



Never Stand Still

Faculty of Arts and Social Sciences

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

## **Final Report**

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**For the Department of Communities, Disability and Community Care  
Services, Queensland**

**Social Policy Research Centre  
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## 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 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 final report provides findings about the outcomes for participants and their families, implementation of the pilot, the process and cost analysis. It also draws together implications for future development of similar programs.

## **Background**

The Self Directed Support pilot had two key objectives: community inclusion and the empowerment of service users to make their own choices about their support (self direction). Self directed support enabled 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 planning and case management, and control over their allocated funding, the program allowed 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 to two groups of people with disability – children and their families, and young adults. One was the Sunshine Coast Children’s Therapy Centre (SCCTC), which supports young children (0-6 years) with physical disabilities and their family carers and significant other informal supporters. SCCTC had one full-time service coordinator. The second was the Acquired Brain Injury Outreach Service (ABIOS) in Brisbane, which supports young adults (20-35 years) with acquired brain injury and physical disability. Existing ABIOS case managers (ten) incorporated the self directed support function into their other responsibilities.

The two providers were funded \$240,000 per year for two years to deliver services under the pilot. The annual budget covered 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 used a longitudinal, mixed methods design to address three sets of research questions:

1. Participant and program outcomes: To what extent had the initiative met its objectives for individual participants?
2. Support model and service delivery processes: How effective was the model in meeting its key objectives: person centred (self directed) support, community inclusion, and early intervention?

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

#### **Outcomes for children, young adults and families**

Flexibility in planning and coordination of a person's needs, a person centred service delivery approach, and empowerment were central to the successful implementation of the program. The findings show that the program achieved its goals of improving wellbeing, independence, resilience and social participation.

*Wellbeing, independence and resilience.* Participants' physical wellbeing had improved from access to therapies and physical activity. This had improved their independence. Family members' wellbeing and resilience to cope with their circumstances had improved through reduced stress about coping with decisions about support needs, paying for support, finding information and arranging support. The wellbeing of young adults and family members was close to that of the Australian population and higher than other carers. Families report that the support prevented them from entering a crisis and perhaps avoiding family breakdown.

*Empowerment.* Young adults have been able to make decisions and act on plans to achieve goals and steps towards goals. Most family members have a better sense of control and capacity to organise, pay for and attend support services for their children.

*Social, community and economic participation.* Young children were able to participate in activities in their family, early childhood groups and school. Young adults participated in sport, social and educational activities and paid employment. Support had enhanced families' resilience and enabled young children and their siblings to do activities together and outside the home.

*Community connections and networks.* Young adults used mainstream community services. Families of young children became familiar with community services and referral opportunities.

#### **Process findings**

The program achieved 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, reached 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 goals were facilitated through strong relationships and support processes implemented by case workers; a partnership approach to planning and decision making where participants need guidance; flexibility in planning, with the option of making changes to plans as circumstances and preferences change; and consistency to the principles of the program design.

*Planning.* SDS planning for young children required sensitivity, especially for families who were adjusting to understanding their child's needs. Parents wanted to be seen as experts of their child's support needs and to make informed decisions about how to best address these. The planning process and the provision of information empowered 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 more effectively engaged with other service providers as a result of this process.

Planning with young adults benefited from a stepped process for goal development, which provided, at its best, a supported and facilitated process of personal development for participants. Most participants in the pilot felt that their plans were self directed, and that they explicitly developed their own goals. Case workers filled in the gaps in meeting those goals, by providing pathways to move towards major goals, or suggestions and options about ways to reach goals. While participants still felt that their ideas needed to be approved before being able to be implemented, they clearly felt the program was in place for them to develop their own ideas about participation and activity.

*Funding.* Having resources to enable plans to be activated was a key to the success of the pilot for children and young adults. By the second half of the project, a few participants had chosen to manage the funding directly, although most left that responsibility with the organisation. ABIOS actively worked to minimise the negative impact of government department finance restrictions, such as delays in payment.

*Coordinator time.* The role of the service coordinator included planning, support, administration and partnership development. The two models in the pilot approached these roles differently – SCCTC relied on a single part-time position, and ABIOS shared the responsibilities among case workers who also supported other programs. The single position had the strength of a consistent approach and focus. As more participants joined the program, the team approach was easier to sustain in terms of time management, integration with other resources in the organisation, peer support, quality control, partnership development and continuity of support after exit.

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

## **Economic implications for program and evaluation**

The providers operated within budget during the pilot. They reported that they absorbed some management costs into their other operations because of the high administrative responsibilities of establishing a new program. The administrative processes to comply with financial accountability, planning processes and evaluation were a high cost to the organisations.

The self directed funding allocation also operated within budget. The families of young children generally spent the funds on weekly fees for therapies and related equipment. The young adults in contrast paid for equipment or study fees to facilitate immediate access to social, community and economic activity.

The benefits of the program were demonstrated through the qualitative data. The young children, their families and young adults benefited from case management, planning and a small budget to assist with organising the support they need to fulfil their goals. Benefits for the participants and their families were evident including wellbeing, independence and resilience; and community, social and economic participation. Initial information and contact with community services and informal networks began for some families and young adults, with the support of the case workers.

## **Implications for self directed support programs**

This pilot was to support people with disabilities and their carers and the approach can also be applied to other groups, such as people receiving support due to ageing and frailty.

### *Eligibility criteria for early intervention*

Defining the target group for 'early intervention' support needs to consider both age and timing of the incidence or identification of need. Both service providers found that the program would have equally benefited wider target groups, when the objective was to reach participants in need of 'early intervention' support. In the case of young adults with acquired brain injury, they found that onset of the impairment rather than chronological age could have been more appropriate. Similarly, any young children at the time of any identified disability support need, rather than under a particular age and with a particular category of disability, could have benefited from this approach.

The pilot demonstrated that the short-term, early intervention through the allocation of case management and funding was effective for empowering participants and their families to move on to accessing other formal and community support.

### *Flexible and empowering planning and support*

Flexible, person centred service delivery and planning maximised the responsiveness to participants' needs. Both concepts were crucial for the empowerment of clients and their supporters to identify needs and set goals; make informed decisions about how to best spend and manage the allocated

funding (whether by the participant or through the supporting agency); and review decisions as needed.

In the case of young adults with acquired brain injury the SDS program enabled them to set goals and plan how to achieve them. ABIOS implemented a stepped process for goal development where staff and participants worked together to scaffold goals into sub-goals, which case workers then discussed in team conferences. This approach facilitated the development of participants' decision making and reduced their financial risks. This required highly skilled, sensitive case management support to empower and support participants to identify goals, planning and realisation.

#### *Control of the allocated funding*

Access to a small individual budget was sufficient to realise goals for some participants that had been previously frustrated for lack of funds. Initially all funds were administered by the service providers and in the second half of the pilot, participants had the choice to self manage the funds. Most participants continued with this choice because they did not want the additional administrative responsibility.

Where the funds were administered by the provider, participants wanted transparent management of the funds, such as flexible access to the funds (eg. vouchers or cash to enable purchase of goods or services on the plan; reimbursement or direct payment to service providers; prompt information about the balance of funds).

Considerations to make self management a viable choice include: continued case management support; clarifying the taxable status of the funds (GST and income); and simple financial accountability systems.

The pilot reinforces evidence that participants want choices to self manage or have their funding managed on their behalf. In both cases, they want access to case management and planning; and information about the funds available and the processes for reimbursement, purchasing and accountability.

#### *Sustaining program outcomes*

The SDS pilot was designed as a short-term intervention and focused on enhancing community networks and inclusion for longer term support. Engagement and networking with other community services and programs was key to the program but the providers did not have sufficient resources to fully implement this aspect of the design. The design of the program was that planning and case work with a focus on community inclusion would have the potential to link participants to formal and informal community support and generate opportunities for social participation and inclusion.

*Staffing capacity and training*

Case managers in self directed support models require sufficient resources and time for relationship building, planning and support provision to clients; collaboration and networking with external partner organisations; administration of plans and funding; and supervision, training and peer reflection to further develop their skills for a facilitative approach with clients.

*Program evaluation and monitoring*

The evaluation and program monitoring were enhanced in this pilot by the early implementation, resources and commitment to the formative evaluation opportunities from the government and providers. The structured longitudinal evaluation enabled informed decisions about funding, program design and improving processes.

## 1 Introduction

From 2009 to 2011 the Disability and Community Care Services, Department of Communities ran the Self Directed Support – Community Inclusion Pilot. The pilot was funded through the Queensland Government’s Prevention and Early Intervention pool. A total of \$1.06 million was allocated to implement and evaluate the pilot over two years (Department of Communities, 2010). The program aimed to enhance independence, capacity and resilience of children and young adults with a physical disability, as well as their families and informal supporters (Section 2.1 details the program objectives).

The Social Policy Research Centre (SPRC), University of New South Wales (UNSW) with Griffith University were contracted by the Department of Communities to evaluate the pilot from 2010 to 2012. The evaluation examined the outcomes, process and costs of the pilot to inform future service development. This is the final evaluation report (earlier reports, available on the web, include Gendera et al 2010, 2011 and Robinson et al 2011).

### 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. Appendix A summarises the evaluation and the full evaluation plan was described in Gendera et al. (2010). The following datasets were available:

#### Program data

The two service providers implementing the pilot provided quantitative program data. The longitudinal analysis was from the start of the program in January 2010 to May 2011 (Program Tracking data); and registration and National Minimum Dataset (MDS) data from January 2010 to June 2011.

The program data from the MDS included basic demographic information and the number of case management hours provided to pilot participants. The Program Tracking data tracked the participants’ identified needs and the support types received to meet these needs. This data source also included key dates and some basic budgetary information.

Most of the quantitative program data were descriptive. The information was grouped into categories where possible. There were a number of inconsistencies in the data: in a few cases, a participant with tracking information could not be matched to service usage data; and some participants had no information available. Budget information was calculated using average costs per service and per hour.<sup>1</sup>

Table 1.1 illustrates SDS participant numbers and data provided for each of the two pilot groups until June 2011.

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<sup>1</sup> See Section 5 for additional information about budget calculations

**Table 1.1 Administrative data, group sizes**

Number of participants	Date	Children 0-6 years	Young adults 20-35 years	Total
Participants with registration data	2010-11	37	42	82
Participants with tracking data	2011	37	16	53
Participants with MDS data	2010-11	40	35	75
Participants with tracking, registration and MDS data provided	2011	34	16	50

Source: Program tracking data as at May 2011, registration and MDS data for July 2010 to June 2011

The registration data indicated that by the end of July 2011, 37 children and 42 young adults had registered with the SDS pilot, a total of 82 service users. The MDS data includes 40 children and 35 young adult participants.<sup>2</sup> These inconsistencies in the samples reflect missing data and difficulties linking some participants across the different program data sources provided. In this report, the source of information is indicated under each table for clarity.

### Personal Wellbeing Index (PWI) data

The Personal Wellbeing Index (PWI) was used to assess the wellbeing outcomes for adult participants (young people and family carers). The PWI is a validated instrument that comprises seven questions relating to 'satisfaction with life domains', about health, security, community participation, and others. Each question is answered on a zero to ten scale of satisfaction. Scores are combined across the seven domains to yield an overall Index score (Cummins et al. 2009). For comparative purposes PWI group value means scores can be compared to population data, or specific sub-groups.

The researchers distributed the PWI surveys to the two service providers who administered the surveys with the SDS participants. The survey options were a standard version and modified versions for people with an intellectual or cognitive disability. These versions of the PWI survey use reduced scales, or simplified scales (smiley faces, sad faces) instead of numbers ranging from zero to ten. ABIOS determined which version was best suited for each person.

In the Evaluation Plan, the PWI survey was to be administered at multiple points in time, once at program entry and if possible every six months thereafter, and upon exit of the program. However, for practical and administrative reasons, surveys were collected where possible, at entry and exit from the program, with at least one survey by July 2011 for one primary supporter for each child, and all young adults and one of their main supporters.

<sup>2</sup> These discrepancies can be partly explained because the MDS reflects the previous reporting quarter and not actual number at time of analysis. Also some participants entered the program and exited shortly thereafter.

Family members and informal supporters completed the survey assessing their own wellbeing and satisfaction with life. Due to ethical considerations no PWI measure was completed for the children (0-6 years).

The PWI findings were based on the following sample of respondents who completed the PWI measure in the first half of 2011: 19 of 42 registered ABIOS participants; and eight ABIOS family members and 33 of 37 registered SCCTC family members and informal supporters. The total survey response was 60.

### Fieldwork data

Longitudinal participant interview data were available from the range of stakeholder groups, including Department staff, young adult participants and informal supporters (Table 1.2). Interviews were conducted in June-July 2010 and June-August 2011.

**Table 1.2 Longitudinal qualitative interviews 2010 and 2011**

	2010 baseline report		2011 second report		
	Children 0-6 years	Young adults 20-35 years	Children 0-6 years	Young adults 20-35 years	Others
Pilot participants	-	10	-	10**	-
Informal support eg. family	10	3	9**	4	-
Service provider staff	1	8*	1	1	-
Service provider manager	1	1	-	-	-
Department staff	-	-	-	-	3

Note: The qualitative samples supplement the full participant population quantitative datasets  
 \* Three interviews with eight ABIOS staff.  
 \*\*longitudinal (repeat) interviews were conducted with five of the 10 ABIOS participants; and four of the nine family members of children participants.

To ensure an unbiased selection of participants we asked service providers to invite the most recent young adult and families of children who entered the program to participate in the research. To measure change over time, participants who were previously interviewed and were still in the program, were invited to take part in a second interview.

It was challenging to obtain detailed information about participants' experiences for the baseline report, due to the short time some participants were in the program. The second round of data collection provided good quality data for all participants who were interviewed and longitudinal, in-depth information from people who were interviewed twice.

Another factor limiting the qualitative data collection was the sensitivity of the topic. Several families were adjusting to their child's additional support needs, the families' circumstances, and contact with the social and community sector. To ensure participants' wellbeing and minimise stress, researchers did not use terminology such as disability or in some cases ask follow up questions if parents or young adults showed signs it might cause them distress.

Few observation data were included because most families chose not to have their child at the interview, to assist with the interview process. Additionally, most parents were time poor, juggling a number of caring duties and responsibilities (e.g. appointments for their child) with part-time work. These circumstances to some extent reduced the participant's ability to fully engage with the research.

## **1.2 Report structure**

The report describes the program as delivered by the two providers and profile of the participants in Section 2, before presenting the findings. The outcomes evaluation findings are presented in Section 3. Section 4 examines the service effectiveness, Section 5 presents the analysis of program costs, and Section 6 draws implications for self directed support programs.

## **2 Program and support model description**

### **2.1 Aims of the Self Directed Support Pilot**

The Self Directed Support pilot had 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 participants, their families and 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 aims to assist them to be their own agents of change (Department of Communities, 2010: 7).

An aim of the pilot was 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 a key to individuals' wellbeing and increased resilience. The program aim was to use strengths of existing community networks to enable participants' independence and self reliance.

The program's further objective was to facilitate participants' cooperation with the community rather than dependence on formal services to work towards their goals. Person centred support and community inclusion combined are 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 were 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 organisation (NGO) service providers funded by the Department to implement the program; and Disability Services and Community Care, Department of Communities staff who oversaw and coordinated the initiative.

Departmental program management included a manager and two project officers to develop systems, resources, training and accountability.

Governance arrangements between the NGOs and the Department included:

- Quarterly reports on service types for the National Minimum Dataset (MDS);
- Detailed progress reports including qualitative and quantitative data; and
- Participation in quarterly consultations groups with Departmental staff.

### **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 was the Sunshine Coast Children's Therapy Centre (SCCTC) located in the Sunshine Coast, which supports young children (0-6 years) with physical

disabilities and their family carers and significant others. The second was the Acquired Brain Injury Outreach Service (ABIOS) in Brisbane, which supports young adults (20-35 years) with acquired brain injury and physical disability.

The two NGOs were each funded \$240,000 per year for two years to deliver services under the pilot. The annual budget covered 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 core features of the service delivery included:

- Strengths based practice approach eg. person centred planning, building on capacity
- 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 2011 SCCTC recruited and supported 40 children and their families, and ABIOS was working with 42 young adults and their informal supporters. In total 82 children and young adults participated in the SDS pilot, which was half of the targeted number for the pilot over two years as defined by the Department (40 participants per annum, per service agency). Some ABIOS and SCCTC participants received a second round of funding.

### **SCCTC service model**

The SCCTC employed a part-time experienced service coordinator, trained in social work 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 service coordinator was 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 were referred to SCCTC from a range of community and allied health agencies, including GPs, paediatricians, and disability services. Families could also self-refer. The range of referral sources were a result of the service coordinator's promotional activities. Once a family with a child with additional support needs was referred to the SCCTC their eligibility for the program was assessed. The eligibility criteria were: children aged 0-6 years with a physical disability; not receiving other Disability

Services; and living in the Sunshine Coast area. Families were either accepted to the pilot, or referred on to other more appropriate services. Accepted families arranged a first planning session with the service coordinator, in most cases a home-visit. During the initial planning phase the family discussed and identified their child's and family's support needs. They also received information and advice about a range of available support and how to best prioritise their needs and wants. When the family decided on a specific approach, the service coordinator assisted them to access the relevant support they needed. Part of this role was to coordinate a number of service providers, where necessary. The planning process and allocation of funding was reviewed every three months.

The SCCTC approach was to first meet the immediate support needs of the pilot participants. Then the aim was to assist families to identify and enhance existing and new informal community support and networks, to strengthen the family's and child's independence and self reliance. The aim of this second step was to build more long term support networks for pilot participants, beyond their direct involvement in the program and after the disbursement of allocated funding. Due to the part-time Coordinator supporting a large number of families, the Coordinator had little time to do any program or community development.

### **ABIOS service model**

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

The ABIOS manager managed the pilot and the rehabilitation coordinator and an ABIOS research and development officer supported the project coordination. This management team together shared the responsibility for conceptual development, implementation of the model, approval of expenditure, staff training, and measuring outcomes. The project coordinator had day-to-day operational responsibilities to ensure case conferences and planning meetings ran smoothly, while the manager maintained an oversight role and approved expenditure. The program was implemented by a team of ten ABIOS staff – the two managers, who also maintained a case load, and eight rehabilitation coordinators (case managers) who worked with a small number of pilot participants alongside other clients.

Young adults entered the program through the established ABIOS referral system, which is concentrated in the health and allied health system (no additional promotion for the pilot was conducted). Once a client was referred to ABIOS, their eligibility for the pilot was assessed. Eligibility criteria were: aged 20-35 years; have ABI and physical disability, not receiving other funded Disability Services. If eligible, they were allocated a case manager, who began to work with them on planning activities. The aim was to develop a plan prior to allocating funds or strategies to meet that goal. ABIOS refined the planning tools provided by the Department, and used these to structure

planning and support activities with the pilot participants. Plans were scheduled for quarterly review. Case managers discussed clients' needs at a team case conference when the person started on the program, or had large changes to their plans or a decision around new spending. The case conferences were to share knowledge, insight and learning about the program.

The planning and spending process was iterative for many young adults in the pilot, with urgent needs 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 planned to exit the pilot after completing the planning stage and spending their allocated funds. Other clients worked with case managers on goals that focused on inclusion in their community in a way that was motivating and personally engaging.

## **2.4 Participant characteristics and target groups**

In this section we analyse available demographic information about the two groups who used the pilot, to assess the extent to which the program reached the target groups.

### **Characteristics of the pilot participants**

Table 2.1 presents the gender and age distribution of SDS pilot participants by June 2011. The age range for children was 1-7 years old. The program was intended for children aged 0-6 year old. The age range could be explained by the age at time of exit from the program; and it could also indicate that the program age criteria did not meet children's needs. More boys (26) than girls (15) were in the program.

The age range for young adults was 20-36 years old (also taking account of exit time from the program), with the majority of participants aged 25-29 years (average age 28 years). A gender imbalance for young adults remained throughout the program, with 74 per cent young men. The number of young women rose from five to nine women in the second year. This gender distribution is consistent with the incidence of acquired brain injury among 15-24 year olds (O'Connor and Cripps, 2000:12-13).

**Table 2.1 Characteristics of pilot participants, June 2011**

	Children		Young adults	
<i>Age</i>				
Actual age range (years)	1 – 7.5		20 - 36	
Average age (years)	4		28	
Number of participants	43		29	
<i>Gender</i>				
	Number	Per cent	Number	Per cent
Males	26	63.4	26	74.2
Females	15	36.5	9	25.7
Number of participants	41	100.0	35	100.0

Source: Program tracking data at May 2011, registration and MDS data July 2010 - June 2011

Note: Some participants were unable to be matched to demographic data.

### Target groups

The program reached its early intervention target group for children. Most families in the program had children aged 0-2 or 4-6 years with less severe developmental delays and additional support needs. In most cases children's needs were identified by a professional, but were rarely diagnosed. Most families prior to the pilot had not used or had little awareness of Department funded disability services, with some exceptions. Some families were on long waiting lists for the Cerebral Palsy League and similar support services.

The main limitations of the program for children were engaging Indigenous and culturally and linguistically diverse (CALD) families. The service provider identified this problem and planned strategies to reach these groups. However, the SCCTC coordinator had no capacity to dedicate extra time for further program development, such as engaging Indigenous and CALD families, networking and promotion; or community development for families in the program, such as setting up a peer-to-peer support group. The lack of capacity for non case management work was a limitation of the program and a concern to the provider.

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

The program also reached some of the target group of young adults with physical disability. ABIOS was funded to provide the pilot to young adults with both acquired brain injury and physical disability. All participants in the pilot had multiple impairments. The young adults came from a range of geographic areas within the bounds of the pilot area, and a range of socio-economic and cultural and ethnic backgrounds. Young adults in the pilot were recruited through the ABIOS general referral stream, and concurrently received other

ABIOS case management services. The pilot was not promoted to the wider community to attract other young people with disability. ABIOS services were promoted through a website, service provider training, publication, research and specific strategies for Indigenous and CALD communities.

### Entry and length of time in the program

Once the program was established, a steady flow of new participants entered the program during 2010 (Table 2.2). Fewer participants entered in 2011, because of the need to plan for transition at the end of the pilot and the limited capacity of the program. Data available about entry and exit from the program were incomplete.

**Table 2.2 Participants entering the program by month of entry**

Year	Quarter	ABIOS	SCCTC
2009	Oct – Dec	1	0
2010	Jan – Mar	8	6
	Apr – Jun	12	7
	Jul – Sept	4	13
	Oct – Dec	4	6
	2011	Jan – Mar	0
Total		29	35

Source: Program registration data for Dec 2009 to March 2011

Note: The total numbers reflect the total valid responses only, as some participants had no entry dates recorded.

On average participants spent 8-9 months in the program (Table 2.3). This average reflects the variation between participants who stayed in the program a short time to complete the planning and achieved their goals; and those who renewed for a second 12-month period, to continue to work incrementally towards long term goal achievement. This pattern was consistent for both the children and young adult groups.

**Table 2.3 Average time in the program by location**

	Clients	Average program length (days) (exited clients)	Average program length (months) (exited clients)
ABIOS	16	271	9
SCCTC	17	234	8
Total	33	286	9

Source: Program registration data for Dec 2009 to March 2011

Note: some clients did not have entry dates

This pattern of duration in the program indicates the sustainability of the outcomes were likely because former participants were sufficiently secure to leave the program before the end of the 12-month period. It also reflects the priority of both providers to link participants to specialist and mainstream services in their own organisations and in the wider community.

### **3 Outcomes for children, young people and families**

The evaluation analysed the outcomes and effectiveness of the pilot program for individual participants and their informal supporters. The program rationale was that linking people with disabilities and their informal supports with their local communities and creating opportunities for meaningful engagement and participation enables participants' independence, self reliance and wellbeing.

In this section, we analyse the extent to which the pilot program 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 analysis was based on program data for all pilot participants from January 2010 to July 2011; interviews with young adults, their informal supports and family members and carers of young children using the pilot; (Table 1.1 and Table 1.2) and personal wellbeing index data from January to July 2011.

#### **3.1 Enhancing participants' independence and families' resilience**

##### **Wellbeing, independence and resilience**

Both sets of participants, including families and children, and young adults and their supporters, reported improved wellbeing, independence and resilience due to participating in the pilot. These findings were consistent with the Personal Wellbeing Index (PWI) data. Data from the PWI indicates that carers in the pilot had higher personal wellbeing rates when compared to Australian carers, described below.

##### *Young children*

All families reported increased wellbeing and independence for their children due to the pilot. Most of the young children in the pilot had the beginning signs of 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, were able to progress to sitting, standing or walking. This progress enabled them to move to other development milestones and to become more independent.

Family members and informal supporters consistently linked improvements in children's physical health, wellbeing and development to the child's involvement in the pilot. Family members reported these positive outcomes as

a result of referrals to regular contact with specialists, individualised therapies and equipment, and overall support provided through the service coordinator. A parent said,

It's been great, it really is intensive early intervention. [Our daughter is receiving] speech therapy, private physio, music therapy, orthotics, 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 orthotics, which are great.

Families who received a second round of funding saw the most improvement for their children. These parents also felt more confident to seek out further programs and activities to continue the improvement. A parent said,

Since Simon<sup>3</sup> has had that trolley for walking, you can't stop him! He didn't want to walk before; now he's always using it ... It looks like he is catching up with other kids his age, development wise.

### *Young adults*

Most young adults with acquired brain injury reported an increase in wellbeing and independence as a result of the program. They consistently reported using the planning process to engage in activities that built their independence and self-reliance. Participants interpreted increased independence in a wide range of ways. Many participants used the planning process and funding to take up exercise, join clubs or purchase equipment which was aimed at building physical strength and resilience.

Having access to tailored support was important to people, so that they could adapt their exercise requirements to their personal circumstances. Beth, for example, found home gym equipment to be of more use than a gym membership, as she would not be able to get there easily. She used the home gym daily, and as a result was now walking independently. Beth said, 'Having the freedom to choose what suited us worked.'

In another case a young woman increased her independence creatively by using the funds to hire a dog trainer to train the unruly family dog. This helped her feel confident in walking in dog, enabling her to get out of the house, and more easily around the neighbourhood.

Participating in the pilot gave many of the young adults a new perspective on what they might do and activities to support their goals. Setting a goal, having the resources to realise it, and actively working towards its achievement, with some encouragement and support, all increased young adults' emotional wellbeing and self esteem, and in some cases also their mental health. Family

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<sup>3</sup> Note: pseudonyms have been used for all project participants and interviewees quoted in this report.

and other informal supporters of the young adults all noted an increase in independence in the person they supported. Two family members said,

Before the pilot [he] was very depressed and often spent much of the day in bed ... Now, he's tinkering in the garage all day ... It's giving him ambition and drive.

It [the pilot] has opened his eyes to possibilities of doing things other than watching TV and drinking.

In some cases the increase in independence was physical – gains made through exercise programs, for example. In other cases, supporters talked about the emotional and psychological gains they observed. Several of the young participants themselves also spoke about the pilot assisting them to gain and maintain a better balance in their lives between addressing needs related to their impairment and participating in their community.

Many participants used the program to support education goals, which contributed to their emotional wellbeing, future financial independence and immediate participation in the community. When we asked young adults to reflect on what they had gained from their involvement in the pilot, most participants felt that they had increased their independence. Their comments included,

I know what I want in this life now, and I'm going to go out and get it. I'm amazed at how far I've got in two years.

Help, support, and the possibility of learning things and doing things I haven't been able to do before. To complete some goals I'd had in the back of my mind for a long time, but hadn't been able to do.

#### *Family members and informal supporters*

The majority of parents of children in the pilot reported positive outcomes for themselves, including increased wellbeing, which was commonly linked to a reduction in psychological and emotional stress and their sense of isolation. Observing the rapid improvements in their children's development and wellbeing gave the parents a sense of hope. They also found the information and coordination of support through the service coordinator very useful. One parent said,

It's taken a huge amount of stress from us. It was such a relief to find this program. We'd been to see I don't know how many GPs and specialists and paediatricians ... and no one would help us or give out any information about how we can find support, and what type of support would help us.

The support model enhanced family members' and informal supporters' independence by strengthening their sense of self esteem and self reliance as carers. It enabled parents and carers to be experts on their children's needs and wellbeing, so they could actively seek out options for their children. 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 also contributed to family members' independence, because they were 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 for strengthening family relationships and contributing to their family's resilience. This finding is consistent with child disability and family resilience literature (Muir et al, 2008). Some mothers also used the impetus from the pilot to address their own health needs.

Informal supporters and family members of young adults had a different focus to the family members of young children, and reported the pleasure they took seeing the progress and satisfaction of the young person they supported. The informal supporters thought the financial component of the pilot was important to resource goals and enable participants to undertake activities which would not otherwise be possible.

Some of these activities indirectly benefited the family or support relationship, such as enabling a mother to have some time to herself during the week while her son was supported by a regular worker to complete some of his planned activities; or emotional benefit to the whole family of a holiday which was funded within the package. Participants' growth in self-confidence and willingness to try new things was seen by informal supporters as very positive, and with benefits to the relationship. Tania, for example, noted the pride of their children since Matt began woodworking and made his workbench, saying, 'Our two boys love it, and we have had to buy them their own little workbenches!'

### *Personal wellbeing*

These positive outcomes noted in the interviews with participants' families and informal supporters were also reflected in the analysis of the personal wellbeing survey. The sample size is small, so the results should be read with

caution. The average personal wellbeing scores were similar to population data and higher than a national sample of Australian carers (72 for SCCTC carers; 75 for ABIOS carers; 75 Australian population; 59 Australian carers; on a scale of 0-100, Table 3.1). These positive findings were sustained throughout the duration of the program.

In second data collection the average PWI scores for informal supporters of children in the program (n=37) were 84, nearly ten points above the average scores of the Australian population (75), and 25 points higher than a national sample of Australian carers (59).

**Table 3.1 Personal Wellbeing Index scores by groups**

Measure	Family/carers children <sup>1</sup>		Family/carers young adults		Young adults		Australian carers <sup>2</sup>	Australian population <sup>3</sup>
	First	Second	First	Second	First	Second		
Participants	43	37	8	2	19	8	3,766	22,912
Mean	75	84	76	75	67	57	59	75
Minimum	46	49	39	70	29	34	-	-
Maximum	96	100	96	79	97	86	-	-

Source: SCCTC and ABIOS collection 2011

Notes: Scale 0-100

1. In second data collection additional 10 cases were available and added to the sample of family and carers of children in the program. The total sample in the first collection increased from 33 to 43 people.

2. Data for Australian carers were from the Cummins, Hughes et al. (2007:4).

3. Australian population figures are aggregated individual PWI data of total combined surveys from 2001-04. The data were from Cummins (2005).

These findings are especially relevant when we compare the scores of SDS family members and informal supporters other Australian carers, as carers are known to be amongst the population groups with extremely low personal wellbeing (Cummins, Hughes, et al. 2007). Cummins (2007: 4) analysed the wellbeing and stress levels of over 3700 carers in Australia. They found that carers in this study had the lowest wellbeing scores (59) compared to other identified demographic groups with very low wellbeing.

The consistent longitudinal (repeat) data from the children's families and carers shows that these positive findings are unlikely to merely be due to the effect of taking part in the pilot program (Table 3.2), although the samples are small. A repeat sample of 32 family members and informal carers of children in the program showed an increased satisfaction with average personal wellbeing and a number of life domains (achievements, personal relationships, sense of safety, feeling part of the community (social inclusion) and future security). Increased satisfaction with the other domains, health and standard of living, were not statistically significant.

**Table 3.2 Longitudinal satisfaction with life domains by children's family or carers**

Measure	Repeat sample of family/carers of children		Statistical significance <sup>1</sup>	Australian carers (age 36-55) <sup>2</sup> n= ~ 1273
	First	Second		
Personal wellbeing index	77	83	.000*	59
Standard of living	80	83	.231	57
Health	74	77	.222	51
Achievements	72	82	.00*	50
Personal relationships	80	87	.008*	52
Safety	86	92	.002*	64
Feeling part of community	75	84	.001*	51
Future security	74	80	.042*	46

Source: SCCTC collection 2011 n=32; Scale 0-100

Notes: 1. Significance tested with repeated sample T-test. \* indicates statistically significant increase in wellbeing.

2. Data for Australian carers are from the Cummins, Hughes et al. (2007: 4).

These findings demonstrate a positive impact on family members' wellbeing over time and longer participation in the program increases it further, especially when compared to the lower PWI scores of a national sample of Australian carers.

Due to the low response rate of family and carers of young adults we could not undertake further analysis for this group of carers (Table 3.3 Table 3.1). Similarly, the second measure for young adults was too small for further analysis.

**Table 3.3 Longitudinal satisfaction with life domains by young adults and their family or carers**

Measure	Young adults ABIOS		Family/carers ABIOS		Australian carers (age 36-55) <sup>1</sup>	Australian population <sup>1</sup>
	First	Second	First	Second		
Respondents	19	8*	8	2	~ 1273	22,912
PWI	67	57	76	75	59	75
Standard of living	70	75	71	65	57	77
Health	65	39	81	75	51	75
Achievements	68	49	69	75	50	74
Personal relationships	63	49	85	85	52	80
Safety	78	74	81	75	64	78
Feeling part of community	65	58	79	75	51	71
Future security	62	56	66	70	46	70

Source: ABIOS collection 2011; Scale 0-100

Notes: 1. Data for Australian carers in the age of 36-55 years (Cummins, Hughes et al. (2007): 53 and authors calculation.

2. These figures represent aggregated individual PWI data of total combined surveys from 2001-04. The data were from Cummins (2005).

\*Including 5 who had only been in the program for one month, which is likely to be too short for measurable impact

## **Empowerment and coordination**

The SDS model was 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.

Family members of young children said the support received was strongly empowering. They particularly appreciated recognition 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 service coordinator] helped us to work out what to get done.'

Participants reported working in partnership with a committed service coordinator as the key to negotiating complex service environments and to help them prioritise their identified needs. All families who were interviewed twice were highly confident in their discussion about choices and how to plan to optimise their choices to achieve better outcomes for their child.

As noted in Section 4.3, families also valued the flexibility of the pilot to pay for a wide-range of identified needs, depending on the children's and families' changing support requirements. A parent said,

[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.

Families said they had a good understanding of what they need and want, but said they often lacked understanding about the range of available resources and support available, or they lacked the 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 was aggravated when they were in the process of learning about the additional support needs of their child, which can, for some families, be full of anxiety. Hence, many families said that receiving personalised assistance through the pilot and having someone 'who listens and understands' was as critical as the access to support itself. They said it was through the assistance of the service coordinator that they feel empowered, informed and emotionally supported to access what they need. Parents said,

[She 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 are 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 was that professionals worked together and coordinated their activities, where appropriate, to meet a person's needs. The strengths of such professional partnerships meant better and more rapid outcomes, in this case, for young children's development. In several cases, family members reported that the coordinated team approach allowed professionals to draw in extra resources to meet their children's needs without having to rely on the funding allocation. A parent said,

The main positives [of the pilot] are the support that [the service 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 was perhaps even more important. The role of the planning and casework elements of the program in making links to other ongoing supports was important to participants and their informal supporters, as was the role of case workers in providing information about options which might be available longer term (such as employment, or ongoing funding for a regular support worker).

The individualised, person-centered and flexible nature of the program was a key to young adults' satisfaction with the program and their sense of empowerment. Empowerment to them was strongly connected to the degree to which young adults felt their ideas and goals were respected and supported. Most participants (13/15) felt that their case workers were supportive and enthusiastic about their ideas and planning goals, as in Phillip's case,

She's great. If she hadn't been there to push me and make me think about things ... She arranges, she takes up my hints, she's fantastic.

Another central aspect of the pilot was the quality of the relationship between the young adult and the case worker, and the workers capacity to coordinate and organise identified support needs. Most participants were either satisfied or highly satisfied with the case work arrangements. Young adults appreciated the rapport, felt supported and respected, felt workers were reliable and that they worked behind the scenes to make things happen. One young woman commented, 'She does what she says she is going to do, and that's important ... She has been there for the long haul.'

Two participants were dissatisfied with the case work arrangements to some degree. Their concerns were about the effectiveness of their case worker working in partnership with them, implementing their ideas for support and funding, and advocating on their behalf in team meetings. Although these two young adults raised some concerns, they still felt that they had benefited from the pilot.

Some of the young adult participants had traumatic or difficult histories, either due to their injury or other life circumstances, which they felt reduced their sense of self-worth and esteem. They found the trust placed in them by the self directed approach in the pilot, and workers' emphasis on decision making and control over allocated funding highly empowering.

### **3.2 Social, community and economic participation**

The program improved the social, community and economic participation of the young children and their family members, including parents and siblings. Young adults reported increases in community and economic participation. Many of the activities that participants identified as goals were community oriented, or located in the community, and therefore involved social interaction and engagement with other people. However, their gains made with social participation were more limited.

As noted above, most young children participating in the pilot made substantial improvements in their motor skills and development, which enhanced their opportunities for social connections in their families and communities (eg. play with siblings and interaction with peers).

The parents of young children consistently reported high levels of satisfaction and rapid outcomes for the child's development when professionals worked together around their child's care and needs. The individualised nature of the support enabled some of the children of school age to take a more active part in 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 service coordinator], and also because the OT and physio are working together.

Family members of young children noted that the program provided 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 viewed the assistance 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 were now able to pay for social and community activities for their other children, such as swimming lessons.

Several mothers reported accessing community programs or facilities to complement the pilot. An example was a mother enrolled in a course at her local library to learn how to use the computer purchased through the program, so that she could help her son with his motor skill development.

While the pilot directly addressed the affordability of their children's support needs, it did not resolve the economic complexities families may be facing. In some cases, where mothers were the primary carers, they had stopped paid work or decreased work hours to meet their child's additional support needs.

Over time, as a result of children's improved wellbeing and independence, some primary carers were able to increase paid work again. Nevertheless the incompatible challenges of remaining highly flexible in their caring role, paying for disability related costs and remaining in a labour market that demands long working hours, added to pressure on families' budgets and resilience.

Young children and their families experienced some of the following key community inclusion outcomes:

- Care and equipment supported children's positive development and wellbeing and social and community participation eg. school attendance
- Children's positive outcomes contributed to families' resilience and positive family relationships, such as primary carers having more time for their other children
- Families were connected to community supports and specialist services eg. through the information from the case coordinator
- Some families avoided entering a crisis and social exclusion. In the extreme, one family said the coordinated support and funding prevented them from selling their home to pay for their child's specialised therapies and
- Some primary carers who had two rounds of funding in the program were able to resume paid work again, as a result of children's positive outcomes that meant for example they could attend child care.

For young adults participating in the pilot, the social community and economic participation outcomes were even more direct. Young adults reported improvements in their community and economic participation. Many of the activities that participants identified as goals were community oriented, or located in the community, and included social interaction and engagement with other people.

Young adults' economic participation increased through purchasing goods and services from their allocated funding, but also through focusing on career development, with the aim to increase their employability over time. Many participants enrolled in TAFE courses or other professional and personal development opportunities. All the participants who were studying said they found it valuable. These activities and pursuits improved the young people's social and community participation and were likely to contribute to their enhanced economic participation in the long term.

The young people's gains in social participation were limited so far. Several young adults noted that the primary social connections they made through the pilot were with their case workers, service providers and other facilitators. The young adults had few examples of ongoing social relationships that had developed from activities within the pilot. One carer questioned whether the support provided to participate in community based activities was leading to

relationship development. She said, [The support worker] is good company, they get on well, but when the funding ends in November, what's changed?'

### **3.3 Community connections and networks**

The final objective was to enhance and connect participants to informal forms of support beyond the program. The majority of the families of young children had limited, if any, prior contact with the social service sector before joining the pilot. Many parents were interested in exploring networks and resources once they commenced the planning process, and most families were on waiting lists for ongoing support.

In the early stages of the pilot, families prioritised meeting their children's immediate support needs over identifying additional forms of informal and community support. However, as they spent longer in the program, many of the mothers requested that their contact details be passed to other mothers in the program for networking and peer-to-peer support. Some requested to set up a playgroup or coffee morning to share ideas, information and resources.

Families also sought out and participated in activities in their local communities, such as attending the local library, swimming lessons at the local pool, and bike riding in local parks. With increased knowledge from the program, they also investigated their eligibility for additional services.

The major challenge to the capacity of the SCCTC model to enhance families' long term community networks was limited staff availability to coordinate and develop this aspect of the program (see Section 3.4).

None of the young adult participants reported developing long term social networks beyond the contact with pilot staff, perhaps due to the short term pilot. The activities, equipment, memberships and educational opportunities pursued through the program may contribute to social network development over time. For example, several participants mentioned in the last interviews that they were waiting for TAFE courses to start, and they expected to meet new people then.

Some people also progressed with incremental steps towards developing their social network. Simon talked about how he was bumping into people he could talk to at the gym more frequently now, but had not been for a coffee or to a BBQ or anything with them yet. This may happen in time, particularly if it was articulated in the planning process that he was keen to pursue this contact further. The gains in confidence and empowerment made by participants through the program could also be expected to improve their capacity to develop social networks.

Some of the young adults' goals were aimed at supporting and developing social networks. For example, in deciding whether or not to use her funds to buy a trike, Lucy checked with a friend,

I rang up my friend, and I said 'You know what, there's a chance I could come bike riding with you if I bought a trike.

What do you think? Would you be caught dead riding beside me with a trike?’ And she laughed and said ‘Yeah, do it, for sure! That’s cool! And then you’ll have this big rack on the back where you can put the picnic hamper!’

Some participants used funds for family holidays, passes to theme parks, and one planned to use funds to travel to her country of origin for a holiday. All these goals were to strengthen family bonds and explore opportunities for reconnecting to and engaging with members of the wider community.

People who already had social networks benefited from achieving goals that strengthened these networks. It was less clear whether the pilot was able to forge new social networks for participants. Building new networks is a complex long term endeavour, and establishing a presence in the community was probably an essential first step in social network development. An advantage of the ABIOS model was that case worker support for participants continued at the end of the pilot, enabling these participants to continue to build on the foundations laid with the SDS planning and funding.

Implications of the pilot may be that the long term nature of developing social networks, particularly for isolated people or people with higher support needs, requires the early development of informal social support circles or the active referral into ongoing support services.

### **3.4 Implications of the outcomes**

The flexibility, planning and coordination of a person’s needs, a person centred service delivery approach, and empowerment were central to the successful implementation of self directed support programs.

The program achieved its goals of improving wellbeing, independence, resilience and social participation of participants and their family members and informal supports.

The program also contributed to community connections for sustainable support and economic participation for young adults and families. This was most challenging for young people without existing social networks to build on because developing new networks is a long term activity.

## 4 Service use and effectiveness of service delivery

This section addresses the effectiveness of the pilot support model, and draws implications for program improvement, including the responsiveness of the model to meet participants' needs; the extent to which the model facilitated self directed decision making and control over allocated funding; and the extent to which it built on participants' and families' strengths and capabilities.

The sources of data used to address this part of the evaluation were interviews with key stakeholders, program observation and Departmental and program data from the service provider and MDS.

### 4.1 Service use

The two groups of pilot participants had different needs and used the program in diverse ways. The following section summarises the available MDS and program data about participants service use from July 2010 to June 2011. It summarises the amount of case management children and young adults received, as well as the different needs identified for each group.

#### Case management

The hours of case management received for all participants ranged from less than an hour to nine hours per week per participant. The median of one hour per week in the first quarter remained constant over the pilot. From the hours of case management support received by each group, it is evident that young adults in the pilot had higher support needs (Table 4.1).

**Table 4.1 Average hours of case management per participant per week**

	July-Sept 2010			Oct-Dec 2010			Jan-March 2011			April-June 2011		
	Range	Median	N	Range	Median	N	Range	Median	N	Range	Median	N
All	1-5	1	47	1-6	1	54	1-3	1	55	1-9	1	56
Children	1-1	1	22	1-2	1	26	1-2	1	29	1-1	1	30
Young adults	1-5	1	25	1-6	2	28	1-3	1	26	1-9	1	26

Source: MDS data for July 2010 to June 2011

Note: Responses less than one hour were rounded up. Some participants were unable to be matched to MDS data.

In the children's group, families consistently received one to two hours of support per week across the four quarters. An explanation for this consistency may be that families' support needs generally remained similar over time eg. access to specialist services and equipment for their child. It may therefore have been easier for the worker to provide more consistent planning support. Some families in the children's group also sometimes needed some months to fully engage in the planning process, due to a range of factors such as family relationships and emotional readiness. The narrower range of case management hours received by children may also be an indication of the restricted capacity that the sole part-time worker could allocate to each family.

For young adults, their identified support needs varied and changed throughout their involvement in the pilot. Case notes for the young adults with lower amounts of case management, such as one hour per week or less, recorded some problems contacting participants, for example, participants' not returning calls or missing appointments. These situations are common for people with acquired brain injury.

The available information indicates that the case management allocation in both models was responsive to the participants' needs, availability and readiness to fully engage. It varied by the amount of time a person required and it changed over time as their needs changed.

### **Types of support received**

The program data indicated that children and young people in the pilot required different types and modes of support. In the planning process participants (or their families in the case of young children) were asked to identify three needs in order of priority. Many participants recorded three needs and some recorded fewer. Fewer recorded needs seemed to be if their needs were more complex or costly than other participants, or that they had not identified all their needs when the program data were provided for analysis. Of the 46 participants with any needs identified and recorded, 145 individual supports were identified. Table 4.2 details their support needs in order of priority identified by the participants and their families for young children.

As expected, participants – particularly in the young adults group – identified a wide range of support needs. The most common needs for children and their families were therapies (physiotherapy, speech or occupational therapy). In some cases the children already received the support and the identified need was to continue with the treatment, when they could not afford them because they were 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 was equipment, which was usually related to the therapy received by the child. Many children also had a third need identified, and these were concentrated on community involvement or family activities, such as swimming lessons or transport.

Young adults had a wider range of support needs than the children in the pilot. The commonalities between participants in the young adults group were education and fitness. They said in the interviews that they were very motivated by career development, and made use of the pilot to redevelop their career post-injury. Educational needs were rated a high priority, and many young adults used their funds to pay for costs associated with study, including books or computers. The second important priority for young adults was increasing personal fitness, participation in sporting activities that may contribute to a person's wellbeing, and also foster community participation. These activities were also linked to increased social and community involvement as a priority across the group.

**Table 4.2 Needs identified by participants in order of priority**

	Number of participants identifying need in order of priority			Total participants with the need
	Priority 1	Priority 2	Priority 3	
<i>Children</i>				
Physiotherapy	27	1	0	28
Specialist equipment	2	7	4	13
Speech therapy	1	4	5	10
Community / family activity	0	3	7	10
Podiatry / orthotics	0	9	0	9
Childcare	3	1	3	7
Occupational therapy	3	2	1	6
Swimming lessons	0	0	6	6
Hydrotherapy	0	3	2	5
Inclusion support service	0	1	1	2
Auslan	0	2	0	2
Horse therapy	0	0	2	2
Transport	0	0	1	1
Specialist medical treatment	0	1	0	1
Computer / software for development	0	1	0	1
Number participants with identified need	36	35	32	
<i>Young adults</i>				
Equip. / fees for Formal education	4	3	2	9
Fitness / training / diet at home	2	2	2	6
Social activities / community involvement	1	4	0	5
Equip./ fees for community education	2	1	1	4
Specialised medical assistance / therapy	2	1	1	4
Sports / social fitness / personal training outside home	0	2	2	4
Assistance with moving house / relocation	2	0	0	2
Computer / internet / technology for personal use	0	0	2	2
Home tutor / parenting program	1	0	0	1
School clothes and equipment for child	0	1	0	1
Swimming lessons	0	0	1	1
Gardening equipment	0	0	1	1
Assistance with personal /employment goals	0	0	1	1
Assistance with gender identity issues	0	0	1	1
Number participants with identified need	7	5	10	
Sources: Children: program tracking data between 2010 and 2011. Young adults: program tracking data supplied in May 2011 for a subset of clients in the program.				
Note: Totals do not represent all participants because some participants did not have a need identified, and some clients were not included in the data				

## 4.2 Participation in organising support

In this section we analyse the extent to which processes in the pilot model empowered participants and their informal supporters to make decisions about their needs and goals.

In SCCTC, the planning process was used by the service coordinator with the families to identify options and to provide them with a range of information about resources they can access, either through other programs, or by drawing on their funding allocation. Families of children participating in the

pilot reported that they felt a sense of control over their allocated funding, and support in the process of setting and prioritising goals. They said,

We were seeking a bit of direction, so it was really useful to have the planning document and process, to talk things though.

We worked out together that he [the son] would need some activities, and we both thought about the types of activities, and worked it out from there.

Most families actively discussed their options within the family, and took charge of planning and prioritising (Section 3.1). Interviews with families showed continued high levels of satisfaction with SCCTC's approach to planning to set and implement goals and drawing on the funding when necessary.

Young adults approached the planning and goal setting process in range of ways. Some participants spoke about living in the moment and dealing with their circumstances on a daily basis. For them plans centred on making changes to their immediate situation, including increasing their fitness, dealing with chronic pain or frustration, and adding more activities to their schedule to have something enjoyable to look forward to do.

Many young adults focused on getting back to work, or learning new skills. In a few cases young people thought and planned more independently and creatively about how to use the funds and support as a springboard to future personal success. Dean, for instance, had career plans that required completing several inter-related courses. By the end of the second round of funding, he had done two of the three courses. In Lucy's case, she used the planning and funding to learning skills to develop her own business. She said,

When I first found out about the pilot, I was so excited, I thought 'wow' this was amazing, I can do this, and this!' ... But I realised it [the funds] goes very quickly. And was it really going to end up helping me to continue where I am, or am I going to fall in a heap at the end when I've spent it all? And I didn't want that to happen, so I tried to space it out, so it's like a little infusion here and there where I'm needing it, and that's working really well for me.

At its best, participants described a partnership approach to planning and decision making with their case workers which supported and extended the goals they identified. A few young adults were seeking new directions but were less sure of what they wanted to do, and had used funds to explore different options.

Some young adults were unsatisfied with the planning process. Two participants wanted to use their funds for speech therapy, but said they were told it was not possible within the program guidelines. They found this frustrating, as they felt communication difficulties were their biggest barrier to

independence and social inclusion. A third participant did use the funding for speech therapy. Three participants said they had other planning goals refused that they had felt were consistent with the program. It was difficult to know if there were other reasons for these situations without knowing the specifics of the decision making, such as prioritising the limited funds, for instance.

In the early stages of the pilot, some ABIOS workers were concerned that some people with acquired brain injury would struggle to make responsible spending decisions. Another concern was their ability to scaffold activities (or sub-goals) in the planning process, and the need to align goals to the program objectives to remain within the program guidelines.

To address these risks, ABIOS implemented a risk assessment process to support young people in their planning process. This focused on a careful planning process, training for workers, working through decisions with participants and the team meeting review process. From the interviews with workers and young adults it appears that this process was carefully implemented, was respectful of individual difference, cultural diversity, and was well integrated with the principles of the program. Young people and ABIOS workers provided many examples of creative solutions which mitigated risk while at the same time maximising participants' choice and control. There were some limitations to autonomy from the point of view of participants, notably the team meeting review process (Section 4.3).

As illustrated in Lucy's case above, most participants interviewed had a strong sense of working step by step towards a bigger goal, such as education as a step towards work, or starting with an exercise physiologist to get strong enough to join a community gym class. Matt's plan was another example. He asked that the plan and photo be included in the evaluation report.

Matt is about to start a woodwork course, to develop his skills in making small pieces of furniture and other items. He and his wife plan to start a small online business to sell these once he gets on his feet. Matt has used his funding to purchase some tools and wood, and was doing voluntary work with a furniture maker while waiting for his course to begin. He was a bit disappointed not to be able to use a Bunnings gift card to buy woodwork incidentals under the rules of the program, but understood it was outside the guidelines.\* He downloaded a plan for a workbench from the internet while waiting, and made his own workbench and set up a workshop in his garage, so he would be ready to go with his business.

\* The use of a Bunnings gift card was within program guidelines; however in this circumstance the parameters for its use were considered within a risk assessment context for the client in question.

**Figure 1: Matt's workbench**



Most ABIOS participants were satisfied with the approach to risk management taken within the pilot, except when the financial rules caused delays or inconvenience (Section 4.3). The two participants discussed above were not satisfied that they had sufficient input into the decision making process about goals which carried a level of risk.

Another possible limitation to the effectiveness of the planning process was the complexity of the staff and participant relationship, and the power differential between case workers and clients. Some ABIOS participants expressed gratitude for the funding and support, and were reluctant to make demands on the pilot, raising questions about the degree to which they would feel prepared to push the planning process. The power differentials between team and clients, in the very best of professional relationships, require careful and skilful management in order for people to feel they able to make demands in a time pressured environment. It was to the credit of the professionalism of the ABIOS case workers that most participants felt the case worker contact was appropriate; they were able to contact their worker whenever they wanted to, and could get a quick response.

The developmental approach taken to planning was a key strength of the pilot. The measures implemented by ABIOS, including training staff in person centred planning; planning processes which were individualised and flexible; and additional resources for workers to overcome difficulties, where identified, have proven to be a very sound approach to developing a solid planning structure.

ABIOS participants discussed their understanding about the need to be prudent in their management of limited finances, and provided examples.

Cameron said, 'I'm not going to use the money just to use the money, you know what I mean? If I use it, I want to use it for something beneficial.' Staff and policy makers shared this view. Policy makers also stressed the importance of funding for 'non-traditional forms of support' as an integral part and underlying philosophy of self directed support.

Workers reported that the major limitation undermining the success of the planning approach for some participants was the short timeframe of the pilot. Young people were at different levels of readiness to plan and progress, hence the process required different amounts of time and levels of support.

### **4.3 Funding allocation**

The program included up to \$4000 per year to support each participant's plan. In the previous section we described how this arrangement had empowered participants (Section 3). This section examines process issues arising from participant experience and program data.

SCCTC operated several approaches to managing the funding allocation during the pilot. In addition to reimbursement of expenses to families and payment of invoices directly to providers of goods and services on behalf of families, SCCTC also offered families the option of self managing their funding during the second half of the pilot if they wished. One family took up this option.

Most SCCTC families indicated that they were happy for the money to held by the service provider, as they felt it would take too much time to manage the money and account for expenditure. They also questioned whether the money would need to be included in an income tax declaration, and whether a separate bank account would need to be set up. The service provider also raised the issue of GST and the fact that the service provider was registered for GST and received this money back, however if individuals were paying for services and equipment, they were not registered for GST and so essentially this would reduce the amount of funding to \$3600 for families who chose to hold the money themselves.

Irrespective of the choice for managing the funds, SCCTC parents suggested acquittal balances be sent regularly via email or posted to families (monthly, rather than the current quarterly system) so that parents could better understand how much money was left in their funding budget. One mother was critical of the timeliness of the process for receiving reimbursement of funds spent by the family, and receiving an updated balance of the amount of money spent. She said,

This is the one thing that I am disappointed in the program about. Maybe there might need to be some guidelines or policy around this when you enter the program, so you know when exactly you will be reimbursed and told of the balance. It would be better if the Government could do a reimbursement system like Medicare for this program – you just go into a local branch and get a refund.

Young adults using the program were responsible and prudent in their approach to planning and spending of funding. All participants felt that access to the funds was a great opportunity to resource their goals, some of which they had held for some time. All participants expressed appreciation for their inclusion in the pilot, and valued their involvement. Two participants were reluctant to spend the whole funding package, so as to leave funds for other participants who may need it more. Most participants were unable to specify the amount of funding they had used or which remained. Some were able to estimate to within a few hundred dollars. Keeping across this level of detail may not have been seen as important for all young adults. However, they all indicated that they felt able to call their case worker and ask how much funding remained.

In the second interviews, the participants commented on the opportunity to self direct funds. Some people had discussed this option with ABIOS, and one participant had recently taken up the self management opportunity. She talked about seeing the benefit of what she had achieved, and how it guided her planning. She said,

I feel responsible, and that I'm moving forward in an organised fashion. I think I can see the benefits of it more than I did earlier, and see the benefits of what I've been able to achieve.

Managing her own funding, she found simultaneously liberating but also isolating. She suggested that it would be helpful to continue to have more frequent contact with her case worker, to be able to bounce ideas off someone before making her decisions.

Other participants preferred that ABIOS continued to hold and administer the funds, while they had control of the decision making process. For some, this was due to the level of trust established with their case workers. Two other young adults felt that holding funds directly would be a burden and worry that they would prefer not to have.

ABIOS managers reported that six clients were self managing their funds, five in part, and one client managed the whole allocation. The clients who were partly managing their own funds averaged a 50 per cent split of self- and ABIOS- managed funding. Another three clients declined the offer of self management, one due to concerns about tax implications of the funding, and the other two because they were satisfied with current arrangements and preferred ABIOS to manage the funds.

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

arrange, and there were delays in the purchase of equipment and services due to the time taken for departmental approval processes.

These limitations to independence and participation in purchasing inhibited the program effectiveness from the point of view of participants. While they were highly satisfied with the program, its processes and outcomes, participants consistently raised the problem of delays in obtaining goods and services and limitations to the ways in which purchasing could occur as factors which they felt could be improved. ABIOS workers, managers and government policy stakeholders also supported these views.

Some participants suggested changing the administrative arrangements, so that finances could be organised more quickly, and waiting times for goods and services were minimised. For example, people did not want to have to ask shop cashiers to phone ABIOS for a credit card number to buy equipment which was part of their planned expenditure. To some people, this was demeaning, and they felt required them to explain about their brain injury and the SDS so that they were not under suspicion of credit card fraud.

The main problems arising from this structure related to strict regulations (unrelated to SDS) of how funding allocated can be spent through Queensland Health, and young adults not being able to take direct control over their budgets. ABIOS case managers, participants and policy makers suggested that participants would be more empowered by having increased control over purchasing.

Most people who participated in the repeat ABIOS interviews said the control they felt over planning and spending had increased. The one exception was someone who wanted more information about options available, such as work, more efficient support, and greater control over funding. Four participants were satisfied in the first interview, and indicated increased satisfaction in the second interview.

The ABIOS process of discussing funding decisions in a team meeting for discussion was not constructed by the ABIOS management team as an approval process, but rather an opportunity for staff to discuss difficult issues, brainstorm, and to validate and affirm staff in their support of the decision making of clients. However, participants consistently viewed it as an approval process where formal decisions about their spending proposals were made. Several comments by participants illustrate this,

I put my ideas forward, and she said 'that *should* be OK, but I'll ask the board, you know, the group of people who are in charge of deciding what the money actually gets spent on.'

[caseworker] thought it was a good idea, and she confirmed it with the headmaster [ABIOS manager], and they thought it was a good idea.

[caseworker] said 'OK', she'll just have to check to make sure they're allowed. She just didn't give me a definite yes or no, she said 'I'll check, and once I've checked, I will let you know.'

And she rang back and said 'yeah, we shouldn't have a problem with those' [goals].

Program participants' understanding that financial decision-making rested with the ABIOS management team restricted the effectiveness of the pilot, because it limited their opportunities for self direction.

ABIOS responded to these constraints on program effectiveness by implementing several strategies to minimise delays and increase flexibility, ranging from the use of a credit card to increase purchasing flexibility, to offering participants in the program the opportunity to self manage their funding.

SDS was designed as a non-recurrent program. Nonetheless, this design limited the way participants could plan, and negatively affected people with higher support needs, who were most likely to require ongoing support to access activities and community-based initiatives. ABIOS workers and managers raised this as an issue early in the research, and it was confirmed through the experience of pilot participants.

Policy makers and participants both echoed their preference for a longer period of funding and support to achieve sustainable outcomes. For example, a young woman was in the pilot for two years (representing two separate intakes) with the same case worker. The first steps were small indirect tasks to eventually regain her apprenticeship. The funds were used for a computer and driving lessons. She now has a job, house and transport, contrasting sharply with her difficult circumstances before the pilot.

#### **4.4 Supporting early intervention and innovation**

The pilot model was 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 was designed as an early intervention initiative to support children, young adults and their families previously not accessing or excluded from other formal assistance, and young children who were showing early signs of additional support needs.

SCCTC children and families continued to experience the program's early intervention focus as described in Section 3.1, resulting in improved outcomes for children.

For ABIOS clients, the concept of early intervention was relevant to the onset of impairment, rather than chronological age. Participants in interviews who were new to receiving supports or services in the disability or health fields (either newly injured, or whose other service contact was with the criminal justice or homelessness systems) expressed higher satisfaction with the

support provided through the pilot than those who were involved with disability related supports before. In comparison to hospital, outpatient physiotherapy and rehabilitation, criminal justice services and homelessness outreach services, participants found the SDS program to be very flexible, person centred and respectful of their preferences, needs and goals.

### **Innovation in service delivery**

A second program goal was innovative service delivery. SCCTC families and children were positive about the innovative aspects of the program, including the way it supplemented existing child and family support and enabled a holistic approach to supporting the family.

The ABIOS case managers described the innovation of the pilot in taking the ideas of young adults that did not fit into traditional disability services and resourcing them to occur within the context of informal supports, free services, courses and generic facilities. When asked what they liked best about the program, many of the ABIOS participants spoke about the program's capacity to promote their empowerment and connection to community. For example, they said,

That it's [the program] looking at me. You know, most services say 'this is what we provide, do you fit into that, yes or no?' This is tailored to me, rather than trying to fit me into what they do, or what they want to fund.

All the programs that come to the hostels say they are about getting you into the community, but this program is helping me get into life, not just the community.

The ABIOS participants who had a good rapport and relationship with their case workers felt they were encouraged to develop innovative ideas to use their funding. Some people were more ready to engage with developing innovative opportunities than others. Where it appeared that people relied more on their case workers to suggest options for their goals, they used more formal arrangements, such as courses, community classes, and gym memberships. Where they took a lead or more active partnership in the planning and implementation of support process, more innovative solutions were also in play, such as an iPhone to support a budding entrepreneur and driving lessons to prepare for work opportunities.

## **4.5 Partnerships**

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

The team relationship between case managers in ABIOS was more complex than in SCCTC, where there was only one service coordinator and her manager. Both service providers continued to see value in their approach.

The SCCTC service coordinator valued the opportunity to spend her entire professional role on the SDS pilot project. The organisational isolation of the service coordinator from the rest of the SCCTC staff limited effective professional peer support, mentoring, and information sharing. 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 solutions. The ABIOS team stressed the opportunities for peer review and input on difficult decision making issues and planning concerns that come from a large team approach to pilot. They also viewed the approach as a support to governance, in that individual case workers were helped by the team review process to develop a rationale to justify planning and expenditure which was non-traditional.

Partnerships between the pilot organisations and other service providers were also important to the pilot's process goals of coordinated care and sustainable service delivery. The approach to partnerships between the pilot organisations and other services providers had not noticeably changed in the period during the pilot. SCCTC identified a goal to extend partnerships by seeking linkages with other service providers to extend the pool of therapists and practitioners. The worker did not act on this plan, due to time pressures on a single coordinator to implement the program. Some community development work was done in the establishment stage and the manager of SCCTC supported these activities.

ABIOS operated within the same model, primarily partnering on the provision of goods and services through the pilot. Participants noted some linkages with other community organisations, where they were linked for voluntary work.<sup>4</sup> ABIOS recruited participants from their usual referral streams because this method was sufficient to fill the available places. The approach meant that strategies for recruiting people not already linked into the service system were untested for this element of the pilot. ABIOS case workers continued to work with participants after they leave the pilot, which removed the urgency to develop partnerships and referral links.

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<sup>4</sup> Interviews with case workers were not conducted, which could have identified other new partnerships.

## 4.6 Process implications for program development

### Lessons from the SCCTC model

The SCCTC service coordinator role worked well supporting families to identify a range of available support and prioritise how to best meet their agreed goals. It built on the coordinator's local knowledge of services. The planning process required great sensitivity, especially for families who were still adjusting to understanding their child's needs. Parents wanted to be seen as experts of their child's support needs and to make informed decisions about how to best address these. The planning process and the provision of information empowered 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 were able to more effectively engage with other service providers as a result of this process. The coordination of individual support identified by the families appeared to have had a high degree of success in outcomes for children taking part in the pilot – families reported rapid improvements in their child's development, as discussed in Section 3.

As the number of families entering the program increased, the time that the coordinator had available for any work other than direct client contact decreased. The part-time position did not have sufficient time to fully meet the needs of the families, develop partnerships and networks or complete the administrative requirements.

The isolation of the service coordinator from the rest of the Centre's activities meant that she focused on the needs of this group of families, but it did not fully take advantage of the co-location with similar programs. For example, other SCCTC staff and programs had the potential to contribute linkages, peer review, support and professional development.

Policy and procedure development was needed for the finances and administration of the program, including communication with participants. A gap identified by the coordinator was an information booklet about the planning process, particularly about how to involve children in planning. In response to this gap, the SCCTC was provided with funding of \$33,200 to develop this information booklet. Program development, such as peer support and group responses to needs could have been examined.

The program could have been more effective if partnerships were fully developed. For example, if the local paediatricians and local GPs were fully aware and understood the benefits of the program, children could have been referred for support as soon as developmental delays were identified. Implications of not partnering with a range of stakeholders included less awareness about the program from stakeholders who might have referred to the program and fewer options to address the variety of support needs, particularly low cost options.

Other restrictions of the current program design were 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 model**

The team approach to case management brought benefits of peer support, integration with other support offered by the organisation and quality control. Participants in the pilot felt that their plans were self directed, and that they explicitly developed their own goals. Case workers filled in the gaps in meeting those goals, by providing pathways to move towards major goals, or suggestions and options about ways to reach goals. Case managers described the stepped process for goal development as a successful way of providing supported and facilitated process of personal development for most of the people with impaired decision-making capacity. While participants still felt that their ideas needed to be approved before being able to be implemented, they felt the program supported them to develop their own ideas about participation and activity.

Having resources to implement plans continues to be a key enabler of the pilot. For some of the participants in the repeat interviews, a developmental pathway can be seen between each year of the program. For example, Dean used his funds to resource a series of inter-connected TAFE courses which he was completing in order to retrain in a new career after his injury. He completed one in the first year, the second in the second year of funding, and was now embarking on the third. For some participants the developmental pathway was less focused. For participants who have recently commenced on the pilot after a new injury, access to individualised planning, support and resources outside of the medical setting made a great difference to both their physical recovery and emotional wellbeing.

The participants' ideas for improving the program were primarily about streamlining administrative and resourcing processes, and greater responsiveness to individual preferences. An example is the development of a framework to support the tracking of expenditure for those clients who self manage funds.

Pilot participants concurrently receive ABIOS case management from the same case worker who supports them with SDS. This case management role continued after the pilot. The good practice in this approach was that participants retained ongoing support and planning over time. Most participants placed importance on their relationship with their case worker (Section 3.1), which was a consideration for the development of the program into the future, particularly if access to funding was to continue to be time-limited.

The financial rules for funding expenditure through a government health department restricted the effectiveness of the program for ABIOS participants by causing delays to the purchase of goods and services and preventing them from receiving timely reimbursement or cash advances for purchases in their

plans. ABIOS actively worked to minimise the impact of these government department finance restrictions.

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

According to service providers delivering the pilot, the greatest gains were young adults, children and their families who previously had limited contact and were unaware of available support services.

In addition, the quickest benefits were to families of young children who already had 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.

Families struggling to meet their children's needs also benefited greatly from the program, specifically from the planning, coordination, and information provision that the service coordinator role provides. Some of these families found it difficult to make the best use of the funding allocation, because they did 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 was beneficial for child and family wellbeing and resilience for these families too. The funding allocation was not sufficient for children with higher support needs who were waiting for access to other free or subsidised support services.

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

The ABIOS pilot may have had some cultural benefits. Workers reported outcomes for participants from CALD backgrounds who were able to access non-traditional support and resources that worked effectively for them. Two participants in interviews who were from CALD backgrounds valued the flexibility of the pilot to meet their particular circumstances.

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

Government stakeholders and service providers identified several groups who could benefit as priority groups for the program, including children with disability aged 10 – 15; parents aged over 40 years with acquired brain injury;

Aboriginal and Torres Strait Islander people with disability, particularly those in communities with high levels of foetal alcohol syndrome and remote communities. One policy maker said

The limited number of groups and the tight scope meant that a lot of parameters haven't been tested. High end needs, rural and remote, the person's capacity to have the money in their bank account ...

### **Future development of the program**

The program achieved 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, reached 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 analysis also identified a number of questions about possible limitations and challenges to this model of support.

Some workers and participants were unclear and need guidance about exit processes, such as funding and participation after 12 months in the program. In ABIOS, because some young adults were already ABIOS clients, some workers were 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 were available, training resources for participants and families 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 needed further development and training about case management processes to manage risk for young adults' needs, in a new climate where people were encouraged to make a far broader range and scope of personal decisions.

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

Opportunities for expanding the program included:

- 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 the impairment, rather than chronological age and
- 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 ongoing support and community integration for participants, and serve as link for providers to provide information and pathways into support services. Parents new to the program in 2011 volunteered to coordinate this, as they were aware that the coordinator does not have time.

The views of participants, service providers and policy makers were consistent that the program was meeting the goals of community inclusion and empowerment. The goals were facilitated through strong relationships and support processes implemented by case workers; a partnership approach to planning and decision making where participants need guidance; flexibility in planning, with the option of making changes to plans as circumstances and preferences change; and consistency to the principles of the program design. The financial and administrative arrangements sometimes compromised the effectiveness of these processes (Section 4.3).

A government stakeholder said,

The key was definitely the planning – the ability to sit down and plan not only your disability specific needs, but plan a life or your interaction with the community ... That's key, I think. It's starting to grab hold of their life goals, and not their disability support goals.

## 5 Economic evaluation

An economic evaluation assesses the cost of the pilot against the outcomes experienced by the participants. 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.

### 5.1 Costs of the program

In this section of the evaluation we analyse cost data provided by the Department and the service providers. These costs were analysed in terms of total program cost and cost per participant.

The cost of program management to the government of the pilot was approximately \$32,000 (July 2009-March 2012 at 5 hours per week for 143 weeks for three project staff and a manager).

The NGOs were 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 was equally allocated to participants regardless of their assessed or perceived level of support needs.

It was 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 were collected. To make the estimates, costs for services were averaged. As the two groups were very different, the costs for each were presented separately.

Although many costs were unclear, it was apparent through the case notes that case workers worked with the young adults and families to provide services that were within budget, and indicated that if a support service cost more than the budget, then the family contributed to the payment. It would be reasonable to assume therefore that the associated program budget for participant expenditure did not exceed the allocated annual budget.

The range of costs for each support type is presented Table 5.1. These costs are based on 50 participants with costs for 44 identified needs. Of these, 38 children, and 12 young adults had costs listed against at least one of their identified needs. The data were incomplete.

**Table 5.1 Cost details of identified needs January 2010 to May 2011**

	Number participants	Range of costs (\$)	Average number of hours	Average cost per hour (\$)	Average total cost per participant(\$)
<b>Total cost of identified needs</b>					
Children	38	619-4000			2287
Young adults	12	996-4429			3231
<b>Children</b>					
<i>Ongoing or weekly services</i>					
Allied therapy (Physio, speech, OT)	51		6	89	573
Child care	1		-	-	1820
Hydro therapy	1		10	40	400
Horse therapy	1		10	35	350
<i>One-off costs</i>					
Equipment	19				517
Medical treatment	1				747
Other home or family costs	5				866
<i>Needs with no direct cost associated</i>					
Assessment for diagnosis	1				
<b>Young adults</b>					
<i>One-off costs</i>					
Community education course	3				270
Equipment for community education	2				2425
Formal education course	1				559
Equipment for formal education	1				2117
Sports/social fitness program /equipment	4				805
Other household costs	3				1374
Other personal costs/social activities	2				2025
Removal costs	1				2250
<i>Ongoing or weekly services</i>					
Personal trainer	1		5	80	400
Support person	1		16	40	640
Driving lessons	1		10	50	500
Swimming lessons	1		20	17.50	350
<i>Needs with no direct cost associated</i>					
Personal assistance –diet and exercise plan, personal and career goals	3				
Assistance with living with family	1				
Assistance with community involvement	2				

Sources: Program tracking data between 2010 and 2011. Young Adults: program tracking data supplied in May 2011 for a subset of clients in the program.

Notes: The number of participants indicated was used to calculate the cost details, and do not represent all participants who received a service, as data for some participants did not indicate finalised costs for services.

Total costs were provided only for participants who had all needs costed and was not 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 were included for information.

The basic cost data shown above indicate that there was wide variation in the cost per service as well as the total cost per participant in the program.

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

This pattern of funding allocation for the young children appears to be because most families prioritised therapeutic assistance before other needs could be met, and for these participants this was delivered in weekly sessions. Only a 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 allocate money to the need with the most impact in terms of community and social involvement and personal wellbeing. This meant that the young adults 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 service 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 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.

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 younger group, however, there may be situations where additional therapy was required and if the budget was already spent, the family could not afford to pay, and free or subsidised support was not available, it might affect access to continued treatment.

## **5.2 Benefits of the program**

Section 3 presented the benefits the participants experienced as a result of the pilot, including changes in participants' wellbeing (satisfaction with personal relationships, health, self reliance); social, community and economic participation; and community connections. They are summarised in Table 5.2.

**Table 5.2 Summary of Self Directed Support outcomes**

Outcome	Description
Wellbeing, independence and resilience	<p>Participants' physical wellbeing improved from access to therapies and physical activity. This improved their independence.</p> <p>Family members' wellbeing and resilience to cope with their circumstances improved through reduced stress about coping with decisions about support needs, paying for support, finding information and arranging support.</p> <p>The wellbeing of young adults and family members was close to that of the Australian population and higher than other carers.</p> <p>Some families reported that the support prevented them from entering a crisis and perhaps avoiding family breakdown.</p>
Empowerment	<p>Young adults were able to make decisions and act on plans to achieve steps towards goals.</p> <p>Family members had a better sense of control and capacity to organise, pay for and attend support services for their children.</p>
Social, community and economic participation	<p>Young children participated in activities in their family, early childhood groups and school.</p> <p>Young adults participated in sport, social and educational activities and paid employment.</p> <p>Support enabled families and siblings to do activities together and outside the home.</p>
Community connections and networks	<p>Young adults accessed mainstream services.</p> <p>Families of young children became familiar with community services and referral opportunities.</p>

### 5.3 Economic implications for program

The providers operated within budget during the program. They reported that they 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 also operated within budget. The families of young children generally spent the funds on weekly fees for therapies and related equipment. The young adults in contrast paid for equipment or study fees to facilitate immediate access to social, community and economic activity.

The qualitative data show that young children, their families and young adults benefited from case management, planning and a small budget to assist with organising the support they need to fulfil their goals. Benefits for the

participants and their families were evident, including wellbeing, independence and resilience; and community, social and economic participation. Initial information and contact with community services and informal networks began for some families and young adults, but this benefit took longer to experience than the others.

## **6 Implications for self directed support programs**

This section draws together the implications of the SDS pilot for similar programs with person centred support and self directed funding. This pilot was to support people with disabilities and their carers and the approach can also be applied to other groups, such as people receiving support due to ageing and frailty. Good practices from the pilot for self directed support programs and more broadly for programs supporting people with disabilities, their families and informal supporters are summarised below.

### **Eligibility criteria for early intervention**

Defining the target group for 'early intervention' support needs to consider both age and timing of the incidence or identification of need. Both service providers found that the program would have equally benefited wider target groups, when the objective was to reach participants in need of 'early intervention' support.

In the case of young adults with acquired brain injury, they found that onset of the impairment rather than chronicle age could have been more appropriate. Similarly, any young children at the time of any identified disability support need, rather than under a particular age and with a particular category of disability, could have benefited from this approach.

The pilot demonstrated that the short-term, early intervention through the allocation of case management and funding was effective for empowering participants and their families to move on to accessing other formal and community support.

### **Flexible and empowering planning and support**

Flexible, person centred service delivery and planning maximised the responsiveness to participants' needs. Both concepts were crucial for the empowerment of clients and their supporters to identify needs and set goals; make informed decisions about how to best spend and manage the allocated funding (whether by the participant or through the supporting agency); and review decisions as needed.

Families of children in the program appreciated the recognition that they are the experts in their child's support needs. Taking decisions about using the funding, and reviewing them as needed reinforced that position, empowering them to make further links to each other and other services. The decision making control enabled them to make creative choices about how to maximise the limited funds. Families appreciated the client centred case management support, such as receiving useful ideas, information and suggestions how to meet identified needs, assistance to organise support for their child, and pathways to connect to a range of community supports and programs.

In the case of young adults with acquired brain injury the SDS program enabled them to set goals and plan how to achieve them. ABIOS

implemented a stepped process for goal development where staff and participants worked together to scaffold goals into sub-goals, which case workers then discussed in team conferences. This approach facilitated the development of participants' decision making and reduced their financial risks. This required highly skilled, sensitive case management support to empower and support participants to identify goals, planning and realisation.

### **Control of the allocated funding**

Access to a small individual budget was sufficient to realise goals for some participants that had been previously frustrated for lack of funds. Initially all funds were administered by the service providers and in the second half of the pilot, participants had the choice to self manage the funds. Most participants continued with this choice because they did not want the additional administrative responsibility.

Where the funds were administered by the provider, participants wanted transparent management of the funds, such as flexible access to the funds (eg. vouchers or cash to enable purchase of goods or services on the plan; reimbursement or direct payment to service providers; prompt information about the balance of funds).

Considerations to make self management a viable choice include: continued case management support; practices to maximise control of decision making around expenditure by program participants; clarifying the taxable status of the funds (GST and income); and simple financial accountability.

The pilot reinforces evidence that participants want choices to self manage or have their funding managed on their behalf. In both cases, they want access to case management and planning; and information about the funds available and the processes for reimbursement, purchasing and accountability.

### **Sustaining program outcomes**

The SDS pilot was designed as a short-term intervention by enhancing community networks and inclusion. Engagement and networking with other community services and programs was key to the program but the providers did not have sufficient resources to fully implement this aspect of the design. Planning and case work with a focus on community inclusion have potential to link participants to formal and informal community support and generate opportunities for social participation and inclusion.

In the case of families of young children in the program, the major limitation was the capacity to develop this part of the program, such as implementing peer support groups. For most of the young adults, these goals took longer than 12 month intervention to develop sustainable social networks and community connections.

### **Staffing capacity and training**

Case managers in self directed support models require sufficient resources and time for relationship building, planning and support provision to clients; collaboration and networking with external partner organisations; administration of plans and funding; and supervision, training and peer reflection to further develop their skills for a facilitative approach with clients.

Opportunities that were not fully realised in the pilot were accessible information about the program and promotion and networking to other providers. As a result some target groups were underrepresented, such as Indigenous and CALD participants, and opportunities for community networks were underdeveloped.

### **Program evaluation and monitoring**

The evaluation and program monitoring were enhanced in this pilot by the early implementation, resources and commitment to the formative evaluation opportunities from the government and providers. The structured longitudinal evaluation enabled informed decisions about funding, program design and improving processes.

## **Appendix A Evaluation methodology**

A longitudinal, mixed method evaluation design was 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 was developed to fit the attributes of the Self Directed Support pilot, the evaluation objectives and the conceptual framework outlined. It was 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 was 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](http://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 had the initiative met its objectives for individual participants?
2. Support model and service delivery processes: How effective was the model in meeting its key objectives, person centred (self directed) support, community inclusion, and early intervention?
3. Economic analysis: What were 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 was conducted in four phases: project plan; baseline analysis; longitudinal analysis; and final analysis. As of November 2010 the evaluation plan was 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 were 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 were: 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 was 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 was 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 were the core objectives of the pilot program. In addition, the PWI was a validated instrument which uses reliable Australian scales which were 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 were 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 were 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 was the minimum recommended to meet the evaluation requirements within the constraints of the budget and respondent burden. It was large enough for case study data to supplement the full cohort continuous longitudinal quantitative data. Baseline qualitative data were 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**

	2010 baseline report		2011 second report		
	Children 0-6 years	Young adults 20-35 years	Children 0-6 years	Young adults 20-35 years	Others
Pilot participants	-	10	-	10**	-
Informal support eg. family	10	3	9**	4	-
Service provider staff	1	8*	1	1	-
Service provider manager	1	1	-	-	-
Department staff	-	-	-	-	3

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

\* Three interviews with eight ABIOS staff.

\*\*longitudinal (repeat) interviews were conducted with five of the 10 ABIOS participants; and four of the nine family members of children participants.

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 was 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 were 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. These data were used to further inform the

outcomes of the pilot. ABIOS was also collecting evaluation data, using a tool their research officer had 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 were compared to the outcomes. The aim was to compare the goals of the program with its achievements, deciding whether the program was economical in terms of tangible benefits produced by money spent. This will help to understand how effectively the government had achieved its objectives. This component of the evaluation heavily relies on outcome and cost data being available and was likely to be stronger in the longitudinal analysis (round two reporting).

## References

- Cummins, R.A. (2005), *Normative Data for the Personal Wellbeing Index, Australia*, Australian Unity Wellbeing Index Version 3 12.0  
[www.deakin.edu.au/research/acqol/.../wellbeing-index/pwi-aus-normative-data-280305.doc](http://www.deakin.edu.au/research/acqol/.../wellbeing-index/pwi-aus-normative-data-280305.doc)
- Cummins, R.A., Hughes, J., Tomy, A., Gibson, A., Woerner, J., and Lai, L. (2007), *Special Report, The Wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1, Australian Centre on Quality of Life, Deakin University, Melbourne.  
[http://www.deakin.edu.au/research/acqol/index\\_wellbeing/index.htm](http://www.deakin.edu.au/research/acqol/index_wellbeing/index.htm)
- Cummins, R.A., Woerner, J. & Chester, M. (2009), *Australian Unity Wellbeing Index – Survey 20.1 Part A: Report, The Wellbeing of Australians – The effect of fires in Victoria and Floods in Queensland*, Australian Centre for Quality of Life, Deakin University, Melbourne.
- Department of Communities (2010), *Self Directed Support Initiative 2009-10. Community Inclusion Pilot Implementation Guide & Toolkit*, Department of Communities, Disability Services Queensland.
- Genera, S., Fisher, K.R., Robinson, S. and Clements, N. (2010), Evaluation Plan of the Self Directed Support Pilot, *SPRC Report 10/10*, for the Department of Communities, Disability and Community Care Services, Queensland, July.
- Genera, S., Fisher, K.R., Robinson, S., Clements, N. and Eastman, C. (2011), Evaluation of the Self Directed Support Pilot Baseline Report, *SPRC Report 6/11*, for the Department of Communities, Disability and Community Care Services Queensland, December 2010.
- 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.
- Robinson, S., Genera, S., Fisher, K.R., Clements, N. and Eastman, C. (2011), Evaluation of the Self Directed Support Pilot Second Report, *SPRC Report 10/11*, for the Department of Communities, Disability and Community Care Services Queensland.