

Evaluation of the Self Directed Support Pilot for Children and Young Adults with a Physical Disability

Evaluation Plan

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Abbreviations

ABIOS	Acquired Brain Injury Outreach Service
DSRC	Disability Studies and Research Centre
MDS	Minimum Data Set
NSW	New South Wales
NHMRC	National Health and Medical Research Council
PWI	Personal Wellbeing Index
Qld	Queensland
SCCTC	Sunshine Coast Children’s Therapy Centre
SPRC	Social Policy Research Centre
UNSW	University of New South Wales

Executive Summary

Disability and Community Care Services, Department of Communities has commissioned an evaluation of the outcomes, process and costs of the Self Directed Support pilot by a research team led by the Social Policy Research Centre (SPRC). The aim of this Evaluation Plan is to provide an overview of the Self Directed Support pilot, the research questions and methodology which will be used to undertake the evaluation.

Background

Self directed support is a way of organising consumer directed care and has been introduced into most developed countries. It is typically characterised by a defined package of funding allocated to the person with a disability or someone in their immediate network of friends or family or a state allocated broker or representative for the purposes of purchasing support that reflects individual needs and preferences (Fisher et al., 2010; Glendinning 2008; Leece & Bornat 2006). It aims to promote personal responsibility, independence, capability and resilience through the delivery of low cost and innovative services chosen by the consumer or their appointed representative, including both selecting the type of support and who delivers it.

The Self Directed Support pilot has two key objectives: community inclusion and the empowerment of service users to make their own choices about their support (self direction). Self directed support enables individuals, their families and their other informal supporters to identify their needs, lifestyles and aspirations, and set personal goals. By giving people with disabilities control over their allocated funding, the Self Directed Support pilot allows them to be 'their own agents of change' (Department of Communities, 2010: 7).

An aim of the pilot is to enhance social and community inclusion of children and young adults with physical disabilities. Linking people with disabilities and their informal supports with their local communities by creating opportunities for meaningful engagement and participation is regarded as a key to individuals' wellbeing and increased resilience. The Self Directed Support pilot aim is to use strengths of existing community networks to enable participants' independence and self reliance.

Evaluation questions

The evaluation uses a longitudinal, mixed methods design to address three sets of research questions:

1. Participant and program outcomes: To what extent has the initiative met its objectives for individual participants?
2. Support model and service delivery processes: How effective is the model in meeting its key objectives, person centred (self directed) support, community inclusion, and early intervention?
3. Economic analysis: What are the costs and benefits of the pilot?

Research Design

The research is based on ethical and participatory research design with people with disabilities and their families and other informal supporters, service providers and Departmental staff. The evaluation will generate information about the Self Directed Support pilot throughout the evaluation period to inform progressive policy and program change. The information will include outcomes and process evaluation data. In addition, the final evaluation report will draw summative conclusions about the pilot program to inform future policy development.

Timeframe

This is a longitudinal evaluation going over almost two years. The first stage of the evaluation, design of research plan and consultation with key stakeholders, commenced in June 2010. The final evaluation report will be delivered to the Queensland Department of Communities in March 2012.

1 Introduction

Disability and Community Care Services, Department of Communities has commissioned an evaluation of the outcomes, process and costs of the Self Directed Support pilot to inform future service development. The program aims to enhance independence, capacity and resilience of children and young adults with a physical disability, as well as their families and informal supporters. The evaluation is from June 2010 to March 2012. The Social Policy Research Centre (SPRC), University of New South Wales (UNSW), in collaboration with the Disability Studies and Research Centre (DSRC) and Griffith University is conducting the evaluation. This plan explains the evaluation methodology and management. It includes:

- Background information;
- An overview of roles and responsibilities of program partners;
- Conceptual approach to the evaluation and key questions;
- Evaluation framework and data collection methods;
- Data analysis process;
- Ethical considerations; and
- Project management, including reporting and timeframes.

1.1 Background to the Pilot

Self directed support is a way of organising consumer directed care and has been introduced into most developed countries. It is typically characterised by a defined package of funding allocated to the person with a disability or someone in their immediate network of friends or family or a state allocated broker or representative for the purposes of purchasing support that reflects individual needs and preferences (Fisher et al., 2010; Glendinning 2008; Leece & Bornat 2006). It aims to promote personal responsibility, independence, capability and resilience through the delivery of low cost and innovative services chosen by the consumer or their appointed representative, including both selecting the type of support and who delivers it. Additionally, this approach to funding for disability support promotes meaningful social inclusion by increasing the opportunity for people with disabilities to participate in their local communities.

Self directed support for disability services can assist people with disabilities and their families to link with a variety of disability specific and mainstream services in their local community. Examples of programs that include small individual funding packages for children with disabilities and their families can be found in Australia, such as the NSW Family Assistance Fund and the WA Level One Funding administered through Local Area Coordinators. Like the Queensland self directed support pilot, these programs share goals about participation, integration and resilience, through the flexible purchase of support outside the specialist service system (Leece & Bornat 2006).

The term ‘resilience’ in relation to families is used to refer to their ability to function effectively or positively in ‘adverse circumstances’ (Master in Schoon, 2006: 7). It can also be used to refer to the ability to achieve developmental milestones, wellbeing and goals despite vulnerability and disadvantage (Schoon, 2006). As such, resilience is an important outcome for the families of children with disabilities. Childhood resilience is a result of the interaction between parenting factors, a stable and safe home environment and influential

adults outside the home (Muir et al., 2008; Masten et al., 1999). Less is known about adult resilience, though two major factors considered to contribute to it are paid employment and a united family (Muir et al., 2008).

Some families where a child has a disability experience additional demands and are more likely to experience risk and vulnerability compared to other families (Muir et al, 2008). Young adults with acquired disabilities experience similar vulnerability as they transition into and experience adulthood. Without adequate support and services these families and people with disabilities can experience significant stress (Muir et al, 2008). Self directed support can assist in mitigating these stresses and improving outcomes for the person with a disability and their family by offering a tailored solution outside the traditional service system (Powers & Sowers 2006). Individually directed support can provide an effective intervention response that can reduce the need for a higher cost of support associated with crises later in life.

1.2 Aims of the Self Directed Support Pilot

The Self Directed Support pilot has two key objectives: community inclusion and the empowerment of service users to make their own choices about their support (self direction). Self directed support enables individuals, their families and their other informal supporters to identify their needs, lifestyles and aspirations, and set personal goals. By giving people with disabilities control over their allocated funding, the Self Directed Support pilot allows them to be ‘their own agents of change’ (Department of Communities, 2010: 7).

An aim of the pilot is to enhance social and community inclusion of children and young adults with physical disabilities. Linking people with disabilities and their informal supports with their local communities by creating opportunities for meaningful engagement and participation is regarded as a key to individuals’ wellbeing and increased resilience. The Self Directed Support pilot aim is to use strengths of existing community networks to enable participants’ independence and self reliance.

The program’s further objective is to facilitate participants’ cooperation with the community rather than dependence on formal services to endeavour their goals. Person centred support and community inclusion combined are seen as a form of early support and an alternative to formal services associated with crisis later on in life (Department of Communities, 2010).

1.3 Roles and responsibilities of the Self Directed Support Pilot partners

The four main stakeholder groups in the Self Directed Support pilot are 1. nongovernment service providers funded by the Department to implement the program; 2. community consultants (case managers) employed by these agencies who work closely with people with disabilities and their families; 3. children and young adults with physical disabilities and their informal supports (family, carers and significant others); and 4. Disability Services and Community Care, Department of Communities staff who oversee and coordinate the initiative.

NGO partnerships and community consultants

The Queensland Department of Communities selected two service providers to implement the Self Directed Support pilot. One is the Acquired Brain Injury Outreach Service (ABIOS) in Brisbane, which supports young people with acquired physical disability. The second is the Sunshine Coast Children’s Therapy Centre (SCCTC) located in the Sunshine Coast, which supports young children (0-6 years) with physical disabilities and their family carers and significant others. The agencies employ community consultants (or support officers) to

identify and work closely with the program participants and their informal supports, local communities, and other services/organisations to achieve greater community inclusion for people with disabilities. ABIOS has added the community consultant responsibilities to all their existing case managers (ten) and SCCTC has appointed a new part-time position to be responsible for all Self Directed Support participants. The manager of the program in each organisation supervises the community consultants and is also responsible for other programs provided by the organisation.

The main responsibilities of ABIOS and SCCTC and their community consultants include:

- Identify children and young people with disabilities and their families not yet receiving disability services, who have limited or no existing community contacts or support networks;
- Determine potential service users eligibility and register applicants;
- Plan and set goals, and support participants' identified and preferred forms of community inclusion, as well as track their progress;
- Monitor and administer individual funding (eg. ensure participants get 'best value' for their money; assist in setting up bank accounts);
- Use capacities and strengths focused community development approaches that help build communities from 'inside out';
- Work closely with a range of stakeholders including disability specific, mainstream and community services, and participants informal support networks;
- Measure participants' outcomes;
- Provide training and professional development opportunities to community consultants and manage their performance;
- Regularly consult with, and report to the Department, and contribute to the knowledge base and future direction of the program; and
- Participate and contribute to the independent evaluation of the program.

Department of Communities

The Disability Services and Community Care, Department of Communities has policy and financial responsibility for the design, implementation and evaluation of the pilot. This includes:

- Select, allocate and administer funding to the two appointed NGOs;
- Disseminate information on the Self Directed Support pilot to the public and relevant advocacy bodies (eg. set-up information on website);
- Oversee and coordinate the initiative (eg. develop and provide documentation, case planning resources and reporting templates for NGO's);
- Respond to questions arising in the implementation and provide ongoing assistance to service agencies; and
- Commission and contribute to the evaluation.

Governance arrangements

Governance arrangements between the NGOs and the Department include:

- Quarterly reports on service types (part of the National Minimum Data Set (MDS));
- Detailed progress reports (analysis of qualitative and quantitative data); and
- Participation in quarterly consultations groups with Departmental staff.

1.4 Service delivery

The two NGOs are funded \$240,000 per year for two years to deliver services under the Self Directed Support pilot. The annual budget covers expenses for management, staff and operational costs; and person centred (self directed) planning and support, community inclusion, and early intervention for 40 participants, including self directed budgets of up to \$4000 per participant.

The Community Inclusion Guide & Toolkit outlines the program design. The core features of the service delivery include:

- A strengths based practice approach (eg. person centred planning);
- Good understanding of the nature of community connections;
- Planning, management and support of long-term community integration for people with disabilities;
- Collaboration and networking with a range of stakeholders to develop opportunities for community inclusion;
- Use of innovative and early intervention approaches; and
- Capacities focused approach to community development.

The Department selected the providers at the end of 2009. From January to July 2010 the providers established their operational systems and marketed the program in the community, recruiting and supporting approximately half the expected total participants for the first year.

2 Evaluation Framework

2.1 Evaluation framework

A longitudinal, mixed method evaluation design will be used to measure longitudinal outcomes for children and young adults with physical disabilities, their families and informal supports; the program process; and costs. The methodological approach has been developed to fit the attributes of the Self Directed Support pilot, the evaluation objectives and the conceptual framework outlined. It is designed within the evaluation constraints such as available and prospective sources of information, budget, timeframe and respondent burden.

Outcomes and process evaluation

The evaluation will generate information about the Self Directed Support pilot throughout the evaluation period to inform progressive policy and program change. The information will include outcomes and process evaluation data. In addition, the final evaluation report will draw summative conclusions about the pilot program to inform future policy development.

One of the key aims of the evaluation is to assess the impact of the Self Directed Support pilot on individual participants and their families. To address this aim, the evaluation will analyse the outcomes of the pilot for participants and will provide an understanding of the extent to which the program has met its core objectives.

Another important aspect of the evaluation is to assess the effectiveness of the support model to empower participants to make choices about the services and supports they require, and to create meaningful and long-term community inclusion for people with disabilities. To address this aim, the evaluation will analyse the Departmental and service provider governance, planning and program delivery processes.

Economic evaluation

In the economic analysis we will compare the costs of the pilot to the outcomes. The aim of this approach is to understand the extent to which costs to outcomes represent value for money over a longer term (eg. reduce the need for more expensive formal services later on in life). The underlying principle of economic analysis is that for the given budget, the government wishes to maximise consumer benefits. The economic analysis will also inform future decisions about the pilot or similar support models for people with disabilities.

2.2 Evaluation questions

The evaluation of the Self Directed Support pilot will address three sets of research questions:

1. Participant and program outcomes: To what extent has the initiative met its objectives for individual participants?

- How have participants and their family and informal supports benefited from this model of support?
- Has the program enhanced participants' social, economic and community participation?
- Have participants and their informal supports established new and meaningful community links and connections?
- To what extent are these community networks of long-term benefit to participants?
- Has the model contributed to participants' independence (self esteem, self reliance) and families' resilience?

2. Support model and service delivery processes: How effective is the model in meeting its key objectives, person centred (self directed) support, community inclusion, and early intervention?

- To what extent does the model reach its target groups of children and young people with physical disabilities who do not use services funded by the Department (unmet need)? Which groups are not reached, and why?
- To what extent are participants empowered to make decisions about their needs and goals, and to take control of their allocated funding?
- How could the support model be changed to build on strengths based and person centred service delivery approaches?
- What are the strengths and weaknesses of the current support model?
- Which aspects of the model are most/least beneficial for supporting community inclusion of people with disabilities?
- To what extent does the model meet criteria of innovation and early intervention?
- What role do partnerships and collaboration play in this model?
- What are some of the strengths/limitations of these partnerships and working relationships? How can they be improved?
- How effective is the governance of individuals' funding allocation and the program as a whole?

3. Economic analysis: What are the costs and benefits of the pilot?

- Does the program provide value for money when comparing costs to outcomes?
- What long-term benefits does the pilot generate (eg. is it likely to reduce the need for more expensive formal services later on)?
- How sustainable are the outcomes of the pilot likely to be?

2.3 Evaluation framework and research questions

This study uses a longitudinal, mixed methods design to address the evaluation questions. The rationale behind the design is discussed in this section. Table 2.1 summarises how the data sources fulfil the research objectives and research questions in the three parts of the evaluation – outcomes, process and costs. In summary the data sources include:

- Document review – policy, documents and literature;
- Administrative and program data – Department specifications, service contracts, financial data and case planning data;
- Qualitative data collection by the evaluation team – case studies, interviews and observation; and
- Quantitative reporting from the providers – quarterly and annual reporting, assessment data and validated Personal Wellbeing Index questionnaires.

The evaluation will be conducted in four phases – project plan; baseline analysis; longitudinal analysis; and final analysis. The phases align with the project schedule and are outlined below. This section also describes the research instruments, sampling framework and methods of analysis.

Table 2.1: Evaluation framework matched to research questions and data sources

Research objectives	Research questions	Document review	Administrative/Qualitative program data	Qualitative interviews	Quantitative reporting
Outcomes evaluation					
1. To investigate the impact of services provided through the Self Directed Support pilot and identify the types of individual outcomes for the children/families and young adults accessing these services	In what ways have participants in each target group benefited from this model of service delivery? - who benefits most and least	x	x	x	x
	What are the outcomes for participants and families involved in the pilot, particularly in relation to – independence (self esteem, confidence, self reliance), work engagement, social interaction and integration, cultural connection and resilience? - which benefits are greatest, least - which protective and risk factors are evident		x	x	x
2. To identify the elements of the approach that promote capacity building including individual, informal supporters resilience					
Process evaluation					
3. To examine what works well and what does not work as well in delivering the Self Directed Support pilot	What is the profile of the participants in each target group? - which people with disabilities are missing - how could access barriers be reduced		x	x	x
	What elements of the pilot are effective or not in supporting participants and their families to achieve their full potential and participate fully in the community? - how does it add to the evidence base of national and international best practice	x	x	x	x
	What can be learnt from the service delivery approaches adopted by each service provider in relation to implementing and delivering a pilot to people with a physical disability? - how can the lessons be generalised to other disability groups?	x		x	
	How does the pilot align with the Department’s strategic directions and can it be integrated into this new service-delivery framework?	x	x	x	
Cost evaluation					
4. To measure whether this type of early intervention approach provides meaning, value and tangible benefits for people accessing the program and is a viable service delivery program for the department	What are the costs compared to the effects and outcomes of the program? To what extent do these represent value for money over the longer term?		x		x

2.4 Phases of the evaluation

Phase 1: Project plan

The evaluation team worked with the Department and providers to refine the evaluation objectives, evaluation questions and research methodology. To minimise respondent burden, the evaluation design supplements existing reporting requirements with minimal supplementary data collection by the service providers and evaluators. As the quantitative and case planning data are collected by the service providers, analysis relies on timely and comprehensive delivery of these data to the evaluators.

A brief literature review was completed about other national and international self directed support programs and related evaluation methodology and findings for comparative purposes. The findings informed the design of this plan. Data collection instruments were developed.

Phase 2: Baseline analysis

The first wave of quantitative and qualitative data collection and analysis will be conducted during this phase. The Phase will conclude with the draft first progress report for comment, amendment and finalisation and presentation to the governance groups and Department.

Phase 3: Longitudinal analysis

The second wave of qualitative and quantitative data collection will occur during this phase, as well as data analysis. A second draft and final progress report and verbal presentation of initial findings will be provided to the governance groups and Department.

Phase 4: Final analysis

At the end of Phase 3, a draft final report will be submitted. Feedback from the Department will be used to revise the draft final report. A final report will be produced, along with a brief summary of findings that is written in a language suitable for wider distribution to stakeholders, such as participating service providers, participants, their families, carers and advocates. A verbal presentation of key research findings will be delivered to relevant stakeholders.

3 Methodology

3.1 Research rationale

This section outlines the findings from the brief literature and document review to design the evaluation. The aim of this review was to identify evaluation methods applied in previous research with people with physical disabilities or neurological impairment, and models of support building on community participation and inclusion. The review provides the rationale behind the design and the methods chosen to answer the research questions.

Longitudinal, mixed methods design

Experimental methods that incorporate a control group are sometimes used in disability research (Krahé and Altwasser, 2006). However they are used rarely due to a number of limitations including some ethical implications, impractical application of methods and high costs involved. Mixed method designs to measure outcomes and process evaluations of community care initiatives are growing in use due to their stronger ethical frameworks, greater practicability and application across a range of domains. One such example is the Local Area Coordination model.

The Local Area Coordination (LAC) model has been operating in Western Australia since the late 1980s, and has been successively implemented in other States and Territories. The objective of the program is to enhance people with disabilities' participation and contribution to their local communities, and strengthen their informal support networks (family carers and significant others) in their caring role. The program, which offers individualised planning and support, builds on a strengths based approach. The person with a disability and their family determine the supports and services that will enhance and build their capacity to greater community participation (Disability Services Commission, 2010a).

A number of consultations and evaluations have assessed service users and informal carers' satisfaction with the program, and the effectiveness and efficiency of the LAC approach, which has been overall described as a 'success story' (Disability Services Commission, 2003: iV). The 2002 evaluation consisted of a longitudinal, mixed methods approach: telephone consumer satisfaction surveys, surveys with family and carers, as well as qualitative consultations with a range of stakeholders (Disability Services Commission, 2003). Another more recent review of the program was based on a qualitative data collection from randomly selected interviews with people using LAC services (eg. people aged under and over 24 years, people with intellectual disabilities and other types of disabilities) (Disability Services Commission, 2010b).

In the late 1990s the LAC model was introduced in Queensland. Stehlik and Chenoweth (2001: 4) point out that the Queensland LAC approach slightly differs from the West Australian version, as it places a 'stronger emphasis ... on community development.' Overall it has been described as potentially 'empowering' and 'value adding' to people with disabilities and their families (Stehlik and Chenoweth, 2001).

The similarities between the Self Directed Support pilot (SDS) and the LAC program include a strong focus on person centred and strengths based support, enhancement of community participation, and strengthening and building of community and family

networks. The strong evaluation history of the LAC model lends weight to the application of a similar evaluation method to our study.

Participatory research methods

The use of participatory methodology is widespread in evaluation research and is increasingly regarded as ‘best practice’ (Fisher and Robinson, 2010). The success of evaluations strongly relies on the meaningful participation of a range of stakeholders throughout the research process: design of methodology, identification and management of potential risks, and data collection, just to name a few.

In the health and community care sector the discussion of the empowerment of service users and participation at program design level is widespread. Ottmann et al. (2008) argue however that for consumer directed participatory action research methods to be sustainable a range of support mechanisms (eg. community development, and capacity building initiatives) need to be built into the process early on, to ensure an ongoing meaningful interaction and integration of consumers at the policy level.

The SDS pilot evaluation design aims to enhance the participation of service users and their informal supports in the evaluation process. This will be facilitated through qualitative data collection processes which focus on the lived experience of service users, recompensing research participants for their contributions (interviews), and by ensuring consumers and their families are represented on the committees informing the evaluation.

Research participant considerations

Research design must take account of individual needs, capacity and barriers to participation. Most commonly research methodologies accommodate this by ensuring that questionnaires and methods used build on participants’ strengths. Examples include providing questionnaires in an easy English version for people with cognitive or comprehension difficulties and including the perceptions of family and informal supports for young children and people unable to communicate opinions about complex concepts. The evaluation will not interview children because of ethical and practical considerations.

Sarah Hall (2010: 35) points out that some benefits of qualitative research methods when exploring the lived experiences of social inclusion for young adults with intellectual disabilities. First they enable for a more ‘complex description and interpretation of the problem’; and second they allow researcher and participant to ‘work together to construct the meaning of the participant’s experiences’.

Indigenous research advice about the evaluation and pilot highlighted the benefit of qualitative methods for engagement and discussion and minimising assessment and quantitative methods that are less likely to take account of Indigenous experience and cultural relevance. The concept of self directed support is compatible with Indigenous values if it respects diverse approaches to child rearing and results in actual support rather than just focusing on planning, process and gatekeeping.

3.2 Methods

The evaluation methods are summarized in Table 2.1 above and discussed in more depth below.

Quantitative data

The evaluation will analyse cost data provided by the Department and the service providers. In addition, it will analyse information collected by the service providers as part of the quarterly and annual reporting on participants' demographics, case planning, service types, and financial reporting. The evaluation will use quantitative data for the full participant population, unless the participant chooses not to have their data included. ABIOS will also transfer quantitative data collected for their two assessment instruments, which the evaluators will analyse to measure longitudinal change.

In addition, the evaluation needs to identify program outcomes for the children and young adults participating in the Self Directed Support pilot as well as their families and other informal supporters. This includes determining whether the pilot promotes individual and informal supporters capacity building (including resilience), and whether it provides meaning and tangible benefits to its participants. For this purpose researchers will analyse supplementary outcome data collected by service providers in the form of surveys with participants and their informal supporters (family carers and significant other).

To assess the outcomes for all adult respondents – the young adult participants of the pilot, their informal supporters and the informal supporters of the children participating in the pilot (one informal supporter per participant) – the evaluation will use data from the Personal Wellbeing Index (PWI) (International Wellbeing Group, 2006). The two selected NGO service provider agencies, ABIOS and SCCTS, have agreed to collect and transfer the PWI data.

The rationale behind this choice of validated instrument is that it contains specific questions on personal wellbeing as well as information on seven life domains that can be used as indicators for assessing resilience, e.g. health, material comfort, work engagement and community participation, which are the core objectives of the pilot program. In addition, the PWI is a validated instrument which uses reliable Australian scales which are short and therefore relatively quick to administer.

The PWI or an alternative instrument will not be administered for the young children group because it is unlikely to be sensitive to change for such a young group and may cause additional distress for the informal supports. In this cohort, the program is expected to show change in wellbeing outcomes for their family and informal supports. Instead we will analyse the case planning data to derive quantitative measures of change in outcomes reflected in the case plan.

In order to measure changes in outcomes for participants and informal supports over time, the instruments will be administered more than once during the time of the pilot. Service providers have agreed to complete the surveys with the participants at entry to the pilot, and every six months thereafter, and upon exit of the pilot (if they leave the pilot before the evaluation finishes).

Since we propose that the data transfer be with the quarterly reporting, this will take account of the progressive enrolment of participants to the pilot. When a provider enrolls a new participant, they can conduct the short survey and submit it with the next quarterly report. Ideally, all participants will be offered the opportunity to be included in the quantitative data collection. For participants entering the pilot after September 2010, only two waves of quantitative data collection will be possible, as collection will finish by October 2011 to enable analysis for the final report.

We do not recommend follow-up surveys after participants exit the pilot, as any subsequent changes in wellbeing or resilience will not be clearly attributable to the pilot and may be due to subsequent opportunities that participants have accessed.

Qualitative data

Interviews and observation

Semi-structured interviews will be conducted with participants of the Self Directed Support pilot, their informal supports, service providers and Department staff about the outcomes and process elements of the evaluation. To address the evaluation objectives and research questions, the qualitative interviews will determine:

- in what ways participants in each target group have benefited from this particular model of service delivery;
- which elements of the approach taken in the pilot promote capacity building (including individual and informal supporter (family and carer) resilience, achieving the participant's full potential and participating fully in the community), and which elements are not as effective;
- to what extent the costs invested in the pilot represent value for money over the longer term;
- what works well and what does not work as well in delivering the Self Directed Support pilot;
- what can be learnt from the service delivery approaches adopted by each service provider in relation to implementing and delivering a Self Directed Support pilot to people with a physical disability; and
- whether this is a viable and replicable service delivery program.

The qualitative sample will include ten pilot participants, 14 informal supporters, six service provider staff and two managers in both regions and three Department officials (Table 3.1). The sample size is the minimum recommended to meet the evaluation requirements within the constraints of the budget and respondent burden. It is large enough for case study data to supplement the full cohort continuous longitudinal quantitative data.

Table 3.1: Longitudinal qualitative interviews (September 2010 and 2011)

	Cohort 1 (0-6 years)	Cohort 2 (20-35 years)	Total sample
Pilot participants	-	10	10
Informal support (eg. family)	10	4	14
Service provider staff	1	5	6
Service provider manager	1	1	2
Department staff	-	-	3

Note: The qualitative samples supplement the full participant population quantitative datasets

The pilot participants and informal supporter qualitative samples will be:

- ten pilot participants from Cohort 2 (20-35 year old young adults). Interview methods will be adapted to the participants' cognitive, communication and literacy capacity and include communication with a trusted person as a proxy if necessary (see below). Qualitative data about Cohort 1 children with disabilities will be collected from the informal supporters only (below) due to budget constraints, and because babies and small children are too young to be directly involved as respondents for ethical and practical reasons;
- 14 informal supporters: Ten from Cohort 1 (0-6 year old children), plus four from Cohort 2 (preference will be for Cohort 2 informal supporters from the same pilot participant respondents). Cohort 1 informal supporters will be asked to respond about their direct family experiences and reflect indirectly on the experience of their children to supplement that Cohort 2 participant sample. If the child is present at the Cohort 1 family carer interview, observation data will be included.

As well as providing a spread across regions and program cohorts, the participant and family carer sampling framework will include people with different types and degree of disability support needs, male and female participants and people from a variety of Indigenous, cultural and linguistic backgrounds, as relevant to the full cohort. Communication assistance including translation and interpreters will be arranged where required and the evaluators are experienced and sensitive to participants' needs relating to gender, culture, disability and sexuality.

The SPRC has research protocols to guide practice with Indigenous and culturally and linguistically diverse people, families, children and communities. Evaluation methods are modified to respect the needs of Indigenous participants and Indigenous researchers are engaged to adapt methodologies and research instruments and to assist with data collection where relevant.

We do not recommend representative sampling because the quantitative data collection includes all participants who permit their data to be analysed in a de identified form and the qualitative case study sampling is only large enough to include at least one person with each diverse characteristic rather than a representative number, which would risk excluding people with less frequent characteristics.

In addition to the pilot participant and family carer samples, researchers will interview eight service provider staff (at least two from each region and cohort, preferably who

work with the pilot participants or manage staff who do) and three interviews with Department staff who oversee the pilot. These may be individual or group interviews, as agreed with the Department and service providers. This worker and management data will be supplemented with incidental observational and discussion data from any evaluator participation in meetings and visits to the service provider facilities.

Since this a longitudinal study, participant and informal supporter interviews will be repeated during the evaluation. The first wave of interviews (baseline) will be conducted in September/October 2010 and the second wave of interviews will be conducted in June 2011. The sample will be supplemented with replacement recruitment if any participants are not available for repeat interviews in the second year of the evaluation. All participant and informal supporter interviews will be conducted face to face in a location preferred by the respondent. The service provider and Department interviews will be conducted face to face or via telephone at the convenience of the respondents and within budget constraints.

A final data source will be phone and email data from other people involved in the pilot responding to public summaries of the evaluation plan and interim results in the formative evaluation approach.

Recruitment strategy

To avoid selection bias and maximise the longitudinal research opportunities, the samples will be selected on the basis of the last pilot participants and their informal supporters who meet the final sampling framework criteria, who entered the pilot before the evaluation began and agree to participate. The evaluators will provide instructions to the service provider for an invitation for participation from the Department, including how to select participants who meet the sampling criteria and make an initial approach with the Department invitation from the service provider or other trusted person to explain the consequences of participating in the evaluation and to gain voluntary permission for the evaluators to meet them; voluntary consent to participate explained by the evaluator; and continuous opportunities to withdraw from the evaluation. Respondents will be reimbursed expenses for participating.

Pilot participants and informal supporters will not be personally approached by the researchers. The pilot participants will initially be invited by a trusted person to participate in the research. If the young person or informal supporter gives their initial consent to the trusted person, the contact details will be passed to the researchers to arrange the fieldwork and to gain full consent to participate. Researchers will ask each young adult pilot participants permission before contacting informal supporters to participate in an interview. This 'arm's length' process aims to avoid real or perceived coercion by the researchers.

Qualitative program data

The evaluation will also analyse qualitative program data about participants who permit the analysis of their de identified data. This will include information collected by community consultants (case managers) throughout the planning and goal setting stage and later ongoing support provision (eg. case planning resource output). Some examples include information from the Participants Planning Tool, Participants Story, or Tracking Sheet.

Program observation

While conducting interviews with key stakeholders, managers and service providers of the two NGO's, the research team will spend time in each of the two fieldwork sites (Brisbane and Sunshine Coast) to explore how the program operates in specific contexts. Also researchers will collect observation data during the interviews with pilot participants and their informal supporters.

Participant observation is a method that has been used in previous research on community and health care service delivery (Fudge et al. 2008: 314). It involves the researchers observing how the service system and partnerships are working (across the individual stages of the pilot and as a whole program) and taking detailed notes about their impressions. The benefit of this approach is that it provides researchers with a richer understanding of the service delivery context and provides an additional source of data which can be triangulated with other data sources. For example, program observation data can be contrasted with what is written in policy documents and procedure manuals with interview data, which can strengthen the overall analysis. Participant observation is an important component of the evaluation as it enables researchers to gain a greater understanding of the factors which can enhance and limit the effectiveness of the pilot program.

Economic evaluation

The evaluation includes a cost analysis to determine whether the pilot provides value for money, positive outcomes for participants relative to costs and viable service program. The evaluators will analyse financial budget and expenditure data provided by the Department and service providers in their quarterly financial and annual reports to examine the costs of the program (including management, establishment, brokerage and administration and participant service costs).

Program costs will be compared to the outcomes. The aim is to compare the goals of the program with its achievements, deciding whether the program is economical in terms of tangible benefits produced by money spent. This will help to understand how effectively the government has achieved its objectives. This component of the evaluation relies on outcome and cost data being available.

The economic analysis will compare the costs with the benefits participants experience a result of the pilot, such as changes in participants' wellbeing (eg. satisfaction with personal relationships, health, self reliance), and social, community and economic participation. These benefits will be compared with either the budgeted or, preferably, the actual expenditure on services, including support and central project management costs.

The cost of the program covers management, operational and community consultant time and expenses and small Self Directed funding packages (\$4,000/per annum). Funding is equally allocated to participants regardless of their assessed or perceived level of support needs. This feature of the model will enable the evaluators to understand under which conditions and for which participants the allocated funding and service model generates the most/least benefits. The evidence from the economic evaluation will be crucial for the development of the Self Directed Support program in the future and similar support models for people with disabilities more broadly.

The next section explores how each of the methods will be analysed in relation to the three sets of research questions.

4 Analysis

Analysis of the data sources will be conducted with the aim of answering each of the sets of evaluation questions as set out in Section 2. The three key research questions are:

1. To what extent has the initiative met its objectives for the participants and their informal supports?
2. How effective is the model in meeting its key objectives, self directed support, community inclusion, and early intervention?
3. What are the costs and benefits of the pilot?

4.1 Participant outcomes

A key objective of the evaluation is to analyse the effectiveness of the program for individual participants. The data for this analysis will be drawn from program data for all the pilot participants and interviews with young adults with disabilities and their informal supporters.

The evaluation will analyse baseline data in order to compare change over time across a number of key outcomes for the pilot, including personal wellbeing, satisfaction with social relationships, and social and community participation. Outcomes data analysis will test the hypothesis that participation in the pilot:

- Improves participant's social, community and economic participation;
- Enhances individuals' independence and families' resilience; and
- Generates long-term community connections and networks with lasting benefits to pilot participants.

The pilot population group Personal Wellbeing Index data will be compared to normative data from comparable population groups.

In addition, fieldwork data collected through interviews with pilot participants and their informal supporters will be analysed to report on participant experiences, perceptions of the support model, and individual outcomes. Interview transcripts will be analysed in accordance with the evaluation questions concerned with whether the program has met its objectives for individual participants. As with the stakeholder interview transcripts, participant interviews transcripts will also be analysed.

4.2 Policy and service system analysis

An important aim of the evaluation is to assess the effectiveness of the pilot support model. It involves analysing the strengths and weakness of the pilot model, the partnership and governance arrangements. The evaluation will also consider issues such as the flexibility and responsiveness of the model to meet individuals' needs and wants; whether it supports self directed decision making and control over allocated funding; and the extent to which it builds on participants' and communities' strengths and capabilities. It will also examine how the model fits into the wider service system.

The main sources of data used to address this component of the evaluation are interviews with key stakeholders, program observation and program document analysis. The interviews will be analysed thematically from the interview notes and recordings in accordance with the evaluation questions about effectiveness of the pilot support model.

4.3 Economic analysis

Economic analysis will assess the cost of the pilot against the outcomes experienced by the pilot participants. These costs will be analysed in terms of total program cost and unit cost per participant. Outcomes that cannot be easily quantified will be discussed in general terms in relation to the unit cost of the pilot services.

5 Project Management

5.1 Deliverables

A timeline of deliverables is below. The content of these deliverables will be as specified in the tender brief and finalised in the Phase 1 design.

Table 5.1: Deliverables and timeframe

Item	Deliverable	Date due
1	Written Project Plan	July 2010
2	First written Progress Report and presentation	3 December 2010
3	Second written Progress Report and presentation	1 September 2011
4	Draft Final Report	22 February 2012
5	Final Report, Summary of Findings and presentation	22 March 2012

The evaluation will take a formative evaluation approach, where the progressive results of the evaluation are fed back into the pilot to improve quality management of the project.

All deliverables will be presented in draft to receive comment, amended and a final version agreed. Drafts will be discussed with the Departmental and Evidence Group, before Departmental approved public versions and summaries are made available to pilot participants and other interested people. Public summaries will enhance the quality of the research relationships, elicit feedback as another source of evaluation data and to contribute to the formative evaluation approach.

With the agreement and permission of the Department, the progressive results will be submitted for national and international publication during the evaluation to contribute to the evidence base on self directed support.

5.2 Evaluation timeframe

The process to fulfil the deliverables will be managed with following the timetable of activities. The timeframe can be adapted in each Phase to accommodate any additional requirements or changes.

Table 5.2: Evaluation activities and timeframe

Phase	Activity	Complete
		2010
Phase 1 Project plan	Sign contract	May
	Meet with Department/ service providers to refine design	June
	Arrange ethics approval UNSW	July
	Submit Evaluation Plan	July
Phase 2 Baseline analysis	Conduct literature review	Jul
	Instrument development and piloting	Aug
	Baseline qualitative data collection	Oct
	Baseline quantitative data collection	Oct
	Analyse baseline qualitative and quantitative data	Nov
	Progress report 1 and presentation	Dec
		2011
Phase 3: Longitudinal analysis	Wave 2 quantitative data collection	Jun
	Wave 2 qualitative data collection	Jun
	Progress report 2 and presentation	Sept
	Wave 3 quantitative data collection	Oct
	Analyse financial data for cost analysis	Nov
		2012
Phase 4: Final analysis	Analyse qualitative and quantitative data	Jan
	Draft final report	Feb
	Final report and presentation	Mar

5.3 Evaluation team

The evaluation team is described in Table 5.3.

Table 5.3: Evaluation team

Responsibility	Researchers
Chief Investigator	Karen Fisher
Queensland services advice	Lesley Chenoweth
Data collection and analysis	Sally Robinson and Natalie Clements
Research design and policy analysis	Sandra Gendera
Disability services advice	Kristy Muir, Beth Goldblatt

The evaluation team has expert knowledge and experience in empirical research, project management and conducting complex evaluations using conceptual frameworks, longitudinal mixed methods and cost analysis. The team is a group of evaluators, researchers and experts with expertise in disability studies, intellectual disability, social policy, human service delivery and program evaluation. The evaluation team is led by the SPRC, in collaboration with Griffith University and Disability Studies and Research Centre (UNSW).

5.4 Program management

SPRC has detailed project management strategies for evaluation research, including risk management, succession planning, quality assurance and communication. The Chief Investigator, Karen Fisher and the evaluation team members are highly experienced in evaluation management and their collaborative work has successfully delivered Queensland disability research and evaluation projects since 2002.

The SPRC project management procedures meet contractual obligations and project outcomes, including project cost estimates. The project costing process aims to ensure realistic estimates of expenditure and best value for money for the commissioning Department. The evaluators have the experience and capacity to manage the timeframe expected in this project, to ensure completion on time and within budget, and to produce the required outputs in quality, reporting and budgetary terms. The evaluators have the technical skills and experience to complete the project. The contract is a fixed cost project, with the risk borne by the SPRC. The only time delays experienced in past projects with the Queensland government were due to Departmental input or feedback, which the project management is able to accommodate.

Evidence group

The role of the Evidence Group is to provide advice to the research team during all stages of the research process including feedback on interim and final reports. Membership includes representatives from the government. A group of external consumer organisations and service providers will also be convened to inform the evaluation analysis.

5.5 Risk management

Potential risks that may impact on the management of the evaluation and collection of data are summarised in Table 5.4, drawing on the evaluation expertise of the evaluators in other Queensland research and evaluation.

Table 5.4: Preliminary risk management strategy

Risk	Likelihood	Severity	Solution
Poor quality quantitative and administrative data	High	High	Close consultation with Department, service providers and governance groups to identify and manage data quality problems. SPRC staff have experience working with Department data
Failure of service provider to recruit case study sample and complete quantitative data	Medium	High	Work actively with service providers to maximise participatory methodology and commitment to the project Recompense participants and informal supports Trained researchers will facilitate participation Interview a range of stakeholders to ensure involvement of participants and informal supporters
Data gaps to address the evaluation objectives	Medium	Low	Triangulate data sources to adjust the outcomes, process and cost analysis. Work with the governance groups and Department to maximise triangulated data sources.
Attrition between waves	Low	High	Protocols for follow up between waves and multiple points of communication. Ensure lessons from previous Australian and international evaluations are followed. Replacement sampling will occur if attrition is unavoidable
Poor quality data collection (inter-rater reliability)	Low	High	Use of standardised instruments which have been used in similar studies. Training for service providers and researchers and good QA systems
Psychological distress or other harm caused to participants and informal supports	Low	High	Stringently designed recruitment and interview procedures. Trained interviewers. Follow up and referral where necessary
Research compromised due to lack of capacity	Low	High	The research centres have a wide range of skills which could be drawn on if needed to enhance capacity of team
Poor communication between researchers and the Department	Low	High	Karen Fisher, Lesley Chenoweth and the team have worked very closely with Queensland policy makers
Research 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
Research design does not meet the policy needs of the Department	Low	High	Design, detailed objectives and dissemination strategy has been developed in collaboration with the Department 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

5.6 Ethics

Ethics approval for this evaluation has been sought from The University of New South Wales Human Research Ethics Committee (HREC), which is registered with the National Health and Medical Research Council (NHMRC). The University of New South Wales is committed to the highest standard of integrity in research. All human research activities are governed by the principles outlined in The National Statement on Ethical Conduct in Research Involving Humans. The University's Code of Conduct for the Responsible Practice of Research sets out the obligations by which all University researchers must abide, including confidentiality, freedom to withdraw, privacy and voluntary participation. The SPRC and UNSW HREC have agreed processes for prompt ethics approval because we conduct many government commissioned disability evaluations within restricted timeframes.

Prior to participation in the research, all participants will be provided with clear, accessible information about participating in the research, voluntary consent to participate (with continuous opportunities to withdraw from the research), respect for individuals' rights and dignity, reimbursement for participation expenses and confidentiality. Participants will also be informed that they can decide at any time to withdraw from the study by revoking their consent. Informed consent will be obtained from pilot participants and informal supporters to participate in interviews and access named administrative data collected by the service providers. Permission to interview pilot participants' informal supporters will also be requested from young adults with disabilities taking part in the pilot.

An easy English version of the information statements and consent forms has been developed. A protocol for developing an ethical research environment and responding to participant risk will be designed before fieldwork begins. If participants agree, responses will be recorded for accuracy and transcription. All identifiable data will be de-identified in any publications resulting from this evaluation. Data from this research will be kept in secure storage at the SPRC, viewed only by the evaluation team for the purpose of the evaluation and destroyed after seven years.

The research team have extensive experience in conducting research with people with physical and intellectual disability. Researchers responsible for carrying out the fieldwork component of the study have undertaken research with children, young people and adults with disabilities and families and service providers.

5.7 Communication plan

Details of the framework for engaging and working collaboratively with participants and families, services, government and nongovernment service providers and other relevant stakeholders involved in the Self Directed Support pilot are summarised in Table 5.5.

Table 5.5: Communication strategy

Communication to	Form	Frequency
Project manager, governance groups, Department, service providers	Written reports, meetings, phone, email, presentations and ad hoc participation in pilot management meetings	Start and finish of each Phase and as required
Participants and informal supporters	With permission of the Department, written summaries of plan and progress inviting input distributed through service provider	Start and finish of each Phase and as required, after approval
Other interested persons or organisations	With permission of the Department, written summaries of plan and progress inviting input on SPRC website and elsewhere as agreed with Department	After each Phase after approval

Critical stages of engagement and collaboration will involve confirming the research methods and tools with the Department in the initial stage of the project. Meetings with the Project Manager to discuss an overview of the project, the context, and schedule meetings with the Project Manager and Working Group, to ensure a common understanding of the requirements of the project, coordinate the project design and discuss the draft methodology. Throughout the project, we will liaise regularly with the Project Manager to design a methodology and analysis that addresses the needs of the Department.

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