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Effectiveness of individual funding approaches for disability support

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Improving the lives of Australians

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Contents

Executive summary v

1 Introduction 1

2 Overview of research methodology 3
- 2.1 Literature review and policy analysis 3
- 2.2 CSTDA National Minimum Data Set 3
- 2.3 Primary data collection 3

3 Use of individual funding 7
- 3.1 Types of individual funding 7
- 3.2 Examples of individual funding 10
- 3.3 Profile of people who receive individual funding 12

4 Summary of individual funding by state and territory 15
- 4.1 Australian Capital Territory—Disability ACT 15
- 4.2 New South Wales—Department of Ageing, Disability and Home Care 16
- 4.3 Northern Territory—Department of Health and Community Services 18
- 4.4 Queensland—Disability Services Queensland 19
- 4.5 South Australia—Department for Families and Communities 20
- 4.6 Tasmania—Department of Health and Human Services 21
- 4.7 Victoria—Department of Human Services 22
- 4.8 Western Australia 23

5 Managing effective approaches to individual funding 25
- 5.1 Introduction 25
- 5.2 Consumer preferences 26
- 5.3 Support according to capacity and vulnerability 30
- 5.4 Administrative systems for managing support responsibilities 34
- 5.5 Viability of the support type and amount of funding 39
- 5.6 Workforce and quality of care 42
- 5.7 Service integration 43
- 5.8 Contextual impact 45

6 Costs of individual funding 49
- 6.1 Cost of individual funding package 49
- 6.2 Cost to government 49
- 6.3 Costs within the individual funding package 50
- 6.4 Other costs not in individual funding package 51

7 Outcomes 53
- 7.1 Personal wellbeing, physical and mental health 53
- 7.2 Social relationships and networks 55
- 7.3 Community and economic participation 56
- 7.4 Control, choice, independence and self-determination 58

Appendixes
- Appendix A: Primary data collection methodology 59
- Appendix B: Commonwealth State Territory Disability Agreement tables 73
- Appendix C: Fieldwork instruments 77
- Appendix D: New Zealand and Denmark individual funding 97
- Appendix E: Other international individual funding 101
- Appendix F: Definitions 105

List of shortened forms 107

Endnotes 109

References 111

List of tables

Table 1:	Interview methods by respondents	4
Table 2:	Funding characteristics of individual funding by respondents, per cent	8
Table 3:	Funding characteristics by disability type for people with disabilities, per cent	9
Table 4:	Individual funding by disability support type	9
Table 5:	Individual funding by disability support type, CSTDA 2006–07	10
Table 6:	Sex and cultural background of people with individual funding, per cent	13
Table 7:	Disability type for people with individual funding by level of support needed, per cent	13
Table 8:	Service provider perception of the outcomes of managing the risks and benefits of individual funding compared to organising disability support other ways	25
Table 9:	Choice about support, per cent	26
Table 10:	Satisfaction with help choosing support by disability type	27
Table 11:	Satisfaction compared to previous disability support	28
Table 12:	Satisfaction with ability to change disability support	29
Table 13:	Service provider perception of client or family control of individual funding	33
Table 14:	Satisfaction with disability support arrangements	40
Table 15:	Frequency of community activities	41
Table 16:	Size of individual funding per client	49
Table 17:	Subjective personal wellbeing, mean score	54
Table 18:	Client outcomes using individual funding compared to other arrangements reported by service providers	55
Table 19:	Satisfaction with social participation	55
Table 20:	Frequency of community activities	57
Table 21:	Individual funding effect on client social inclusion compared to other arrangements reported by service providers	57
Appendix tables		
Table A1:	People with disabilities questionnaire—question sources	61
Table A2:	Service providers questionnaire—question sources	63
Table A3:	Case study and questionnaire site data	68
Table B1:	Age as a percentage of people who have individual funding, 2006–07	73
Table B2:	Sex as a percentage of people with individual funding, 2006–07	74
Table B3:	Indigenous status as a percentage of people with individual funding, 2006–07	74
Table B4:	Primary disability as a percentage of people with individual funding, 2006–07	74
Table B5:	Presence of another disability as a percentage of people with individual funding, 2006–07	75
Table B6:	Existence of an informal carer as a percentage of people with individual funding, 2006–07	75
Table B7:	Daily support needs as a percentage of people with individual funding, 2006–07	75

List of boxes

Box 1:	Individual funding	7

Executive summary

This report, by the Social Policy Research Centre (SPRC), examined the effectiveness of individual funding of disability support and aimed to inform policy to improve the provision of disability support. The study was commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The research methodology included a literature review; secondary data analysis of the Commonwealth State Territory Disability Agreement (CSTDA) National Minimum Data Set (NMDS); interviews with policy officials from all states and territories; case studies with 10 disability service providers, involving interviews with people with disabilities and staff; and questionnaires for people with disabilities and service providers.

Use of individual funding

Individual funding is defined in this report as a portable package of funds allocated for a particular person that facilitates control over how they purchase their disability support needs. The way individual funding is organised varies in relation to who holds the funds, which parts of it are portable and what disability support types it can be spent on from which parts of the market.

The profiles from the CSTDA and surveys show that individual funding is more likely to be used by people of working age with low support needs, by male and non-Indigenous service users, by people with one disability and by people without informal care networks. This applies across disability types and disability support services. Although disability employment service users are classified as receiving individualised funding in CSTDA data, the type of individualised funding for disability employment services does not fall within the scope of the definition used for this research.[1] This should be taken into account when viewing the results of the CSTDA NMDS analysis.

Individual funding in the states and territories

Australian government disability agencies demonstrate a growing policy interest in individual funding and self-directed approaches. They are developing policies and guidelines, extending pilots, introducing and refining models and conducting evaluations to better understand consumer outcomes.

The dominant approach to individual funding in Australia is a portable individual funding package held by a service provider, except in Western Australia (WA), which has a longer history of individual funding and use of direct funding.

Jurisdictions are aiming to offer a continuum of individual funding approaches, with varying levels of control and choice for the person. Such a mix of approaches requires a diversified, viable disability support sector to offer support options that include informal, formal, specialised, general and professional support, with a range of consumer control.

Managing effective approaches to individual funding

Person-centred disability support

Policy officials, service providers, people with disabilities and their family members agreed that, overall, individual funding in Australia facilitates control and choice in support provision. Mechanisms for facilitating consumer preferences include individual needs assessments, planning and goal setting processes, as well as flexibility in how funds are spent. These mechanisms are often successfully employed.

Achieving flexibility, choice and control depends to some extent on the type of individual funding. Packages that are managed by the person with a disability, their family or a facilitator and that can be spent in the

open market, can generally be tailored more easily towards the consumer's preferences than more restrictive packages or those that must be spent through a single service provider.

Opportunities to support people with significant cognitive disabilities to exercise their preferences are often more limited. Most commonly, family members, friends or informal carers (if they are available) assist with interpreting their needs. The level of funding provided through individual packages is generally not sufficient for these people to live independently.

Support according to capacity and vulnerability

Government and advocacy organisations are the main providers of information about individual funding options. Service providers give ongoing information to existing individual funding clients through planning and reviews. Service providers support choice and decision making by involving family and friends in support planning.

Some people with disabilities and their families who manage individual funding in the open market reported that they do not have sufficient information to help them manage their individual funding.

Administrative systems to support management responsibilities

Government and service providers assist people and families to manage the funds, through mechanisms such as providing information and training to people with disabilities and WA's Local Area Coordination. Some people with disabilities receiving direct payments said they lack sufficient administrative support.

State and territory governments have accountability requirements to reduce the risk to government and people with disabilities of improper use of individual funding. The accountability processes sometimes vary for direct funding to the person with a disability compared to accountability processes where the funding is paid to an organisation. A small number of examples of abuse of direct funding were discussed; however, these were managed through regular auditing processes.

Service providers and people with disabilities generally feel that existing accountability mechanisms are effective to protect the client, provider and government. However, some providers reported that government accountability processes can be cumbersome and expensive. Some providers also complained about the cost burden of some legal requirements such as occupational health and safety and insurance regulations. Legislative change might be required to clarify the impact of direct funding on income support and taxable income to facilitate greater access by people with disabilities.

Viability of support type and amount of funding

Individual funding managed by a single service provider is often restricted to one disability support type, such as accommodation support, which limits the effectiveness of the individual funding package to achieve holistic life goals.

Insufficient funds may be a problem for people with complex needs or few informal support networks. Some service providers have developed mechanisms to maximise the effectiveness of the available funding support, such as supporting the development of informal support networks to supplement the formal support.

Workforce and quality of care

The availability of qualified support workers for disability support under any type of individual funding is affected by the level of remuneration offered.

Whoever manages the funding needs mechanisms to safeguard support workers' working conditions and the quality of care to the client, especially where support provision is less monitored.

Where individual funding allows people with disabilities to employ their own support workers, people appreciate the flexibility and control this offers. It often leads to stable employment of support workers

because of improvements to working conditions and to the relationship between the support worker and the person receiving support.

Service integration

Most service providers report high levels of interagency cooperation. Coordination is most pronounced for people requiring extensive support and for those who manage their own funds and are therefore likely to engage with multiple providers. Interagency cooperation is mostly informal.

The most common formal coordination mechanism is circles of care to include service providers and informal carers. Support for informal carers varies with funding type. It is available through self-managed packages that include family support options

Contextual impact

Transition from traditional funding approaches to individual funding may be difficult for service providers and even pose a threat to their viability. To lessen this risk, governments have put mechanisms in place such as base funding and transition assistance for service providers.

In addition, new service providers have emerged to respond to individual funding opportunities, including new organisations that provide brokerage, planning, management support and disability support.

Some states and territories are experimenting with individual funding as a way to address high unmet need. For example, they offer small flexible packages that rely on maximising integration between informal and formal disability support.

Like the allocation of other specialist disability support, access to individual funding is not transferrable between states. People receiving individual funding are inhibited from moving interstate because they risk losing the benefits of the size of the package, control and flexibility they currently receive.

Costs of individual funding

The average individual package funding size in this study was $28,500 and ranged from $700 to $250,000. The variation relates to disability support type and support need.

The average management cost was 14 per cent of the individual funding package and ranged from 5 to 22 per cent. This is similar to the management cost of other disability and community services.

Individual funding has not increased the total specialist disability support cost to government. Officials said some individual funding is more cost-effective than other models of organising support, particularly where it supplements social housing and informal care.

Some government officials and service providers said that costs were higher during the transition to a mixed system of funding and organising disability support, because during the transition, new systems need to be established to support informed decision making and accountability for people using individual packages.

Individual funding packages pay for disability support and management support. The cost of disability support and management support is not usually less expensive than other forms of organising disability support. Rather it enables choice in the types of disability support the funding is spent on, who provides it, and when and where it is provided.

Some packages are not sufficient to pay for all the disability support a person needs, either because of restrictions on the amount available or what it can be spent on, or because the funding allocated for the assessed need is insufficient to meet the actual cost. In these cases the person receiving the support, informal carers or service providers incur the additional costs of the disability support or the costs of managing the support, either in time or expenses, or the person does not receive the support they need.

Outcomes of individual funding

The outcomes data compared people's experiences before and while using individual funding; outcomes for people with disabilities who have individual funding with the outcomes for people whose disability support is organised in other ways; and an Australian population norm for personal wellbeing.

Most people using individual funding experienced personal wellbeing, and physical and mental health at levels similar to both the Australian population norm and the Victorian norm of people with intellectual disabilities. In the interviews, they attributed these positive results to the better control they have over the way they organise their disability support.

Using a standard measure of personal wellbeing, scores on all domains (standard of living, achievement in life, personal relationships, personal safety, community connectedness) were similar or higher than the scores for the broader Australian population, except for personal health and future security. The scores of people using individual funding were also higher than normative data for Victorians with intellectual disabilities in the domains of personal health, achievement in life and personal safety, but lower in personal relationships, community connectedness and future security.

People with disabilities and their families also commented on how changing to individual funding had improved the wellbeing of family members because they could share the responsibilities. They were worried about what would happen in the future when the family members could not help manage the individual funding.

Most people were happy with their social relationships and community participation. Service providers attributed this to the whole-of-life approach they can take providing support for people with disabilities who have individual funding compared to disability support clients who have other arrangements. The type and amount of individual funding used by people with disabilities sometimes limited the contribution individual funding could make to their social participation. For example, if it was support restricted to economic activity, the person could not use support workers to attend social events.

All respondents said that individual funding had improved their control, choice, independence and self-determination in their lives.

Possible limitations of the primary data

Possible limitations to the primary data collection were addressed using mixed methods, including validated scales in the instruments, and incorporating advice from people with disabilities, families and providers through piloting and draft versions.

- The survey response rates from people with disabilities and service providers were approximately 50 per cent. While the response rate and sample sizes are acceptable for this analysis, the sample sizes may decrease the generalisability of the conclusions.
- Using proxy interviews and questionnaire completion with family members instead of people with disabilities where cognitive impairment presented a problem to communication enabled contribution of information about these people's experiences. The proxy views might compromise the validity of the data collected.
- Using simplified scales in the easy English survey for people with disabilities enabled participation by people for whom the full scale might have been too complex. A possible limitation is that scales with fewer points can have lower sensitivity compared with full point scales.
- Comparison data about the experiences of outcomes and risks of people with disabilities who do not use individual funding was available from two sources: asking service providers to compare support they provide to people organised through individual funding with support organised in other ways; and asking the people with disabilities to compare their current individual funding support service experience to their support service experience prior to individual funding. A control group was not included. Conclusions drawn from comparing people receiving support organised through individual funding to people receiving support organised in other ways should be read with this analysis framework in mind.

1 Introduction

This report, by the Social Policy Research Centre (SPRC), University of New South Wales (UNSW), examined the effectiveness of approaches to individual funding of disability support. The study was commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and aimed to inform policy to improve the provision of disability support. The project examined the effectiveness of individual funding with regard to the following questions:

- What is the impact of the individual funding approach on costs of support and outcomes for the person?
- What characteristics of individual funding approaches improve effectiveness? Characteristics may relate to funds-holding, brokerage, case management, administration, monitoring, quality control, population supply and demand management, and service integration.

The research used a mixed method design. Following a literature review, preliminary secondary data analysis was conducted on the Commonwealth State Territory Disability Agreement (CSTDA) National Minimum Data Set to build a demographic profile of people with disabilities who have individual funding in Australia. Interviews were conducted with policy officials from all states and territories in Australia regarding the jurisdictional application of individual funding. Case studies were conducted with 10 disability service providers in New South Wales, Queensland, Victoria and Western Australia, involving interviews with people with disabilities, families and staff. Finally, questionnaires for people with disabilities and service providers were distributed to case study and additional questionnaire sites to supplement the interview data collected. A comprehensive explanation of the methodology is included in Appendix A.

The report summarises how people and organisations have managed effective individual funding and their experiences of costs and outcomes.

- Section 2 summarises the methodology.
- Section 3 describes what individual funding is in Australia and who uses it.
- Section 4 summarises individual funding policy in each state and territory.
- Section 5 discusses how risks and benefits of individual funding are managed and experienced by people with disabilities, service providers and policy officials.
- Sections 6 and 7 present the costs and outcomes of individual funding.
- The appendixes detail the methodology, CSTDA data analysis and fieldwork instruments.

2 Overview of research methodology

The research aimed to determine the generalisable characteristics and contextual factors of individual funding approaches to disability support that are cost-effective. The research included mixed quantitative and qualitative methods: a national and international literature review and policy analysis, CSTDA National Minimum Data Set analysis and national interviews and questionnaire with stakeholders (people with disabilities, service providers and officials). The mixed methods facilitated triangulation of data to ensure reliability. UNSW ethics approval was gained for the project. This section gives a brief overview of the methodology, with further details in Appendix A.

A framework for analysis was designed to be consistent with the policy context of the United Nations (UN) Convention on the Rights of Persons with Disabilites, CSTDA policy processes and legislative context, including Disability Standards and Disability Action Plans. A disability rights framework consistent with the UN Convention on the Rights of Persons with Disabilities (UN Convention 2006) was applied to the research to inform design decisions such as data variables (for example, costs, outcomes, contextual factors, support needs and characteristics of the person and their community), framework for analysis and discussion of policy implications.

2.1 Literature review and policy analysis

A national and international literature review was conducted to identify key characteristics of cost-effective individual funding approaches to disability support. The data from the literature review was situated in the Australian national policy context. It also reviewed how specific situations, such as location (metropolitan, regional, rural and remote), cultural background (including Indigenous and culturally and linguistically diverse populations) and age (for example, young people and ageing) affect individual funding. Research and policy from comparable international sources were included in the review.

2.2 CSTDA National Minimum Data Set

The second part of the analysis was from the CSTDA National Minimum Data Set (CSTDA NMDS) (now known as the Disability Services National Minimum Data Set). The analysis provided descriptive data on the extent of individual funding approaches by disability support type. It also supplemented the literature review by examining individual needs (location, background and age). The results presented as part of the CSTDA NMDS analysis should be viewed with caution, keeping in mind that they include recipients of case-based employment support, which is not covered under the scope of the project (see endnote 1).

2.3 Primary data collection

The third part of the analysis was primary data collection through interviews and questionnaires with people with disabilities, families, service providers and officials about their experiences of individual funding for disability support (Table 1).

Table 1: Interview methods by respondents

	People with disabilities	Service providers	Government agencies
Face-to-face interviews	20	7	1
Telephone interviews	12	5	7
Questionnaires	100	20	0
Total	**132**	**32**	**8**[(a)]

(a) 23 officials in eight agencies.
Note: See Table A3 for details.

Interviews with officials

Each state and territory government disability agency participated in structured telephone or face-to-face interviews between November 2008 and January 2009. Twenty-three government officials participated in the individual and group interviews. The interviews explored the risks and benefits associated with individual funding identified in the literature review; current individual funding policy in the jurisdiction; contextual policy perspective on the approaches to individual funding; and current examples in the state or territory. Officials were invited to comment and amend the draft descriptions of their jurisdiction presented in Section 4.

Individual funding examples: instruments and samples

Instruments

Primary data collection themes covered the research questions: characteristics and effectiveness of individual funding; costs; outcomes; characteristics of the people; and contextual constraints and facilitators to implementation. Details about the instruments, administration and samples are available in Appendix A.

Sampling framework

The sample population for the individual funding examples was people involved in any individual funding arrangement within the definition of the project: a portable package of funds allocated for a particular person who is supported to choose how to spend it on their disability support needs (Section 3.1).

Sampling began by identifying any individual funding available in Australia meeting this definition. The sample was identified from previous research, the literature review, suggestions from key stakeholders and contact with government agencies. The researchers contacted managers from these individual funding programs to inform them about the research and ask if they would be willing for the program to be part of the research case studies or questionnaires.

Case studies

Case studies were selected from individual funding programs in Queensland, New South Wales, Victoria and Western Australia. Ten case studies were selected to include a range of disability support types, disability types and individual funding types (Table A3).

In the case studies, semi-structured interviews were administered with the program manager and four people with disabilities and family members if the person could not directly communicate with the researcher. Interview methods included face-to-face, telephone, individual and group interviews and narrative methods according to the preference of the respondent.

The manager and people with disabilities in the case studies also completed the questionnaires (see below). Managers also distributed additional questionnaires to people with disabilities in each program, aiming for 10 respondents in addition to the four interviewed. In one case study, client data were only available through

the questionnaire rather than client interviews. An additional two service providers participated in interviews but they were not included as case studies because no client data were available.

Questionnaires

In all states and territories, further service provider and people with disabilities questionnaires were distributed to all individual funding programs that were willing to participate, and that did not participate in the case studies, to increase sample size for the quantitative analysis.

As with the case studies, researchers gave questionnaires to one manager and at least 10 people with disabilities. Managers were asked to select all people who had individual funding or a random selection.

The questionnaire response rates were approximately 50 per cent (100 questionnaires from people with disabilities distributed by service providers to approximately 200 people; and 20 questionnaires from service providers distributed by the researchers to approximately 40 organisations).

Questionnaire distribution and return was by post, fax, email or telephone interview. Paper or electronic self-report questionnaires were the primary quantitative data collection instrument. People with disabilities were offered an easy English questionnaire to complete themselves, with the assistance of a trusted person, by proxy through a trusted person or on the telephone with a researcher.

Data limitations

Possible limitations from the primary data collection process include the following.

- The survey response rates from people with disabilities and service providers were approximately 50 per cent. While the response rate and sample sizes are acceptable for this analysis (results were analysed for significance using small sample tests), the sample sizes may decrease the generalisability of the conclusions.
- Using proxy interviews and questionnaire completion with family members instead of people with disabilities where cognitive impairment presented a problem to communication enabled contribution of information about these people's experiences. The proxy views might compromise the validity of the data collected.
- Use of simplified scales in the easy English survey for people with disabilities enabled participation by people for whom the full scale might have been too complex. A possible limitation is that scales with fewer points can have lower sensitivity compared with full point scales.
- Comparison data about the experiences of outcomes and risks of people with disabilities who do not use individual funding was available from two sources: asking service providers to compare support they provide to people organised through individual funding with support organised in other ways; and asking the people with disabilities to compare their current individual funding support service experience to their support service experience prior to individual funding. A control group was not included. Conclusions drawn from comparing people receiving support organised through individual funding to people receiving support organised in other ways should be read with this analysis framework in mind.

The limitations were addressed through using mixed methods, including validated scales in the instruments and incorporating advice from people with disabilities, families and providers through piloting and draft versions. The limitations and the potential effects are outlined in greater detail in Appendix A.

3 Use of individual funding

This section describes the types of individual funding people are using in Australia, including: characteristics of how it is organised and which disability support types are included in the packages; examples of individual funding packages; and a profile of the people using individual funding.

3.1 Types of individual funding

Characteristics of how individual funding is organised

Individual funding is a way of organising consumer-directed care that has been introduced into most Western European countries and parts of North America. In the United Kingdom (UK) individual funding is generally referred to as 'direct payments', in the United States of America (US) as 'self-determination', in Canada as 'self-managed care' and in some European countries as 'cash for care'.

A defined package of funding is allocated to be spent on the disability support services of a particular person in the way that best suits them, including the disability support type and who provides the support. It contrasts with block funding, where a government or contracted service provider is funded to provide a defined disability support type to a defined number of people or as many people as they can. Some individual funding is offered in Australia, as detailed in this report. We use the term 'individual funding' rather than 'individualised funding' for reasons of plain English.

Box 1: Individual funding

The core of individual funding is that it is a portable package of funds allocated for a particular person who is supported to choose how to spend it on their disability support needs. Characteristics of the way individual funding is organised that vary are:

- who holds and manages the funds
- which parts of it are portable
- which disability support types it can be spent on from which parts of the market.

These characteristics of individual funding are discussed in this section. Many variations of these characteristics occur in terms of who manages the planning, choices, decisions, employment, quality, finances, changes and accountability. The variations depend on policy and program definitions; legal requirements; the person's capacity, preferences and informal support; and the availability of support from the range of providers, including government, non-government and, occasionally, private agencies. These variations are discussed in Sections 4 and 5.

Other parts of the support system that we refer to in this report to examine individual funding are:

- Management support—administrative and information support to assist people with individual funding to organise their disability support if the person chooses not to organise it themselves or does not have the capacity to do so.
- Disability support—specialist disability support, mainstream support or other goods, services or equipment required to meet the person's needs for self care, mobility, communication, community access and decision making.

- Specialist disability support—disability support funded under the CSTDA (now National Disability Agreement—NDA). Support types include accommodation support, community support, community access, respite, employment, advocacy, information and print disability services. The services examined in this report are accommodation support, community support, community access and respite (employment support is only included in the CSTDA NMDS analysis, Appendix B). People with disabilities may also receive specialist assistance through the Home and Community Care (HACC) program (23 per cent of HACC clients are aged less than 65 years; DOHA 2008, Table 3A). The data analysis in this report relates only to individual funding under the CSTDA.
- Service provider—organisations that provide support services. In the Australian context, usually a non-government organisation or government and sometimes private providers, contractors or employees.

If people receive formal disability support, it is usually provided in combination with informal care from family and friends. Most people with disabilities in Australia only receive informal support (AIHW 2007b; Productivity Commission 2007).

Table 2: Funding characteristics of individual funding by respondents, per cent

	People with disabilities (n=100)	Service providers (n=20)
Funding held by:		
service provider	49	80
client, family or carer	45	25
financial facilitator	15	20
Funding is portable:		
between agencies	47	100
between facilitators	17	65
Funding can be spent on:		
multiple service providers	33	70
open market and service providers	24	65

Notes: Respondents might interpret the meanings of the characteristics of individual funding differently.
Percentages equal more than 100 because individual funding characteristics are not mutually exclusive.
Source: People with disabilities and service provider surveys.

People with disabilities and service providers were asked about the three characteristics of the individual package they receive or supply (who holds the funds, which parts are portable and where can it be spent) (Table 2). The responses vary between the people with disabilities and providers because the number of clients associated with each provider varies (Table A3).

Less than half the people hold the funds themselves (45 per cent). The funds were portable between agencies for nearly half the clients (47 per cent) or between facilitators (17 per cent). The funds could be be spent flexibly on multiple providers for only 33 per cent and in the open market for one-quarter of people with individual funding.

According to the service provider responses, the funding in most individual packages in the sample is held by the service provider (80 per cent). In some cases, the person controls the money but it is still financially managed by a service provider or facilitator. In other cases, the service provider retains control over the funding and consults with the person. Twenty per cent of funds are held by a financial facilitator.

All service providers reported that individual funding is portable between service providers and almost two-thirds reported funding to be portable across facilitators. Similarly, over two-thirds of service providers reported that the packages they manage could be spent on multiple providers and on the open market.

Among people with disabilities, half said they hold the funds, except for people with physical disabilities, of whom only one-third said they hold the funds themselves (Table 3).

Table 3: Funding characteristics by disability type for people with disabilities, per cent

	Cognitive (n=59)	Sensory (n=25)	Physical (n=59)	Psychiatric (n=19)
Funding held by:				
service provider	13.6	44.0	59.3	36.8
client, family or carer	49.2	52.0	32.2	63.2
financial facilitator	16.9	4.0	8.5	15.8
Funding is portable:				
between agencies	44.1	44.0	54.2	42.1
between facilitators	16.9	24.0	18.6	15.8
Funding can be spent on:				
multiple service providers	37.3	48.0	33.9	26.3
open market and service providers	28.8	20.0	25.4	15.8

Notes: Respondents could report more than one disability type. Respondents might have different interpretations about the meanings of the characteristics of the individual funding.
Source: People with disabilities survey.

Disability support types

Another important aspect of individual funding is what disability support types the package can be spent on. In the research, accommodation support was the most prevalent type of disability support organised under individual funding, followed by advocacy and information (Table 4).

Table 4: Individual funding by disability support type

	Service providers	
	Number	Per cent
Accommodation support	13	59.0
Advocacy and information	8	36.3
Community access—other	7	31.8
Community access—transition to work	5	22.7
Community support	5	22.7
Respite	5	22.7

Notes: Percentages equal more than 100 because providers can supply multiple support types.
Disability support types are defined by CSTDA (AIHW 2007c).[2]
Source: Service provider surveys (n=19) and interviews (n=12).

This research sample is different to the CSTDA information about individual funding. In the CSTDA data the most common disability support type purchased under individual funding is employment support (endnote 1), followed by community support and community access (Table 5). This difference may be due to the sampling strategy (Appendix A), the small sample size and changes in individual funding service provision since the 2006–07 period.

CSTDA data shows that individual funding in Australia is not yet widespread (Table 5). Just over one-quarter of the packages of disability support services are provided through individual funding arrangements and, within each disability support type, people with individual funding range from 20 to 35 per cent of people using that support type. These proportions are limited by not including employment support and double counting people who use an individual funding arrangement for more than one disability support type.

Table 5: Individual funding by disability support type, CSTDA 2006–07

	People using each individual funding support type[a]		Individual funding per cent of CSTDA support type[a]	All people using each CSTDA support type[a],[b]	
	Number	Per cent		Number	Per cent
Community support	20,458	34.7	20.7	98,598	44.9
Community access	16,203	27.4	30.4	53,236	24.3
Accommodation support	13,290	22.5	35.5	37,473	17.1
Respite	9,065	15.4	30.2	30,058	13.7
All individual funding[a], [b]	59,016	100.0	26.9	–	–
All CSTDA support[a], [b]				219,365	100.0

(a) People may be counted more than once because they can use multiple support types.
(b) Excluding employment services in the CSTDA (see endnote 1). Case-based funding of disability employment services is classified as individualised funding for the purposes of the data in the CSTDA National Minimum Data Set. Under this classification all disability employment service users in the CSTDA data receive individualised funding. However, in relation to disability employment services, individualised funding refers to the calculation of the funding amount that is paid to the service provider, not the control of expenditure given to the service user.
Note: '–'=not applicable.
Source: CSTDA includes individual funding from states, territories and the Australian Government.

3.2 Examples of individual funding

Examples of types of individual funding in Australia include individual packages held by a service provider, held by the person to spend through providers but not on the open market, or held by the person to spend on the open market. Each is described below with examples provided. International examples of individual funding are described in Appendix D and E.

Individual packages held by a provider

An individual budget or package is held by a service provider, and the person with a disability can choose and change their provider and choose how their budget is spent, within the limits of the program definition. Budget types can include holistic support packages across program types and funding boundaries to meet the broad and changing spectrum of individual needs. The budget can include an allocation to the provider for administrative, coordination or management costs.

Victoria—individual support packages

Victoria has been providing individual support packages for a number of years. It has recently combined its Support and Choice, HomeFirst, Community Options and Futures for Young Adults into one program, Disability Services Individual Support Packages. The draft guidelines (Department of Human Services 2008, p. 8) outline the aims of the Individual Support Packages, to enable people with disabilities to meet their goals and exercise choice in obtaining support that assists them pursue their own lifestyles.

> Through individualised planning, the person is able to determine what supports they need to achieve their goals, who will provide the supports and how and when the supports should be provided.

While the aim is to provide flexibility to meet the needs and preferences of the person with a disability and their family, the guidelines outline the parameters within which the support needs to fall. The categories for support are: residential care services; personal and in-home support; health and professional services; skill development services; leisure support; aids and equipment; transport; and case management.

Individual budget held by the person to spend through providers

An individual budget or package is held by the person to spend through approved providers. The funding can be allocated to a financial intermediary to manage on behalf of the person with a disability to pay for support and to assist with planning, organising and purchasing support from a range of providers.

Western Australia—My Place

My Place works with people with disabilities and their families to find accommodation that meets the client's needs. The aim is to provide flexible, individualised accommodation options based on personal choice. Each person supported has a dedicated service coordinator who assists in designing and facilitating the lifestyle and accommodation supports chosen. The coordinator works with individuals to find a house that is comfortable, well equipped, accessible, affordable, close to services and in a suburb preferred by the person with a disability. The service operates around a person-centred approach that offers personal choice, consumer control and flexibility.

Victoria—Direct Payments Pilot Project

The Victorian Direct Payments Project operated from January 2006 to June 2007. Disability Services, Department of Human Services (DHS), worked in partnership with a group of people with disabilities, their families and carers, known as the Direct Payments Consultants Group (DPCG). While the pilot was called a 'direct payment' scheme, the guidelines required the pilot users to purchase supports through recognised disability providers. People with disabilities were not able to use the funds to employ personal assistants or support workers.

The evaluation of the Victorian Direct Payments Project (LDC Group 2007) identified a number of positive outcomes for the users, related to increased flexibility, control and improved lifestyles. Direct payments users stated they had greater flexibility to achieve goals, wider options for recreation and activities, and that they were able to access more options including recreation, transport and the purchase of medical and equipment aids.

Direct payment to the person to spend in an open market

The funding is paid directly to the person or their substitute to manage and purchase the support they need on the open market, through direct employment, an agency or other providers. Support might include administrative and financial support to plan and manage the purchasing and accountability.

NSW—Attendant Care Program (ACP) Direct Funding Pilot

The Direct Funding Pilot was conducted by the NSW Department of Ageing, Disability and Home Care (DADHC) during 2007, as an option in the Attendant Care Program (ACP). The ACP provides support to individuals

with physical disabilities through a range of tasks and activities to allow them to live and participate in their community. Funds were provided directly to 10 ACP clients for the direct purchase of personal care services, including the employment of support workers. The people using the support were responsible for attendant carer employment and management and were accountable to DADHC for the management of funds and reporting.

The evaluation of the NSW Attendant Care Program Direct Funding Pilot showed a positive response from the initial participants, in terms of improvements in the quality, control and flexibility of their care (Fisher & Campbell-McLean 2008). The direct funding participants reported that they had experienced improved outcomes in health and wellbeing; confidence and self-esteem; and community, social and economic participation. The government is examining ways of expanding the lessons from the pilot to other parts of the ACP.

3.3 Profile of people who receive individual funding

One-quarter of disability support funded under CSTDA is organised through individual funding (Table 5). The profile of people who receive individual funding is diverse, both Australia-wide and in the survey sample for this study. This section describes the profiles of people using individual funding from the CSTDA and the survey data. For more information on data and methodology, see Appendix B. The CSTDA data used for the analysis below includes case-based funding of disability employment services (see endnote 1). However, it needs to be kept in mind that such case-based funding of disability employment services is not included in the definition of individual funding used in the empirical part of this study.

CSTDA profile

A demographic profile of people with disabilities who have individual funding in Australia was drawn from the CSTDA National Minimum Data Set (AIHW 2007c). Use of individual funding was compared against other independent variables and significant mean differences are presented below (see Appendix B, Tables B1 to B7).

Age—Older and younger people are less likely to have individual funding. Across all independent variables service users aged 20 to 59 years had individual funding at higher rates than other age categories. The lowest rates were by service users aged 0 to 19 years and 60 years and over, consistent with the finding from the literature review that older and younger people are less likely to have individual funding arrangements.

Sex—Men are more likely than women to receive individual funding. This finding is consistent with the finding from the literature review that sex may have an impact on access to individual funding.

Indigenous status—Non-Indigenous service users have individual funding at higher rates than Indigenous service users within their population categories. This confirms the literature review finding that service users from an Indigenous or cultural minority may be disadvantaged in access to individual funding.

Primary disability—As a proportion of CSTDA service users grouped according to their primary disability, almost 80 per cent of people with a specific learning disorder or ADD have individual funding, as well as more than half of service users with a psychiatric or physical disability diagnosis. People with other disability types (intellectual, acquired brain injury, autism, sensory impairment and neurological disorder) receive individual funding at rates of between 31 and 50 per cent of their CSTDA population groups. Developmental delay (within the CSTDA, this disability type refers only to users aged 0 to 5 years) recorded the lowest access to individual funding at 3.3 per cent of their CSTDA population group.

Multiple disability—Multiple disability was included in the profile to test a link between service users with multiple disabilities, multiple support needs and service support capabilities. CSTDA data shows that service users with the presence of two or more disabilities have lower rates of individual funding than people without.

Presence of an informal carer—Service users without informal care networks are more likely to have individual funding than service users with informal carers.

Level of support need—Service users with high daily support needs are less likely to have individual funding than service users who require little to no daily living support.

Research respondent profile

The profile of people with disabilities who participated in the research was similar to the CSTDA profile. People who had individual funding were more likely to be men than women, non-Indigenous and not from a culturally or linguistically diverse background (Table 6). However, the gender profile was different to the Australian population, with significantly more men than women participating in the research.

Table 6: Sex and cultural background of people with individual funding, per cent

	Female (n=39)	Male (n=59)	Total (n)
Indigenous Australian	2.6	1.7	2
Culturally or linguistically diverse background (CALD)	27.6	10.2	13
Other (non-Indigenous and non-CALD)	76.9	88.1	85

Notes: No respondents said they were Indigenous **and** from another culturally and linguistically diverse background.
Sex missing=2.

Source: People with disabilities survey.

The most common disability types for people with individual funding were physical and cognitive (Table 7). The smallest group was psychiatric disability. Most people said they need support always or sometimes. People with physical disabilities reported always needing support significantly more often than people with other disability types. These results could either reflect the sampling process or show that individual funding is more likely to be available to people with particular disability types and support needs.

Table 7: Disability type for people with individual funding by level of support needed, per cent

Disability type	Always need support	Sometimes needs support	No support but still finds things difficult[(a)]	No support needed[(a)]	Total (n)
Physical	66.1*	32.2*	0.0*	1.7*	59
Cognitive	45.8	50.8	3.4	0.0	59
Sensory	56.0	40.0	0.0	4.0	25
Psychiatric	36.8	52.6	5.3	5.3	19

(a) As the sample is comprised entirely of people receiving disability support, responses in these categories are unexpected. The categories are derived from CSTDA data definitions.

Notes: Respondents could report more than one disability type.
*significant α=0.05.

Source: People with disabilities survey.

Summary

- Individual funding is a portable package of funds allocated for a particular person to spend on their disability support needs as they choose.
- The way individual funding is organised varies according to: who holds the funds, which parts of it are portable and what disability support types it can be spent on from which parts of the market.
- The profiles from the CSTDA show that individual funding is more likely to be used by people of working age with low support needs, across disability types and disability support types.

4 Summary of individual funding by state and territory

This section summarises individual funding policy and practices in Australian states and territories to the end of 2008. Each jurisdiction is described in terms of approaches to individual funding and policy development, examples and future pathways. The descriptions are not intended to be comprehensive and do not represent policy statements. Rather they offer an overview across Australian jurisdictions with a snapshot of individual states and territories. They demonstrate the variety of approaches taken, as well as common themes. Experiences of managing effective approaches to individual funding, and costs and outcomes, are analysed in later sections. For policy documents and detailed descriptions of programs, see the websites of each state and territory disability agency.

4.1 Australian Capital Territory—Disability ACT

Individual funding approaches

ACT individual funding is primarily through Individual Support Packages (ISPs). The funding package is held by a service provider, is portable, and consumers and their families participate in making choices. The person with a disability and their family can decide, within the parameters of the guidelines, how the funds will be used to obtain the support they need and respond to their individual circumstances. Any person with a disability is able to apply for a package.

Implementation of ISPs is based on a number of principles and delivered through funding mechanisms as outlined in the ISP Policy and Procedures. ISPs are based on individual need and subject to guidelines on what the funding can and cannot be used for. They start from the principle that the person with a disability and their families are in the best position to identify and design the support they need. The procedures ensure that individuals and families have access to independent advice about the development of packages and support options. Further, support is consistent with disability service standards. ISPs aim to facilitate participation in the community and socially valued roles for the person with a disability.

Funding packages can be recurrent, non-recurrent or a combination. They are offered in three ways:

- funding allocated for an individual, which allows for portability of packages between providers and for personal choice regarding support
- individualised funding, which allows a person to select an agency to provide the support
- individual grants, to meet a one-off specific support requirement as a direct payment.

People with disabilities and their families are involved in the early stages in identifying, planning and designing a range of support to meet needs. Changing service providers requires a ‘variation to contract’ and while portability does occur, the majority of people usually remain with one service provider.

According to the officials, consumer views about ISPs are mixed. Some consumers are satisfied, especially when the ISP is straightforward and involves only one support service and one provider. Some consumers want to use the ISPs more flexibly and independently and have the funding directed to them rather than the service providers. The officials said that, ‘Overwhelmingly people are saying they want choice’. While there is some choice, it is limited by the size of the market and the fact that the ACT has a small service sector.

Examples

Quality of Life grants are an example of direct payments to be spent in the open market. They are a one-off direct payment, with the funds being paid directly to the person. The grants aim to enable the person to access community resources, support and activities. For example, people may use the grant to access a social or recreational activity; other people buy a piece of equipment. The grants are small and non-recurrent, usually less than $5,000, aimed at enhancing a person's quality of life.

The ACT has a small service provider base, which has implications for individual funding approaches, given there is not always a choice of providers. The Quality of Life grants are important in that they allow consumers to purchase support more flexibly from non-traditional sources. The grants have demonstrated that some consumers wish to access support outside the traditional service system. For this reason, ACT officials indicated they are reluctant to use an individual funding approach where the funds are held by the person for spending through service providers. By accessing the open market, individual funding has opened up a broader range of support services beyond the existing service system.

Future developments

ACT officials indicated they will continue to offer a range of individual funding options from direct funding to management by service providers. They said that some people with physical disability may prefer to receive the funding directly and plan and budget for their support over the year. Some people with intellectual disabilities and their families may prefer not to have control of the funding and for the package to be held by a broker or service provider to manage employment, insurance and administrative and reporting requirements.

They considered a mix and diversity of funding approaches and mechanisms as important. Officials suggested that the disability support system needs to accommodate different forms of funding—from base funding through to direct payments.

Officials raised the importance of people with disabilities and their families having input into the future development of individual funding in the territory. They said that people with disabilities and families need information so they can make decisions and informed choices; so they know the advantages and any disadvantages; and are offered advocacy if and when they need it.

4.2 New South Wales—Department of Ageing, Disability and Home Care

Individual funding approaches

Stronger Together, the NSW Government's 10-year plan for disability, flags a commitment to more flexible and innovative support arrangements for people with disabilities, their families and carers. Services are linked to an individual's needs and packaged to enable people to continue to live in their own home, with an emphasis on early assistance.

DADHC currently has a range of disability programs, which have aspects of individualised support, that are variously situated in relation to user choice and control. These programs offer various aspects of flexibility and portability across a multidimensional continuum of control and choice.

Some disability programs in NSW, such as respite, allow for more flexible approaches that respond to the person's choices within a respite 'package'. However, these programs are not fully consistent with an individual funding approach because they are not portable or do not maximise choice outside of a particular service type.

DADHC currently offers two models of individual funding. In the first, the funding package is portable and held by the service provider, which provides or buys disability support for the person. In the second, the person

or family receives a direct payment to purchase disability support from the open market, including service providers.

The officials reported that well-developed systems are required to underpin the individual funding approach, including data systems that have the capacity to capture the complexity of supports purchased and the outcomes attained. They considered it important not to overburden the program with administration that outweighs the benefits. Their goal is to build on current systems where appropriate. They recognised the need to build the diversity of the service system, keeping some supply-driven capacity and putting in place greater capacity to respond within a client demand driven environment. This should be supported by standard data collection systems and consistency across regions.

Examples

There are a number of programs funded by DADHC that personalise service delivery by providing greater choice and flexibility to clients and their carers.

Attendant Care Program (ACP)

In ACP, the funding is held by the person or an intermediary. An evaluation of the ACP conducted in 2007 demonstrated personal outcomes for participants of the pilot, including a '… return to a sense of control, managing their own life and maximising independence, choice and activities' (Fisher & Campbell-McLean 2008, p. 1). In the ACP, consumers organise their own personal care arrangements in a more flexible way, including choosing who provides the care.

Extended Family Support program

The Extended Family Support program provides up to $50,000 for families with a child with a disability at risk of relinquishing care. It aims to put in place 'whatever it takes' types of supports to keep the child in the family care context wherever possible, and help parents to regain a sense of control and capacity to manage the care routines.

Community Participation—Self Management Program

In the Community Participation—Self Management Program, funding is held and managed by a financial intermediary to purchase support on behalf of the person. At this stage, the person is unable to hold the funds directly, as tax arrangements have not been agreed with the Australian Taxation Office. Officials reported that experience from the program suggests consumers may be cautious accepting new models and need information to assist in understanding them. They said that in the early stage of the self-managed program, the participants needed information about the programs aims, functions and mechanisms. DADHC engaged the peak body Council for Intellectual Disability to inform families about the packages: this experience showed that some families needed more assistance to plan support. The forthcoming evaluation of Community Participation will examine these themes.

Some families have reported that the Community Participation—Self Management Program has given them the opportunity to try different support, that they are more 'in control' and that support is more community-oriented and individualised. For example, one person leaving school used the package to develop her own stationery design and printing business, with assistance from her father. The package supported her to access TAFE courses, art classes, self-esteem and physical activity classes. She was able to exhibit her art at an expo at the local café to promote her business.

Family Assistance Fund (FAF)

FAF increases the capacity of families to provide ongoing care for a child or young person with disability in their home. Small amounts of discretionary funding are provided to families to help them address needs that

cannot be met through the standard range of services, are not available from other funding sources, or would otherwise be unaffordable.

NSW Younger People in Residential Aged Care (YPIRAC) Program

The NSW YPIRAC In-reach and In-Home Packages aim to improve the quality of life of younger people living in, or at risk of inappropriately entering, residential aged care facilities though the provision of a range of formal and informal supports and increased community engagement. It uses individual funding mechanisms to achieve these goals.

Future developments

NSW is in the development phase and will continue to adopt a coordinated approach, in partnership with people with disabilities and their families, advocates and service provider peak bodies, in the development of its individualised support packages.

DADHC has placed emphasis on collecting a strong evidence base on which to determine how these approaches will be further developed and implemented in New South Wales. The research includes an 'Evaluation of services accessed by DADHC clients', which will describe current supports and services received by people with disabilities and their carers, and the patterns and trends of usage over time. It will also capture the characteristics of effective models of individualised support, and what key stakeholders would like to see in such an approach. The second piece of research, a Participation Action Research Strategy, will assist in transitioning from traditional and standardised approaches of service delivery to more personalised approaches. This research will overlay four pilots that incorporate individualised approaches. Both pieces of research will complement what is scant existing evidence on this issue, both nationally and internationally.

4.3 Northern Territory—Department of Health and Community Services

Individual funding approaches

Geographic and historical factors in the Northern Territory (NT) have had an impact on the way individual funding has developed. These factors include a disability service system still in development; absence of large disability institutions and service providers; and geographic and population factors of remoteness, isolation, transience and lack of family support. The NT does not have a robust block-funded service system to meet people's needs. Consequently, they have relied on individual funding to fill the gaps in service provision. Officials stressed the need to consider the particular circumstances of the territory in the development of individual funding.

Individual Support Package (ISP) funding was introduced in 2000, at the same time as the NT Local Area Coordination (LAC) system was launched. While ISP is still a key part of the territory's disability support provision, the Local Area Coordination has been disbanded and replaced with a system of Disability Case Coordinators and Case Managers. Individual Support Packages start with a needs assessment, develop a budget and identify a suitable provider. The panel meets monthly to discuss applications, make decisions and prioritise, and approves funds. The government prefers to arrange funding agreements with a relevant service provider to distribute the funds. Formal contracts with service providers include reporting, monitoring and ensuring funds are being used for approved purposes. In theory, packages are portable. If the client wanted to change providers the ISP would be re-presented to the panel. In practice another service provider may not be available.

The service context in the territory is that support is often in short supply and organisations sometimes do not market themselves well to people in receipt of direct funding. Rural and remote areas often have no service organisations. In less than half the ISPs, the person holds the funds and has a less formal contract. In these

ISPs, the government does not have as much control over the funding. Funding is allocated quarterly and the person is required to provide an acquittal form to substantiate purchases. The person is able to purchase support from the open market or from a service provider. Sometimes informal arrangements are used, for example, with neighbours. A major area for direct funds is respite, where a family uses the funds to engage a neighbour or friend to come into the home and look after the person to provide some respite for carers. People with intellectual disabilities are able to access packages; many people in this client group are under public guardianship. The package may be directed to the family, carer or guardian. The officials are concerned about inadequate accountability when funds are paid directly to the person and cases where funds are not used as intended.

As at 2009 the government had not received client feedback about the system of direct payment and has not conducted an evaluation. They have the sense that consumers are satisfied with their current arrangements and would not want to take up other alternatives. Officials noted a number of benefits where the ISP is held by the service provider, rather than directed to the person, including: ensuring that support happens; accountability of public funds; funds are spent as intended; quality of care is more assured; and the service provider is better equipped to deal with employment matters (for example, occupational health and safety, insurance, staff conflict, tax).

Examples

The main program utilised in the territory is the Individual Support Packages (ISPs) described above. Priority is given to accommodation support and respite. Community access has lower priority. This reflects the high demand and low supply of accommodation and respite.

Future developments

The purpose of replacing the LAC with Disability Case Coordinators was to introduce a more professional service involving needs assessment and planning. The intention was to improve personalisation, monitoring and responsiveness to change. The NT is striving to implement a more equitable approach between people with disabilities, including inequities of people receiving large packages compared to other people receiving small packages or no support. They aim to tighten the implementation of individual funding and ensure basic support services are available.

4.4 Queensland—Disability Services Queensland

Individual funding approaches

The main approach to individual funding in Queensland is individual funding packages held by a service provider to provide an agreed service to an individual. A small number of people receive direct payments to spend in an open market or employ staff. In Queensland, individual funding is conceptualised as a tailored response to assessed need, which can be delivered through a range of funding mechanisms. The officials said approaches to individual funding should not focus only on how the money is organised.

A mix of funding methodologies in Queensland includes block funding, targeted funding, individual funding and more recently the development of hybrid funding models. Legislation in Queensland specifies that the government can only provide funds to incorporated non-government organisations. As a result, if a person receives funding directly, they must incorporate as an organisation and meet the requirements of a service provider. Approximately 10 people receive direct funding; most are people with physical disability. Generally it may be more difficult for people with intellectual disabilities to meet the legal requirements for incorporation, although their families may seek to do so to receive and administer the funding on their behalf. A small number of families have incorporated to become the service provider for their family member with intellectual disability. The officials said consumers' experiences suggest that direct funding can work very well in some situations—for example, in rural and remote areas where there are limited service providers.

Examples

Queensland is piloting a hybrid funding model that combines base block funding for the service provider to deliver shared accommodation support and individual funding for the person to provide for additional individual care needs and community access. This model attempts to accommodate service provider viability and flexibility, control and portability for the person. The pilot model has been developed in particular for people who require a greater number of support hours. It follows an assessment of the level and actual cost of supports and replaces the reliance on the pooling of individual funding packages—for example, for people living in a group home to meet the group needs. The separate allocation of additional staff support hours for individual care needs increases the portability of the support, as accommodation models are independently viable.

Future developments

Disability Services Queensland has had a particular focus on strengthening the service system in terms of transparency, accountability, quality and standards. They are now seeking to improve consumer outcomes from individually tailored services in response to assessed needs, so that services better meet a person's changing needs over time. Future service delivery will have a greater focus on building people's capacity to live in the community, rather than just on specialist disability support. Different service models might develop to meet this goal of community inclusion.

4.5 South Australia—Department for Families and Communities

Individual funding approaches

Individual funding in South Australia (SA) is based on portable funding held by a service provider. While individual funding packages are common, they are not available across all service types in SA. Individual funding operates as a brokerage model to registered providers. The Disability Services Provider Panel registers providers that meet criteria before they can receive brokerage funding on behalf of a person.

An allocation is made to a person on the basis of their assessment. For example, the assessment may determine that a person needs an amount of respite, personal care and community access. A package is then calculated to purchase these support types. The person is asked if they prefer particular providers and where possible the person's preference is met with one or more providers. The package aims to provide choice for the person. Packages are portable to another provider—for example, in cases where the person is dissatisfied. The rationale of introducing individual packages was to enhance personal choice, independence and self-determination; and promote a service system responsive to personal need.

Examples

One example of portable individual funding packages is the Day Options program for people with intellectual disabilities. Packages are available for people leaving school but not entering employment services, following an assessment process. Consumers are able to choose the provider for their package.

Each year SA organises a Disability Expo, to provide information to people with disabilities and their families about the available service providers. The expo is tailored to school leavers and families and assists the person to choose a provider. Information is a critical component of allowing consumers to make informed decisions about their preferred provider.

Future developments

In 2008 the Minister for Families and Communities committed the disability agency to introduce 'self-managed' approaches to the provision of disability support, consistent with national policy commitments. The SA agency is considering the policy options to develop and implement self-managed approaches and transition to a new system.

4.6 Tasmania—Department of Health and Human Services

Individual funding approaches

The main approach to individual funding is the Individual Support Program (ISP), where the funds are portable and held by a service provider. Under the ISP, the person with a disability applies for a number of support hours up to 34 hours per week to receive personal care and respite assistance. The hours are allocated to the person and the funding contract is made with the non-government service provider. While Tasmania does not directly fund the person, the government enters into a three-way contract with both the person and service provider. The contract with the person identifies the number of support hours per week and allows the person to choose which service provider offers the support. The contract with the service provider is a formal funding agreement. Importantly, the funding is portable so that the person or family can change service provider at any time.

One of the challenges to the government in the program is that they do not have unit costs for hours of support, so the cost varies between organisations. A reform process is aiming to develop a unit cost for support to provide consistency across the sector. This would prevent competition according to price and allow quality of support to become the critical factor.

The rationale for introducing the ISP was the demand from people with disabilities for greater flexibility within the service response. The dominant service model in Tasmania is a group home for people with intellectual disabilities. The government recognised that other disability groups needed support, including people who wanted to remain in their own homes or live in more independent housing in the community. People with physical disability and degenerative conditions in particular use the ISP, as well as people with intellectual disabilities who have the capacity to remain at home but did not have this option in the past. In summary, the ISP has responded to consumer demand for greater service flexibility and facilitated support services outside traditional congregate care. Consumers would like to see the ISP expanded to respond to the high unmet demand for individual funding.

Examples

Tasmania is also trialling direct funding, where the person has more control of their funding. The person enters a contract with a non-government organisation (NGO); hires their own staff and manages a support roster; and pays an administration fee to the organisation. This is a more 'self-directed' approach than the ISP because the person has more control over the support workers. The pilot seems to be working well in cases where the person and/or their support network, such as family, friends or advocates, have the capacity to self-direct. The officials cautioned that it is important that the person or support network understand employment responsibilities and have a good relationship with the NGO. The NGO is not the employer but provides the administrative support, including staff payment.

Tasmania also directly funds people who have set themselves up as a business entity or company for their own ISP. The organisation typically has a board of directors with treasurer and secretary functions and operates to provide the support services required. Some challenges of this option are compliance requirements, as for any NGO, and attracting and keeping board members. Packages range from $60,000 to $120,000. The majority of support purchased is personal care.

Future developments

Tasmanian officials expect that individual funding will continue to grow in Australia. The Department of Health and Human Services is reviewing aspects of the ISP. For example, packages are capped at 34 hours per week but some people need more hours to remain in their own home. Providing additional support hours might be more cost effective than moving to congregate support. The program currently does not have the capacity to lift the cap on hours.

The self-directed pilot described above will also be extended. Officials said the pilot was more cost effective than individuals setting themselves up as a company. The officials would like to see a continuum of approaches. They recognise that the self-directed model will not suit everyone and that people do not always want or have the capacity to employ staff and manage administration.

4.7 Victoria—Department of Human Services

Individual funding approaches

Individual funding started more than a decade ago in Victoria, beginning with portable funding packages held by a service provider. It was initially applied to the Futures for Young Adults Program. At the beginning the funding was used to purchase traditional disability support services, for example, day services. Over time it progressed to encompass a broader range of services; focus on individual plans for people; and provide a flexible combination of support. Victoria's motivation in introducing individual funding and changes in service provision are about 'shifting the control to the end user'.

Victoria has three options where support packages are based on an individual plan, attached to the person and are portable. The funds can be held by a service provider, or a financial intermediary, or direct payment, which is still in development.

The individual funding administrative mechanism is part of a broader commitment to individual planning and support to facilitate greater personal control. The officials said the funding mechanism alone is insufficient to achieve the goals of control and flexibility. Other prerequisites for change are service providers' viability; consumer skill development to make informed decisions and exercise preferences; and a shift towards 'self-directed' approaches. Victoria has adopted the language of 'self-directed approach', rather than 'individual funding', to provide a stronger basis for personal control and remove the focus from the finances. The three components of the approach are self-directed planning, support and funding.

The introduction of individual support packages through the Support and Choice initiative opened up the range of services; a broader client base assessed services; and there was a focus on planning. People are supported to access non-traditional, non–centre based activities. Support and Choice is open to anyone with a disability in Victoria, across the age spectrum, whereas previous programs focused on disability types or school leavers. In the second option, the financial intermediary is the bill payer and is responsible for reporting and accounting to government and the person with disability for how funding is spent. However, decisions about how the money is spent rests with the person and their family. People with intellectual disabilities also access packages, often with family members supporting them to manage packages. Victoria has a number of people in receipt of direct payments, where a nominated person makes payments on their behalf.

Officials reported there are a variety of views among some service providers to developments in individual funding, often relating to concerns around organisational viability. The providers are concerned that if funds are portable, consumers will move their funding away from disability providers—for example, to a local gym for their activities. The experience in Victoria so far is that this only happens occasionally. Consumers may need a long time to develop new preferences to change support types.

The majority of growth funding in Victoria over the last five years has been allocated to individual funding packages. Officials said they now offer a range of packages dependent on personal needs. A large number of the packages are used for attendant care.

Examples

Futures for Young Adults, Support and Choice and HomeFirst (an attendant care program) are examples of programs in Victoria with individual funding. These programs are now combined into one program, Individualised Support Packages (ISPs), with one set of guidelines. The focus is now on the person's needs, rather than the program.

An example of the impact of the packages is that larger ISPs are assisting people in group homes to move into more independent accommodation. The funding package is used to provide support in their new housing. Packages are used to create more flexible responses to people's needs, including accommodation support. Some people have moved home to their family, others to supported accommodation, private rental or public housing. More choice in housing is being provided through use of individual funding.

Victoria implemented a direct payment pilot with a small number of consumers (2006–07). The evaluation (LDC Group 2007) found higher consumer satisfaction and cost-effectiveness because consumers were able to negotiate more support with the funding provided, largely because they were doing the administrative work themselves. Change in satisfaction related to greater levels of choice, flexibility and control, compared to previous dissatisfaction with service providers.

Future developments

Over the last year Victoria has focused on streamlining the range of programs offering individual funding into one cohesive program, Individualised Support Packages, with one set of guidelines. Victoria is developing a resource allocation tool to assist in the assessment process and funds allocation. The tool aims to facilitate access and equity within the individual funding approaches.

In 2009 they focused on enhancing people's access to services locally and build strengths within local communities. They also unbundled support in day services, with the aim that all consumers accessing day services have portable funds, as part of day service reforms. Victoria is adopting a strategic approach regarding its change management and reforms, outlined in 'Support Your Way: a self-directed approach for Victorians with disability (2009)'.

4.8 Western Australia

Individual funding approaches

Western Australia (WA) applies the full range of individual funding approaches, with portable funds held by providers, facilitators and direct funding to individuals and families. Direct funding is facilitated through the Local Area Coordination (LAC) program, which has been running for approximately 20 years, the longest in Australia. Approximately 1,500 people receive direct payments (approximately $10 million per year).

When LAC began 20 years ago, the funding was spent locally, consisted of small amounts and focused on flexibility. Over time, administrative, accountability and reporting requirements increased and the funding amount and complexity has grown. A review of the LAC in 2003 identified that some consumers and families managed high levels of funding in complex packages. This presented risks to the person, families and LAC from the administrative burden and responsibilities of managing the direct payments.

To resolve this risk an additional shared management model is now available, where the funding is held in partnership with the service provider and person, allowing the person varying degrees of direction and management of their support. This shared system offers a continuum of administrative responsibilities. Consumers can fully manage their funds; or have a service provider manage the administration and finances, but still allow personal control over how the funding is spent, including employment of support workers.

All funding in WA is now individualised, except some respite and therapy. For example, all accommodation support providers such as group home operators now receive funding for individuals, not block funding. WA refers to this as a 'notional allocation against each individual', not an individual package. The rationale behind individualising the funding through a notional allocation is to facilitate portability for the consumer. A result of the funding changes is that some consumers have moved from more traditional service types, such as group homes and day centres, to more personalised support types.

In some support types, block funding is still provided to the service provider to fund capacity and therapy services, for a number of places rather than people.

Examples

WA's system of direct payments is integrated with its LAC. Each LAC works with people and families to assist them to access and manage direct payments. WA has an accountability framework with guidelines for use of funds and responsibilities for managing public funds. They also have principles to guide the development and use of direct funds. Direct payments range from one-off grants of $50, to small flexible funding packages of around $5,000, through to larger packages up to approximately $100,000.

Evaluations of LAC have identified that, generally, most people and their families highly value direct payments and consider them to be a key element of the LAC. Direct payment provides a level of control to individuals and families, allows them to 'call the shots' and decide who will provide the support and when. Support is often more informal and flexible than in the past, responding to the needs of consumers.

Future developments

WA is committed to continuing to offer the range of individual funding approaches. The state is refocusing the use of direct payments to build people's natural support networks. Families are also demanding better options, life experiences and futures for their family member.

WA will explore new options for people wanting to self-manage their funds, for example, through shared management models and new support arrangements such as microboards. Officials identified streamlining financial and administrative systems as a priority, as well as a greater focus on outcomes and flexibility. They considered that individual funding should lead to more support options and personal choices and move away from shared care, group and congregate service models.

Summary

- Australian disability agencies demonstrate a growing policy interest in individual funding and self-directed approaches. They are developing policies and guidelines, extending pilots, introducing and refining models and conducting evaluations to better understand consumer outcomes.
- The dominant approach to individual funding in Australia is a portable individual funding package held by a service provider, except in Western Australia, which has a longer history of individual funding, including a system of direct payments.
- Jurisdictions are aiming to offer a continuum of individual funding approaches, with varying levels of control and choice for the person. Jurisdictions confirmed that flexibility of service provision was a key motivator for the person with a disability and their family in seeking individual funding.
- One of the strengths of individual funding identified across jurisdictions is its potential to provide consumers with the opportunity to access a wider range of support, including non-traditional support.
- States and territories support a diversified disability support sector with a mix of funding approaches to achieve a range of viable disability support options including informal, formal, specialised, general and professional support.

5 Managing effective approaches to individual funding

5.1 Introduction

This section presents the findings about managing individual funding to achieve disability support policy goals, where the challenges lie and how they can be addressed. The section is structured according to the benefits and risks identified in the literature review. No additional risks were identified in the interviews. Risk management strategies are identified throughout the section.

The discussion includes findings from the literature review and policy analysis, from the interviews with people with disabilities, policy officials and service providers, and from the survey of service providers and people with disabilities. Table 8 summarises the service provider survey responses about the outcomes from the way they manage the risks and benefits of individual funding compared to other ways of organising disability support. Each subsection refers to the relevant results presented in this table.

Table 8: Service provider perception of the outcomes of managing the risks and benefits of individual funding compared to organising disability support other ways

		Per cent of service providers				
	Mean	Not at all	A little	Mixed	A lot	Very much
Driven by client's wishes	8.9	0.0	0.0	0.0	26.3	73.7
Enables client to exercise choice, decision making, control and consent and to change support arrangements	9.1	0.0	0.0	0.0	21.1	78.9
Facilitates type, quality and quantity of support that client wants	7.2	5.3	0.0	26.3	42.1	26.3
Planning, administration, accountability and legal mechanisms protect client and agency	8.1	0.0	0.0	10.5	57.9	31.6
Support workers' conditions are protected	7.7	0.0	5.6	16.7	38.9	38.9
Improves availability of qualified support workers	4.9	16.7	11.1	38.9	22.2	11.1
Coordination with other providers, support workers, families and informal carers	8.2	0.0	0.0	5.3	52.6	42.1

Notes: Continuous scale 0–10 (1–5 in simplified survey), 0=not at all, 5=mixed, 10=very much.
Survey question: Comparing people who have individual funding with people who organise their support in other ways, how does your agency manage the following risks and benefits?

Source: Service provider survey (n=19).

5.2 Consumer preferences

The literature review suggests that good approaches to individual funding adopt principles about consumer preferences including consumer driven, person-centred support; facilitating independent living in the community; and flexibility in the way support is organised, each discussed below. Leadbeater, Bartlett and Gallagher (2008, p. 9) argue for a transformational approach to public services, through the use of self-directed services that allocate budgets to people so they can shape the support and services they need.

Self-directed services and personal budgets can be responsive to user demand. They can shift away from inflexible, centralised, building-based services, such as day care centres and group homes, towards more flexible, informal and decentralised provision, often organised around a person's home in their community.

Consumer driven, person-centred support

According to the literature review, individual funding is intended to be driven by the person needing support in a way that focuses on empowerment, self-determination, consumer control and access to valued resources and supports. For example, the Seattle 2000 Declaration on Self Determination and Individual Funding sees self-determination as the rationale and guiding principle for individual funding.

Individual funding is underpinned by the principles and practice of person-centred support. Glynn and Beresford (2008, p. 2) describe person-centred support as:

> … a new umbrella term to cover a wide range of new developments and approaches, from 'person-centred planning' to direct payments, concerned with putting service users at the centre of policy and practice to ensure that the support they receive is shaped primarily by their individual and collective rights and needs, hopes and goals.

The focus of individual funding approaches is on person-centred support, rather than on technical, administrative, financial and accountability issues (d'Aboville 2006). Person-centred support underpins individualised planning and support as tools to enhance quality of life.

In the study, individual funding appeared to be successful overall in achieving its aim of person-centred disability support. People across all disability, funding and support types reported a high level of control over their support and a general feeling that their services were arranged around their needs. One person said:

> I feel very empowered. I feel like I have power over who comes into my house, when they come into my house and what they do while they are there.

Over 90 per cent of people using individual funding or their family indicated that they were able to choose what they want to do regarding disability support type and who provides the support (Table 9).

Table 9: Choice about support, per cent

	Yes	No	People (n)
Choice about support (choice of service provider, support staff, support services)	92.4	7.6	79

Note: Missing=21 suggesting that some people might have found the question difficult to understand.
Source: People with disabilities survey.

Similarly, all service providers felt that individual funding support was driven by the person's wishes (Table 8).

According to policy officials and service providers, typical mechanisms used to achieve consumer driven and person-centred support in individual funding are individual assessments, individual planning and goal setting processes. People with disabilities and their families are involved in planning and developing individual support packages.

There appears to be a relationship between planning mechanisms used and the disability type of the person. According to case study interview data, people with physical disabilities more often used the needs assessment process to determine the level of daily support required and how it would be arranged. In contrast, people with cognitive and psychiatric disabilities and their families said they made greater use of individual planning processes to arrange and change the support they needed.

Families of people with severe communication or cognitive disabilities indicated difficulties involving the person in the support planning process. Service providers said they addressed this limitation by working closely with the families to learn how their family member communicates and what their interests and goals are.

Irrespective of the person's disability type, most people were satisfied with the assistance they received to choose the disability support they needed (Table 10).

Table 10: Satisfaction with help choosing support by disability type

		Per cent			
	Mean	Very unhappy–unhappy	Mixed	Happy–very happy	People (n)
Physical	7.5	1.9*	13.2*	84.9*	53
Sensory	7.3	4.2	12.5	83.3	24
Psychiatric	7.4	0.0	23.0	76.0	17
Cognitive	6.6	2.1	17.0	80.9	47
Total per cent satisfaction	7.0	2.4	16.5	81.2	85

Notes: Continuous scale 0–10 (1–5 in simplified survey) 0=very unhappy, 5=mixed, 10=very happy.
* significant difference compared to people with other disabilities α=0.05.
Percentage totals are not exactly 100 due to rounding.
Source: People with disabilities survey.

People with physical disabilities reported significantly higher satisfaction than others with the assistance they receive to choose the disability support they want. This may indicate a need to improve assistance to support people with other disability types to make these choices.

People with disabilities and service providers both suggested a link between the characteristics of the individual funding and their ability to achieve person-centred support. In general, managing one's own funds or having them managed by a financial facilitator appeared to ensure a higher level of control over choosing support.

Overall, most people in this study said their disability support was better now than before they used individual funding (Table 11). No people with disabilities who were interviewed reported that their current support arrangements were worse than their previous arrangements.

Table 11: Satisfaction compared to previous disability support

		Per cent			
	Mean	Much worse–worse	Mixed	Better–much better	People (n)
Compared to previous support	6.7	0.0	28.6	71.4	49

Notes: Continuous scale 0–10 (1–5 in simplified survey) 0=much worse, 5=mixed, 10=much better.
Only answered by people who had previous support not with individual funding.
Source: People with disabilities survey.

However, some interviewees reported that they had observed no benefit of their support organised through individual funding, or that some aspects were better and others worse. People with cognitive disabilities participating in a transition to work program reported that many of the services they accessed now were identical to previous ones. Transition to work programs are funded by state governments as an intensive, time-limited program designed to teach people with disabilities the skills they need to participate in the workforce. Some states' transition to work programs have standardised services, and therefore it can be expected that the type of funding to access these programs would not affect the support outcomes.

Similarly, some people with physical disabilities receiving attendant care and who managed their own workers stated that while they enjoyed the flexibility and choice of their current arrangements, the additional administrative requirements of person-centred planning and support could be difficult. This is explored in greater depth in Section 5.4. One person said:

> It's a trade off having to take care of the payroll for my workers ... at times it can be pretty arduous.

Independent living in the community

Most individual funding employs a framework that promotes independent living for people with disabilities, based on principles of enhancing autonomy, control and choice for the person with a disability in securing their preferred support. The framework is embedded in the paradigm of disability and community, which aims to build the capacity of individuals, families and communities. Hatton analysed the experience of 196 people using self-directed support through In Control in the UK and found that 72 per cent said they had more choice and control over their lives (Leadbeater, Bartlett & Gallagher 2008, p. 32). Choices about independent living usually result in living in the community with family or friends, in contrast to residential care (Bleasdale 2001).

In the case studies, some large and flexible individual funding packages that were self-managed by people with disabilities or their families allowed support types that facilitated independent community living. This was common to the vast majority of interviewees using this type of funding. As one family member said:

> We got funding from the government and we were able to buy a house. So we set the kids up in the house and employed [provider] as the care provider for them giving them the full-time care in the house.

Organisations providing support under individual funding echoed the opinions of the people with disabilities and their families who accessed them. However, one service provider raised a concern about individual packages alienating people with disabilities from the traditional disability service system and the social opportunities it presents. Developing social networks is an important part of living independently in the community. The provider said:

> One thing that always comes up in the conferences and meetings we have with other providers is how the self-managed funding packages keep people with a disability from making friends. Someone always brings it up. If someone has a family support package, for example, they can arrange for their children to go out on a community access program, but they can't pay for their friends to go along as well.

Instead, people with disabilities, families, organisations and governments organising support through individual funding concentrate on forming social connections specific to the person's needs, including family,

friends, local community, and where relevant, disability service social opportunities. In this way, social connections do not only rely on the specialist disability support services.

Other people said the restrictions on the size of the package and what it could be spent on limited their capacity to live independently. For example, people with physical disabilities with attendant care support stated that their capacity to live independently in the community was limited by the number of funded hours. One person with a physical disability said:

> There are allowances and times where I can get my workers or have money spent on getting me to work, but ... if I had the hours of support to have my carers take me to the shops or movies with friends on a more regular basis I would, but they just aren't there.

Likewise, some people with cognitive disabilities were not able to live independently in the community because of the limited size of the package. According to their families, the level of resources and support provided through individual funding packages fell far short of their needs. Informal carers such as family and friends said they filled this gap.

Policy officials did not discuss the benefits or risks of individual funding for people with disabilities living independently in the community. They did speak about how individual funding was able to foster community and economic participation. By tailoring support to a person's community and employment routines, people with disabilities are better able to engage in community activities and employment. For example, they said personal care can be provided at the time needed to assist a person to prepare for their working day. These outcomes rely on the package being sufficiently large and flexible enough to facilitate access to the appropriate mix of informal, mainstream and specialist support.

Flexibility

People with disabilities and their families seek the greater flexibility available from individual funding (Allen Consulting Group 2007). For example, the Victorian Individualised Funding Project evaluation found individual funding had the potential to put flexibility into practice. 'Feedback from families was unanimous in saying that flexible funding gave them the opportunity to seek out new activities that suited their family member' (Laragy 2008, p. 15).

Confirming this, service providers and people with disabilities in this study spoke of the significant flexibility of support arrangements that individual funding offered (Table 12). They change the support arrangements and support types as needed (see also Section 5.5). While some people with disabilities believed their individual funding should have a greater scope in what it could purchase and how it could be spent, the general view was that individual funding was highly flexible. One person said:

> Compared to my last type of funding, attendant care is just great. It used to be the latest I could go to bed was 9 at night. I used to cry when they did this, it was like being a child again. Now I get to choose exactly what I want and I feel so much happier.

Table 12: Satisfaction with ability to change disability support

		Per cent			
	Mean	Never–rarely	Sometimes	Often–always	People
Can change services when needed	6.2	16.0	22.2	61.7	81

Note: Continuous scale 0–10 (1–5 in simplified survey), 0=never, 5=sometimes, 10=always.
Percentage total is not exactly 100 due to rounding.
Source: People with disabilities survey.

Officials considered the portability of individual support packages between providers important to meet consumer demand for flexibility and control. They also noted that individual packages needed to be reviewed and changed in response to changes in disability support needs and preferences. In practice, most consumers

do not change providers, perhaps because they do not have sufficient experience or information. Some policies limit changes to packages, for example, by putting caps on the number of support hours; or they prescribe rigid review periods, dependent on a panel convening. One strategy to ensure flexibility is to allow consumers to bank emergency hours for unexpected changes.

Individual funding can empower consumers to purchase a variety of support types, rather than relying on the group support that has dominated past disability services. Examples from jurisdictions show how consumers are using quality support tailored to their needs. Small packages, such as the ACT Quality of Life program, can be used very flexibly, while larger packages provide more disability support but have the disadvantage of more formalisation and accountability.

Flexible individual funding also allowed many people with disabilities to use services that are specific to their particular needs and goals. All service providers in this study thought that individual funding enabled people to exercise choice and change support arrangements (Table 8).

However, some people with disabilities who managed their own support and their family members raised concerns about their obligation to use all their funding and the restrictions placed on how it can be spent. Funding or services allocated on a weekly basis, for example, do not allow for variation in need over weeks or months. They also expressed a fear that if the full allocation of funding were not used it would be reduced or revoked entirely.

Packages managed by people with disabilities and their family members that could be spent in the open market seemed to be the most flexible for purchasing non-traditional disability support types. One family member said:

> About a year ago I quit smoking and was trying to replace it with exercise. I couldn't leave my daughter at home unattended so I asked my facilitator if they could help me buy a treadmill. I ended up paying about $150 of $1,500 and the family support covered the rest. We need to justify that what we are buying is related to my daughter's disability, but otherwise we are able to purchase whatever we need.

In contrast, packages managed and spent through single service providers were limited by the types of support available through that provider. These mixed findings regarding flexibility are reflected in the questionnaire responses from people with disabilities. More than one-third of respondents felt they could not or only sometimes change services if required (Table 12).

Summary

- Policy officials, service providers, people with disabilities and their family members agreed that overall, individual funding allowed for control and choice in support provision.
- Mechanisms for ensuring consumer preferences are met include individual needs assessments and goal setting, as well as flexibility in how funds are spent. These mechanisms are often successfully employed.
- Flexibility, choice and control depend to some extent on the type of individual funding. Packages that are managed by a facilitator or the person with a disability and that can be spent in the open market can generally be tailored more easily towards the consumer's preferences than more restrictive packages or those that must be spent through a single service provider.
- People with significant cognitive disabilities are more restricted in exercising consumer preferences. Their family members often interpret their needs. The level of funding provided through individual packages is generally not sufficient to facilitate independent living.

5.3 Support according to capacity and vulnerability

Effective approaches to individual funding recognise and address differences in capacity and vulnerability of people seeking disability support. They include mechanisms to support the person's informed choice about

the suitability of individual funding approaches; and to exercise choice and decision making if they choose to receive individual funding.

Support for informed choice about individual funding approach

Choosing to participate in individual funding and which approach is most suited to the person is a complex process. Good quality approaches include processes to support that informed choice, alongside other available formal and informal support. People need information to make decisions whether to choose an individual funding approach, which type is most suited to their needs and how to make the necessary changes and arrangements. For example, in most countries when individual funding options are introduced, most people choose support organised through providers or financial facilitators rather than direct payments. Glasby, Glendinning and Littlechild (2006, p. 281), writing of the UK experience, urge caution about direct payments:

> … it may not be appropriate to assume that direct payments are the solution for all people who are eligible for community care services … there may be other, more appropriate means by which some groups of disabled or older people can exercise greater choice and control over their support services.

Similarly, the experience of Attendant Care Program in NSW was that most people chose to allocate the package to one provider, fewer chose a cooperative model and only 10 people participated in the direct funding pilot (Fisher & Campbell-McLean 2008). The NSW government provides guidelines and policy officer advice to inform that choice and the person can change their choice.

The review of Australian and overseas literature identified a number of risks in devolving purchasing power to service users in the absence of support for informed choices (Cass & Thompson 2008, p. 38):

> Individual users are likely to have more restricted information about available services … and service choices are much easier to make and fulfil by people who have extensive resources on which to draw. These resources include income and assets; knowledge of service structures and practices; personal skills in dealing with professionals and managers.

In this research, decision making support provided by government agencies included information and guidelines, facilitators and coordinators, case managers, and use of peak bodies and advocacy organisations to work closely with people with disabilities. For example, NSW DADHC engaged the Council for Intellectual Disability to provide information to people and their families about the Community Participation self-managed pilot.

People with disabilities and their family members confirmed that government and disability advocacy bodies were the main providers of information about individual funding options, rather than service providers. They were mostly satisfied with the information they were given. One person with a disability said:

> I was very unhappy with the kind of help I used to get, so I contacted the government and I was told about attendant care. When it came to choosing a provider I was given a whole list to choose from and just went from there contacting people.

Most people with disabilities were happy or very happy with the support they received to make decisions related to choosing their support (81.2 per cent; Table 10). Satisfaction was similar across disability types, with the exception of people with psychiatric disabilities, who indicated slightly lower levels of satisfaction.

Some people with disabilities or their family members who managed their own funding and purchased services through the open market expressed concerns about the amount and quality of information they were given. Often they had to expend a great deal of effort to find the information that they needed. Two family members said:

> There is help to find out about the kinds of services that are available, but mostly we need to go out and find out about it ourselves … You might go to one place and then speak with someone who knows about someone else, it can be a word of mouth thing. But you do need to go out and find out for yourself.

> Because we manage all of our own funds and the only real person we have contact with regularly is just a financial facilitator working with the government, it can be really frustrating to find out what things are out there for my daughter.

Support to exercise choice and decision making

Experience internationally varies as to how people with restricted capacity for decision making or communication can be supported to participate in individual funding if they choose to do so. Risks are that, without support, they can be excluded from choosing individual funding options; professionals or informal carers become substitute decision makers without the person's effective input; or their support needs are not adequately addressed because they cannot manage the complexities required of them. These risks have been most commonly experienced by people with unstable support needs, such as some people with psychiatric disability. Also vulnerable to these risks are people with multiple additional needs, including cognitive or communication needs, younger or older people, people with limited education or who are socioeconomically disadvantaged. These reasons might be accentuated by their experiences due to their location, sex, culture, language, religious or Indigenous background.

Good individual funding approaches address this risk of excluding people with restricted capacity and additional vulnerabilities by developing management structures to facilitate choice, consent and decision making about their preferred disability support. Examples include communication support, advocacy and supported decision making, such as support circles or microboards in Canada (Bleasdale 2001). The UK In Control program is an example of assisting people with learning disabilities to access and manage personal budgets (Leadbeater, Bartlett & Gallagher 2008).

Ongoing support after the initial choice about whether to participate in individual funding and establishing the first support arrangements is also necessary to facilitate changes as required. Williams and Holman (2006, p. 73) concluded:

> People with learning difficulties need ongoing support to manage direct payments. It was not sufficient to arrange the direct payments, give some initial support and then simply withdraw.

WA Local Area Coordination provides ongoing support to people and their families in receipt of direct payments. The WA approach is premised on the view that families are usually in the best position to decide what is right for their family members with disabilities. The LAC assists families to establish enduring relationships in their community.

The United Kingdom experience is a low take-up of direct payments by people with learning difficulties, due to limited support to manage consent and care arrangements. In 1996 the Community Care (Direct Payments) Act UK was passed, giving direct payments a legislative base and authority. In 2001 the legislation was strengthened to make it mandatory for local authorities to offer direct payments to all persons eligible for community care services who consent to and are able to manage payments. Despite the promotion of direct payments in the UK and its legislative underpinning, the take-up has been slow and uneven, with London and south-east England having a higher take-up and Scotland having a very low take-up. The take-up of direct payments by different user groups has been uneven. People with physical disabilities are the main users, compared to people with learning disabilities or mental illness (Glasby & Littlechild 2006). A risk is that individual funding without adequate support might privilege people with disabilities who may be the most able and least vulnerable—for example, young, educated, professional people with physical disability.

In Australian states and territories, some mechanisms are in place to support the capacity of the person to exercise choice, consent and express their preferences. For example, advocates, family members and informal carers and networks are able to provide support to manage funding packages. The officials raised the need for policy mechanisms and structures to address access and equity for different consumer groups, as seen in the Community Participation program.

The NSW Self Managed Community Participation (CP) client group is primarily young people with cognitive disabilities. NSW officials noted that some people need more support in their planning than others and that

support is through formal services and informal support from significant people in their lives. Decision making support is embedded in the self-managed CP pilot, which provides funding for administrative support as well as a support worker assisting with the development of the individual plan. The officials said decision making support structured into the program is integral for its success.

All service providers in this study indicated that people received high or very high levels of support to make service use decisions (Table 13). This is consistent with the people with disabilities survey results (Table 10). Service providers stated that a key feature of determining a care plan for the person with a disability was ensuring they had adequate information on what services were available to them. A service provider said:

> A lot of our administrative costs go towards holding training seminars and sending out information packs about how our clients can do the things they need to do to choose the people who work for them.

Table 13: Service provider perception of client or family control of individual funding

		Per cent of service providers				
	Mean	Not at all	A little	Mixed	A lot	Very much
Client or family's:						
Awareness of amount of funding entitled to	7.5	0.0	5.3	26.3	15.8	52.6
Awareness of rules and systems of funding	6.3	5.3	10.5	31.6	26.3	26.3
Help received for client to make decisions	7.4	0.0	5.3	15.8	47.4	31.6
Use funding in flexible and creative manner	7.6	0.0	10.5	10.5	26.3	52.6

Notes: Questions 5–8. Continuous scale 0–10, 0=not at all, 5=mixed, 10=very much.
Percentage totals are not exactly 100 due to rounding.
Source: Service provider survey (n=19).

At the same time, service providers recognised the difference in the capacity of people with disabilities to make informed decisions about the types of support they could use under individual funding. They established mechanisms for accounting for differences in impairment or ensuring that within the mechanisms available every effort was made to promote individual choice. This was most commonly achieved by developing support networks that involved both formal and informal carers working in consultation with the person with a disability to determine an appropriate care plan.

Service providers and people with disabilities confirmed that informed decision making was supported through the use of ongoing review mechanisms. Most commonly these take place on an annual or biannual basis; however, people with disabilities and their family members could change the support outside these review processes. These mechanisms were common to and functioned similarly across all disability, service and funding types. One person said:

> If there was something about the things I was doing here that I didn't like, I know I could go up to my case manager and tell them and they would do their best to find something different.

People with disabilities were satisfied with how these review mechanisms worked for them. The freedom to change support was particularly extensive for people with disabilities or their family members who managed their own funding in the open market.

The main problems identified with these processes related to the type and quantity of service they could purchase as determined by their funding package (Section 5.5).

Summary

- Government and advocacy organisations are the main providers of information about individual funding options. Service providers give ongoing information to existing individual funding clients and ensure regular reviews.
- Service providers support choice and decision making processes for different impairment levels by involving informal networks of family and friends in support planning.
- Officials in all states and territories affirmed the need to provide support to people with disabilities and their families to enable informed choice about individual funding and to exercise choice and decision making.
- Some people with disabilities who manage individual funding in the open market feel they do not have adequate information.

5.4 Administrative systems for managing support responsibilities

Effective approaches to individual funding address three aspects of administrative systems to manage the disability support responsibilities. These are the management structures to organise the support; accountability requirements for the public funding; and legal mechanisms to facilitate the funding option without disadvantaging the person financially.

Managing the support responsibilities

As well as support to exercise choice and decision making about their preferred support discussed above, the other set of administrative support for a person to access individual funding relates to managing the support arrangements. Some people need administrative support services and intermediaries for advice or purchase of support for planning, brokerage, case management, financial and technical management, accountability, employment, risk management (abuse, neglect, exploitation, injury) and peer support.

Cass and Thompson (2008, p. 40) summarised the risks of poorly managed individual funding as identified in submissions to the Australian Senate (2007) Funding and Operation of the Commonwealth State Territory Disability Agreement, as follows:

- The procedures for managing individualised packages of funding were complex and could be too difficult for some people. This risk is also explored in Section 5.3.
- It should be possible to be self-sufficient using only traditional agency-based services.
- Control over the funding could simply pass from agencies to brokers without providing autonomy for the person with a disability.
- Reducing contact with agency staff could lead to greater isolation, and vulnerability to exploitation and abuse.
- Individualised funding could mean governments evading any further responsibility, either for the individual service user or for service innovation and development.

Good approaches to individual funding offer administrative support to people with disabilities if they need it to manage the technical, financial and accountability requirements of individual funding, in particular when the funding is provided directly to the person. Mechanisms can include facilitators, brokers, network builders, financial intermediaries, advocacy and consumer organisations, microboards, independent living centres, or networks of family members, guardians or friends.

A risk of poorly managed individual funding is that the administrative support mechanism might replace the decision making and control of the person with a disability (Williams & Holman 2006). This risk is more likely if the administrative and accountability requirements of individual funding are too onerous.

Officials reported that managing support responsibilities and accountability for public funds are two key challenges facing government agencies. Some jurisdictions noted they are still in the process of developing reporting and accountability systems for individual funding. Risk management strategies employed by states and territories include:

- Funding is provided to the non-government organisation, rather than directly to the person.
- Funding is held by a financial intermediary to pay bills and manage the financial reporting, including acquittals, audits and statements of how the funding is spent.
- Funds are paid quarterly to the person rather than as a large yearly payment, to ensure the person does not run out of funds early.
- Clear policy, funding guidelines and parameters for how the funds can and cannot be spent are developed.
- Annual individual plans are developed, including a funding plan that clearly outlines how funds will be used, with a review at the end of year.
- Local Area Coordinators provide ongoing monitoring to consumers in receipt of direct payments.
- Complex financial issues, cases where people are experiencing problems and cases where funds may not have been used as intended may be transferred to a management agency to resolve.
- Regular monitoring and auditing processes are in place.
- A range of individual funding approaches to minimise risk are offered, for example, the WA Shared Management model.

According to service providers in this study, current planning, administration, accountability and legal mechanisms are effective in protecting both the client and agency. Almost 58 per cent of service providers reported that present mechanisms are effective in protecting the agency and clients, with a further 32 per cent reporting that mechanisms are very effective (Table 8).

A protective mechanism often employed by service providers is information and training for clients. This may involve close contact with new clients and continued engagement with existing clients about changes in support arrangements through case managers and information seminars. Information includes advice on how to recruit and select support workers or service providers. One manager said:

> Family managed funding must go hand in hand with capacity building ... Compare it to a micro business—how good would you be? A family may already have run a small business and understand logical, neat systems; others would need to learn this.

Only half of the service providers in this study reported that people with disabilities and their families had good levels of awareness of the rules and systems of individual funding (Table 13). Some service providers tried to assist people with disabilities by putting together extensive information, including lists of preferred providers, what services they offered, and how those services were relevant to certain disability types. Thus service providers played an important role in providing information on how to manage not only support responsibilities but also the disability support itself.

In the case of people whose money was managed by or spent through one provider, this degree of support was not necessary, as service providers managed the responsibilities themselves. However, this highlighted one of the risks of individual funding identified above, that packages may pass between government and service providers or brokers without the involvement of people with disabilities or their families. Some people with disabilities with this form of individual funding were unaware of what support it could or could not be used to purchase.

Generally people with disabilities and their family members were happy for service providers to manage the administrative responsibilities of their funding package; however, they stated they would welcome greater

involvement in the management process if this resulted in more information on what their funding could be spent on. One family member said:

> I would love to be able to purchase a special chair for my son when he goes to his service provider every day, for his back problems … I have no idea of whether or not I can do this with his funding.

For people with disabilities or their family members who organised their own support through a financial intermediary, that person or organisation took on the responsibility of fund management. One provider developed resources, guidelines and quality assurance mechanisms to assist people with disabilities to manage their support. The manager said:

> We have a list of preferred providers and standards. The quality of service provision is influenced by cost, people may choose to go cheap to get more hours but there is more risk involved. Our facilitators point out the risks to families while they are going through the guidelines and provide information and share experiences … Also regular audits ensure we maintain the standards. We evaluate the preferred providers list annually and discontinue with them if we are not happy.

Some people with disabilities and their family members receiving direct payments to spend through the open market described needing more information than they were receiving. Some direct payment packages, for example, require expense projections at the beginning of each month. Some of the difficulties experienced as a result of this lack of information are also outlined in Section 5.3. For the families of people with disabilities managing their own funds in the open market, estimating the funds they will spend over a monthly period can be difficult, particularly if they do not have access to service costs, or if needs and the amount of services required change in that time. One family member said:

> We have these monthly budget projections. It's quite difficult having to estimate exactly what you need to spend … especially if we don't know what my daughter's situation will be like at the end of the month.

Other direct payment packages spent through the open market included balance sheets that were sent to people with disabilities and their families at the end of every month. Some families said understanding the information included on these sheets was difficult. This is an example of one of the risks of individual funding identified above: managing the support responsibilities of a package may be too difficult for people with disabilities or their family, and this may put at risk the amount of disability support the person has access to. One family member said:

> We've been getting these balance sheets for five years, ever since we started with our facilitator. I'm only just getting the hang of them now! They tell us whether or not we have money left over and if we need to make up for any the next month, sometimes we go over.

Accountability for public funds

One of the administrative responsibilities of disability support funding is financial accountability to ensure public funds are spent appropriately. Who is responsible for this accountability depends on the individual funding approach and the degree of involvement of the person with a disability in the administrative tasks: accountability may rest with the person themselves or their informal carers, the contracted service provider or a contracted financial adviser.

Good management systems recognise the risk to the person, informal carers, provider and government of insufficient support to manage financial accountability. Options to support accountability responsibilities include advisers, contracted management support, training, resources and simplified clear guidelines, including exclusions such as the employment of family members. The accountability process is sometimes simplified if the person receives direct payments. Small packages, such as the ACT Quality of Life program, can be used very flexibly, without onerous reporting and financial accountabilities. The larger packages provide more disability support; however, they require more formalisation and accountability.

For example, the evaluation of the Victorian Direct Payments Project (LDC Group, 2007, pp. ix–x) outlines the range of financial, administrative and accountability requirements of the direct payments user:

- direct payment user signs a deed of agreement with Department of Human Services (DHS)
- consumer opens a bank account for the sole purpose of direct payments
- DHS transfers funds each month according to the funding schedule
- consumer has responsibility for arranging the purchase and payments of their chosen services and supports
- consumer has responsibility for complying with the accountability requirements as specified in the deed and direct payments user manual
- DHS monitors direct payments users monthly and undertakes three-monthly financial reviews.

The policy consideration about how to make accountability requirements manageable under the various individual funding approaches is relevant to the Australian policy context where governments have traditionally sought accountability from the organisations that receive funding rather than from the people who are supported. Risks include increased cost to the person because of a lack of expertise; no economies of scale; and risks of underfunding or inappropriate financial management transferred from the government and service provider to the person. The risk without appropriate support might be greater for people with additional vulnerabilities or restricted capacity.

Another risk is that the accountability responsibilities may rest with informal carers, who again might not have the capacity or time to manage this. For more information on the relationship between individual funding and informal carers refer also to Sections 5.3, 5.4, 5.7 and Table 17.

People with disabilities and family members pointed out that while a possible implication of individualised funding is that informal carers may need to spend time assisting the person with disability to evaluate and make choices, and to manage service provision and accountability requirements (Section 5.3), informal carers also often have to commit significant time to trying to access adequate care under other ways of organising care. Under individual funding, these possible organisational demands on informal carers may potentially be offset by flexibility to provide support to carers (Section 5.7). The personal wellbeing results discussed at Table 17 highlight the interrelationship between wellbeing and informal care.

Without adequate support for individual funding, carer groups have raised concerns about the stress of caring without adequate government support (LDC Group 2007, p. 52). As reported by a direct payment user:

> As long as the person's primary carer is prepared to be a strong advocate and able to keep track of everything involved with direct payments it can work, but without this support it could be very difficult. (LDC Group 2007, p. 59)

People with disabilities and their families in this study were generally managing accountability requirements well once they had settled into their program, as discussed above and in Section 5.5. Service providers detailed a number of mechanisms to ensure that disability support funds are properly managed and accounted for. Consistent with other interview findings, this was particularly relevant in the case of direct payments managed by people with disabilities or family members. Accountability mechanisms generally involved some form of reporting or auditing on a regular time-limited basis. This ensured that over a set period the funding was spent appropriately and that if it was not, measures were in place to ensure it would be in the future. A manager said:

> We support the family to work through the issues and cost out how the money will be spent. We have an accountability process. We use 'placement by supply' forms to document the process and budget. One copy goes to us, one to the worker and one to the family. Money is distributed every four weeks after the forms are received. We either top up the money the family has spent or reimburse them for the money spent during that month.

While accountability mechanisms were usually effective, some service providers gave examples of rare cases of improper fund management, such as:

> The worst experience we had was when a particular family, under our agreement, engaged their own staff for a period. There was a lot of bad practice that had previously been established and what they did was staff were using false names—it was all about tax evasion. We basically terminated the agreement.

The evidence from WA, where direct payments have been used for 20 years, suggests that in only a small number of cases are funds not used as intended. Most people are careful, cautious and judicious in the way they use their funding. The officials said that consumers have a vested interest in using the money wisely, as they need it daily to provide disability support for such basic requirements as assistance to get out of bed in the morning.

One service provider found the auditing processes for individual funding financially burdensome. They said they had to monitor their business practices to account for the government's auditing process, which cost additional money that had to be taken from disability support.

Legal mechanisms

Because individual funding is a relatively new approach in most states and territories, a risk is that legal mechanisms in relation to obligations and eligibilities have not been clarified. For example, before the NSW ACP direct funding pilot started, it took two years to clarify these questions so that participants were not affected in their eligibility for income support or taxable income (Fisher & Campbell-McLean 2008). In contrast, the Victorian Direct Payments Project did not have that clarification (LDC Group 2007, p. xiii):

> A significant issue which impacted the Direct Payments Project and which must be resolved if direct payments are to be expanded to more people in future, is obtaining a ruling from the Department of Families, Communities and Indigenous Affairs (FaCSIA) in regards to Centrelink benefits.

It may be that legislative change is required to address these questions across Australia to facilitate greater access to some of the individual funding approaches.

Service providers in this study identified no major problems with the legal mechanisms surrounding individual funding. People with disabilities or their family members relied on service providers and government agencies for knowledge and management of legal issues and mechanisms. Only a few problems with legal mechanisms were mentioned.

First, providers operating under attendant care models of support stated they faced additional requirements to ensure the safety of support workers in the home of the person supported. This was necessary to ensure that their support workers were adequately insured against physical injury. One service provider noted how they addressed this question:

> All of our service users have their own ABN and are registered as their own business … This means that god forbid should someone injure themselves, they are covered under our insurance policy … Also we have a lot of training seminars teaching carers the types of situations and hazards to expect working in someone's home.

Second, service providers running centre-based day programs said that while the legal mechanisms relating to insurance were clearly defined, insurance premiums for both case workers and people with disabilities were higher than in similar industries.

One service provider speculated that personal abuse of people with disabilities by their support workers was a risk of some individual funding approaches. Employing people to work in a home environment without the monitoring of a service provider leaves people with disabilities vulnerable to abuse. Problems and benefits of individual funding in terms of the quality of care experienced by people with disabilities are explained at greater length in Section 5.6. One family mitigated this risk by increased security measures to monitor support workers:

> We've got security in place. There are cameras outside and inside the house, not where you need to protect privacy but in places where you know if somebody has gone off and left him alone and being abused and whatever.

According to the interview data, most people with disabilities and their families were unaware of specific legal requirements of individual funding or had not experienced any negative impacts, such as abuse, that required them to be aware. People who were aware tended to hold larger packages for spending through the open market and for these people responsibility for managing legal requirements was held by their financial facilitators.

Summary

- States and territories have put accountability requirements in place that reduce the risk to government, and to some extent to clients, of improper use of individual funding.
- Service providers generally feel that existing mechanisms are effective in protecting both agency and clients.
- However, some government accountability processes and legal requirements are cumbersome and expensive, especially occupational health and safety and insurance regulations.
- Service providers play an important role in assisting people to manage their funds, through mechanisms such as providing information and training to clients.
- Examples of abuse exist; however, these are effectively managed by auditing processes and close observation.
- Some people with disabilities receiving direct payments lack the necessary administrative support.
- Legislative change might be required to clarify the impact of direct funding on income support and taxable income to facilitate greater access by people with disabilities.

5.5 Viability of the support type and amount of funding

Individual funding approaches vary regarding entitlement, eligibility, assessment processes and rationing. These variations influence whether the funding package meets the person's support needs, how it fits with informal support and how responsive it is to changes in the person's needs and preferences. A risk of individual funding is that it may not include mechanisms to address insufficient funding, to allow the funds to be spent on the type of support that the person needs, to meet the person's changing or fluctuating support needs, or to help foster informal networks.

Amount of funding

Insufficient funding was identified by some people with disabilities and their families as an issue requiring further attention. Most commonly this was the case for families caring for people with severe cognitive or communicative disabilities, who had either been unsuccessful in applying for additional funding or whose applications were pending. Almost one-third of people with disabilities or their families were unsatisfied or had mixed feelings about the amount of support received due to lack of funding (Table 14). One family member said:

> The funding we get now is totally insufficient for what we need. We can only afford one weekend of respite a month and then there's the cost for diapers and medication, it all adds up. We've applied for more funding before, but so far we haven't been able to get it.

Table 14: Satisfaction with disability support arrangements

		Per cent			
	Mean	Very unhappy–unhappy	Mixed	Happy–very happy	People (n)
Types of support used	6.9	2.1	11.5	86.5	96
Amount of support received	6.6	5.7	25.3	69.0	87
Help received in choosing support	7.0	2.4	16.5	81.2	85

Note: Continuous scale 0–10 (1–5 in simplified survey), 0=very unhappy, 5=mixed, 10=very happy. Percentage totals are not exactly 100 due to rounding.
Source: People with disabilities survey (n=100).

Scandinavian countries tend towards relatively generous entitlements for all people with support needs regardless of age, and flexibility in how the entitlements can be spent. Most Australian states and territories have a fixed total budget for disability support and tightly assess eligibility and competing critical need between people without support. In WA if the person's needs change they must resubmit a new application, which the government compares to the relative need in other applications. In NSW, ACP support funds are capped at a maximum number of support hours per week.

People with disabilities and their family members noted that they were able to apply for additional funding from the relevant state government body. However, the process of applying for more funding was described as lengthy, often unsuccessful and even when successful, the additional funding given was sometimes inadequate or similarly restrictive. One family member said:

> We desperately need more funding. We've made about two separate applications to the government for more but both have been unsuccessful. We have another one being processed at the moment. It's not that we don't need the funding, because we really do.

Support types

Individual funding can empower consumers to purchase a variety of support types tailored to their needs. Most people with disabilities in the study were happy with their service support arrangements (Table 14). Most people were happier with the type of support and help choosing the support than the amount of support they receive.

Some packages have restrictions on the type of support provided. This was common for personal care packages, where personal care was the only disability support available through the package. Service providers reported restrictions on how funding can be spent. Asked to what extent individual funding facilitated the type, quality and quantity of support that a person wants, only 26 per cent answered 'very much', another 42 per cent 'much' and 26 per cent said 'mixed' (Table 8). One manager said:

> Before we moved to individual funding … we were able to buy something simple like a roller door for the garage of one of our wheelchair clients. Now the only thing we can give them is attendant care. It's not our choice, it's what government tells us to do.

Support and funding arranged through a single provider was generally restricted to supporting parts of a person's needs. One manager said:

> When it comes to the type of support we provide to our clients it is mainly about transiting them into a workplace, either supported or unsupported depending on the level of their impairment. We also have some social programs, but for our individual transition to work clients it's about their employment future.

Likewise, some people with disabilities noted that their individual funding did not help them to achieve community integration and participation. Almost one-third of people with disabilities indicated they were completely or somewhat disengaged from their community (Table 15). Comparison to other people with disabilities who use support arrangements other than individual funding was not available. One person said:

> I don't really have much of a life outside of my service provider or outside of home. I only really go out once a fortnight to the movies and it's always with my mum or my sister.

Table 15: Frequency of community activities

		Per cent			
	Mean	Never–rarely	Sometimes	Often–always	People (n)
Frequency of activities in community (e.g. movies, park, shopping)	6.5	6.4	23.4	70.2	94

Note: Continuous scale 0–10 (1–5 in simplified survey) 0=never, 5=sometimes, 10=always.
Source: People with disabilities survey.

Changing support types

People with disabilities and their family often changed the types of support they purchased or purchased new support in accordance with changing needs (see also Section 5.2). Most commonly they change support arrangements and support types but remain with the same provider. One family member said:

> We often change the types of support our daughter gets. Sometimes it's because we don't need that specific type of support anymore, sometimes it's because we just haven't found the right provider. But we absolutely have the freedom to do that.

Some people with disabilities and their families who had other formal support arrangements before individual funding reported difficulties in the process of changing to individual funding. This was particularly the case for people with disabilities changing from block funding to individual funding. These difficulties related primarily to the administrative requirements of the block funder to change away from the former support. One person said:

> I didn't always have my carers organised the same way that I do now. I used to be living in a type of home care environment. When I was looking to change to my current provider the number of forms I had to fill out, the things I had to do, it was amazing. I think [the former provider] had something against me.

Informal networks

Many state and territory officials, those from WA in particular, spoke of the need for individual funding to foster informal and natural support for people with disabilities. Relying on formal support may isolate people from their community, while building natural networks can support vulnerable persons and protect against abuse and neglect. Officials reported that specialist disability support is intended to supplement other resources in the community.

Within the limitations of restricted funding packages, some service providers were able to develop informal networks to extend the support available. A manager said:

> When one of our clients is having a particularly hard time because of family issues or whatever we get everyone from their life involved in a communication circle around the client so everyone is aware of the types of things they are doing and everyone can help out with other aspects of their support they might not usually be involved with.

Summary

- Individual funding managed by a single service provider is often restricted to certain spheres of life, such as accommodation support, which restricts achieving holistic personal goals.
- Some service providers have developed mechanisms to extend the available support, such as supporting the development of informal support networks.
- Insufficient funds in individual packages may be a problem for some people with complex and changing needs.

5.6 Workforce and quality of care

Most support services include support by formal workers or informal carers, in addition to other expenditure on equipment, goods and transport. Quality care requires management of workers and coordination with informal carers. The recruitment and employment of support workers needs to be in line with best practice employment procedures, with safeguards in place to minimise the exploitation of either the person with a disability or the worker. Another risk of some individual funding approaches is that they may compromise the quality of care if, for example, the introduction of the approach results in inadequate regulatory control or unregulated industrial conditions for support workers.

Direct employment of support workers by the person with a disability or their family is not common in Australia, unlike internationally. This is partly because the main form of individual funding in Australia is funds held by the service provider, who employs the support workers. The provider has the responsibility to ensure employment conditions and quality standards are met. Where direct employment occurs (Queensland, Northern Territory, New South Wales, Western Australia), officials said consumers are satisfied with their employer responsibilities. People with disabilities who employed their own support workers echoed this, stating the level of flexibility and choice they now had over their support workers outweighed the additional responsibilities they had as an employer. For more evidence of the experiences of people with disabilities and their families employing their own support workers refer to Section 5.4.

Many people reported a high level of control over recruitment, which enabled them to hire workers with suitable personalities and skill sets that were directly relevant to the needs of the client. The mechanisms used to support this control are explained at length in Section 5.4. Such control was consistent across individual funding approaches and was highly appreciated by the people with disabilities and their families. A family member and a person with a disability said:

> What we can offer our son he could never get from an agency. The support people he has, we have picked them because of some part of their character that our son is going to relate to and feel at ease with. So those sorts of things I don't think an agency can pick up and manage the same.

> When it comes to hiring my workers I put an ad in the paper asking for all of the necessary qualifications. I'm tube fed, for example, so whoever I hire needs to have that skill, to be able to install and change it.

Many of the people with disabilities and families interviewed for this study employed quality workers who had been with them for a long time. People who employed support workers said that the reasons workers are attracted to them is that they know the pay is good and their employers are average people. This is consistent with the ACP direct funding evaluation, which found that support workers enjoyed above award conditions and the people employing them met all legal employment requirements (Fisher & Campbell-McLean 2008).

WA guidelines for direct payments permit consumers to pay a neighbour or friend to provide support, based on reimbursement rather than a wage. Other jurisdictions do not allow individual funding to be used for paying neighbours or friends. This is to avoid the risk of inhibiting the development of natural support, and to ensure Disability Service Standards are met. WA has the safeguard of Local Area Coordinators who are available to monitor support arrangements.

This study found that some workers' conditions are poorly protected, especially where workers are hired directly by people with disabilities or their families. Fieldwork observations indicated that some people were concerned with getting the most hours of support possible, employing carers willing to work at below the industry award. They said this was due to insufficient funding rather than choice. Presumably this is either reimbursement of expenses or illegal payment below minimum wages. One person said:

> My main carer has been here for 10 years and all of that time she has been $12 an hour. I would like to have more money so that I can pay her better.

Additionally, some people employing support workers directly noted that while they have control over employment, they still experience problems with the quality of their workers. This was attributed to their

inexperience with an employer role. It can also be explained by a lack of information and management support from providers, which is explained at length in Sections 5.3 and 5.4. One person said:

> When I started with my provider I had a few workers that were lemons. They made it through the interview process with me but in the end we were just incompatible. Now I'm much more experienced and I get a feel straight away for the person I'm interviewing.

Where support workers were employed by only one family over an extended period, other service providers were concerned about lack of training opportunities for workers. They suggested that workers' skill development could be improved if they worked for an agency, or if individual funding incorporated a training component.

Most service providers reported that individual funding was successful in improving the availability of qualified support workers (Table 8). One-third of providers suggested that the model was successful or very successful in this aim, while a further 39 per cent found it to be moderately successful. The development of successful working relationships between support workers and clients or their families, together with ongoing support and training by the provider, were seen as key features leading to support worker development and retention.

Less than one-third of service providers reported that the individual funding model had little success in increasing availability of qualified support workers (Table 8). These providers generally needed extended recruitment processes to assemble a well-trained workforce and achieve high staff retention rates. They said that individual funding restricted the availability of workers due to poor remuneration, especially where support was organised by the person with a disability or their family. One service provider was able to overcome these difficulties by undertaking a comprehensive budgeting process with families who self-managed their funding and determining wages for their workers. As part of this process any tasks the families required of their workers were assigned a minimum and recommended wage, the determination of which impacted on the quality and quantity of workers available. In some instances individual funding lowered the administrative costs for the service provider, and where those savings were passed onto support workers the quality and number of workers increased.

Overall, service providers reported success in implementing policies to protect the conditions of support workers, with almost 80 per cent of service providers suggesting that conditions were protected to a high or very high extent (Table 8). No service provider interviewees commented negatively on their ability to protect the rights and conditions of workers operating under individual funding.

Summary

- The level of remuneration affects the availability of qualified support workers.
- Whoever manages the funding needs mechanisms to safeguard both service standards for the service user, and working conditions for employees, against risks where conditions are less scrutinised.
- Where individual funding allows people with disabilities to hire their own support workers, they appreciate the flexibility and control this offers. It often leads to suitable and long-term employment of support workers.

5.7 Service integration

Disability support packages can include disability specialist support and various mainstream services. Some also include the development and support of informal care networks, strengthening family and social relationships. Individual funding provides a new driver for service providers to engage with each other and with informal carers and focus on the provision of dynamic and holistic packages of support across support types. The advantages of integrating individual funding within the broader progressive disability sector are suggested in the experience of the Western Australian Local Area Coordination. Rather than establishing parallel processes or stand alone responses, individual funding approaches can be located, for example, within a disability advocacy organisation, such as independent living centres or Local Area Coordination projects.

Interagency coordination

Officials affirmed the importance of interagency coordination and cooperation in supporting people using individual funding. They considered a mix of specialist and non-specialist services important, along with complementary informal support.

Service providers reported that individual funding generally increased the necessity and ability to communicate effectively with other agencies. For example, knowing the extent of progress experienced by someone with a cognitive disability attending behavioural therapy is important to an organisation providing the same person with community access. One service provider said:

> There are a lot of things we need to know about our clients and a lot of things that are relevant to us providing the support we do. For example, if someone has frequent seizures we need to know about their medical needs and who to contact while we are with them, so we speak to their specialist.

Overall, 95 per cent of service providers reported high or very high levels of integration with other providers, support workers, families and informal carers (Table 8). They stated that interagency cooperation usually happened through informal information sharing rather than formal structures. Where formal cooperation had been established, it was often as part of extensive support arrangements and in the form of circles of care involving the person with a disability and everyone who provided them with support. The purpose of these arrangements was to promote close contact between support providers so that relevant information about the person with a disability was available when required.

However, the extent to which interagency coordination occurred depended on the type of funding used and the type of service provided. People with disabilities managing their own funds were more likely than others to engage with multiple providers to deal with the different aspects of their disability and support. As a result, communication between these providers was important to gain a complete understanding of the person with a disability's needs and how best to tailor support.

By comparison, people with disabilities using less intensive forms of support through individual funding, such as attendant care, required less interagency cooperation from their service providers, as all of their support was arranged through a single agency.

People with disabilities and their family seemed generally unaware of the interagency coordination that took place as a result of their funding package. They were, however, aware of the benefits they had received as a result. This was observed particularly in the case of people with complex health and mental health needs, who required coordination between multiple agencies in order to ensure that their needs were being met within all spheres of their support.

> There was a time a couple of years ago I got really crook and I came a bit unstuck. As a result of that we worked out a plan whereby I have a loop of people here in the workplace like my mental health nurse, my case manager, my doctor and we sort of set up a system when if I come to work and I'm not looking great my case manager might say 'we need to call your mental health nurse'.

Support for informal carers

The support provided under individual funding for informal carers relates to both information and management support and disability support. For the most part, the only support provided to informal carers under individual funding was information and management support (Sections 5.3 and 5.4)—for example, how to manage the administrative responsibilities of individual funding, and information regarding the types of services that can be purchased. Informal carers were largely satisfied with the level of information and management support they received. A family member said:

> Our financial facilitator is great. Often when we want something it's just a case of giving him a call and letting him know. Usually his job is just to okay anything we do want to buy with the funding, but he also gives us a lot of information on what we can get and how we can spend the funding we have.

Certain funding types promoted support for informal carers more readily than others, particularly self-managed funding packages that could be spent through the open market and were intended for family support. Such family support packages recognised the needs of both the people with disabilities and their family members. A positive example was where a family member said:

> My son was having a wedding down on the Gold Coast. We were able to get tickets for myself and my daughter to go down and see him for it. It was all paid for under our support package.

In contrast, funding packages held by or which could only be spent through a single service provider were more restrictive in the way they integrated with the person's informal networks. The support offered by these packages was often specific to a disability support type and did not include the needs of informal carers. An exception was respite care, which was available through services for people with cognitive disabilities. However, as some families of people with more complex disabilities stated, the level of respite care provided was inadequate for their needs. For example, one family member said:

> We get two days respite care a month, it just isn't enough. I can't work and my husband can only work a few days a week. They can't be put together either and with where we live I'm driving to take my son to respite for about as long as he's in respite. We definitely need more of it and just not respite care, but more help financially.

Summary

- Most service providers report high levels of interagency cooperation. Interagency cooperation is most pronounced for people requiring extensive support and for those who manage their own funds and are therefore likely to engage with multiple providers.
- Interagency cooperation is mostly informal. The most popular formal mechanism is circles of care, which includes service providers and informal carers.
- Support for informal carers varies with funding type. It is available through self-managed packages that include family support options, while packages held by a single provider are usually disability specific.
- Support for families was primarily information and management support. Other support was provided by family packages; however, these are a vast minority of funding packages.

5.8 Contextual impact

Contextual risks of providing individual funding options include the impact on managing total supply and demand, and impact on the way service provider organisations operate.

Population demand for disability support

Depending on the way the total budget for disability support and the allocation to individual packages is managed (Section 5.5), approaches to individual funding risk allocating limited funds to a small proportion of people needing support. In contrast, effective approaches can encourage new initiatives in addressing support needs by encouraging a mix of general support, disability support and informal care networks.

The interviews with policy officials demonstrated the importance of context to the development and implementation of individual funding approaches. For example, in locations with a small population base and few or no disability organisations, and in rural and remote areas, individual funding fills an important gap in the service system by providing funds to people with disabilities to purchase support directly.

Service provider viability

Officials and service providers were concerned that individual funding may pose a threat to the economic viability of service providers that are used to a block funding model. They were worried in particular about

smaller providers if they do not have funding sources other than individual packages, without a sufficient administrative cost component (Section 6.3).

The questionnaires showed that most people using individual funding purchase all or some of their support from within the existing service system (Table 2). This is also the trend internationally. Therefore a challenge is for the service sector to change their flexibility, responsiveness and quality in the way they organise service delivery.

Officials said that the context of the disability service sector as a not-for-profit sector affects the development of individual funding approaches, especially with approaches that are more market oriented. This might be a risk if the changes are incompatible with the goals of improving consumer control of quality, affordable support. Officials suggested that the response of service providers to individual funding is mixed, with some providers more ready to accept the new approaches. Officials want to involve service providers in discussions about individual funding to assist them through transition periods so they can respond to people's needs rather than fit the people to the organisation.

Officials emphasised the need to address service provider viability. They raised the need to balance funding allocation so that a variety of support services are available in the sector for people to choose from. As one official stated:

> People say we have all this money [to buy disability support] but we don't have anything to spend it on. We want to make sure there is a service system there which people can go to.

Some jurisdictions have grants for base funding to service providers. This safeguards against providers relying solely on the consumers' individual funding packages, especially where the funding may be paid in arrears of service. For example, Queensland's hybrid model provides base funding for the organisation, as well as an individual payment to the person, typically used for community access. Most jurisdictions have one-off grants to providers for capital, training and quality improvement costs.

Small organisations in particular may not be financially viable if they receive only individual packages, without supplementary infrastructure grants. In the ACT, according to an official, some consumers requested that their individual support package be transferred to base funding for the service provider. These were typically consumers who purchased only one support type in their package, such as a day service. By transferring the funding, they did not have to worry about any administrative or reporting requirements and still received the same service from the provider as under an individual package.

Most service providers in the research had either commenced operation in response to the opportunity to provide individual funding support or had added individual funding to their existing support options. These providers did not report a viability problem. Some providers in the sample had changed gradually from traditional forms of disability support funding to individual funding over the years and had also not experienced great difficulties in the transition.

Only one service provider in the sample had changed entirely from block funding to individual funding. The manager we spoke to had had difficult experiences in that transition, particularly relating to additional administrative efforts and the requirement to account for numerous individual packages. According to this service provider, the changes in administrative arrangements did not result in an improvement of the type or quality of services available. The manager said:

> We operate the exact same way we always have, the only difference is we've had to hire two new administrative staff, pay for new auditing software and take on new contracts. We struggled with having to come up with the extra money.

One of the risks of individual funding identified in the literature was the concern held by people with disabilities and their families over whether moving interstate would jeopardise the level of support they currently receive through individual funding. This risk also applies to other ways of organising disability support because the allocation of specialist disability support is state-based. One family managing funds in

the open market for their son noted how this state allocation system limited their capacity to move between states:

> My wife is very career minded, and she has been offered a lot of jobs interstate. We don't want to move though because we know we won't be able to get the same level of funding for our son we are getting now.

Summary

- Transition from traditional funding approaches to individual funding may be difficult for some service providers and even pose a threat to their viability. To manage this risk, governments have put mechanisms in place such as base funding and transition assistance for service providers.
- In addition, new service providers have emerged in response to individual funding opportunities.
- Like the allocation of other specialist disability support, access to individual funding is not transferrable between states. People receiving individual funding are inhibited from moving interstate because they risk losing the benefits of the size of the package, control and flexibility they currently receive.

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6 Costs of individual funding

This section presents the findings about costs to government, consumers and providers of individual funding support.

6.1 Cost of individual funding package

The individual package funding size varied greatly (Table 16). The average size of a funding package across all people in all agencies that provided data was $28,621, but the range was from $700 to $250,000. The variation generally relates to disability support type. Small packages were more likely to be used for transition to work support, attendant care or family support for people with cognitive disabilities and large packages were for accommodation support, multiple service brokerage and respite care. The majority of service providers offered multiple disability support types to people with multiple disability types.

Table 16: Size of individual funding per client ($)

	Average	Minimum	Maximum
Average annual funding per client	28,621	5,075	74,000
Minimum annual funding	10,210	700	34,000
Maximum annual funding	73,188	10,000	250,000
Annual management and admin costs as proportion of client package (%)	14.4	5.0	22.0

Note: Each organisation provided an average size of package (row 1), size of smallest package within the organization (row 2) and size of largest package within the organization (row 3).
Source: Service provider survey (n=17).

Administrative costs also varied greatly across agencies, ranging from 5 to 22 per cent of the package. No relationship between the average package size or administrative costs and number of clients at the agency was evident, which might have indicated economies of scale. Administrative costs are discussed further in Section 6.3.

6.2 Cost to government

Cost to government of individual funding includes the individual funding package itself, usually contracted to a service provider or to the person themselves and administrative costs. The categories of administrative costs are similar to the costs of other ways of organising specialist disability support funding. They include determining eligibility and allocation, monitoring financial accountability, supporting quality standards and organising other general and specialist services not included in the package.

Officials expressed contrasting views about the cost to government of individual funding approaches. Some reported the following views.

- Total costs have not increased as a result of individual funding and funding for individual funding has come from existing disability support programs.
- Individual funding can be cost-effective, for example, where individual funding packages are used to support a person to remain in the family home or social housing in their community. These housing options are cheaper than group homes.

- Individual funding is a mix of cost savings and cost increases.
- The cost to government can be higher for individual funding than block funding, because individual funding does not have the same economies of scale.
- Direct funding can be resource intensive for government. Providing support and assistance to one person to manage their funding is often greater than the support provided to one service provider offering support to a number of people.
- Individual funding costs more for government, which has had to develop and manage new allocation, reporting and monitoring mechanisms, to enable government to account for each person's funding package.
- Self-managed approaches are complex and require whole layers of government administrative processes. Individual funding is not the 'simple' approach that some advocates may suggest.

Some of these comments about higher costs could reflect the additional costs of changing from a system of entirely block funding to a mixed system. Service providers reported a similar transition cost (Section 6.3). They could also reflect higher costs of some people who require additional management support to organise their disability support if they do not have capacity or informal support to do that themselves. Sections 5.3 and 5.4 emphasised the importance of management support systems, particularly information, for the sustainability of individual funding for people with these needs.

6.3 Costs within the individual funding package

Costs covered by the individual package include the disability support (Section 5.5) and the management support or administrative costs (Section 5.4). Earlier sections discussed the benefits of flexible spending within the package, including the ability to respond to changing preferences and needs (Section 5.2). Also discussed was how inadequate funding to meet these needs restricts the potential for the person to fulfil their rights (Section 5.5). This cost problem is shared with other forms of organising disability support funding.

Disability support costs

Disability support costs are the direct expenses to provide the disability support. They include employment costs of support workers, equipment, goods and other services. People with disabilities and service providers did not comment on savings from individual funding about these costs.

The largest disability support cost is employment of support workers. In Australia, these costs are generally driven by industrial relations conditions. These costs are higher in cases, such as better industrial conditions for government-employed support workers, above award conditions offered by some employers and examples of direct employment by people with disabilities who pay above award to retain quality support workers. The impact of individual funding on these employment costs therefore relates to who employs the support worker (government, non-government, private and direct employment).

The interviews revealed situations where people were apparently paying support workers less than award rates (Section 5.6). This could possibly be explicable if the payments were expenses rather than wages. If not, the arrangements would be illegal. The impression from some people with disabilities involved in the fieldwork was that some support workers were employed at below the industry award rate; however, the researcher did not clarify this.

Other costs paid for with the individual funding package include equipment, goods and other services. Smaller packages tended to be spent on these types of costs, a finding that was reflected through the fieldwork. People with disabilities and service providers commented on the flexibility that individual funding can introduce to facilitate payment of these costs (Sections 5.2 and 5.5). They also noted that some individual funding arrangements remain restrictive about spending on these items, which limits the responsiveness of the package to people's needs.

Management support costs

The second type of costs paid for with an individual package are management and administrative costs. These include:

- support worker employment support, for example, training, recruitment, occupational health and safety
- information, advice or administrative support for planning, brokerage, case management, financial and technical management and accountability
- risk management from abuse, neglect, exploitation and injury—systems, insurance and monitoring.

On average service providers said they spend 14 per cent of the package on management costs (range 5 to 22 per cent; Table 16). This is consistent with research about other community services provision and interestingly, direct funding, which averages 10 to 15 per cent management costs (Auditor General of Victoria 1994; Conroy 2005; Fisher & Campbell-McLean 2008).

Some providers described the problems they have with management costs not as the proportion of funding allocated to management costs. Rather, they argued the hourly rate for disability support that the package is benchmarked against is sometimes too low, with the effect that the actual surplus after direct disability support cost is far lower than 15 per cent. One manager said:

> We get 15 per cent for program management … but, the problem is that the benchmark rate is too low. For a direct hour of service delivery we get about $33 an hour, when it actually costs us over $40 to deliver, so we have to account for other hours that are indirect hours. Why don't they just fund the hour of support appropriately?

Some experience of individual funding shows that management costs can sometimes be lower than other ways of organising disability support funding—for example, if the people do it themselves or they have business experience. However, conclusive evidence that the management costs of organising individual funding is less expensive that other ways of organising the financial management of disability support does not exist. Indeed the comments by government officials (Section 6.2) highlight where management costs can be more expensive because of additional management support required to support the person's capacity for decision making. This was generally consistent with the findings in the fieldwork, where few service providers observed any benefits individual funding had in relation to their administrative and management costs.

Some service providers reported that they have changed their business practices to cover the higher management costs compared to managing block funding. This is explored in greater depth in Section 5.8. A manager said:

> If you compare the work that we have to do with every funding plan, every variation to service agreement, monitoring what is happening with the funding with each person—that is a lot. When you get a block grant, say from HACC, to provide social support or respite then you just account for your hours and the administrative burden is far less.

6.4 Other costs not in individual funding package

Individual funding packages only pay for disability support and management support. The person supported, their family and service providers incur other costs not included in the package, such as time, expenses and non-specialist disability support. These people also incur similar costs associated with using block-funded support. The risk from individual funding is the greater management support responsibilities are likely to incur time and expenses that might not be covered in the package in the short or long term. This finding was for the most part not experienced by people with disabilities using individual funding. According to the fieldwork, however, people with disabilities and their families using certain types of funding and support did mention the difficulties associated with managing their support responsibilities, highlighted in Section 5.4. A person with a disability and a provider where the funding held by person for spending through a service provider said:

> So what I do is I pay my [support workers], I do the time sheets and I send an acquittal once a month and [the service provider] puts the money back into my account, although sometimes it doesn't go in quick enough and I am taking it out of my own money to pay the girls which can be a bit difficult at that time.
>
> One of our failings is that often we are not quick enough at getting the money out to them and they'll complain to us and rightly so.

Conversely, some people using individual funding are able to spend it on management costs they could not previously claim (Fisher & Campbell-McLean 2008).

One of the principles of disability support in some states is not to pay for costs of informal care that would otherwise have been offered or paid for by family and friends. A family member where the funding is held by person for spending through a service provider said:

> My daughter will come out and help me and I will cover her petrol and stuff, but there's no flexibility in the arrangement for me to be able to give them anything for their help.

Summary

- The average individual package funding size was $28,500 and ranged from $700 to $250,000. The variation relates to disability support type and support need.
- The average management cost was 14 per cent of the individual funding package and ranged from 5 to 22 per cent. This is similar to the management cost of other community services.
- Individual funding has not increased the total specialist disability support cost to government. Officials said some individual funding is more cost-effective than other models of organising support, particularly where it supplements social housing and informal care.
- Some government officials and service providers said that costs were higher in the transition to a mixed system of funding and organising disability support and establishing systems to support informed decision making and accountability for people receiving individual packages who vary in their capacity to manage the requirements.
- Individual funding packages pay for disability support and management support. The cost of disability support and management support is not usually less expensive than other forms of organising disability support. Rather it enables changes in the types of disability support the funding is spent on.
- Some packages are not large enough to pay for all the disability support a person needs, either because of restrictions on the amount available or what it can be spent on, or the funding allocated for assessed need is insufficient for the actual cost of meeting that need. In these cases the person receiving the support, informal carers or service providers incur the additional costs of the disability support or costs of managing the support, either in terms of time or expenses; or the person does not receive the support they need.

7 Outcomes

This section presents the findings about outcomes for people with disabilities who have individual funding. Australian and international evaluations of individual funding approaches have measured these outcomes in comparison to outcomes for people who have other arrangements for their disability support and comparison to the experience of people who do not need support (for example, Fisher & Campbell-McLean 2008; Laragy 2008; LDC Group 2007; Stancliffe & Keane 2000). They note differences in outcomes and experience by people with different capacity, vulnerabilities, disadvantages, location, culture and language and socioeconomic conditions.

7.1 Personal wellbeing, physical and mental health

People with disabilities and their families who have individual funding reported a similar or higher level of personal wellbeing compared to the rest of the Australian population (Table 17). No significant differences about wellbeing were found as a function of disability type, but it varied by their level of support need. Their comments reflected the same level of satisfaction with their wellbeing and the link to the way they can organise their disability support. A person with a disability who has individual funding said:

> Because everything is easy here and I'm doing the things I like, it means no stress. And when I'm not stressed, I feel healthier generally. My confidence is sky high and my drive is good.

Many people who had changed to individual funding from other ways of organising their disability support reported that their current support was generally far better than their past support (Table 11), in addition to recording a high overall personal wellbeing in Table 17. One person said:

> I used to be with another provider before [this one] and they were nothing like these guys. They aren't a patch on this place, there was nowhere near that level of support I get now to do the things I want like that individual plan. My whole life, my health, has changed. There were times when if I had the smallest problem I would be in hospital for a week, not anymore.

People with disabilities also reflected on how the new arrangements had also improved the wellbeing of their families, such as in the case of respite support. A person with individual funding said:

> I suppose it's good [having respite weekends] because it gives Mum and Dad a break over the weekend and stuff and I can do whatever I want and get away from Mum and Dad [laughs].

Some people were worried that the benefit to their wellbeing would be only temporary if informal support arrangements changed. In particular people with disabilities whose families helped manage their individual funds in the open market were concerned about what would happen once their informal support was no longer available to help with the administrative responsibilities of individual funding. A person with a disability said:

> [I] fear for the future when [my] parents are no longer here. [I] fear because of my vulnerability.

A common theme reported by people who rely on family as primary carers to manage their individual funding disability support is a concern that there will be no one to care for them once their parents are unable to continue the role due to old age or death. Similarly, a person with a disability said:

> I am scared that my mum and dad are old.

Using a standard measure of wellbeing, scores on all domains (standard of living, achievement in life, personal relationships, personal safety, community connectedness) are similar or higher than the scores for the broader Australian population, except for personal health and future security (Table 17). The scores of people using individual funding are higher than normative data for Victorians with intellectual disabilities in the domains of personal health, achievement in life and personal safety, but lower in personal relationships, community connectedness and future security.

Table 17: Subjective personal wellbeing, mean score

Domain	Simplified survey	Standard survey	Australian normative data 2008[(a)]	Intellectual disability normative data[(b)]
Personal wellbeing	76.9	72.4†	74.8	77.1
Standard of living	86.5*	77.7	76.7	75.2
Personal health	71.5*†	64.0*†	74.8	70.5
Achievement in life	83.0*†	78.8*	72.5	79.3
Personal relationships	79.5*†	81.9	78.7	82.1
Personal safety	82.3*†	77.1	79.3	79.3
Community connectedness	80.3†	76.1*†	70.4	81.8
Future security	57.5*†	56.9*†	71.1	72.4

(a) Cummins (2008).
(b) McGillivray et al. (2008).
Notes: Personal Wellbeing Index is comprised of seven equally weighted domains (standard of living, personal health, achievement in life, personal relationships, personal safety, community connectedness and future security (International Wellbeing Group 2006).
* significant difference compared against Australian population norms at α=0.05.
† significant difference compared against Victorian sample of people with mild moderate intellectual disability at α=0.05.
Individual clients as an aggregate reported a mean subjective wellbeing score of 73.7 per cent, falling within the Australian normative range of 73.4–76.4, consistent with the theory of subjective wellbeing homeostasis (International Wellbeing Group 2006).
Differences in overall subjective wellbeing were found as a function of whether an easy English or regular version of the questionnaire for people with disabilities was answered. The mean subjective wellbeing score for the easy English questionnaire was 76.9 per cent, higher than 10 point version with a mean score of 72.4 per cent. A possible explanation is the higher number of proxy respondents. Because the reasons for the difference cannot be confirmed, comparison to normative data is tested for significance separately for each group.
Source: People with disabilities survey (n=100).

A lower perception of health is unsurprising for some people with disabilities, who also experience physical disabilities affecting their health. Poor perceptions of future security probably reflects their concerns about future availability of informal support and options to change the level of formal support. People who require constant support have lower levels of wellbeing than people requiring lower levels of support but the difference is not statistically significant.

Service providers also reported that the support provided to people with individual funding by their organisation assisted greatly in improving the personal wellbeing and health of people with disabilities using individual funding compared to other people without individual funding (Table 18). The greatest difference was to improve community participation and social networks. They generally attributed this to the whole-of-life approach they took in providing support for people with disabilities who have individual funding.

Table 18: Client outcomes using individual funding compared to other arrangements reported by service providers

		Per cent				
	Mean	Much worse	Worse	Mixed	Better	Much better
Community participation (e.g. going out more in the community)	7.5	0.0	0.0	27.8	38.9	33.3
Social benefits (that is, relationships with family and friends)	7.4	0.0	0.0	29.4	41.2	29.4
Access to relevant support services	7.2	0.0	0.0	35.3	41.2	23.5
Employment and education services	7.1	0.0	0.0	33.3	44.4	22.2
General wellbeing	7.1	0.0	0.0	33.3	44.4	22.2
Mental health	7.0	0.0	0.0	33.3	55.6	11.1
Physical health	6.6	0.0	0.0	47.1	41.2	11.8

Notes: Continuous scale 0–10, 0=much worse, 5=mixed, 10=much better. Minimum response=4 for general wellbeing, all other outcomes=5.
Responses to all questions positively correlated. No significant difference between means.
Percentage totals are not exactly 100 due to rounding.
Source: Service provider survey (n=17).

While the type and amount of individual funding used by people with disabilities often limited the disability support types available (Section 5.5), service providers said they tried to assist with all aspects of a person's life. These ranged from coordination with professionals from which a client received treatment to comprehensive diet and exercise plans. One manager said:

> When it comes to the type of service we provide we are mainly interested in employment support of course. But at the same time we understand the everyday needs of our clients and with that in mind we have a number of programs in place that try and put together all parts of the clients life so they can support and give information on one another.

7.2 Social relationships and networks

People with disabilities who have individual funding reported moderate to high levels of satisfaction with their social relationships (Table 19). Over two-thirds of respondents indicated very high or high levels of satisfaction with time spent with family and friends.

Table 19: Satisfaction with social participation

		Per cent			
	Mean	Very unhappy–unhappy	Mixed	Happy–very happy	People (n)
Amount of time spent with family and friends	6.3	9.8	20.7	69.6	92
Future employment, education or activity prospects	5.6	7.2	33.7	59.0	83

Note: Continuous scale 0–10 (1–5 in simplified survey), 0=very unhappy, 5=mixed, 10=very happy.
Percentage totals are not exactly 100 due to rounding.
Source: People with disabilities survey.

These observations are mirrored by those of service providers, over two-thirds of whom report that individual funding clients are better or much better off in terms of social benefits such as relationships with family and friends compared with people using traditional funding arrangements (Table 18).

Generally people with disabilities and their family members indicated that the type of support they received under individual funding helped build social relationships and networks, with exceptions described below. Several interviewees with a disability that used attendant care reported that the model facilitates the forming of close relationships with support workers, at both a professional and personal level. A person with a disability and a family member who have funding held by the person for spending through a service provider said:

> My [support workers] reckon it's like coming over to have a cup of coffee. One of them had to leave because she was moving to the country and she is now working in a child care centre. She says to me that she wishes she was back here because she 'has to work now'. I'm pretty flexible and relaxed but things still get done.

> He's giving something to people—he has people stay in his room rent-free. It's company on a different level to a support person coming in—a shift worker doing the shift and going home. It's building and developing a relationship that forms into something much more than that with a shift worker. He can entertain, he meets their friends, he goes to things he wants to do—it's more a lifestyle than a support.

However, building these same relationships outside of the home with people other than support workers was difficult for some people who use personal care. They attributed this to restrictions within their support package, such as being able to attend social events. One person said:

> That's something I think there needs to be work done on. There are allowances and times where I can get my workers or have money spent on getting me to work, but there's nothing that has as much money spent on it regarding doing anything social like visiting friends. It's more tied into what is economically better for the country.

For people using other types of individual funding the experience of developing and maintaining social relationships and networks was overwhelmingly positive. The family of a person with profound cognitive disabilities, for example, reported the wide availability of social programs within their child's support. They thought that individual funding to access these programs contributed positively to their building their own social networks. The family member said:

> It's so easy for my son to make friends while he is here, he goes out with them all the time, he never stops talking about it.

Some people experienced problems with support arranged through some types of individual funding to promote social relationships and network building. These were consistent with the observation made on the type and amount of funding available to a person with a disability presented in Section 5.5. However, generally people with disabilities and their family members reported positive outcomes in this area of their lives.

7.3 Community and economic participation

Suitable support types and amount of funding help a person with a disability to achieve social integration, personal life goals and economic independence where possible. More than half of people with disabilities who have individual funding were happy with the extent of their social and economic participation and they frequently went out into the community (Table 19, Table 20).

Table 20: Frequency of community activities

		Per cent			
	Mean	Never–rarely	Sometimes	Often–always	People (n)
Frequency of activities in community (e.g. movies, park, shopping)	6.5	6.4	23.4	70.2	94

Note: Continuous scale 0–10 (1–5 in simplified survey), 0=never, 5=sometimes, 10=always.
Source: People with disabilities survey.

People using individual funding reported generally high levels of community participation, with 70 per cent of people reporting participating in community activities such as seeing movies, visiting parks or shopping often or all the time. A further 23 per cent of people reported sometimes engaging in community activities.

This result was supported by data from service providers, most of whom said that individual funding clients within their agencies experience better or much better community participation compared with those who organise their disability support in other ways (72 per cent; Table 18) and approximately two-thirds (63 per cent) said an effect of individual funding compared to other arrangements was to improve social inclusion of people with disabilities who have individual funding (Table 21).

Table 21: Individual funding effect on client social inclusion compared to other arrangements reported by service providers

		Per cent				
	Mean	Much worse	Worse	Mixed	Better	Much better
Achieve social inclusion	7.2	5.3	0.0	31.6	26.3	36.8

Note: Continuous scale 0–10 (1–5 in simplified survey), 0=much worse, 5=mixed, 10=much better.
Source: Service provider survey (n=19).

While no quantitative data was gathered about paid employment, most people with disabilities who have individual funding reported being happy or very happy with future employment, education and activity prospects (Table 19). Similarly, two-thirds of service providers indicated that individual funding clients have better or much better employment and education benefits than people whose disability support is organised in other ways (Table 18).

The extent to which people with disabilities experienced an increase in their community and economic participation depended on the type and amount of individual funding available, according to people interviewed. People with intellectual disabilities participating in a paid employment and training program, for example, were without exception very happy with their ability to participate in the cash economy. This is linked directly to the payment for their work. One person said:

> I've got a job, a proper job that I get paid for. I spend money quickly though and I get help from my mum in making sure I save properly.

Similarly, people with a physical disability using attendant care were happy with the extent to which their support could be used to get them to and from work. They said:

> Once a month I get a weekend where a carer will stay for the weekend so mum and dad can go out and get a break. On these days I can do whatever I want—go to the shops, go to the movies, to the beach or whatever, as long as one of them can drive my car.
>
> I need someone to help me get dressed in the morning. If I don't then my day ends before it has begun. Because I have my own business and I work, that support is so important.
>
> He goes out and does voluntary work in the community, we employ people to be with him five days a week and we have alternate weekends of respite.

7.4 Control, choice, independence and self-determination

The fourth intended benefit of individual funding is to improve control, choice, independence and self-determination. All respondents said that individual funding had improved these aspects of the lives of people who had it. Two people said:

> I can organise a carer to start at 8 am or 9 am, that's up to me. If I need more assistance at uni, I can cancel one of my respite days to cover that time.

> It's a very flexible service that they have tailored around me, not me around the service. So if I want to go out during the day and I cancel a service, like a lunch time service, for example, I can do that and use it another time.

All service providers indicated that support organised through individual funding was driven by client's wishes to a high or very high extent. Nearly two-thirds of service providers indicated that people with disabilities and their families, proxies or carers could spend their funds on the open market rather than choosing only from approved providers (Table 2). Service providers also reported that people generally used funding in a flexible and creative manner, with 79 per cent of providers reporting people doing so to a high or very high extent (Table 13). Most people with disabilities agreed (Table 9). A manager said:

> Self-managed community participation is about tailoring the program to the needs of the client. We have people that range from participating in Paralympics Equestrian training to people providing a volunteer gardening service for elderly neighbors. It is all based on what the client wants their life to involve.

Summary

- The outcomes data compared: people's experiences before and while using individual funding; outcomes for people with disabilities who have individual funding with the outcomes for people whose disability support is organised in other ways; and an Australian population norm for personal wellbeing.
- Most people using individual funding experienced personal wellbeing, physical and mental health at levels similar to both the Australian population norm and the Victoria norm of people with intellectual disabilities. In the interviews, they attributed these positive results to the better control they have over the way they organise their disability support.
- Using a standard measure of personal wellbeing, scores on all domains (standard of living, achievement in life, personal relationships, personal safety, community connectedness) are similar or higher than the scores for the broader Australian population, except for personal health and future security. The scores of people using individual funding are also higher than normative data for Victorians with intellectual disabilities in the domains of personal health, achievement in life and personal safety, but lower in personal relationships, community connectedness and future security.
- People with disabilities and their families also commented on how changing to individual funding had improved the wellbeing of family members because they could share the responsibilities. They were worried about what would happen in the future when the family members could not help manage the individual funding.
- Most people were happy with their social relationships and community participation. Service providers attributed this to the whole-of-life approach they can take providing support for people with disabilities who have individual funding compared to disability support clients who have other arrangements. The type and amount of individual funding used by people with disabilities sometimes limited the contribution individual funding could make to their social participation. For example, if it is support restricted to economic activity, the person could not use support workers to attend social events.
- All respondents said that individual funding had improved their control, choice, independence and self-determination in their lives.

Appendix A: Primary data collection methodology

The research included mixed quantitative and qualitative methods: a national and international literature review and policy analysis, Commonwealth State Territory Disability Agreement (CSTDA) National Minimum Data Set (NMDS) analysis and national interviews and questionnaire with people with disabilities, service providers and officials.

This appendix describes the primary data collection instruments, collection process and the individual funding program samples. The overview of the methodology is described in Section 2. It includes the primary data collection sampling and recruitment methods. This appendix does not repeat that information.

All instruments were drafted with advice from key stakeholders and piloted before use. Final versions are included in Appendix C.

Questionnaires

Paper and electronic self-report questionnaires were the main quantitative data collection instrument due to ease, speed and low cost of administration. Questionnaires were primarily continuous scales and multiple choice questions, supplemented by optional open response questions. A reliance on such question types and a relatively short length allowed the average respondent to fill out the questionnaire in approximately 20 to 30 minutes.

While the questionnaires were designed for printing, they were distributed to service providers (and subsequently clients) electronically unless a paper copy was requested. Many responses were therefore received electronically by the SPRC. Responses returned electronically had higher levels of readability, increasing data quality.

In addition to the regular version, an easy English version of the people with disabilities (PWD) survey was distributed for people with cognitive or comprehension difficulties. People with disabilities or their families or carers self-selected which version of the PWD questionnaire they answered. The easy English questionnaire varied from the regular version with slightly modified language and reduced choice scales using 5 points rather than 10 points. On both versions, visual prompts were provided as an alternative way of conceptualising responses. This version of the questionnaire was tested with the advice of an expert in easy English.

Questionnaire for people with disabilities

The questionnaire for people with disabilities was divided into three main sections (Appendix C).

Section 1: About your life

This section related to the self-reported happiness of the person with a disability and different aspects of their life. The section began with the inclusion of the personal wellbeing index (International Wellbeing Group 2006). The personal wellbeing index is a standard quantitative tool for measuring subjective wellbeing. The easy English version of the questionnaire included a validated modified version of the index for people with more profound cognitive or sensory disabilities, which included visual aids (Cummins & Lau 2005). The personal wellbeing index provides a set of basic outcomes that can be compared against the national disabled and non-disabled means.

The section also included three questions asking respondents to self-rate their satisfaction with the primary outcomes for disability services in accordance with the UN Convention on the Rights of Persons with Disabilities (UN Convention 2006). These relate to how happy people with disabilities are with the relationships they have, their future education, employment or activity prospects and their ability to

participate independently in the community. These questions provide valuable outcomes information that can be compared against other variables tested in the instrument.

Section 2: About your services

This section included five questions asking people with disabilities to self-rate how happy they were with the extent to which the services they purchased met the key principles of individual funding. The principles are from In Control Australia, a peak body of individuals and organisations advocating on behalf of individual funding and include how happy a person is with: the extent of the support they receive, the types of support they receive, the help they get to choose that support and how easily it can be changed (In Control Australia 2009).

The final two questions in this section used past support as a control variable to test overall satisfaction with the support people with disabilities purchased now through individual funding. It asked how satisfied people with disabilities were with the support they receive now in comparison to the support they used to receive if it was arranged through a funding type other than individual funding. It was important to identify this demographic within the research population to test empirically the extent to which individual funding has improved the satisfaction of people with disabilities with their services.

Section 3: About you

This section requested basic demographic information of the respondent for use in later analysis. The demographic questions included were taken from CSTDA NMDS variables that showed large mean differences in access to individual funding. The data collected from these questions can be used both to test the validity of the findings within the preliminary CSTDA analysis and also to compare these demographics against the outcome variables included in Sections 1 and 2 of the questionnaire.

Table A1: People with disabilities questionnaire—question sources

Question	Section	Source
1. How happy do you feel about your life as a whole?	1: About your life	Personal Wellbeing Index
2. How happy do you feel about the things you have? Like the money you have and the things you own?		
3. How happy do you feel about how healthy you are?		
4. How happy do you feel about the things you make or the things you learn?		
5. How happy do you feel about getting on with the people you know?		
6. How happy do you feel about how safe you feel?		
7. How happy do you feel about doing things outside your home?		
8. How happy do you feel about how things will be later on in your life?		
9. How happy do you feel with the amount of time you spend with your family and friends?	1: About your life	UN Convention on the Rights of Persons with Disabilities
10. How happy are you with your future employment, education or activity prospects? For example, job, school, TAFE, volunteering, activities.		
11. How often do you do things in the community? For example, movies, park, shopping.		
12. How happy are you with the types of support you are using now?	2: About your services	In Control Australia, principles of self-directed funding
13. How happy are you with how much support you get?		
14. Do you get to choose what you want to do?		
15. How happy are you with the help you get to choose what you want?		
16. How much do you feel you can change your services when you want to?		
17. Can you remember what types of support you used before the ones you use now?		
18. Are the services you use now better or worse than the support you used before?		

Note: For demographic questions see Appendix C.

Service provider questionnaire

The service provider questionnaire was divided into four sections (Table A2).

Section 1: Client profile

This section asked service providers to estimate how many clients within their agency used individual funding and the types of disabilities they had. The disability types included in this section were taken from the CSTDA NMDS.

Section 2: Client experiences of individual funding managed by your agency

The first part of this section asks service providers to comment on the benefits they have observed of support arranged through individual funding in relation to a number of key life outcome areas. These outcome areas were a combination of the personal wellbeing index used in the questionnaire for people with disabilities as well as some of the key outcomes of individual funding for people with disabilities identified in the literature review.

This section also includes questions from the In Control Australia principles of effective individual funding use for comparison against the data collected in the questionnaire for people with disabilities (In Control Australia 2009). These are independent living, knowledge of amount of funding, self-determination, access to information about individual funding, flexibility of funding type, support according to capacity and mechanisms for legal and administrative accountability. This section included the opportunity to report on how well the manager believed their organisation achieves these principles.

Section 3: Managing risks and benefits

This section asks service providers to comment on how well they believe their organisation and the type of funding they help manage and purchase services with addresses some of the risks associated with individual funding. These risks and the questions relating to them were all identified in past research and evaluations in the literature review and through the policy officials interviews and cross-reference with the people with disabilities questionnaire.

Section 4: Costs

This section asks service providers to comment on the costs associated with individual funding, including amounts and ranges of packages, in addition to any other expenditure incurred as a result of operating under the funding type. This data was collected to build a cost framework for comparison against other types of disability support and funding.

Table A2: Service providers questionnaire—question sources

Question	Section	Source
1. Estimate how many clients use individual funding in your agency now.	Section 1: Client profile	CSTDA NMDS variables
2. What types of disability do the individual funding clients experience?		
3. Are clients who use individual funding in your agency better or worse off than people with similar needs who organise their support in other ways, in the following parts of their life? Mental health Physical health General wellbeing Access to relevant services Social benefits Employment and education benefits Community participation	Section 2: Client experiences of individual funding managed by your agency	Personal Wellbeing Index, In Control Australia, literature review
4. How much does individual funding help to achieve the social inclusion of clients?		
5. How much are clients or their family aware of the amount of individual funding to which they are entitled?		
6. How much are the clients or their family aware of the rules and systems of individual funding?		
7. How much do the clients have the help they need to make decisions?		
8. How much do the clients or their family use individual funding in a flexible and creative manner? Please write examples below.		
9. To what extent is the support that is organised through individual funding driven by the clients' wishes?	Section 3: Managing risks and benefits of individual funding	Literature review, policy officials interviews
10. How much does individual funding enable clients to exercise choice, decision making, control and consent and to change support arrangements?		
11. How much does individual funding facilitate the type, quality and quantity of support clients want?		
12. How well do the individual funding planning, administration, accountability and legal mechanisms protect the client and the agency?		
13. How well are the conditions of support workers protected under individual funding?		
14. How much does individual funding improve the availability of qualified support workers?		
15. How much does your agency work with other service providers, support workers, families and informal carers to support individual funding clients?		
16. If you were working for your agency before and after individual funding started, how difficult was the transition for the agency?		

Note: For cost data questions see Appendix C.

Interviews

Semi-structured interviews were administered to service providers and people with disabilities. Semi-structured interviews direct responses towards research questions, while allowing the interviewer to probe for additional information and expand on any interesting information provided by the interviewee. Interviews were designed to last for approximately 40 minutes; however, the time taken varied greatly as a function of the interviewee's willingness and ability to share information. Interviews were conducted in person where possible; however, for budget and staff availability reasons some interviews were conducted by telephone.

The interview analysis was conducted after the data collection period. Summaries were carried out on the interview recordings and key themes listed under the headings used in Sections 5 and 7, which answered the research questions identified in the literature review. Quotes attributable to these themes and the conclusions observed were also recorded and can be found throughout the analysis in this report.

Interview schedules were constructed for people with disabilities and service providers. The explanations for these are included below.

Interview for people with disabilities

The interview schedule for people with disabilities tested themes similar to the survey for the purposes of data triangulation. The questions and prompts included in the schedule (Appendix C) were designed to expand on the themes that were identified in the literature review as a supplement to the quantitative data collected through the surveys. They were also designed to give people with disabilities and their families an opportunity to explain in their own words what their experience of individual funding had been.

The interview process for people with disabilities began by completing the questionnaire in Appendix C. At the beginning of the interview, interviewees were asked to comment on any answers in the questionnaire that were placed at either extreme of the 10 or 5 point scales. This was done to identify and expand on any obvious positive or negative aspects of their support or their life and determine any relationship with the type of funding they accessed.

Interviewees were then asked to give some information about themselves, the services they accessed and the type of individual funding they used. This was done to build a rapport with the interviewee and to place the following responses in a context that related to their service and funding type.

The final section of the interview schedule asked people with disabilities or their family to comment on the risks of individual funding identified in the literature review (Section 2). Specifically it dealt with their positive and negative experiences of support outcomes, how these related to their support type and any suggestions they had for improving the support they received or how it was managed.

Interview for service providers

The themes in the interviews with service providers were similar to those explored in their survey. The interview schedule (Appendix C) was designed to expand on these themes to supplement the quantitative data collected through the surveys.

The interview process for service providers began by completing the questionnaire (Appendix C). At the beginning of the interview, interviewees were asked to comment on any answers in the questionnaire that were placed at either extreme of the 10 or 5 point scales. This was done to expand on any positive or negative aspects of the support offered by the provider or the outcomes they had observed for people with disabilities operating under individual funding.

Service provider interviewees were then asked to give a brief description of the types of services they provided, the clients they serviced and the forms of funding they operated under. This was done to build a

rapport with the interviewee and to place the following responses in a context that related to the service, funding and disability type relevant to their organisation.

The final section of the interview schedule asked service providers to comment on the risks and benefits of individual funding identified in the literature review (Section 2) and their organisations' experiences of them. Specifically it asked if any of the risks were relevant to the type of services provided by the organisation or how they were funded and how any problems were overcome.

Case study sample

Case studies were conducted with 10 disability service providers in Queensland, New South Wales, Victoria and Western Australia. A brief description of each case study is included below. Table A3 lists the data collected from each case study and where additional interviews were conducted in states where further information was required.

Victoria

Karden Disability Support Foundation

Karden Disability Support Foundation (KDSF) is a not-for-profit organisation established in 2005 to provide customised support services. People with an individual budget negotiate with Karden to provide supports for an agreed cost. Supports include planning, support workers for personal care and community access, and administrative services. Karden holds the budget and provides accounts as required. Support workers are recruited to match the individual's needs and they are employed, trained and supported by Karden.

Personal Lifestyles Assistance Project

Personal Lifestyles Assistance (PLA) was established in 2003 as a semi-autonomous group supporting people with disabilities and family members to look beyond traditional disability service provision for support and activities. *Melba Support Services* provides PLA with administrative support and holds the individual budget for some, but not all, members. PLA is governed by a committee consisting of one person with a disability, family members and the manager. Principles of person-centredness, community inclusion, rights and empowerment underpin its work. PLA assisted in the creation of a number of independent projects that continue to receive coordination support through PLA: these include *One by One* and *Living Distinctive Lives*. *One by One* is a family-governed collective that tailors supports to seven people with an intellectual disability so they can pursue an individual life in the community. Melba Support Services holds an individual budget for each person in this project. *Living Distinctive Lives* is also family-governed and it focuses on creating personalised supports for members to live in their private home. Not all members in this project have their individual budget held by Melba Support Services.

Disability Attendant Support Services Inc. (DASSI)

DASSI is a not-for-profit disability organisation in Victoria that provides attendant care to people with a physical disability. Their areas of service include personal care and mobility support for rehabilitation, education and recreational activities. DASSI oversees the recruitment of attendant carers and other care professionals; however, the clients who use their service are given the choice of who works with them. DASSI operates under a number of disability funding types, including accepting referrals from the Transport Accident Commission (TAC) for attendant care.

New South Wales

Allowance Incorporated

Allowance Inc. is accessed by people with a physical disability who organise their own support under the attendant care program. The attendant care program provides people with a physical disability weekly hours of support they are permitted to allocate in accordance with their own wishes and lifestyles. Allowance Inc.

has for 17 years provided administrative and information support for attendant care users, assisting them with logistical and financial support in advertising for, interviewing and hiring their own care workers. Allowance Inc. additionally manages the administrative responsibilities of their clients, including payroll, superannuation, taxation and occupational health and safety requirements.

Living Linkage Sunnyfield Independent

Sunnyfield offers disability services to young people with mild to moderate intellectual disabilities. The organisation offers community participation (CP) support, transition to work support, day programs, accommodation support and supported employment, and has been in operation for over 50 years. Sunnyfield operates supported employment services and a transition to work program in addition to a comprehensive social access program for its community participation clients. Sunnyfield works in consultation with its clients and their family members to develop person-centred plans that work towards achieving meaningful goals both in terms of transiting to employment and general wellbeing.

Greenacres Community Participation Program

The Greenacres Community Participation Program is a large disability service provider operating in the greater Illawarra area just outside of Sydney. They provide a number of services for a variety of disability types but primarily intellectual and developmental disability. This research considered their transition to work and community participation programs. Unlike some transition to work programs, Greenacres has on its premises Australian Disability Enterprises, which provide supported employment for people with disability. Greenacres' transition to work clients therefore have the opportunity to undertake work experience in a real workplace and get paid prior to moving into the workforce. Another aspect of Greenacres is that they are a Registered Training Organisation delivering tailored courses internally and they also have strong links with workplace training professionals. People with disabilities at Greenacres can be trained internally or attend New South Wales TAFE accredited courses to improve their employment opportunities.

Queensland

Mamre

Mamre has provided support to families with a member with a disability within Brisbane for over 25 years. Mamre places great emphasis on building capacity within families to develop a long-term positive vision and plan for their family member with a disability. Mamre's Pave the Way assists families throughout Queensland with lifelong planning. Mamre receives both block and individualised funding from Disability Services Queensland and Home and Community Care. Every six months, each family receiving family support plans with Mamre how best to use their allocated funds. Over half of the families prefer their funds to be transferred directly to them. They then manage the funds and direct the service in accordance with their six-monthly plan. Mamre assigns a key worker to each family to assist them to plan and manage their funds. Mamre recruits workers emphasising personal positive values, a good match with the family and appropriate life experience over formal skills training.

Horizon Foundation Inc.

Horizon Foundation Inc. originally began in 1982 as a respite care service for parents of children with a disability, but now offers a range of services for people with disabilities individually and their families. Within Horizon Foundation is the Axiom Family Support Program (FSP), which provides support to individuals and their families that have gained FSP funding. Approximately 70 per cent of Axiom's 120 families supported have individual funding packages and through these are able to purchase family support and post-school support. An interesting feature and challenge faced by Horizon is that it operates over three Disability Services Queensland regions.

Western Australia

Disability Services Commission (DSC)

The Disability Services Commission (DSC) is a Western Australian state government agency responsible for advancing opportunities, community participation and quality of life for people with disabilities. The Commission provides a range of direct services and support and also funds non-government agencies to provide services to people with disabilities, their families and carers and has been operating since 1993. One of the unique aspects of the DSC is their use of Local Area Coordinators. Local Area Coordinators operate as a service coordinator rather than a service provider and, as such, can help the person with a disability and their families/carers to plan, select and receive needed supports and services through approved providers and the open market. The overall aim of Local Area Coordination is to support people with disabilities to live within their broader communities. Each Local Area Coordinator is responsible for an average of 65 families.

Perth Home Care Services Inc. (PHCS)

Perth Home Care Services (PHCS) has been providing community-based support services for people with disabilities since 1970. PHCS provides a range of support to a range of disability types, including visiting support where support workers provide assistance in the home or community for a designated number of hours per week and alternative family care where the person with a disability lives in the home of an alternate carer who is paid a tax free carer reimbursement. Increasingly PHCS is the agency of choice to provide services to people with a significant level of disability and complex care needs who have been funded by the Disability Services Commission. PHCS employs approximately 600 support workers in city and country areas.

South Australia

Enhanced Lifestyles Inc.

Enhanced Lifestyles Inc. is a member-driven organisation that offers personal care opportunities to people with a physical disability. Their main service is to provide people with disabilities with personal attendants to assist with home-based care and general assistance. Personal carers are recruited and selected by Enhanced Lifestyles Inc. and after the initial employment process people with disabilities are given final selection over their carers. Enhanced Lifestyles Inc. are currently in the process of developing new models of support that account for the needs of people with disabilities while they are on holidays and help them live more independently in the community through transition programs.

Table A3: Case study and questionnaire site data

Service provider name	Service provider interviews	Client interviews	Service provider questionnaires	Client questionnaires	Total individual funding clients supported	Clients' disability types	Individual funding disability support type
Case studies							
Greenacres community participation program	1	4	1	19	221	All	Transition to work, community access
Living linkage Sunnyfield Independent	1	3	1	6	22	All except physical	Transition to work, community access
Allowance Incorporated	1	4	0	1	–	Physical	Attendant care
Disability Services Commission	1	4	1	3	–	All	Service brokerage
Perth Home Care Services Inc.	1	4	1	4	200	All	Home care
Horizon Foundation Inc.	1	4	1	3	140	All	Family support, post-school options
Karden Disability Support Foundation	1	4	1	4	52	All except psychiatric	Attendant care, person directed support
Personal Lifestyles Assistance Project	1	4	1	9	50	All except psychiatric	Service brokerage
Townsville Independence Program for Adult Community Living Inc.	1	1	1	1	8	All except psychiatric	Service brokerage
Enhanced Lifestyles Inc.	1	0	1	3	56	Physical	Personal attendants, service brokerage
Questionnaires only							
Mamre Association	1	0	1	0	120	All except psychiatric	Family support, respite and home care
DASSI Victoria	1	0	1	0	–	Physical	Attendant care
Community Options	–	–	1	10	24	All	Respite, attendant care, home care

Table A3: Case study and questionnaire site data (continued)

Service provider name	Service provider interviews	Client interviews	Service provider questionnaires	Client questionnaires	Total individual funding clients supported	Clients' disability types	Individual funding disability support type
Lifestyle Solutions	–	–	1	10	35	All	Transition to work, respite, attendant care, community access
Community Connections NSW	–	–	1	1	30	Cognitive	Respite, attendant care
Northcott Disability Services	–	–	1	4	82	All	Community access, accommodation, transition to work, family support
Ability Options Inc.	–	–	1	0	38	Cognitive	Brokerage, accommodation, transition to work
Carpentaria Disability Services Inc.	–	–	1	0	3	All except psychiatric	Supported living, accommodation, community access
Kyabra Community Association	–	–	1	0	3	All (family-based support)	Family support
Family Based Care Northwest	–	–	1	8	–	All	Respite, brokerage
St. Michaels Association	–	–	0	1	–	Cognitive and physical	Community access, respite, accommodation support
Community Living Project	–	–	1	13	–	Cognitive	Community access, brokerage
Total	**12**	**32**	**20**	**100**	–	–	–

Note: '–'=not applicable.

Ethics

Ethics approval was granted by the UNSW Human Research Ethics Committee. All participants provided informed consent before participating in interviews. No identifying information was recorded in either interviews or questionnaires, except for service provider questionnaires, for purposes of follow up data. Where identifying information was inadvertently provided by the participant, it was made anonymous during data entry. People with disabilities who participated in interviews and questionnaires received a $30 gift voucher for their expenses.

Methodological limitations and concerns

Response rate

Out of the 200 anticipated questionnaires from people with disabilities, 100 responses were received. While the majority of persons contacted did not provide reasons for refusal, some hinted at having participated in a number of studies prior to this and not seeing any action or outcomes resulting from their participation.

Out of 16 anticipated service provider interviews, 12 were conducted. Reasons for not meeting the response target include factors such as a limited number of service providers, reluctance for people in the organisation to answer on its behalf and time constraints among service provider staff.

There are methodological limitations resulting from the relatively small sample size. Due to the sensitivity of 0–10 scales (1–5 easy English), the low number of responses prevents sophisticated statistical analysis. Collapsing scales into 5 or 3 points somewhat alleviates this problem; however, resolution and usefulness of differences between client/funding types are compromised. Additionally, several demographic factors such as culturally and linguistically diverse background or Indigenous status were not captured to a great enough extent to enable analysis. Regarding the service provider questionnaire data, descriptive comparisons across funding types were conducted on the 20 responses that were received (20 was the target sample size), as well as chi square tests for significance.

Triangulation with interview and other data serves to minimise the negative effects of the relatively low response rate, improving the usefulness of both types of data in a mutually supportive fashion.

Another methodological concern was the response rate of interviewees. Generally service providers preferred to independently recruit their clients for the interview process. As outlined in Table A3, some service providers were able to recruit more people with disabilities for interviews than others. Subsequently, the interview data collected from these case studies may be overrepresented in the fieldwork analysis. Any negative effect of this response rate was minimised by triangulating the interview data with the other data collected, including the literature review, policy officials interviews and questionnaires.

Easy English questionnaires for people with disabilities

Reduced choice scales were employed in the easy English version of the people with disabilities questionnaire. The questionnaire was answered by 30 per cent of respondents. Scales with fewer points have the drawback of lower sensitivity compared with full point scales. The drawbacks of such lower sensitivity were mitigated by collapsing all responses into 5 or 3 point scales for reasons outlined above. This procedure was not able to be carried out in the case of the Personal Wellbeing Index (PWI) due to its low threshold for significance in variation from Australian normative scores. The Personal Wellbeing Index (and its individual domains) was therefore calculated separately for those who answered the regular questionnaire and those who answered the easy English version. While substantial differences in scores exist between these two groups, it is not possible to determine what proportion of variation is due to differences in scale sensitivity and what proportion is caused by systematic differences between those who opted to answer the simplified version. Respondents to the easy version had higher PWI scores. This may be because they have higher wellbeing or it may be a direct result of lower scale sensitivity (for example, responding at 80 per cent of scale maximum because this is closer to the real score (72 per cent) than 60 per cent, therefore inflating their score by 8 per cent). This

second explanation is less likely because the reduced scale has been validated (Cummins & Lau 2005). A third explanation could be the greater incidence in this group of families/carers answering on behalf of the person by proxy and possibly inflating scores.

Difficulties in integrating data between regular and simplified questionnaires arose largely due to reduced scales rather than language/wording differences. Future investigations should consider utilising the same scales for all respondents, instead utilising strategies such as simplified language or assistance by the researcher/family member to increase accessibility for participants with cognitive or language difficulties.

Personal Wellbeing Index and proxy respondents

The individual domains forming the PWI (standard of living, safety and so on) are designed to be interpreted by the respondent in order to maximise validity. For this reason, the literature on this instrument states that it should not be answered by proxy on behalf of the person. Literature on studies involving persons with intellectual or cognitive disability suggests that such people are strongly susceptible to response bias, answering in a way they perceive to be desirable to the interviewer or other people present. For this reason, a participant's immediate carer should not be present while this instrument is administered (a friend to provide support is acceptable). Furthermore, the researcher or anyone present while the instrument is administered should provide clarification on language or 'moral support' only and should not clarify meaning or intent of questions.

While the research team was generally not present during questionnaire administration, comments left by proxy respondents on the people with disabilities questionnaires suggested these requirements were not met. For this reason, PWI data should be interpreted with caution.

It should be noted that the relatively strict administration requirements presented in the instrument literature suggest a 'best-case' scenario. These requirements need to be considered in the context of the target group for this research, from whom this data could not be gathered if the requirements were to be met. Furthermore, the people with disabilities questionnaire is one of many instruments and data sources used in this study. Triangulation with other instruments makes a partial loss of validity in administering the PWI instrument acceptable.

Interviews with families of people with disabilities

In certain circumstances during the data collection phase it was more appropriate to complete interviews with the families of people with disabilities rather than the person themselves. Generally family members only participated in the interviews if the person with a disability they were representing possessed a significant cognitive or communicative impairment. As with the concerns raised over proxy respondents to the PWI, a risk of asking family members to assume the part of the person with a disability during interviews was that it may compromise the quality of the data collected. Family members may comment on their own experiences rather than those of the person they were representing; though interviewers attempted to solve this by reminding interviewees that the experiences of people with disabilities were the focus of the research.

The option of excluding this disability group from the research was unjustified, as it would have compromised the generalisability of the sample and raised far greater methodological concerns than already posed. Additionally, including family members in the research was important to different aspects of the research, specifically those relating to the support provided under individual funding to informal carers.

Comparison to people with disabilities receiving disability support not organised through individual funding

Comparison data about the experiences of outcomes and risks of people with disabilities who do not use individual funding was available from two sources: asking service providers to compare support they provide to people organised through individual funding with support organised in other ways; and asking the people with disabilities to compare their current individual funding support service experience to their support service

experience prior to individual funding. A control group was not included. Conclusions drawn from comparing people receiving support organised through individual funding to people receiving support organised in other ways should be read with this analysis framework in mind.

Appendix B: Commonwealth State Territory Disability Agreement tables

Commonwealth State Territory Disability Agreement (CSTDA) AIHW minimum datasets were the primary material used for constructing the demographic profile of individual funding shown in Section 2.2 (AIHW 2007b). The datasets are available in the public domain and include administrative data collected by state and territory governments around Australia on their individual disability populations. CSTDA data is available from 1999 through to 2007; however, analysis can only be carried out on data from 2003–04 to 2006–07 as these are the only datasets with individual funding as a variable for analysis.

As described in endnote 1, all disability employment service users are classified as receiving individualised funding in CSTDA data (and hence the data below includes disability employment service users), but individualised funding for disability employment services is not within the definition used for this research because, in relation to disability employment services, individualised funding refers to the calculation of the funding amount that is paid to the service provider, not the control of expenditure given to the service user. This should be kept in mind when viewing the information included in the tables below.

Service users' access to individual funding is the dependent variable for this profile. Independent demographic variables compared against individual funding status include age, sex, Indigenous background, primary disability, presence of another disability, existence of an informal carer, labour force status and need for support in activities of daily living. Independent variables not used include country of birth, need for an interpreter, residential setting and living arrangements. The variables used in the profile were selected on the basis of their relevance to the preliminary findings in the literature review, which identified a number of subgroups of people with disabilities who have less access to support services.

Additionally, data about clients were filtered within the CSTDA dataset on the basis of type of service use, including: accommodation support, community access, community support, respite and employment. Basic mean tests were the primary form of analysis for this profile, as other tests for significance require either smaller population sizes or access to the raw data. All percentages are a percentage of total group including missing data.

Table B1: Age as a percentage of people who have individual funding, 2006–07

Age	Total CSTDA population	Have individual funding within CSTDA population	Have individual funding within age group	Unknown if have individual funding within age group
0–19 years	29.8	6.3	22.7	37.0
20–39 years	33.3	21.7	64.8	6.6
40–59 years	27.8	14.7	52.5	6.2
60 years and over	8.9	1.7	19.9	6.4
All	100[(a)]	44.6		15.7
Number	232,253	103,733		

(a) Percentages equal 100 including missing values.
Source: CSTDA NMDS.

Table B2: Sex as a percentage of people with individual funding, 2006–07

Sex	Total CSTDA population[(a)]	Have individual funding within CSTDA population	Have individual funding within sex	Unknown if have individual funding within sex
Male	59.0	27.7	46.9	16.5
Female	40.4	17.0	41.6	14.2

(a) Percentages do not total 100 because of missing values.
Source: CSTDA NMDS.

Table B3: Indigenous status as a percentage of people with individual funding, 2006–07

Indigenous status	Total CSTDA population	Have individual funding within CSTDA population	Have individual funding within Indigenous status	Unknown if have individual funding within Indigenous status
Indigenous	3.7	1.5	40.0	18.5
Non-Indigenous	90.7	42.8	47.1	15.0

(a) Percentages do not total 100 because of missing values.
Source: CSTDA NMDS.

Table B4: Primary disability as a percentage of people with individual funding, 2006–07

Primary disability	Total CSTDA population[(a)]	Have individual funding within CSTDA population	Have individual funding within disability type	Unknown if have individual funding within disability type
Intellectual	33.0	16.3	49.5	9.8
Psychiatric	15.3	9.0	59.2	2.8
Physical	13.3	7.7	58.1	13.1
Developmental delay	10.0	0.1	3.3	37.3
Sensory	7.1	2.3	32.8	13.5
Autism	5.7	2.2	38.9	25.3
Neurological	5.3	1.6	31.1	16.8
Acquired brain injury (ABI)	4.4	1.7	39.2	11.2
Specific learning/ADD	3.5	2.8	79.7	11.9

(a) Percentages do not total 100 because of missing values.
Source: CSTDA NMDS.

Table B5: Presence of another disability as a percentage of people with individual funding, 2006–07

Presence of another disability	Total CSTDA population[(a)]	Have individual funding within CSTDA population	Have individual funding within presence of another disability	Unknown if have individual funding within presence of another disability
Yes	34.2	15.7	46.0	8.0
No	55.7	28.3	50.7	13.7

(a) Percentages do not total 100 because of missing values.
Source: CSTDA NMDS.

Table B6: Existence of an informal carer as a percentage of people with individual funding, 2006–07

Existence of an informal carer	Total CSTDA population[(a)]	Have individual funding within CSTDA population	Have individual funding within existence of an informal carer	Unknown if have individual funding within existence of an informal carer
Yes	44.9	15.7	34.9	17.1
No	46.4	28.1	60.5	6.1

(a) Percentages do not total 100 because of missing values.
Source: CSTDA NMDS.

Table B7: Daily support needs as a percentage of people with individual funding, 2006–07

Support needs	Total CSTDA population[(a)]	Have individual funding within CSTDA population	Have individual funding within support needs	Unknown if have individual funding within support needs
Always or unable to do	24.6	9.0	36.9	12.4
Sometimes	34.7	17.1	49.3	11.1
Some but uses aids	5.8	3.9	67.8	3.0
None	17.1	11.6	67.5	5.0

(a) Percentages do not total 100 because of missing values.
Source: CSTDA NMDS.

Appendix C: Fieldwork instruments

Instrument 1: Survey for people with disabilities

UNSW

The University of New South Wales

Individual funding for disability support

Survey for people with disability

The government has asked us to do research about the way your disability support is organised. Disability support includes support from workers, family and friends with your activities, accommodation, work and personal care. The research is about how your support is paid for, how much control of your support you have and how happy you are with it and your life.

Please answer as many of the questions as you can and write any comments. Someone can help you if you want them to. An easy English version is available if you would prefer.

Phone us if you have a question or you want to do the survey by phone - Ryan Gleeson, Tomasz Sitek or Brooke Dinning, Social Policy Research Centre, 02 9385 7800.

Return the survey to sprc@unsw.edu.au, fax 02 9385 7838, or post to Social Policy Research Centre, UNSW 2052 by 27 February.

All the information you give will be confidential.

Please tick all the boxes that apply to you so we know about the type of funding you use

- I manage the money for my disability support ☐
- My family holds the money ☐
- A service provider holds the money ☐
- A financial facilitator holds the money ☐
- I can change which agency provides the support – funding for support is portable ☐
- I can change who organises the money for my support – funding for facilitating is portable ☐
- I can use more than one service provider at one time ☐
- I can spend the funds to pay for any person or organisation I want, not only with approved providers ☐

Tick here if someone helped you understand the questions ☐

You might find it easier to answer any questions with the pictures below.

Very unhappy	Unhappy	Mixed	Happy	Very happy
-2	**-1**	**0**	**1**	**2**
--	**-**	**0**	**+**	**++**
☹☹	☹	😐	☺	☺☺

For office use Organisation code

About your life

1. Can you tell me how happy you are about these parts of your life at the moment?

How happy do you feel about <u>your life as a whole</u> ?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

How happy do you feel about the things you have? Like the money you have and the things you own?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

How happy do you feel about how healthy you are?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

How happy do you feel about the things you make or the things you learn?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

How happy do you feel about getting on with the people you know?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

How happy do you feel about how safe you feel?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

How happy do you feel about doing things outside your home?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

How happy do you feel about how things will be later on in your life?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

Comments

2. How happy do you feel with the amount of time you spend with your family and friends?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

3. How happy are you with your future employment, education or activity prospects? For example job, school, TAFE, volunteering, activities

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

4. How often do you do things in the community? For example movies, park, shopping?

0	1	2	3	4	5	6	7	8	9	10
Never					Sometimes					All the time

Comments

About your services

5. How happy are you with the types of support you are using now?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

6. How happy are you with how much support you get?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

7. Do you get to choose what you want to do?

Yes ☐

No ☐

8. How happy are you with the help you get to choose what you want?

0	1	2	3	4	5	6	7	8	9	10
Very unhappy					Mixed					Very happy

9. How much do you feel you can change your services when you want to?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Sometimes					Always

10. Can you remember what types of support you used before the ones you use now?

Please describe. *(Leave blank if you have not used any other types of support)*

11. Are the services you use now better or worse than the support you used before? *(Leave blank if you have not used any other types of support)*

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

Comments

About you

12. Are you

Female ☐
Male ☐

13. What is your age in years _____

14. Do you have a culture or language background from somewhere other than Australia?

Yes ☐ please describe _____
No ☐

15. Do you have an Indigenous background?

Yes ☐
No ☐

16. Tick all the disability types that describe your needs

Cognitive eg. intellectual, learning or developmental ☐
Sensory eg. visual, hearing ☐
Physical ☐
Psychiatric eg. mental illness ☐
Other (please describe) _____

17. Tick the level of support you need each day

Always need support ☐
Sometimes need support ☐
No support but I still find things difficult ☐
None ☐

18. Would you like to tell us anything else about your support or how it could be better?

Comments

Thank you for completing this survey

Instrument 2: Survey for people with disabilities (easy English)

UNSW

The University of New South Wales

Individual funding for disability support

Survey for people with disability

Easy English version

- We are from the University of New South Wales. We are doing research for the government with people with disability about the help they use.
- We would like to ask you questions about who helps you during your week. The questions are about
  - How you choose your help
  - What type of help you use now
  - How your help is paid for
  - How happy you are with the help you use
  - And how happy you are about what you do
- Please answer all the questions you can and write anything else you want to say.
- Someone can help you with the questions if you want them to.
- When we use your answers no one will see your name.

Phone us if you have a question or you want to answer the survey by phone - Ryan Gleeson, Tomasz Sitek or Brooke Dinning, Social Policy Research Centre, 02 9385 7800.

Return the survey to sprc@unsw.edu.au, fax 02 9385 7838, or post to Social Policy Research Centre, UNSW 2052 by 27 February.

For office use Organisation code

2

Please tick all the boxes about you so we know about the help you use

- I hold the money for the help I use ☐
- My family holds the money ☐
- A service provider holds the money ☐
- A financial facilitator holds the money ☐
- I can change which agency provides the support – funding for support is portable ☐
- I can change who organises the funds – funding for facilitating is portable ☐
- I can use more than one service provider at one time ☐
- I can spend the funds in the open market, not only with approved providers ☐

Tick here if someone helped you understand the questions ☐

You might find it easier to answer the questions with any of these pictures

Very sad	A little bit sad	Neither happy nor sad	A little bit happy	Very happy
-2	**-1**	**0**	**1**	**2**
--	**-**	**0**	**+**	**++**
☹☹	☹	😐	☺	☺☺

Questions about your life

1. Can you tell me about how happy you are with these parts of your life at the moment? Please circle the faces that describe you

	Very sad	A little bit sad	Neither happy or sad	A little bit happy	Very happy
How happy do you feel about <u>your life as a whole</u>?	☹☹	☹	😐	☺	☺☺
How happy do you feel about the things you have? Like the money you have and the things you own?	☹☹	☹	😐	☺	☺☺
How happy do you feel about how healthy you are?	☹☹	☹	😐	☺	☺☺
How happy do you feel about the things you make or the things you learn?	☹☹	☹	😐	☺	☺☺
How happy do you feel about getting on with the people you know?	☹☹	☹	😐	☺	☺☺
How happy do you feel about how safe you feel?	☹☹	☹	😐	☺	☺☺
How happy do you feel about doing things outside your home?	☹☹	☹	😐	☺	☺☺
How happy do you feel about how things will be later on in your life?	☹☹	☹	😐	☺	☺☺
Write anything you want to say about these questions					

- The next questions ask you about how happy you are with parts of the help you get and how happy you are with the things you do each week
- The numbers under each question are like the faces in the last question, each of them tells us how happy or sad you are about something
    - Number **1** means you are **very sad -** ☹☹
    - Number **2** means you are a **little bit sad -** ☹
    - Number **3** means you are **neither happy nor sad -** 😐
    - Number **4** means you are a **little bit happy -** ☺
    - Number **5** means you are **very happy -** ☺☺

2. How happy are you about the time you spend with your family and friends?

1	2	3	4	5
Very sad		Mixed		Very happy

3. How happy are you about what you will do in the future? Like a job, school, TAFE, volunteering, activities

1	2	3	4	5
Very sad		Mixed		Very happy

4. How often do you do things in the community? Like going to the movies, park, shopping

1	2	3	4	5
Never		Sometimes		All the time

Write anything you want to say about these questions

<u>Questions about the help you use</u>

The next questions are about help you use from workers, family and friends to help you do what you want to do.

5. How happy are you with the help you use now?

1	2	3	4	5
Very sad		Mixed		Very happy

6. How happy are you with how much help you use?

1	2	3	4	5
Very sad		Mixed		Very happy

7. Do you get to choose what you want to do?

Yes ☐
No ☐

8. How happy are you with the help you get to choose what you want to do?

1	2	3	4	5
Very sad		Mixed		Very happy

9. How much do you feel you can change the help you use when you want to?

1	2	3	4	5
Not at all		Sometimes		Always

10. Can you remember what type of help you got before the help you use now?

Please describe **(Do not answer if you did not get any other help before)**

11. Is the help you use now better or worse than the help you used before? **(Do not answer if you did not get any other help before)**

1	2	3	4	5
Much worse		Mixed		Much better

Write anything you want to say about these questions

Questions about you

12. Are you

Female ☐
Male ☐

13. What is your age in years _____

14. Do you have a culture or language background from somewhere other than Australia? Like Chinese, Italian

Yes ☐ please describe _____
No ☐

15. Do you have an Aboriginal or Indigenous background?

Yes ☐
No ☐

16. Tick all the disability types that describe your needs

Cognitive – like intellectual, learning or developmental ☐
Sensory – like visual, hearing ☐
Physical ☐
Psychiatric – like mental illness ☐
Other (please describe) _____

17. Tick the level of support you need each day

Always need support ☐
Sometimes need support ☐
No support but I still find things difficult ☐
None ☐

18. Do you want to tell us anything else about the help you use or how it could be better?

Write anything you want to say about these questions

Thank you for doing this survey

Instrument 3: Survey for service providers

UNSW

The University of New South Wales

Individual funding for disability support

Survey for Service Providers

The Australian Department of Families, Housing, Community Services and Indigenous Affairs – FaHCSIA – has asked us to research individual funding arrangements for support services for people with disability. Types of individual funding being examined are i) money paid to people with disability to buy support or ii) portable individual funding packages paid to service providers or financial managers to organise, manage or provide services for people with disability. The research is about what people prefer, how their life changes and cost of support. In this survey we ask service providers questions about the **individual funding managed by your agency**, client experiences of it, how it is arranged and costs.

Please answer as many of the questions as you can and add any comments.

Phone us if you have a question or you want to do the survey by phone - Ryan Gleeson, Tomasz Sitek or Brooke Dinning, Social Policy Research Centre, 02 9385 7800.

Return the survey to sprc@unsw.edu.au, fax 02 9385 7838, or post to Social Policy Research Centre, UNSW 2052 by 27 February.

All the information you give will be confidential.

Name of service provider ……..…

Your name and position ……..……

Contact details (phone and email) ……...

Please answer these questions first so we know what individual funding is in your agency:

Can the client change providers (funding for support is portable)?
Yes ☐ No ☐

Can the client change which person or agency organises the funds (funding for facilitating is portable)?
Yes ☐ No ☐

Can the client use more than one service provider at one time?
Yes ☐ No ☐

Can the client spend the funds in the open market, not only with approved providers?
Yes ☐ No ☐

Who holds the funds?
Client ☐ Family, proxy, carer ☐ Provider ☐ Financial facilitator ☐

For office use: NSWGRE

Client profile

1. Estimate how many clients use individual funding in your agency now _____

2. What types of disability do the individual funding clients experience? (tick all)

Cognitive eg. intellectual, learning or developmental	☐
Sensory eg. visual, hearing	☐
Physical	☐
Psychiatric eg. mental illness	☐
Other (please describe)_____	

Client experiences of individual funding managed by your agency

3. Are clients who use individual funding in your agency better or worse off than people with similar needs who organise their support in other ways, in the following parts of their life?

Mental health

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

Physical health

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

General wellbeing

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

Access to relevant services

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

Social benefits (eg. relationships with family and friends)

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

Employment and education benefits

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

Community participation (eg. going out more into the community)

0	1	2	3	4	5	6	7	8	9	10
Much worse					Mixed					Much better

Comments

4. How much does individual funding help to achieve the social inclusion of clients?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

5. How much are clients or their family aware of the amount of individual funding to which they are entitled?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

6. How much are the clients or their family aware of the rules and systems of individual funding?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

7. How much do the clients have the help they need to make decisions?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

8. How much do the clients or their family use individual funding in a flexible and creative manner? Please write examples below

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

Comments

Managing risks and benefits of individual funding

Comparing clients who use individual funding with people who organise their support in other ways, how does your agency manage the following risks and benefits?

9. To what extent is the support that is organised through individual funding driven by the clients' wishes?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

10. How much does individual funding enable clients to exercise choice, decision making, control and consent, and to change support arrangements?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

4

11. How much does individual funding facilitate the type, quality and quantity of support clients want?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

12. How well do the individual funding planning, administration, accountability and legal mechanisms protect the client and the agency?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

13. How well are the conditions of support workers protected under individual funding?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

14. How much does individual funding improve the availability of qualified support workers?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

15. How much does your agency work with other service providers, support workers, families and informal carers to support individual funding clients?

0	1	2	3	4	5	6	7	8	9	10
Not at all					Mixed					Very much

16. If you were working for your agency before and after individual funding started, how difficult was the transition for the agency?

0	1	2	3	4	5	6	7	8	9	10
Very difficult					Mixed					Not at all difficult

Comments

Costs

17. What is the average **annual** amount of individual funding per client?

    $_____

18. What is the range of funding per client per annum (highest and lowest)?

    $_____to $_____

19. What is the average **annual** management and administrative cost per individual funding client (that is, costs not for direct support)?

    $_____ (or _____% of the package)

20. If individual funding includes any capital expenditure, what is the average annual capital cost per individual funding client?

    $_____

Comments

21. Do you have any further comments about individual funding?

Comments

Thank you for completing this survey

Instrument 4: Interview with people with disabilities

1

The University of New South Wales

Individual funding for disability support
Interview with people with disabilities

The government has asked us to do research on the way your disability support is organised. The research is about how your support is paid for, how much control of your support you have and how happy you are with it and your life.

Please complete the consent form.

Please complete the survey (do it with the interviewer now if it is not done yet).

Ask interviewee if the interview can be recorded for easy analysis.

1. Do you have any comments about your answers to the survey?
    - **Example:** Expand on answers at the extremes of the scale.
    - Does the way your support is organised affect the parts of your life listed in the survey? Can you give examples of good and bad effects?

2. Can you briefly tell me about your support services?
    - **Example:** what type of support do you get? who organises, provides and pays for it?

3. Problems and benefits of individual funding

We want to know about how people manage the problems and benefits of individual funding compared to other ways of organising disability support. Please tell us about what you have learned about managing the following problems and benefits. In particular we want to know about:

- Your good and bad experiences?
- Your particular needs eg. your support needs, how you make decisions, service types you use, how the support meets your culture, language, age and location needs?
- Ways you have solved problems?
- Suggestions for improvement?

a. Getting the support you want – is your support organised so that you can do what you choose, with the people you choose, when and where you choose?
    - **Example:** planning, future goals, flexibility, change
    - How did you choose what support you get?

- What parts of your support are good or bad?

b. Help to choose and organise support – do you have the help you need to make informed choices about whether to use individual funding, to exercise choice and make decisions about your support, and to plan and organise your support?
    - **Example:** information and someone to answer questions about rules, systems, support types, risks, benefits; facilitator, trusted person, peers
    - Have you changed your support before? How did you do that? Did someone help you?
    - Which parts of your support do you want to change? How would you do that?
    - If you use a provider, are they helpful when you want to change your support?
    - Can your family help make changes to your support when you want them to?

c. Administrative systems for responsibilities – does someone help you or do you have a way to manage planning and organising the support and telling the government how much the support costs?
    - **Example:** managing support responsibilities; accountability for public funds; legal mechanisms – tax, insurance, government benefits
    - Do you have any problems with managing the way your support is organised? Does someone help you? Who do you ask if you have problems?

d. Sufficient funding and the right support types – do you have enough funding and can you choose different support to meet your needs when your needs and choices change?
    - **Example:** flexible, creative, ageing, health, future visions, future prospects, employment, participation
    - Is the support enough to help you do want you want to do?

e. Is the support good quality and do the workers do what you want them to?
    - Do you like the workers who give you support? Do they give you the support you need? Do you want them to change how they support you?

f. Does the support help you use the services other people use or aren't directly related to your disability, like doctors and public transport, and help you spend time with your family?
    - **Example:** mainstream services; families and informal care.

4. Do you want to tell us anything else about individual funding or the way your support is organised?

Thank you for participating. Please contact us if you have other ideas. Do you want a copy of the results?

Instrument 5: Interview with service providers

UNSW

The University of New South Wales

Individual funding for disability support

Interview with Service Providers

The federal government has asked us to research individual funding for people with disability. Types of individual funding are i) money paid to people with disability to buy support or ii) portable individual funding packages paid to service providers or financial managers to organise, manage or provide services for people with disability.

In this interview we ask you about the **individual funding managed by your agency**, client experiences of it, how it is arranged and costs.

Please complete the survey (do it with the interviewer now if it isn't done yet)

Please complete the consent form.

Ask interviewee if the interview can be recorded for ease of analysis.

1. Can you briefly tell me about your agency and what your role is?
    - **Prompt:** History, funding, clients, service types?

2. Do you have any comments about your answers to the questionnaire you completed before this interview?
    - **Prompt:** Ask interviewee to expand on survey responses that were at the extremes of the ten point scale.

3. Risks and benefits

We are most interested in how your agency manages the risks and benefits of individual funding compared to other disability support arrangements. Please comment on what your agency has learned about managing the following risks and benefits. In particular we wish to know about:

- Good and bad experiences?
- Accounting for variation in client support needs, client decision making capacity, service type, age, culture and language, location?
- Ways you have solved problems?
- Suggestions for improvement?

a. Accounting for consumer preferences –
    - **Prompt:** client driven, person centred support; facilitates independent living in the community; flexibility in the planning process.

b. Providing support according to the person's capacity and vulnerability –
    - **Prompt:** support for informed choice about whether to use individual funding; support to exercise choice and decision making in the planning process.

c. Identifying administrative systems for responsibilities –
    - **Prompt:**
    - Do the administrative requirements of individual funding exclude the client from the decision-making process?
    - Is the money used in individual funding being spent appropriately? What measures are there to ensure this?
    - Do legal mechanisms surrounding disability services support the use of individual funding? Are they clearly defined?
    - Are there adequate information sharing policies for communicating with other providers if a client leaves your agency? Has a client come to your agency in this way? What was the experience of it?

d. Viability of the support type and amount of funding –
    - **Prompt:** sufficient funding; respond to changed support needs and preferences

e. Impact on the workforce and quality of care –
    - **Prompt:** workers conditions; availability of qualified workers

f. Effective service integration under individual funding –
    - **Prompt:** disability specialist services; mainstream services; families and informal care.

g. Contextual impact of individual funding –
    - **Prompt:**
    - Does individual funding impact adversely on the total amount of money available to people with a disability?
    - Responsiveness of providers to change
    - Does individual funding impact adversely on the number of support workers available for other types of support?
    - Viability and sustainability of your organization?

4. Do you want to comment on anything else about individual funding that came to mind when you did the questionnaire or this interview?

Thank you for participating. Please contact us if you have other ideas. Do you want a copy of the results?

Confirm arrangements for completing the people with disability interviews.

Appendix D: New Zealand and Denmark individual funding

New Zealand

History

The Office for Disability Issues[3] within the Ministry of Health is the New Zealand government instrumentality responsible for promoting the New Zealand Disability Strategy, and monitoring actions to enable the participation and inclusion of people with disabilities. Their main focus is on disability issues in government and cross-sector policy, and they provide support to the Minister for Disability Issues. They also take the initiative in influencing attitudes and behaviours towards people with disabilities throughout society as a whole.

The New Zealand Disability Strategy, 'Making a World of Difference—Whakanui Oranga' (ODI 2001), is mandated under the New Zealand *Public Health and Disability Act 2000* (Litmus 2008). It sets out a general framework for government departments and other government agencies to use in considering disability issues at every level of decision making. The strategy was developed on the basis of consultations with a wide range of individuals, groups and organisations involved in disability issues. It contains 15 objectives, each of which is underpinned by a detailed set of actions (ODI 2001).

The earliest individualised funding (IF) initiative in New Zealand was introduced in Christchurch in 1998, although it was a short-term pilot project that had no further influence on the national development of IF programs. Between 1999 and 2001, further IF initiatives were introduced in an ad hoc way in a number of areas throughout the country. At the end of 2001, the Ministry of Health imposed a moratorium on any further developments 'until an equitable national framework with consistent, transparent and safe criteria for accessing it had been produced and agreed' (NZ MOH 2003, p. 2). Part of the framework involved the creation of an IF Agency (IFA) with two main functions: to support people with disabilities in the management of their IF budgets; and to provide information and training (NZ MOH 2003).

According to the 2006 *Work in Progress* annual report from the Minister for Disability Issues to the House of Representatives on implementing the New Zealand Disability Strategy, the Ministry of Health had spent the past 12 months phasing in a nationwide IF program, having implemented the program in Taranaki and Wanganui with plans to extend it to the Waikato region in the near future (ODI 2006, p. 17). It is not clear how far the implementation has subsequently progressed, given that there was no mention of IF in the next year's annual report to parliament (ODI 2007), nor in the MOH *Annual Reports* for 2006 and 2007.

Definition/organisation

As defined by the New Zealand Ministry of Health, IF 'is an administrative arrangement [for some for younger people with high or very high complex support needs] that enables them to hold, manage or govern their own needs-assessed budgets. [It] provides the opportunity for some disabled people to manage the personal support services they require in the way that they believe meets their needs best' (NZ MOH 2003, p. 1). It has the following characteristics:

- It was intended 'as a first step to a wider application' (NZ MOH 2003, p. 7).
- In the initial stages IF was to be made available only for younger people (that is, those below the age of 65 years—NZ MOH 2002), because the demand for IF was greatest among younger people. However, the MOH *Health of Older People Strategy* did make a commitment to developing an individualised funding framework for older people (NZ MOH 2002, p. 17) through the District Health Boards once the two-year program had been evaluated. Moreover, there were some older people who already had IF arrangements under the earlier, more limited schemes, and they would continue to be the responsibility of the relevant District Health Boards (NZ MOH 2003, p. 5).

- It was to be made available only to those with 'high and complex needs', that is, those whose support needs could not be met simply. Examples of complex needs included requirements for personal assistance with dressing, cooking, helping in and out of bed, toileting, and not just with showering or bathing (NZ MOH 2003, p. 4).
- All people with disabilities under the age of 65 years with complex needs (as assessed by a Needs Assessment Service Co-ordination—see below) were to be eligible, children as well as adults, people with intellectual disabilities as well as those with physical disabilities.[4]
- People did not have to manage their own budgets. A parent, guardian, carer or family/whānau member could be approved as a budget manager for the budget-holder, but payment for this could not be made from the IF budget funds. The program would contain provision for the appointment of independent advocates for the person with disability (NZ MOH 2003).
- Budget-holders, whether or not they managed their own budgets, would become employers with responsibility for hiring, managing, paying, training and making contracts with their support workers. Help and support for this would be available from an Individualised Funding Agency (see below), part of whose role would be to organise resources that would take on such tasks as invoicing, tax and so on, for those budget-holders who were unable to do it for themselves or who did not want to. This service would not be free, but allowance for these costs would be included in the IF budget (NZ MOH 2003, p. 10).
- The assessment service for the new IF program would be provided by Needs Assessment Service Co-ordination (NASC) agencies. Assessments would look at someone's personal, environmental and social risk factors, including the ability to perform basic tasks, communication, mobility, getting in and out of bed, cooking, washing, dressing and so on, and the availability and extent of existing support systems. Once someone had been assessed as eligible, they would be referred to an Individualised Funding Agency (IFA) (NZ MOH 2003, p. 13).
- IFAs would be responsible for arranging IF for the person following referral from a NASC agency, and supporting them in their management and use of the budget, including training them in all the aspects they take up, including the full IF (NZ MOH 2003, p. 12). The review of the implementation of the National Disability Strategy from 2001 to 2007 said that the MOH had begun contracting in 2005 with a disability organisation, Manawanui-In-Charge,[5] to provide an individualised funding service (Litmus 2008, p. 25). On their website, this agency said they offered information and support with:
  - deciding how to manage the payments
  - keeping records, for example, a separate bank account, timesheets, pay as you earn (PAYE) records, receipts, invoicing and so on
  - drawing up job descriptions
  - drawing up Employment Agreements, Contracts for Services
  - staff recruitment
  - requirements and responsibilities of being an employer
  - rates of pay, PAYE, Accident Compensation
  - insurance and health and safety requirements
  - information on being a good employer
  - emergency staffing plans
  - information on staff induction and training.

- And finally, IF budget-holding was not to be a 'once and for all' commitment. If someone's circumstances changed, or they just changed their mind, they could stop the IF arrangements and receive direct services instead (NZ MOH 2003, p. 10).

Denmark

The government instrumentality responsible for matters concerning people with disabilities is the Danish Disability Council.[6] The Council was established in 1980, following dialogues between the authorities and representatives of people with disabilities. It is made up of equal numbers of representatives of people with disabilities and public authorities, and a number of people with special expert knowledge from various sectors are attached to it, thus strengthening its professionalism and ensuring the widest possible scope of knowledge and experience concerning disability policy. The Ministry of Social Affairs appoints the chairman. It is intended as an effective central body for coordinating initiatives for equal opportunities for people with disabilities, and it works in close cooperation with the Equal Opportunities Centre for Disabled Persons. Its tasks are to:

- monitor the situation of people with disabilities in Danish society
- act as an advisory body to Government and Parliament on issues relating to disability policy
- take initiatives and propose changes in areas affecting the living conditions of people with disabilities.

All central authorities are expected to take the Council's advice in the area of disability.

The peak body for disability organisations in Denmark is the Disabled Peoples Organisations Denmark (DPOD).[7] It was founded in 1934 (as 'De Samvirkende Invalideorganisationer'—DSI), and currently has 32 member organisations representing more than 320,000 people with disabilities. It nominates seven of the members of the Danish Disability Council.

In the Nordic countries, including Denmark, schemes of individualised funding/direct payments are known as 'personal assistance'. The personal assistance scheme gives a person with disability a subsidy from the local authority to employ someone to assist them with care, supervision and attendance. The subsidy covers the full cost of the care, including 24-hour care if necessary. To be eligible, the person must require an intensive level of support. The person with disability administers the scheme and becomes the employer of their personal assistant (Danish Disability Council 2002, p. 41).

In 2000, Denmark had especially low numbers of people with disabilities employing personal assistants (in comparison with Sweden and, to a lesser extent, with Finland). Denmark has much stricter eligibility criteria than Sweden, but it has also been suggested that this low rate of involvement in the personal assistance scheme is due to people's satisfaction with the availability of home help. The two programs are seen as 'functional alternatives', despite the fact that personal assistance schemes strongly emphasise self-determination and user control. Moreover, to a great extent, notions such as personal assistance were developed in countries with completely different welfare models from the Nordic one, in particular, the liberal and market-oriented welfare model of the United States (Hvinden 2004, pp. 173–74, 185). As the Danish Disability Council notes, an important element of the Danish welfare model is the principle of compensation, that is, the belief that society should offer people with disabilities whatever services and aids they need, both to make good the consequences of the disability, and to give them as far as possible a basis for equality with other citizens. This welfare model is also based on the assumption that, as citizens, people with disabilities are not expected to depend on family or friends, or on charity, for help with intimate tasks such as help with personal care and hygiene (Danish Disability Council 2002, pp. 11–12, 43. See also: Askheim 2003; Ungerson 1997; eds Ungerson & Yeandle 2008).

In one municipality in Denmark (Svendborg), claimants for personal assistance services must be engaged in at least one of the following activities in order to qualify—paid work, volunteer work, education, adult education, sport or cultural activities—or to have responsibility for children. However, this requirement was dropped from January 2009. Another requirement is that the person must need at least 37 hours a week of personal care. The average annual cost per person is €80,000, but the cost varies from €8,000 to €400,000. The chief problem

with the personal assistance scheme is the need for the person with disability to be an employer. This is not a responsibility any other Danish citizen is expected to take on as a normal part of daily life, and most people with disabilities have not been trained for the role. The fact that the personal assistant has to work in someone else's private home can also be a problem (Kræmmer 2008).

Appendix E: Other international individual funding

The following text is an extract from Fisher, KR, Parker, S, Purcal, C, Thaler, O, Abelson, P, Pickering, E & Griffiths, M 2008, *Effectiveness of supported living in relation to shared accommodation*, report for Disability Policy and Research Working Group, SPRC Report Series 18/08.

United States

A current trend in disability support is the shift towards 'consumer directed' support programs, involving mainly individually negotiated and/or directly purchased personal assistance services tailored to the needs and preferences of the person with a disability. Most such services are funded through Medicaid, which is a limited medical insurance program aimed at low-income earners, and is means-tested.

New Hampshire Self-Determination Project, New Hampshire, USA

Overview	A state-based program focused on the administrative side of the client–government relationship. Working to affect a shift in administrative practices towards more individualised and person-centred planning and service provision including both formal and informal care. Enabled by a grant from a healthcare foundation and continued with the support of the state government, 'Learning stakeholder' workgroups were established with participants including people with disabilities, family members, carers and administration professionals in order to develop administration and planning practices based on the principle of self-determination.
Innovative dimensions	Including all levels of stakeholders in the development of administration practices and a focus on best-practice standards in person-centred planning.
Model of support	Services administered include all levels and types of support necessary for the person, including personal assistance and community integration.
Key principles	Focusing on the principles of self-determination and empowerment through cooperation and integration. Encouraging a shift from 'program-driven services' to 'consumer-directed supports'.
People supported	Both adults and children (and their guardians) with disabilities necessitating all levels of support.
Benefits and challenges	Constant cooperation and revision of practices ensures constantly evolving standards and an ability to maintain the person-centred focus of the program and administration practices. Systemic change is difficult to establish and can be costly to update. Not all stakeholders involved are equal participants in the process due to lack of access to necessary information and technology.
Evaluation and research	Lord and Hutchinson (2003) mention the constant evaluative nature of the program as well as the annual program-wide evaluations, which have found the program to be successful in increasing the level of satisfaction and control for people with disabilities. The evaluations were conducted using specially formulated tools also created in the process.
Contact, refs	<www.unh.edu/rwj/index.html> Lord & Hutchinson (2003) <www.unh.edu/rwj/states/nh.html> <www.rwjf.org/programareas/resources/grantsreport.jsp?filename=027576.htm&pid=1144>

Home Based Support Services Program, Illinois, USA

Overview	A state-based program providing individualised budgets for adults with intellectual disabilities living at home and their parents. The program is intended to prevent out-of-home placement for people with intellectual disabilities by enabling them and their carers to access services that will remove strain from informal carers (generally parents) and encourage community integration.
Innovative dimensions	People and their families receive cash payments in lieu of services and purchase preferred services based on their own needs.
Model of support	Services are purchased directly by guardians of people as necessary from a stipend paid by the state. Frequently purchased services include respite care, personal assistance, home modifications, employment services and transportation.
Key principles	The program is aimed at normalising the life-course of people with intellectual disabilities and encourages community living and family participation.
People supported	The program provides means-tested funding for people with intellectual disabilities living with their guardians and receiving a mixture of formal and informal care. As of 2004, 1,436 families were receiving the benefit, with 1,632 on the waiting list (Caldwell 2006).
Benefits and challenges	Individualised funding and needs-based service purchasing facilitates community living and helps alleviate the hardships faced by guardians of people with disabilities. Very long waiting lists due to high demand for the program and lack of funding have made it hard to access for many people.
Evaluation and research	Caldwell (2006) evaluated the effect of the program on levels of out-of-home placement as well as satisfaction of both people with intellectual disabilities and their families. In a 10-year study he found that the program indeed decreased instances of out-of-home placement (as compared with families on the waiting list) and resulted in increased levels of satisfaction among the people and their families.
Contact, refs	Family Assistance/Home-Based Support, 405 William G. Stratton Building, Springfield, IL 62765-000, (800) 843-6154, ext. 3, option 1, Fax: (217) 782-9535, <Dhsdb09@dhs.state.il.us>, <www.he.net/~altonweb/cs/downsyndrome/index.htm?page=ilresources.html>

United Kingdom and Europe

Since 1997, a central feature of the British model for the provision of support services for people with disabilities has been direct payments. An outcome of disability advocacy groups' calls for empowerment and consecutive British governments' commitment to the transfer of social services into the private sector, local authorities have, since 2001, been required to offer, and encourage the take-up of, direct payments in lieu of services. Such services are instead purchased directly by the recipient with the payments. Direct payments recipients are still, however, a small minority (less than 2 per cent as of 2003) among recipients of disability support services (Riddell et al. 2005). Direct payment programs are also available in several European countries including The Netherlands, Italy and Austria, with varying levels of universality, funding and restrictions (Ungerson 2004). The welfare states of central and southern Europe such as Germany and Italy remain focused on informal and community-based care, many times merging the two. Direct Payment programs in Italy have been noted as encouraging a formalisation of family and community care arrangements due to the lack of restrictions on the use of the direct payments (Ungerson 2004).

Current spending (as of 2004) on disability benefits, both in cash transfers and in services, among European Union member states is Euro 220,753,000,000, making up 8.1 per cent of total expenditure on social services. Forty-one per cent of this funding goes to disability services—65.3 per cent to accommodation services and the rest going to support services (10.3 per cent), rehabilitation and other disability services (Eurostat 2007).

In Sweden and Norway, all institutional provision of care and accommodation has been abolished in favour of community living, which has been enshrined as a right in law. The most widely utilised method of support in these is small-scale staffed residential accommodation (for example, group homes, cluster-housing) with 0.4 per cent of the population under the age of 65 years in Nordic countries (Sweden, Denmark, Finland and Norway) being supported in such settings (Emerson 2004; Hvinden 2004).

Examples of innovative models of accommodation support in Europe, particularly the UK, are described below. They illustrate the policy preference for consumer-directed and individualised services among European governments.

Direct Payments program, National, UK

Overview	Currently being promoted as a central method of individualised service funding for people with disabilities in the UK, direct payments offer cash payments transfers to people with disabilities or their guardians in lieu of directly provided or contracted services. Recipients' needs are assessed and a corresponding level of funding is decided upon, with which the recipient purchases any services they prefer. Recipients decide the level, type and provider of the services and take on the responsibility of administration of the services.
Innovative dimensions	Transferring almost complete control of support services from administration professionals onto the person in order to provide them with exactly the help they need and prefer is seen as very empowering for people with disabilities.
Model of support	The recipient purchases the support they prefer and may choose from any model available on the market (apart from paying a relative living with them). A common model is support from one-on-one personal assistants providing personal care as well as general assistance (for example, housekeeping, transport), in a quasi-informal care arrangement.
Key principles	Empowerment and equalisation of the social position of people with disabilities with that of the general populace. Completely individualised support planning.
People supported	Less than 2 per cent of people receiving some type of disability support purchase it through direct payments, although raising this to a more substantial proportion is a central objective of the Department of Health. Since 1999, the program has been open to any person in the UK with disability support needs.
Benefits and challenges	Empowerment for people with disabilities and better satisfaction due to individually tailored care models as well as a more cost-efficient way of deliver services. Possible far reaching effects on the welfare state due to complete privatisation of welfare services. Complex high-level administration changes. Transferring responsibility onto the person may also transfer risk if mistakes are made or plans fail, possibly due to complex administration requirements.
Evaluation and research	The concept of direct payments in general, and the British model in particular, are a focus of much social research and researchers have found both higher levels of satisfaction and quality of life for direct payment recipients, but also reasons for concern for future equity of service provision.
Contact	<www.direct.gov.uk/en/Hl1/Help/ContactUs/ContactUsForm/index.htm>

Persoonsgebondenbudget (PGB)—Person Centred Budget, National, Netherlands

Overview	A national direct payment system providing cash payments to people with disabilities in lieu of the services as necessary. Recipients receive an individually calculated monthly allowance to purchase services on the open market or from an informal carer. Recipients decide the type, level and provider of care that they prefer and take responsibility for administration of the funds and accountability to the government.
Innovative dimensions	Empowerment and individualised services for people with disabilities with an opportunity to recognise and enable the continuation of informal care, thus maintain stability for the recipient.
Model of support	Users create their own model by purchasing any service covered by the program (ADL and IADL support). The most common type of service purchased by recipients is personal assistance either from an existing informal carer or an unprofessional private carer.
Key principles	Independence and individualised support services in order to empower people with disabilities.
People supported	The program is currently available to all people with disabilities and has grown since the removal of a cap on the proportion of funding that was available to it from the disability services budget. In 2004, nearly 70,000 people received at least some services through direct payments.
Benefits and challenges	Higher levels of independence and individualisation of services promote greater satisfaction with support. Low administration costs and enterprising recipients make the program a cost-efficient way of providing services. Possible wide-reaching consequences for welfare provision equity due to privatisation of services. Complex administration requirements may discourage innovative support models.
Evaluation and research	Several studies evaluating the program have found higher levels of satisfaction, quality of life and independence among recipients. Research has also shown, however, that the private small-scale care market that is necessary for recipients to purchase care services has not developed as expected and this heavily constricts the level of choice in services that is available to recipients.

Appendix F: Definitions

Individual funding	Portable individual packages that facilitate consumer control over choices about how disability support funds are spent. Funds: • are held by the person or their family, a facilitator or service provider • are portable between service providers or facilitators when the person chooses • can be used to buy support from service providers or in an open market. We use 'individual' rather than 'individualised' for plain English.
Management support	Administrative and information support to assist in organising the funding and disability support if the person chooses not to organise it themselves or does not have the capacity to do so.
Disability support	Specialist disability support, mainstream support or other goods, services or equipment required to meet the person's needs for self care, mobility, communication, community access and decision making.
Specialist disability support	Disability support funded under the Commonwealth State Territory Disability Agreement (CSTDA) (replaced by the National Disability Agreement in January 2009). Support types funded under the CSTDA include accommodation support, community support, community access, respite, employment, advocacy, information and print disability services. The services examined in this report are accommodation support, community support, community access and respite. People with disabilities may also receive specialist assistance through the Home and Community Care (HACC) program, not included in this report.
Service provider	An organisation that provides support services. In Australia, usually a non-government organisation or government agency and sometimes private providers, contractors or employees.
Disability type	The type of impairment, limitation or restriction that a person has, grouped into broad categories: cognitive, sensory, physical or psychiatric.

List of shortened forms

ACP	Attendant Care Program (NSW)
AIHW	Australian Institute of Health and Welfare
CP	Community Participation program (NSW)
CSTDA	Commonwealth State Territory Disability Agreement, now National Disability Agreement—NDA
DADHC	NSW Department of Ageing, Disability and Home Care
FaHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
HACC	Home and Community Care
ISP	Individual Support Packages
LAC	Local Area Coordination
MOH	(New Zealand) Ministry of Health
NDA	National Disability Agreement
NASC	Needs Assessment Service Co-ordination (New Zealand)
ODI	(New Zealand) Office of Disability Issues
PWI	Personal Wellbeing Index
SPRC	Social Policy Research Centre, University of New South Wales

Endnotes

1 Case-based funding of disability employment services is classified as individualised funding for the purposes of the data in the CSTDA National Minimum Data Set (NMDS). Under this classification all disability employment service users in the CSTDA data receive individualised funding. However, in relation to disability employment services, individualised funding refers to the calculation of the funding amount that is paid to the service provider, not the control of expenditure given to the service user. Accordingly, individualised funding for disability employment services does not fall within the scope of the definition used for this research, which includes consumer control of how funding is spent. Therefore, disability employment services are not included in the discussion in this report.

2 Under the CSTDA NMDS, accommodation support includes large and small residentials/institutions, hostels, group homes, attendant care/personal care, in-home accommodation support, alternative family placement or other accommodation support; community support includes support needed by an individual to live in a non-institutional setting (other than support with basic needs of living, such as meal preparation and dressing, which are included under accommodation support); community access includes services designed to provide opportunities for people with disabilities to gain and use their abilities to enjoy their full potential for social independence, including transition to work programs; respite provides short-term, time-limited breaks for families and other care givers of people with disabilities; advocacy services that are designed to enable people with disabilities to increase the control they have over their lives through the representation of their interests and views in the community; and information/referral, mutual support/self help groups and alternative formats of communications (AIHW 2007a, p. 6).

3 <http://www.odi.govt.nz/nzds/>.

4 Although in practice it is available only for younger people with intellectual disabilities with very high complex support needs (see Mirfin-Veitch 2003).

5 <http://www.incharge.org.nz/about/team.htm>.

6 <http://www.dch.dk/english/index.htm>.

7 <http://www.handicap.dk/english/about_dsi>.

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Occasional Papers

1. *Income support and related statistics: a ten-year compendium, 1989–99*
   Kim Bond and Jie Wang (January 2001)

2. *Low fertility: a discussion paper*
   Alison Barnes (February 2001)

3. *The identification and analysis of indicators of community strength and outcomes*
   Alan Black and Phillip Hughes (June 2001)

4. *Hardship in Australia: an analysis of financial stress indicators in the 1998–99 Australian Bureau of Statistics Household Expenditure Survey*
   J Rob Bray (December 2001)

5. *Welfare Reform Pilots: characteristics and participation patterns of three disadvantaged groups*
   Chris Carlile, Michael Fuery, Carole Heyworth, Mary Ivec, Kerry Marshall and Marie Newey (June 2002)

6. *The Australian system of social protection—an overview (second edition)*
   Peter Whiteford and Gregory Angenent (June 2002)

7. *Income support customers: a statistical overview 2001*
   Corporate Information and Mapping Services, Strategic Policy and Knowledge Branch, Family and Community Services (March 2003)

8. *Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*
   Commonwealth Department of Family and Community Services submission to the 2003 House of Representatives Standing Committee on Ageing (October 2003)

9. *Inquiry into poverty and financial hardship*
   Commonwealth Department of Family and Community Services submission to the Senate Community Affairs References Committee (October 2003)

10. *Families of prisoners: literature review on issues and difficulties*
    Rosemary Woodward (September 2003)

11. *Inquiries into retirement and superannuation*
    Australian Government Department of Family and Community Services submissions to the Senate Select Committee on Superannuation (December 2003)

12. *A compendium of legislative changes in social security 1908–1982*
    (June 2006)

13. *A compendium of legislative changes in social security 1983–2000*
    Part 1 1983–1993, Part 2 1994–2000
    Bob Daprè (June 2006)

14. *Evaluation of Fixing Houses for Better Health Projects 2, 3 and 4*
    SGS Economics & Planning in conjunction with Tallegalla Consultants Pty Ltd (August 2006)

15. *The 'growing up' of Aboriginal and Torres Strait Islander children: a literature review*
    Professor Robyn Penman (November 2006)

16. Aboriginal and Torres Strait Islander views on research in their communities
Professor Robyn Penman (November 2006)

17. *Growing up in the Torres Strait Islands: a report from the Footprints in Time trials*
Cooperative Research Centre for Aboriginal Health in collaboration with the Telethon Institute for Child Health Research and the Department of Families, Community Services and Indigenous Affairs (November 2006)

18. *Costs of children: research commissioned by the Ministerial Taskforce on Child Support*
Paul Henman; Richard Percival and Ann Harding; Matthew Gray (July 2007)

19. *Lessons learnt about strengthening Indigenous families and communities: what's working and what's not?*
John Scougall (March 2008)

20. *Stories on 'growing up' from Indigenous people in the ACT metro/Queanbeyan region*
Cooperative Research Centre for Aboriginal Health in collaboration with the Telethon Institute for Child Health Research and the Department of Families, Housing, Community Services and Indigenous Affairs (April 2008)

21. *Inquiry into the cost of living pressures on older Australians*
Australian Government Department of Families, Housing, Community Services and Indigenous Affairs submissions to the Senate Standing Committee on Community Affairs (August 2008)

22. *Engaging fathers in child and family services: participation, perception and good practice*
Claire Berlyn, Sarah Wise and Grace Soriano (December 2008)

23. *Indigenous families and children: coordination and provision of services*
Saul Flaxman, Kristy Muir and Ioana Oprea (June 2009)

24. *National evaluation (2004–2008) of the Stronger Families and Communities Strategy 2004–2009*
Kristy Muir, Ilan Katz, Christiane Purcal, Roger Patulny, Saul Flaxman, David Abelló, Natasha Cortis, Cathy Thomson, Ioana Oprea, Sarah Wise, Ben Edwards, Matthew Gray and Alan Hayes (June 2009)

25. *Stronger Families in Australia study: the impact of Communities for Children*
Ben Edwards, Sarah Wise, Matthew Gray, Alan Hayes, Ilan Katz, Sebastian Misson, Roger Patulny and Kristy Muir (June 2009)

26. *Engaging hard-to-reach families and children*
Natasha Cortis, Ilan Katz and Roger Patulny (June 2009)

27. *Ageing and Australian Disability Enterprises*
Shannon McDermott, Robyn Edwards, David Abelló and Ilan Katz (June 2010)

28. *Needs of clients in the Supported Accommodation Assistance Program*
Australian Institute of Health and Welfare (May 2010)