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

Baseline report

Sandra Gendera, Karen R. Fisher, Sally Robinson, Natalie Clements and Christine Eastman

Social Policy Research Centre, UNSW

Karen Fisher, Sandra Gendera, Christine Eastman

Griffith University

Lesley Chenoweth, Sally Robinson, Natalie Clements

Authors

Sandra Gendera, Karen R. Fisher, Sally Robinson, Natalie Clements and Christine Eastman

Contact for follow up

Karen Fisher, Social Policy Research Centre, University of New South Wales, Sydney NSW 2052, ph: (02) 9385 7800 or email: karen.fisher@unsw.edu.au.

Acknowledgements

Suggested citation

Contents

List of tables and figures

Abbreviations

ABIOS	Acquired Brain Injury Outreach Service
ABI	Acquired Brain Injury
ADHD	Attention Deficit Hyperactivity Disorder
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). This baseline report provides early findings about the outcomes for participants and their families, implementation of the pilot the process and cost analysis. It also draws together arising questions for the pilot and implications for future development of the program.

Background

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 access to case management and control over their allocated funding, the program allows them to be their own agents of change (Department of Communities, 2010: 7).

The Queensland Department of Communities selected two service providers from a negotiated tender process to implement the Self Directed Support pilot. One is the Sunshine Coast Children's Therapy Centre (SCCTC), which supports young children (0-6 years) with physical disabilities and their family carers and significant others informal supporters. SCCTC has one full-time services coordinator. The second is the Acquired Brain Injury Outreach Service (ABIOS) in Brisbane, which supports young adults (20-35 years) with acquired brain injury and physical disability. All ABIOS case managers (ten) have incorporated the self directed support function into their other responsibilities.

The two providers are funded $240,000 per year for two years to deliver services under the 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 per year, including self directed budgets of up to $4000 per participant.

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?

Analysis from the baseline information is tentative because some data sources and comparative longitudinal data are not yet available. Information was available about

49 participants (23 in SCCTC and 26 in ABIOS). The baseline analysis raises questions to follow up in the remainder of the evaluation.

Preliminary outcomes findings

It is clear that flexibility, planning and coordination of a person's needs, a person centred service delivery approach, and empowerment are central to the successful implementation of the program.

The baseline interviews with families of young people and service providers reveals that already the program is achieving its goals of improving wellbeing, independence, resilience and social participation. Longer term observations will be needed to analyse the impact of the program on community connections for sustainable support and economic participation for young adults and families. Information about who is not benefiting from the program will also be important to analyse as the program progresses.

Preliminary process findings

Lessons from the SCCTC support model

The SCCTC services coordinator role works well supporting families to identify a range of available support and prioritising how to best meet their agreed goals. The role does not have sufficient time to develop partnerships and networks fully. The isolation of the services coordinator from the rest of the Centre's activities means that she can focus on the needs of this particular group of families, but it may also limit the potential of the program. For example, other SCCTC staff are also key partners who could provide linkages, peer review, support, and are critical to professional peer development.

Overall the planning process works well and requires great sensitivity in the approach, especially for families who are still adjusting to understanding their child's needs. Parents want to be seen as experts of their child's support needs and be able to make informed decisions about how to best address these. The planning process and the provision of information empower family members and carers to take charge of their situation, and to actively seek out resources and information related to meeting their child's needs. The families are able to more effectively engage with other service providers as a result of this process. The coordination of individual support identified by the families appears to have had a high degree of success in outcomes for children taking part in the pilot – families have reported rapid improvements in their child's development, as discussed further in Section 3.

The program is likely to be even more effective once partnerships have been fully established, for example, when the local paediatricians and local GPs are fully aware and understand the benefits of the program, so that children can be referred for support as soon as the developmental delay is identified. Some restrictions from the current program design are the limited funding allocation, in particular, for children with higher support needs, and the exclusion of some groups of children from the program, such as children aged older than six years and children without physical disability and diagnosed with an intellectual disability or behavioural problems.

Lessons from the ABIOS support model

For young adults in the pilot, ABIOS case managers see that having access to resources to implement the plans is a key success for the pilot. Some of the young adults have been engaged with the service system for a long time but with only limited success. The new opportunities that are now possible with funds to purchase education and personal development, equipment and activities are highly meaningful and motivating. The case management has enabled facilitated decision making to set immediate goals that can eventually lead to larger long term goals.

The financial rules for funding expenditure through a government health organisation are restricting the effectiveness of the pilot. The rules preclude participants from purchasing and being reimbursed for small items, are slow and cumbersome and result in delays to purchasing equipment and resources, and waste a substantial amount of worker and manager time.

The stepped approach to goal development which case managers describe for people with impaired decision-making capacity provides, at its best, a supported and facilitated process of personal development for participants. There is a risk that if goals are not developed explicitly by participants, they may not meet their agenda for self-direction. The evidence from the program manager and case managers is that they maintain consistency in the pilot approach and use a process of regular peer review through the case conference to ensure individual case managers justify that goals meet the principles of the program. The views of the young adults and those who support them will be analysed in future evaluation reports to verify their experiences.

Children and young adults most and least likely to benefit from this model of support

According to service providers delivering the pilot, the support model is most useful for young adults, children and their families who previously had limited contact and were unaware of available support services.

The families of young children who have a good understanding of children's developmental needs and what support services could meet these needs, and the confidence to speak up and negotiate the service system benefit quickest.

In addition, families struggling to meet their children's needs also benefit greatly from the program, specifically from the planning, coordination, and information provision that the services coordinator role provides. Some of these families may find it difficult to make the best use of the funding allocation, because they may not have the capacity to understand, follow up or go to the numerous practitioners or support services from which their child could benefit. However, the assistance has been beneficial for child and family wellbeing and resilience for these families too. The funding allocation is not sufficient for children with higher support needs who are waiting for access to other free or subsidised support services.

The view of workers supporting the young adults is that young adults who already have established goals, or who are self-directed, are more likely to benefit quickly from the pilot. Some young adults also quickly benefit from gains to their self-esteem, if they have had a previous background of marginalisation, and so the experience of expending individual funds is in contrast novel and rewarding.

Some early evidence shows that the ABIOS pilot may have some cultural benefits. Workers reported on outcomes for participants from CALD backgrounds who were able to access non-traditional support and resources which worked very effectively for them. This will be analysed in the next report.

There is some concern among the ABIOS workers that some people might not be benefiting or are excluded from the pilot. In particular people with acquired brain injury who have acquired the impairment within the last five years (and thus fall within the ABI early intervention criteria), but who fall outside the chronological age range for the program, are ineligible for the pilot. ABIOS case managers frequently expressed their frustration that people above the 35 years were excluded although they were likely to benefit greatly from access to the program.

Future development of the program

While the pilot and the evaluation is still in its early stages of implementation, there is emerging evidence that the program is at this point achieving its process objectives: empowerment of service users and their families to identify their needs, set personal goals and make informed decisions about the support they need. The pilot, designed as an early intervention approach, is reaching its main target groups – children showing early signs of additional support needs, young adults with physical disability, and their families and informal supports, previously excluded or not accessing more formal support. The preliminary analysis has also identified a number of questions about possible limitations and challenges to this model of support.

Immediate questions

Some workers and participants are unclear and need guidance about exit processes, such as funding and participation beyond a 12-month period. In ABIOS, because some young adults are already ABIOS clients, some workers are unsure whether to commence planning and then introduce the SDS pilot, or introduce the pilot first, then start planning with the funding in mind.

Some ABIOS workers thought that to address the young adults' lack of experience with planning and decision making where resources are available, training resources for participants and families to support learning in this area may be helpful, prior to formal planning.

Workers identified the importance of supervision, peer support, interaction with other workers within their agency, and strategies for culturally appropriate ways to engage families from non-English speaking and Indigenous backgrounds.

ABIOS workers said they need further development and training about case management processes to manage risk for young adults' needs, in a new climate where people are encouraged to make a far broader range and scope of personal decisions.

The administrative processes to comply with financial accountability, planning processes and evaluation are a high cost to the organisations.

Longer term program design

Opportunities for expanding the program include:

- Avoiding terminology such as 'disability' to include families who do not identify with the category or may not have a diagnosed disability;

- Extending the program beyond physical disability and six years of age, to include children with mental health disorders, learning difficulties, and challenging behaviours, up to ten years of age;

- For young adults, revising eligibility to length of time since acquiring impairment, rather than chronological age;

- Promotional material to explain the program in a way that is attractive and understandable for young adults and families of young children.

SCCTC workers suggested that enhancement of the community development and capacity building aspects of the pilot would be important, for example, by introducing peer-to-peer support groups (eg. playgroups) for children, their families and carers. Such a platform could provide on-going support and community integration for participants, and serve as link for providers to provide information and pathways into support services.

Economic implications for program and evaluation

The providers have operated within budget for the first 6 months of the program. They reported that they have absorbed a lot of management costs into their other operations because of the high administrative responsibilities of establishing a new program. The self directed funding allocation has also operated within budget. The families of young children have generally spent the funds on weekly fees for therapies and related equipment. The young adults in contrast have paid for equipment or study fees to facilitate immediate access to social, community and economic activity.

The baseline qualitative data shows that young children, their families and young adults are benefiting from case management, planning and a small budget to assist with organising the support they need to fulfil their goals. Preliminary benefits for the participants and their families are evident including wellbeing, independence and resilience; and community, social and economic participation. Initial information and contact with community services and informal networks is beginning for some families and young adults, but with the support of the case workers, this benefit is taking longer to experience than the others.

1 Introduction

In 2009 the Disability and Community Care Services, Department of Communities launched the Self Directed Support – Community Inclusion Pilot (pilot). The pilot is funded through the Queensland Government's Prevention and Early Intervention pool. A total of $1.06 million has been allocated to implement and evaluate the pilot over a two year period until the end of 2011 (Department of Communities, 2010). 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 (see 2.1 for a more detailed overview of program objectives).

In 2010 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 was contracted by the Department of Communities to undertake the evaluation of the pilot. The evaluation is from June 2010 to March 2012 and looks at the outcomes, process and costs of the pilot to inform future service development.

1.1 Evaluation method

The longitudinal, mixed method evaluation design measures longitudinal outcomes for children and young adults with physical disabilities, their families and informal support; 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. Appendix A is a summary of the evaluation and the full evaluation plan is available at Gendera et al. (2010). For this report the following datasets were available.

Program data

The two service provider agencies, contracted to implement the pilot, provided quantitative administrative data for this baseline report covering the period between January and June 2010. The quantitative data comprises two sources of information: extract from the National Minimum Dataset (MDS) which includes basic demographic information (Section 2.4) and the number of case management hours provided to pilot participants (Table 4.1); and program data which tracks the identified needs and support types used by participants (Table 4.2). This data source also includes key dates and some basic budgetary information.

Most of the quantitative data used in this report is of a primarily descriptive nature. In the report we group the information into categories where possible. In some cases, a participant with tracking information could not be matched to service usage data, and some participants had no information available. Budget information is calculated using average costs per service and per hour[1].

Table 1.1 shows participant numbers and data provided for each of the two pilot groups until June 2010.

---

[1] See Section 5 for additional information about budget calculations

Table 1.1 Baseline administrative data, group sizes

Number of participants	Children 0-6 years	Young adults 20-35 years	Total
All participants with program data	23	26	49
Participants with MDS data provided	13	21	34
Source: Program and MDS baseline data for January - June 10			

In the baseline report we primarily use the program data sample to maximise the available data. As noted earlier, some participants listed in the program data do not have corresponding MDS information. The program data indicates that 23 children and 26 young adults had made contact with the service agencies prior to August 2010, however, only 13 children and 21 young adults had any associated MDS data.[2] For clarity purposes the source of information is indicated under each table. We anticipate that MDS data for all participants will be provided for the second round of data analysis.

Fieldwork data

For this baseline report participant interview data was only available from informal support (eg. family) of children. In total researchers conducted ten interviews with mainly parents of children with physical and multiple disability. Data of young adults and their informal support was not available and will be included in round two reporting. We also conducted and analysed 10 interviews with service providers and managers, two with SCCTC staff, and eight from ABIOS. For an overview of qualitative data collected by the end of November 2010 refer to Table 1.2.

To ensure an unbiased selection of participants we asked service providers to approach and invite the most recent families who entered the program to participate in the research. In some instances this meant that participants had very short term experience with the program. Consequently, obtaining detailed or in-depth data about their experiences is a challenge. The longitudinal data collection will provide more in-depth information of participants' perceptions of the program.

Another factor impacting on qualitative data collection relates to the sensitivity of the topic. Several families are still adjusting to their child's additional support needs, the families' circumstances, and the interaction with the social and community sector. To ensure participants' well-being and minimise stress, researchers did not use terminology such as disability or in some cases ask follow up questions if parents showed signs of distress.

Little observation data is included in this baseline report. Most families chose not to have their child at the interview, so that the parents would not be interrupted. Children were either asleep, at child care, or school when interviews were conducted. Additionally, most parents are time poor, juggling appointments for their child with part-time work, and caring for other children in the family which can limit participant's ability to fully engage with the research.

---

[2] This is because the MDS reflects the previous reporting quarter and not actual number at time of analysis.

Table 1.2: Longitudinal qualitative interviews (September-November 2010)

	Children 0-6 years	Young adults 20-35 years	Total
Pilot participants	-	8	8
Informal support (eg. family)	10	0	10
Service provider staff	1	7	8
Service provider manager	1	1	2
Department staff	-	-	-

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

As noted above, the baseline qualitative data collection is currently on going. The full qualitative longitudinal sample will include at least ten young adult pilot participants, 14 informal supporters of children and young adults, six service provider staff and two managers, and three Department officials (see Appendix A Evaluation Methodology for an overview of proposed samples).

2 Program and support model description

2.1 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 program 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 support with their local communities by creating opportunities for meaningful engagement and participation is regarded as a key to individuals' wellbeing and increased resilience. The program 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).

2.2 Roles and responsibilities of the Self Directed Support Pilot partners

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

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.

Governance arrangements between the NGOs and the Department seem productive and providers raised no issues of concern. The relationship appears to have benefitted from the early developmental work of the Department in establishing the model, provision of trainings and tools for planning and tracking participants' progress. Providers particularly appreciate the freedom to adapt the tools to the specific client requirements.

The effectiveness of the governance arrangements will be examined in the later stages of the evaluation.

2.3 Service delivery and service model

The Queensland Department of Communities selected two service providers from a negotiated tender process to implement the Self Directed Support pilot. One is the Sunshine Coast Children's Therapy Centre (SCCTC) located in the Sunshine Coast, which support young children (0-6 years) with physical disabilities and their family carers and significant others. The second is the Acquired Brain Injury Outreach Service (ABIOS) in Brisbane, which support young adults (20-35 years) with acquired brain injury and physical disability.

The two NGOs are funded $240,000 per year for two years to deliver services under the 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, designed by the Department and Sanderson and Associates, outlines the program delivery. 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 June 2010 the providers established their operational systems and marketed the program in the community. By August 2010 SCCTC had recruited and supported 23 children and their families, and ABIOS was working with 26 young adults and their informal support. At the time of the ABIOS interviews in November 2010, 32 young adults were engaged.

SCCTC service model

The SCCTC employs an experienced services coordinator, trained in social work, on a part-time basis to case manage families and contribute to wider community development (eg. organise play groups to enhance peer support for children, family members and other informal support). The services coordinator is also in charge of promoting the pilot (eg. development of social marketing tools) and recruiting eligible families from a wide range of backgrounds, including Indigenous and CALD communities.

Children and their families are referred to SCCTC from a range of community and allied health agencies, including GP's, paediatricians, and Disability services. Families can also self-refer. The range of referral sources are a result of the services coordinator's promotional activities. Once a family with a child with additional

support needs have been referred to the SCCTC they are assessed for their eligibility to take part in the pilot. The eligibility criteria are: children aged 0-6 years with a physical disability; not receiving other Disability Services; and living in the Sunshine Coast area. Families are either accepted to the pilot, or referred on to other more appropriate services. Accepted families arrange a first planning session with the services coordinator, in most cases a home-visit. During this initial planning phase the family discusses and identifies their child's and/or the families' support needs. They also receive information and advice about a range of available support and how to best prioritise their needs and wants. When the family decides on a specific approach, the services coordinator assists them to access the relevant support they need. Part of this role is to coordinate a number of service providers, where necessary. The planning process and allocation of funding is reviewed every three months.

The SCCTC approach is to first meet the immediate support needs of the pilot participants. Then the aim is to assist families to identify and enhance existing and new informal community support and networks, to strengthen families' and persons' independence and self reliance. The aim of this second step is to build more long term support networks for pilot participants, beyond their direct involvement in the program and after the disbursement of allocated funding. A question for the evaluation will be to observe whether this expectation is achievable.

ABIOS service model

Young adults, aged 20-35 years, with acquired brain injury (ABI) and physical disability, receive support to take up the Self Directed Support pilot through ABIOS. ABIOS is a government service, funded by Queensland Health to provide specialist community-based rehabilitation to enhance the service system for people with ABI and their families.

The pilot is managed by the ABIOS Manager, supported by a project coordination role carried out by a Rehabilitation Coordinator and an ABIOS research and development officer. This management team together shares the responsibility for conceptual development, implementation of the model, approval of expenditure, staff training, and measuring outcomes. The project coordinator has day-to-day operational responsibilities to ensure case conferences and planning meetings run smoothly, while the manager maintains an oversight role and approves expenditure. The program is implemented by a team of ten ABIOS staff – the two managers, who also maintain a case load, and eight Rehabilitation Coordinators (case managers) who work with a small number of pilot participants alongside other clients.

Young adults enter the program through the already established ABIOS referral system, which is concentrated in the health and allied health system (no additional promotion of the pilot is conducted). Once a client has been referred to ABIOS, they are assessed for suitability for the pilot. Eligibility criteria are: aged 20-35 years; have physical disability, not receiving other funded Disability Services. If eligible, they are allocated a case manager, who begins to work with them on planning activities. The aim is to develop a plan prior to the allocation of funds against a goal, or strategies to meet that goal. ABIOS has refined the planning tools provided by the Department, and uses these to structure planning and support activities with the pilot participants. Plans are scheduled for quarterly review. Case managers discuss clients' needs at a team case conference when the person is starting on the program, has significant

planning changes, or has a request for new spending. The case conferences aim to share knowledge, insight and learning about the program.

The planning and spending process becomes iterative for many young adults in the pilot, with urgent needs being met first, and case managers describing the need for major life goals to be broken into consecutive strategies for people to be able to tackle them. Some young adults are already planning to exit the pilot after completing the planning stage and spending their allocated funds. Other clients are working with case managers on goals which focus on being included in their community in a way that is motivating and personally engaging.

2.4   Participant characteristics and target groups

In this section we provide an analysis of available demographic information about the two groups using the pilot and assess the extent to which the program is reaching its designated target groups and possible limitations.

Characteristics of the pilot participants

Limited demographic information is available about the pilot participants. For the children group, the average age of the participants on entry to the program is three years, with the youngest child six months old and the eldest child six years old. The children range in age, with ten children aged younger than two years old, and another nine children aged five or over. More boys than girls are in the program (63 per cent).

The ages of the young adults group on entry into the program ranges between 20 and 35 years, with the majority of participants in the 25-29 age bracket, and the average age of the participants being just under 27 years. Most of the participants in the young adults group are men, with only five women out of the 26 participants (19 per cent). The gender distribution is consistent with the incidence of acquired brain injury among 15-24 year olds (O'Connor and Cripps, 2000, p.12-13).

Table 2.1 Characteristics of pilot participants, June 2010

	Children		Young adults	
All	23		26	
Age				
Age range (years)	0.5 - 6		20 - 35	
Average age (years)	3		27	
Gender	Number	Per cent	Number	Per cent
Males	10	62.5	21	80.7
Females	6	37.5	5	19.2
Valid responses	16	100.0	26	100.0

Source: Program and MDS baseline data January - June 2010
Note: Children: Valid N 16/23 Young adults: Valid N 26/26, some participants were unable to be matched to demographic data.

Target groups

In the case of children, the program is reaching its early intervention target group. Specifically families with children aged 0-2, or 4-6, where the child's developmental delays and additional support needs have been identified by a professional, but are

less severe and rarely diagnosed. Most families prior to the pilot were not using or aware of other support funded by the Department, with some exceptions. Some families are on long waiting lists for the Cerebral Palsy League and similar support services.

Children who have not been reached so far are from Indigenous and CALD families. SCCTC explains this as due to a shortage of time in the services coordinator's role for networking and promotion of the program. The SCCTC services coordinator is designing strategies to reach out to these groups, including networking with Indigenous-specific and CALD-specific agencies.

Some children and their families who could benefit from the type of support offered by the pilot are excluded because they do not meet the eligibility criteria. For example, children with more severe developmental delays are excluded because they do not have a mild or moderate physical disability, even though some of these children are not receiving other government funded support. Other children with intellectual or behavioural developmental delays (eg. autism or ADHD) are excluded if they do not have a physical disability.

In the case of the young adults with physical disability, the program is reaching some of the target group. ABIOS was funded to provide the pilot to young adults with both acquired brain injury and physical disability. Hence, all participants in the pilot have multiple impairments. The young adults come from a range of geographic areas within the bounds of the pilot area, and a range of socio-economic and cultural and ethnic backgrounds. As at November 2010, young adults in the pilot have only been recruited through the ABIOS' general referral stream. The pilot has not been promoted to the wider community to attract other young people with disability. ABIOS services are promoted through a website, service provider training, publication, research and specific strategies for Indigenous and CALD communities. The implications of this restricted approach will be explored during the evaluation.

ABIOS has raised concerns that the age restriction placed by the pilot (20-35 years) may not be appropriate to meet the pilot's aims of early intervention for this group. It excludes other younger and older people with acquired brain injury, who could benefit from the program. ABIOS suggested revising eligibility guidelines to proximity to the time acquiring the impairment, rather than chronological age.

3 Outcomes for children, young people and families

A key objective of the evaluation is to analyse the outcomes and effectiveness of the pilot program for individual participants and their informal supporters. In this section we analyse the extent to which the pilot has achieved outcomes in the following three key domains:

- Enhanced individuals' independence and families' resilience;

- Improved participant's social, community and economic participation; and

- Generated long-term community connections and networks with lasting benefits to pilot participants and their informal supporters.

The data for this analysis is from program data for all the pilot participants to June 2010 and interviews with family members and carers of young children using the pilot (Section 3). Interview data from young adults and their informal supporters were not available at time of writing and will be included in the next report. Personal Wellbeing Index data from the pilot population group will also be included in the next report.

3.1 Enhancing participants' independence and families' resilience

Wellbeing, independence and resilience of children and families

Family members and carers of young children reported improved child and family members wellbeing, independence and resilience due to participating in the pilot.

Young children

Most of the young children in the pilot had only begun to show signs of additional support needs and their needs were usually classified as mild to moderate. For this early intervention group, parents reported frequently seeing rapid changes in their child's self esteem and self reliance as their motor skills and abilities improved. For example, when they entered the program some children could not walk, sit upright, or hold their head up. In some cases, children, after receiving a few weeks or months of intensive therapy and use of equipment, are able to progress to sitting, standing or walking. This progress has allowed them to start to move on to other development milestones and enabled them to become more independent.

Family members and informal supporters consistently linked transformations in the children's development to their involvement in the pilot, from the regular contact with specialists, individualised therapies and equipment, and overall support provided through the services coordinator. Parents said,

> It's been great, it really is intensive early intervention [our daughter is receiving] speech therapy, private physio, music therapy, orthodics, makaton resources, and a walking trolley ... The change in her motor development and coordination have been dramatic ... [they] are clearly the result of the intensive therapy and the orthodics, which are great.

> [Our son] loves to be independent, and the physio and OT have just been great for him!

Informal supporters

The parents said they also experienced immediate reduction in psychological, emotional stress and their sense of isolation. Most parents reported feeling a sense of hope from seeing rapid improvements in their child's development and wellbeing from the support received through the program. They found the provision of information and coordination of support through the services coordinator very useful. One family said,

> It's like all of a sudden we can see the light, and it's been a huge relief. It's just taken the pressure off us. I mean, private health insurance just doesn't cover much.

The support model is also enhancing family members' and informal supporters' independence by strengthening their sense of self esteem and self reliance as carers. The program is enabling parents and carers to be experts on their child's needs and wellbeing, so they can actively seek out options for their child. As a result some family members expressed increased confidence in their caring role. In one case a mother's confidence was raised through regular contact with practitioners who gave her practical advice and showed her specific techniques how to support her child's development. She said,

> [Our son has] definitely benefited. And I think it's because ... when you have a week to week appointment, you [as a parent] have the space and time to do specific things with [your child], that gets the results. And you've got someone to check in with, if [your child is] not doing so well.

The flexibility of the pilot is also contributing to family members' independence, because they are able to use support and purchase items depending on their child's and the family's needs. A parent said,

> There is that flexibility, to use [the money] how you want to. [without the money] it's very difficult when you already have a host of other appointments, where you have to do something that's fixed in a certain way.

Several families mentioned that participating in the pilot enabled the family to spend more quality time together as a family, '… trying to enjoy the children and trying to spend as much time with them as you can'. They felt that having the time and resources to spend as a family was an important factor strengthening family relationships and contributing to their family's resilience. This finding is consistent with child disability and family resilience literature (Muir et al, 2009).

According to the ABIOS workers, for young adults participating in the pilot, being able to implement goals, through having the resources to put plans into action is a key outcome to date. The funding enabled some existing ABIOS clients, who had goals and plans in place prior to participating in the pilot, to finally realise their goals. Case managers reported an example of a young adult saying 'I used to have that goal, but had to abandon it, because I couldn't afford it on the pension'. Now they could purchase the equipment or enrol in TAFE courses and have their needs met. The person-centred and flexible approach allowed them to move on with their life. Most

workers mentioned the empowerment, satisfaction, mental health and wellbeing improvement of many young adults in the pilot, and viewed the pilot as having positive effects on their self esteem. The views of young adults and their informal supporters about the benefits will be analysed in the next report.

Empowerment and coordination

The model is based on person-centred service delivery to maximise responsiveness to the person's needs, coordinate their support and to empower the person and their family to take responsibility in relation to their support needs and other aspects of their life.

Overwhelmingly family members of young children experienced the support received as strongly empowering. They particularly appreciated being recognised as experts in their children's care. They viewed receiving information and direction about available support during the planning stage as critical to assisting them to make informed decisions. One family said, 'We knew what we needed ... and [the services coordinator] helped us to work out what to get done.' Participants perceived working in partnership with a committed services coordinator as the key to negotiating complex service environments and to help them prioritise their identified needs. As noted in Section 4.3, they also highly valued the flexibility of the pilot to pay for a wide-range of identified needs, depending on the child's and families changing support requirements. Families said,

> I just want to say thanks to the government for this program. The flexibility of it is fantastic! As I said before, it opens your options up in helping your child, apart from just seeing specialists.

> [It] is good that you know that there is a pot of money that you can review ... and we weren't stuck into some kind of program that worked a few weeks ago, but isn't now, and that it can be dynamic.

While families have a good understanding of what they need and want, they said they often lack understanding about the range of available resources and support available, or lack means to purchase them. In many cases the participants described the overall service system as disjointed and impersonal, making it difficult for families to negotiate their service pathways. Their confusion is aggravated when they are in the process of learning about the additional support needs of their child, which can, for some families, be loaded with anxieties and insecurity. Hence, many families said that receiving personalised assistance through the pilot and having someone 'who listens and understands' is as critical as the access to support itself. They said it is only through the assistance of the services coordinator that they feel empowered, informed and emotionally supported to access what they need. Parents said,

> [The services coordinator is] really willing to help, to do anything that she can, which to me is so satisfying after seeing quite a few years of not having anyone wanting to help or listen.

> As I said [the pilot] was just a breather for us to have someone who understood, someone who knew the sort of difficulties that we were facing. Because [my child's needs are] not as severe ... It's still

> constantly a thing on your mind of how are we going to physically,
> financially and emotionally manage this?

A further key to person-centred service delivery is that all professionals work together and coordinate their activities, where appropriate, to meet a person's needs. The strengths of such professional partnerships mean better and more rapid outcomes, in this case, for the young children's development. In several cases, family members reported that the coordinated team approach had allowed professionals to draw in extra resources to meet their child's needs without having to rely on the person's funding allocation. A parent said,

> The main positives [of the pilot] are the support that [the services coordinator] gives, as well as the planning process, also the fact that all the therapists that we see are working together around [our daughter's] needs. The team approach is much more effective.

In the case of young adults with acquired brain injury with higher support needs participating in the pilot, person-centred service delivery is perhaps even more important. The following case study reported by a case manager highlights this point,

> A participant who used to work as a tradesman before he acquired his brain injury has as his goal to return to work. Due to the severity of his injury, this is a very long term goal. His case manager, after much research of possible options, suggested a local men's shed which was opening soon as a starting point. His mum was not keen. While waiting for the men's shed to be built, the case manager linked the young adult in with a support worker to go to the gym. They have recently decided to do a couple more things together during the week, as the two young men have hit it off. It's likely that this man is going to need support once the pilot finishes. Accordingly, his case manager has applied for carer respite funding, so his mum can continue to employ his support worker at the end of the pilot and he can continue to go out and cement the connections he is currently making with his support worker.

The views of young adults about empowerment and coordination will be included in the next evaluation report.

3.2   Social, community and economic participation

The program has improved the social, community and economic participation of the young children, young adults and their family members, including parents and siblings.

As noted above, young children participating in the pilot have made substantial improvements in their motor skills and development, which enhances their social connections in their families and communities (eg. play with other siblings, interaction with peers). A family said,

> We've been put in touch with a private physio through the program, and she is quite dynamic ... just in the two sessions so far ... he was

> doing things that he hadn't been before ... you just need that regular kind of contact.

The parents of young children consistently report high levels of satisfaction and rapid outcomes for the child's development when professionals work together around their child's care and needs. The individualised nature of the support provided through the pilot is enabling some of the children of school age to more actively take part in activities at school. A parent said,

> [My son is] able to take part more in the classroom because of the OT coming to the school to do assessments and that. [These positive outcomes are happening] because of the support from [the services coordinator], and also because the OT and physio are working together.

Family members of young children noted that the program is providing them with access to a range of community support – in particular to specialist services and resources as well as equipment – from which they would have remained excluded otherwise. They view the assistance provided as critical to enabling the families' and children's involvement with their communities (eg. specialised adaptations to enhance children's school participation). Some of the parents reported that they are now able to pay for social and community activities for their other children, such as swimming lessons.

However, in several cases, where mothers are the primary carers of young children, they have given up work or decreased work hours to meet the children's additional support needs. Added to this, in many cases the primary carers are ineligible for assistance from Centrelink, such as carers allowance or carers benefit, because the child does not have a diagnosis. While the pilot addresses the affordability of their children's support needs, it does not resolve the economic complexities families are facing. The incompatible challenges of remaining highly flexible in their caring role, paying for disability related costs and remaining in a labour market that demands full commitment and long-working hours, add irresolvable pressure to families' budgets and overall resilience. A parent said,

> And that's where I get really frustrated with the Government. How do you expect parents to survive and be able to be good parents at the same time, and not have fights with each other? They really don't understand.

For this group of young children and their families, community inclusion outcomes are mainly of an indirect nature: highly important care and equipment support children's positive development and wellbeing, which contributes to families' resilience and positive family relationships, such as primary carers having more time for their other children. For example, one family that was in a critical stage when they entered the pilot, has avoided entering a crisis and becoming socially excluded because the coordinated referrals and support received prevented their need to sell their home to pay for their child's specialised therapies.

For young adults participating in the pilot, the social, community participation outcomes are more direct and tangible. Many participants have signed up to TAFE

courses or other professional and personal development opportunities (eg. participation in physical exercise programs, development of photography skills; Table 4.2). All these activities and pursuits improve the young person's social and community participation and possibly also contribute to their enhanced economic participation in the long term.

3.3 Community connections and networks

One of the pilot's objectives is to enhance and connect participants to informal forms of support beyond the involvement in the program. The majority of the families of young children have had limited if any prior contact with the social service sector before getting involved with the pilot. Many parents are interested in exploring existing networks and resources once they commence the planning process. And most families are on waiting lists for more on-going support.

Due to the delayed start and recruitment of families of young children into the pilot, longer-term community inclusion and identification of informal support appears to have only just commenced for some families. In the early stages of the pilot families have prioritised meeting their children's immediate support needs (eg. access to specialised services and therapies) over identifying additional forms of informal/community support.

Only a small number of families reported exploring informal community connections which can provide additional support and potentially enhance families' resilience. Furthermore it appears that families' understanding of the pilot program mainly revolves around the individual funding allocation and to a much lesser extent on building and enhancing informal networks of support. It therefore remains to be seen the extent to which the pilot program can achieve its aim of strengthening families' existing and new community networks.

Also for young adults in the pilot long term community connections are not necessarily a key outcome of the program, and in some cases less evident. The 'stepped' nature of some of the goals being set with young adults means that some of the activities and resources are not directly engaged in developing community inclusion. It is clear, however, that the ABIOS operational framework requires case managers to justify any goals which do not have a clear community inclusion focus, and detail how they build towards community interaction and inclusion.

Purchasing laptop computers, internet access and other technology is a recurring goal. Workers and management link these purchases to study, brain training and social interaction with family overseas in order to establish community connection. A change in ABIOS' practice links the focus on community inclusion with ease of access to resources. Workers report the process is more efficient. For example, they can truncate processes to assess learning capacity prior to purchase of equipment by focusing on the social and participation gains from the purchase. As one worker noted,

> Maybe they'll go to TAFE, and maybe they'll meet someone, just because they're out there. You know, just because they're out there participating rather than sitting at home by themselves all day long.

Overall at this early stage in the evaluation and implementation of the pilot it is still too early to determine the long-term community outcomes of the Self Directed Support pilot.

3.4   Outcomes implications for program and evaluation

It is clear that flexibility, planning and coordination of a person's needs, a person centred service delivery approach, and empowerment are central to the successful implementation of self directed support programs.

The baseline interviews with families of young people and service providers reveals that already the program is achieving its goals of improving wellbeing, independence, resilience and social participation. Longer term observations will be needed to analyse the impact of the program on community connections for sustainable support and economic participation for young adults and families. Information about who is not benefiting from the program will also be important to analyse.

4 Service use and effectiveness of service delivery processes

An important part of the evaluation is to assess the effectiveness of the pilot support model to discern implications for program changes and improvement. This involves analysing how the program has evolved during the implementation, the strengths and weaknesses of the pilot model, including the partnership and governance arrangements, and responsiveness of the model to meet participants' needs.

In this section we consider the degree of responsiveness of the model to meet pilot participants' needs; the extent to which the model facilitates self directed decision making and control over allocated funding; and the extent to which it builds on participants' and families' strengths and capabilities. We 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 Departmental and service provider program data and MDS data. Interview data from the young adults (20-35 years) in the pilot is not included in this report, due to an ethics approval delay. Their views will be important for future analysis and conclusions about questions arising in this section.

4.1 Service use

The two groups of pilot participants have different needs and use the program in different ways. The following section summarises the MDS and program data about service use from January to June 2010. It summarises the amount of case management they used as well as the different needs identified by each group.

Case management

The hours of case management received ranges from less than an hour to eight hours per week per participant, with a median of two hours per week in the first quarter and 1.5 hours in the second quarter of service for the participants who received two quarters of service (Table 4.1).

Table 4.1 Average hours of case management per participant, January to June 2010

	January to March			April to June		
	Range hours	Median hours	Participants	Range hours	Median hours	Participants
All participants	1 - 8	2.0	35	1 – 6	1.5	14
Children	1 - 8	1.0	14	1 – 4	1.0	4
Young adults	1 - 6	2.0	21	1 – 6	2.0	9

Source: MDS baseline data for January - June 10
Note: Responses less than one hour were rounded up to one hour, some participants were unable to be matched to MDS data.

In the children's group, one participant received eight hours of case management each week in the first quarter of service, however this dropped to less than an hour in the second quarter of service. In the young adults group, two participants received more

case management service hours than most participants. These two participants received six and five hours each week over the two quarters. There were no notes in the program data that indicate why these two participants needed more case management time than other participants, however both have positive outcomes noted in their case files. Case notes for the young adults with lower amounts of case management (e.g one hour per week or less) indicate some problems about contact and communication with participants, for example, participants' not returning calls or meeting appointments. Communication does not appear to be a problem in the children's group according to the program data available.

It seems from this initial information that the case management allocation is responsive to the participants' needs and available. It varies by the amount of time the participant wants and changes over time as their needs change. The implications of the different approaches to allocating case management hours will explored during the evaluation.

Types of support received

The program data indicates that the children and young people receive different types and modes of support. Participants were asked to identify three needs in order of priority. Most participants recorded three needs and some recorded fewer. This appears to be because their needs are more complex or costly than other participants, or that they had not identified all their needs when the program data was provided for analysis. Between the 43 participants with any needs identified and recorded, 107 individual support were identified. Table 4.2 details their support needs in order of priority identified by the participants and their families.

Table 4.2 Needs identified by participants in order of priority, January to June 2010

	Number of participants identifying need in order of priority			Total participants with identified need
	Priority 1	Priority 2	Priority 3	
Children				
Physiotherapy	14	1	0	15
Specialist equipment	1	4	1	6
Speech therapy	0	4	2	6
Podiatry/orthotics	0	3	1	4
Occupational therapy	1	2	0	3
Hydrotherapy	0	1	2	3
Inclusion support service	0	1	2	3
Transport	1	0	1	2
Home modifications	1	0	0	1
Specialist medical treatment	0	1	0	1
Child care	1	0	0	1
Assessment for diagnosis	1	0	0	1
Community/family activity	0	0	4	4
Number of identified needs	20	17	13	
Young adults				
Equipment/fees for community education	3	3	3	9
Sports/fitness/personal training outside home	1	4	2	7
Equipment/fees for formal education	4	2	1	7
Fitness/training/diet at home	3	0	2	5
Public transport assistance	0	3	0	3
Computer/internet for personal use	1	1	0	2
Hydrotherapy	1	0	0	1
Specialist medical treatment	1	0	0	1
Moving expenses	1	0	0	1
Home tutor/parenting program	1	0	0	1
Technology for independence	1	0	0	1
CODA assistance	1	0	0	1
Budgeting, meal planning, cooking	1	0	0	1
Computer/software for work	0	1	0	1
Podiatry/orthotics/shoes	0	1	0	1
School clothes and equipment for child	0	1	0	1
Specialist equipment	0	1	0	1
Rehabilitation to return to work	0	1	0	1
Social activities	0	0	1	1
Swimming lessons	0	0	1	1
Career counsellor	0	0	1	1
Cooking/gardening supplies	0	0	1	1
Equipment for organisational skills	0	0	1	1
Optometry	0	0	1	1
Physiotherapy	0	0	1	1
Speech therapy	0	0	1	1
Number of identified needs	19	18	16	

Source: Program and MDS baseline data for January – June 2010
Notes: Number of participants with at least one need identified: 20 children, 19 young adults. Totals do not represent all participants because three children and seven young adults did not have any needs identified.

As expected, participants – particularly in the young adults group –identified a wide range of support. The most common needs for children and their families are therapies

(physical therapy, physiotherapy, speech or occupational therapy). In some cases these services were already being received by the children and the identified need is to continue with the treatment, when they could not afford to pay for them because they are no longer eligible for free therapy or they could not afford more. In other cases the program enabled the purchase of new therapies. The second most common need is equipment, which is usually related to the therapy received by the child. A small number of children have a third need identified, and these appear to relate more directly to community involvement or family activities.

There are also some commonalities between participants in the young adults group: educational needs is rated a high priority, as well as personal fitness and participation in sporting activities that may contribute to a person's wellbeing and foster community participation. The case managers said that the young people usually nominate purchases that are consistent with the needs, goals and activities of peers of their age, centring on technology, study and goods. Young adults have a wider range of support needs than the children in the pilot. For young adults education and activities are a priority across the group and appear to be linked to increased social and community involvement.

4.2   Participation in organising support

In this section we analyse the extent to which processes in the support model help to empower participants and their informal supports to make decisions about their needs and goals.

In SCCTC, the planning process is used by the services coordinator to empower families, identify options and to provide them with a range of information about resources they can access, either through alternative programs, or by drawing on their funding allocation. Families of children participating in the pilot report that they feel a large degree of control over their allocated funding, and support in the process of setting and prioritising goals. One family said,

> [the services coordinator] is fantastic the way she sits down with you and says, well, this is what we can do for now, until we get the rest of the tests back, and then we can assess that and then we can talk to these people, it's really fantastic.

As most parents are still absorbing the fact that their child has developmental delays, some of them find the planning process confronting and stressful at first. One parent said,

> I was very hesitant, as I was trying to work out what was needed – I began with physio, speech therapy, orthotics, but [the services coordinator] helped us to plan what exactly we needed, and also to prioritise ... The planning process was really confronting for us, but we did find it really helpful in terms of planning and setting goals.

Nevertheless, all families reported that they find it extremely useful and rewarding to identify their challenges, needs, and goals. Most families are actively discussing within the family their options, and taking charge of planning and prioritising (see 3.1 in the outcomes section). The benefits and limitations of this early intervention

approach for families in the early stages of emotional adjustment will be examined in the evaluation.

In the case of young adults, participation in organising support is operating differently to the young children's program. The opinions of the workers are included here and the views of the young adults will be included in the next evaluation report.

The workers described their relationship with the young adults respectfully and consistent with the principles of the program design – to achieve community inclusion and empowerment to make their own choices about their support. Internal processes of consultation between team members and approval of decision-making and purchasing are in place within the staff and management team through the team case conference process (described in Section 4.3) and financial management procedures. Workers gave many examples of support and goals that demonstrate facilitated and independent goal development, which may indicate that the pilot processes safeguard appropriate spending, rather than any control of participants. In some cases, the structure of approval through Queensland Health finance procedures has resulted in delays to goods and services being obtained. It remains to be seen what the views of the young adults are about their level of control over goals and decisions. These questions will be examined through the client interview data in the evaluation.

In the early stages of developing the pilot, ABIOS workers were concerned that people with acquired brain injury in particular would struggle to make responsible spending decisions. Ten months into the program, workers reported clearly that most participants understood the processes of the program, made well-considered and responsible decisions, sometimes with support, and spent funds economically. For example, a worker said:

> One person who has a history of sometimes extreme violent and anti-social behaviour was accepted into the pilot. Her goal was to use her funding to support the enrolment of her child in school, to buy their uniforms, bag and lunchbox, and to pay for their excursions for the year. Then, she felt he could go to the school and volunteer to help as a parent.

ABIOS workers described the planning process as overwhelming for several of the participants in the pilot. They lacked experience of personal empowerment and practice in resolving lifestyle problems when solutions are possible from the resources available in the program. As one worker described it:

> A lot of my clients struggle with planning, because 'they're so used to never having any money, to not being able to go anywhere, or do anything … so they can't even comprehend that there could be a solution to some of these massive lifestyle problems'.

Several ABIOS workers stressed the importance of identifying the purpose of planning and goal setting and aligning it with the program objectives. For example, one participant's goal of getting gym equipment at home does not fit community inclusion goals, but when the underlying purpose of the goal was revealed to be to get strong enough to get out of the house, then it does fit. The case managers also emphasised the importance of scaffolding activities in the planning process to achieve

a long term goal. The sub-goals, which the client may not initially be able to identify as important, in the long term help them get to their goal. The implications of these steps in the planning process for program design and client participation will be examined in the evaluation.

The risk assessment process implemented by ABIOS appears carefully implemented, respectful of individual difference and conceptually linked to the principles of the program. The young adults have made a range of challenging decisions about goals, which presented case managers with ethical issues to navigate, and responsibilities to determine. The case managers were committed to resolving these key issues, because before participating in the program the young adults had not had the resources available to make or attain the goals. For example, a case manager said:

> A participant in the pilot wanted to buy a mountain bike, to fulfil his goal of fast bike riding. He had been injured in the past doing this, and showed lots of other risky behaviour. With his agreement, his family were involved in the planning process, and after a risk assessment was done, an alternative goal was eventually identified which was less risky, but still interesting and motivating for him.

The case workers and the families participating in the pilot believe that working in partnership is the key to the long-term success of the model. They said that participating in decision making was the best way for young adults and families to identify and prioritise their support needs and how to best meet them. The perspective of the young adults will be included in the next evaluation report.

The extensive case notes provided in the program data suggest that most young adults and families of young children are participating consistently in the program, however a few case managers and the services coordinator reported some difficulty engaging children and young adults. Two children were identified as being more difficult to engage than the other children, and the reasons appear to be about the timing of organising services and support for these families. Although support was in place for these children, it appears that the children were not able to access support as quickly as other children in the group.

With the young adults, there appear to be more instances of participants not receiving all of the support they had initially identified. Analysis of staff and management interview data indicates a number of possible reasons for these barriers which the evaluation will probe. These include the need for some young adults to have quite structured support for decision making to assist them to make decisions which are in keeping with the program objectives (possibly arising from their impairment); complex planning relationships between participants and the case managers which at times involve difficulties with communication and negotiation on the part of clients (assertiveness, knowledge of alternatives, and so forth); one decision being prioritised over another (and funds needing to be directed accordingly); personal problems taking precedence over participation in the program; and in a small number of instances the services identified (e.g school) would not accept the young adult as a client.

As this is baseline data and these participants are all still in the program, the overall patterns of participation are unable to be examined in more detail. When the views of

the young adults are available, a more considered analysis of participation will be possible.

4.3 Funding allocation

The program has up to $4000 per year to support each participant's case plan. In the outcomes section we describe how this arrangement has empowered participants (Section 3.1). These funding allocation practices and questions raised by the participants will be examined during the evaluation.

The SCCTC has a mixed approach to managing the funding allocation. Families can either pay for expenses agreed to in the case plan and are reimbursed afterwards; or where it is possible, service providers directly invoice the SCCTC for support they provide to the children and their families. This process was negotiated with the Department and set up to ensure that goods and services purchased by the families are consistent with their plan and the parameters of the program. Currently families receive an update on their budget balance every three months as part of the planning review process.

When asked if they were satisfied with the current funding arrangements families overwhelmingly expressed great satisfaction with the set-up. Overall families felt the arrangement suited their needs best and they were also reluctant to receive lump-sum payments instead. The main reasons for families' satisfaction is that they feel they remain in full control of how the funding is to be spent, while they have very little extra administrative burden with reporting. Parents said,

> She asks me what I want to do each time we pay for something from the money.

> I don't even see any money, so that's really good. The physio just bills [the services coordinator], or the SCCTC. We trust that it's all being handled appropriately.

Also families felt that receiving direct lump sum payments would pose a risk, as the monies might not be spent as purposeful as this is the case with the direction and support of the services coordinator. A parent said, 'I'm really happy that it's that way, as it would be too easy to spend the money quickly on things.'

Families said they do not have direct oversight of their budget and they are not involved in the administration of allocated money. While families were highly satisfied overall with the support received, the coordination of their needs and the funding allocation arrangements, some felt that a more regular review of the balance of their funding allocation was needed. They would prefer to be able to keep a closer track of their funding balance. Some families are keeping their own records, while others have suggested receiving more regular up-dates of their unspent funds.

Parents suggested acquittal balances be sent via email or posted to families on a more regular basis so that parents have a better understanding of how much money is left in their individual funding budgets. Effective program development will be examined in the evaluation.

The SCCTC services coordinator and CEO both oversee the funding allocations to manage the financial operation of the program. The CEO monitors the planning and spending of each funding allocation, which allows for oversight and provides another perspective about potential options to access and to meet the needs of individual families.

The funding allocation arrangements for young adults are subject to the Queensland Health finance rules because ABIOS is a government health organisation. The rules are inflexible, requiring invoices to be raised, restrictions on the use of petty cash, and other high-level administrative processes to ensure financial accountability. It is difficult to fit the program within this financial system because it seeks to spend funds on non-traditional purchases and through processes that empower the young person to make the decisions, choices and purchasing.

The result of health finance rules is that young adults are not able to spend money themselves and be reimbursed. Instead they must be accompanied by case managers who purchase goods on their behalf, which also has significant time implications for case managers to fulfil the administrative responsibilities. The rules have also inhibited timely purchase of computers, where prices change rapidly; and prevented the purchase of local services, such as personal training, where a provider may not have the correct supplier paperwork.

The main problems arising from this structure relate to strict regulations of how funding allocated can be spent for this group and young adults not being able to take direct control over their budgets. ABIOS case managers have suggested that participants would be more empowered by having increased control over purchasing, rather than workers maintaining control of these processes, as is currently the case. Feasible funding management will be examined in the evaluation.

ABIOS are attempting to address these problems by using gift vouchers to assist young adults to meet goals for which choice is essential. For example, when buying a small wardrobe of work clothing, a client particularly wanted to choose from a selection of stores in order to get best value for money, to maximise her choice and to increase the pleasure and social inclusion by shopping with a friend. ABIOS was required, however, to register these vouchers as gifts and donations with Queensland Health.

ABIOS is responsible for ensuring that the decisions of clients comply with the principles and guidelines of the program laid down by the Department. In order to do this, decisions about planned expenditure are taken by case managers to a team case conference for discussion prior to approval. Applied against individualised funding theory and practice, there are both benefits and risks to this approach. The case conference approach allows for creative contributions of colleagues in the case of sometimes difficult decision making processes for complex clients. It also has the capacity to protect individualised decision making, as workers may act to mediate or lobby on behalf of clients' decisions, putting them in a broader context of social justice or self determination.

The approach may, however, run the risk of limiting the autonomy of decision making for young adults with disability in a program designed to support self determined funding. This is because a case conference agreement and manager approval, within

the framework set down by the Department program guidelines, are needed prior to expenditure of funds for the decisions of individual clients. Delays caused by Queensland Health financial procedures (unavoidable for ABIOS, and which they have put considerable energy into mitigating) have impacted on the speed of access to goods and services at times, and clients are unable to purchase goods and be reimbursed. Workers report, however, that this structure has been helpful as a 'brake' in several instances where young adults may have difficulty with decision-making due to cognitive impairment. ABIOS workers are committed to empowering service users and to implement the pilot according to principles of inclusion and development of social networks.

Tensions between compliance with program principles and guidelines, safeguarding, risk management and self-determination will be considered in the evaluation. Whether other case coordination practices can achieve this process outcome, instead of relying on Queensland Health finance approval processes, will also be examined.

This report does not yet have information from the young adults and their families about their perspectives of the ABIOS funding allocation arrangements which will be very valuable. It will be included in the next evaluation report.

4.4 Supporting early intervention and innovation

The pilot model is designed to support early intervention and innovation through case management, community engagement and a small funding allocation. This section examines the participant and worker experience of these goals of the model.

Early intervention

The pilot is designed as an early intervention initiative. In particular the pilot aims to support children, young adults and their families previously not accessing or excluded from other formal assistance, and to young children who are showing early signs of additional support needs. Most of the young children had not previously received disability services, either because their disability support needs did not meet eligibility criteria, that is they were not considered severe enough; or because they had not received a formal diagnosis. One parent said,

> But what we needed was something further ... I guess, the disability
> is not severe, or it is not a recognised disability, and you're just not
> eligible for anything ... unless you do something privately which we
> just can't afford.

Most of the children's support needs can be characterised as early intervention. Most of them had only started to show additional support needs and some families were on waiting lists for more long-term and on-going support.

Family members of children recognised the importance of early intervention support and yet they had already encountered the shortage of early intervention support. One parent said,

> There should be more compassion, more understanding for families
> that do have children with needs, no matter if it's a mild need or a
> severe need.

Family members highlighted that providing families with support early on would prevent them from entering a crisis, such as family breakdown, at a later stage. They also noted that when receiving the early support it could, for example, assist families to better meet their children's needs, such as practical knowledge and skills about how to undertake simple therapeutical interventions. A parent said, 'We need the right information, at the right time that suits our particular needs.'

For ABIOS clients, the concept of early intervention is relevant to the onset of impairment, rather than chronological age. ABIOS case managers expressed concern at an age-related eligibility criterion for the program. While understanding the need for boundaries around program eligibility, they all thought that onset of impairment is a more relevant measurement than chronological age for people with acquired brain injury. The implications for program design and client eligibility will be examined in the evaluation.

Innovation in service delivery

A second program model goal is innovative service delivery. Overall the families of young children appreciate the quick and non-bureaucratic access to the pilot, the flexible self directed funding and worker's outreach capacity, and the current funding allocation arrangements. The families said that having a services coordinator to assist families in the planning process and coordination of their needs, someone who shows genuine empathy and understands their needs – 'someone to talk to' – is as essential to the success of the pilot program as the individual funding allocation itself. A parent said,

> [The pilot] was kind of a breath of fresh air.... the last couple of months [I spent] going to so many different appointments at the hospital on a weekly basis, and it's exhausting, and it's time consuming....I just felt quite a bit of relief really, because I thought, ok we are going to have something or someone to support us through this.

> [The pilot] is great because [the services coordinator] comes here so I don't have to travel all over the place, and she checks up on us to see how we're going.

The ABIOS case managers described that contributing creative and innovative ideas and have them agreed to was highly motivating for the young adults. As one worker said, their suggestions include ideas 'that would never be considered by any rehabilitation service.' Workers reported that for the young adults, the process of nominating the goals and spending is a clear benefit for participants. They said the individual funding makes access easy to a broader range of options than was previously possible when they were trying to link people to vacancies in existing, free services, courses and generic facilities. The views of the young adults about innovative service delivery will be included in the next evaluation report.

4.5   Partnerships

The SDS support model relies on partnerships between practitioners within the organisation to plan and administer the program; and with other service providers, to promote the pilot, strengthen referral pathways, professional development and

information sharing. The pilot is designed as a medium-term intervention with a small funding allocation to each participant, which means that referral and coordination with other support services is likely to be necessary to fulfil their needs.

The team relationship between case managers in ABIOS is more complex than in SCCTC, where there is only one services coordinator and her manager. In ABIOS, the team of ten case managers meet three times a month to discuss issues relating to the pilot, working through key problems and strategising around issues. All workers reported this had benefits for the program and for the development of understanding of ways of working, which supported participants while meeting responsibilities and managing risks. Robust discussions about difficult questions had assisted case managers to crystallise their thinking, and to develop a strategy to support the young adult.

Partnerships between the pilot organisation and other service providers are also important to the pilot's process goals of coordinated care and sustainable service delivery. The children, young adults and their families need to be linked into community support and informal networks to ensure on-going support. For example, most of the young children concurrently use a range of support services. In many cases, the therapists actively work together, also working with relevant other providers, such as schools to meet the child's needs. Family members were highly satisfied with this collaboration (see 3.1).

The services coordinator spoke of the benefits of having knowledge and connections to other networks to make best use of existing support services to supplement the funding allocation, such as allied health visits covered under Medicare and Department of Education funding to hire teacher's aides or extra therapy.

The major restriction on working effectively in partnerships is the shortage of time for the SCCTC services coordinator to pursue networking and collaboration with other agencies. Some community development work was done in the implementation stage and the manager of SCCTC is supporting these activities. The organisational isolation of the services coordinator from the rest of the SCCTC staff has also limited effective professional peer support, mentoring, and information sharing. Ways of addressing this limitation will be examined in the evaluation.

The ABIOS workers described the partnership approach between case managers and service providers in the community for casework, promotion, and information sharing as an extension of their 'business as usual'. The key to being able to expand their usual partnerships was the capacity to purchase goods and services with the funding allocations. Case managers reported that this enabled participants to avoid waiting lists, to use mainstream non-disability support and classes, and to 'kick-start' goals they had been working on with people for some time.

4.6   Process implications for program development and evaluation

Analysis from this baseline information is tentative because some data sources and comparative longitudinal data are not yet available. It raises questions to follow up in the remainder of the evaluation.

Preliminary lessons from the SCCTC support model

The SCCTC services coordinator role works well supporting families to identify a range of available support and prioritising how to best meet their agreed goals. The role does not have sufficient time to develop partnerships and networks fully. The isolation of the services coordinator from the rest of the Centre's activities means that she can focus on the needs of this particular group of families, but it may also limit the potential of the program. For example, other SCCTC staff are also key partners who could provide linkages, peer review, support, and are critical to professional peer development.

Overall the planning process works well and requires great sensitivity in the approach, especially for families who are still adjusting to understanding their child's needs. Parents want to be seen as experts of their child's support needs and be able to make informed decisions about how to best address these. The planning process and the provision of information empower family members and carers to take charge of their situation, and to actively seek out resources and information related to meeting their child's needs. The families are able to more effectively engage with other service providers as a result of this process. The coordination of individual support identified by the families appears to have had a high degree of success in outcomes for children taking part in the pilot – families have reported rapid improvements in their child's development, as discussed further in Section 3.

The program is likely to be even more effective once partnerships have been fully established, for example, when the local paediatricians and local GPs are fully aware and understand the benefits of the program, so that children can be referred for support as soon as the developmental delay is identified. Some restrictions from the current program design are the limited funding allocation, in particular, for children with higher support needs, and the exclusion of some groups of children from the program, such as children aged older than six years and children without physical disability and diagnosed with an intellectual disability or behavioural problems.

Preliminary lessons from the ABIOS support model

For young adults in the pilot, ABIOS case managers see that having access to resources to implement the plans is a key success for the pilot. Some of the young adults have been engaged with the service system for a long time but with only limited success. The new opportunities that are now possible with funds to purchase education and personal development, equipment and activities are highly meaningful and motivating. The case management has enabled facilitated decision making to set immediate goals that can eventually lead to larger long term goals.

The financial rules for funding expenditure through a government health organisation are restricting the effectiveness of the pilot. The rules preclude participants from purchasing and being reimbursed for small items, are slow and cumbersome and result in delays to purchasing equipment and resources, and waste a substantial amount of worker and manager time.

The stepped approach to goal development which case managers describe for people with impaired decision-making capacity provides, at its best, a supported and facilitated process of personal development for participants. There is a risk that if goals are not developed explicitly by participants, they may not meet their agenda for

self-direction. The evidence from the program manager and case managers is that they maintain consistency in the pilot approach and use a process of regular peer review through the case conference to ensure individual case managers justify that goals meet the principles of the program. The views of the young adults will be analysed in future evaluation reports to verify their experiences.

Children and young adults most and least likely to benefit from this model of support

According to service providers delivering the pilot, the support model is most useful for young adults, children and their families who previously had limited contact and were unaware of available support services.

The families of young children who have a good understanding of children's developmental needs and what support services could meet these needs, and the confidence to speak up and negotiate the service system benefit quickest.

In addition, families struggling to meet their children's needs also benefit greatly from the program, specifically from the planning, coordination, and information provision that the services coordinator role provides. Some of these families may find it difficult to make the best use of the funding allocation, because they may not have the capacity to understand, follow up or go to the numerous practitioners or support services from which their child could benefit. However, the assistance has been beneficial for child and family wellbeing and resilience for these families too. The funding allocation is not sufficient for children with higher support needs who are waiting for access to other free or subsidised support services.

The view of workers supporting the young adults is that young adults who already have established goals, or who are self-directed, are more likely to benefit quickly from the pilot. Some young adults also quickly benefit from gains to their self-esteem, if they have had a previous background of marginalisation, and so the experience of expending individual funds is in contrast novel and rewarding.

Some early evidence shows that the ABIOS pilot may have some cultural benefits. Workers reported on outcomes for participants from CALD backgrounds who were able to access non-traditional support and resources which worked very effectively for them. This will be analysed in the next report.

There is some concern among the ABIOS workers that some people might not be benefiting or are excluded from the pilot. In particular people with acquired brain injury who have acquired the impairment within the last five years (and thus fall within the ABI early intervention criteria), but who fall outside the chronological age range for the program, are ineligible for the pilot. ABIOS case managers frequently expressed their frustration that people above the 35 years were excluded although they were likely to benefit greatly from access to the program.

Future development of the program

While the pilot and the evaluation is still in its early stages of implementation, there is emerging evidence that the program is at this point achieving its process objectives: empowerment of service users and their families to identify their needs, set personal goals and make informed decisions about the support they need. The pilot, designed

as an early intervention approach, is reaching its main target groups – children showing early signs of additional support needs, young adults with physical disability, and their families and informal supports, previously excluded or not accessing more formal support. The preliminary analysis has also identified a number of questions about possible limitations and challenges to this model of support.

Immediate questions

Some workers and participants are unclear and need guidance about exit processes, such as funding and participation beyond a 12-month period. In ABIOS, because some young adults are already ABIOS clients, some workers are unsure whether to commence planning and then introduce the SDS pilot, or introduce the pilot first, then start planning with the funding in mind.

Some ABIOS workers thought that to address the young adults' lack of experience with planning and decision making where resources are available, training resources for participants and families to support learning in this area may be helpful, prior to formal planning.

Workers identified the importance of supervision, peer support, interaction with other workers within their agency, and strategies for culturally appropriate ways to engage families from non-English speaking and Indigenous backgrounds.

ABIOS workers said they need further development and training about case management processes to manage risk for young adults' needs, in a new climate where people are encouraged to make a far broader range and scope of personal decisions.

The administrative processes to comply with financial accountability, planning processes and evaluation are a high cost to the organisations.

Longer term program design

Opportunities for expanding the program include:

- Avoiding terminology such as 'disability' to include families who do not identify with the category;

- Extending the program beyond physical disability and six years of age, to include children with mental health disorders, learning difficulties, and challenging behaviours, up to ten years of age;

- For young adults, revising eligibility to length of time since acquiring impairment, rather than chronological age;

- Promotional material to explain the program in a way that is attractive and understandable for young adults and families of young children.

SCCTC workers suggested that enhancement of the community development and capacity building aspects of the pilot would be important, for example, by introducing peer-to-peer support groups (eg. playgroups) for children, their families and carers. Such a platform could provide on-going support and community integration for participants, and serve as link for providers to provide information and pathways into support services.

5 Economic evaluation

An economic evaluation assesses the cost of the pilot against the outcomes experienced by the participants. These costs are analysed in terms of total program cost and cost per participant. The underlying principle of the economic analysis is that for the given budget, the government wishes to maximise participant benefits. The economic analysis also informs future decisions about the pilot or similar support models for people with disability.

5.1 Costs of the program

In this section of the evaluation we analyse cost data provided by the Department and the service providers. 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).

The NGOs are each funded $240,000 per year for two years to pay for management, operational and case workers time and expenses and small self directed funding packages ($4,000 per year per person). Funding is equally allocated to participants regardless of their assessed or perceived level of support needs.

It is difficult to estimate actual program costs based on the budget information provided by the services, as the information was not located in one place and many of the costs had not been finalised by the time the data was collected. To provide these estimates, costs for services were averaged. As the two groups were very different, the costs for each are presented separately.

Although many costs are unclear in this round of data analysis, it is apparent through the extensive case notes that case workers work with the young adults and families to provide services that are within budget, and have indicated that if a support service is more than the budget then the family contributes to the payment. It would be reasonable to assume therefore that the associated program budget for participant expenditure does not exceed the allocated budget.

The range of costs for each support type is examined Table 5.1. These costs are based on 35 participants with costs for 44 identified needs. Of these, 17 children, and 14 young adults had costs listed against at least one of their identified needs. The data are incomplete.

Table 5.1 Cost details of identified needs January to June 2010

	Number participants	Range of costs ($)	Average number of hours	Average cost per hour ($)	Average total cost per participant ($)
Total cost of identified needs					
Children	8	1091-4001			2084
Young adults	2	1850-3991			2921
Children					
Ongoing or weekly services					
Allied therapy (Physiotherapy, speech, OT)	21		7	96	630
Hydrotherapy	2		10	43	425
Child care	1		-	-	1820
One-off costs					
Equipment	10				330
Medical treatment	1				747
Other home or family costs	1				3691
Needs with no direct cost associated					
Assessment for diagnosis	1				
Young adults					
One-off costs					
Community education course	3	315-1350			688
Equipment for community education	2	625-2300			1462
Formal education course	3	400-855			605
Equipment for formal education	4	1715-4000			2307
Sports/social fitness program /equipment	4	50-725			329
Other household costs	4	249-2500			930
Other personal costs/social activities	4	130-1048			575
Needs with no direct cost associated					
Personal assistance – budgeting, cooking	1				
Public transport training / use	2				
CODA assistance	1				

Source: Program tracking data for Jan – June 2010
Notes: The number of participants indicated were used to calculate the cost details, and do not represent all participants that received a service, as many participants did not indicate finalised costs for services.
Total costs are provided only for participants that had all three needs costed and will not be representative of all participants, it may also not be a final cost as some budget was left over for these clients.
A small number of identified needs involved no direct cost (e.g. additional case management, budgeting assistance), these are included for information.

The basic cost data shown above indicate that there is wide variance in the costs per service as well as the overall costs per participant in the program.

The most immediate finding apparent in the data is the method in which the allocated budgets are spent. For the young children, the budget is generally allocated to a service that is delivered over a number of weeks (usually six) and then reviewed. The costs above only include one round of services. Equipment is then purchased from the budget and then if there is any remaining money, it is used on other expenses.

This pattern of funding allocation for the young children appears to be because almost the families prioritised therapeutic assistance before other needs could be met, and for

these participants this is delivered in weekly sessions. Only a very small number of participants in the younger group prioritised a need that required a one-off cost.

The young adults tended to prioritise their spending on one-off items. Usually this was some kind of equipment to assist them with formal or community study. They appeared to be more focussed on allocating money to the need that is going to have the most impact in terms of community and social involvement and personal wellbeing. This meant that the young adults appear to have spent their budget early on in their participation in the program with the intention that they will use the item/s they purchased to participate in the community over a long period of time.

An example that illustrates the typical difference between the spending patterns of the two groups would be physiotherapy for a young child compared to a young adult purchasing clothing, shoes and purchasing a gym membership. For the child, the services coordinator booked in six weeks of physio to be reviewed upon completion. The physiotherapist recommended that the family purchase some equipment and then with the remaining money was spent on a family activity. The young adult on the other hand decided that they would like to prioritise their fitness and get out of the house more. They decided that they would join a gym, so they required the money to buy clothes and shoes and a gym membership.

Data about annual expenditure are not yet available for analysis. It can be assumed that for the adults this one-off expenditure followed by community participation would not incur any major cost outlays after the initial expenditure. For the young group, however, there may be situations where additional therapy is required and if the budget is already spent, the family cannot afford to pay, and free or subsidised support is not available, it might affect access to continued treatment.

5.2 Benefits of the program

The evaluation will answer two research questions:

- 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?

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); social, community and economic participation; and community connections.

When the longitudinal outcome data are available they will be compared to costs. Outcomes that cannot be easily quantified will be discussed in more general terms in relation to the unit cost of the pilot services.

The baseline qualitative data about outcomes is only available for the young children and their families. Qualitative data for the young adults and quantitative data for both groups will be analysed in the next report. Preliminary findings show that most young children and their families are experiencing benefits from participating in the program (Table 5.2).

Table 5.2: Preliminary Self Directed Support outcomes analysis

Outcome	Description
Wellbeing, independence and resilience	Young children's physical wellbeing and development has improved from access to therapies. This has improved their independence.
	Family members wellbeing and resilience to cope with their circumstances has improved through reduced stress about coping with decisions about support needs, paying for support, finding information and arranging support.
	Families report that the support is preventing them from entering a crisis and perhaps avoiding family breakdown.
Empowerment	Family members have a better sense of control and capacity to organise, pay for and attend support services for their children.
	Young adults have been able to make decisions and act on plans to achieve preliminary steps towards goals, according to case managers.
Social, community and economic participation	Young children are able to participate in activities in their family, early childhood groups and school.
	Support has enabled families and siblings to do activities together and outside the home.
	Young adults have participated in sport, social and educational activities, according to case managers.
Community connections and networks	Families of young children are becoming familiar with community services and referral opportunities.

5.3 Economic implications for program and evaluation

The providers have operated within budget for the first 6 months of the program. They reported that they have absorbed a lot of management costs into their other operations because of the high administrative responsibilities of establishing a new program. The self directed funding allocation has also operated within budget. The families of young children have generally spent the funds on weekly fees for therapies and related equipment. The young adults in contrast have paid for equipment or study fees to facilitate immediate access to social, community and economic activity.

The baseline qualitative data shows that young children, their families and young adults are benefiting from case management, planning and a small budget to assist with organising the support they need to fulfil their goals. Preliminary benefits for the participants and their families are evident including wellbeing, independence and resilience; and community, social and economic participation. Initial information and contact with community services and informal networks is beginning for some families and young adults, but with the support of the case workers, this benefit is taking longer to experience than the others.

Appendix A Evaluation Methodology

A longitudinal, mixed method evaluation design is used to measure longitudinal outcomes for children and young adults with physical disabilities, their families and informal supports; the program process; and costs of the pilot. 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.

The evaluation aims to generate information about the Self Directed Support pilot throughout the evaluation period to inform progressive policy and program change. Key areas of the evaluation include outcomes and process evaluation; and an economic analysis that compares the costs of the pilot to the outcomes for people with disabilities and their families and informal support.

This is a summary of the more comprehensive evaluation plan of the Self Directed Support Pilot (Gendera et al. 2010). (Also available under www.sprc.unsw.edu.au/media/File/3_SDS_Evaluation_Plan.pdf)

Evaluation questions

The evaluation of the Self Directed Support pilot addresses 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?

Data sources

In summary the data sources used to answer the evaluation questions include:

- Document review – policy, documents and literature;

- Administrative and program data – Department specifications, service contracts, financial data and case planning data;

- Qualitative data collected by the evaluation team – case studies, interviews and observation data; and

- Quantitative reporting from the service providers – quarterly and annual reporting, assessment data and validated Personal Wellbeing Index questionnaires.

The evaluation is conducted in four phases: project plan; baseline analysis; longitudinal analysis; and final analysis. As of November 2010 the evaluation plan has been completed and published.

Methodology

The evaluation uses quantitative and qualitative data and incorporates a participatory methodology. The participatory research design acknowledges that the success of the evaluation strongly relies on the meaningful participation of a range of stakeholders throughout the research process.

Quantitative data

The main sources of quantitative data for this evaluation are provided by the Department respectively the two selected NGO service provider agencies, SCCTS and ABIOS, as part of their quarterly and annual reporting on participants' demographics, case planning, service types, and financial reporting.

The two sources of information are: extracts from the National Minimum Dataset (MDS) which includes basic demographic information and the number of case management hours provided to pilot participants; and program data which tracks participants' identified needs and support types used. The information on processes and outcomes provided in this baseline report capture the early stages of the pilot implementation. Longitudinal data analysis will allow the evaluation to measure change over time.

To assess the outcomes for all adult respondents – the young adults, their informal supporters and the informal supporters of the children participating in the pilot (one informal supporter per participant) – the evaluation is collecting data from the Personal Wellbeing Index (PWI). The two service provider agencies have agreed to collect and transfer the PWI data for the adult pilot participants. By November 2010 this process had not yet commenced. 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 evaluation framework was designed to assess outcomes for children and young adults participating in the pilot by analysing supplementary outcome data, in form of standardized measures collected by service providers. However it became clear that no strengths-based validated instruments are available to assess outcomes especially for young children and their carers. After careful consideration of the possible negative impacts on families the researchers in consultation with the Department decided not to collect any supplementary data (apart from the PWI for the adult population).

Qualitative data

Researchers are conducting semi-structured interviews with pilot participants, their informal supports, service providers and Department staff about the outcomes and process elements of the evaluation.

The total qualitative sample includes at least ten pilot participants, 14 informal supporters, six service provider staff and two managers in both regions and three Department officials (Table A.3). 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. Baseline qualitative data is being collected from September to December 2010, and longitudinal data will be collected in September 2011.

Table A.3: Longitudinal qualitative interviews (September 2010 and 2011)

	Children 0-6 years	Young adults 20-35 years	Total
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

We do not recommend representative sampling because the quantitative data collection includes all participants who permit their data to be analysed in a deidentified 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.

To avoid selection bias and maximise the longitudinal research opportunities, the samples are 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 evaluation also uses qualitative program data about participants who permit the analysis of their deidentified data. This data includes information collected by case workers throughout the planning and goal setting stage and later ongoing support provision (eg. case planning notes).

Program observation

While conducting interviews with key stakeholders, managers and service providers of the two NGO's, the research team spends time in each of the two fieldwork sites (Brisbane and Sunshine Coast) to explore how the program operates in specific contexts. This data is used to further inform the outcomes of the pilot. ABIOS is also collecting evaluation data, using a tool their research officer has developed for the purpose.

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 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 are 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 heavily relies on outcome and cost data being available and is likely to be stronger in the longitudinal analysis (round two reporting).

References

Department of Communities (2010), *Self Directed Support Initiative 2009-10. Community Inclusion Pilot Implementation Guide & Toolkit*, Department of Communities, Disability Services Queensland.

Gendera, S., Fisher,K.R., Robinson, S. and Clements, N. (2010), *Evaluation Plan of the Self Directed Support Pilot*, SPRC Report 10/10, prepared for the Department of Communities, Disability and Community Care Services, Queensland, July.

Muir, K., Tudball, J. & Robinson, S. (2008), Family resilience where families have a child (0-8 years) with a disability, SPRC Report 10/08, report prepared for the Disability Policy and Research Working Group (DPRWG), Commonwealth State/Territory Disability Agreement Australian Government, June 2008.

O'Connor, P. and Cripps, R. (2000), *Needs and opportunities for improved surveillance of brain injury. A progress report*. AIHW cat. no INJACAT 27, Australian Institute for Health and Welfare, Canberra.