge and compatible;
- less turnover – because of the pay and conditions, rapport and satisfaction;
- better training – more attuned to the person's specific needs and preferences;
- committed attendant carers – because of rapport with the participant; and
- the process is more efficient – because direct relationship with attendant carer and fewer overheads.

The direct funding participants report that as a result of the better care arrangements, the quality of their care has improved in terms of:

- consistency;
- reliability; and
- flexibility.

With improved quality of care they report that they have experienced improved outcomes in terms of:

- health and wellbeing;
- confidence and self esteem; and
- community, social, economic participation.

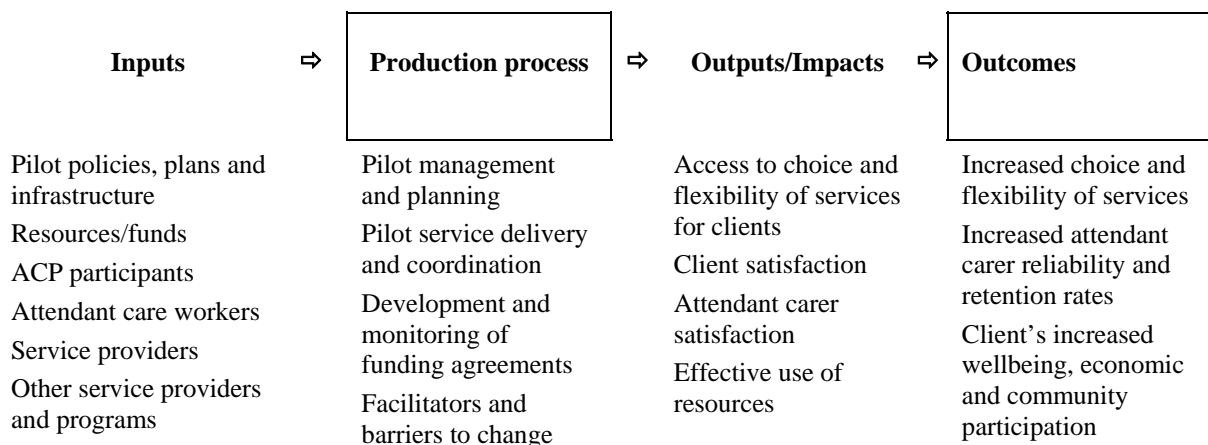
These improvements in care arrangements, quality of care and outcomes are evidenced from participants' reports of their experience before direct funding compared to now; and in contrast with the experiences of some, but not all, comparison participants in the main ACP. The final data collection in the second half of the evaluation will add to the evidence of these changes.

Appendix A: Methodology

Evaluation framework

The evaluation incorporates both a process and outcomes evaluation. As well as exploring stakeholders' views and experiences of the implementation of the project the evaluation also explores outcomes for participants and the pilot project as a whole. The operational basis for the evaluation is a program theory approach (Figure A.1).

Figure A.1: Evaluation Conceptual Approach



This approach distinguishes four distinct but closely linked stages in the process of human service delivery: inputs, process, outputs and outcomes. It is particularly valuable in attempting to understand the complex interaction of individuals, communities, NGOs and government agencies over time. It helps draw attention to the ways in which the program is operationalised and implemented, how this impacts on the delivery of services, and how the consequences of these are eventually expressed in terms of outcomes. Within this framework a participatory methodology is also adopted. This involves stakeholders being consulted and engaged at each stage of the evaluation including design, collection and analysis. This method gives some ownership of the evaluation to stakeholders and provides early evaluation feedback to the implementation and improvement of the program.

The evaluation uses longitudinal and comparison measures for people in the program, combining both quantitative and qualitative data analysis techniques. These methods are described in more detail below.

Key Evaluation Questions

Individual clients

- Does the direct funding pilot lead to increased clients wellbeing and enable them to maximise their participation in the community?
- Does the pilot lead to increased participant and attendant carer satisfaction levels?

Governance

- Are appropriate and effective governance arrangements in place to support the establishment and ongoing development of the pilot?

Service systems

- Does the pilot offer greater choice and flexibility of services compared to existing funding arrangements?
- Does the pilot provide a more effective and efficient use of resources compared to existing arrangements?

Longitudinal data collection

The evaluation uses primary data collection methods with the participants in the pilot program, other clients in existing ACP arrangements and other participants, particularly from DADHC and service providers. Research instruments measure the range of outcomes and process experiences described in the design section above. This includes a short questionnaire to collect information on outcomes for clients around their health, personal wellbeing and community participation. Data collection is at the beginning and end of the evaluation for the pilot client group (February 2007 and October 2007); beginning of the evaluation for the comparison sample of other clients in the existing ACP (February and March 2007); and the middle of the evaluation for other participants (April 2007).

Table A.1: Samples

Task	Measurement	Number
Pilot participants	Beginning and end	10
Comparison existing ACP clients	Beginning	25
Other participants (particularly providers, attendant carers and officials)	Middle	5

The samples are:

- All clients in the pilot program who consent to participation (approximately 10);
- A matched sample of comparison clients in the existing ACP. Matching is on demographics (as available eg. age, gender, cultural and linguistic background, education, income source); support needs (eg. hours, type); disability; and location (eg. metropolitan, regional and rural); and
- A sample of other participants including government officials responsible for the pilot implementation, policy, service delivery; attendant carers; service providers; and informal carers and family if applicable. Disability support groups are being consulted through the Expert Advisory Group on Physical Disability.

References

- Australian Bureau of Statistics (ABS) (2006), *National Health Survey: Summary of Results 2004-05*, No. 4364.0, ABS, Canberra, ACT.
- Carmichael, A and L. Brown (2002), 'The future challenge for direct payments' *Disability & Society*, 17(7): 797-808.
- Fisher, K.R., A. Anderson and K. Muir (2007), *Attendant Care Direct Funding Pilot Project Evaluation Plan*, report prepared for NSW Department of Ageing, Disability and Home Care, SPRC Report Series 3/07.
- Heggie, D (2005), 'Service challenges - packaging, dream or reality?', National Accommodation and Community Support Conference, March 30 - 31, Melbourne.
- Hughes, V., (2006), 'The empowerment agenda: civil society and markets in disability and mental health', *Institute of Public Affairs Backgrounders*, IPA, Melbourne.
- International Wellbeing Group (IWG) (2005), *Personal Wellbeing Index*, Australian Centre on Quality of Life, Deakin University, Melbourne
http://www.deakin.edu.au/research/acqol/instruments/wellbeing_index.htm.
- Jacobsen, J. (1997), 'Market theory in human services: dancing with wolves or better choice?', *Interaction*, 11(1): 21-5.
- Lord, J and P. Hutchinson, (2003), 'Individualised support and funding: building blocks for capacity building and inclusion', *Disability & Society*, 18, 1, 71-86.
- Maglajlic, R., D. Brandon, and D Given (2000), 'Making direct payments a choice: a report on the research findings', *Disability & Society*, 15(1): 99-113.
- NSW Council of Social Service (NCOSS) (2006), *Working together in NSW: good funding policy and practice*, NCOSS, Sydney.
- Pearson, C. (2000), 'Money talks? Competing discourses in the implementation of direct payments', *Critical Social Policy*, 20(4): 459-77.
- Physical Disability Council of NSW (PDC) (2006), 'Personal assistance in NSW', www.pdcnsw.org.au/priorities/support/06/decentsociety.html 7.6.06.
- Poll, C, S. Duffy, C. Hatton, H. Sanderson, and M. Routledge (2006), *A Report on In Control's first phase 2003-05*, In Control Publications, London.
- Siminski, P, S. Robinson, K.R. Fisher, P. Saunders, and M. Roughley (2002), *Service delivery costs for specialist disability services. Paper 4: Funding model*, Disability Services Queensland, Brisbane, unpublished.
- Spandler, H (2004), 'Friend or foe? Towards a critical assessment of direct payments', *Critical Social Policy*, 2(79): 187-209.
- Witcher, S, K. Stalker, M. Roadburg and C. Jones (2000). *Direct Payments: The Impact on Choice and Control for Disabled People*, Scottish Executive Central Research Unit, Edinburgh.
- Yoshida, K, V. Willi, I. Parker and D. Locker (2004), 'The emergence of self-managed attendant services in Ontario: direct funding pilot project - an independent living model for Canadians requiring attendant services', *Research in the Sociology of Health Care*, 22: 177-204.