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UNSW
AUSTRALIA

**Direct funding trial for attendant care support
Evaluation plan**

Never Stand Still

Faculty of Arts & Social Sciences

Social Policy Research Centre

REPORT 6/2014

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Direct funding trial for attendant care support

Evaluation plan

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ABBREVIATIONS

ABS	Australian Bureau of Statistics
ADHC	NSW Department of Family and Community Services, Ageing, Disability and Home Care
NDIS	National Disability Insurance Scheme
NIIS	National Injury Insurance Scheme
NSW	New South Wales
PWI	Personal Wellbeing Index
SDAC	Survey of Disability, Ageing and Carers
SPRC	Social Policy Research Centre
TAC	Transport Accident Commission, Victoria
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNSW	UNSW Australia

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Research team

Karen R. Fisher, Christiane Purcal, Rosemary Kayess and Fred Zmudzki

1 INTRODUCTION

1.1 BACKGROUND

The NSW Safety, Return to Work & Support Division includes the Lifetime Care and Support Authority of New South Wales (the Authority), which provides treatment, rehabilitation and care for people following a motor vehicle accident. The Authority is trialling direct funding of the assessed attendant care needs for lifetime care participants and has commissioned the Social Policy Research Centre (SPRC) to evaluate its Direct Funding Trial. This evaluation plan outlines the evaluation framework, research methodology and project management arrangements.

Australian states and territories are responsible for the provision of disability specialist services to people with disability. Funding derives from federal and state governments. Services are subject to federal legislation and national service standards and are changing in the context of major reform under the NDIS and implications of the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

The Direct Funding Trial is conducted in the context of social policy and 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) legislation anticipates the possibility of all disability related support, including injury related disability, to be offered with a direct funding option.

NSW policy developments go hand in hand with the federal policy context. The first stage of the NDIS implementation has begun at launch sites, including the Hunter region in NSW, and the Authority's Lifetime Care and Support Scheme meets the NIIS requirements for motor accidents in NSW.

Direct funding has been introduced internationally and nationally (Purcal et al., 2014). In addition to the NIIS and NDIS reforms, NSW has one of the most open forms of direct funding, through the Attendant Care Program and High Needs Support Pool (Fisher and Campbell-McLean, 2008), which offer direct funding, cooperative funding and service provider funding options. Such innovative reforms require quality assurance mechanisms, including rigorous evaluation, to ensure that the outcomes and outputs of the policy changes are achieved in an efficient, effective and sustainable manner.

1.2 DIRECT FUNDING TRIAL

The Authority was established in 2006 and is a growing organisation. Currently about 900 people participate in the lifetime care scheme, and approximately 125 people enter the scheme each year. As the scheme has got older, there has been a shift in the profile of participants towards more life-long than interim participants. As a consequence the Authority is no longer focusing only on the intensive rehabilitation needs of participants but also on facilitating participants to live in their local community post rehabilitation.

In line with the national and international developments in disability services described above, the Authority wishes to use a person centred approach and increase choice and control for its participants, through the option of direct funding for assessed attendant care needs.

The Motor Accidents (Lifetime Care and Support) Act 2006 allows the Authority to provide funds to participants directly to meet their assessed treatment and care needs. The Authority has an Australian Tax Office ruling and a Social Services determination allowing that

participants can receive direct funding for their assessed attendant care needs without this money being considered as income for taxation purposes.

The Authority is conducting a one year direct funding trial from April 2014 to March 2015. The trial tests the Authority's direct funding process and informs best practice for a future rollout of direct funding.

About 15 lifetime care participants will join the direct funding trial. Participation in the trial is voluntary, and people need to be assessed by the Authority as eligible for direct funding. Eligibility criteria include 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.

Trial participants receive the money for their assessed accident related attendant care needs directly from the Authority and use this money to purchase the attendant care services they need, including domestic and gardening services. Direct funding is intended to give people more choice and control over their attendant care services. People can:

- choose their own attendant care provider
- 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.

Two models of direct funding are being offered in the trial. In the first model, trial participants are responsible for managing all aspects of funding, including bookkeeping, administration, insurance and workers compensation. They receive initial training and support from the Authority if needed.

In the second model, trial participants who are not able or do not wish to manage part or all of direct funding themselves will receive ongoing support to manage the direct funding process. This option will be available once specialist service providers have been identified.

The trial participants' budget is based on the Authority's assessment of their attendant care needs and the participants' request for care. The hourly rate is a composite rate based on the Authority's Attendant Care Fee Schedule and includes money to pay the attendant care worker and the participants' administration costs. Direct funding budgets and arrangements are reviewed at the person's scheduled Care Needs Review or earlier if the person or the Authority has concerns or if the person's needs or circumstances change.

2 EVALUATION FRAMEWORK

2.1 EVALUATION AIMS AND QUESTIONS

The evaluation assesses the experiences and wellbeing of people with attendant care to determine whether direct funding of attendant care meets the needs of participants and achieves intended outcomes for participants and the Authority.

The aims of the Direct Funding Trial evaluation are:

1. Design and apply an evaluation framework
2. Measure effectiveness, efficiency and appropriateness of direct funding
3. Establish a basis of comparison to enable interpretation of data (participants at similar level of injury and stage post injury who are not receiving direct funding)
4. Evaluate whether direct funding meets the needs of participants
5. Evaluate whether direct funding achieves intended outcomes for participants
6. Evaluate whether direct funding achieves intended outcomes for the Authority
7. Evaluate whether there are other ways to achieve the same outcomes for participants and for the Authority
8. Advise whether resources can be allocated more efficiently
9. Make recommendations on any improvements to direct funding.

The aims of the evaluation answer the key research questions, which are:

1. Does direct funding meet the needs of participants and achieve intended outcomes for them?
2. Does direct funding achieve intended outcomes for the Authority?
3. What are the implications for other ways to achieve similar outcomes for other participants and for the Authority?

The length of the evaluation period is 17 months, from January 2014 to June 2015. It includes two months prior to the start of the trial, the 12 months of the trial and three months post trial. This is to enable the evaluation framework to be designed at an early stage and to inform the management and refinement of the trial.

2.2 CONCEPTUAL APPROACH

The evaluation is underpinned by a developmental approach (Patton 2011). This form of evaluation is most appropriate for investigating new, innovative programs as it facilitates continuous program development and enhancement. A developmental evaluation approach also ensures that the methodology is responsive to site issues, differing contexts and the variety of research participants.

The evaluation adopts an inclusive, participatory research approach. In general, participatory evaluation methods help to manage the sensitive process of disability policy and practice change, which affects the people using the services, families, carers, workers and service providers (Fisher and Robinson 2010). In the Direct Funding Trial evaluation, inclusive and participatory research methods enable a variety of trial participants and people from a comparison group to take part in the evaluation. This includes, for example, people with different types of injuries, communication requirements, ages and locations (metropolitan, regional or rural). By including a range of people, the evaluation determines what support is best for which people and under which circumstances to make direct funding feasible for them in the future.

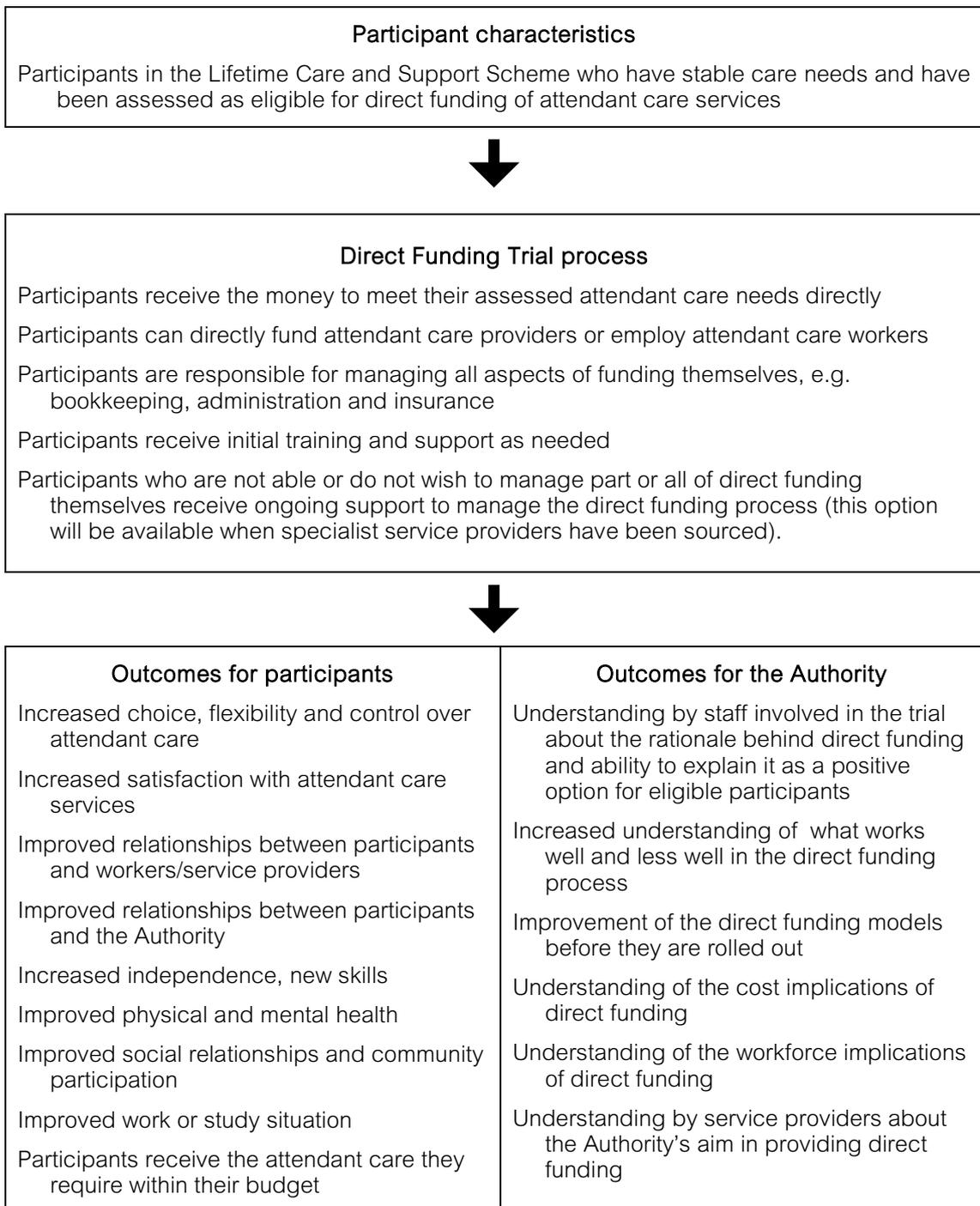
To achieve the evaluation aims, a process and outcomes evaluation as well as an economic analysis are included. The process component explores participant and other stakeholder experiences with the implementation of the trial. Outcomes of direct funding for participants and the Authority are assessed, and the economic evaluation compares the costs of the trial and direct funding with those of attendant care provided by the Authority.

2.3 DIRECT FUNDING TRIAL PROGRAM LOGIC

A program logic articulates the elements of a program, in this case the Direct Funding Trial, and describes how these elements fit together to meet an identified need. A program logic fulfils several functions in an evaluation. It expresses relationships between the inputs, processes and outcomes of a program. This is important for any evaluation, as it helps to determine 'for whom, in what circumstances and in what respects a family of programmes work' (Pawson, 2006, p.25). In addition, a program logic draws attention to how the program is influenced by the wider service system, the policy context and other external contextual factors (McLaughlin and Jordan, 1999). Finally, a program logic helps to determine the evaluation methodology.

The program logic for the Direct Funding Trial is presented in Figure 1 below.

Figure 1: Direct Funding Trial program logic



2.4 PHASES OF THE EVALUATION

The evaluation was conducted in three phases.

PHASE 1: START UP

The evaluation team works closely with the Authority's project manager and other key stakeholders to develop an agreed evaluation framework. This process includes briefing meetings and consultations with the Authority and other stakeholders about details of the attendant care provided by the Authority and of the Direct Funding Trial, roles of the Authority and SPRC in the evaluation, communication and risk management, availability of outcomes and cost data that can be used for the evaluation, options for data collection, and policy and program sensitivities. These discussions help refine evaluation objectives and determine the program logic for the Direct Funding Trial.

During this phase, SPRC conducts a short review of available literature and data on evaluation methodologies of programs similar to the Authority's Direct Funding Trial. Both the literature review and the program logic help refine the evaluation methodology. Phase 1 also includes obtaining ethics approval for the evaluation from UNSW's Human Research Ethics Advisory Panel.

SPRC produces the evaluation plan, outlining background, methodology and management of the evaluation.

PHASE 2: DURATION OF THE TRIAL

The agreed evaluation framework is applied. SPRC and the Authority conduct the first round of data collection, as per the methodology below. SPRC analyses the data and produces the interim evaluation report.

PHASE 3: POST TRIAL

SPRC and the Authority conduct the second round of data collection, as per the methodology below. SPRC analyses the data and produces the final evaluation report.

2.5 DELIVERABLES

The deliverables are:

- Evaluation plan
- Interim evaluation report
- Final evaluation report

The evaluation plan and reports are provided first in draft form, and the feedback provided by the Authority is incorporated into final outputs. With the permission of the Authority, the evaluation plan, interim and final evaluation reports are made publicly available to contribute to the evidence base on direct funding, and accessible versions are produced and agreed on with the Authority.

The evaluation phases, deliverables and timeline are summarised in the project plan (Table 1) below.

Table 1: Project plan

Phase	Tasks	Deliverables	Time
1 Start up	Briefing meetings and consultations with the Authority and other stakeholders SPRC seeks ethics approval SPRC reviews literature and documents Fieldwork planning and development of data collection instruments SPRC drafts evaluation plan and revises according to feedback from the Authority	Evaluation plan	January–March 2014
2 During trial	Briefing meetings and consultations with the Authority and other stakeholders Apply evaluation framework 1 st round of data collection SPRC drafts interim evaluation report and revises according to feedback from the Authority	Interim evaluation report	April 2014–March 2015
3 Post trial	Briefing meetings and consultations with the Authority and other stakeholders 2 nd round of data collection SPRC drafts final evaluation report and revises according to feedback from the Authority	Final evaluation report	March–June 2015

3 METHODOLOGY

3.1 METHODOLOGICAL CONSIDERATIONS

A short literature review was conducted of evaluations of programs similar to the Authority's Direct Funding Trial, in order to inform the methodology of this evaluation, especially the selection of data collection tools. While there is a large body of literature on the evaluations of individualised funding policies in human service delivery generally, policy content and client groups often differ from those supported by the Authority's Direct Funding Trial. Therefore, the data collection tools used in other evaluations are not necessarily appropriate for this research.

Many evaluations of individualised funding policies use one type of data collection approach, either quantitative research methods such as phone surveys or client questionnaires, or qualitative methods such as in-depth interviews with policy participants (Ottmann et al., 2009). Mixed methodologies, combining quantitative and qualitative data collection methods, are generally considered more useful to gain a comprehensive understanding of people's lives and experiences (Mason 2006). Mixed methods enable triangulation of data and thus help validate research findings, they can complement each other, and they are regarded particularly useful in social policy research, as people's lived experiences are multi-dimensional.

Some direct funding program evaluations use mixed methods to explore a range of participant outcomes, experiences with the funding process, and program costs and benefits. One example is the large-scale evaluation of the UK Individual Budgets Pilot Programme (Glendinning et al., 2008). It included qualitative interviews with service users, project staff, managers and service workers alongside several quantitative tools to measure service users' emotional and physical wellbeing, as well as their satisfaction with life domains such as social participation and control over their daily life. Tools included the General Health Questionnaire (GHQ-12) and the Adult Social Care Outcome Toolkit (ASCOT).

LDC Group (2007) is an example of an Australian evaluation of a direct payment trial, in this case for people with disability in Victoria. Its mixed methodology included consultations with stakeholders and qualitative interviews with trial participants, alongside participant surveys to measure change since direct payments started and simple scales to assess satisfaction with support documentation.

There are few evaluations specifically of self-directed models of attendant care support that are similar to the Authority's Direct Funding Trial. SPRC's evaluation of ADHC's direct funding pilot in the Attendant Care Program (Fisher & Campbell-McLean, 2008) used a mixed method approach including in-depth interviews, the Personal Wellbeing Index (PWI) and ABS health questions with pilot participants and a comparison group.

A similar methodology was employed in the two unpublished evaluations of the Victorian Transport Accident Commission's (TAC) self-purchasing pilot (Market Access Consulting and Research 2004 and 2012). Self-purchasing is similar to the Authority's direct funding trial in intent and design. In addition to in-depth qualitative interviews with program participants, TAC used a range of psychometric measures of people's wellbeing and program outcomes: the Affect Balance Scale, Self Esteem Scale, Spheres of Control measure and Community Integration Questionnaire. It should be noted that, as the sample was quite small, these psychometric measures were administered only as an indication of the types of responses possible from such a sample and not a reliable measure of these outcomes for the population as a whole. In addition, the TAC evaluators devised a satisfaction scale about control of

services, and they replicated an overall service satisfaction question from the regularly conducted TAC client feedback survey.

The evaluation of the Direct Funding Trial uses a mixed method approach, as detailed below. The methods include administrative, financial and survey data about trial participants and the comparison group, qualitative interviews, surveys, and focus groups. Psychometric measures, as were used in the UK Individual Budgets and the TAC evaluations, are not applied because the sample for this evaluation is very small, and the measures do not fit with the program logic. The PWI, used in ADHC's direct funding pilot evaluation, is included in the methodology because it measures outcomes across a range of life domains, as intended by the Direct Funding Trial. In addition, questions from the TAC and the Authority's participant feedback surveys are included, because they are tested and yield comparison data from a similar client group.

The methodology includes longitudinal and comparison measures. It has been designed within budgetary and time considerations, to answer the evaluation questions and meet the evaluation aims.

3.2 METHODS

The evaluation uses mixed methods for data collection, including administrative, financial and survey data about trial participants and the comparison group, qualitative interviews, surveys, and focus groups.

SAMPLE

The study sample includes all participants in the Direct Funding Trial and, for comparison, people who receive attendant care through the Authority's lifetime care scheme but are not participating in the trial. In addition, family members, attendant care providers and agency staff take part in the evaluation.

All trial participants are included in the evaluation if they agree, as well as a larger number of comparison clients, who resemble the trial participants in demographic and injury-related aspects, particularly age, gender, age at injury, time since injury, level of disability, presence of other members in the household, work or study situation, and location (metro/rural). Cultural background is not included as a criterion, as the Authority has a relatively small group of lifetime care clients. It is possible to match trial participants and non-participants on criteria such as type of injury, household members and work situation, but the pool is too small to include cultural background as well.

Sample sizes are summarised in Table 2.

Table 2: Sample sizes

Type of interview or other technique	People with attendant care		Families		Attendant care providers ⁴	Agency staff and managers ⁴
	Trial participants ³	Comparison group	Trial participants ⁴	Comparison group		
Program and financial data ¹	Up to 15	More than 15				
Face to face data collection (interview, survey, observation, inclusive methods)	Up to 15	Up to 15				
Telephone interviews			Up to 15	Up to 15		
Focus groups ²					1	1

1 Potential program data for all participants and comparison group if available, Baseline Model 1 only, second round could include Model 2 if operational

2 Multiple people per group

3 Two rounds of data collection from trial participants and their families

4 Staff and managers of the Lifetime Care and Support Authority of NSW, other agencies involved and attendant care service providers; two rounds of data collection

There are two rounds of data collection from trial participants, and their families if trial participants agree: close to the beginning of the trial (May 2014) and at the end of the trial (March 2015). A second round of data collection adds a longitudinal component to the evaluation, which helps to determine whether and how initial process issues with the trial have been resolved, and whether outcomes for participants have improved. At the time of the first round of data collection, between seven and ten people are expected to have started the trial, and by the second round, 15 people are expected to be in the trial.

Two rounds of focus groups are conducted with attendant care service providers, as well as staff and managers from the Authority and other agencies involved, to capture their insights at the beginning and end of the trial.

One round of data collection from the comparison group is sufficient to compare outcomes, as their attendant care arrangements continue as before.

The relatively small sample size limits the statistical significance of the evaluation findings, although it yields enough information for meaningful outcome analysis and comparison between trial participants and non-participants.

QUANTITATIVE DATA

Administrative data

Administrative data held by the Authority about trial participants and the comparison group includes demographics, type of injury, accommodation, support needs (functional and care assessment needs scores), and types of support received (both from services and family). The administrative data used for the evaluation is collected by the Authority and transferred to SPRC for analysis.

Cost data

An economic evaluation of the Direct Funding Trial determines efficiency and cost effectiveness of the trial, and assesses value for money. The economic evaluation is based on financial data regarding trial participants and the comparison sample as well as costs to the

Authority of conducting the trial. The Authority is collecting all financial data to transfer to SPRC for analysis.

Cost items include:

- cost of attendant care, separated by direct care and administration
- one-off establishment costs for direct funding (Authority costs for setting up processes and developing guidance, start-up costs for trial participants, evaluation of the trial)
- ongoing start-up costs to the person (including time)
- ongoing start-up costs to the Authority (training, equipment, administration)
- ongoing recurrent costs to the Authority (internal staff, external case managers)

Retrospective support cost data of participants of the Direct Funding Trial is reviewed, where available, for comparative reference and service delivery trends.

The cost analysis will initially examine the composition of cost categories between the trial participants and the comparison attendant care group. The direct funding model requires that participants initially establish systems and procedures to independently manage all aspects of their care. These require establishment costs in the initial 12 month study period that would be expected to reduce in subsequent years once systems are in place and management experience is developed.

In order to provide perspective for this establishment cost component, estimated model scenarios will be developed to contextualise the likely skew towards first year set up costs, compared to expected ongoing recurrent care costs. This is a potentially positive factor in medium term cost effectiveness as set up costs taper off, and management skills are developed. The combined cost profiles will be positioned in the context of the qualitative and quantitative client outcomes to indicate in broad terms the cost effectiveness of the direct funding model.

The economic evaluation will be undertaken primarily from the perspective of Lifetime Care and Support as the funding authority.

Surveys

Surveys with trial participants and the comparison group focus on individual outcomes of attendant care in various life domains, and on satisfaction with attendant care services received. Validated or tested instruments are used so that comparison can be made to other research. The Personal Wellbeing Index (International Wellbeing Group, 2013) measures quality of life, and survey questions measuring satisfaction with attendant care services and life circumstances are consistent with those from the TAC's and the Authority's client satisfaction surveys, to enable comparison with both organisations' larger data sets.

The research design is inclusive by taking account of individual needs, capacity and barriers to participation. The survey uses plain English, and an Easy read version is used when appropriate.

The Authority recruits survey participants, obtains voluntary consent from each participant and provides SPRC with the necessary contact details to set up the surveys.

SPRC conducts the surveys with trial participants and the comparison group. Surveys are usually done in conjunction with the qualitative interviews described below, or at other times convenient to the evaluation participants. Draft survey questions are in the Appendix.

QUALITATIVE DATA

Interviews

Qualitative, semi-structured interviews with trial participants and the comparison group explore individual outcomes of attendant care and experiences with the process of receiving support. Key outcomes include: increased sense of control, choice and independence about attendant care services; improvements in physical and mental health, in social relationships and community participation, and in relationships with workers and service providers; and return to work or study where possible.

Interviews with family members cover the family's experiences with attendant care, perceived outcomes for the person receiving care and, for family members of trial participants, their feedback on the Direct Funding Trial.

The research design is inclusive by taking account of individual needs, capacity and barriers to participation. Interview schedules are designed to be flexible and to rely on the skills and judgement of the researchers, who have prior experience interviewing people with disability. The interview schedules use plain English and are simplified by the researchers depending on the needs of the participants.

Observational data is also collected for each person during the interview, including observation of the participant's interaction with other people and their environment. This method is particularly useful for participants less able to take part in a conversation based interview. Participants can also be encouraged with visual cues, such as photographs, faces displaying different emotions, or drawings, if this assists them to share information.

The interview process includes inviting a nominated and trusted support person to attend the interview where necessary. A support person is someone who sits in on an interview with a participant to help that person communicate in the best way possible with the researcher. This approach helps to make the research inclusive and ensure that information is gathered from all participants. A protocol is applied to guide supporters about their role to protect the primary perspective of the person being interviewed.

The Authority recruits interview participants, obtains consent from each participant and provides SPRC with the necessary contact details to set up the interviews.

SPRC conducts all the interviews, up to a total of 40 interviews split between the first and second rounds of data collection. This includes up to 10 face to face interviews to locations within metro Sydney. The remainder is carried out by phone. Draft interview questions are in the Appendix.

Focus groups

Focus groups with agency staff and managers, as well as attendant care providers, address process evaluation questions, for example how well the trial implementation is working, the trial's impact on service provision, and outcomes for people and families. Focus groups with agency staff and managers may include case coordinators and external case managers, members of the Authority's participant reference group, and members of the Authority's expert advisory group.

The Authority arranges the focus groups, recruits focus group participants and obtains their consent. SPRC conducts the focus groups. Draft focus group questions are in the Appendix.

4 ANALYSIS

The data analysis compares trial participants and the comparison group, triangulating data from various sources and research methods where possible. To address the evaluation questions, the main focus of the analysis is to assess outcomes for people in the trial and for the Authority, and compare trial outcomes and costs.

5 PROJECT MANAGEMENT

5.1 EVALUATION TEAM

The evaluation team is led by Associate Professor Karen Fisher, SPRC (Chief Investigator). She is supported by lead researchers within SPRC and Époque Consulting. The evaluation team comprises:

Table 3: Evaluation team

Role	Name and organisation
Chief Investigator	Karen Fisher, SPRC, UNSW
Project Manager & Analyst	Christiane Purcal, SPRC, UNSW
Disability Advisor	Rosemary Kayess, SPRC, UNSW
Senior Health Economist	Fred Zmudzki, Époque Consulting

5.2 COMMUNICATION AND RISK MANAGEMENT

COMMUNICATION STRATEGY

Face to face meetings between SPRC evaluation team and Authority managers occur at the beginning and throughout the evaluation, to agree on evaluation design, responsibilities and timelines. In-between these meetings, evaluation progress and tasks are discussed at fortnightly teleconferences between SPRC and the Authority.

Communication types and frequency can be adjusted at any point in the evaluation to maintain a close working relationship and modify methodologies and timelines as necessary.

Risk management

The primary risks in this evaluation are time management, data collection and data transfer. The research design can be amended to respond to potential recruitment or data issues as they occur. Possible risks and solutions are identified in Table 4.

Table 4: Risk management strategy

Risk	Likelihood	Severity	Solution
Poor quality program and financial data	Med	Med	Close consultation with the Authority and other stakeholders to identify and manage data quality problems
Data gaps to address the evaluation aims	Med	Low	Triangulate data sources to adjust the outcomes, process and cost analysis. Work with the Authority to maximise triangulated data sources
Poor quality data collection (inter-rater reliability)	Low	High	Use of standardised instruments which have been used in similar studies. Training for evaluators and good QA systems
Psychological distress or other harm caused to evaluation participants, evaluators	Low	High	Stringently designed recruitment and interview procedures. Trained interviewers. Follow up and referral where necessary
Evaluation compromised due to lack of capacity	Low	High	SPRC has a wide range of skills which could be drawn on if needed to enhance capacity of team
Poor communication between evaluators and the Authority	Low	High	Karen Fisher and the team work closely with the Authority
Evaluation does not adhere to budget	Low	High	Budget is based on previous experience of several projects, all of which have reported on time and within budget. Budget risk is borne by SPRC
Evaluation design does not meet the policy needs of the Authority	Low	High	Evaluation design, objectives and dissemination strategy are developed in consultation with the Authority and can be amended during the project
Evaluation team fails to work effectively	Low	Low	Build on history of collaboration and protocols for accountability and communication
Evaluation team member unavailable	Low	Low	Succession plan within the evaluation team for continuity

5.3 ETHICAL CONSIDERATIONS

Human research activities are governed by the principles outlined in the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council, 2007). The Research Code of Conduct sets out the obligations on all University researchers, staff and students to be aware of the ethical framework governing research at the University and to comply with institutional and regulatory requirements. SPRC is concerned in all research studies to maintain high standards of ethical practice, to respect confidentiality and privacy of research participants, and to ensure that any information disclosed by participants during the course of the research is used only for those purposes expressly stated to the participants. The evaluation methodology and all research instruments and forms are submitted for approval by the UNSW Human Research Ethics Advisory Panel to ensure that the research complies with these standards.

Potential participants are supplied with clear statements about the use to which information collected from them will be put, and about the measures taken by the researchers to ensure that their privacy and confidentiality are maintained. SPRC researchers ensure that all participants give informed consent to participating in the research. All consent forms and other information about the research is written in plain English and culturally appropriate. Our

researchers are sensitive to participants' needs and requirements relating to Aboriginality, language and cultural background, gender, disability and sexuality. Researchers also belong to relevant professional quality organisations such as the Australasian Evaluation Society, and SPRC research is informed by its Indigenous Research Strategy and Protocol.

All project team members have met all relevant state and/or territory working with children requirements.

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APPENDIX: DRAFT RESEARCH INSTRUMENTS

DRAFT INTERVIEW QUESTIONS – PEOPLE WITH ATTENDANT CARE

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 financial support towards your care from other sources?
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-employed 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 the Authority/your contact with the Authority 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

- For comparison group:
 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?

- For DFT participants:

Introduction to the trial

13. How did you find out about the trial?
14. Why did you decide to participate in the trial? (potential benefits)
15. Did you get adequate information from the Authority 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?
16. Did anyone help you make the decision?
17. How did you find the approval process for the Direct Funding Trial?

Management of direct funding

18. What kinds of costs did you incur in setting up direct funding? E.g time, financial costs
19. How well has the process of direct funding worked since it started?
 - a. Quality of start-up training and support from the Authority 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 the Authority, 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 the Authority?
 - g. Set-up costs that we haven't covered – time, purchases, training paid by you?
20. Would you like any other or ongoing support for managing direct funding?

Review

21. 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)
22. Have your expectations of the trial been met?
23. Would you also like to receive direct payments for types of funding other than attendant care?
24. What monitoring and review processes are in place and how effective are they?
25. How could the process of direct funding be improved?
26. What has been the best / the worst aspect of direct funding?
27. Would you like to continue with direct funding into the future?

General

28. Is there anything else you would like to say about your attendant care support and the Direct Funding Trial?

DRAFT 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

DRAFT INTERVIEW QUESTIONS – FAMILY MEMBERS OF PEOPLE WITH ATTENDANT CARE

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?

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

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?