# Attendant Care Program : Direct Funding Pilot Evaluation : Final Report

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THE UNIVERSITY OF NEW SOUTH WALES

# ATTENDANT CARE PROGRAM DIRECT FUNDING PILOT EVALUATION

## FINAL REPORT

## FOR THE NSW DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

**SPRC Report 11/08**

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# Abbreviations and glossary

| | |
|---|---|
| ABS | Australian Bureau of Statistics |
| 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.<br><br>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.<br><br>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 |

# Executive Summary

*ACP direct funding pilot*

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. The evaluation compares three ACP funding options, which differ in who employs the attendant carers, who receives the funding from DADHC and who is responsible for management 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. DADHC pays the funds to the service provider and the service provider is accountable to DADHC for the management of funds and reporting. Thirty two service providers are registered with DADHC to provide this model.
- Cooperative model – the client is the attendant carers' employer; the service provider supplies administrative and management support. DADHC pays the funds to the service provider and the service provider is accountable to DADHC for the management of funds and reporting. One provider offers this model.
- Direct funding – the client is responsible for all attendant carer employment and management. DADHC pays the funds directly to the client, who is accountable to DADHC for the management of funds and reporting.

The pilot project is providing funds directly to ten 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.

*Participant outcomes*

When participants in direct funding are compared with clients in the ACP employer and cooperative models, improvements in outcomes are observable. Some of the outcomes are due to the different profiles between the groups, in terms of age, sex and socioeconomic circumstances. The benefits they experienced were:

- higher average personal wellbeing than averages for other ACP clients and other Australian adult population norms;
- a return to a sense of control, managing their own life and maximising independence, choice and activities;
- better average physical health than other ACP clients and similar to the general population;
- higher average satisfaction with physical health than other ACP clients and improvements in pain and physical risk management;
- higher average satisfaction with mental health than other ACP clients (and more satisfied with mental than physical health);

- higher average satisfaction with personal relationships than some other ACP clients, other Australian adult population norms and satisfaction increased during the pilot;
- active social networks; improved family relationships; control in home – impact on partner and children; less pressure on family; more quality social time with family; improved friendships because of greater flexibility;
- participation in paid work, study or active in their community, including increased participation for some people; in addition, some comparison group clients thought direct funding could help them improve their participation through better control of care;
- better average prior socioeconomic position than some comparison clients; and
- higher average satisfaction with feeling part of community than other ACP clients and the general population.

*Care arrangements*

Participants chose to be in the pilot to achieve the following goals:

- enhance independence, flexibility, reliability, customised training;
- improve control over life, hours, money and attendant carer conditions;
- achieve a direct relationship with attendant carers;
- avoid the complexity of the ACP employer model experienced by some people, such as rigid methods of managing care arrangements, recruitment, limited flexibility and control and cost inefficiencies; and
- extend the control and flexibility of the ACP cooperative model already experienced by participants who were using it.

Most ACP clients had not heard of direct funding. Before participating in the pilot, direct funding participants and other comparison ACP clients thought the risks might be in relation to liability, insurance, tax, OH&S, pensions and the scope of support; and financial and management responsibility.

The type of support received is similar in all ACP options. The direct funding participants experienced improved flexibility to change the content of the support and respond to specific needs eg. access to education, work and shopping. Like other ACP clients, they supplement the ACP formal care with support from family or friends and HACC.

They experience better quality of care than they had previously had because of the additional control they have over their choices of attendant carers, training, support and conditions. In relation to reliability, flexibility and choice, they experienced improvements relative to their past experience and relative other ACP clients (except people who had previously used the cooperative model). Examples are ability to change arrangements and receive short episodes of care. This control has a positive impact on informal care and participation arrangements. Most ACP cooperative model clients and some ACP employer model clients experience most of these benefits already.

Many people with experience of the ACP employer model spoke of problems relating to the quality and organisation of support. ACP employer model service providers could investigate how to change care arrangements so that clients are more likely to achieve their goals for quality of care.

Relationships with attendant carers improved because they have trust, commitment, a direct personal relationship and they can negotiate and resolve problems directly. They are more satisfied with their support, although some said they need more hours of care, which can be reassessed.

Management of attendant carers has improved in terms of conditions and satisfaction. Recruitment and retention has improved because they can offer better work conditions. Recruitment has been easier outside the cities. Some people still use back-up from agencies. Unlike the ACP employer and cooperative models, they have the flexibility to improve pay rates and conditions and offer variable rates for shifts, tasks and bonuses for good service. They offer support, training and OH&S that is personalised to their support needs and the experience of the attendant carers. Some participants pay experienced carers to train others. The participants have a greater commitment to training and OH&S because of the consequences for their own care and employment responsibilities. Attendant carer satisfaction has increased because they have better pay and conditions and a direct relationship. Problem solving is more direct and immediate.

*Cost effectiveness*

The cost to DADHC of ACP direct funding is similar to other ACP employer and cooperative models. All participants managed their funds close to budget, some returning a surplus, which on average was similar to that of the main program (surplus 5 per cent of total grants). Participants who were highly cost efficient in managing their funds paid mid-range attendant carer pay rates (average over $28 per hour) and mid-range other costs (12-16 per cent of total costs) (Table 5.3). The measured outcomes were comparative improvements in health and wellbeing, confidence and self-esteem, family relationships and community, social and economic participation.

*Implications for policy*

The evaluation has implications for the development of possible ACP direct funding models and ways to improve service delivery quality within ACP employer and cooperative models.

Client capacity and support in direct funding

Participants need the capacity to develop skills and knowledge in the following areas or have the support of people with this capacity:

- understanding the way ACP works, its guidelines, limitations and obligations;
- financial and human resource management, such as employment responsibilities (payroll, superannuation, tax, insurance and accountability), support and training for employees, OH&S requirements and contract management;
- sophisticated understanding of managing attendant carer relationships, such as negotiation and communication skills, how to resolve problems and seek advice, and conflict resolution; and

- information technology management skills for recording and reporting, managing attendant carers and rostering.

Options for direct funding policy therefore include:

- continue the direct funding option for the people who participated in the pilot;
- extend the option in ACP to other people;
- develop processes to assess capacity or identify the support required; and
- develop direct funding options in other DADHC programs for people with similar capacity or support.

Administrative Support for Direct Funding

Implications for further policy options include:

- continue the administrative support provided through the policy official, group teleconferences and internet forum, written guidelines, regular reporting and feedback, responsive problem and question solving;
- develop guidelines about who would most likely prefer and benefit from a direct funding option compared to other ACP funding options. This would assist to people make the most suitable choices and minimise risks to the person and the Department;
- provide administrative support to develop capacity such as training, peer support, guidelines, administrative toolkits and software; and
- provide access to an experienced policy official familiar with all ACP options responsible for responding to participants' questions and managing, assessing and preventing risks to support and financial management.

Attendant carer employment

Implications for attendant carer employment conditions include (details in Section 3.4):

- conditions for direct funding attendant carers improved, such as pay rates, conditions, training and OH&S;
- conditions for other attendant carers could be improved by considering how service providers might replicate the experience of the pilot attendant carer conditions within the other ACP options;
- the availability and conditions of formal care workforce are unlikely to be affected by an ACP direct funding option, given the small number of direct funding attendant carers compared to the entire formal care workforce. However, positive lessons from the pilot experience could have an indirect effect on improving conditions; and
- modifying the relationship between family care and formal care, such as employing family members for emergency and back-up.

These implications are in the wider context of likely changes to the attendant carer workforce, due to the shortage of formal and informal carers.

Cost and accountability

Direct funding is cost effective in terms of improving relative outcomes for the same or lower costs. The participants managed their financial obligations responsibly and within the intention of the pilot. Implications for policy options include:

- continuing allocation of an experienced policy official to support program implementation, including responding to queries from the participants and managing financial accountability;
- maintaining management systems to monitor and protect against financial and support risks to clients and government. The experience of monthly and annual reporting for new participants contributed to this risk management. The Department could review reducing the frequency of reporting for clients who successfully manage care hours and finances within budget after an initial period; and
- examining the financial implications of allowing participants to apply the cost savings to purchase additional care, expenses or management improvements.

ACP Employer and Cooperative Models

Direct funding complements the ACP employer and cooperative models. Many of the results about quality of care could be transferable to all the ACP options. Implications for policy options include replicating the direct funding approach to the following aspects of organising ACP in the other models:

- care arrangements – responsive to client's needs; flexible (time, travel and tasks); client focused in management and arrangements (care fitting the person's needs); tailored to meet individual needs; and maximising independence and control.
- attendant carer conditions – training, OH&S, pay and conditions, direct relationship between attendant carers and clients, hours and tasks; and
- financial management and accountability – managing hours and clients' incidental management costs.

*Conclusion*

The evaluation shows an overwhelmingly positive response to the direct funding pilot from the initial participants. The elements reported as contributing to improved care arrangements are:

- attendant carer quality – because of improved pay and conditions, so they are more likely to be skilled, knowledgeable 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.

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.

# 1 Background

## 1.1 Attendant Care Program Direct Funding Pilot Description

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/Territory Disability Agreement and administered by DADHC.

The report compares three ACP funding options, which differ in who employs the attendant carers, who receives the funding from DADHC and who is responsible for management 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. DADHC pays the funds to the service provider and the service provider is accountable to DADHC for the management of funds and reporting. Thirty two service providers are registered with DADHC to provide this model.
- Cooperative model – the client is the attendant carers' employer; the service provider supplies administrative and management support. DADHC pays the funds to the service provider and the service provider is accountable to DADHC for the management of funds and reporting. One provider offers this model.
- Direct funding – the client is responsible for all attendant carer employment and management. DADHC pays the funds directly to the client, who is accountable to DADHC for the management of funds and reporting.

The pilot project is providing funds directly to ten 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 disability with high personal support needs, who have the capacity to manage administration of funding directly. People in receipt of direct funding are responsible for all legal, financial and accountability requirements as well as managing or contracting out 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).

Direct payments from government to consumers to purchase care is one form of individualised funding (Rummery, 2007). The rationales are to improve consumer control, flexibility, quality and cost efficiency. However, direct payments without adequate program support present risks to consumers, workers and government, such as care quality, cost, quantity, abuse and worker conditions. The ACP direct funding pilot is the first full direct payments option for people with disability in Australia

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.

## 1.2 Evaluation

The Department commissioned the Social Policy Research Centre (SPRC) and Disability Studies and Research Institute (DSaRI) 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, families 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 2007; follow-up measures October 2007; and process, outcomes and economic analysis (Appendix A).

## 1.3 Report Structure

The report is structured in the following way:

- Section 2 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 presents the comparative outcomes for the people in the pilot, including changes since entering the program and comparison to other people using ACP employer and cooperative models.
- Section 3 presents evidence of changes in care arrangements compared to the main ACP, including support received, impact on quality of care and management of attendant carers.
- Section 4 discusses the governance arrangements for the pilot including support from DADHC, transition to direct funding, implementation and accountability requirements.
- Section 5 discusses the impact on the service system, including financial management and cost effectiveness analysis.
- Section 6 summarises implications for policy development in direct funding, employer and cooperative models.
- Section 7 draws conclusions from the evaluation about the effectiveness of the pilot.

Personal details about participants have been removed or changed in the qualitative data to protect their identity.

# 2 Participant Outcomes

Does the direct funding pilot lead to increased participants' wellbeing and enable them to maximise their participation in the community?

Does the pilot lead to increased participant satisfaction levels?

The first purpose of the evaluation is to review the outcomes for the people in the direct funding pilot. This section presents information about who is using direct funding, compared to people in the ACP employer and cooperative models. 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. Information about the direct funding participants was collected in April and October 2007; and the comparison participants in June 2007. The people in the direct funding and comparison groups are similar (Table 2.1), although they have some differences (sex, location and participation), which are discussed below.

**Table 2.1: Profile of Participants**

| | Direct funding (10) | Comparison (26) |
|---|---|---|
| Age | 25-59 years (range)<br>41 years (mean) | 20-65 years (range)<br>51 years (mean) |
| Sex | 20% women | 69% women |
| Impairment | 8 spinal injury<br>1 cerebral palsy<br>1 SMA* | 15 spinal injury<br>2 cerebral palsy<br>1 SMA*<br>3 multiple sclerosis<br>2 spina bifida<br>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<br>10% retired | 35% paid work/study<br>27% retired<br>38% not in paid work |

Notes: *SMA – Spinal Muscular Atrophy
**CALD – Culturally and linguistically diverse

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). 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.

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

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. Most (8/10) live with family members. In contrast, 23 per cent of the comparison group did not have that level of informal support, and all of these people are women. In the direct funding group, the family members described themselves as an extension of the attendant carers and a back-up. For example, some of them provide the overnight support, cooking, cleaning, shopping, some personal care and additional needs when they are unwell. Some people also call upon neighbours if necessary. This was similar to the comparison group members who had high support needs and family support.

The biggest contrast between the intervention and comparison group is economic participation. All direct funding participants are employed, retired or studying 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 support needs.

## 2.2 Outcomes

The evaluation investigates if direct funding pilot leads to increased wellbeing and participation in the community; and whether it leads to increased participant satisfaction levels.

Respondents from both groups participated in interviews, which included discussion and standardised questions. The measurement tools are based on instruments used in the evaluation of similar programs nationally (Appendix A; 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 people in the pilot. The measured outcomes include personal wellbeing (confidence, esteem, physical and mental health); social networks; and community and economic participation. Outcomes are analysed by comparing baseline and follow-up data and data collected

from people in the existing ACP arrangements; and normative data from similar programs and the validated instruments used in the data collection.

Results are positive. Participants reported improved outcomes in all domains, including satisfaction, participation and wellbeing at both the baseline and follow-up interviews. They did not report any negative effects from direct funding, except for the time responsibility.

Case study on participant outcomes

Natalie had lived away from her rural family to attend high school, gap year and university. Following her injury, Natalie returned to live with her family because of her high support needs. The injury, together with returning home, compromised her independence and control of her life. It was a big adjustment for her and her family. Direct funding has restored her independence because she is in charge of her care. She has been able to travel to Sydney with her attendant carers to become admitted as a lawyer and is now practising. In the rural town, her attendant carers pick her up from social activities at night. Her family feels it has taken pressure off them and her mother has returned to paid work.

As well as discussing their quality of life, the respondents each completed the Personal Wellbeing Index (PWI), an internationally validated instrument (IWG, 2005). The evaluation only has very small samples so the results should be interpreted cautiously. The baseline and follow-up measures of PWI for direct funding participants is higher on average than other ACP clients in all domains (Table 2.2).

**Table 2.2: Personal Wellbeing Index**

| | Direct funding (10) | | | | Comparison (26) | | Australia |
|---|---|---|---|---|---|---|---|
| | Baseline | | Follow-up | | | | |
| | Mean | range | mean | range | mean | range | mean |
| PWI | 83 | | 86 | | 71 | | 75.02 |
| Life as a whole | 82 | 70-100 | 89 | 60-100 | 69 | 30-100 | 77.63 |
| Standard of living | 79 | 70-100 | 88 | 60-100 | 75 | 30-100 | 77.28 |
| Health as a whole | 81 | 60-100 | 82 | 50-100 | 63 | 10-100 | 75.09 |
| Achievements | 83 | 60-100 | 87 | 60-100 | 71 | 10-100 | 74.19 |
| Personal relationships* | 87 | 70-100 | 88 | 50-100 | 69 | 20-100 | 79.81 |
| Safety | 88 | 70-100 | 83 | 50-100 | 77 | 10-100 | 77.63 |
| Feeling part of the community | 83 | 60-100 | 84 | 60-100 | 72 | 0-100 | 70.52 |
| Future security | 80 | 60-100 | 84 | 60-100 | 72 | 10-100 | 70.49 |

Notes: Personal Wellbeing Index (PWI). Scale 0-100 where 0=completely unsatisfied, 100=completely satisfied (IWG 2005)
* Baseline and follow-up measures are significantly different only at 10% Chi-Square. No other domains significantly change between baseline and follow-up.

The lowest score for direct funding participants in any domain is 50 in the follow-up measures. 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.

Between the baseline and follow-up PWI measure for the direct funding participants, only satisfaction with personal relationships significantly changed.[1] It had improved or remained the same for all direct funding participants except one. Reasons for this improvement are discussed below.

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.

Attendant carer satisfaction is discussed in Section 3.4.

**Health and wellbeing**

Most of the direct funding participants stated that their health and wellbeing is very good or excellent (60-80 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 (56 per cent very good or excellent; ABS 2006).

**Table 2.3: Health and Wellbeing**

| | Direct funding (10) | | Comparison (26) |
|---|---|---|---|
| | Baseline | Follow-up | |
| Poor | - | 1 | 1 |
| Fair | 1 | - | 6 |
| Good | 3 | 1 | 12 |
| Very good | 3 | 3 | 4 |
| Excellent | 3 | 5 | 3 |

Similarly, people in the direct funding group reported higher average satisfaction with their physical and mental health than the comparison group (on a scale of 0-100, 81 and 90 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. The participants' comments about their health

[1] This observation is based on a Chi-Square test using a 10% confidence interval. If stricter 5% confidence interval is applied, no significant change is found. A t-test on the mean scores showed no significant change using a 5% and a 10% confidence interval.

and wellbeing are consistent with these scores. Attendant carers and families also agreed. The measures of health and wellbeing did not change significantly between the baseline and follow-up for direct funding participants.

**Table 2.4: Satisfaction with Physical and Mental Health**

| | Direct funding (10) | | | | Comparison (26) | |
|---|---|---|---|---|---|---|
| | Baseline | | Follow-up | | | |
| | mean | range | mean | range | mean | range |
| Physical health | 76 | 50-100 | 81 | 50-100 | 67 | 20-100 |
| Mental health | 93 | 80-100 | 90 | 60-100 | 77 | 30-100 |

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

This difference between the groups may have been present 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 average 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 participants are less likely to use agency attendant carers so the quality of care is higher on average. 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 how ACP assisted their mental health, such as, 'I would be insane if I didn't have attendant care.' Many people 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.

Positive changes for direct funding participants included regular meals and being supported by attendant carers to medical procedures. Similarly, a comparison participant said attendant care facilitated her access to dental care. However, other ACP employer model comparison participants commented on the negative impact that restrictions in their ACP arrangements has on their physical and mental health, 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 the pilot and comparison 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. One direct funding participant had also experienced financial abuse when he first entered the pilot, when an attendant carer stole money from his direct funding operating account. The bank replaced the money. Another direct funding participant had experienced mild verbal 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 their own hands, therefore 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. Attendant carers and family members commented on this too. 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 reported, 'I am able to manage my own life, not be a passive recipient without any choice. I can satisfy my own lifestyle. I feel empowered and that I have a sense of control.' It has given some participants the opportunity to learn new management, business and communication skills, for example dealing with the Australian Taxation Office and using bookkeeping software.

It has resulted in participants enhancing their confidence and ability to manage and communicate with attendant carers. An attendant carer had noticed, 'He is more motivated, positive. He says, "Get me up, we have lots to do." He has purpose and control.' A family member commented that having an active role in administering the direct funding has given the participant a new focus, which is appropriate to his background in financial management. 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 ACP employer model participant said,

> I feel I should be in control of my own care … I feel very disempowered by the service provider. 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 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 on average (average satisfaction score of 88 compared to 69 in the comparison group; Table 2.2). Even from a high baseline, the direct funding participants' satisfaction improved between baseline and follow-up. Comparison group people who have active relationships tend to be the ones who reported satisfaction with their level of control and flexibility.

Direct funding participants reported that family relationships improved since entering the pilot. Benefits they reported including greater control over their home environment; less stress on family members; and more flexibility to make social arrangements with family and friends, each described below.

*Control in the family home*

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. Family members spoke of the importance of knowing and trusting the attendant carers as they enter the family home and have a significant impact on all family members.

Family members said they had better relationships with the attendant carers under direct funding, which increased security and safety especially for the three participants with children. 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. Now my son knows the carers better.' This also means his wife is less stressed.

Other family members said, 'It gives him peace of mind, so I have peace of mind.' 'It takes the pressure off the whole family.' 'I feel better knowing that the carers are trustworthy and reliable, and reassured that they will do their best.' 'We feel really settled. Everything is going really well. It's so great to have a proactive role in your own life and control over who is in your home.' A direct funding participant 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.

*Less stress on 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. One participant said, 'My relationship with my partner has improved because there is less pressure on [them].' Direct funding for one participant has meant that both he and his wife are able to work from home and care for their baby twins. The wife said,

> It has been a morale booster. It is so much better, we can change times, for example if we go out for dinner or if it is a public holiday and we want to get up later. The carers are more motivated and we have give and take both ways.

Direct funding family members talked about the reduction in stress and anxiety for them and the whole family, since the direct funding. One partner said she was previously very stressed with the care situation and tended to take it out on him [participant]. She reports improvements in their marital relationship. Family members also said they felt less pressure and better supported. A partner said,

> Anxiety about his care has massively decreased … sometimes I had to ring work to say I'd be late as his carer hadn't arrived. I had to be home when the carers were there. Now that we have trustworthy, reliable [carers], that's changed. We both get to work on time and I am able to attend things like parent-teacher interviews and even go to stay with family for a night.

Two direct funding participants said,

> I had two carers off sick with the flu this winter. It was the first time that [my partner] didn't have to pick up the pieces. I see this as directly due to the increased pay and the emergency loading payment.

> 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.

This is in contrast to both their previous experiences and the family arrangements and family breakdown reported by some of the comparison participants.

*Improved social arrangements*

By changing the caring responsibility of family members, direct funding has improved the quality of their time together. Another family is now able to arrange regular social time together as a couple or with their adult child. Some comparison participants have the same benefit under their current ACP arrangements.

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. Another family member said that direct funding meant being able to negotiate changes in times allowed them to have a more active social life, 'It's not normal to have your husband put to bed at 6:30pm.' This participant previously used a HACC provider. Impact on friendships and social participation is discussed further in the next section.

Most direct funding participants live with family members (8/10). Their family members and friends supplement their formal care. However, the comparison between the direct funding and other ACP clients shows that direct funding is not dependent on having informal carers or family. More relevant, is the question common to many people using ACP – is 35 hours formal care sufficient for their support needs when combined with any available informal care? This question is assessed when anyone joins ACP. Financial management through employer, cooperative or direct funding options is a later consideration, not dependent on access to family support. Some participants from all groups raised the problem of insufficient ACP hours and restricted access to other services if they receive ACP. ACP has processes to reassess hours and guidelines for access to other services.

**Community, social and economic participation**

The direct funding pilot is intended to improve opportunities for community, social and economic participation.

*Community and social participation*

The direct funding participants all reported that the benefits of managing their own care have contributed to their lifestyle and participation in community life. They have higher average satisfaction with feeling part of the community (84 compared to 72; Table 2.2). Some direct funding participants, who have significant physical support needs, 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 comments such as, 'I am a loner'; '… it's not much fun being a quadriplegic.'; 'I would really like to be working.'; '… I would like to get out more, I'm trying to get part time work – I was doing work at AQA but that ran out.'; '… never employed but would like to work.' Some of them reflected that if they had more control over their care they might be able to achieve these goals.

Greater flexibility in transport arrangements has meant the direct funding participants are more active in the community and doing more with their friends and family. Flexibility in employment arrangements in direct funding has also helped them travel for work, study, holidays and to visit family in other regions of the state. For example, one participant talked about socialising at night and attending university commitments. The attendant carer is able to drive them. This is especially important in regional areas where taxis are not available at night. They know they can get back home when they are ready and they will not be late for their attendant carer.

One person who had previously not gone out often increased his social participation from the beginning to end of the evaluation, 'I go out lots of times now if I have an invitation, or to the local shops. Having a carer to go with me gives me peace of mind for safety when I wheel around.'

Some comparison participants said they are restricted in their ability to travel with their attendant carer nationally and internationally. Other people are clearer about their entitlements and their provider is responsive. Some direct funding participants wanted greater portability interstate and internationally so that they could travel and live outside the state for longer periods.

*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, however at least half the participants have increased their roles and work capacity since accessing direct funding. Examples of direct funding enabling them to increase their capacity to participate include travelling nationally for their business; attending university lectures; and working more hours. 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 by working from home. Another participated added, 'My art is going really well. I am starting to look for part-time research work.'

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 person 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. Some ACP cooperative participants experience benefits similar to the direct funding participants. One employs an attendant carer who also has office duties said,

> 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 chose the times I have support so I can get to work on time. Furthermore, I have the confidence in undertaking my Masters.

However, in contrast with the direct funding participants, 38 per cent of the comparison group were not engaged in active economic participation. The direct funding group on average are younger (41 years) compared to the comparison group (51 years), which may also affect their participation in paid employment and study.

The two groups are also 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 (84

compared to 72; Table 2.2). Cost of living constrains the active participation of some comparison group because they are not in paid employment. 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.

*Implications of participation findings*

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, some people in the comparison group identified that if they had the opportunity to use a direct funding model, 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 3.

Alternatively, ACP employer providers could attempt to change management practices to achieve some of the flexibility and control available in the direct funding and cooperative models. These differences in care arrangements are discussed further in Section 3.

## 2.3 Summary of Participant Outcomes

When participants in direct funding are compared with clients in the ACP employer and cooperative models, improvements in outcomes are observable. Some of the outcomes are due to the different profiles between the groups, in terms of age, sex and socioeconomic circumstances. Participants experienced benefits to their health and wellbeing, confidence and self-esteem, relationships with family and friends and participation in community, social and economic activities. In summary the benefits were:

- higher average personal wellbeing than averages for other ACP clients and other Australian adult population norms;
- a return to a sense of control, managing their own life and maximising independence, choice and activities;
- better average physical health than other ACP clients and similar to the general population;
- higher average satisfaction with physical health than other ACP clients and improvements in pain and physical risk management;
- higher average satisfaction with mental health than other ACP clients (and more satisfied with mental than physical health);
- higher average satisfaction with personal relationships than some other ACP clients, other Australian adult population norms and satisfaction increased during the pilot;

- active social networks; improved family relationships; control in home – impact on partner and children; less pressure on family; more quality social time with family; improved friendships because of greater flexibility;
- increased participation in paid work, study or community life for some people; in addition, some comparison group clients thought direct funding could help them improve their participation through better control of care; and
- higher average satisfaction with feeling part of community than some other ACP clients and the general population.

# 3 Care Arrangements

Does the pilot offer greater choice and flexibility of services compared to existing funding arrangements?

Does the pilot lead to increased attendant carer satisfaction levels?

The second goal of the evaluation is to understand the impact of direct funding on the quality of the care arrangements. Participants in the direct funding pilot concluded that the model offers greater choice and flexibility of services compared to funding arrangements in either the existing ACP cooperative or employer models. This section discusses the findings from the participants, family members, attendant carers, officials and service provider managers. The analysis contrasts their experience before entering the pilot, baseline and follow-up; 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 have built a better relationship with the attendant carers based on mutual trust and respect.

The section discusses the reasons for choosing direct funding, from the perspective of people who did and did not chose to participate; support received through ACP compared to support received prior to ACP; quality of care under each of the models; and management and satisfaction of attendant carers under direct funding.

## 3.1 Reasons for Choosing Direct Funding

### Information about direct funding

Some direct funding participants have used ACP for many years. They heard about the direct funding pilot 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.

Their experience of applying for the pilot was positive. The participants said the information provided by DADHC was sufficient. 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 availability of emailed information and contact was helpful to them. Detailed information was only available from DADHC central office rather than from the service providers or regional offices.

The development of the direct funding pilot took a long time. The timeframe between expressing interest and starting the pilot was much longer than they expected, while details were resolved. As it was new they were grateful that the details were sorted out before the program started. Before they entered the program a small number of direct funding 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.

### Reasons for changing to direct funding

All the direct funding 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. Two people previously used the cooperative model (Table 3.1). 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.

The direct funding 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 rigid methods of managing care arrangements and felt they were not getting individualised support. They said they did not want to rely on a 'bureaucratic service provider', by which they meant problems such as communication, poor support and attendant carers pay and conditions; described in more detail in Section 3.3). 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. Some 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.'

At the end of the evaluation, all the participants are interested in continuing in the direct funding option except one. They did not anticipate any new risks. The reason for the person considering returning to the cooperative model is because of the time to complete the management responsibilities in direct funding, particularly reporting and accountability. He feels that he gains the same benefits from the cooperative model, without the additional responsibilities.

The other participants are concerned that the pilot should continue. 'Overall very happy with it and definitely hoping it continues.' They want to continue to experience the benefits they have enjoyed during the pilot period and know that other people can also make the choice to self manage their funds. 'Once you have this kind of control, everything in your life is improved. It is like a positive domino effect.'

### Comparison group views about direct funding

Most comparison group participants had not heard of direct funding. When they participated in the evaluation interview, 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 that could be applied to their situation now and resolve the problems they were having. These included arranging the attendant carers they wanted, cutting out the service provider role, attracting quality and reliable attendant carers, providing customised training to suit their individual

needs and improving pay and work conditions. Some people felt they are doing all the management of the care arrangements anyway (eg. rosters, timesheets, negotiation and on the job training) and the service provider creates difficulties by fulfilling management obligations in rigid and unresponsive ways (eg. OH&S and recording of hours). Some people felt that money is wasted in the unresponsive service provider management systems and direct funding might free up some funds to improve pay and conditions for attendant carers, and thereby improve the quality of care, without compromising OH&S and employment responsibilities. One ACP employer model participant 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 ACP cooperative model participant 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.

### 3.2 Support Received through ACP

Most people in both groups receive the maximum hours of support (34 hours plus one hour emergency care) (Table 3.1).

**Table 3.1: 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 ACP 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 comparison group ACP cooperative model clients'

comments about the care management experiences are most similar to the direct funding participants' experiences.

### Types of assistance

All evaluation participants receive personal care depending on their support needs. In addition, some people receive domestic assistance e.g. cleaning, meal preparation, shopping; transport assistance; and administration/organisation services. Generally the types of assistance received are similar in both groups. The direct funding participants tend to have more flexibility to change the care arrangements 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, do errands and shopping. All direct funding participants have family or friends who provide additional support (Table 2.1).

People in direct funding, employer and cooperative models commented 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 three direct funding participants, despite the allocation of set-up funds. They had interpreted that they must still wait on PADP to purchase a hoist or more suitable wheelchair, or pay with their own savings if it did not fit within the guidelines for the set-up funds.

### Choosing the provider

Comparison group participants chose their service 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 and control 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 service 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.'

### ACP support compared to prior support

The evaluation participants sought ACP support when they heard about it from professionals or other people with disability. Before receiving ACP, most people in the comparison group received HACC services. They changed from HACC providers because of the quality of care; the maximum hours available in the HACC program were insufficient for their needs; 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 had previously used a brokerage HACC provider but changed to ACP because the hours available in HACC were insufficient for her needs when her condition changed. A comparison participant could not work before he joined ACP because of unreliability of the HACC service. The impact of ACP is that it has allowed him to maintain a fulltime job. He said,

> [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.

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 moved to a shared house when he got ACP.

### 3.3 Quality of Care

Direct funding participants reported improved quality of care because they have greater control over their choice of attendant carers, training and support for the attendant carer. They said this control results in better quality care such as consistency. Their attendant carers have knowledge, skills and attributes to match the person's needs and preferences. Family members reiterated these opinions, commenting that, 'When using the service provider there was high turnover of staff – no consistency, which meant low quality care. The biggest thing is keeping the same team.' Another family member said that, 'Just knowing that carers are going to show up also creates a feeling of confidence and security for us all.'

Three aspects of quality of care are discussed: reliability, flexibility and choice; relationships with attendant carers; and satisfaction with support.

Case study on quality of care

Ben is married with two young children and works full time in his own professional business. He lives in a regional area and has a good team of attendant carers. He was previously using a service provider who he felt was not supporting him, but at the same time was imposing restrictions on his care, for example having to wait two weeks for a new attendant carer to start. He is able to keep a better track of the hours he uses and use the direct funding to cover first aid training and associated administration costs such as phone calls. He finds brokering the payroll tasks to a local bookkeeper is working well and he gets much better value with his funding. The attendant carers are happier, better trained and the relationships have improved significantly. As a result, the whole family is better supported.

#### Reliability, flexibility and choice

All direct funding participants and family members reported improved choice and flexibility, except former ACP cooperative model participants, who already experienced these qualities. For example, one direct funding participant can use an

attendant carer for half an hour when he returns home from work because the attendant carer lives nearby. A family member said the care arrangements had, 'changed from restrictive to reliable and flexible.'

Participants and family members reported that attendant carers are more reliable. A participant said he had not experienced one instance of an attendant carer not turning up since being on direct funding. Another person said his attendant carers always turn up on time now, so he can carry out his planned activities. This has a fundamental impact on their daily life because it has implications for being on time for work, quality of physical care, being able to make arrangements and keep them and having a predictable routine. Two participants 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.

> Direct funding is more flexible. We don't have to ring a provider, who is difficult to contact. We can more directly communicate with the workers. The carers are also happier to directly ask about issues such as holidays and pay.

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. One person reflected that he is able to arrange his care to meet his range of needs. His attendant carers can respond flexibly to daily changes to support needs to suit changes in his work, social and home life. Several ACP cooperative model participants also reported having this control already. One direct funding participant contrasted this with the difficulties she had before direct funding,

> In my experience … even though the agency made every effort to provide flexibility, they were limited by the arrangements made with employees. I could not offer to pay more to the carer who rode her bicycle in the middle of winter to my house to get me out of bed at 4.45am, so that I could get to work on time. Needless to say she managed to keep it up for a while, but soon realised that she could get a job in a cafe, start at 9:00, work a longer shift and get paid the same, if not more. My family took over, filling the gaps as I struggled to find another carer willing to do the job.

They made emergency arrangements through various means such as paying an emergency shift allowance, attendant carers negotiating with each other to cover shifts, using an agency and relying on informal carers.

**Relationships with attendant carers**

A further reason for change in the quality of care is improved relationships between attendant carers and participants according to the participants, family members and attendant carers. They have built and enhanced trust, which has benefited the participants' quality of care and the attendant carers' conditions. A participant noted,

> The relationship between the 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.

Similarly, another participant said, 'The buck stops with me now. I have noticed subtle shifts in the way they respond to directions.' Direct funding participants feel they have a supportive and mutually beneficial relationship with the attendant carers. One said 'I'm now not regarded as simply a passive recipient of care, but as an active, equal manager of the process. DADHC's perception of me has also changed.' Some direct funding participants said that their experience of the ACP employer model was that the service provider's control over the relationship with the attendant carer undermines the ongoing relationship between client and attendant carer; for example, understanding who is the boss.

The attendant carers have greater professional commitment because of the direct personal relationship. The participants and attendant carers report more 'give and take' in the relationship because of that commitment. Negotiating changes to usual routine can be done directly and without fuss from the perspectives of both the participants and attendant carers. Examples given relate to social and work arrangements, such as social, exercise and travel arrangements.

Family members said the better relationship has improved the attendant carers' reliability. Another family member commented that the attendant carers negotiate with each other to fill in shifts. Direct funding participants and their family members reinforced that the direct funding model allowed them to better look after their attendant carers and create positive relationships. They reported that this, together with better pay and conditions resulted in less sickness and late notice of being unable to attend a shift.

**Satisfaction with the support**

The level of satisfaction with support differed between the direct funding participants and many people in the comparison group. All people using direct funding are overwhelmingly satisfied with their care. They reported improved consistency of care. A participant said that they were satisfied because, 'direct funding is so much better as we have greater control.' Another participant reflected that, 'It is so great not having to justify my life to a coordinator who doesn't know me or hasn't even met me'. Family members said, 'Because there is a better relationship with the attendant carers, we can tell them exactly how we want things done.' and 'Better and more direct messages are passed on between the us and the carers.' A family member concluded the interview by saying, 'it's all positive and its really helping the people it's meant to.'

People who had previously used the ACP employer model noted that the biggest quality impact of direct funding is that the service focus is now on the participant. A family member succinctly said, 'Before it was what [the service provider] wanted, the times they could arrange staff. Now the focus is on him.' The reasons for improved satisfaction with care arrangements are summarised in Section 3.5.

Several comparison people also commented on the high quality of their attendant carers. One person, who manages the support herself in the ACP employer model,

recruits her own attendant carers through word of mouth and advertisements; and she uses the provider for training, records and equipment. She questions the rigid management processes of her provider. Another ACP cooperative model participant 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 are very dissatisfied (25 per cent). Most people who are dissatisfied use the ACP employer model. The main dissatisfaction about the cooperative model is a lack of an emergency back-up system, discussed below. People who are dissatisfied had a range 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 penalty rates so weekends and nights often are uncovered; no guaranteed times; and
- organisation – accrual and recording of hours by the provider; responsiveness; communication; availability for contact and discussion with the provider; provider prioritising the attendant carer over the participant; flexibility; restrictive responses to OH&S obligations; reliability of timing and accuracy 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 people from all three ACP models 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. Another said '35 hours a week is not much when you consider the range of tasks that need to be completed'. Some people suggested that ACP needs to increase the maximum to 42 hours, particularly since more people with disability are ageing. They did not explain why 42 hours would be sufficient. ACP has a process for reassessing hours if someone's support needs change.

Some comparison participants made suggestions about how to improve their satisfaction with care. They suggested accreditation of staff to improve the standard of care. Providers are currently accredited by DADHC and have the responsibility to train staff. Several ACP cooperative model participants 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 procedures for when an attendant carer fails to arrive need to be improved. Other

people spoke about already having this arrangement through their provider. The cooperative model providers are currently investigating these difficulties.

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.

### 3.4 Management and Satisfaction of Attendant Carers

The final aspect of care arrangements is the management of carers. Direct funding participants report having more stable attendant carers, and therefore enhanced consistency of care. They can offer better pay and conditions, which results in better quality of attendant carers, more stability, and better relationships. A participant summarised why the financial arrangements had such an impact on the management of attendant carers, which improved her quality of care,

> Probably the most crucial benefit is that it adequately responds to the inherent necessity for flexibility that is part of providing personal care. Given that the work I can offer my carers is limited to personal care work and that my personal needs change and will continue to change over time, I need a structure for paying my carers that is as flexible as possible so that I can attract them to work for me and retain them into the future.

Case study of management of attendant carers

Carlos previously used the ACP employer model. He had many problems with communication with the service, rostering carers and the payroll system. The attendant carers were not previously getting superannuation. He has kept quality carers that were going to leave the service provider that previously provided his care. He has used his skills in financial management and business to manage his direct funding responsibilities, has become more focused during his days and is developing new skills and experience. Direct funding has allowed him to improve his social networks, as he is able to go out late at night and still get to bed, because he has a better relationship with his attendant carers and they are being remunerated much better. His reputation as the town's party animal remains intact.

#### 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 immediately after the interview.

As ACP participants can only offer a total of 34 hours per week for their staff and they need a pool of staff, each attendant carer only works a small number of hours. Unlike many other similar services (group homes, nursing homes, nursing agencies etc) ACP offers short shifts, often at unsociable hours. Participants generally have to have at least 5 carers to cover illness, holidays and different tasks and hours (same person usually cannot work both ends of the day). Therefore each carer is working a

small amount of hours each week, often ACP is their second job or they are studying or parenting and juggling ACP around other commitments. In ACP it is important to retain a pool of carers even though you cannot guarantee them much work.

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 to pay attendant carers to enhance the commitment and availability of staff. This is largely due to better pay and conditions.

*Recruitment*

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 and some have not had to recruit. Some attendant carers resigned from their previous service provider because the conditions under direct funding are 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 the 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.'

Direct funding ensures that participants have primary responsibility for recruiting suitable staff, thereby increasing compatibility and retention. The participants and family members felt that it was appropriate that the person receiving the care is the one determining the required skills, experience and qualifications of carers rather than the service provider. One family member said,

> Non-nursing trained staff often have a better attitude to enabling independence and many tasks are not nursing, such as washing, cooking, and errands. For example, uni students are suitable as carers as they have flexible hours and provide a peer network.

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. Participants living in regional areas report greater support, 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. However, people in small towns do have difficulties recruiting staff, particularly for some shifts.

*Retention*

Participants have improved the retention of their attendant carers because the pay, conditions and relationships are better under direct funding. At the end of the evaluation, most participants had retained the same carers. When asked about job security, one attendant carer felt she 'had a safe, good relationship.' Some participants had employed additional carers to cover sick leave.

One family member said that the 'best thing about direct funding was being able to attract and retain better carers so that his [participant] needs are better met'. An attendant carer agreed, saying, 'When you get a good carer you want to look after them, so you can hold onto them for quality and consistency of care.' For example, one participant said his attendant carers are now receiving superannuation for the first time.

Retention is a problem for some participants because of the small number of hours they can offer. Two participants are using agencies to fill in some regular shifts, odd hours and emergencies. Participants are reporting better control and more choice when using agencies as back-up. One person has familiar carers when he uses the agency, which is important for managing his physical health risks. People who are using agencies for back-up care are reporting a positive response from agencies and more direct communication.

*ACP employer and cooperative models*

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

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 ACP employer model participants 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.

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

**Pay and conditions**

All of the direct funding participants spoke about the importance of increasing the pay rates for carers and saw this is a practical way to improve the overall quality of care and support. One said, 'The main thing for me has been to have flexible hours by

paying higher pay for the carers.' They all pay above award rates. The pay rates vary between direct funding participants and between shifts (Section 5.1).

Case study of pay and conditions

Michael has developed a detailed system under direct funding with clear policy and procedures for his care, fixed term contracts and review processes, grievance policies and innovative supports for the attendant carers. He has tailored in-home training with the help of respected private occupational therapist. He has structured the contract, pay and conditions (within the parameters of the award) to suit his particular needs and also the needs of his attendant carers at a given time, for example implementing emergency shift loadings and return shift loadings. Attendant carers are more willing to cover undesirable shifts because of the better pay and conditions. For example, he needs to get up at 5am to attend early classes at the local college (which he was previously unable to do because his attendant carers were not willing to come at that time). His attendant carers are now more responsive to his requests because he is officially managing the arrangements. With flexible and quality care, he has less pain and stress and has returned to his creative work. His family relationships have improved now that his family are not regularly providing him with personal care.

Most direct funding participants offer variable pay rates because their needs vary throughout the week and some shifts harder to cover. For example, in a regional area a participant may live far from attendant carers, and so pay a higher rate at night time when it is a short shift. Rates also vary 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 when carers are called in on late notice.

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. All carers' contracts were renewed under this arrangement. 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.

All participants have written employment contracts with their staff. Some participants sought legal and accounting advice to write the contracts. Some participants suggested that DADHC provide support to prepare contracts, in the form of a pro forma, individual advice or pro bono legal support.

In contrast, some comparison group participants in the employer models commented that the quality of their care was compromised by poor pay rates, no penalty rates with some providers and poor payroll management. They said the impact is 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.

Pay and conditions have improved for direct funding attendant carers. Reasons include the direct relationship between the participant and attendant carer so they are able to change the pay and conditions in response to the needs; an attempt to ensure

committed, reliable staff; competition for employment within the sector and with other employers who have better pay, longer and more convenient shifts; and lower overheads so they have more funds available for employment costs. These reasons are likely to continue to protect attendant carers against any potential vulnerability in their pay and conditions associated with a small employer.

**Training and occupational health and safety**

All direct funding participants have developed information, training and occupational health and safety (OH&S) processes specific to their needs. The participants and attendant carers commented on the effectiveness of the new systems discussed below.

*Information*

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 log sheets. This is done in consultation with the attendant carers and can be reviewed easily and without delay, as had been previously experienced when using a service provider. Some participants reported that in the ACP employer model their experience was that these systems were unnecessarily rigid and unsystematic, such as unclear policy about client logbooks, including questions of where the information is stored, who has access to it and how it is used.

One 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. An attendant carer noted the benefit of working directly for the participant is the development of a positive team approach, 'We can fill in for each other and provide a good routine for the client and a circle of support.'

*Training*

Participants have implemented training options such as on the job training from the participant, other attendant carers and professionals; local training; and ACP provider training when relevant. 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 online resources, courses, manuals and guidelines through organisations such as Paraquad. Direct funding attendant carers access local, relevant training, such as first aid training and seminars, and training on specific health conditions and treatments (not impairment).

Other examples of training are paying senior attendant carers and community nurses and occupational therapists to conduct on the job training for new attendant carers and assessments as required. One direct funding participant pays a senior attendant carer an extra fee to conduct in-home training. This has a significant impact on the subsequent quality of care provided to the participant, including consistency and management of health needs, such as assisted coughing and pressure care. 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.

The quality of 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. Participants reported that training costs are also less than before the pilot because they are able to recruit experienced and qualified attendant carers and lower the staff turnover.

These approaches to training have improved the quality of care according to the participants and attendant carers. The attendant carers found the specific, local training useful, even though they were experienced carers. Training 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. A family member reflected that providing paid training was a morale booster for the attendant carers. Another family member said that the personal approach to training made the quality of care better and based on individual needs.

*Occupational health and safety*

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. An attendant carer appreciates that the participant has improved the safety of the attendant carer and participant by investing in safety and first aid equipment.

Several participants use occupational therapists to conduct OH&S assessments of their home and personal care routines. One person has a stretching routine for the attendant carers. 'The carers said that it was the best and most relevant training they'd had because they were problem solving together.' The participants reported no instances of injuries or insurance claims during the pilot.

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. This did not appear to be the experience of the attendant carers in the pilot. A participant said,

> Quality and consistency of care has increased considerably because of better training, the carers are paid on time and there is direct communication … The carers respect me more because I am doing all this work [managing the care] and they appreciate it … They are more reliable, punctual and professional.

*Comparison to ACP employer and cooperative models*

Some 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 meaning their attendant carers had to travel. Training was also inaccessible for some attendant carers and participants in terms of public transport access, and the times it was offered. Comparison participants commented that for many attendant carers it is their second job so the timing is impossible. In addition, they reported that some providers still require compulsory general training for people

who have vast relevant experience, and have no flexible approach in delivering training.

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

**Attendant carer satisfaction**

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. 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, and processes are less complicated.

Interviews with attendant carers supported the participants' perceptions of their improved satisfaction now that their pay and conditions are settled. Many of the attendant carers have experienced increased pay and conditions in their new care arrangements. A 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.' An attendant carer said her pay had increased and the employment relationship had substantially improved. In contrast, in her former relationship with the service provider, she had experienced poor rostering, low pay and a disrespectful attitude to her needs.

Another attendant carer who switched from a provider to direct funding expressed her frustration about the former employer, remarking that, 'They had been doing "bugger all" – not supporting the client or the carers … the government was paying a middleman to do an insufficient job.' In contrast, she said under the direct funding arrangements she feels well looked after and able to enhance the give-and-take type relationship with the participant. Another attendant carer said that the direct funding has had a positive impact on the client 'amazingly and improved everything' including enhancing flexibility of care so that work and social life is made easier. She said, '[I think] he feels in control of his life – why shouldn't he be the boss!' Another attendant carer said, 'It's an excellent program it would be mad to stop it'. An attendant carer acknowledged that the direct funding participant can feel more confident expecting his attendant carers to be committed and reliable, which is especially important when they are required to work from 5:30-7:30am each weekday to get him ready for work.

In relation to the management of the direct funding option, attendant carers reported that teething problems with the administration of the arrangements have been sorted out. They thought that if the option continued, new participants and their attendant carers would benefit from guidelines about how to manage direct funding. Uncertainty about the continuation of the direct funding option is affecting attendant carers; for example if they need to prove continuity of employment for home-loans or to plan for future security.

### Problem solving

Problems between participants and attendant carers solved during the pilot included communication about pay rates, number of hours and pay periods. The attendant carers thought the participants should consult and decide the conditions prior to the direct funding employment relationship. They did not raise problems about tax, superannuation, insurance or OH&S.

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 ACP cooperative and employer models commented that they already have the benefits from good relations with their attendant carers without needing direct funding. Similarly, the service provider managers noted that helping clients and attendant carers to manage their relationship is one of the biggest reasons for clients changing between ACP service providers.

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.' Participants did not report any instances of dismissal.

## 3.5 Summary of Care Arrangements

In summary, the reasons the participants chose to be in the pilot were to achieve the following goals:

- enhance independence, flexibility, reliability, customised training;
- improve control over life, hours, money and attendant carer conditions;
- achieve a direct relationship with attendant carers;
- avoid the complexity of the ACP employer model experienced by some people, such as rigid methods of managing care arrangements, recruitment, limited flexibility and control and cost inefficiencies; and
- extend the control and flexibility of the ACP cooperative model already experienced by participants who were using it.

Most ACP clients had not heard of direct funding. Before participating in the pilot, direct funding participants and other comparison ACP clients thought the risks might be in relation to liability, insurance, tax, OH&S, pensions and the scope of support; and financial and management responsibility.

The support received through ACP is similar in both groups. The direct funding participants experienced improved flexibility to change the content of the support and respond to specific needs eg. access to education, work and shopping. Like other ACP clients, they supplement the ACP formal care with support from family or friends and HACC.

They experience better quality of care than they had previously had because of the additional control they have over their choices of attendant carers, training, support

and conditions. In relation to reliability, flexibility and choice, they experienced improvements relative to their past experience and relative other ACP clients (except people who had previously used the cooperative model). Examples are ability to change arrangements and receive short episodes of care. This control has a positive impact on informal care and participation arrangements. Most ACP cooperative model clients and some ACP employer model clients experience most of these benefits already. Many people with experience of the ACP employer model spoke of problems relating to quality and organisation. ACP employer model service providers could investigate how to change care arrangements so that other people can also achieve their quality of care goals.

Relationships with attendant carers improved because they have trust, commitment, a direct personal relationship and they can negotiate and resolve problems directly. They are more satisfied with their support, although some need more hours of care, which can be reassessed through ACP.

Management of attendant carers has improved in terms of conditions and satisfaction. Recruitment and retention has improved because they can offer better work conditions. Recruitment has been easier outside the cities. Some people still use back-up from agencies. Unlike the ACP employer and cooperative models, they have the flexibility to increase pay rates and conditions and offer variable rates for shifts, tasks and bonuses for good service. The offer support, training and OH&S that is personalised to their support needs and the experience of the attendant carers. Some participants pay experienced carers to train others. The participants have a greater commitment to training and OH&S because of the consequences for their own care and employment responsibilities. Attendant carer satisfaction has increased because they have better pay and conditions and a direct relationship. Problem solving is more direct and immediate.

# 4 Governance

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

The third aspect of the evaluation is to review whether appropriate and effective governance arrangements are in place to support the establishment, implementation and development of the direct funding option. Direct funding participants, attendant carers and government officials are satisfied with the governance arrangements. ACP service providers said the arrangements have not had an impact on their normal operations.

## 4.1 DADHC Support

A DADHC senior policy official is responsible for establishing and implementing the pilot (approximately 10 hours per week). She is responsible for financial management monitoring and reporting. The policy official arranges teleconferences with all the participants to share information and is available to respond to questions as they arise.

The position is supported by DADHC managers and informed by the Department's Physical Disability Expert Advisory Group. Other parts of the Department were also consulted in the establishment process, such as for legal, human resource and taxation advice. Payment is managed through Businesslink, a NSW government agency responsible for financial payments.

All participants are satisfied with the support provided by DADHC, both with the communication with the policy official and the system support to respond to new questions. They noted improvements in the support process as the pilot has progressed, such as initial late payments to some participants. They find the internet forum and teleconferences useful. The internet forum might be improved through using a moderator, one participant noted. They suggested that these methods of communication could be supplemented with informal face to face meetings to share ideas and systems, perhaps in geographical areas.

## 4.2 Transition to Direct Funding

Most participants experienced a smooth transition from the main ACP to the direct funding pilot. Some people had problems 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 some 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 suggested exploring whether new participants needed an option for training and development on administrative responsibilities and managing attendant carers. They see this as a way for other people to take advantage of the lessons from direct funding pilot. One person suggested that DADHC could arrange mentors to help new participants transition from ACP to direct funding. Another suggested a training manual, templates of spreadsheets and examples of software used by participants.

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. For example, a teleconference could be arranged to review and share their experiences. They suggested that their contribution 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.

### 4.3 Implementation

Most participants did not report ongoing difficulty with taxation, impact on government benefits and insurance, discussed below; and financial arrangements, such as pay rates and superannuation, once they established the appropriate systems (Section 5.1).

Taxation and government benefit questions were resolved before the pilot was implemented, 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;
- participants are not businesses so they cannot claim the GST; and
- if participants paid family members a fee for administration (they cannot employ family members as attendant carers) this could affect the family members income eligibility for carers benefit.

One family member raised a problem that Commonwealth Carer Respite Centre did not recognise the participant as an ACP provider (only other agencies) and therefore would not broker respite hours to the participant's regular carers. The partner of the participant then had to cancel her planned break away. While it is correct that ACP direct funding clients are not providers, this should not affect access to respite services according to DADHC.

All participants have taken out insurance coverage as necessary for employment and caring responsibilities, for example, domestic workers compensation. All direct funding participants commented that the cost was reasonable ($27.50 - $80 per year) and easily arranged. They have established occupational health and safety systems (Section 3.4).

The participants and DADHC have not resolved access to insurance for client injury. Some of the participants are not concerned because they feel they manage the risk. However, others were concerned enough to continue to seek an insurance option. None felt they should leave direct funding pilot if the question could not be resolved. The uninsured risk also applies in the ACP cooperative model.

## 4.4 Accountability Requirements

Participants signed a funding agreement with the Department, equivalent to agreements with ACP service providers. Accountability is required through monthly and annual reporting from the participants. Reports include expenditure, payment and hours of care in the form of electronic and documentary evidence. This enables DADHC to analyse management of funds, hours and cost variation per participant. It also facilitates advice to participants to improve risk management of hours and finances. Some participants experienced difficulty aligning the monthly report with fortnightly attendant carer pay but these problems are resolved. One participant has changed to weekly pay to attendant carers to overcome this problem.

By the final interview, participants reflected that the reporting process had become more efficient. For example, for one participant, the attendant carers enter the daily hours and the participant enters them into the reporting form each week.

They suggested that once people are established in direct funding that they reduce to less frequent reporting, such as 3 or 6-monthly. The officials concurred with this suggestion after people have a trial period on the model to assess the risks for the participant and the government in terms of adequately managing the use and cost of support hours. Financial management and accountability are discussed further in Section 5.

# 5 Effective Use of Resources

Does direct funding provide an effective and efficient use of resources compared to existing arrangements?

The final evaluation question is whether direct funding provides an effective and efficient use of resources compared to existing arrangements. From the perspective of the ten participants, attendant carers and government officials it is cost effective because quality of care and participant outcomes are better within the same cost or less cost for most participants. In this section, the financial arrangements and the participants' experiences are analysed against the financial management data and discussed relative to the other ACP models. The cost and outcomes are summarised using cost effectiveness analysis.

## 5.1 Participants' Financial Arrangements

Participants are responsible for managing both the attendant carer employment costs and all other financial costs associated with employment, caring and accountability to government for how they use the funds. During the pilot, they managed their financial obligations responsibly and within the intention of the program. These arrangements are discussed below in terms of funding, administrative arrangements, attendant carer pay rates and managing support hours.

### Funding

The annual grant is calculated and managed in the same way as payments to ACP service providers in terms of assessed number of hours by cost per hour:

- the number of approved ACP hours, up to 34 hours plus one emergency hour per week, annualised. Hours are calculated based on a DADHC assessment when they enter ACP and reassessed as required; by
- $37.92 per hour in 2006/07 ($39.17 in 2007/08).

Funding from the Department is paid prospectively into the participant's bank account each calendar month (1/12 of the annual grant). In addition, some participants received establishment funds on an as needs basis for software and office related expenses, as available in all ACP options (maximum $968 for 4/10 participants). Some people already had business and care equipment so they did not have additional set up costs. They reported that the establishment funding was an important consideration for the people who used it.

Participants are satisfied with the funding arrangements from DADHC, after the delay in the first payments was resolved. They did not experience any payment problems in the second half of the pilot. Initially, they raised questions about what the funding could cover, for example hiring a hoist for travel, repairing a hoist, ironing, gardening and carers expenses when travelling. They said specific questions like this are sorted out by referring to the ACP Guidelines or by DADHC resolving questions as they arise.

### Administration

The participants have a range of methods for administering the funds (Table 5.1). Half the participants do it themselves, but two have changed from self-administration to

contracting to a bookkeeping company because it was too time consuming. One has a bookkeeper check his records each month. Another had initial support from an accountant but she did not need ongoing advice after the systems were established. Two pay a family member for administrative support; for one family member it was a new skill.

**Table 5.1: Direct Funding Administration**

| | Number of participants |
|---|---|
| Self administration eg. MYOB* | 5 |
| Contracted to bookkeeping company | 4 |
| Contracted to ACP provider | 1 |

Note: *Mind Your Own Business software

In most cases, the impact of these arrangements is that administrative costs are lower than other ACP models (Table 5.2 and Table 5.3). However, as discussed below, costs other than gross attendant carer pay are very high for some contracted administration (up to 28 per cent of total costs).

Most participants took several months to establish systems. By the last evaluation interview, they had become efficient and are satisfied with their management systems. One participant takes two hours per fortnight for payroll. A family member said, 'Direct funding saves time and bother, faxing and phoning the agency could take days for a response.' Another mentioned that it takes extra time but it was worthwhile because of the improved quality of care.

For the people who self-administer direct funding, when asked how they would make alternative management arrangements, for example if they were sick, they said they would pass the responsibility to a trusted family member or friend (paid or unpaid) or contract the administration. Several had trained a partner or friend for back-up, because it would be a conflict for attendant carers to be responsible for their own administration. One participant has documented the policies and procedures so that it can be handed to someone to manage if she is unwell. One person said he would leave direct funding and return to the cooperative model if he became unwell.

### Attendant carer pay rates and administrative costs

The largest costs are attendant carer employment costs (average 89 per cent of total costs, Table 5.2; average gross pay 83 per cent of total costs, Table 5.3). Direct funding attendant carer pay rates range from $24.00 to $27.50 (annualised average $27.07; range $22.43-31.60; Table 5.2). These pay rates are higher than the rates paid in the ACP employer and cooperative models (approximately $19.80-23.80). Some people pay more for nights or weekends (eg. $32.50), split shifts and bonuses (also Section 3.4). Split shift allowances are important for attendant carer travel costs. Two people reduced the pay rate to have more funding in reserve, either before or during the pilot. Others increased it from $21.50 and $23.80 to $24 and $25 after they had saved funds. Some people pay a fixed day rate when they travel. Bonuses are '… to increase commitment, motivate and give the carers are reason to assist more.'

**Table 5.2: Financial Management to July 2007 (annualised)**

| | Hours | | Cost $ | | Cost per hour $ | | Per cent of ongoing costs | |
|---|---|---|---|---|---|---|---|---|
| | Mean | Range | Mean | Range | Mean | Range | Mean | Range |
| Hours funded p.a. [1] | 1789 | 1720-1825 | 67,820 | 65,249-69,240 | 37.92 | - | - | - |
| Saved hours prior direct funding[2] | 16 | 0-63 | - | - | - | - | - | - |
| Hours used (total costs) p.a. | 1802 | 1685-2145 | 50,143 | 38,361-65,081 | 36.36 | 32.80-39.73 | 100 | 100 |
| Attendant carer costs[3] | - | - | - | - | 32.48 | 28.82-38.23 | 89.31 | 78.12-97.76 |
| Administrative costs | - | - | - | - | 3.88 | 0.88-8.17 | 10.69 | 2.24-21.88 |
| Attendant carer average gross hourly rate[4] | - | - | - | - | 27.07 | 22.43-31.60 | 83.07 | 73.31-95.63 |
| Establishment funds/costs | - | - | 2,212 | 0-7,066 | - | - | - | - |
| Annualised unspent funds after cost of saved hours [2] | (21) | (253)-102 | 18,709 | 2,145-31,215 | - | - | - | - |
| Actual unspent funds after cost of saved hours [2] | | | 1,989 | (340)-6,200 | - | - | - | - |

Source: DADHC financial records

Notes: 1. Actual funding and costs from Nov 06-Feb 07 to June 07
2. Up to 50 saved hours can be carried forward to the following financial year
3. Salary plus on-costs (salary, PAYG tax, superannuation, workers compensation insurance, leave provisions, agency contractors, transport allowance)
4. Gross (salary plus tax) see Table 5.3 for details

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

> DADHC paid the agency [$37.92] for every hour of my care, and the [attendant] carers were 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 … *my* funding!

Administrative costs include accountancy and payroll, postage, bank fees, insurance, stationery, telecommunications and training, fuel, computer equipment and software, books, office furniture and equipment, staff support (training and meetings), workers safety equipment), OH&S report, advertising and recruitment. Under the ACP cooperative and employer models, clients incur overhead costs that they cannot recover, such as telephone costs for arranging carers, which they can now reclaim.

Administrative costs average 11 per cent of ongoing costs (range 2-22 per cent, Table 5.2). With an alternative definition of total costs less gross salaries, other costs average 17 per cent (range 4-27 per cent, Table 5.3). Data about the administrative cost of ACP employer and cooperative models are not available. The direct funding

administrative cost average is similar to DADHC expectations for other programs (10 per cent), however two people had an administrative cost 15 per cent or more.

**Table 5.3: Attendant Carer Gross Pay Compared to Total Costs and Funding, per Participant**

| | Per cent of total costs | | Average hourly cost ($) | | | |
|---|---|---|---|---|---|---|
| | Carer gross pay* | Other costs | Attendant carer pay rate | Attendant carer & agency pay rate* | Total cost | Balance from funding ($37.92) |
| | 87.04 | 12.96 | 27.81 | 28.55 | 32.80 | 5.12 |
| | 87.25 | 12.75 | 28.78 | 28.78 | 32.98 | 4.94 |
| | 83.74 | 16.26 | 22.43 | 29.20 | 34.87 | 3.05 |
| | 73.40 | 26.60 | 26.07 | 26.07 | 35.52 | 2.40 |
| | 84.80 | 15.20 | 28.32 | 30.54 | 36.02 | 1.90 |
| | 71.80 | 28.20 | 26.79 | 26.79 | 37.31 | 0.61 |
| | 73.31 | 26.69 | 25.66 | 27.36 | 37.33 | 0.59 |
| | 95.63 | 4.37 | 28.00 | 36.26 | 37.92 | 0.00 |
| | 94.15 | 5.85 | 25.28 | 36.82 | 39.11 | -1.19 |
| | 79.54 | 20.46 | 31.60 | 31.60 | 39.73 | -1.81 |
| Average | 83.07 | 16.93 | 27.07 | 30.20 | 36.36 | 1.56 |

Note: * includes agency and contractors

When calculated as total annualised hourly rates, costs were less than funding for most participants (8/10) but slightly greater for two participants (Table 5.3). People with the highest cost surplus had high attendant carer pay rates (average over $28 per hour) and mid-range other costs (12-16 per cent of total costs). People with deficits or breakeven costs had either high pay rates (over $30 per hour) or high other costs (20-28 per cent). For two of these participants, the very high pay rates were due to high use of agency staff. DADHC budget management is not affected by participants' different hourly pay rates and other costs because the annual grant is fixed on basis of assessed hours needed and reconciled against hours used at the end of the financial year.

Participants identified that they are experiencing more 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. Most participants report that usual monthly costs for attendant carers and expenses are less than payments, which they can then save for unexpected costs or care. They have flexibility to use additional resources to improve the quality of care, such as specific training, staff bonuses, infrastructure and consumable equipment, such as slip-on wet shoe covers.

### Managing support hours

DADHC's end of financial year reconciliation of hours and funds in the direct funding pilot is the same as grants management with ACP service providers. DADHC reconciles hours funded and used against funds granted and expended. Most people (8/10) were in surplus or broke even in the cost of the number of hours used at the end of the financial year (Table 5.4).

**Table 5.4: Reconciliation of Total Funding, Costs and Hours, per Participant**

| | Funding ($) | Total expenditure & commitments ($) | Balance of hours in pilot | Saved hours* | Surplus/deficit ($) |
|---|---|---|---|---|---|
| | 41,712 | 33,554 | 53 | 50 | 6,199 |
| | 40,638 | 32,931 | 73 | 50 | 5,748 |
| | 44,947 | 40,531 | 224 | 50 | 2,457 |
| | 40,369 | 36,723 | 85 | 50 | 1,687 |
| | 45,157 | 42,226 | 33 | 33 | 1,638 |
| | 44,818 | 43,362 | -15 | 0 | 1,455 |
| | 39,334 | 37,550 | -24 | 46 | 0 |
| | 27,902 | 27,901 | -6 | 0 | 0 |
| | 31,497 | 31,517 | -9 | 0 | -20 |
| | 45,128 | 45,519 | 21 | 0 | -390 |
| Average | $40,150 | $37,182 | 44 | 28 | $1878 |

Note: *Balance in pilot reconciled against saved hours from pre-pilot

Surplus funds from unused funds and excess hours (50 hours can be carried forward) are deducted from the participants' grant in the following financial year. All participants had managed their accounts sufficiently to absorb the reconciliation and did not have negative feedback about the process. The proportion of recouped surplus funds (5 per cent of total grants – $19,189) is similar to the other ACP models (4 per cent).

Although four participants broke even or had a small deficit (less than $400), it was only a small adjustment to future payments or forfeiting surplus hours. All participants and DADHC managed the risk of overspending through the monthly reporting process.

In addition, most people (6/10) saved hours to carry forward into the following year (average 28 hours). Some people were very conservative in their use of hours so as to manage their budget. This resulted in them sacrificing some hours because a maximum of 50 hours can be carried forward. One person said that carrying forward more than 50 hours should be considered so as to meet future needs related to illness.

During the pilot, participants are not able to receive more hours of care if their hourly total cost is lower than the funding level. Presumably, an effect of this restriction and the end of year reconciliation process is that some participants manage funds to spend excess funding on higher payments to attendant carers or administrative costs rather than returning it to DADHC.

The participants reported that they manage their hours and budget by averaging between months. One person averages 32 hours most weeks so that he can accrue hours for other months. Other people use this same strategy. Another person juggles the number of hours each week according to his needs. His priority is to stay in budget and cover the shifts. Direct funding participants said are unclear how to access the emergency care hours.

The success of the pilot in managing support hours and finances indicates that the Department could examine the option of allowing participants to purchase additional care with savings from their financial management. Additional care could be in the form of additional support or emergency hours; expenses such as transport or

equipment; or management expenses to improve quality such as professional assessments, specialist training for attendant carers and other employee benefits.

## 5.2 Cost Effectiveness

Cost effectiveness analysis provides information about the value added by ACP direct funding. It examines the cost to government of direct funding compared to ACP existing arrangements. The cost of the program per participant is calculated and the change in outcomes per participant is examined. The purpose of the analysis is to derive implications and recommendations for future funding options.

### Costs of ACP direct funding

Annual costs to DADHC of the direct funding pilot are presented in Table 5.5. Other costs to participants, attendant carers and family members were not available. The estimate of recurrent program costs per participant per year is approximately $70,000 plus any future Businesslink charge for grant payments to clients (not charged during the pilot). The cost includes the policy official time plus the funding grant.

**Table 5.5: Annual Costs of Pilot ($)**

| | | Pilot cost | Ongoing cost | Per person (10) |
|---|---|---|---|---|
| Program manager | | N/A | N/A | N/A |
| Program officer | 10 hours per week | 21,679 | 21,679 | 2,168 |
| Annual grant | Assessed hours x hourly rate | 678,200 | 678,200 | 67,820 |
| Participant establishment costs | As required | 22,119 | - | - |
| **Costs specific to direct funding pilot** | | | | |
| Establishment costs | | Advice from DADHC staff and external advisory group | - | - |
| Businesslink | Mechanism to pay grants to participants | No charge | N/A | N/A |
| Evaluation cost | Commissioned | 77,000 | - | - |
| Total | | | | $69,988 |

Source: DADHC financial records
Note: N/A – not available

Comparison costs to the other ACP models are not available. The costs are likely to be similar because the cost components are the same: program manager and program officers to support the program; internal and external advice; annual grants for each ACP client based on assessed hours by hourly rate; one-off payments to clients as required; process to pay grants internal to DADHC for payment to service providers or external to DADHC (Businesslink) for payment to clients under direct funding.

### Benefits of ACP direct funding

Outcomes discussed in Section 2.2 were assessed with three comparisons: people in the ACP direct funding pilot with other ACP clients; change over time for the ACP

direct funding participants; and direct funding participants compared to the general population. Qualitative and quantitative measures were used. On average, improvements were measured in all outcomes – health and wellbeing, confidence and self-esteem, family relationships and community, social and economic participation (Table 5.6).

**Table 5.6: Comparative Participant Outcomes during Pilot**

| Outcome | Explanation | Direct funding | | Comparison | | Average comparative outcome |
|---|---|---|---|---|---|---|
| | | Baseline | Follow-up | ACP clients | Normative | |
| Personal wellbeing | Personal Wellbeing Index (PWI)[1] | 83 | 86 | 71 | 75 | Higher average personal wellbeing than other ACP clients, other Australian adult population norms |
| Confidence, self esteem | Interviews | - | - | - | - | Return to a sense of control and managing own life, maximises independence, choice and activities |
| Physical health | Responded excellent, very good to ABS general health[2] | 60% | 80% | 27% | 56% | Better physical health than other ACP clients, similar to the general population. |
| | Satisfaction with physical health (0-100) | 76 | 81 | 67 | - | Higher average satisfaction with physical health than other ACP clients; improvements in pain and physical risk management. |
| | Satisfaction with mental health (0-100) | 93 | 90 | 77 | - | Higher average satisfaction with mental health than other ACP clients (and more satisfied with mental than physical health) |
| Personal relationships | Satisfaction personal relationships (PWI) | 87 | 88* | 69 | 80 | Higher average satisfaction with personal relationships than other ACP clients, other Australian adult population norms and satisfaction increased during the pilot |
| | Family and friends active in their lives | 100% | 100% | 77% | - | All have active social networks; improved family relationships; control in home – impact on partner and children; less pressure on family; more quality social time with family; improved friendships because greater flexibility. |
| Participation | Proportion work (paid or voluntary), study or retired | 100% | 100% | 62% | - | All work or are active in their community; some have improved their work or study participation; Better prior socioeconomic position than the comparison clients, Some comparison group clients thought direct funding could help them improve their participation through better control of care |
| | Feeling part of the community (PWI) | 83 | 84 | 72 | 71 | Higher average satisfaction with feeling part of community than other ACP clients and general population. |

Notes: [1.] Personal Wellbeing Index (PWI). Scale 0-100 where 0=completely unsatisfied, 100=completely satisfied (IWG 2005)

* Baseline and follow-up measures are significantly different at 10% Chi-Square. No other PWI domains significantly changed between baseline and follow-up.

[2] ABS 2006.

The data have several limitations to be considered when interpreting the results: the sample is very small (10); the first measure was collected up to 6 months after the participants had started in the pilot, so direct funding could already have improved the baseline measure; and the profile of the direct funding participants is different to the ACP employer and cooperative model clients in terms of age, sex and socioeconomic status, which are likely to have affected the outcomes.

**Summary of cost effectiveness**

The evaluation shows positive outcomes on all measures; positive changes to care arrangements; and an effective governance structure from the Department. Direct funding complements other ACP options. The cost to DADHC of ACP direct funding is similar to ACP employer and cooperative models. All participants managed their funds close to budget, some returning a surplus, which on average was similar to that of the main program (surplus 5 per cent of total grants). Participants who were highly cost efficient in managing their funds paid mid-range attendant carer pay rates (average over $28 per hour) and mid-range other costs (12-16 per cent of total costs). The measured outcomes were comparative improvements in health and wellbeing, confidence and self-esteem, family relationships and community, social and economic participation.

# 6 Implications for Policy Options

The pilot has been successful from the perspective of the participants and DADHC officials managing the program. The evaluation findings have implications for policy in terms of the development of possible ACP direct funding models and ways to improve service delivery quality within the other ACP options of ACP employer and cooperative models. The implications have been discussed throughout the report and are summarised below.

## 6.1 Client Capacity and Support in Direct Funding

The results of the pilot show this model is suitable for people with the skills and capacity of people who entered the pilot. Quality of care and outcomes improved. Although most of the participants live with family members or housemates, like the other ACP options, direct funding is not dependent on having informal carers or family to supplement the care or administrative support.

The participants in both groups and the service provider managers emphasised the need for participants to have the capacity to develop skills and knowledge in the following areas or have the support of people with this capacity:

- understanding the way ACP works, its guidelines, limitations and obligations;
- financial and human resource management, such as employment responsibilities (payroll, superannuation, tax, insurance and accountability), support and training for employees, OH&S requirements and contract management;
- sophisticated understanding of managing attendant carer relationships, such as negotiation and communication skills, how to resolve problems and seek advice, and conflict resolution; and
- information technology management for recording and reporting, managing attendant carers and rostering.

Most direct funding participants would like to continue to use the direct funding option. They all managed the pilot within or near to budget. No pilot participants presented an ongoing risk in terms of accessing sufficient care or financial risk to the Department due to their management of the direct funding option.

In addition, if the pilot was extended as an option for other people, the comparison group research found that the type of people who would most likely prefer it are ones who are dissatisfied with the quality of care arrangements in the ACP employer model (Section 3.3); and some people in the ACP cooperative model who are interested in extending their control and management of their care arrangements, including the pay and conditions of attendant carers. At least in the short term, only a minority of clients are likely to choose the direct funding option because of the additional employment and financial responsibilities.

Options for direct funding policy therefore include:

- continue the direct funding option for the people who participated in the pilot;
- extend the option in ACP to other people;
- develop processes to assess capacity or identify the support required; and

- develop direct funding options in other DADHC programs for people with similar capacity or support.

Administrative support for this capacity is discussed in Section 6.2.

### 6.2 Administrative Support for Direct Funding

The results of the pilot show that the participants were satisfied with the Department's administrative support provided through the policy official, group teleconferences and internet forum, written guidelines, regular reporting and feedback, responsive problem and question solving.

Implications for further policy options include:

- develop guidelines about who would most likely prefer and benefit from a direct funding option compared to other ACP funding options. This would assist to people make the most suitable choices and minimise risks to the person and the Department;
- provide administrative support to develop capacity such as training, peer support, guidelines, administrative toolkits and software; and
- provide access to an experienced policy official familiar with all ACP options responsible for responding to participants' questions and managing, assessing and preventing risks to support and financial management.

### 6.3 Attendant Carer Employment

If the direct funding option continues, implications from the pilot results for attendant carer employment conditions to consider include the following, discussed in more detail in Section 3.4:

- conditions for direct funding attendant carers improved – pay rates, conditions, training and OH&S;
- conditions for other attendant carers could be improved by considering how service providers might replicate the experience of the pilot attendant carer conditions within the other ACP options;
- availability and conditions of formal care workforce are unlikely to be affected by an ACP direct funding option, given the small number of direct funding attendant carers compared to the entire formal care workforce. However, positive lessons from the pilot experience could have an indirect effect on improving conditions; and
- modifying the relationship between family care and formal care, such as employing family members for emergency and back-up.

These implications are in the wider context of likely changes to the attendant carer workforce, due to the shortage of formal and informal carers.

### 6.4 Cost and Accountability

The direct funding pilot confirmed that the option is cost effective in terms of improving outcomes for the same or lower costs. The participants managed their financial obligations responsibly and within the intention of the pilot.

Implications for policy options include:

- continuing allocation of an experienced policy official to support program implementation, including responding to queries from the participants and managing financial accountability;
- maintaining management systems to monitor and protect against financial and support risks to clients and government. The experience of monthly and annual reporting for new participants contributed to this risk management. The Department could review reducing the frequency of reporting for clients who successfully manage care hours and finances within budget after an initial period; and
- examining the financial implications of allowing participants to apply the cost savings to purchase additional care.

### 6.5 Implications for the ACP Employer and Cooperative Models

The evaluation results show that a direct funding option complements the ACP employer and cooperative models. Clients are likely to continue to choose the option most suitable for their needs, preferences and capacity.

Many of the results about quality of care are transferable to all the ACP options. The Department could also apply these results to examining how the benefits of direct funding to improved quality of care and participant outcomes could be extended to other people with different capacity and support needs.

Implications for policy options include replicating the direct funding approach to the following aspects of organising ACP in the other models:

- care arrangements – responsive to client's needs; flexible (time, travel and tasks); client focused in management and arrangements (care fitting the person's needs); tailored to meet individual needs; and maximising independence and control.
- attendant carer conditions – training, OH&S, pay and conditions, direct relationship between attendant carers and clients, hours and tasks; and
- financial management and accountability – managing hours and clients' incidental management costs.

# 7 Conclusion

The evaluation shows an overwhelmingly positive response to the direct funding pilot from the initial participants. Their 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 of improved pay and conditions, so they are more likely to be skilled, knowledgeable 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.

# 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**

| Inputs ⇨ | Production process ⇨ | Outputs/Impacts ⇨ | Outcomes |
|---|---|---|---|
| Pilot policies, plans and infrastructure<br>Resources/funds<br>ACP participants<br>Attendant care workers<br>Service providers<br>Other service providers and programs | Pilot management and planning<br>Pilot service delivery and coordination<br>Development and monitoring of funding agreements<br>Facilitators and barriers to change | Access to choice and flexibility of services for clients<br>Client satisfaction<br>Attendant carer satisfaction<br>Effective use of resources | Increased choice and flexibility of services<br>Increased attendant carer reliability and retention rates<br>Client's increased wellbeing, economic and community participation |

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 or end of the evaluation for other participants (April or October 2007).

**Table A.1: Samples**

| Task | Measurement | Number |
|---|---|---|
| Pilot participants | Beginning and end | 10 |
| Comparison existing ACP clients | Beginning | 26 |
| ACP service provider managers | Middle | 2 |
| Family members | End | 5 |
| Attendant carers | End | 3 |
| Government officials | End | 2 |

The samples are:

- All clients in the pilot program who consent to participation;
- A sample of comparison clients in the existing ACP; and
- A sample of other participants including government officials responsible for the pilot implementation, policy, service delivery; attendant carers; service providers; and family (partners and parent). Disability support groups were consulted through the Physical Disability Expert Advisory Group.

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