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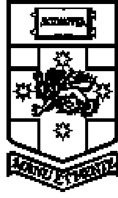

ATTENDANT CARE DIRECT FUNDING PILOT PROJECT EVALUATION

INTERIM REPORT

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Acknowledgements

Thank you to everyone who contributed to this research, particularly people who participated in the interviews and the advisory group members.

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Suggested Citation:

Fisher, K.R., and C. Campbell-Mclean, Attendant Care Direct Funding Pilot Project Evaluation: Interim Report, SPRC Report No. 11/07, prepared for the Department of Ageing, Disability and Home Care, UNSW, November 2007.

Contents

List of tables and figures

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

Abbreviations and glossary

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

1 Background

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

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

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

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

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

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

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

1.1 Evaluation Progress

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

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

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

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

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

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

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

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

Table 2.2: Personal Wellbeing Index

	Direct funding (10)		Comparison (26)		Australia
	mean	range	mean	range	mean

Table 2.3: Health and Wellbeing

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

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

Table 2.4: Satisfaction with Physical and Mental Health

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

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

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

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

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

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

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

Confidence and self-esteem

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

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

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

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

A

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

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

3 Governance

The second set of questions for the evaluati

Taxation

Taxation questions have been resolved, including:

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

4 Care Arrangements

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

4.1 Reasons for Choosing Direct Funding

Information about direct funding

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

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

Reasons for changing to direct funding

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

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

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

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

Expectations before and during entering direct funding

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

Comparison group views about direct funding

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

They saw potential benefits from the model and that it could be applied to their situation now and could resolve the problems they were having such as getting the attendant carers they wan4(am)y002 Tc 0CeEMC[(rm (.aiy00x.15 Tdr.004 Tc 0.6146 Tpb k2lla-2.15

Table 4.1: Attendant Care Program Support Profile

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

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

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

Types of assistance

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

People in both groups raised the problem that they were unclear about the degree to

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

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

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

The response by some people is to minimise contact with the provider and maximise their own control of the care arrangements (at least five people). One person expressed his frustration by saying '... [they] are putting that many rules on me that I might as well go back into an

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

Recruitment and retention of attendant carers

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

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

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

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

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

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

Some comparison group participants do not have problems recruiting attendant carers.

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

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

In contrast, some comparison group participants in both cooperative and employer models commented that the quality of their care was compromised by pay rates, no penalty rates with some provi

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

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

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

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

Attendant carer satisfaction

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

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

Problem solving

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

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

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

5 Direct Funding Service System

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

5.1 Effective Use of Resources

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

Financial management

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

Efficiencies in administrative and overhead costs

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

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

5.2 Impact on ACP Providers and Clients

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

6 Implications for Policy

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

6.1 Continuation of the Pilot

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

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

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

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

6.2 Client Capacity

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

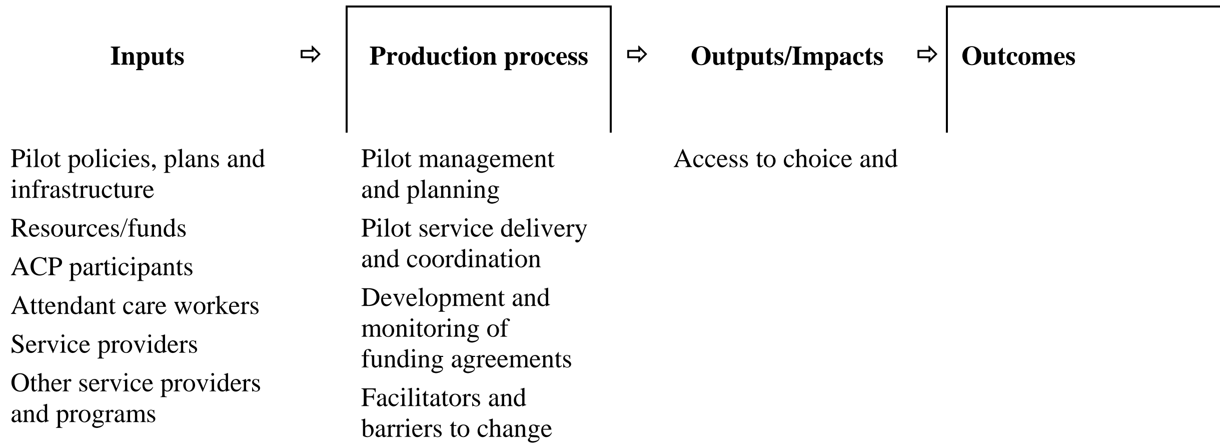
The participants in both groups and the service provider managers emphasised the need to have the capacity to develop skills in financial and human resource management; as well as a sophisticated understanding of managing attendant carer relationships.

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



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