

# Direct Funding Trial: Final evaluation report

Prepared for:

Lifetime Care and Support Authority

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Identifying details in the research participants' stories have been changed to ensure anonymity.

The views expressed in this publication do not represent any official position on the part of the Social Policy Research Centre or the Lifetime Care and Support Authority, but the views of the individual authors.

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## Abbreviations

ABS	Australian Bureau of Statistics
ACIA	Attendant Care Industry Association
ASIA	American Spinal Injury Association
CANS	Care and Needs Scale
DFT	Direct funding trial
HREC	UNSW Human Research Ethics Committee
IT	Information technology
Lifetime Care	Lifetime Care and Support Authority
LTCS	Lifetime Care and Support Scheme
NDIS	National Disability Insurance Scheme
NIIS	National Injury Insurance Scheme
NSW	New South Wales
PWI	Personal Wellbeing Index
SCI	Spinal cord injury
SPRC	Social Policy Research Centre
TAC	Transport Accident Commission, Victoria
TBI	Traumatic brain injury
UNSW	University of New South Wales Australia

## Brief summary

The Lifetime Care and Support Authority (Lifetime Care) provides treatment, rehabilitation and care for people who have been severely injured in a motor vehicle accident in New South Wales (NSW). Lifetime Care is planning to offer its scheme participants the opportunity to have increased choice and control over the way their supports are delivered and managed. In 2014 and 2015, Lifetime Care conducted a trial of direct funding of attendant care and commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to evaluate the trial. The evaluation used mixed research methods and included trial participants and comparison groups. A process and outcomes evaluation, as well as an economic analysis, were conducted. This report presents the evaluation findings.

Most trial participants reported positive impacts of direct funding in various areas of their lives. More than the comparison group, trial participants were able to adjust their attendant care support to suit their needs better and enhance their quality of life.

Trial participants had positive experiences with direct funding. Increased control over providers, workers and support arrangements gave them opportunities to address previous issues with their support and adjust support to their needs. Almost all managed their packages well. Relationships with workers, providers and Lifetime Care improved, and no-one perceived that direct funding had negative impacts on them.

As lessons from the trial emerged, Lifetime Care adjusted policies and procedures where necessary. Internally, staff were trained to understand the aims and processes of direct funding. Questions from participants were addressed as they arose. Monitoring procedures were under review, and the views of attendant care service providers were considered.

The economic analysis found that the cost of direct funding support packages was stable and similar to those of non-trial participants, while Lifetime Care's program management costs were relatively low.

The positive experiences of trial participants and the economic analysis show that the model is feasible. Suggestions for how the model can be further improved as it is rolled out to other people and other support types include:

- Lifetime Care could review the support available for direct funding participants, including clarity of information, scope and content of setup support, and ongoing administrative, legal and peer support.
- Involving attendant care service providers more in the transition to direct funding might support them to further increase the consumer focus of their workforce.
- Adjustments to governance of direct funding might include streamlining administrative procedures and reviewing monitoring arrangements.

## Executive summary

The Lifetime Care and Support Authority (Lifetime Care) provides treatment, rehabilitation and care for people who have been severely injured in a motor vehicle accident in New South Wales (NSW). Under the Lifetime Care and Support Scheme (LTCS), people receive support according to their assessed needs, including attendant care. Lifetime Care was a NSW Government statutory authority until August 2015, when it became part of Insurance & Care NSW (icare), an organisation created by the Government to deliver the State's insurance and care schemes.

Lifetime Care is planning to offer scheme participants the opportunity to have increased choice and control over the way their supports are delivered and managed. In 2014 and 2015, Lifetime Care conducted a trial of direct funding of attendant care, in order to test the direct funding process and inform best practice for a future rollout of direct funding as a service model across the agency.

Twelve scheme participants were approved to participate in the direct funding trial. Eleven were included in the evaluation; one participant had joined the trial later. All were provided with funding on a fortnightly basis enabling them to purchase and manage their own attendant care support. This included choosing specialist attendant care and mainstream providers and employing their own attendant care workers. Individual funding for participants was calculated using information about the participant's assessed care needs.

Lifetime Care commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to evaluate the direct funding trial. This report presents the evaluation findings.

### Evaluation methodology

The evaluation ran concurrently with the trial, from January 2014 to December 2015. It used mixed research methods, including a literature review, program and financial data collection, interviews, surveys and focus groups. Research methods were inclusive, to enable a variety of Lifetime Care scheme participants to take part in the evaluation. The methodology contained a longitudinal component, with two rounds of data collection.

The study sample for the evaluation included 11 participants in the direct funding trial and, for comparison, a group of nine people who received attendant care through Lifetime Care and who were not participating in the trial, but were comparable regarding the ranges and proportions of their demographic characteristics (the comparison group). In addition, family members, attendant care providers and agency staff participated in interviews and focus groups. Financial and demographic information was collected about the trial participants, the comparison group and a data comparison group comprised of all Lifetime Care scheme participants who were more than two years post-injury, had a spinal cord injury and received attendant care (n=106). A process and outcomes evaluation as well as an economic analysis were conducted.

### Participant characteristics

As part of the surveys and interviews, the research participants provided demographic and socio-economic characteristics. Similar information was available for the data comparison group, except cultural background and economic participation, which Lifetime Care did not record in its administrative dataset. The majority of the 11 trial participants were men, had

a spinal cord injury, lived in regional NSW, lived with family members and were not in paid work or were retired. Their demographics were similar to those of the comparison group (9 people) and data comparison group (106 people).

According to the attendant care needs assessments that Lifetime Care conducts for each participant in its support scheme, trial participants and comparison group members spanned a wide variety of support needs, in line with people's injury type and severity. Seven trial participants (63%) were in the higher support needs categories, having 'high level complete' spinal cord injuries (five people) or a traumatic brain injury (two people). The proportion of people with these needs was lower in the comparison groups.

Trial participants and comparison group members are funded for support based on their assessed care need and their choice. In both groups, all people with high support needs and most of those with medium needs chose to receive informal support from family members, in addition to paid support from workers.

### **Outcomes for trial participants**

The direct funding trial aimed to improve participants' experiences of attendant care, by letting people choose how they organise their support. Improvements in support arrangements were considered likely to impact other areas of people's lives, such as enhancing their wellbeing, independence, health, social relationships and economic and community participation. Findings are compared with the experiences of the comparison group and are based on surveys and interviews with research participants in both groups, and on observations.

Most trial participants reported positive impacts of direct funding in various areas of their lives. Trial participants reported that they were able to adjust their attendant care support to suit their needs better and enhance their quality of life.

In the survey, trial participants and comparison group members both rated their personal wellbeing similarly and close to the Australian population. The most prominent exception was health, which trial participants and comparison group members rated on average lower than the Australian population. Their injury caused ongoing physical health issues for many of them. There was little change in trial participant responses between survey rounds one and two.

The survey also showed that research participants in both groups had a generally high sense of empowerment, particularly about making important decisions in their lives, being in control and having meaning in their lives. The average and range of empowerment scores were higher for the trial participants than the comparison group.

In the interviews, a few people in both groups said that their attendant care support had helped them to regain some physical skills or independence, indicating that direct funding was not necessarily the critical factor in that change. Trial participants were pleased that they could use direct funding to better tailor their support towards achieving their goals. In addition, several trial participants had acquired business skills since starting direct funding, which they found valuable, and one reported improved mental skills and independence.

The treatment and rehabilitation support funded by Lifetime Care ensured that participants' physical and mental health were generally well managed in both groups, although some health issues remained or recurred as a consequence of their injuries. Unlike the

comparison group, several trial participants described how direct funding had enabled them to adjust their attendant care support so that it suited their physical health needs better. Two trial participants said they experienced 'less stress' with direct funding, because they could better meet their support needs by adjusting when and how support was provided, with simpler processes.

People in both groups, particularly those with high support needs, commonly received regular informal family support instead of some form of paid attendant care. Often this was a personal choice, but sometimes it reflected inadequate paid support, for example insufficient availability or reliability of workers. Some trial participants used direct funding to adjust family support to the level they wanted, by recruiting better or more reliable workers, or by changing support worker tasks. This also helped improve family relationships. Availability of workers was a necessary prerequisite to achieving this change. The responsibility for managing the direct funding was sometimes shared with family members, which they said could be stressful, although worthwhile.

Attendant care support helped people in both groups to manage social contacts and take part in social activities. Trial participants found that direct funding further enhanced their social lives as the flexibility of their support allowed them to go out later or on short notice, to travel further than before, or to arrange needed transport.

People in both groups experienced barriers to economic participation, but some had been able to return to their previous jobs (two trial participants and one comparison group member). Two other trial participants saw direct funding as a path to self-employment, where they could apply the business and employer skills they were gaining from managing their direct funding budgets. One of them started a business during the trial period.

### **Implementation of the trial**

Participants' and Lifetime Care's experiences with the implementation of the direct funding trial were the focus of the process evaluation. It examined how the trial was implemented, what worked well in the process, how Lifetime Care improved the direct funding model during the trial, and how the model could be further adjusted before the rollout. The findings indicate to what extent intended outcomes of the trial for Lifetime Care (program logic, Figure 1.1) were achieved; and they indicate the attendant care-related outcomes for trial participants (support provision, choice, satisfaction and relationships).

The process findings are based on information from two rounds of interviews and focus groups at the beginning and end of the trial with Lifetime Care staff and managers, attendant care service providers, and staff members from the independent direct funding training provider engaged by Lifetime Care; experiences and emerging issues from the viewpoint of Lifetime Care throughout the trial; the costs of developing and funding the trial in comparison with established attendant care support; and information from the surveys and interviews with research participants.

Trial participants had overwhelmingly positive experiences with direct funding. Increased control over providers, workers and support arrangements gave them opportunities to fix previous shortcomings and adjust support to their needs. All trial participants said their quality and flexibility of support had increased since they started direct funding. Relationships with attendant care workers and providers improved for all trial participants; they had the impression that workers and providers respected them more because they were in control. Almost all managed their packages well, although one left the trial. Some

participants asked for more or different support from Lifetime Care in setting up or managing direct funding. These requests and the support they needed cannot be generalised because it varied by person, largely dependent on the capacity of Lifetime Care staff to identify and respond to the gaps in each person's prior experience related to managing direct funding.

In the survey, trial participants responded with particularly high scores and narrow ranges to two statements: that attendant care increased their quality of life and that it supported them to live more independently. Trial participants acknowledged potential risks of direct funding but managed these well; generally they felt safe and perceived a sense of goodwill on all sides.

Lifetime Care staff and service providers understood the aims of direct funding and the rationale behind it. Lifetime Care Coordinators involved in the trial saw the benefits of direct funding for participants. Continuous monitoring of the trial enabled the ongoing identification and resolution of issues as they arose. Staffing resources were not available to develop other models such as financial intermediary models at the time. This has now been addressed as a business priority.

The selection of trial participants was restrictive to protect both the participants and Lifetime Care. The selection process involved recommendations by Coordinators, an eligibility check and a risk assessment. The process seemed effective, considering that most trial participants managed direct funding well and benefitted from it.

Lifetime Care trial managers adjusted their guidance for staff and participants as the trial progressed. Documents were redrafted according to feedback, and rules were clarified as issues arose. Management decided to keep involving new Coordinators in preparation for a wider rollout of direct funding. Coordinators still expressed confusion and uncertainty about direct funding procedures by the end of the trial.

An independent specialist training provider supplied the initial training needs of participants, with additional support from Lifetime Care Coordinators. The provider's support was compatible with the needs of some of the participants but not all. This experience indicates that options might be to offer specialist training from a range of providers to match participants' preferences and to supplement the Lifetime Care support with ongoing assistance, such as peer support.

Monitoring of direct funding expenses occurred via fortnightly statements that trial participants submitted to Lifetime Care. The agency found its manual system time consuming and planned to streamline and update it, however regular monitoring was a valuable method of ensuring funding was being used appropriately and that participants were managing their care. Similarly, the agency planned to develop processes for monitoring the trial participants' financial and legal compliance, as well as participant and support worker safety, as part of a wider direct funding policy.

To manage relationships with service providers, Lifetime Care included some providers in the evaluation and explored workforce implications of direct funding with them. Providers were trying to compete in the new marketplace by offering consumer-directed approaches.

The economic analysis examined the costs of developing and funding the trial in comparison with established attendant care support, in context of the outcomes for direct funding trial participants. The analysis found that the cost of direct funding support

packages was stable and similar to non-trial participants, while Lifetime Care's program establishment and management costs were relatively low, representing below five percent of attendant care support costs in the trial.

Lifetime Care and participants regarded the trial as successful, and Lifetime Care planned to develop direct funding into a service management option for attendant care within one year. Experience from the trial was informing design plans for the policy, including offering participants a wider range of setup support to meet their individual needs and preferences, a range of options for fund management, ongoing administrative advice, simple reporting systems, regular monitoring and peer support, as summarised below.

### **Implications for policy development**

The evaluation found that almost all participants in the direct funding trial experienced significant positive outcomes, at levels of support cost that were stable and equivalent to comparable people who were not in the trial. Analysis of the implementation process of direct funding showed what worked well and what could be improved for both participants and Lifetime Care. The findings contribute to intended outcomes for Lifetime Care, as they increase understanding about direct funding and its implementation.

At the time the evaluation ended, Lifetime Care had identified that the development of direct funding was a business priority and planned to develop a direct funding option for the self-management of attendant care within the next 12 months.

The policy implications below are based on the evaluation findings and grouped into three areas: support for direct funding participants, attendant care workforce issues and governance of direct funding.

#### *Support for direct funding participants*

Lifetime Care could review the information about direct funding for potential participants, and develop an information and advice pack so they can more easily understand their responsibilities and the processes required in setting up and managing direct funding.

People with large, complex direct funding programs may need more or a different type of set-up support than was provided during the trial. Some trial participants suggested funding for accounting advice to establish financial and administrative structures.

Lifetime Care might consider how to support people who need assistance with recruiting workers. This need may be due to a shortage of suitable workers in their location, or because they have support needs that require workers with specific skills.

- In the trial, Lifetime Care showed flexibility by allowing one participant to employ family members, where the participant was not able to meet their support needs with the available specialist workforce. This caused difficult issues for the participant and the family members. Lifetime Care intended to apply the current policy of not allowing family members and friends to provide paid support to future direct funding participants.
- Administrative support options could make direct funding accessible to people who want or need support with managing their budget. These support options could include providers engaged by Lifetime Care or information from Lifetime Care about suitable providers.

Trial participants asked for optional access to support and advice whenever issues with direct funding arose. Lifetime Care could offer expert legal and accounting support as needed, arrange peer support, keep involving independent training providers, or a combination of the above.

### *Attendant care workforce issues*

To help ensure that direct funding participants can access a suitable attendant care workforce wherever they live and whatever their needs are, Lifetime Care could encourage attendant care service providers to offer more consumer-directed approaches. Lifetime Care has observed that the market was already adjusting to the increased choice and control environment, as the industry had been going through several years of reform in preparation for rollout of the National Disability Insurance Scheme (NDIS) in 2016-17. The Attendant Care Industry Association (ACIA) and National Disability Services (NDS) have been the primary drivers of these reforms.

To help protect training interests and workplace conditions of attendant care workers employed under direct funding arrangements, Lifetime Care could explore suitable mechanisms in cooperation with unions, professional organisations and provider organisations. These would be in addition to the current role of ACIA, which works with unions that are representing attendant care support workers and also offers individual membership to workers.

Worker safety could be considered when setting up direct funding and monitored regularly. Lifetime Care could inform participants about their responsibilities, provide resources so they can manage effectively, and maintain some oversight via the regular contact between Coordinators and participants.

### *Governance of direct funding*

Thorough training of staff and improvement of guidance documents, based on the experiences during the trial described above, might reduce confusion among staff about direct funding rules and procedures, increase Coordinators' inclination to nominate potential direct funding participants, and further reduce risks for Lifetime Care.

Potential risks in participants' budgeting of attendant care funds might be managed by offering administrative support through specialised providers and increasing financial oversight by Lifetime Care directly or by contracted providers.

Regular monitoring, at least quarterly, of direct funding participants' obligations regarding tax, superannuation and insurance would help to protect participants and Lifetime Care from potential liability.

Streamlining reporting procedures could reduce Lifetime Care's administrative load. A participant's suggestion was to create electronic expense statements that are integrated with Lifetime Care's finance system.

To ensure direct funding participants' safety from physical harm and financial exploitation, Coordinators would need to regularly check participant wellbeing. Lifetime Care would need to develop guidelines and set frequency of checks; at least six-monthly intervals seem reasonable and should be reviewed for adequacy.

The evaluation generated extensive feedback from trial participants about their reasons for choosing direct funding and the benefits they experienced. This feedback could be used to guide improvements in Lifetime Care support to people who do not receive direct funding, for example regarding flexibility of support and control over support arrangements.

# 1 The direct funding trial

Lifetime Care provides treatment, rehabilitation and care for people who have been severely injured in a motor vehicle accident in New South Wales (NSW). People who are eligible for the Lifetime Care and Support Scheme (LTCS) may have a spinal cord injury, moderate to severe brain injury, amputations, severe burns, or are blind, as a result of the accident. Under the scheme, people receive support according to their assessed needs, including attendant care, case management, rehabilitation, medical services, home modifications, equipment and training. Everyone accepted into the LTCS enters under a two-year interim eligibility period as it can be difficult to predict recovery. The interim period allows those who make a good recovery to leave the Scheme. About 180 people enter the LTCS each year as interim participants, and after two years, approximately 120 continue as lifetime participants.

Lifetime Care was established in 2006 as a NSW Government agency. In August 2015 it became part of Insurance & Care NSW (icare), an organisation created by the Government to deliver the State's insurance and care schemes. Lifetime Care is a growing organisation. At 30 June 2015, there were 681 lifetime participants and 355 interim participants in the scheme.

Lifetime Care is planning to give participants the option to receive direct funding for their assessed attendant care needs. Participants can then use the funding to organise their attendant care support themselves. Attendant care support includes assistance with personal care, domestic assistance, shopping, gardening, any travel costs to attend treatment and rehabilitation services (e.g. hydro exercises, gym, doctors' appointments), and some community access. The intention of direct funding is to use a person-centred approach that increases choice and control for participants without significant budget implications for Lifetime Care.

In 2014 and 2015, Lifetime Care conducted a trial of direct funding of attendant care, in order to test the direct funding process and inform best practice for a future rollout of direct funding across the agency. The direct funding trial was consistent with national disability policy change that emphasises individual choice and control for reasons of rights, effectiveness and efficiency. In the long term, the National Injury Insurance Scheme (NIIS) and the National Disability Insurance Scheme (NDIS) legislations anticipate the possibility of all disability-related support, including injury-related disability, to be offered with a direct funding option.

Participation in the direct funding trial was voluntary, and people needed to be assessed by Lifetime Care as eligible for direct funding. Eligibility criteria included having stable attendant care needs, being able to manage direct funding by themselves or with support, and having a low risk of physical harm or financial abuse. Twelve Lifetime Care participants joined the direct funding trial, including 10 with spinal cord injuries and two with traumatic brain injuries. The total number was consistent with expectations, although recruitment to the trial took longer than Lifetime Care had anticipated. Eleven trial participants were included in the evaluation; one participant had joined the trial later.

Trial participants received the money for their accident-related attendant care needs from Lifetime Care and used this money to purchase the attendant care support they needed, including domestic and gardening services. People could:

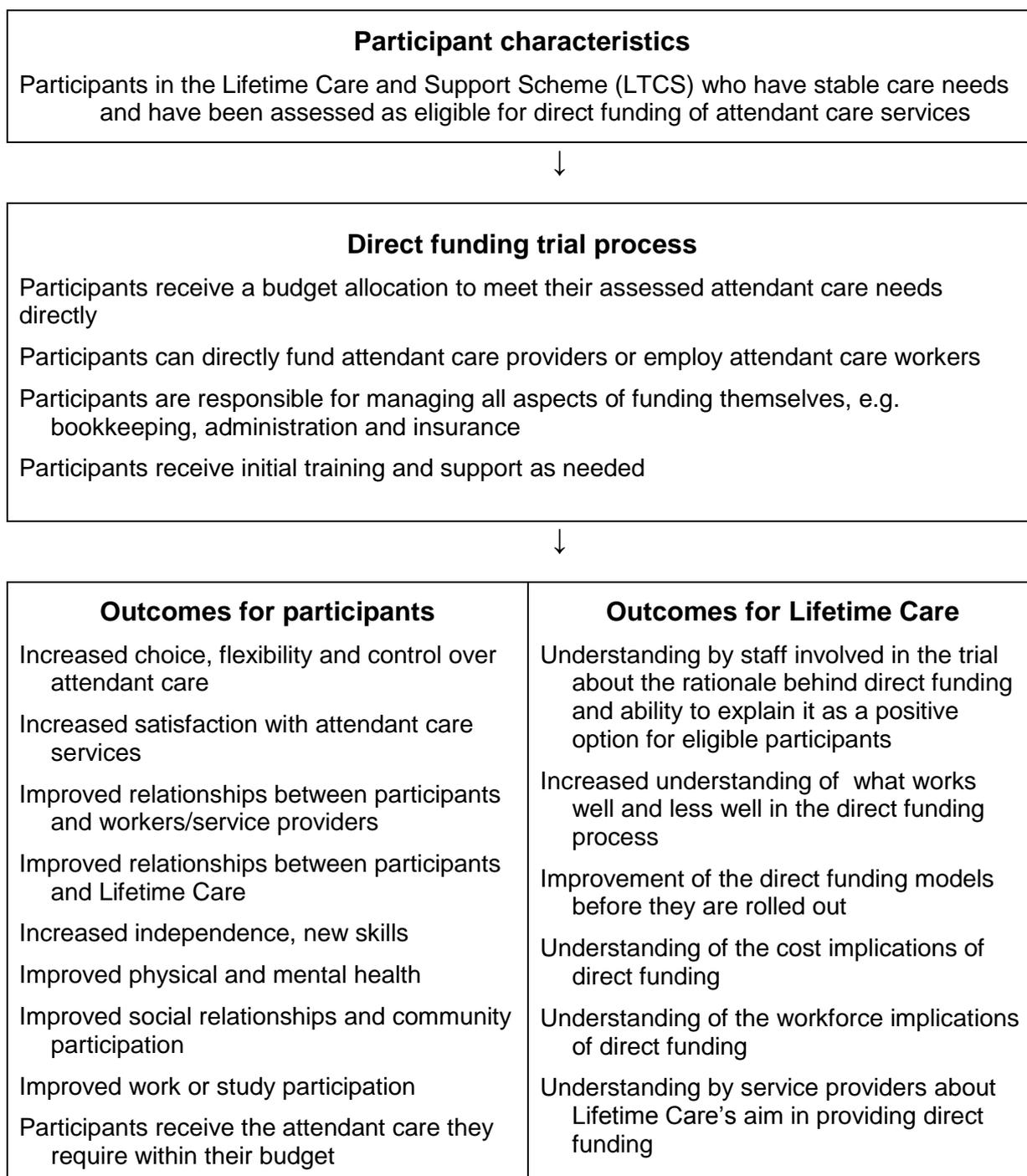
- choose their own attendant care providers
- employ their own attendant care workers
- pay their attendant care provider or worker directly
- negotiate directly with their attendant care provider around their attendant care schedule and any changes they may wish, within their budget.

The trial participants' individual budget was based on Lifetime Care's assessment of their attendant care needs and the participants' request for care. The budget included an amount to cover administration costs, estimated at one-quarter of the total budget. Direct funding budgets and arrangements were reviewed at the person's scheduled Care Needs Review, or earlier if the person or Lifetime Care had concerns or if the person's needs or circumstances changed.

Trial participants were responsible for managing all aspects of their direct funding, including bookkeeping, administration, insurance and workers compensation. They could manage direct funding themselves, with the support of a family member or with external support that they arranged. Lifetime Care offered trial participants initial legal advice, access to a specialist training organisation for individualised training and support, and access to their Lifetime Care Coordinator to obtain additional information and support.

The program logic for the direct funding trial, describing the inputs, processes and intended outcomes of the program, is presented in Figure 1.1 below.

**Figure 1.1: Direct funding trial program logic**



Lifetime Care commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to evaluate its direct funding trial. The evaluation assessed the direct funding process to determine possible improvements before the rollout, and it explored whether direct funding of attendant care met the needs of participants, and achieved intended outcomes for participants and Lifetime Care.

The evaluation ran concurrently with the trial, from January 2014 to December 2015. Details of the evaluation approach, research methodology and project management arrangements were published in the evaluation plan (Purcal et al. 2014). The SPRC provided an interim

evaluation report to Lifetime Care in June 2015. The evaluation findings are presented in this report and relate to the process of organising the trial, the outcomes and costs of the trial, and implications for the rollout of direct funding. The appendices include details about the evaluation methodology, trial participant experiences with direct funding, the economic analysis and the research instruments.

## 2 Characteristics of research participants

This section describes the characteristics of research participants in the trial and comparison groups. It includes their demographic profiles and attendant care arrangements.

### 2.1 Demographic profile of trial participants and comparison groups

As part of the surveys and interviews the research participants provided demographic and socio-economic characteristics. Similar information was available for the data comparison group, except cultural background and economic participation, which Lifetime Care did not record in its administrative dataset.

As explained in Appendix A 1III, the comparison group was chosen to be similar to the trial participants regarding the ranges and proportions of their demographic characteristics. Table 2.1 shows that trial participants and comparison group members were similar in many respects, as intended:

- they had a similar age range, from 24 to over 65, and both groups had an average age in their 40s
- most had a spinal injury
- most lived outside of Sydney
- few people were from culturally and linguistically diverse backgrounds and no-one identified as having an Indigenous background
- almost all lived with family members; this included partners, children, parents and other relatives
- more than one-half were not in paid work or retired.

The predominance of people with spinal injury was because Lifetime Care focussed on recruiting people with this type of injury who wanted to manage their direct funding themselves. Also, three of the trial participants were self-employed. It is likely that they would already have the necessary business skills to manage their attendant care budget and therefore be more likely than other people to choose direct funding.

The main differences between the groups were the higher proportions of men and self-employed people in the trial group. Differences may be due to self-selection of the nine people in the comparison group, (out of the total 18), who agreed to take part in the evaluation.

Given the overall similarity of the groups, the evaluation findings reported below seem to provide a valid comparison between the support experiences and outcomes of trial participants and comparison group members.

**Table 2.1: Demographic profile**

		Trial participants		Comparison group		Data comparison group	
		Years		Years		Years	
Age (at December 2014)	Range	24-68		24-79		20-90	
	Average	41		48		41	
		<i>n=11</i>	<i>Per cent</i>	<i>n=9</i>	<i>Per cent</i>	<i>n=106*</i>	<i>Per cent</i>
Gender	Men	8	73%	4	44%	84	79%
	Women	3	27%	5	56%	22	21%
Type of injury	Spinal	9	82%	8	89%	106	100%
	Brain	2	18%	1	11%	-	-
Location	Regional	10	91%	7	78%	77	73%
	Metro	1	9%	2	22%	29	27%
Household composition	Living with family, partner, others	9	82%	8	89%	74	70%
	Living alone	1	18%	1	11%	32	30%
Cultural background	CALD**	2	-	2	-	n/a	-
Economic participation	Not in paid work or retired	7	64%	5	56%	n/a	-
	Employed or self-employed	4	36%	1	11%	-	-
	Looking for work after study	-	-	3	33%	-	-

\*includes comparison group

\*\*CALD – culturally and linguistically diverse

To provide context, Table 2.1 also presents demographics of the larger data comparison group, which included all Lifetime Care scheme participants who were more than two years post-injury, had a spinal cord injury and received attendant care. Main differences to the trial participants and comparison group were that the larger data group included a higher proportion of men and of people who lived alone, and a wider age range.

## 2.2 Support needs and arrangements

Lifetime Care assesses attendant care needs for each participant in its support scheme and puts support arrangements in place, in consultation with the participants. The extent of support, support types and individual support arrangements vary widely, depending on the person's assessed care needs and the level of support requested.

Trial participants and comparison group members spanned a wide variety of support needs, in line with people's type and severity of injury. Regarding spinal injury, Lifetime Care classifies a participant's level of function according to the internationally established American Spinal Injury Association (ASIA) classification (Motor Accidents Authority of NSW and Lifetime Care and Support Authority 2007). The ASIA score includes a prefix indicating the level of the spinal cord injury, from highest to lowest section of the spinal column, C – cervical, T – thoracic, L – lumbar and S – sacral. This is combined with a category indicating the severity of the injury, either 'complete' or 'incomplete', where an injury is considered 'incomplete' if there is some function below the level of injury extending for more than three segments of the spinal column. Specifically the grouping is derived from the ASIA score alpha component where 'A', 'B' and 'C' are defined as 'complete', and 'D' and 'E' are considered 'incomplete'.

Based on the ASIA scores, Lifetime Care identifies broad spinal cord injury groups reflecting general levels of support. Cervical injuries (abbreviated as 'C') represent the most severe level with generally high support need, and lower level injuries are combined for all lower segments (thoracic, lumbar and sacral, abbreviated as 'TLS') and are generally associated with lower levels of support. The combined categories of completeness and injury level are closely associated with support needs and are used in this report to examine cost of support profiles (Appendix C11).

In the evaluation, these definitions and groupings of spinal cord injury level were used to establish a broad proxy indicator, which aligns with higher or lower levels of support in the majority of cases. However, it is recognised that there is significant variation in the clinical definition of spinal cord injuries, which is potentially reflected in ASIA score classifications. In particular there is variation in motor and sensory differences for respective spinal cord injury levels resulting in cases of ambiguity for definitions of 'completeness'. Examples include zones of partial preservation, where some function remains below the injury site but below which no motor and sensory function is present. This is relatively common. There are also cases of lateral preservation, where partial function on one side remains but not the other, or at a different level. And there are cases of recovery of function, where substantial motor or sensory function below the injury site may return.

In this context, the broad grouping of spinal cord injury participants is presented as the best available basis for comparative level of support sub groups, despite potential variation in some ASIA scores. Overall this type of definition complexity is not a significant issue for trial group analysis, as there are no 'incomplete' higher level 'C' cases, resulting in all of the higher need group having 'complete' higher level 'C' injuries.

In the Lifetime Care dataset, the ASIA level of injury groups are used to indicate four broad levels of support need, from high to low:

- Complete C
- Complete TLS

- Incomplete C (no trial participants)
- Incomplete TLS

To assess support needs of people with a traumatic brain injury, Lifetime Care uses the well-established Care and Needs Scale (CANS) score (Tate 2011). The CANS ranges from a maximum score of seven, representing the highest need for support, and reduces in increments to one.

Table 2.2 shows that the majority of trial participants and comparison group members were in the higher support needs categories, having ‘complete’ injuries. Out of the three study groups, trial participants had the most severe injuries and highest support needs, with 45 percent being in the ‘complete C’ category, compared with 33 percent in the comparison group and 19 percent in the data comparison group. Hence trial participants and comparison group members were fairly similar, with a majority having relatively high needs. The data comparison group as a whole had a lower needs profile.

The two trial participants with traumatic brain injury had a reported CANS score of seven and four respectively, indicating very high support need for one, and medium for the other. The CANS score of the comparison group member was unknown, but the person indicated in the interview that they had low support needs.

**Table 2.2: Level of injury and comparative support needs**

	Comparison groups							
	Trial participants		Comparison group		Data comparison group**		Total	
	n	%	n	%	n	%	n	%
Spinal injury level								
Complete C	5	45%	3	33%	20	19%	25	21%
Complete TLS	3	27%	3	33%	49	46%	52	44%
Incomplete C	0	0%	1	11%	23	22%	23	20%
Incomplete TLS	1	9%	1	11%	14	13%	15	13%
TBI	2	18%	1	11%	0	0%	2	2%
<b>Total</b>	<b>11</b>	<b>100%*</b>	<b>9</b>	<b>100%*</b>	<b>106</b>	<b>100%</b>	<b>117</b>	<b>100%</b>

Source: Lifetime Care client program data

Notes: C = cervical, TLS = thoracic, lumbar and sacral, TBI = traumatic brain injury

\* Percentages do not add up to 100 due to rounding error

\*\* Includes comparison group

Consistent with the wide range of support needs among research participants, their support arrangements also varied widely. Arrangements usually involved a combination of paid and informal family support. Examples are provided below to illustrate the arrangements of interview participants with low, medium and high support needs. Arrangements were similar in essence for trial participants and comparison group members of similar levels of support need.

- High support needs (24/7):

A trial participant has arranged support workers for 106 hours each week (about 15 hours per day). They do personal care, housework and provide

help to move around the farm, for example by opening gates. Support at night and between workers' shifts is provided by the partner.

Support workers for a comparison group member come every morning and evening, and two afternoons while the informal support is at work. They do all personal care, housework, stretches and provide support for various activities in the afternoon like working on the computer, and transporting to doctors' appointments. Informal supports are available at other times and during the night.

- Medium support needs (daily):

A trial participant does all his personal care himself. The support workers come every morning and afternoon to do cleaning, shopping and cooking.

A comparison group member gets support for five hours each morning and three hours at night. The workers help with personal care and housework, shopping, and they provide support to go to church on Sundays.

- Low support needs (less than daily):

A trial participant receives one hour of house cleaning support every two weeks, plus five hours for a thorough house cleaning once a year.

A comparison group member has a cleaner for two hours each week and gets lawn mowing done as needed, about every two to four weeks.

In addition to attendant care support from workers, most research participants received informal support from family members. This included the eight research participants who had 24/7 support needs: each had at least one family member living with them who provided some daytime as well as night time support. The latter might be only for emergencies, or it might involve regular care such as turning the person in bed.

## **2.3 Summary of characteristics of research participants**

- The majority of the 11 trial participants were men, had a spinal cord injury, lived in regional NSW, lived with family members and were not in paid work or were retired. Their demographics were similar to those of the comparison group (9 people) and data comparison group (106 people).
- Seven trial participants (63%) were in the higher support needs categories, having 'high level complete' spinal cord injuries (5 people) or a traumatic brain injury (2 people). Their arrangements supported their capacity to manage direct funding. These proportions were lower in the comparison groups.
- Trial participants and comparison group members had arrangements for attendant care support that varied according to their needs, choice and availability of paid support and informal family support. In both groups, all people with high support needs and most of those with medium needs received informal support from family members, in addition to paid support from workers.

## 3 Outcomes for trial participants

The direct funding trial aimed to improve participants' experiences of attendant care, by letting people choose how they organise their support. Improvements in support arrangements were meant to impact other areas of people's lives, such as enhancing their wellbeing, independence, health, social relationships and economic and community participation (Figure 1.1). This section reports on quality of life outcomes in various domains. Findings are compared with the experiences of the comparison group. They are based on surveys and interviews with the research participants and on observations. Changes in outcomes for trial participants between the first and second round of data collection are mentioned when they occurred.

### 3.1 Personal wellbeing and empowerment

In the survey, trial participants and people in the comparison group were asked about their feelings of personal wellbeing in various life domains and their general sense of empowerment. The numbers of people in both groups were small, and therefore findings should be interpreted with caution. Among the trial participants, six took part in both rounds of the survey, and a further four completed just one round (two additional people per round). Since 73 percent of trial participants completed the survey at least once, the scores below give some indication of their state of mind as a group. It is unknown whether the comparison group answers were representative of all Lifetime Care participants who received attendant care.

Respondents completed the Personal Wellbeing Index (PWI), an internationally validated instrument (Cummins, 2005), to indicate their subjective wellbeing in relation to their life as a whole and seven life domains. Findings are presented in Table 3.1 and compared with the Australian population in general. It appears that the subjective wellbeing of both groups of research participants was close to the Australian population or higher in some domains, most prominently personal relationships, feeling part of their community and future security. In other domains, particularly health and life as a whole, research participants scored their wellbeing lower than did the Australian population.

**Table 3.1: Personal Wellbeing Index (PWI) scores**

Thinking about your own life and personal circumstances, how happy are you with your:	Trial participants (n=8)				Comparison group (n=9)		Australian population
	Average		Range		Average	Range	Average
Survey round	1	2	1	2			
Life as a whole	68.8	66.3	50-100	50-80	71.1	20-100	77.8
Standard of living	77.5	73.8	50-90	50-100	73.3	10-100	78.9
Health	60.0	55.0	20-90	20-90	67.7	40-100	74.0
Achievements in life	71.3	67.5	50-100	50-80	65.5	10-100	73.8
Personal relationships	77.5	77.5	50-100	60-90	80.0	10-100	78.8
Safety	78.8	72.5	50-90	40-100	76.6	50-100	80.9
Feeling part of your community	71.3	71.3	40-90	50-90	75.6	0-100	72.4
Future security	76.3	63.8	40-100	30-90	70.0	20-100	70.8

Sources: Participant and comparison group surveys; Cummins et al., 2012

Method for calculating scores: Survey participants were asked to rate their satisfaction with each PWI domain on a scale of 0-10, where 10 represents the highest level of satisfaction. Each score is an average of the answers of survey participants, converted to a 0-100 point range.

Comparing trial participants and comparison group members, there is no consistent pattern. Trial participants recorded higher wellbeing than the comparison group in some life domains – standard of living, achievements in life, feeling of safety and future security – and lower wellbeing in other domains, namely life as a whole, health, personal relationships and feeling part of their community. The lowest score overall was trial participants' satisfaction with their health, at 60 points (round 1) and 55 points (round 2).

Within life domains, scores had a generally wider range in the comparison group than the trial participants, with comparison group scores below 50 recorded in seven of the eight domains, but in only three domains among the trial participants.

The aggregate scores of trial participants in the second round of surveys were the same or slightly lower than in the first round. Of the six people who completed both rounds, three had a lower PWI average score overall (that is, in the eight items combined) in the second round, one had a higher score, and two reported the same in both rounds.

Overall, the scores show that the subjective wellbeing of respondents was similar between the two groups and relatively close to the Australian population. The most prominent exception was health, which trial participants rated up to 19 points lower than the Australian population and comparison group members, six points lower. An obvious reason is the respondents' injury, which in many cases substantially limited their mobility and ability to live independently, and which often caused ongoing physical health issues.

Research participants also answered questions about their sense of empowerment regarding their life circumstances; whether they could make important decisions, had control and meaning in their lives and could adapt to changes (Table 3.2). Scores were consistently higher than the PWI scores above, indicating that participants had a generally high sense of empowerment. Although some scores decreased between survey rounds one and two, trial participants reported higher scores than the comparison group almost all the time. This indicates a greater sense of empowerment among the trial participants surveyed, however the small sample sizes preclude wider generalisations.

**Table 3.2: Satisfaction with current circumstances**

How much do you agree with the following statements:	Trial participants (n=7 in 1 <sup>st</sup> round, n=8 in 2 <sup>nd</sup> round)				Comparison group (n=9)	
	Average		Range		Average	Range
Survey round	1	2	1	2		
I can make important decisions about my life	91.4	86.3	80-100	50-100	91.1	80-100
I am in control of my life	90.0	85.0	70-100	70-100	84.4	30-100
I have meaning in my life	85.7	86.3	50-100	70-100	82.2	20-100
I am able to adapt to changes in my life	87.1	82.5	40-100	50-100	81.1	20-100

Sources: Participant and comparison group surveys; questions mirror those in internal TAC surveys, to enable comparison if TAC survey results become public.

Notes: Method for calculation of scores: Survey participants were asked to rate their level of agreement with the statements presented on a scale of 0-10, where 10 represented the highest level of agreement. Each score is an average of the answers of survey participants, converted to a 0-100 point range.

### 3.2 Skills and independence

Direct funding is intended to improve people's skills and independence. Lifetime Care limited the direct funding trial to people who were more than two years post-injury and whose attendant care needs were relatively stable, intending to minimise risks associated with managing budgets and support provision to both the participants and Lifetime Care. Comparison group members were matched to have similar characteristics, including stable support needs. Due to these selection criteria, the research participants' skills and independence were not expected to change significantly during the evaluation.

A few people in each group found that their attendant care support had helped them to regain some physical skills or mobility during the previous 12 months, indicating that direct funding was not necessarily the critical factor in that change. For example, one woman in the comparison group said she had started to walk independently and had learnt to use her hands better. Similarly, a trial participant felt that his mobility had increased, partly because attendant care workers supported him with hydro exercises. He said that direct funding had helped because it allowed him to have workers trained to support him in the pool in ways that were not previously possible. By the second interview he said he could now get in and out of bed by himself rather than having to be lifted. His next independence

goals included eating a hamburger with both hands and getting back on the rowing machine. He said: “Direct funding gives me the freedom to pursue those goals”.

In contrast, one comparison group member said he was so frustrated with the quality of his attendant care support workers that he felt compelled to learn to do some personal care activities himself. He said he had raised this repeatedly with his Coordinator, but the issue had not been resolved.

Several trial participants mentioned they had acquired business skills since starting direct funding. Two people said that the opportunity to learn bookkeeping, business management and employer skills was one reason for going on the trial. One person said:

I am pretty good with that stuff, I wanted to develop and increase those skills. I don't want to depend on other people.

The trial participants said they had found learning business skills very valuable and were pleased with their achievement. One person felt that having to give guidance to his directly employed support workers had improved his mental skills and independence:

Direct funding has increased my confidence, and I do a lot more. People say I think better as well. I second-guess myself less.

### **3.3 Physical and mental health**

Improved health is another intended outcome of direct funding. In the interviews, the majority of trial participants as well as comparison group members reported good physical and mental health. Some interviewees did have health problems, which was consistent with the mixed health satisfaction scores in Table 3.1. Most physical health issues were ongoing or recurring and a consequence of people's injuries. Problems included urinary tract or chest infections, shoulder and back pain, and strain injuries in elbows, wrists and hands. Other one-off health issues were mentioned, such as a broken hip and bladder stones. Mental health problems also occurred in both groups, mostly depression and anxiety as a result of people's accident and major injury.

Attendant care, in combination with other support provided by Lifetime Care, helped most interviewees to maintain their health, address acute problems or improve their overall feeling of wellness.

Regarding physical health, one man in the comparison group said his support workers had learned how to keep him clean, so he had had no urinary tract infections for more than a year. In another example, a woman found that body maintenance support such as massages, physiotherapy and personal training had kept her so mobile and fit that she had not suffered pressure sores and therefore had not needed personal care support.

Trial participants were more likely than comparison group members to talk about their own efforts to do exercises, keep fit and generally manage their physical condition because they could arrange the support most effectively for their needs. For example, one person said they maintained muscle tone by frequently exercising their entire body, and another managed fatigue and a sore back by resting after work.

Several trial participants described how direct funding had enabled them to adjust their attendant care support so that it suited their physical health needs better. In particular, a

woman could now arrange to get her oven and floors cleaned regularly, and two people arranged for support workers to accompany them into the pool for regular hydro exercises; previously a family member had to be available to come into the pool.

Regarding mental health, most interviewees indicated that good attendant care support helped them to feel happy and adjust to their new life. One comparison group member said:

My support workers are kind and considerate. I feel well cared for. There is no use complaining, I feel lucky to be alive and accept what happened.

A few people discussed mental health problems. In the comparison group, one person had had severe depression after their accident, which had been successfully treated with psychological, psychiatric and medical support organised by Lifetime Care. Another person had anxiety due to brain injury, which was not well managed. The person said inadequate attendant care support exacerbated their anxieties and prevented them from attending specialist mental health appointments.

Among the trial participants, two people said they experienced 'less stress' due to direct funding. This was because they could better meet their needs by adjusting when and how support was provided, and because processes were simplified.

### **3.4 Social relationships and community participation**

Direct funding intends to help people improve their social relationships and community participation. Research participants and their family members commented on how their attendant care support influenced family relationships, connections with friends, and social activities.

#### **Family relationships**

The level of family involvement in the research participants' support was mixed. Among the 11 trial participants in the study, seven (or two-thirds) had at least one family member who provided regular, practical support, including help with personal care, housework, transport and night-time care. This applied mostly to people with high support needs. The other four had little or no injury-related support from family members; they could meet their relatively low support needs through the attendant care workers. Of the nine people in the comparison group, four had significant family support. Similarly to the trial participants, three of them had high support needs.

Where family members did provide support, they often did so instead of having attendant care workers, as a matter of choice. As a result, people accessed fewer hours of attendant care support than their assessment of overall care needs indicated. This reflected personal choice, as many interviewees said they preferred to have some private time; for example, family members said:

I am here of a day and can do housework and tend to [person], so there is no need to have a carer around all the time. I get up at night if necessary because personally I wouldn't like someone here 24 hours, 7 days a week.

I prefer to take [person] to appointments and shopping. We like to do this together and keep the carers for one section of our lives, the in-house support.

Adequate attendant care support allowed families to access as much formal support as they needed and wanted. For them, family support was an expression of positive relationships. This was consistent for both the trial participants and comparison groups.

However, some family support reflected inadequacies of attendant care. Two people in the comparison group felt that some of the paid support was not to the standard they needed, particularly housework such as cleaning and cooking, and these tasks were taken on by family members. In one of these cases, the person receiving attendant care said:

I would much prefer to have better attendant care, so that when my brother and sister-in-law visit we can just be social.

Two of the trial participants would like more night-time support to relieve strain on family members but could not find enough suitable workers, indicating that direct funding by itself cannot necessarily guarantee availability of suitable staff to meet support needs. In contrast, some trial participants were able to use direct funding to adjust family support to the level they wanted. Three people gave examples, explaining that they:

- engaged a good gardener so that parents and friends did not need to help out anymore
- arranged reliable support so that their partner did not need to stay home when care workers cancelled on short notice
- got support workers to do errands with them sometimes so that their partner could have time alone at home.

One trial participant said his family appreciated him more now that he organised his support himself: “They like that I am having a go, not sitting back and giving up”. Another said direct funding had improved his marriage. Now that his directly employed support workers – rather than his wife – helped him with physical work outside the house such as fencing and painting, the strain on their marital relationship had reduced.

People in both groups who had lower support needs generally chose not to use family support. One said:

Most definitely, attendant care enables me to have normal family relationships with my daughters. Without attendant care, they would have to put their lives on hold.

### **Friends and social activities**

Most research participants had active social lives, often enabled by their attendant care support. Trial participants as well as comparison group members talked about visiting friends and neighbours and taking part in community activities with the support of their attendant care workers. For example, one woman went to the club every Thursday and had lunch with family or friends on Sundays. Another woman had spent the morning of the interview getting a lotto ticket, then buying plants at the nursery and having a coffee. One man said “I get out quite a bit”. He visited his girlfriend regularly and was looking for a house with her. Another man said attendant care support made it possible to go to shops that had steps and that he could otherwise not enter.

Two trial participants said that direct funding had enhanced their social lives. They could now easily change support worker shifts to go out for dinner at night and go to bed late, or they could take workers with them to visit friends out of town. This had been much more complicated before and required more effort, notice and negotiation. One of these trial participants said: “My lifestyle is far more liveable now, direct funding is excellent”. Family members agreed, for example:

With direct funding there is much more flexibility in what we can do. It is much easier to get out of the house, to go to the movies, for dinner, or just for a drive.

Transport seemed a crucial factor in determining whether people could have the social life they wanted, as most people talked about it without being asked. In both groups there was a wide range of experiences. Most people lived out of reach of good public transport. Some people could drive themselves, either in a regular or a modified car. Those who were not able to drive themselves still often needed a modified car, for example to fit a wheelchair. Lifetime Care covers the cost of modifications, but the purchase of a suitable vehicle is not covered by Lifetime Care and is not financially possible for some. One person in the comparison group had family friends who organised fundraising for a vehicle that could be modified, but others in both groups who had not received such generous community support felt frustrated.

People in the comparison group had varied experiences regarding supported transport. Some regretted that visiting friends or attending family or community events was not covered by Lifetime Care or their support provider, but others found that such activities were covered, possibly because attendance at these activities was part of the person’s rehabilitation program.

Trial participants appeared to have more control than those in the comparison group over transport and therefore their social lives: several people talked about using their direct funding to arrange transport to social activities, although others did not because they were unsure of the rules.

### **3.5 Economic participation**

Direct funding is intended to enable people to arrange their economic participation in the way they wish to. As shown in Table 2.1, the majority of trial participants and comparison group members were not involved in paid work or study at the time of the interviews (15 people, or 75%). Their situations and plans differed widely:

- 3 people had been retired at the time of their accident; 1 of these would like to return to volunteer work
- 1 had retired recently, was now engaged in volunteer work
- 3 had finished studying and were looking for work
- 4 would like to return to work or study
- 4 did not wish to work or study at this stage.

All who were interested in finding work or in studying, and those who had finished their studies, said that Lifetime Care was supporting them to achieve their goals. Experiences

were similar across trial and comparison groups. Coordinators explored options with people and put supports in place to make work or study possible. For example, Lifetime Care had organised a teacher at TAFE to support one of the men in the comparison group, mostly to explain study questions to him. He found the support helpful: “Whenever I needed the teacher she was available”. Lifetime Care had then organised a vocational rehabilitation service provider to help him find a suitable part-time job, and he felt this was going well at the time of the interview.

Similarly, people received support to return to their previous job. One woman said Lifetime Care had provided her with transport to and from work until she could drive her own car again. She said:

That was a lot of mileage, a lot of funding. I am very, very grateful for it.

A few people experienced barriers to working or studying. One woman in the trial group wanted to do a computer course but was not able to sit in a TAFE class all day. She was looking for a course to do at home. A man in the comparison group felt discouraged by what he perceived as widespread, negative employer attitudes:

I am a quadriplegic and get sick with bladder and chest infections. Who would employ me?

Some people in both groups had successfully returned to work or their own business. For example, one man started a consultancy business in a construction-related sector he had worked in previously. A woman who went back to her previous job said her employer had made office modifications and changed her role:

In the early days they could have let me go. I think they didn’t because I made an effort, and my boss understands my disability needs, due to personal experience in his family.

Two trial participants saw direct funding itself as a path to self-employment. One of them said that learning the skills involved with managing her attendant care funding was “like learning to run a small business; I expect it will open up other doors”. Another trial participant already used his new business skills to manage other people’s support and direct funding packages. By the time of the second interview, he was managing the package that another man in town was receiving from his insurance company. Between the two of them, he was employing five full-time and two part-time support workers and was planning to expand further. At the same time, he had employed someone to mow his lawn and drive him around, and he was now trying to find other customers so this person could work full-time: “I actually started a lawn-mowing business”.

### 3.6 Summary of outcomes for trial participants

Most trial participants reported positive impacts of direct funding in various areas of their lives. More than the comparison group, trial participants were able to adjust their attendant care support to suit their needs better and enhance their quality of life.

- In the survey, trial participants and comparison group both rated their **personal wellbeing** similarly and close to the Australian population. The most prominent exception was health, which trial participants and comparison group members rated lower than the Australian population. Their injury caused ongoing physical health

issues for many of them. There was little change in trial participant responses between survey rounds one and two.

- The survey also showed that research participants in both groups had a generally high sense of **empowerment**, particularly about making important decisions in their lives, being in control, and having meaning in their lives. The average and range of empowerment scores were higher for the trial participants than the comparison group.
- In the interviews, a few people in each group said that their attendant care support had helped them to regain some physical **skills** or **independence**. Trial participants were pleased that they could use direct funding to better tailor their support towards achieving their goals. In addition, several trial participants had acquired business skills since starting direct funding, which they found valuable, and one reported improved mental skills and independence.
- The support provided by Lifetime Care ensured that **physical and mental health** were generally well managed in both groups, although some health issues remained or recurred as a consequence of their injuries. Unlike the comparison group, several trial participants described how direct funding had enabled them to adjust their attendant care support so that it suited their physical health needs better. Two trial participants said they experienced 'less stress' with direct funding, because they could better meet their health needs by adjusting when and how support was provided, with simpler processes.
- People in both groups, particularly those with high support needs, commonly received regular informal **family** support instead of some paid attendant care. Often this was voluntary but sometimes it reflected inadequate paid support, for example insufficient availability or reliability of workers. Some trial participants used direct funding to adjust family support to the level they wanted, by getting better or more reliable workers, or by changing support worker tasks. This also helped improve family relationships. Availability of workers was a necessary prerequisite to achieving this change. The responsibility for managing the direct funding was sometimes shared with family members, which they said could be stressful, although worthwhile.
- Attendant care support helped people in both groups to manage social contacts and take part in **social activities**. Trial participants found that direct funding had further enhanced their social lives, as the flexibility of their support allowed them to go out later or on short notice, to travel further than before, or to arrange needed transport.
- People in both groups experienced barriers to **economic participation**, but some had been able to return to their previous jobs (two trial participants and one comparison group member). Two trial participants saw direct funding as a path to self-employment, where they could apply the business and employer skills they were gaining from managing their direct funding budgets. One of them did start a business during the trial period.

## 4 Implementation of the trial

This section examines how the trial was implemented, what worked well in the process, how Lifetime Care improved the direct funding model during the trial, and how the model could be further adjusted before the rollout. It also discusses the findings of the process evaluation in the order of the program logic, Figure 1.1, that is, the participants' and Lifetime Care's experiences with the implementation of the direct funding trial, and a summary of the economic analysis.

The section is based on information from two rounds of interviews and focus groups at the beginning and end of the trial with Lifetime Care staff and managers, attendant care service providers, and staff members from the independent direct funding training provider engaged by Lifetime Care; experiences and emerging issues from the viewpoint of Lifetime Care throughout the trial; analysis of the costs of developing and funding the trial in comparison with established attendant care support; and information from the surveys and interviews with research participants.

### 4.1 Lifetime Care project management

The direct funding trial was led by a member of Lifetime Care's executive. A senior staff member managed the trial, while internal steering and external advisory groups provided implementation oversight and advice. Allocated staff resources were 1.5 days a week for the trial manager, who left the position in November 2014. The project was then managed by the Attendant Care Manager. The attendant care team supported the Coordinators, dealt with issues as they arose and improved some trial documentation, but there was limited potential for further development in direct funding program development or rollout during this period. In September 2015, project management was taken over by a new officer employed to progress Lifetime Care's work on improving the choice and control of participants within the scheme.

Lifetime Care expected that the transfer to icare in 2015 would provide good opportunities to progress the policy because the new organisation had an innovative culture, with a CEO and Board who would drive change.

During the trial, project managers were responsible for developing procedures for direct funding, from eligibility checking to monitoring; creating information material for potential trial participants; training stakeholders; and managing issues as they arose. These aspects are discussed below.

### 4.2 Information about the aims of the trial

As part of the trial, Lifetime Care informed staff, particularly the Coordinators, about the rationale behind direct funding, so they could explain it as a positive option to eligible participants. At the same time, attendant care service providers were informed about the aims of direct funding (program logic, Figure 1.1). To this end, trial managers presented at staff and service provider meetings, placed articles in staff newsletters, distributed guidance documents about the trial and organised a staff training session with the independent training organisation that also advised trial participants.

These strategies appeared to be successful. In the first-round focus groups, Lifetime Care staff said they understood and agreed with the intended benefit of direct funding to provide participants with more control over their support. They anticipated that direct funding would

be particularly useful for people who needed support out of hours or lived in less accessible locations. By the second round, 13 Coordinators had been directly involved with the trial through their scheme participants. They were unanimous that direct funding benefited participants by increasing their control and flexibility. Management observed a culture change among Coordinators in general, who they said were used to organising support with service providers but now started to see the benefits of handing over control to scheme participants.

Similarly, service providers felt that direct funding gave participants more control, power and independence. They thought it was beneficial for people with good decision-making capacity, realistic expectations and a Coordinator who provided them with adequate information. However they did not expect large proportions of their clients to choose direct funding; they felt that they provided choice and person-centred support already and that many people would not want to self-manage their package.

### **4.3 Selection of trial participants**

Coordinators were closely involved in selecting potential trial participants. They were tasked with identifying people who might have the capacity and inclination to trial direct funding and, if Lifetime Care agreed, discussing the option with them. If anyone wanted to proceed, a formal eligibility checklist and risk assessment were completed (section 1). The risk assessment considered whether the person, if they received direct funding, was at risk of harm to themselves or others, financial mismanagement or financial abuse.

Lifetime Care management regarded the selection process as effective in identifying suitable participants for the trial. This is supported by the trial participants' overwhelmingly positive experiences and capable management of direct funding so far, as described in the previous sections.

Lifetime Care staff and service providers who took part in the focus groups said that the selection process was appropriately restrictive during the trial, to maximise use of Lifetime Care and service provider resources, and to avoid service disruption and disappointment for participants. They agreed with the gradual rollout process and progressively widening eligibility as the experience with the model increased. Most thought that Lifetime Care should offer ongoing administrative support so that direct funding would in the future be potentially available to a broader range of participants in the LTCS.

During the second year of the trial, Coordinators suggested additional Scheme participants who they considered suitable for direct funding, and some Scheme participants asked for direct funding of their own accord because they had heard about the trial. Management decided to not include additional people in the trial but concentrate on developing a direct funding policy during 2016 (4.9).

### **4.4 Participant experiences with the trial**

Trial participants had positive experiences with the direct funding trial. Increased control over providers, workers and support arrangements gave them opportunities to fix previous shortcomings and adjust support to their needs. Almost all managed their packages well. Relationships with workers, providers and Lifetime Care improved, and no-one perceived that direct funding had negative impacts on them. A summary of participant experiences is presented here, and details are in Appendix B.

The trial participants' main reason for choosing direct funding was dissatisfaction with their previous attendant care support, including inadequate quality and consistency of support, restricted range of tasks, and flexibility and limited choice of workers. Three trial participants opted for direct funding also for its own sake as a meaningful activity, a path to future employment, or as putting them in charge of their own support. All trial participants said they had adequate decision-making support about joining the trial.

Lifetime Care offered various sources of advice to trial participants in setting up direct funding, especially its appropriate legal and administrative structures. Most people found the advice helpful, and many supplemented it from their own sources such as accountants and lawyers. The process took several weeks to a few months. In the future, people suggested clearer information from Lifetime Care would be beneficial, and it appears that people with large, complex direct funding programs may need more or different set-up support than was available from Lifetime Care at the time.

Once their programs were set up, most trial participants appeared confident in managing direct funding. They either employed an accountant or were doing the bookkeeping themselves, which seemed generally straightforward and took little time. Several people pointed out benefits of managing their own attendant care budget, such as saving overheads that could be used for additional or better-quality support. Setting up rosters did not present problems; people talked about allocating shifts amicably among their workers and with providers. Some people needed to adjust workers' pay and tax schedules because they had received incomplete information about their obligations. One person left the trial due to difficulties with paying invoices.

Choosing their providers and workers gave trial participants the opportunity to employ support that suited their needs and preferences. All of them appreciated the control it afforded them. Two people mentioned recruitment difficulties, and both had high, 24-hour support needs. One person suggested that Lifetime Care prepare detailed suggestions about how to recruit workers.

All trial participants said their flexibility of support had increased since they started direct funding. This included more flexibility in scheduling – deciding when and how often support is provided; and more flexibility in types of support – which tasks the workers perform.

Relationships with attendant care workers and providers improved for all trial participants. People had the impression that workers and providers respected them more because they were in control. At the same time, both sides could build closer, more personal relationships because they dealt with each other directly, not through organisations. As a consequence, quality of support improved.

Some trial participants felt their relationship with Lifetime Care had improved because they had fewer conflicts to resolve; because they enjoyed the helpful oversight and more personal, face-to-face contact while direct funding was set up; or because they received special permissions relevant to their circumstances. Everyone appreciated the understanding and responsiveness of their Coordinator.

Survey answers were consistent with the interview findings that, overall, trial participants and comparison group members experienced relatively high satisfaction with their attendant care. Most trial participant scores increased between the first and second round of surveys. Trial participants responded with particularly high scores and narrow ranges to

two statements: that attendant care increased their quality of life and that it supported them to live more independently (both around 90 points out of 100).

Trial participants acknowledged potential risks of direct funding, related to financial and management issues, workplace conditions and safety, and a few trial participants experienced such problems. Most solved the issues themselves or with the support of Lifetime Care, and one person left the trial due to difficulties managing direct funding. People suggested that management risks could be minimised if Lifetime Care organised administrative support and increased financial oversight. Workplace safety could be maximised through vigilance and through checking workers' training history. Generally, trial participants felt safe and perceived a sense of goodwill on all sides.

## 4.5 Guidance for staff and participants

The trial managers drafted resource documents to guide Lifetime Care staff and potential participants in setting up direct funding. The documents explained the processes, responsibilities and potential risks of this new funding method.

Successfully training the Coordinators was particularly important, as they needed to introduce direct funding to participants and answer questions while people were on the trial. As anticipated, Coordinators found the procedures initially confusing. At the first focus group, they were unsure about aspects of the implementation of direct funding, for example how to reconcile expenses and allocate funding, the rules for accumulating support hours to use later, and their role in communicating the change in funding arrangements to service providers.

Over the following year, trial managers at Lifetime Care continued to train and support Coordinators. They organised another workshop and redrafted documents in early 2015 to clarify direct funding procedures. However they found that Coordinators preferred personal, case-by-case guidance to written documentation. This was time-consuming for managers but reflected the realities of a small trial. Case-by-case advice was also necessary because each trial participant presented unique issues that needed to be resolved, prompting Coordinators to seek clarification from trial managers at head office.

Most Coordinators involved in the trial supported only one trial participant and were applying the procedures for the first time. Over the life of the trial, there were 13 Coordinators for the 11 trial participants, with two Coordinators supporting two participants each and four participants experiencing a change of Coordinator during the trial. Management found it beneficial to keep involving new Coordinators: they learned from others already on the trial, they raised new questions that could be resolved during the trial phase, and they helped widen the knowledge base in preparation for a wider rollout of direct funding.

In the second focus group towards the end of the trial, the Coordinators still expressed confusion and uncertainty about direct funding procedures. For example, they said they did not understand the reporting forms and did not know how to answer participants' questions about accounting.

The Coordinators suggested that Lifetime Care arrange:

- a contact in Lifetime Care (or external, but organised by Lifetime Care) for Coordinators to source accurate information or to refer trial participants

- formal training for new Coordinators when they were assigned a person on direct funding
- checklists and detailed handbooks for setting up direct funding, aimed at both Coordinators and participants
- individual, hands-on support for participants in the setup of direct funding and an ongoing contact for optional advice
- administrative support options for participants.

During the trial, participants received guidance from their Coordinators (as described above), from an independent specialist training provider employed by Lifetime Care, and from their own sources. Like the Coordinators, several trial participants requested more direction than was initially available for setting up direct funding and more clarity around rules (4.4, Appendix B).

The independent training provider had prepared training modules covering human resources, budgeting, reporting and risks, but adjusted their training to each individual's needs: "We assist people to develop something that works for them". The provider also found that trial participants' needs regarding the extent and intensity of training varied widely, from no training at all to several face-to-face training sessions and ongoing telephone support. Generally, people with higher support needs and larger attendant care budgets requested more training than others. The training provider felt that ongoing training was important to help people explore the opportunities of their direct funding and adjust it to their changing needs over time.

The independent provider's support was compatible with the needs of some of the participants but not all. This experience indicates that options might be to offer specialist training from a range of providers to match participants' preferences and to supplement Lifetime Care support with ongoing assistance, such as peer support.

In the training provider's experience, peer support in particular was a successful method of providing ongoing assistance. During the trial, the training provider organised peer support among trial participants, by encouraging some who had started the trial earlier to share their experiences with people who had joined later. The training provider suggested that Lifetime Care facilitate ongoing peer support, both for participants and for their families.

## 4.6 Monitoring

One aim of the trial was to make the direct funding process as simple as possible for trial participants and Lifetime Care, while protecting both from additional attendant care costs and workplace liability, and protecting the trial participant from personal risks. As described earlier, trial participants received initial training about their safety and about their responsibilities towards attendant care workers and Lifetime Care. During the trial, Lifetime Care set up monitoring procedures and reviewed its initial approaches.

Direct funding expenses were monitored via expense statements that the trial participants had to complete and send to Lifetime Care fortnightly. The expenses were then manually entered into Lifetime Care's finance system and checked and, once approved, the next fortnight's funding was released to the participant's nominated bank account. While most trial participants were happy enough with the system at their end (Appendix B 1III),

Lifetime Care found it cumbersome and inefficient, due to the manual procedures and multiple handling involved. The agency was investigating alternative means of processing funds, including IT solutions such as banking products, computer and mobile apps.

Monitoring expense statements made Lifetime Care aware of rare cases of unapproved use of funds. Two trial participants had used their direct funding for expenses that they regarded injury-related but Lifetime Care did not, e.g. furniture removal. The trial participants were advised and refunded the amounts. In another instance, Lifetime Care observed that a participant had transferred large sums of money into another account for unknown reasons. The participant was reminded that all funding related to the direct funding agreement must be maintained in the one nominated account. The participant rectified this and transferred the money back into the account.

The trial participants' financial and legal responsibilities also needed to be monitored, in particular whether they paid adequate taxes, insurance and superannuation for workers, and whether they reported regularly to the tax office. Coordinators felt that they did not have the required professional knowledge to monitor compliance (4.4); instead they suggested Lifetime Care needed to arrange regular audits and offer trial participants administrative support.

Workplace safety was considered in the setup process for direct funding, as described from the trial participants' perspective (4.4, Appendix B). From the service providers' perspective, those who participated in the focus group and interview were concerned about risks for support workers under direct employment, in particular exploitation and abuse by the client; financial risk from having two employers and resulting increases in tax liability; and reduced access to training and professional development opportunities. Service providers suggested that Lifetime Care fund a peak body of providers to explore structures that would represent interests of the workforce employed under direct funding arrangements.

In the trial Lifetime Care did not specifically arrange for regular monitoring of employment practices. During the two years of the trial, one attendant care worker lodged a complaint about mistreatment by a trial participant who was employing them, but the complaint was dismissed (Appendix B 1VIII). Several trial participants maintained individual worker employment below the threshold entitling the worker to superannuation payments, but many workers enjoyed higher hourly pay and increased flexibility in work hours (Appendix B 1III). By the end of the trial, Coordinators had heard no complaints from workers, apart from the maltreatment case mentioned above.

Potential personal risks to trial participants, such as maltreatment by workers or financial abuse, were not reported during the trial. According to the interviews with trial participants, they all felt safe with the providers and workers they had chosen, and they had full control over managing their budget themselves or had supportive families. Lifetime Care was conscious of the potential risk of harm to trial participants, but had not yet found a suitable insurance product for injuries to trial participants caused by their directly employed workers (Appendix B 1VIII). Instead Coordinators checked in with trial participants regularly to monitor their wellbeing.

Similarly to the trial participants, people in the comparison group did not report maltreatment by workers. Lifetime Care managed this risk by sourcing attendant care support only from providers that it had vetted and approved, and by responding to

complaints. Comparison group members confirmed in the interviews that issues with quality of care were generally addressed quickly and effectively by Lifetime Care (Appendix B 1IV).

#### **4.7 Economic analysis**

The economic analysis examined the costs of developing and funding the trial in comparison with established attendant care support, in the context of outcomes for direct funding trial participants. The analysis found that the cost of direct funding support packages was stable and similar to non-trial participants, while Lifetime Care's program management costs were relatively low, representing below five percent of attendant care support costs in the trial. A summary is presented here, and details are in Appendix C.

Attendant care made up three-quarters of injury-related support costs for trial participants and just over one-third for the data comparison group. This difference reflects the selection of people for the trial who were living at home and had stable support needs.

The average cost of attendant care support varied significantly across types of injury and the related levels of support. Estimated average cost of support per year for the highest level of spinal cord injury was around \$180,000 per person (up to \$314,000), compared to below \$10,000 per year on average for lower level injury participants.

The cost analysis showed that support packages for the 11 trial participants were stable and at similar cost levels to attendant care support organised by Lifetime Care for corresponding levels of injury.

Program establishment and management costs were relatively low, representing below five percent of attendant care support costs in the trial. The initial investment supported improved outcomes for trial participants and potential ongoing benefits for future direct funding participants.

#### **4.8 Managing relationships with service providers**

Lifetime Care manages its relationships with service provider organisations to ensure that scheme participants receive good quality attendant care. The agency was aware that direct funding would change market conditions for approved service providers, because direct funding participants could choose other specialist providers, mainstream service providers or directly employ workers. During the trial, Lifetime Care aimed to understand the workforce implications of its direct funding model (program logic Figure 1.1). Since the trial was small, impact on service providers was limited.

In the focus groups, service providers and Lifetime Care staff discussed potential impacts of direct funding on provider organisations and support workers. They based these opinions on their experiences with the trial, with other direct funding programs, and with the model of Lifetime Care-organised support.

Lifetime Care staff expected service providers to be wary of direct funding due to potential loss of business, especially if the provider supported only a small number of people. Workers might resign and prefer to be employed directly by the person, as did happen in some cases during the trial. Staff assumed that if the trial participant had a small amount of attendant care, service providers might be happy for them to leave because the administrative cost was high compared to the care revenue, but if they were a larger user, providers might be concerned.

Service providers who participated in the focus group and interview said the impact on their organisations would depend on the proportion of clients who chose direct funding. They expected that most people would not want the financial responsibility of direct funding but prefer to maintain support arrangements as they were. This would apply especially to existing clients who were happy with their current support. Providers expected that future new clients might be more likely to consider direct funding.

The service providers who participated in the focus group felt they were well prepared to compete for directly funded clients. They said that, unlike many others in the disability service sector, they were already providing person-centred care to each of their service users, regardless of funding type. To be able to accommodate client preferences, the organisations over-recruited workers, and they advertised for workers with different interests so they could be matched with clients. They also tried to match clients' personal preferences with their existing staff. Within the organisations, members of client support teams covered each other and might arrange rosters among themselves. Sometimes the organisations built dedicated support worker teams for individual clients, without cross-sharing of workers to other clients. They mentioned an example where such a dedicated team had been formed, and the client had chosen to organise the roster themselves.

The organisations said they could not accommodate every client request, usually due to workplace safety and award constraints, such as penalty rates for shifts longer than eight hours. Also, flexibility was limited by workers' own commitments, for example, to their children and other family members. Therefore they often needed to work out a compromise in negotiating attendant care arrangements with consumers.

One of the service providers taking part in the evaluation had a client who had joined the Lifetime Care direct funding trial but remained a customer. The provider said they were now much less involved than before with oversight of the person's attendant care program. Another provider had had a client through Lifetime Care who went onto the trial and directly employed staff, including some staff who left the provider and now received higher pay from the client. The provider felt that they were competing in an unfair marketplace, where people on direct funding could offer higher hourly pay rates because they had lower overheads than an organisation.

In another case where a trial participant directly employed their previous workers, the workers had inadvertently breached their contract with the provider. Subsequently, Lifetime Care strengthened its guidance procedures for Coordinators, prospective trial participants and the independent training provider, to ensure that the workers' contractual responsibilities were checked before direct employment was arranged. Lifetime Care was also planning discussions with service providers to avoid similar cases in the future.

#### **4.9 Development of a direct funding policy**

When the trial ended in December 2015, Lifetime Care planned to develop direct funding within the next year into a service management option that could be expanded across Scheme participants and transferred to services other than attendant care (e.g. physical health needs). Now that they were part of icare, Lifetime Care felt they had the potential to work closely with their finance department to develop modern solutions for direct funding processes and monitoring. Within icare, the IT case management system of Lifetime Care would also be revised, in conjunction with those of the other schemes.

At the end of the trial, and considering the lessons that had emerged during the two-year trial phase, Lifetime Care's considerations for the design of a direct funding policy included:

Eligibility: designing direct funding in such a way that it would be a viable option for Scheme participants. This would include people with all types of injuries, and it would need to consider the inclusion of children and Scheme participants who live overseas. At this stage, management did not find it appropriate to offer direct funding to interim participants of the Scheme; in their view, having completed rehabilitation and having stable support needs were prerequisites.

Risk and capacity: exploring participant risk and capacity individually. Management planned to develop a safeguarding approach for participants seeking to manage their supports through direct funding. This approach was to assist in identifying participants' support needs for direct funding.

Setup support: providing effective support for participants to set up direct funding. This would include clear, comprehensive documentation and personal guidance that would be hands-on, practical, able to be delivered face-to-face and available across the State.

Employing family members: not using Lifetime Care funds to pay for family members or friends to deliver support to a participant. This policy aimed to support family and friends to maintain their personal relationships. In the trial, difficult issues arose where family members were employed to provide formal support. Lifetime Care would address the complex issue of employing family members within a direct funding arrangement as part of the policy development.

Fund management: establishing a range of options to provide participants more opportunity to have more involvement in self-directing their care, for example, involvement in staff recruitment and management of rosters. Providers might include financial intermediary services or attendant care service providers. Scheme participants would be able to choose the option that suited them best. A continuum of options would provide steps into increasing self-managing over time, rather than rapidly transitioning from a service provider managing the whole program straight to direct funding.

Ongoing support: offering participants a contact point for ongoing advice about administrative issues.

Reporting: improving systems so that they would be simple and easy to use for both participants and Lifetime Care. Management said they envisaged "modern IT solutions", possibly replacing paper expense statements with electronic banking using a debit card.

Monitoring: implementing regular reviews to ensure direct funding participants fulfil their obligations regarding tax, superannuation and insurance. Suitable review personnel and intervals needed to be determined.

Lifetime Care Coordinators: consideration of concentrating direct funding expertise to a few Coordinators in each office rather than spreading direct funding participants among many Coordinators with limited expertise. This was to ensure that Coordinators could support direct funding participants well.

Peer support: encouraging peer support among direct funding participants. They expected this would become more feasible as participant numbers increased.

In developing a direct funding policy, Lifetime Care also needed to consider questions concerning budget allocation that had emerged during the trial, including:

- Would Lifetime Care suspend direct payment if the participant was not receiving the attendant care, for example when they were in hospital or on holiday?
- When participants went on holidays, should they pay flights and day allowances for attendant care workers from their direct funding budget, or should this be a separate service request?

#### 4.10 Summary of implementation of the trial

As lessons from the trial emerged, Lifetime Care adjusted policies and procedures. Internally, staff were trained to understand the aims and processes of direct funding. Questions from participants were addressed as they arose. Monitoring procedures were under review, and the views of attendant care service providers were considered.

- **Participant experiences** with the trial were overwhelmingly positive. Increased control over providers, workers and support arrangements gave them opportunities to fix previous shortcomings and adjust support to their needs. All trial participants said their quality and flexibility of support had increased since they started direct funding. Relationships with attendant care workers and providers improved for all trial participants; they had the impression that workers and providers respected them more because they were in control. Almost all managed their packages well and only one left the trial. Some participants asked for more or different support from Lifetime Care in setting up or managing direct funding. These requests and the support they needed cannot be generalised because it varied by person, largely dependent on the capacity of Lifetime Care staff to identify and respond to the gaps in each person's prior experience related to managing direct funding.
- In the survey, trial participants responded with particularly high scores and narrow ranges to two statements: that attendant care increased their quality of life and that it supported them to live more independently. Trial participants acknowledged potential risks of direct funding but managed these well; generally they felt safe and perceived a sense of goodwill on all sides.
- Internal **Lifetime Care management** of the trial had limited staff allocation. The managers felt that this impacted on their capacity to refine the model. Continuous monitoring of the trial allowed the early identification and resolution of issues as they arose. Staffing resources were not available to develop other models such as financial intermediary models at the time. This has now been addressed as a business priority.
- Lifetime Care staff and service providers understood the **aims of direct funding** and the rationale behind it. Lifetime Care Coordinators involved in the trial saw the benefits of direct funding for participants.

- The **selection of trial participants** was targeted to protect both the participants and Lifetime Care. The selection process involved recommendations by Coordinators, an eligibility check and a risk assessment. The process seemed effective, considering that most trial participants managed direct funding well and benefitted from it. Lifetime Care expected that when direct funding was expanded some participants might need significantly more support than the trial participants did.
- Lifetime Care trial managers adjusted their **guidance for staff and participants** as the trial progressed. Documents were redrafted according to feedback, and rules were clarified as issues arose. Management decided to keep involving new Coordinators in preparation for a wider rollout of direct funding. Some Coordinators still expressed confusion and uncertainty about direct funding procedures by the end of the trial, indicating a need for continued training and reflective supervision to refine the extension of direct funding.
- An independent specialist **training provider** supplied the initial training needs of participants, with additional support from Lifetime Care Coordinators. The independent provider's support was compatible with the needs of some of the participants, but not all. This experience indicates that options might be to offer specialist training from a range of providers to match participants' preferences and to supplement the Lifetime Care support with ongoing assistance, such as peer support.
- **Monitoring** of direct funding expenses occurred via fortnightly statements that trial participants submitted to Lifetime Care. The agency found its manual system inefficient and planned to streamline and update it. Similarly, the agency planned to develop processes for monitoring the trial participants' financial and legal compliance, as well as participant and worker safety, as part of a wider direct funding policy.
- To **manage relationships with service providers**, Lifetime Care included some providers in the evaluation and explored workforce implications of direct funding with them. Providers were trying to compete in the new marketplace by offering consumer-directed approaches.
- The **economic analysis** examined the costs of developing and funding the trial in comparison with established attendant care support, in the context of outcomes for direct funding trial participants. The analysis found that the cost of direct funding support packages was stable and similar to non-trial participants, while Lifetime Care's program establishment and management costs were relatively low, representing below five percent of attendant care support costs in the trial.
- Lifetime Care and participants regarded the trial as successful, and Lifetime Care planned to **develop direct funding** into a service management option for attendant care within one year. Experience from the trial informed design plans for the policy, including offering participants a wider range of setup support to meet their individual needs and preferences, a range of options for fund management, ongoing administrative advice, simple reporting systems, regular monitoring and peer support.

## 5 Implications for policy development

The evaluation found that almost all participants in the direct funding trial experienced significant positive outcomes, at levels of support cost that were stable and equivalent to comparable people who were not in the trial. Analysis of the implementation process of direct funding showed what worked well and what could be improved for both participants and Lifetime Care. The findings contribute to intended outcomes for Lifetime Care, as they increase understanding about direct funding and its implementation.

This section discusses implications of the evaluation findings for a direct funding policy within Lifetime Care. The overwhelmingly positive experiences of trial participants demonstrate that direct funding of attendant care support is feasible for people participating in the Lifetime Care and Support Scheme. Any difficulties that participants or Lifetime Care experienced during the trial indicate how rules and processes could be improved, to develop a direct funding policy that is transferable to other people and other support types. At the time the evaluation ended, Lifetime Care had identified that the development of direct funding was a business priority and planned to develop a direct funding option for the self-management of care within the next 12 months (4.9).

The suggestions below regarding policy design are based on the evaluation findings and grouped into three areas: support for direct funding participants, attendant care workforce issues and governance of direct funding.

### 5.1 Support for direct funding participants

- Lifetime Care could provide clear information about direct funding for potential participants, so they can more easily understand their responsibilities and the processes required in setting up and managing direct funding.
- People with large, complex direct funding programs may need more or different set-up support than available during the trial. Some trial participants suggested funding for accounting advice to establish financial and administrative structures.
- Lifetime Care might consider how to support people who need assistance with recruiting workers. This need may be due to a shortage of suitable workers in their location, or because they have support needs that require workers with specific skills.
- In the trial, Lifetime Care showed flexibility by allowing one participant to employ family members, where the participant was not able to meet their support needs with the available specialist workforce. This caused difficult issues for the participant and the family members. Lifetime Care intended to apply the current policy of not allowing family members and friends to provide paid support to future direct funding participants.
- Administrative support options could make direct funding accessible to people who want or need support with managing their budget. These support options could include providers engaged by Lifetime Care or information from Lifetime Care about suitable providers.
- Trial participants asked for optional access to support and advice whenever issues with direct funding arose. Lifetime Care could offer expert legal and

accounting support as needed, arrange peer support, keep involving independent training providers, or a combination of the above.

## 5.2 Attendant care workforce issues

- To help ensure that direct funding participants can access a suitable attendant care workforce wherever they live and whatever their needs are, Lifetime Care could encourage attendant care service providers to offer more consumer-directed approaches. Lifetime Care deemed that the market was already adjusting to the increased choice and control environment, as the industry had been going through several years of reform in preparation for rollout of the NDIS in 2016-17, with the ACIA a primary driver.
- To help protect training interests and workplace conditions of attendant care workers employed under direct funding arrangements, Lifetime Care could explore suitable mechanisms in cooperation with unions, professional organisations and provider organisations. These would be in addition to the current role of ACIA, which works with unions that are representing attendant care support workers and also offers individual membership to workers.
- Worker safety could be considered when setting up direct funding and monitored regularly. Lifetime Care could inform participants about their responsibilities, provide resources so they can manage effectively, and maintain some oversight, via the regular contact between Coordinators and participants.

## 5.3 Governance of direct funding

- Thorough training of staff and improvement of guidance documents, based on experiences during the trial described in this report, might reduce confusion among staff about direct funding rules and procedures, increase Coordinators' inclination to nominate potential direct funding participants, and further reduce risks for Lifetime Care.
- Potential risks in participants' budgeting of attendant care funds might be managed by offering administrative support through specialised providers and increasing financial oversight by Lifetime Care directly or by contracted providers.
- Regular monitoring, at least yearly, of direct funding participants' obligations regarding tax, superannuation and insurance would help to protect participants and Lifetime Care from potential liability.
- Streamlining reporting procedures could reduce Lifetime Care's administrative load. A participant's suggestion was to create electronic expense statements that are integrated with Lifetime Care's finance system.
- To ensure direct funding participants' safety from physical harm and financial exploitation, Coordinators would need to regularly check participant wellbeing. Lifetime Care would need to develop guidelines and set frequency of checks; at least six-monthly intervals seem reasonable and should be reviewed for adequacy.
- The evaluation generated extensive feedback from trial participants about their reasons for choosing direct funding and the benefits they experienced. This

feedback could be used to improve Lifetime Care support to people who do not receive direct funding, for example regarding flexibility of support and control over support arrangements.

# Appendix A Evaluation methodology

The evaluation used mixed research methods, including a literature review, program and financial data collection, interviews, surveys and focus groups. Research methods were inclusive, to enable a variety of Lifetime Care scheme participants to take part in the evaluation. The methodology contained a longitudinal component, with two rounds of data collection. Comparison groups of people who received attendant care support from Lifetime Care but were not taking part in the direct funding trial were included to assist with the interpretation of data from trial participants.

A process and outcomes evaluation as well as an economic analysis were conducted. The process evaluation explored participant and other stakeholder experiences with the implementation of the trial. Outcomes of direct funding for participants and Lifetime Care were assessed, and the economic analysis examined the costs of developing and funding the trial in comparison with established attendant care support.

Ethics approval for the evaluation was granted by the Human Research Ethics Advisory Panel at UNSW.

## I. Evaluation questions

The evaluation questions were:

1. Does direct funding meet the needs of participants and achieve intended outcomes for them?

Indicators are:

- participants receive the attendant care that they require within their budget
- outcomes such as: increased choice, control, flexibility, satisfaction, independence; and improved health, relationships with workers, social relationships, community participation and employment or training situation.

2. Does direct funding achieve intended outcomes for Lifetime Care?

Indicators are:

- outcomes such as: increased understanding of what works well in direct funding, of the cost and workforce implications; increased understanding among Lifetime Care staff and service providers about direct funding; improvement of direct funding before rollout.

3. Are there other ways to achieve similar outcomes for participants and Lifetime Care?

This includes recommendations about:

- improvements to direct funding
- more efficient resource allocation.

This evaluation report addresses the first evaluation question in sections 3, 4.4 and Appendix B, the second in section 4 and Appendix C, and the third in section 5. Section 2 describes demographic and support need characteristics of trial participants and the comparison groups.

## II. Data collection methods

The data collection methods for the evaluation were a literature review, quantitative and qualitative data collection. The sample for data collection was comprised of 11 trial participants, a comparison group (9 people), a larger data comparison group (106 people) and other stakeholders.

The methodology was inclusive by taking account of individual needs, capacity and barriers to participation. Instruments were flexible and could be modified depending on the preferences and needs of research participants.

### **Literature review**

At the beginning of the evaluation, the SPRC conducted a short literature review of evaluations of programs similar to Lifetime Care's direct funding trial. The review informed the methodology of the evaluation, especially the selection of data collection tools. Findings of the literature review are summarised in Purcal et al. 2014.

### **Quantitative data**

Quantitative data for this evaluation included demographic and cost data from Lifetime Care, and surveys with trial participants and comparison group members collected by the SPRC.

The datasets used for the evaluation integrated Lifetime Care financial records with demographic and injury details about trial participants and the comparison groups. This supported the development of estimated average cost per person by level of spinal cord injury sub group to examine variation in support between comparative levels of injury.

Financial data included:

- retrospective support costs for comparison groups from 2010 to 2014, to provide historical perspective and a comparative baseline
- direct funding payments from Lifetime Care to trial participants for each participant since they joined the trial, to provide cost data for the trial and enable comparison with non-participants in the trial
- supplementary data from individual case files recording actual hours of care purchased by trial participants through their direct funding packages.

The number of care hours for trial participants prior to entering the trial were derived from retrospective Lifetime Care financial data based on composite average cost per hour rates for each year, in line with the method used for the control group figures.

Quantitative demographic data for the trial and comparison groups included age, gender, type and level of injury, presence of other members in the household and location of residence. The survey with trial participants and the comparison group collected additional information about cultural background and employment status.

Lifetime Care also provided estimates of internal agency costs for setting up and managing the trial. These included expenses for staff training, project manager and support Coordinator time, start-up costs paid to trial participants and the cost of initial training for trial participants in setting up and managing their direct funding. The assessment of these estimates is preliminary given the relatively small number of 11 participants in the trial. Program set-up costs could be considered an investment that will potentially provide ongoing benefits to current and increasing numbers of future participants as the program is fully developed.

The survey with trial participants and comparison group members focused on individual outcomes of attendant care in various life domains, and on satisfaction with attendant care services. To enable comparison with larger datasets, the survey questions were consistent with the Personal Wellbeing Index (Cummins 2005) and with as yet confidential client satisfaction surveys from Lifetime Care and its equivalent agency in Victoria, the Transport Accident Commission (TAC).

The survey used plain English and could be completed by the research participant themselves or together with the interviewer or a trusted person. In the first round of data collection, 12 out of 17 survey participants (71 per cent) chose to complete the survey at the time of the interview; in the second round, 3 out of 9 (33 per cent) did so. Where the interview was conducted face to face, people chose to complete the survey themselves and then handed it to the interviewer, and in the case of telephone interviews, people dictated their answers to the interviewer. The other research participants completed the survey in their own time and sent it to SPRC. An Easy Read version of the survey was available, but was not used by any participant in the data collection.

The survey is included in Appendix D, and sample sizes are in Table A.1 below.

### **Qualitative data**

Qualitative data collected for the evaluation included:

- semi-structured interviews with trial participants and the comparison group (about individual outcomes of attendant care and experiences with the process of receiving support)
- semi-structured interviews with family members of trial participants and the comparison group (about the family's experiences with attendant care and the direct funding trial, and perceived outcomes for the person receiving care)
- observation during interviews (of the participant's interaction with other people and their environment)
- focus groups with Lifetime Care staff and managers, as well as attendant care providers (about the trial implementation process, the trial's impact on service provision, and outcomes for people and families)
- interviews with staff members of the independent direct funding training provider engaged by Lifetime Care
- reflections by Lifetime Care managers responsible for the trial (this included focus groups, internal trial review documents and a log of process issues).

The SPRC conducted all interviews and focus groups, except one interview with a trial participant that was conducted by the person's Coordinator because it was the trial participant's preference. Interview schedules used plain English and were modified by the researchers depending on the needs of the participants.

It was emphasised with all participants that the interview was entirely flexible: the questions were only a guide, people could decline to answer questions if they wished, or instead of answering questions they could tell their story. Feedback from some early interview participants indicated that the interview schedule, which they received ahead of the interview, could appear long and therefore intimidating. In response, a short version was developed to give participants an indication of the topics that might come up in the interview. The interview and focus group questions are in Appendix D.

Evaluation interviews with research participants who lived in the Sydney metropolitan area were conducted face to face in the first round of data collection, if the person agreed. Due to budget limitations, all interviews outside of Sydney were conducted by phone. Skype was available as an alternative option to a phone interview, but no-one chose skype.

### **III. Sample and recruitment**

The study sample for the evaluation included all participants in the direct funding trial and, for comparison, a similar number of people who received attendant care through Lifetime Care but

were not participating in the trial. In addition, family members, attendant care providers and agency staff participated in interviews and focus groups. Financial and demographic information was collected about a data comparison group comprised of all Lifetime Care scheme participants who were more than two years post injury, had a spinal cord injury and received attendant care; this included the nine comparison group members.

The first round of data collection occurred between May 2014 and April 2015, while Lifetime Care participants successively joined the trial. People were approached for interviews and surveys after they had finished setting up direct funding and settled into their new arrangements, between one and two-and-a-half months after the start of their direct funding. Two trial participants had had informal direct funding arrangements for one and two years respectively before the trial officially started.

The first round of financial data collection was undertaken as at the end of March 2015 and established baseline figures for all trial participants and the data comparison group.

The first round of focus groups with Lifetime Care staff and attendant care service providers was conducted at the beginning of the trial in May 2014, when there were two trial participants. A first interview with two staff members from the independent training provider engaged by Lifetime Care to support trial participants in setting up their direct funding was conducted in April 2015, after they had provided initial training to trial participants.

The second round of data collection with trial participants, families, staff and providers occurred at the end of the trial, between October and December 2015. Its purpose was to add a longitudinal component to the evaluation, to determine whether and how initial process issues had been resolved, and whether intended outcomes of the trial had been achieved for participants and Lifetime Care. By the second round of data collection, trial participants had been receiving direct funding for between seven months and nearly three years, with most having had direct funding for more than one year.

The second round of financial data collection was completed as at the end of October 2015 and included further records extracted from the Lifetime Care finance system, as well as details reported by trial participants to the agency about attendant care arrangements, actual hours of support and direct funding management costs.

One round of data collection from the comparison group and their family members was considered sufficient to compare costs and outcomes, as their attendant care arrangements continued as before. Interviews and surveys with the comparison group occurred alongside the first round with trial participants.

Trial participants were recruited by Lifetime Care to take part in the evaluation. Lifetime Care obtained voluntary consent from participants and provided SPRC with contact details to set up the interviews and surveys. Ten of the 11 people who had joined the trial by April 2015 agreed to complete the interview and survey, and the person who chose not to take part gave permission for a family member to be interviewed.

Comparison group members were selected to include a wide range of demographic characteristics and attendant care needs similar to the trial participants. Lifetime Care selected 18 scheme participants for the comparison group. Out of those, nine completed the interview and survey.

Family members were recruited for interviews through the person receiving attendant care. All trial participants and most comparison group members were asked to give consent for a family member who lived with them to take part in an interview, and to ask the family member for their consent. This indirect recruitment process respected the authority of the person receiving attendant care to decide how their experiences were included in the research.

Lifetime Care arranged the focus groups, recruited focus group participants and obtained their consent. SPRC conducted the focus groups.

Sample sizes are summarised in Table A.1.

**Table A.1: Sample sizes for data collection**

Method	People with attendant care			Families			Attendant care providers		Lifetime Care staff and managers		Direct funding training provider		
	Trial participants	Comparison group	Data comparison group	Trial participants	Comparison group		1	2	1	2	1	2	
<i>Data collection round</i>	1	2	1	1	1	2	1	1	2	1	2	1	2
Program and financial data	11	11	9	106*									
Interviews: face to face	3	1	3	1		1							
Interviews: phone	5	7	6	3	4	2							
Surveys	8	9	9										
Focus groups (number of participants)							4	1	8	4	2	2	

\* includes the 9 comparison group members

#### IV. Limitations

The relatively small sample size of trial participants and the comparison group limits the statistical significance of the evaluation findings. However, the qualitative interviews yielded rich case study data. Combined with the reflections from Lifetime Care staff and the focus groups, the data enabled a comprehensive assessment of process issues in conducting the trial, of outcomes both for participants and Lifetime Care, and of suggested implications for the rollout of direct funding. In addition, the interim data collected in the first evaluation round established a baseline of experiences and expectations regarding direct funding that was available to Lifetime Care to inform the remainder of the trial.

Due to budget limitations, face-to-face interviews outside of the Sydney metropolitan area were not possible. Telephone conversations were conducted instead. This restriction potentially limited the participation of people who were not able or not comfortable to do the interview remotely.

The trial was limited to people who chose to manage direct funding themselves or had arranged their own management support. Three trial participants had arranged their management support, all by partners or parents, including the two with traumatic brain injuries. Therefore, due to limited sample size and need for confidentiality, experiences of people with traumatic brain injuries and for any person who wanted management support for direct funding could not be explored separately.

The financial records for trial participants reflected typical payment processing cycles, including some variation in timing of payments and the respective timeframes covered by invoices processed against approved funding packages. This was a potential source of minor variation when deriving estimated hours of care per month, and in annualising of figures for a small number of individuals. However, the annualising of figures was a minor factor as most of the 11 trial participants had completed a full or almost full year on the trial for the round 2 data collection as at 31 October 2015.

Given the small sample sizes, in particular the smaller sub groups by injury level, statistical analyses of average cost figures were not appropriate. The figures are presented as indicative preliminary costs for further validation when direct funding is rolled out to more scheme participants.

## Appendix B Trial participant experiences with direct funding

This section discusses the trial participants' experiences with direct funding. It includes process issues around the setup and organisation of direct funding as well as impressions of how direct funding impacted on attendant care support. The intention of the policy is to increase people's control over their support, improve relationships with support workers and Lifetime Care and generally improve satisfaction with attendant care services (Figure 1.1). Findings are compared with the experiences of the comparison group, where applicable. They are based on surveys and interviews with the research participants and on observations. Changes in the experiences of trial participants between the first and second round of data collection are mentioned where they occurred.

### I. Reasons for choosing direct funding

Most trial participants found out about direct funding from their Lifetime Care Coordinator. The Coordinators had been briefed by Lifetime Care about the trial and asked to approach people who might be interested and eligible. Two trial participants had contacted Lifetime Care of their own volition and asked for direct funding because they wanted to improve their support. One of these people knew about direct funding because they had experience in the disability and health sectors, the other had heard positive experiences of people with direct funding packages from other organisations.

Most people decided to take part in the trial because they were dissatisfied with one or several aspects of their attendant care support, including: inadequate quality of support, restricted range of tasks and flexibility regarding number of hours and times of the day, limited control over which workers came to the home, and insufficient reliability of service provision and amount of support available. For example, trial participants said about their previous support:

The gardening service was not doing enough work for the hours they charged. I felt they were taking advantage of being a government contractor. They were taking Lifetime Care for a ride.

I could not make roster changes short-term. It was always a drawn-out process, involving someone from the service provider as a middle-man.

Attendant care workers did not go into the pool with me so I couldn't do hydro exercises.

You never knew which worker was coming. I didn't get on with all of them, so I was always dreading who would turn up.

Sometimes carers just didn't come, so my wife had to stay home from work and help.

One man had problems with consistency and amount of support from the previous provider, but he was hesitant to go on the trial because he had high support needs and knew that managing his support would be a major effort. 'I waited for six months hoping for a miracle', but when support did not improve he decided to commit to the trial.

In addition to wanting to resolve issues with their support, three trial participants opted for direct funding also for its own sake. They saw it as a meaningful activity, a path to future employment (3.2, 3.5), or because they wanted to be in charge of their support. People said:

I have lost so much with the injury, this gives me at least a little bit of control back.

Before my accident, my life was my life, and now every Tom, Dick and Harry knows everything about it. I don't like that. With direct funding I have less people to deal with.

All trial participants said they had decision-making support about joining the trial to the extent they wanted and needed. Joining the trial was voluntary, and all participants were comfortable with their decision. Many had discussed it with their families, and everyone sought information about the trial, its obligations and opportunities from various sources as they saw fit: their Coordinators, accountants, insurance companies and solicitors, as well as an independent direct funding training provider paid for by Lifetime Care for the trial.

Of the nine comparison group members, five said they were interested in direct funding – two because they were dissatisfied with their current support, and three because they felt capable to manage their own support and felt they would enjoy the task. One of the comparison group members who was dissatisfied with his support had started the paperwork for joining the trial but then pulled out. He had found better providers, he did not want to have financial management responsibilities, and he preferred to wait until Lifetime Care had established effective processes during the trial. Four comparison group members were not interested in direct funding because they were satisfied with their support. For example, one person said:

I am happy with the system as it is and don't think I could get any better support if I organised it myself.

## II. Setting up direct funding

Once people had decided to join the trial and Lifetime Care had formally approved their participation, legal and administrative structures had to be set up. These included as a minimum:

- signing a contract generated by Lifetime Care between the agency and trial participants setting out rights and obligations of both sides
- opening a new bank account specifically for the attendant care funds; this was the participant's responsibility.

Trial participants who chose to directly employ their attendant care workers also needed to organise:

- payroll and accounting systems
- workers' compensation insurance
- general liability insurance.

Lifetime Care prepared guidance documents for trial participants as an overview of what was required. Advice was available from their Coordinator throughout the process. Lifetime Care also offered up to \$1000 to enable participants to access their own legal advice in relation to the contract.

Lifetime Care paid for training from an independent training agency that was sourced from a sparse market of providers with knowledge and skills in direct funding. The expectations were that this training would cover essential aspects of the requirements on participants in directly funding their care, with the intent of ensuring they understood their responsibilities as an employer. This

included insurance requirements; recruitment and staff management advice (human resources); and financial management in relation to wages, tax and super.

The extent to which these offers were taken up differed among trial participants. Generally, people accessed more support if they had a large funding package, planned to self-employ workers or lacked previous work experience in accounting or management. A woman who was self-employed and had a relatively small package just talked with her Coordinator: 'There was more help available, but I didn't need it.' Another woman also declined training because she felt she did not need it:

In my case, direct funding just involved opening a bank account, which I did myself without any problems. If I decide to directly employ workers in the future, I will ask about insurance and other obligations then.

Seven people chose to get support from the independent training provider. This involved at least one face-to-face meeting for initial information and for assessing the person's training needs and subsequent training sessions as required, covering issues such as employing staff, budgeting, reporting, risks and IT. Most people found this support helpful. One person said:

Through the training I became aware of the benefits of direct funding. They were very good, lovely people, they opened up windows for us. It helped that one of the people from [training provider] was using a wheelchair. They had a similar life experience.

Two trial participants would have preferred more support from the training provider, such as information about insurance and tax liabilities, and practical support in setting up accounting procedures. They said the training provider was not able to give them the advice they needed and instead referred them to accountants and lawyers. Generally the trial participants seemed proactive and searched for the information they needed from appropriate sources, including their business partners, accountants, lawyers and insurance companies. For example, people said:

I did my own research because I was interested in it. I talked to my accountant and a solicitor.

I asked one of my business partners how to get insurance for staff and pay their taxes and salaries. With that and the checklist from Lifetime Care I figured it out.

I talked it through with my insurance company, and I arranged workers comp by adapting the public liability insurance for my property to cover the attendant care workers.

The implications for policy development are that some participants needed more or different advice and support than the training provider could offer; different or additional sources would need to be found.

Several people needed to set up bookkeeping, either due to the large size of their package or because they employed their own workers. Some engaged professional accountants, and one employed their daughter-in-law (who was a qualified accountant) as a bookkeeper with Lifetime Care's permission. Others acquired computers and software, which Lifetime Care paid for, to do their own accounting and scheduling. Some purchased this equipment as an overhead from their initial six-week direct funding buffer, thereby reducing the buffer and exposing them to risk around budget management. Lifetime Care would need to develop clarification and operational criteria in their future direct funding policy.

The process of clarifying responsibilities and setting up the necessary administrative and legal structures took several weeks to a few months for each of the trial participants. This time might

reduce as operational guidelines, advice for participants and practical set-up support improve, and as Coordinators become more familiar with direct funding. Overall, people seemed satisfied with how Lifetime Care had supported them through the process. One person said:

The process to move onto direct funding has been uncomplicated. I have to give credit to Lifetime Care for being accommodating.

Two trial participants described significant difficulties in setting up direct funding. Both managed large packages with 24-hour support and several workers. One of them felt that the training provider engaged by Lifetime Care could not tell him anything new. In hindsight, he would have preferred Lifetime Care to pay an accountant to set up the financial and administrative structures of direct funding for him, including contracts, wages and taxes. He estimated this would have cost less than the training and would have saved him several weeks of stress and hard work. Similarly, the other trial participant considered the training provider support insufficient. Such experiences indicate that people with large, complex direct funding programs may need more or different set-up support than was available in the trial. Several trial participants suggested that Lifetime Care develop a package with clear, step-by-step instructions for how to set up direct funding or engage advisors to help participants set up their accounting and provide support until participants felt competent.

### **III. Management of direct funding**

Trial participants were required to manage direct funding themselves or arrange management support. This included organising bookkeeping, budgeting funds and setting up rosters. Participants had to meet the cost for their time and expenses in managing direct funding out of their budget allocation, which included an hourly component for management.

First, regarding bookkeeping, those who got attendant care support from a provider organisation had few management responsibilities and found the bookkeeping process uncomplicated. They received regular invoices from their providers and paid them out of their direct funding bank account. For example, one woman said:

This is not a big job. I can do it on the computer and it doesn't involve travelling. It takes me only a few minutes.

Trial participants who employed workers themselves had either engaged an accountant or were managing the funds themselves. One man said:

Employing a bookkeeper was a good decision. I highly recommend it. I don't have that expertise and don't want to acquire it.

Where people chose to do bookkeeping themselves, they often got advice from the training provider engaged by Lifetime Care, or they had previous business management experience. People bought accounting software and used their own accountants as back-ups if necessary. One man was not aware that his direct funding allocation included a proportion for managing the package and suggested that Lifetime Care allocate additional funds for bookkeeping.

Bookkeeping was complex for people who directly employed workers (Appendix B II). Three trial participants, including one who had a bookkeeper, only learned about some of their obligations regarding workers' pay, superannuation and tax after starting their program. This caused frustration and anxiety. Trial participants resolved the issues by seeking clarification on the internet, from accountants or from the independent training provider paid for by Lifetime Care. All would have preferred comprehensive and clear information from the start. This confirms the observation above (Appendix B II) that people with complex direct funding programs may need more or different information and support than was available during the trial.

Even people with smaller, simpler programs may benefit from additional support. Several people asked for Lifetime Care to offer optional information and advice on an ongoing basis, for example one man said:

It would be good if you could call someone if you weren't sure about something. The case manager wouldn't necessarily be able to help, it needs more an accountant-type person.

Ongoing support and advice may have prevented the failure of the trial for one participant. After he had set up his modest program and successfully managed it for several months, Lifetime Care Coordinators said he fell behind with paying invoices and decided to leave the trial. As he did not take part in the second round of interviews, his views about the reasons for leaving the trial are not known.

Trial participants were required to submit fortnightly forms to Lifetime Care, detailing their expenses over the period. Receipt of this form triggered transfer of the next fortnightly direct funding allowance from Lifetime Care. Trial participants said they spent between 30 minutes and two hours a fortnight on this task, and most people found it easy and straightforward. A few issues arose during the trial, for example: one person with a large funding package often received invoices from a provider organisation late, making the flow of her funding uneven. She solved this problem by using part of the buffer amount that Lifetime Care had deposited into trial participants' accounts until expenses were reconciled. In another example, a person submitted his expense statements irregularly, leaving his direct funding bank account nearly empty at times. He suggested that, in the future and for any wider rollout of direct funding, Lifetime Care establish an electronic reporting system:

I would find an online form much easier. Paper is outdated, and someone at Lifetime Care has to enter it into their system anyway.

The second element of direct funding management was that trial participants had to budget their allocation over time. If there were unused funds in a fortnightly budget allocation, they remained in the bank account and were carried over to be available at a later time. Conversely, if people over-spent, for example due to sudden ill health or another short-term emergency, they could use their buffer of funds. As reported above, the buffer was also used to smooth out irregularities in the flow of provider invoices.

All trial participants said they were aware of how much money they could spend and how much was left in their bank account at any time. No-one mentioned any problems with budgeting, and several people pointed out financial benefits of managing their own attendant care budget. Two people had changed to cheaper providers, giving the person more hours of service for their allocated funds. People managed their budget as a whole and made efficiencies in the way they managed the administration. This enabled them to pay their workers a higher hourly rate than their organisation had, in order to reward quality service and establish goodwill for the future. One paid the workers a Christmas bonus. Two people paid for higher-quality support: one woman employed a relatively expensive but reliable and good-quality gardening provider, and a man paid for higher-quality personal care:

I have more funds available through cutting out the middle man and using a large amount of the administrative portion for [attendant] care. This makes a big difference – I can employ better qualified workers.

Another person said she was saving part of the overheads: 'That gives me an extra hour here and there.'

Finally, trial participants needed to organise their own roster of workers and providers. This task was relatively simple for people who received a few hours of housework or gardening support per

week but complex for those with 24-hour support needs and several workers who they employed directly.

No-one appeared to have problems setting up and managing their rosters. People talked about allocating shifts amicably among their workers and with providers, and some people found it helpful to use software support for rostering.

#### **IV. Control over attendant care support**

A main goal of direct funding is to increase people's control over their attendant care support. This includes choice over who provides the support and flexibility about how and when the support is provided. Experiences of trial participants are discussed first and then compared with those of people in the comparison group.

##### **Choosing providers and workers in the trial**

When people joined the direct funding trial, they could choose different attendant care provider organisations, including organisations that were not on the Lifetime Care approved provider list and mainstream providers, or employ their own attendant care workers. The 11 trial participants had a variety of arrangements:

- 2 people had kept the same provider and same workers as before
- 4 people had the same workers but were directly employing them now
- 1 person had the same provider on weekends and directly employed the same workers during the week
- 2 people were directly employing all their workers, who were a mix of same and new workers
- 1 person had a mix of same and new providers
- 1 person had engaged a new provider.

This wide diversity among such a small group indicates that direct funding gave each person the opportunity to individualise their support, choosing the combination of providers and workers that suited their particular situation best.

The reasons for people's choices were related to their original motivations for joining the trial (Appendix B I). Two people stayed with their providers and workers because they were satisfied with the support they received but wanted to pay them directly and be able to change support if they wished. One of these people also said they preferred to remain with an agency because they did not want to deal with staff management and insurance issues.

Those who kept the same workers but were now employing them directly did so because they liked the workers but wanted more control over how and when they received support. This is discussed further in the following section on flexibility.

Change of providers or workers occurred when people were not satisfied with their support. One person engaged a new cleaner – a mainstream service provider who would do the cleaning tasks she needed; another changed gardeners because he felt the previous gardener was not doing adequate work for the hours charged. One man recruited male support workers to help him with physical tasks on his property that he considered meaningful; previously, female agency workers would sit with him inside the house. Another man was now directly employing workers because he had experienced inconsistent and inadequate support from his previous service provider

organisation. Making these decisions gave people a feeling of control over their attendant care support. As one man put it:

I am now in the loop. This is my private home, and I have control over what happens. It is like at my job: when a subcontractor is not pulling their weight, they will be reviewed.

Experiences with recruiting new providers or workers varied. Most people said it was easy to find new gardeners or cleaners who they were happy with. It took one woman six months to find a reliable gardener, but she preferred this to having Lifetime Care organise her gardening because she wanted to control her support provision. Those who chose to employ their previous workers said the workers arranged the change with their organisation, and often they remained with the organisation part-time. Several people who lost staff during the trial found it easy to recruit replacements.

Two people mentioned significant recruitment difficulties, and both had high, 24-hour support needs. Both wanted to recruit additional workers to cover more hours so their relatives would provide less support. First, a man could not find qualified support workers in his small, remote home town. He felt this was due to shortage of providers as well as lack of flexibility among the existing providers. For example, generic community care providers would not perform bowel care and assist with medications because they regarded these as medical procedures. The trial participant was frustrated:

I feel in small towns like ours we are at the mercy of local providers.

With the agreement of Lifetime Care, he stopped requiring formal qualifications from applicants, but just asked for relevant experience relating to various support tasks. In addition, Lifetime Care allowed him to pay family members for some of the extensive support they gave, by having them employed through a service provider under an 'exceptional circumstances' provision. By the end of the trial a solution had not been found. The participant reported family members were ageing and wanted professional workers to take over. Lifetime Care reported solutions had been offered but not accepted; the agency perceived a conflict of interest on the part of the family members who relied on the income from providing attendant care. Lifetime Care felt this case highlighted problems regarding conflict of interest and impact on family relationships when approval was given to employ family, and that the issue needed thoughtful exploration when designing a direct funding policy.

Second, a woman who was managing her partner's direct funding package had a business management background yet found the recruitment process challenging because of her partner's high, specialised needs, which required careful selection and thorough training of workers. Living near a regional centre, she received dozens of applications whenever she advertised. She employed six support workers at a time, had had several staff changes during the first year of direct funding and was looking for more staff to achieve 24 hour support: 'I am always recruiting or training.' To support direct funding participants in the future, particularly those with large funding packages, she suggested that Lifetime Care prepare detailed recommendations about how to recruit workers. These could include:

... letting people know where they can advertise for care workers on the internet for free. I found that out myself, no one told me, and it saved a lot of money.

### **Flexibility of support in the trial**

In the interviews all trial participants said their flexibility of support had improved since they started direct funding. They all considered this an important change, and they gave numerous examples of having more flexibility in scheduling – deciding when and how often support is provided; and more flexibility in types of support – which tasks the workers perform.

Flexibility in scheduling was possible because trial participants received their allocated funds as a lump sum every fortnight but were not required to use them at set times. Firstly, this meant that people could vary their activities from day to day according to their preferences. As described in 3.4, they used their attendant care support to go out or visit friends and family when they wanted to. People also could receive personal care when it suited them best, such as showering early in the morning or going to bed late at night.

Secondly, it meant there was flexibility over time. People were pleased that they could use fewer hours than allocated at one time and then have accumulated hours for other occasions. This made it possible to adjust support to changing needs and preferences. Some examples from the interviews with trial participants:

My wife had a day off work a couple of weeks ago, so we decided to leave the carer so we could have a bit more quality time.

I could organise for care workers to come on my five-day work trip last week.

Care workers can go home early if they are not needed.

If I need to go away for work for a couple of days, I can tell the workers not to come to my house because I don't need any cleaning and cooking done.

I can bank gardening hours during the winter and then get larger jobs done, like planting.

I am able to manage my health problems better because I can save support hours for when I get sick with a urinary tract infection.

Trial participants said they did not have such flexibility in scheduling before direct funding. It was now possible because they controlled the allocated funds in their bank account, as mentioned above, but also because they had more control over short-term roster changes. People consistently said that before they got direct funding, any roster changes had been a drawn-out process involving several steps. For example:

Before direct funding, when I was with [service provider], any change was cumbersome. If I needed an extra hour, I would have to apply to [provider], they checked with Lifetime Care, then it was approved. I could never go out for dinner spontaneously.

Now that trial participants dealt directly with service providers or their directly employed workers, they found roster changes fast and easy. This experience was common among the people interviewed, whether they had low or high support needs. They either arranged short-term roster changes with their workers or providers, or the workers re-allocated shifts among themselves. Everyone said these arrangements were agreeable to the workers as well because they allowed them more flexibility, for example to swap shifts to suit their own needs. One man believed his workers were prepared to be flexible because he paid them more than their previous employer.

Increased flexibility around support tasks was also appreciated. People said they could include support tasks under direct funding that they had not been able to cover before. They mentioned several reasons: approved providers had high industry standards that were not always needed in practice but precluded them from certain tasks; people could now employ mainstream service providers who performed a wider range of tasks; some tasks were time-consuming and possible only with accumulated hours; and assessors might recommend that Lifetime Care cover fewer cleaning or gardening tasks than people required.

With access to accumulated hours and mainstream service providers – particularly gardeners and cleaners – trial participants could, for example:

- arrange additional cleaning tasks such as oven, window or floor cleaning more often than was approved before direct funding
- get heavy gardening work done that required the use of a bobcat
- employ a registered nurse to perform bowel care rather than a trained support worker.

One person said:

Under direct funding, the position descriptions are more open. The workers can be more my personal assistants rather than support workers. I think this is a nicer title and fits my needs better, for example someone supporting me to look around my property by opening gates.

For several trial participants, the flexibility under direct funding had resolved a problem of insufficient quantity of attendant care. Now that they could vary support schedules and tasks they felt they received enough support for all their needs.

Some people shifted their funding allowances from gardening to housework and personal care as needed and averaged out the total, whereas others thought this was not permitted and kept allowances separate. This indicates a need to clarify the rules.

One person said she would like direct funding to be extended to other support payments from Lifetime Care. She wanted more flexibility with medications, for example try out vitamins or new medications that might be beneficial, and she said she would have made different decisions than Lifetime Care about her home modifications and used the money saved for buying a car that she could drive. A few people said they already had informal approval to organise other support, in particular maintenance of equipment and ordering medical supplies. Two trial participants said they were not interested at the moment to get direct funding for support types other than attendant care. They felt they had enough flexibility and good provision, for example in their physiotherapy treatments, and did not want the administrative work of organising and paying for it.

### **Experiences in the comparison group**

All comparison group members who took part in the interviews felt they had some control over their attendant care support. They could choose their providers and individual workers, change arrangements if they wanted to, and had some flexibility over scheduling and support tasks.

Several people recounted that they were still recovering in hospital when Lifetime Care introduced providers to choose from or request alternatives. People said they were 'very pleased' to have that choice. Their selection criteria always included that they had a positive, friendly impression of the organisation. Other criteria were that the provider was based close to the person's home; that it was a big, non-profit organisation; or that the provider was prepared to adapt their care routine to the person's preferences, for example continuing bowel care procedures established in hospital.

Since starting attendant care, some comparison group members had changed providers. Two people had found their support unreliable, and Lifetime Care arranged replacements that both were happy with. Another man in the comparison group said he went through several yard maintenance and housework providers before he found good quality service. He suggested Lifetime Care vet their providers. Those who had remained with the same provider were confident that they could change when they wanted to, and that Lifetime Care would organise it.

Several people said they had rejected support workers in the past because they did not like them or were not satisfied with their work. Replacements were arranged either directly with the provider or through Lifetime Care. This worked well, except in one case where a woman said the provider kept sending workers who did not respond to her needs and injuries adequately. She felt the workers were not informed about her needs and not qualified to support her effectively, for example give her medication. She had now involved her Lifetime Care Coordinator.

Some people in the comparison group also experienced flexibility in scheduling and support tasks, for example they could change their daily routines or housework tasks without problems. A family member said:

It is easy to change hours. If I want a different start time the next day, I'll ask the girls, then tell [the provider]. Everyone is very accommodating.

Two people said Lifetime Care made allowances for additional support needs such as long medical appointments, by letting them accumulate unused support hours or providing a special fortnightly allocation.

Three people in the comparison group wanted more flexibility. One man would prefer more flexible evening shift times. He would like to go to bed at midnight, at least on weekends, but the latest that the provider and the workers were willing to arrange was a 9:30 pm finish during the week, and 10:30 pm on Fridays and Saturdays. He said:

It's frustrating, but I can understand that the workers refuse to come late at night, especially since they don't get paid for their travel time or mileage. One of the workers drives 45 minutes each way.

He dealt with the issue by cancelling support on Saturday nights permanently and sleeping in his chair. The good quality of care he received otherwise helped him accept the constraints.

Two people said they wanted Lifetime Care to be more flexible around support tasks. A woman said her injury prevented her from doing heavy gardening work such as pruning, cutting hedges and putting mulch down. She said the Coordinator informed her Lifetime Care would not pay for these tasks as they were considered beautification issues, whereas guidelines advised that garden maintenance was to provide safe and easy access.

Similarly, a man needed heavy gardening work done as well as additional work in the house not covered by his attendant care support, such as changing lightbulbs and smoke detectors. Both felt they were not receiving enough support for their needs. They now organised and paid for these services themselves. Lifetime Care said such cases might reflect poor care needs assessments, although scheme participants would always be expected to pay for their everyday living expenses.

### **Summary of control over attendant care support**

All trial participants said they had more control since receiving direct funding, because they could exercise wider options regarding providers and workers, experienced increased flexibility and felt in charge of their support. It appears that a major aim of the direct funding trial, namely increased control over support for participants, was achieved. A few people had difficulties recruiting enough suitable support workers.

Many people in the comparison group were satisfied with their level of control over attendant care support. Some said they had as much choice and flexibility as they wanted. This can be seen as a testament to Lifetime Care's effectiveness in organising support that suits the person, and to the responsiveness of service providers. Others would like more control, as the examples above show. Some might not be aware that they could change service providers or request more flexibility or

support. Alternatively, direct funding might suit them and other comparison group members who had already expressed an interest in direct funding (Appendix B I).

## V. Relationships with attendant care workers and providers

Direct funding is intended to improve relationships between participants and attendant care workers and providers. People with direct funding are the employers of their workers and providers rather than Lifetime Care. All trial participants felt that this had shifted their relationship fundamentally. Workers and providers now negotiated tasks, schedules and payments with the person holding the funds and were accountable directly to them, not to Lifetime Care anymore.

Trial participants had the impression that workers and providers respected them more because they were in control. At the same time, some people observed that they had built closer, more personal relationships with their workers because both sides had chosen to work with each other and they were dealing with each other directly, not through organisations. According to the trial participants, quality of support improved in various ways:

- workers became more responsive to people's wishes about how to support them
- tasks were completed more diligently because trial participants checked before processing payment
- there was less staff turnover than before as trial participants could decide who they hired
- scheduling problems could be quickly and easily fixed
- additional tasks, for example in cleaning or gardening, could be agreed on
- worker reliability and consistency improved
- attendant care funds were saved because providers were paid only for work carried out.

One trial participant summed it up as: 'This is now a happier environment.'

Some people changed workers or providers during the trial because they were not satisfied with the service. One man said, 'I found sacking the worker very difficult', but he accepted this task as part of his role as an employer. Another person had a legal dispute with one of their workers after they fired the worker, but all charges against the trial participant were dismissed.

Comparison group members were quite satisfied with their relationships with workers and providers. They talked about the workers being friendly, professional, kind, polite and reliable, and generally providing a good quality service. People were appreciative of the support they received and had accepted the workers coming into their home, to the extent that some stated 'they have become more like family'. A few people had changed providers or workers in the past, as discussed above (Appendix B IV), and at the time of the interview one woman was not satisfied with her workers, who she said lacked the knowledge and skills to support her adequately. She said she had raised the issue repeatedly with her Coordinator, but it had not yet been resolved.

Most people in the comparison group had contact only with the workers, while Lifetime Care dealt with provider organisations. For example, when one man was not satisfied with the quality of cleaning that a worker did, he informed Lifetime Care, which in turn asked the provider to send a different worker. This process seemed to suit people. One woman reported a different experience: she felt that Lifetime Care expected her to dismiss providers who she was not happy with, and she found this difficult.

## VI. Relationships with Lifetime Care

One of the intended outcomes of direct funding is improved relationships between Lifetime Care and direct funding participants. According to the interviews, both trial participants and comparison group members were generally content with their relationship with Lifetime Care, including frequency of contact and responsiveness.

Everyone spoke positively about their Coordinator, who was their first-line contact with the agency. People said their Coordinator understood their needs, helped when issues arose with any of their support and were responsive when asked to adjust support plans, for example organise more support hours, different specialist support or additional equipment.

One person in the comparison group was disappointed that his original Coordinator did not advocate for his needs within the agency. The process to change Coordinators was uncomfortable because he had to attend an interview at Lifetime Care offices to try and resolve issues with the Coordinator. He would have appreciated more flexibility and respect from Lifetime Care for his request to change Coordinators but was happy with the new Coordinator.

A few people were frustrated with general Lifetime Care restrictions, for example about attendant care tasks (IV). One person from the comparison group said:

The Coordinator understands my needs because he has seen my house and knows me personally. But I think head office has a script of what level of support I am entitled to given my type of injury, and they don't look at individual cases.

Trial participants were able to resolve such frustrations by managing their own funds and support provision, as described above. Some felt their relationship with Lifetime Care had improved since they joined the trial because they had fewer conflicts to resolve; or they enjoyed the helpful oversight and more personal, face-to-face contact that Lifetime Care provided while direct funding was set up.

Two trial participants appreciated Lifetime Care's special permission to employ family members for some of their support, arranged through a provider. Both had experienced exceptional circumstances, including shortage of professional support workers and special support needs of the trial participant. Another person wanted the option to employ family members extended to all direct funding participants, so family members would get paid for at least some of the support they provided, because it would create more flexibility, for example around late bedtimes, and because it would increase the family's privacy. Lifetime Care felt the issue of family employment needed thoughtful exploration when designing a direct funding policy, due to potential conflict of interest and impact on family relationships.

## VII. Survey findings about satisfaction with attendant care

Direct funding is intended to increase people's satisfaction with their attendant care support (see program logic, Figure 1.1). The sections above describe various aspects of satisfaction discussed in the interviews. Trial participants and comparison group members also answered broad questions in the survey about satisfaction with their support, concerning access, quantity and quality of support, and its impact on quality of life and independence. Survey questions were about the last 12 months. For most trial participants in the first round of surveys, this period included a longer time before direct funding and a few months on the trial; in the second round, it was mostly or entirely while they were taking part in the trial. As the sample was small, findings should be viewed with caution and not generalised.

The survey answers (Table B.1) support the qualitative experiences and outcomes described above. Overall, trial participants and comparison group members stated relatively high satisfaction with their attendant care services, with a lowest average score of 77.5 in both groups. Support

satisfaction levels were similar to satisfaction with current circumstances (Table 3.2) and higher than the Personal Wellbeing Index scores (Table 3.1).

**Table B.1: Satisfaction with attendant care support**

How much do you agree with the following statements:  In the last 12 months...	Trial participants (n=8 in 1 <sup>st</sup> round, n=9 in 2 <sup>nd</sup> round)*				Comparison group (n=9)	
	Average		Range		Average	Range
Survey round	1	2	1	2		
Getting access to attendant care services was easy	77.5	80.0	50-100	40-100	82.2	50-100
Choosing an attendant care provider was easy	78.8	81.1	50-100	30-100	77.5	10-100
The amount of attendant care I receive is reasonable	81.3	78.9	20-100	30-100	82.2	40-100
The quality of the attendant care I receive is high	80.0	88.9	20-100	70-100	77.8	10-100
Attendant care supports me to live more independently	88.8	92.2	60-100	80-100	80.0	30-100
Attendant care increases my quality of life	92.5	92.2	70-100	80-100	86.7	30-100

Sources: Participant and comparison group surveys; questions mirror those in internal TAC surveys, to enable comparison if TAC survey results become public.

Notes: Method for calculating scores: Survey participants were asked to rate their level of agreement with the statements presented on a scale of 0-10, where 10 represented the highest level of agreement. Each score is an average of the answers of survey participants, converted to a 0-100 point range.

\*One of the trial participants with traumatic brain injury was not able to answer these questions. The person's partner recorded their own experiences because they organised the trial participant's attendant care support.

In both groups, the aspect of attendant care support that respondents were happiest with was that it increased their quality of life, while the least satisfactory aspect was the ease of choosing an attendant care provider. The range of scores was often wide, from as low as 10 in the comparison group and 20 among the trial participants, to 100 in both groups and for all questions. This reflects experiences reported in the interviews: largely positive, with a few problems in both groups.

Most trial participant scores increased between the first and second round of surveys. People responded with particularly high scores and narrow ranges to two statements: that attendant care increased their quality of life and that it supported them to live more independently. The increases and positive answers may reflect trial participants' high satisfaction with the choice and flexibility of direct funding, which they explained in the interviews.

## VIII. Risks of direct funding

According to the survey and interview responses reported above, trial participants had largely positive experiences with direct funding. They were happy with their support and managed their packages well. Several trial participants saw potential risks of direct funding, related to financial and management issues, workplace conditions and safety, and a few trial participants had experienced problems.

First, trial participants considered budgeting a potential risk factor. If people mismanaged their budgets they might not retain enough funds for ongoing support provision. This applied especially to large, complex packages with different types of attendant care and several service providers and workers. Participants felt that potential budgeting risks could be minimised by organising administrative support. In addition, Lifetime Care provided financial oversight, including fortnightly expense monitoring and regular reviews of direct funding at participants' scheduled review of support needs. One trial participant suggested that Lifetime Care also conduct six-monthly financial audits. A few budgeting issues occurred during the trial (Appendix B III) and were resolved on a case-by-case basis.

Effective budgeting also relied on timely and accurate fund transfer from Lifetime Care into the trial participants' bank accounts. This worked well. Only one person reported that Lifetime Care had once inadvertently lowered her funding. It was quickly adjusted when she told the agency.

Second, bookkeeping posed potential risks. Trial participants anticipated that mistakes in rostering or in paying wages could upset their workers. Everyone said they took particular care to maintain positive relationships with their workers by agreeing on roster changes and paying them well and on time.

In addition, tax regulations needed to be monitored. At the time of the interviews, direct funding was not considered income for tax purposes, and one trial participant had compelled Lifetime Care in his direct funding contract to notify him if the regulations changed.

Third, workplace safety needed to be maximised, to protect workers from accidents and trial participants from liability. Where people chose to employ provider organisations, the providers were responsible for arranging liability insurance. One trial participant said she always checked that her providers had arranged adequate cover for their workers. Inside the house she tried to remove any possible occupational safety risk, for example keeping the stairs clean to reduce the risk of slipping.

Those who directly employed workers had personal responsibility for ensuring workplace safety. One trial participant had his house professionally checked for potential risks, another realised partway into the trial that he had additional training obligations to his employees. He organised a series of relevant training sessions, which he paid for with surplus support hours.

Suggestions from trial participants to maintain workplace safety included:

- make sure workers advise of any previous injuries and have approval to work with those injuries
- check workers have training about all the support tasks they provide and get them to sign off on it
- put any other training in place – e.g. manual handling of the person when walking with the help of workers, exercising in the hydro pool, putting the person to bed, infection control, support for spinal injuries including toileting
- develop job descriptions and have them approved by appropriate professionals.

Fourth, workers were entitled to adequate pay and working conditions according to industry awards. As mentioned earlier (Appendix B III), some trial participants who directly employed workers became fully aware of their obligations only after several months on the trial, potentially exposing them to compensation claims. All rectified their arrangements. One person had a legal dispute with one of their workers, but all charges against the trial participant were dismissed. He said, 'this is the downside of direct funding'. Lifetime Care offered support and gave him the option to leave the trial, but he preferred to resolve the issue himself with the help of professional friends, and to remain on direct funding. He said:

It was stressful, but I enjoyed doing it, and I am happy I resolved it. It gave me something to think about. I want to run my own show.

Lifetime Care might try to operationalise solutions in a direct funding policy, however this may not always be possible as each workplace dispute is different and may be a consequence of individual personality clashes.

Trial participants who directly employed workers needed to arrange liability insurance themselves, by including it under their home and contents insurance. Lifetime Care provided some advice and included the cost for insurance in the overheads component of the direct funding budget. One person said they had a risk assessment conducted at their house as part of setting up direct funding.

Lifetime Care had not found a suitable insurance product for injuries to trial participants caused by their directly employed workers. Trial participants were not concerned about this risk; they said they managed it by employing workers they trusted. One person said:

I am aware that a small risk to me remains because I can't get insurance for myself. But direct funding is worth it.

Last, people needed ongoing capacity to manage direct funding. Over time, their life might change and other commitments increase, such as work or children; or they might be temporarily unavailable, for example if they got seriously ill. Trial participants felt safe in the knowledge that direct funding was completely voluntary and reversible. One man said:

I don't see any risk. I always have the option to go back to Lifetime Care managing my support if I want to.

As mentioned earlier (Appendix B III), one person did not manage their funding adequately without support. The participant chose to withdraw from the trial.

Overall, trial participants seemed to be aware of potential risks of direct funding as they applied to them and had plans to manage those risks. This is likely a result of thorough and personalised information provided by Lifetime Care during the set-up process. Trial participants felt safe and perceived a sense of good will on both sides. A woman said:

If there was any problem, I would call Lifetime Care, and I am sure they would work something out. They are learning as well and feeling their way through as issues emerge. They are doing the best they can.

Among the nine people in the comparison group, four did not see any risks in direct funding, only benefits; one had not known or thought about direct funding; and four people envisaged potential risks similar to those mentioned by the trial participants, in particular budgeting and personal capacity. In addition, two people in the comparison group were concerned about managing employment relationships with workers, negotiating with provider organisations and protecting workers' rights to adequate pay and job security. These concerns indicate training and information needs should people decide to receive direct funding in the future.

## Appendix C Economic analysis

The economic analysis component of the evaluation examined the costs of direct funding compared with attendant care support organised by Lifetime Care. Direct funding expenses incorporated the cost of developing and establishing the trial and the cost of the direct funding packages themselves. The costs of the direct funding trial were examined in context of the benefits of direct funding for participants (section 3 and Appendix B).

The cost analysis was undertaken using financial data from Lifetime Care corporate systems combined with demographic and type of injury details, to develop comparative level of injury sub groups for the trial and comparison groups. The analysis incorporated all payments made by Lifetime Care for each trial participant and data comparison group member. Additional details were collated in the second round of data collection from individual case files to determine the actual number of attendant care hours purchased by trial participants.

The cost data was also used to establish estimated hours of support, based on invoice cost and composite cost of care per hour figures provided by Lifetime Care. The total cost per year and estimated average cost per person per month provided the program cost framework. The cost of informal support for trial participants and comparison group members, and potential offsets with attendant care support, was not consistently documented and was not available to the evaluation.

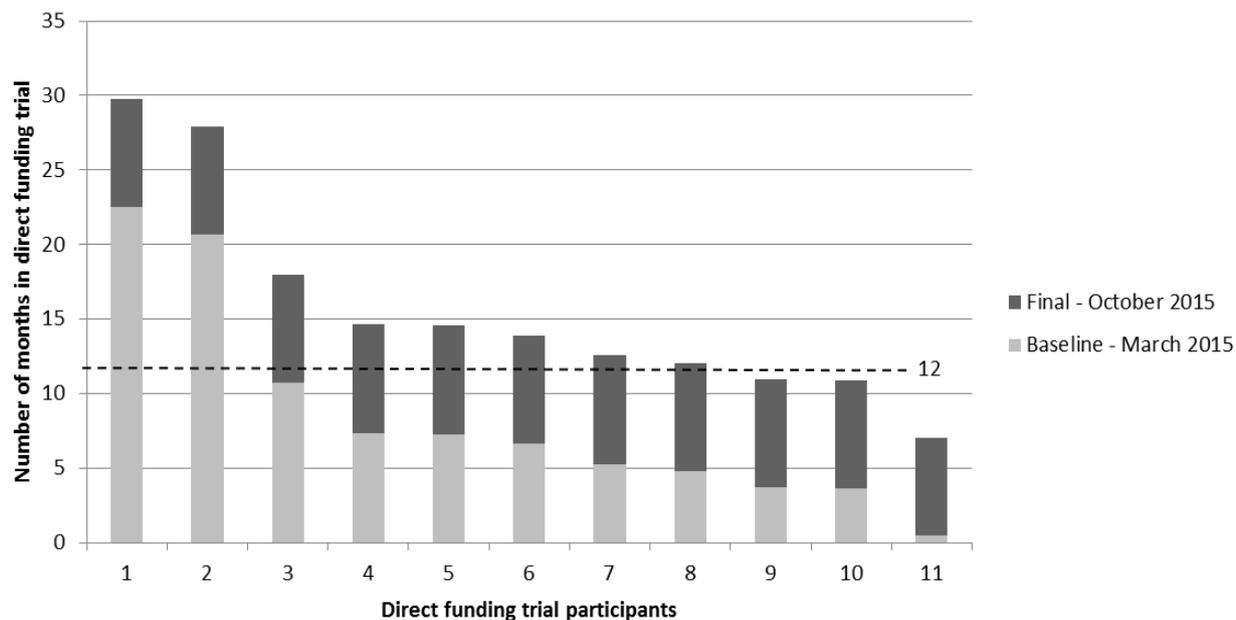
### I. Cost of attendant care support

Attendant care support costs for trial participants and the data comparison group were extracted from Lifetime Care's corporate finance systems. The data includes support costs for each trial participant since they started direct funding and retrospective support costs from 2010 for the data comparison group. The comparison group data was incomplete due to variation in the dates when people started receiving attendant care or transitioned to direct funding. The average cost figures are based on people for whom data was available for each complete year, resulting in slight variation in sample sizes across years, but utilising the maximum sample sizes without the increased potential variation in annualising based on partial years.

The cost data for both trial and data comparison groups was combined with injury details to assess costs by severity of injury and the related level of support. The second round of data provided a follow up of baseline cost figures for the 11 trial participants and included the trial participants' reported records of hours of support actually purchased with direct funding budgets.

The follow up data increased the duration participants had been in the program. At the baseline data collection as at March 2015, two of the 11 trial participants had been approaching two years of direct funding, and the others had been in the trial for between one and eight months, reflecting the ongoing intake into the trial (Figure C.1). The final data collection point in October 2015 extended the dataset to include a complete 12 months or near 12 months in the program for 10 of the 11 trial participants, providing a more substantial cost base for the analysis and reducing the need to annualise direct funding cost figures.

**Figure C.1: Months in direct funding trial – baseline and final data collection**



Source: Lifetime Care program data

Cost data for trial participants was complete. It included their direct funding budgets for attendant care and all other injury-related expenses paid by Lifetime Care since they had joined the trial. The retrospective cost figures for the data comparison group were incomplete, partly because some people had joined the scheme after 2010, and partly because of variation in reported attendant care cost categories and record-keeping arrangements at Lifetime Care. The available retrospective data was sufficient to estimate average attendant care cost by injury level for the years 2012 to 2014.

The retrospective cost data shows that attendant care made up three-quarters of support costs for trial participants and just over one-third for the data comparison group (

Table C.2). This difference reflects the inconsistency between the groups in time periods included in the data and the selection of people for the trial who were living at home and had stable support needs. Compared to the time the participants were in the trial, other people with attendant care in the data comparison group used more additional support, for example for home modifications, purchase of equipment, hospital services and case management. Complete cost tables are in Appendix C V.

**Table C.2: Lifetime Care support comparison by cost category**

	<b>Trial participants since joining the trial (n=11)</b>	<b>Data comparison group 2010-14 (n=106)</b>
<b>Lifetime Care cost category</b>	<b>Per cent of total cost</b>	
605 - Personal assistance (attendant care)	75.0%	35.7%
802 - Home modifications	-( <sup>2</sup> )	10.6%
702 - Equipment	5.4%	8.2%
902 - Hospital inpatient services – Lifetime Care schedule	-	6.1%
501 - Case management	-	5.2%
503 - Provider travel and accommodation	-	4.6%
701 - Disposables	3.3%	4.2%
607 - Inactive sleepover	2.8%	-
503 - Provider travel and accommodation	2.0%	-
602 - Domestic assistance	1.4%	
911 - Pharmaceuticals	-	1.9%
307 - Occupational therapy	-	1.6%
505 - Reports and plans	-	1.6%
501 - Case management	1.7%	-
705 - Vehicle modifications	-	1.4%
904 - Private hospital inpatient - Procedures	-	1.3%
303 - Physiotherapy	-	1.3%
412 - Supported accommodation service (care and hotel)	-	1.2%
504 - Participant travel and accommodation	-	1.1%
603 - Gardening and home services <sup>(1)</sup>	-	-
Other support items <sup>(3)</sup>	8.4%	14.0%
<b>Total</b>	<b>100.0%</b>	<b>100.0%</b>

Source: Lifetime Care financial data. Total cost for 11 trial participants from joining the trial till end of March 2015 (data was complete), and total cost for all 106 people in the data comparison group, 2010-2014 (data was incomplete).

Notes: (1) These were paid in addition to gardening and home services included in the attendant care budgets.

(2) '-' indicates less than 1%. (3) Other support items were below 1% each, see Appendix C V.

For further analysis, the financial data was combined with the injury levels as described in section 2.2 to examine average attendant care costs for trial participants and data comparison group members. The comparative focus was on attendant care-related cost categories, namely Personal Assistance (cost group 605), Domestic Assistance (602) and Gardening and home services (603), using composite hourly payment rates for attendant care support, which Lifetime Care indexes biannually. The figures are based on composite annual rates of \$45, \$48, \$51 and \$52 for 2012, 2013, 2014 and 2015 respectively. Cost data was annualised as a linear extrapolation where full-year program participation was not complete.

Estimated average costs for the comparison group were calculated for 2012, 2013 and 2014. Cost figures for the trial participants are based on 2015, when the majority of the trial participation occurred. The comparative estimated average costs for each level of injury subgroup are presented in Figure C.3. The figures reflect higher support levels associated with higher levels of injury, with the average attendant care cost per person significantly higher for people with 'Complete C' cervical injuries than for those in the other injury level groups.

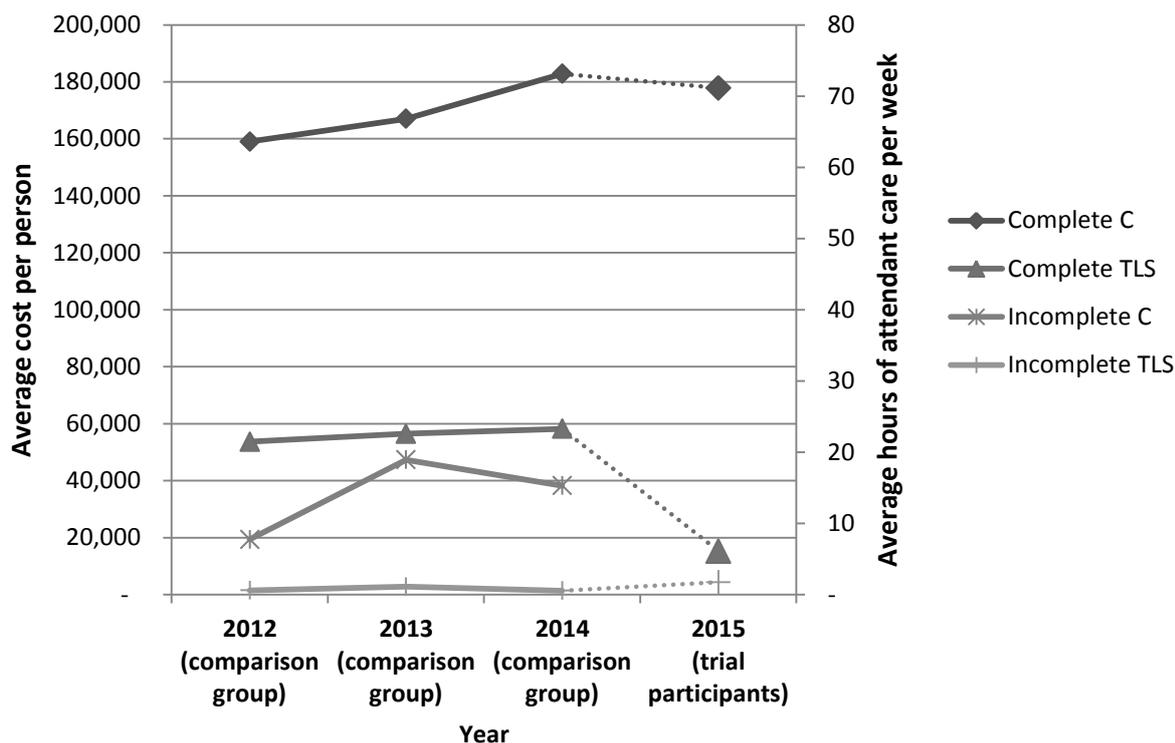
In the data comparison group, attendant care for people with the most severe, higher-level and complete cervical injuries cost on average around \$160,000 in 2012 and increased to approximately \$180,000 per person per year in 2014. Support for the lower level 'Complete' injuries (thoracic, lumbar and sacral) cost about \$60,000 per year on average. Both groups of 'Incomplete' injuries reflect relatively lower support needs at an average cost below \$50,000 per person per year.

Estimated attendant care cost for the nine trial participants with spinal cord injury was similar to the comparison group cost or below. Trial participants with the highest level of complete cervical injuries had an average annual cost of attendant care of \$177,882, slightly below the 2014 comparison group figure of \$182,829 and slightly lower again if comparison group figures were recalculated in 2015, which would incorporate established year-on-year indexing. This highest injury level sample represented the largest trial subgroup (n=5).

For trial participants in the complete TLS group, average annual cost was estimated at \$15,336 compared to \$58,241 for the comparison group in 2014. This group consisted of only three trial participants, and the lower average cost was primarily the result of one person reporting reduced cost. Also, in a small sample, cost variation may result from occasional breaks in support, for example if in hospital or away from home.

There were no participants in the trial group with an incomplete cervical injury (Table 2.2 above); the comparison group equivalent is included for reference. The incomplete TLS figure is the result of a single trial participant in this level of injury group with an annual cost of \$4,440 reflecting a low level of support similar to the comparison group.

**Figure C.3: Average attendant care cost per person by level of spinal cord injury**



Source: Lifetime Care financial and client data

Notes: 1. Spinal cord injury level: C = Cervical, TLS = thoracic, lumbar and sacral; severity of injury and level of support need generally reduce from Complete C gradually to Incomplete TLS.

2. Data comparison group figures based on complete years 2012 to 2014 (n=43); Trial participant data based on total annualised figures for 9 trial participants with spinal injuries as at 31 October 2015.

The figures are based on sample sizes too small to be tested for statistical significance. They are presented as indicative estimates, subject to validation when further program data is available.

## II. Lifetime Care expenses for the trial

In order to estimate the costs incurred by Lifetime Care in establishing direct funding with trial participants, Lifetime Care management provided estimates of internal agency costs for staff training, project manager and Coordinator time, start-up costs paid to trial participants and the cost of initial training for trial participants in setting up and managing their direct funding.

Lifetime Care estimated that internal setup costs for the direct funding trial were just above \$46,000 (Table C.4). More than 99 per cent was for project manager time, and additional small amounts were spent on staff training and an external advisory group. As mentioned above (4), program management time appeared insufficient to progress development of the direct funding program or its rollout.

**Table C.4: Lifetime Care management costs for direct funding trial**

<b>Cost item</b>	<b>Amount \$</b>
Project manager time	\$45,615
Staff training by independent provider	\$400
External advisory group	\$80
<b>Total</b>	<b>\$46,095</b>

Source: Lifetime Care internal records, October 2013 till December 2015.

As described in section 4, the Lifetime Care Coordinators were closely involved in identifying potential trial participants, in supporting them during the setup phase of their direct funding program, and in ongoing monitoring and review. For this evaluation report, Coordinators estimated the time they had spent with trial participants, from identifying them till the start of their direct funding and in each month afterwards. Lifetime Care expected that Coordinators would initially spend a considerable amount of time discussing direct funding with the participant and working through issues in setting it up, and that time investment would be lower once trial participants had settled into their direct funding routine.

This expectation was fulfilled, as

Table C.5 shows. Coordinators spent more than 12 hours on average from identifying a person as a potential trial participant to the start of direct funding. In the first month of direct funding, the average was 2.7 hours, and this continued to decline to 0.7 hours per month in months 10 to 12 of the trial. Correspondingly, average Coordinator cost per trial participant decreased from \$636 before the start of direct funding to \$35 per month in months 10 to 12. At the same time, the range of hours that Coordinators spent with a trial participant decreased, from 3 to 25 hours before the start of the trial to 0 to 2 hours per month in months 10 to 12, indicating that direct funding processes stabilised for all trial participants. This was consistent across different sizes and degrees of complexity of the direct funding packages.

Comments by the Coordinators suggest that a routine involvement with a trial participant of between 15 minutes and 2 to 3 hours per month could be expected once direct funding was established. Hours might increase temporarily if particular issues arose. For example, the conflict between a trial participant and their staff mentioned earlier (section 4.6) involved seven hours of the Coordinator's time in one month. Similarly, Coordinator involvement regarding recruitment difficulties of a trial participant who lived in a rural community was 22 hours over two months. This data is not included in the table below, because both instances concerned people who had been on direct funding informally before the trial started, and they occurred in their second and third year on direct funding respectively. If participation in direct funding increased, such isolated instances would not impact substantially on overall direct funding costs for Lifetime Care. They might even be avoided due to incorporating lessons from the trial into a wider direct funding policy.

**Table C.5: Estimated cost of Coordinator time, direct funding trial**

Time period	Total hours	Total cost (\$)	Range (hours per trial participant per month)	Number of trial participants*	Average hours per trial participant per month	Average cost (\$) per trial participant per month
Form identifying participant to start of direct funding	126	\$6,363.00	3 – 25	10	12.6	\$636
Month 1 of direct funding	27	\$1,363.50	0.3 – 12	10	2.7	\$136
Month 2	21	\$1,060.50	0.3 – 7	10	2.1	\$106
Month 3	19	\$959.50	0.3 – 7	10	1.9	\$96
Months 4 – 6	28	\$1,414.00	0 – 3	10	0.9	\$45
Months 7 – 9	25	\$1,262.50	0 – 3	10/9	0.9	\$45
Months 10 – 12	15	\$757.50	0 – 2	8/7	0.7	\$35
<b>Total</b>	<b>261</b>	<b>\$13,180.50</b>				

Source: Lifetime Care internal records.

Lifetime Care costed Coordinator time at an average of \$50.50 per hour over the period.

\* Number of participants in the trial for whom data was available.

Finally, Lifetime Care committed to pay trial participants' reasonable costs for setting up direct funding. These costs included training by the independent provider engaged by Lifetime Care and additional setup costs (

Table C.6). As mentioned above, training was offered to all trial participants and tailored to people's needs. Seven people took up the offer. They had widely varying training needs and lived mostly in regional areas, which incurred travel and accommodation costs for training provider staff. As a result, training costs per trial participant ranged from just over \$1,000 to \$14,500, with an average of about \$5,600.

In addition to the training, Lifetime Care paid for legal and accountancy advice as well as office equipment including computers. Some restrictions applied: the agency offered up to \$1,000 per person for legal advice, plus office and computer equipment corresponding to the size and complexity of people's direct funding budgets. As with the training, seven of the 11 trial participants (about two-thirds) took up the offer. Lifetime Care expended \$1,640 on average and a total of almost \$11,500. As the agency dealt with individual requests from trial participants, it clarified rules around purchasing computer equipment and otherwise considered the costs reasonable.

The \$7,500 fee to an attendant care service provider was unforeseen (section 4.7). As with the computer equipment, the case gave Lifetime Care the opportunity to clarify rules around the process for directly employing previous workers and to put safeguards in place so a liability of this kind would not occur again.

**Table C.6: Trial participants' setup costs paid by Lifetime Care**

Cost item	Total amount	Range	Number of trial participants	Average amount per trial participant
Direct funding training by independent provider (incl. training needs assessment, training sessions, travel, phone, skype and e-mail support)	\$39,230	\$1,140 - \$14,500	7	\$5,610
Additional setup costs (incl. legal and accountancy advice, office and IT equipment, software)	\$11,490	\$520 - \$2,950	7	\$1,640
Fee to service provider for workers' breach of contract	\$7,500	-	1	-
<b>Total</b>	<b>\$58,220</b>			

Source: Lifetime Care internal records.

In total, Lifetime Care's internal agency costs for the trial, including staff training, project manager and Coordinator time, start-up costs and training for trial participants, were about \$117,500.

### III. Cost of support purchased through direct funding

The second round of data collection included records from trial participant case files and fortnightly expense statements, reporting the actual number of hours of attendant care support purchased through their direct funding packages.

Given the small number of trial participants in each level of injury subgroup, the associated variation in levels of support and the related need to compare corresponding injury types, the primary focus for comparison was the highest level complete cervical injuries. This group represented the highest average support levels and cost of support, approximately 70 hours per week and \$180,000 per year per person (Figure C.3) and also included the largest trial subgroup (n=5 of the total trial group of 11).

The number of attendant care hours purchased by this highest injury level group during the trial period reflected the characteristic variation in support need ranging from below 30 to over 100 hours per week, with an average of 67.6 hours per week. This compared with a similar level of 69.0 hours per week for the larger complete cervical comparison group (n=20). Although this was a small trial sample (n=5), the actual care hours purchased indicate that participants were securing and managing similar levels of support to the comparison group for the related level of injury.

In order to examine support hours on the direct funding trial specifically, the estimated attendant care hours for the five complete cervical participants was separately collated for their time prior to entering the trial. Although the derived pre-trial hours were based on composite cost of care rates, the estimate indicates that the trial participants were purchasing slightly increased numbers of care hours, 67.6 hours per week compared to 65.4 hours per week for the 12 months prior to transitioning to the trial.

Being based on a small sample of five participants, the estimated hours of care are not statistically significant. They are preliminary figures indicating that trial participants were purchasing additional

care hours compared to their pre-trial attendant care support. This finding corresponds to the experience described by some trial participants (Appendix B III), who used savings from management costs or hourly rates to purchase additional support hours. The cost analysis also shows that trial participants purchased and managed their attendant care within equivalent pre-trial budgets.

#### **IV. Comparative effectiveness of the direct funding trial**

Given the relatively small size of the trial participant group and the insufficient basis for statistically significant estimates, the economic component of the evaluation did not incorporate a formal cost effectiveness analysis. This section provides a comparative assessment of program effectiveness, considering direct funding package costs, program establishment costs and program outcomes.

While newly established programs of support may require significant additional costs, the program data for trial participants and the data comparison group showed that the average cost of direct funding packages was no higher and in many cases marginally below the cost of the attendant care support for the comparison group for comparable levels of injury (Figure C.3). This reflected Lifetime Care's approach to base direct funding budgets on stable levels of support previously funded by the agency and delivered through approved service providers. Thus direct funding guidelines and program controls limited the risk of significant cost overruns, while incorporating opportunities for trial participants to utilise their packages in more flexible and potentially more efficient ways.

As presented in Appendix C 0, Lifetime Care's costs of developing and administering the trial were relatively low compared with the total cost of attendant care under the trial. Program costs including manager and Coordinator time as well as trial participants' setup costs were about \$117,500 against total attendant care support costs of \$2.7 million for trial participants, or 4.4 per cent. Internal Lifetime Care setup costs were predominantly an up-front investment that would continue to benefit people joining the direct funding model in the future. As the number of trial participants was small, the start-up costs are only indicative.

On the outcome side, the evaluation identified substantial benefits of direct funding for trial participants, in particular increased choice, flexibility and quality of support, and associated improvements in various life areas, for example social relationships, mental health, skills and independence (section 3 and Appendix B).

Overall the trial group demonstrated stable support costs, with relatively low establishment and overhead costs, while achieving improved program outcomes. Based on 11 trial participants, the evaluation provides preliminary indicative evidence that the program is relatively cost effective compared to attendant care support organised through Lifetime Care.

## V. Complete cost tables

**Table C.7: Lifetime Care support for trial participants by cost category**

<b>DFT Cost Category - Group 1</b>	<b>Cost (\$)</b>	<b>Cost (%)</b>
605 - Personal assistance	2,027,398	75.02%
702 - Equipment	146,144	5.41%
701 - Disposables	88,630	3.28%
607 - Inactive sleeper	76,415	2.83%
503 - Provider Travel and Accommodation	55,083	2.04%
501 - Case management	45,602	1.69%
602 - Domestic assistance	37,398	1.38%
603 - Gardening and home services	25,257	0.93%
706 - Repairs and Maintenance of Equipment	19,373	0.72%
504 - Participant Travel and Accommodation	19,299	0.71%
911 - Pharmaceuticals	17,394	0.64%
505 - Reports and plans	17,335	0.64%
307 - Occupational therapy	13,820	0.51%
301 - Exercise and Physical Rehabilitation Programs	13,209	0.49%
303 - Physiotherapy	12,806	0.47%
407 - Education Support Services	8,105	0.30%
308 - Other Treatment and Rehabilitation Services	7,050	0.26%
108 - Care Needs Review	7,021	0.26%
302 - Psychology	6,939	0.26%
121 - Other Assessment	6,385	0.24%
118 - Registered Nurse Assessment	3,697	0.14%
908 - General Practitioner	3,676	0.14%
801 - Building Modifications Occupational Therapist	3,135	0.12%
606 - Respite and Other Support Services	3,080	0.11%
913 - Other Hospital Costs	3,065	0.11%
704 - Prostheses and orthoses	3,026	0.11%
604 - Registered Nursing Care	2,882	0.11%
802 - Home modifications	2,875	0.11%
104 - Social Work Assessment	2,636	0.10%
923 - Anaesthetist	2,607	0.10%
800 - Home modification project manager	2,561	0.09%
705 - Vehicle modifications	2,154	0.08%
904 - Private Hospital Inpatient - Procedures	2,024	0.07%
404 - Driving	1,785	0.07%
105 - Rehabilitation Medical Specialist Assessment	1,752	0.06%
910 - Hospital - Practitioner Pathology & Radiology	1,493	0.06%
101 - Initial Rehabilitation Needs Assessment	1,280	0.05%
309 - Podiatry	810	0.03%
304 - Dietician	770	0.03%
609 - Care Coordinator Fee	750	0.03%
919 - Urologist	740	0.03%
925 - Neurologist	739	0.03%
103 - Clinical Psychology / Psychology Assessment	675	0.02%
610 - Program Establishment Fee	658	0.02%
102 - Occupational Therapy Assessment	635	0.02%
915 - Orthopaedics	546	0.02%
909 - Specialist - Other	518	0.02%
410 - Relative accommodation and travel	507	0.02%
608 - Attendant care worker training	453	0.02%
106 - Physiotherapy Assessment	270	0.01%
918 - Ophthalmology	155	0.01%
<b>Grand Total</b>	<b>2,702,616</b>	<b>100.00%</b>

Source: Lifetime Care financial data. Table displays total cost for all 11 trial participants from joining the trial till end of October 2015.

**Table C.8: Lifetime Care support for data comparison group by cost category**

<b>Lifetime Care cost categories</b>	<b>Total cost \$</b>	<b>Total cost %</b>
605 - Personal assistance	20,284,048	35.7%
802 - Home modifications	5,993,230	10.6%
702 - Equipment	4,668,817	8.2%
902 - Hospital inpatient services - LTCS schedule	3,468,026	6.1%
501 - Case management	2,953,567	5.2%
503 - Provider Travel and Accommodation	2,637,792	4.6%
701 - Disposables	2,379,922	4.2%
911 - Pharmaceuticals	1,073,318	1.9%
307 - Occupational therapy	924,141	1.6%
505 - Reports and plans	915,354	1.6%
705 - Vehicle modifications	819,042	1.4%
904 - Private Hospital Inpatient - Procedures	765,624	1.3%
303 - Physiotherapy	727,925	1.3%
412 - Supported accommodation service (care and hotel)	685,192	1.2%
504 - Participant Travel and Accommodation	616,990	1.1%
604 - Registered Nursing Care	498,893	0.9%
602 - Domestic assistance	466,619	0.8%
800 - Home modification project manager	379,768	0.7%
909 - Specialist - Other	376,878	0.7%
603 - Gardening and home services	313,846	0.6%
411 - Transitional accommodation daily room fee	290,691	0.5%
301 - Exercise and Physical Rehabilitation Programs	277,849	0.5%
108 - Care Needs Review	266,267	0.5%
706 - Repairs and Maintenance of Equipment	255,418	0.4%
607 - Inactive sleepover	243,468	0.4%
901 - Public Hospital Inpatient Services - Acute	243,292	0.4%
801 - Building Modifications Occupational Therapist	236,509	0.4%
804 - Workplace modifications	218,207	0.4%
910 - Hospital - Practitioner Pathology & Radiology	207,049	0.4%
915 - Orthopaedics	205,285	0.4%
919 - Urologist	195,780	0.3%
903 - Hospital inpatient rehabilitation services- other	184,789	0.3%
302 - Psychology	182,976	0.3%
404 - Driving	160,276	0.3%
908 - General Practitioner	156,886	0.3%
105 - Rehabilitation Medical Specialist Assessment	153,829	0.3%
410 - Relative accommodation and travel	148,124	0.3%
923 - Anaesthetist	139,344	0.2%
506 - Incentive mileage	134,998	0.2%
118 - Registered Nurse Assessment	134,267	0.2%
922 - Registered Nursing Treatment	100,614	0.2%
408 - Accommodation management	98,847	0.2%
308 - Other Treatment and Rehabilitation Services	87,069	0.2%
201 - Return or Transition to Work Program	84,738	0.1%

609 - Care Coordinator Fee	82,350	0.1%
920 - Intensivist	81,994	0.1%
917 - Neurosurgery	80,983	0.1%
401 - ADL training	77,702	0.1%
906 - Transitional living unit - LTCS schedule	71,540	0.1%
704 - Prostheses and orthoses	69,880	0.1%
202 - Vocational Services	68,186	0.1%
101 - Initial Rehabilitation Needs Assessment	66,663	0.1%
102 - Occupational Therapy Assessment	58,285	0.1%
106 - Physiotherapy Assessment	56,618	0.1%
409 - Accommodation	50,966	0.1%
406 - Pain management programs	44,672	0.1%
309 - Podiatry	43,475	0.1%
905 - Private Hospital Inpatient - Rehabilitation	42,898	0.1%
914 - Psychiatrist	42,036	0.1%
119 - Neuropsychology Assessment	38,789	0.1%
110 - Approved assessor - treatment and rehabilitation	33,099	0.1%
305 - Speech pathology	32,459	0.1%
103 - Clinical Psychology / Psychology Assessment	27,813	0.0%
203 - Vocational Training	27,647	0.0%
306 - Social work	27,253	0.0%
107 - Educational / Vocational Capacity Assessment	26,635	0.0%
921 - Dental Surgery	26,152	0.0%
907 - Hospital outpatient services	24,436	0.0%
304 - Dietician	21,941	0.0%
913 - Other Hospital Costs	18,718	0.0%
606 - Respite and Other Support Services	18,343	0.0%
403 - Counselling/Behaviour management	18,088	0.0%
610 - Program Establishment Fee	15,951	0.0%
121 - Other Assessment	13,992	0.0%
405 - Leisure/Avocational management	12,591	0.0%
925 - Neurologist	11,928	0.0%
912 - Ambulance travel	10,919	0.0%
805 - Other modifications	9,833	0.0%
502 - Interpreter and translation services	9,460	0.0%
703 - Pressure garments	9,268	0.0%
109 - Eligibility Assessment	8,487	0.0%
407 - Education Support Services	8,291	0.0%
413 - Rehabilitation Day Program	8,035	0.0%
916 - Burns and Plastics	8,014	0.0%
104 - Social Work Assessment	6,712	0.0%
608 - Attendant care worker training	4,669	0.0%
204 - MyOwnFuture	2,558	0.0%
601 - Community Support or Day Program	2,182	0.0%
918 - Ophthalmology	985	0.0%
402 - Cognitive/Behavioural training	390	0.0%
120 - Speech Pathology Assessment	231	0.0%

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<b>Total</b>	<b>56,779,681</b>	<b>100.0%</b>
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Source: Lifetime Care financial data; cost in \$.

Table displays total cost for all 106 data comparison group members from 2010-2014. Data was incomplete.

## Appendix D Research instruments

### Interview questions – Direct funding trial participants (long)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

#### Attendant care arrangements

1. What attendant care services are you receiving (hours, content, service provider)?
2. Are you happy with your attendant care support? (hours, reliability, consistency)
3. Are you receiving all the attendant care support you need?
  - a. If not, what extra support do you require and why are you not able to access this?
  - b. Do you receive support towards your care from other sources (specialist, mainstream, informal support)?
4. What processes are in place to review your attendant care package if you are unhappy?

#### Outcomes of attendant care

5. Choice, control and flexibility
  - a. What sort of choice do you have about your attendant care support (provider, workers, schedules, daily routines)?
  - b. Can you change your attendant care services if you want to? Have you changed anything in the past/ **since joining the DFT**?
    - How easy is it to change?
    - **DFT participants:** change of provider? Self employing carers?
  - c. Would you like any kind of choice and control over your support that you don't have at the moment?
    - What restricts your choice and control in these areas?
  - d. Do you get help to make decisions about your support? Would you like more help?
6. Autonomy and independence
  - a. Are you happy with your relationship with the attendant care workers/providers?

- **DFT participants:** Has there been a shift in the relationship between you and the support workers/service providers since the trial started (shift in balance of power)?
- b. Have you developed any new skills or gained more independence in the last year?
  - **DFT participants:** bookkeeping, being an employer, other skills and types of independence, moving house?
- c. **DFT participants:** Has your reliance on Lifetime Care/your contact with Lifetime Care changed since being on the trial (quantity, quality)?

## 7. Physical and mental health

- a. How is your physical health? Has it changed in the past year?
- b. How is your mental health/ how happy are you? Has it changed in the past year?
- c. Has your attendant care support influenced any aspects of your physical and mental health?
  - **DFT participants:** Any change since starting the trial?

## 8. Social relationships and community participation

- a. Has your attendant care support influenced any aspects of your personal relationships and community participation?
  - Relationships with family, friends, support workers
  - Being able to go out, taking part in recreational, cultural and community activities, travelling

## 9. Return to work (paid, unpaid) or study

- a. What is your current work or study situation?
- b. Are you happy with it? What would be ideal?
- c. Has your attendant care support helped with fulfilling your work or study goals?
- d. **DFT participants:** Any change due to the trial?

## 10. Goals and plans

- a. For the coming year?
- b. Anything you would like to change about where you live, what you do during the day?
- c. Does your attendant care support help you to achieve those goals?

## Experiences with the direct funding process

### *Introduction to the trial*

11. How did you find out about the trial?
12. Why did you decide to participate in the trial? (potential benefits)
13. Did you get adequate information from Lifetime Care to help you make a decision about whether or not to participate in the trial?
  - a. also: did someone go through the contract with you?
14. Did anyone help you make the decision?
15. How did you find the approval process for the Direct funding trial?

### *Management of direct funding*

16. What kinds of costs did you incur in setting up direct funding? E.g time, financial costs
17. How well has the process of direct funding worked since it started?
  - a. Quality of start-up training and support from Lifetime Care and My Voice?
  - b. Direct employment – recruitment, salary negotiations? Employing family members?
  - c. Change of provider?
  - d. Financial administration – setting up bank account, filling in fortnightly claim forms, filing invoices, receiving funding from Lifetime Care, paying service providers?
  - e. Up to date and timely information about service use and remaining funds?
  - f. Legal and industrial matters – e.g. insurance and workers comp for direct employment; \$1000 of legal advice from Lifetime Care?
  - g. Set-up costs that we haven't covered – time, purchases, training paid by you?
18. Would you like any other or ongoing support for managing direct funding?

### *Review*

19. Are there any negative impacts on you, or any future risks, from being in the trial? (e.g. time consuming, stress, reduced self esteem, lack of insurance for you)
20. Have your expectations of the trial been met?
21. Would you also like to receive direct payments for types of funding other than attendant care?
22. What monitoring and review processes are in place and how effective are they?
23. How could the process of direct funding be improved?
24. What has been the best / the worst aspect of direct funding?
25. Would you like to continue with direct funding into the future?

## General

26. Is there anything else you would like to say about your attendant care support and the Direct funding trial?

## Interview questions 1<sup>st</sup> round – Direct funding trial participants (short)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

### About your support

1. What attendant care services are you getting?
2. Do you receive other support towards your care?

### About the Direct funding trial

3. Why did you decide to participate in the trial?
4. How did you find the process for approval and setup?
5. How has the process worked so far?
6. What are the effects of direct funding on you and your life?

For example: arranging attendant care support; dealing with attendant care workers; your health; social relationships; work or study.

7. What do you think are the benefits or drawbacks of direct funding?

### General

8. Is there anything else you would like to say about your attendant care support and the direct funding trial?

## Interview questions 2nd round – Direct funding trial participants (short)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

1. Since the last time we spoke, what have been your experiences with direct funding?
2. What, if anything, has changed?  
For example: your attendant care services; your service providers or workers; other support you receive?
3. What have been your experiences with administration and accounting of direct funding?
4. What are the effects of direct funding on you and your life?  
For example: arranging attendant care support; dealing with attendant care workers; your health; social relationships; work or study; accommodation; plans for the future.
5. Have your expectations of direct funding been fulfilled so far?
6. Do you have any suggestions for Lifetime Care if they extend direct funding to other parts of the service?
7. Is there anything else you would like to say about your attendant care support and the direct funding trial?

## Interview questions – People with attendant care (long)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

### Attendant care arrangements

1. What attendant care services are you receiving (hours, content, service provider)?
2. Are you happy with your attendant care support? (hours, reliability, consistency)
3. Are you receiving all the attendant care support you need?
  - a. If not, what extra support do you require and why are you not able to access this?
  - b. Do you receive support towards your care from other sources (specialist, mainstream, informal support)?
4. What processes are in place to review your attendant care package if you are unhappy?

### Outcomes of attendant care

5. Choice, control and flexibility
  - a. What sort of choice do you have about your attendant care support (provider, workers, schedules, daily routines)?
  - b. Can you change your attendant care services if you want to? Have you changed anything in the past?
    - i. How easy is it to change?
  - c. Would you like any kind of choice and control over your support that you don't have at the moment?
    - i. What restricts your choice and control in these areas?
  - d. Do you get help to make decisions about your support? Would you like more help?
6. Autonomy and independence
  - a. Are you happy with your relationship with the attendant care workers/providers?
  - b. Have you developed any new skills or gained more independence in the last year?
7. Physical and mental health
  - a. How is your physical health? Has it changed in the past year?

- b. How is your mental health/ how happy are you? Has it changed in the past year?
- c. Has your attendant care support influenced any aspects of your physical and mental health?

8. Social relationships and community participation

- a. Has your attendant care support influenced any aspects of your personal relationships and community participation?
  - i. Relationships with family, friends, support workers
  - ii. Being able to go out, taking part in recreational, cultural and community activities, travelling

9. Return to work (paid, unpaid) or study

- a. What is your current work or study situation?
- b. Are you happy with it? What would be ideal?
- c. Has your attendant care support helped with fulfilling your work or study goals?

10. Goals and plans

- a. For the coming year?
- b. Anything you would like to change about where you live, what you do during the day?
- c. Does your attendant care support help you to achieve those goals?

Experiences with direct funding

11. Do you think you would like to receive direct funding in the future? Yes/no – why

12. What do you think are the benefits / drawbacks of direct funding?

General

13. Is there anything else you would like to say about your attendant care support and the Direct funding trial?

## Interview questions – People with attendant care (short)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

### About your support

1. What attendant care services are you getting?
2. Are you happy with your attendant care support?
3. What are the effects of attendant care support on you and your life?

For example: arranging attendant care support; dealing with attendant care workers; your health; social relationships; work or study.

4. Do you receive other support towards your care?

### About direct funding of attendant care

5. Would you like to receive direct funding in the future?
6. What do you think are the benefits or drawbacks of direct funding?

### General

7. Is there anything else you would like to say about your attendant care support and the Direct funding trial?

## Interview questions – Family members of people with attendant care (long)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

### Formal and informal support

1. What formal and informal support does your family member receive? (hours, content, provider)
  - a. Your relationship to family member?
  - b. Do you provide support to the person using attendant care?
  - c. Does anyone else provide informal support? What type and how much?
  
2. How do you feel about the attendant care support your family member receives?
  - a. Type of support, flexibility, consistency, quality of care, emergency arrangements?
  - b. Has there been any attendant care support your family member has not been able to receive? What was the reason?
  - c. How well do monitoring and review processes work?
  
3. **For DFT participants:** How does the attendant care support through the direct funding trial differ from the previous support?
  - a. Provider, flexibility, consistency, quality of care, relationship with workers?
  
4. **For DFT participants:** Do you provide assistance to your family member to manage/administer direct funding?
  - a. What type and how much?
  - b. What would happen if you were away or sick?

### Outcomes of attendant care

5. What impact do you think attendant care support is having on you?
  - a. Employment, social activities, care responsibilities, relationship with your family member
  - b. **For DFT participants:** Any change since starting the trial?
  
6. What impact is the support having on family relationships/ household dynamics?
  - a. **For DFT participants:** Any change since starting the trial?

7. What impact do you think the attendant care support is having on your family member?
- a. Feeling of control
  - b. Confidence, independence
  - c. Physical and emotional wellbeing
  - d. Social relationships and community participation
  - e. Employment
  - f. Relationships with support providers and workers
  - g. **DFT participants:** Any change due to the trial?

Benefits and drawbacks of direct funding

8. What do you think are the benefits of direct funding?
9. What do you feel may be drawbacks of direct funding?
10. **For DFT participants:** Is there any way the trial could be improved?
11. Is there anything else you would like to say about your family member's attendant care support and the Direct funding trial?

## Interview questions – Family members of people with attendant care (short)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

### About support for your family member

1. Do you provide support to your family member using attendant care?

### About attendant care support

2. How do you feel about the attendant care support your family member receives?
3. What impact is attendant care support having on you?  
For example: employment, social activities, health.
4. What impact is the support having on family relationships?
5. What impact do you think the attendant care support is having on your family member?

For example: deciding about attendant care support; dealing with attendant care workers; health; social relationships; work or study.

### Benefits and drawbacks of direct funding

6. What do you think are the benefits or drawbacks of direct funding?

### General

7. Is there anything else you would like to say about your family member's attendant care support and the Direct funding trial?

## Interview questions 2<sup>nd</sup> round – Family members of trial participants (short)

**Please note:** These questions are only a guide. We can talk about some or all of them, or you can just tell me your story.

1. Since the last time we spoke, how have you felt about the attendant care support your family member receives?
2. What impact is direct funding having on you?  
For example: employment, social activities, health, organising support.
3. What impact is direct funding having on family relationships?
4. What impact do you think direct funding is having on your family member?  
For example: deciding about attendant care support; dealing with attendant care workers; health; social relationships; work or study.
5. Have your expectations of direct funding been fulfilled so far?
6. Do you have any suggestions for Lifetime Care if they extend direct funding to other parts of the service?
7. Is there anything else you would like to say about your family member's attendant care support and the direct funding trial?

## Focus group questions 1<sup>st</sup> round – Lifetime Care staff and managers

### Program goals

1. What do you see as the main aims of the direct funding trial?
2. Were there any particular groups of people who the trial was aiming to benefit?

### Experience of service design and implementation

3. Who was involved in the design of the trial?
  - a. Were all relevant stakeholders involved?
  - b. Were there any complications or delays?
4. Has the trial been implemented in line with original timelines?
  - a. If not what were the reasons for this?
5. Has the trial been implemented in line with original financial plans?
  - a. If not what were the reasons for this?
6. How effective is governance of the trial?
  - a. participant reference group
  - b. expert advisory group?
7. How could the process of direct funding be improved?
  - a. Approval process
  - b. Financial administration
  - c. Review process

### Program outcomes

8. Do you think that the trial is beginning to meet its original aims and objectives?
    - a. Has the trial allowed clients and service providers to arrange more flexible and efficient service?
  9. Is the trial having any unintended effects?
  10. What do you see as the potential risks for successful implementation of the trial?
    - a. How do you anticipate overcoming these risks?
    - b. Has there been any mismanagement of funds?
  11. What do you hope will be the main achievements of the trial?
  12. Do you think direct funding is ready to be rolled out to other people and services?
- Is there anything else you would like to say about the direct funding trial?

## Focus group questions 2<sup>nd</sup> round – Direct funding trial managers

1. What is your experience with the implementation of the trial?
  - a. Timelines, governance, revision and fine-tuning
  
2. How could the process of direct funding be improved?
  - a. Approval process
  - b. Financial administration and reporting
  - c. Monitoring
  - d. Support for trial participants
  - e. Support for staff
  
3. Do you think that the trial is meeting its aim, that is to assist clients and service providers to arrange more flexible and efficient service?
  
4. What do you think are other effects of the trial, both intended and unintended?
  
5. What do you see as the potential risks of direct funding, both for the participants and Lifetime Care?
  - a. How do you anticipate overcoming these risks?
  - b. Has there been any mismanagement of funds?
  
6. Have lessons from the trial affected the way Lifetime Care arranges other support with these or other clients?
  - a. how other services are organised by Lifetime Care
  - b. how other services delivered by service providers
  - c. how clients are encouraged to arrange flexible, efficient services?
  
7. What are your plans for extending direct funding to other scheme participants and other types of support?  

  
8. Is there anything else you would like to say about the direct funding trial?

## Focus group questions 2<sup>nd</sup> round – Lifetime Care staff

1. What is your experience with the implementation of the trial?
  - a. Timelines, governance, revision and fine-tuning
  
2. How could the process of direct funding be improved?
  - a. Approval process
  - b. Financial administration and reporting
  - c. Monitoring
  - d. Support for trial participants
  - e. Support and training for staff
  
3. Do you think that the trial is meeting its aim, that is to assist clients and service providers to arrange more flexible and efficient service?
  
4. What do you think are other effects of the trial, both intended and unintended?
  
5. What do you see as the potential risks of direct funding?
  - a. How do you anticipate overcoming these risks?
  - b. Has there been any mismanagement of funds?
  
6. Have lessons from the trial affected the way LTC arranges other support with these or other clients?
  - a. how other services are organised by LTC
  - b. how other services delivered by service providers
  - c. how clients are encouraged to arrange flexible, efficient services?
  
7. Do you think direct funding is ready to be rolled out to other people and services?
  
8. Do you have any other suggestions for LTC if they extend direct funding?
  -
  
9. Is there anything else you would like to say about the direct funding trial?

## Focus group questions – Attendant care providers

### Attendant care provision

1. Please talk about any service options you provide to promote choice, control and flexibility of attendant care support?
2. What feedback do you receive from clients about the choice and flexibility of attendant care support?
  - a. Are clients able to access the support they require?
  - b. How easy is it for clients to change their support?
  - c. Have you received any complaints, e.g. quality of support, consistency of care, emergency back-up?
3. How have you responded to requests for greater choice or flexibility of support in the past? What are your future plans for responding?

### Direct funding trial

4. What do you think about the direct funding trial?
  - a. Do you think it will provide greater control and flexibility to clients? If so in what way?
5. Are there specific groups of people who you think direct funding is suitable for?
6. What role if any did you play in informing clients about the trial?
7. Have any of your clients opted to receive support through the direct funding trial?
  - a. What support do you provide to clients participating in the direct funding trial (attendant care, fund management)?
  - b. Why do you think your clients decided to participate in the trial?
  - c. Did they have any concerns? How did you respond?

### Impact on service provision

8. What has been the impact of direct funding on your service (workload, staffing, training, scheduling, types of support, cost)?
  - a. What aspects of your business have changed?
  - b. Are these changes positive or negative?
  - c. How effective are review and monitoring processes for the trial?
9. How does this differ from other support packages your clients receive?
10. What emergency/back up support is available to clients participating in the trial and what role do you play in this?

11. From your perspective, is direct funding a good thing?

- a. benefits for clients and/or care workers?
- b. risks for clients and/or care workers?

### **Outlook**

12. How could the process of direct funding be improved?

13. Do you think direct funding should be rolled out to other people and services?

14. Is there anything else you would like to say about the direct funding trial?

## Interview questions – Direct funding training provider

### About your organisation

1. Your work in general
2. How and when did you get involved in Lifetime Care's Direct funding trial?
3. What services do you provide to DFT participants?
4. How have these services evolved since the trial started?

### Direct funding trial implementation

5. What do you think works well in:
  - a. the governance of the trial
  - b. the implementation of the trial
    - supporting participants' decision
    - approval process
    - start-up training (legal, employment)
    - financial administration
    - ongoing support for managing DF
6. What could be improved?
7. What do you see as potential risks for the implementation of direct funding?

### Direct funding trial outcomes

8. Do you think direct funding will provide clients with:
  - a. more choice, control and flexibility
  - b. better relationships with service providers
  - c. improved health
  - d. more social relationships, community and economic participation
9. Are there specific groups of people who you think direct funding is suitable for?
10. What do you expect will be the impact of DF on service providers?

### General

11. Have trial participants raised any issues about the DFT with you, or any needs, that we haven't discussed?
12. Do you think direct funding should be rolled out to other people and services?

13. Is there anything else you would like to say about the direct funding trial?

## Survey – People with attendant care

### Quality of life

The following questions ask how satisfied you feel, on a scale from zero to 10, where zero means you feel no satisfaction at all, and 10 means you feel completely satisfied.

1. Thinking about your own life and personal circumstances, how satisfied are you with:

	Not satisfied at all										Completely satisfied	
	0	1	2	3	4	5	6	7	8	9	10	
... your life as a whole	<input type="checkbox"/>											
... your standard of living	<input type="checkbox"/>											
... your health	<input type="checkbox"/>											
... what you are achieving in life	<input type="checkbox"/>											
... your personal relationships	<input type="checkbox"/>											
... how safe you feel	<input type="checkbox"/>											
... feeling part of your community	<input type="checkbox"/>											
... your future security	<input type="checkbox"/>											

## Attendant care services

I'd like you to tell me how strongly you agree or disagree with a few statements about attendant care services funded by the Authority. Please use a scale of 1 to 10, where 1 is strongly disagree and 10 is strongly agree.

### 2. In the last twelve months:

	Strongly disagree								Strongly agree	
	1	2	3	4	5	6	7	8	9	10
Getting access to attendant care services was easy	<input type="checkbox"/>									
Choosing an attendant care provider was easy	<input type="checkbox"/>									
The amount of attendant care I receive is reasonable	<input type="checkbox"/>									
The quality of the attendant care I receive is high	<input type="checkbox"/>									
Attendant care supports me to live more independently	<input type="checkbox"/>									
Attendant care increases my quality of life	<input type="checkbox"/>									

### Current circumstances

3. Thinking about your current circumstances, I'd like you to tell me how strongly you agree or disagree with each of the following statements on a scale from 1 to 10, where 1 is strongly disagree and 10 is strongly agree.

---

	Strongly disagree					Strongly agree				
	1	2	3	4	5	6	7	8	9	10
I can make important decisions about my life	<input type="checkbox"/>									
I am in control of my life	<input type="checkbox"/>									
I am able to adapt to changes in my life	<input type="checkbox"/>									
I have meaning in my life	<input type="checkbox"/>									
I need more information from the Lifetime Care and Support Authority	<input type="checkbox"/>									
There are now long delays waiting for services to be approved by Lifetime Care and Support	<input type="checkbox"/>									

---

4. Is there anything else you would like to tell us about attendant care or your quality of life?

## Demographics

1. Gender:            male    or    female
2. Age:
3. Suburb:
4. Who lives with you:
5. Cultural background:
6. ATSI:    yes    or    no
7. Language spoken at home:
8. Type of injury/disability:
9. Date of injury:
10. Date started receiving attendant care:
11. Direct funding trial participant:    yes    or    no

## Survey 2<sup>nd</sup> round – Direct funding trial participants

Has anything changed in your life since the last time you did this survey that might affect your answers? This could be a good or a bad change.

No

Yes

What was it? \_\_\_\_\_

### Quality of life

The following questions ask how satisfied you feel, on a scale from zero to 10, where zero means you feel no satisfaction at all, and 10 means you feel completely satisfied.

1. Thinking about your own life and personal circumstances, how satisfied are you with:

	Not satisfied at all										Completely satisfied
	0	1	2	3	4	5	6	7	8	9	10
... your life as a whole	<input type="checkbox"/>										
... your standard of living	<input type="checkbox"/>										
... your health	<input type="checkbox"/>										
... what you are achieving in life	<input type="checkbox"/>										
... your personal relationships	<input type="checkbox"/>										
... how safe you feel	<input type="checkbox"/>										
... feeling part of your community	<input type="checkbox"/>										
... your future security	<input type="checkbox"/>										

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Choosing an attendant care provider was easy	<input type="checkbox"/>										
The amount of attendant care I receive is reasonable	<input type="checkbox"/>										
The quality of the attendant care I receive is high	<input type="checkbox"/>										
Attendant care supports me to live more independently	<input type="checkbox"/>										
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I am in control of my life	<input type="checkbox"/>									
I am able to adapt to changes in my life	<input type="checkbox"/>									
I have meaning in my life	<input type="checkbox"/>									
I need more information from the Lifetime Care and Support Authority	<input type="checkbox"/>									
There are now long delays waiting for services to be approved by Lifetime Care and Support	<input type="checkbox"/>									

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4. Is there anything else you would like to tell us about attendant care or your quality of life?

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