
D Existing self-directed support arrangements in Australia

It is hard to assess the extent to which self-directed support is important in the current Australian disability system. The national statistics relate to ‘individualised funding’, with the ambiguities that term entails (chapter 8). If the broad definition of individualised funding is adopted, many Australians with disability are already using individualised funding (tables D.1 and D.2).¹ However, this broad definition includes the capacity of someone allocated an entitlement for a given service type to choose between service providers providing that service, rather than the capacity to have a budget and allocate it among many different services. For instance, among other purposes, Job Capacity Assessments are undertaken to determine individualised approaches to employment assistance for people with disability, with people referred to specific employment and support services based on their assessed needs. The person can switch service providers, but does not have much freedom about what they can spend or do at any given service provider. The Government makes payments to a Job Services Australia providers based on a fee and outcome basis, with no veto by the client if they are unhappy with the performance of the provider. Yet the national disability statistics characterise employment services as entirely ‘individualised’ funding.

Nevertheless, at least the potential to exercise some choice is a feature of this broadly defined individualised funding. Therefore, its patterns of use may still provide indications of the factors that can shape the uptake of choice-based funding arrangements. Some of the key patterns emerging are:

- people without informal carers are much more likely to use individualised funding, with rates of use for those without informal carers being very high for people with physical disabilities (table D.1). This is likely to reflect the fact that those with a physical disability are more likely to have the skills and confidence to make choices, and the lower level of disability associated with people not needing informal care (which is also consistent with the high use of individualised funding by people with no need for support in activities of daily living (table D.2).

¹ Based on the definition used in the national minimum data set for use of CSTDA services.

- use of individualised funding is not much different by Indigenous status or ethnic background (with people from non-English speaking backgrounds actually making more use of individualised funding)
- use by age follows an inverted u-shape, being low for the young, highest for those aged 20–29 years and slowly declining with subsequent ages.

Table D.1 People getting informal care have lower use of individualised funding

Australia, CSTDA clients, 2007-08^a

Primary disability	Share with individualised funding		Share of category with informal carer ^c	Total population ^d
	With informal carer ^b	No informal carer		
	%	%	%	No.
Intellectual	45.8	58.1	63.6	77 320
Specific Learning/ADD	34.0	98.0	17.2	7 961
Autism	31.2	78.5	74.8	14 547
Physical	33.1	86.4	38.4	36 382
Acquired Brain Injury	32.0	48.5	51.5	9 957
Neurological	23.4	47.8	52.7	12 889
Sensory	14.7	48.3	38.1	16 881
Psychiatric	24.9	73.0	22.0	40 031
Developmental Delay	3.0	1.4	72.5	7 007

^a In categorising people using individualised funding, the AIHW notes that this funding arrangement should have all of the following characteristics: (i) the funding dollars are provided from within the CSTDA program; (ii) funding dollars are allocated to an individual on the basis of needs assessment, funding application or similar process; (iii) these funding dollars may be directly under the control of the individual or their carer/advocate; or may be managed by, or in consultation with, a CSTDA funded agency to access a range of services for the individual; or may be given directly to the CSTDA funded agency who provides the service to the individual; (iv) the funding is transportable and able to move with the individual if they choose to use another service; (v) the individual funding package is generally related to a policy ethos of fostering individual choice and autonomy. ^b The table shows the take-up of individualised funding by disability by receipt of informal care. For example, around 46 per cent of people with an intellectual disability with an informal carer use individualised funding, while 58 per cent of people with an intellectual disability with no informal carer use individualised funding. It should not be assumed that the remainder do not use individualised funding, as a small share of people did not state whether they did or not. ^c This is the share of the particular disability group who have an informal carer. For example, around 64 per cent of people with an intellectual disability have an informal carer. ^d This is the total population of people using CSTDA services by disability type.

Source: Users of all CSTDA-funded services, 2007-08 from AIHW 2007-08 CSTDA NMDS service user data.

Table D.2 The current use of ‘individualised funding’

Australia, CSTDA clients, 2007-08^a

<i>Various categories of disability</i>	<i>Share with individualised funding</i>	<i>Total population in category</i>
	%	No.
Need for support in activities of daily living		
Always or unable to do	32.6	55 377
Sometimes	41.4	69 638
None but uses aids	16.8	5 259
None	82.9	73 585
Not stated	13.4	41 887
Total	46.6	245 746
Service type		
Accommodation support	36.0	37 690
Community support	21.6	103 976
Community access	32.2	54 374
Respite	32.9	31 524
Employment	100.0	89 935
Indigenous status		
Indigenous	44.8	10 948
Non-Indigenous	49.1	221 215
Age		
0-9 years	6.4	36 521
10-19 years	38.8	34 680
20-29 years	70.5	42 550
30-39 years	60.6	37 616
40-49 years	57.2	40 195
50-59 years	53.7	32 055
60 years and over	25.6	21 931
Ethnicity		
Australia	47.4	203 399
Other English-Speaking Countries	56.5	9 885
Non-English Speaking Countries	61.5	17 857

^a See table above for the definition of individualised funding. All percentages relate to the total population of users of CSTDA services in the relevant categories. The share of people not using individualised funding is not equal to 100 less those who are using this approach as some people did not state what they used.

Source: Users of all CSTDA-funded services, 2007-08 from AIHW 2007-08 CSTDA NMDS service user data.

While these aggregate numbers provide some insights, they exaggerate the diffusion of genuine self-directed support and do not indicate the significant differences among jurisdictions in providing such support. Some states — Western Australia and Victoria — have relatively developed arrangements, while most others currently have small-scale and trial programs (see below).

The dominant model for self-directed support is one in which people with disability and their carers:

- are assessed for their needs and an individual budget created through a resource allocation process
- form personal plans specifying their goals and needs
- make choices about how to spend the money, but with the money held by an intermediary that undertakes the administrative tasks associated with purchasing, accountability, and meeting statutory obligations (for example, tax and insurance arrangements for people employed by the family).

Arrangements in which people get direct payments are not the norm, and in many of the pilot programs, there are significant limits on what people can spend. In general, people are not permitted to hire family members.

Western Australia

Western Australia has the most developed and long-standing arrangements for some kind of self-directed support in Australia. As one service provider in that state put it:

Individualised funding has been progressively implemented across Western Australia since 1988 and applies to all recipients of State government disability funding since 2005. ...No other state or territory has such a comprehensive and well-tested system of individualised funding in place. (Perth Home Care Services, sub. 520, p. 6)

Most funding allocated to people with disability is based on individual assessment, allows portability of funding between service providers and provides the capacity for client-directed customisation of services (Fisher et al. 2010, pp. 23–24). Block funding is rarely used to fund service providers.

The main arrangements for self-directed support involve an intermediary service provider

Excepting arrangements involving the Local Area Coordination program (see below), people have many options for managing their individual budget (the direct care grant) allocated to them by the Disability Services Commission (DSC). These arrangements all involve an intermediary organisation, whose responsibilities vary depending on the degree of control desired by the person with disability or their family (the ‘client’). The development of the service design and subsequently the funding plan is a joint exercise between the client and the agency that they have selected. The DSC provides a 15 per cent loading to the intermediary organisation

above the direct care funding grant to perform its intermediary function.² There is a continuum of options for clients, depending on the disability provider. For example, *My Place* offers three broad options.

Shared management

This involves the client managing and co-ordinating their own services, but having an approved organisation administer the funds. The client designs and run their own service, but the intermediary pays support workers, calculates PAYG tax and submits it the Australian Tax Office, deals with any insurance and superannuation obligations, and acquits funding use back to the funding body (typically the DSC). In this model, the intermediary is like an accountancy firm hired by a small business.

Under shared management, the intermediary can help their client:

- set up a legal entity entitled to employ and pay staff, which allows flexible options for hiring support workers and for determining their conditions. This could include a neighbour or someone else chosen by the person with disability (or their family). In all but rare cases (such as in a remote location), employment of family members would not be permitted
- to engage an independent contractor to provide the supports, giving the people with disability the capacity to choose their carers and to form flexible arrangements with them with fewer legal responsibilities
- form a ‘micro agency’ comprising a small management committee made up of the family and other people in the social network of the person with disability. The micro agency coordinates services from the direct care funding provided through the intermediary service provider (but can supplement that with funding from other sources such as a family trust). The intermediary arranges an Australian Business Number, prepares and submits Business Activity Statements to the ATO and provides other financial and administrative services

Shared management with coordination

This is similar to the above, with the client designing their own services and employing their own carers, but with all of the coordination, administrative and financial functions undertaken by the intermediary organisation, including helping recruit, train and supervising carers. The client makes a payment (\$8000) to the

² The arrangements are described by My Place (an intermediary) at <http://www.myplace.org.au/services/index.html> and in My Place (sub. 217).

intermediary organisation to employ a service coordinator to perform the coordinating role.

Provider management

In this case, the intermediary performs all the tasks associated with service delivery, including designing the support package. As with the above, the client makes a (\$8000) payment for this function.

Other providers use other approaches

While *My Place* offer the above three arrangements, some Western Australia disability providers do not offer the full range across the continuum of consumer control or they use different mechanisms. For example, Perth Home Care Services offers many options across the continuum, but the mechanisms for shared management are not exactly the same as *My Place*. Perth Home Care Services provides highly detailed guidance to its clients about the spectrum of options for taking up or contracting out the responsibilities for self-directed care. It provides contacts, checklists and most relevant forms for employing staff, dealing with tax, workers' compensation, police checks and other obligations for those people who want to undertake any or all of these roles (Perth Home Care Services 2010).

Direct consumer funding and the Local Area Coordination program

While the above arrangements are the dominant approaches to self-directed support in Western Australia, the Local Area Coordination Program also includes a capacity for self-directed funding. It is one option for support through the Local Area Coordination (LAC) program,³ which has been in place since 1988. In the year ending June 2009, 1374 people had used LAC direct consumer funding, receiving funding of \$9.55 million annually (or just \$7000 each).

The direct funding component in the LAC program includes untied funding to cover low-cost, one-off, critical urgent needs (for example, an emergency need for respite services) and tied funding agreements. Tied funding involves the development of an

³ The LAC program is centred on a coordinator, who helps people plan, organise and get the services they need, including provision of information and advocacy. The coordinator also works with the family, carer and community to support their roles. For example, a coordinator may encourage voluntary community activities that support people with disability. There are around 50–65 people with disability per coordinator. The coordinator assists around one in seven LAC users to apply direct funding. Users of the LAC program must be aged less than 65 years at the time they apply to the scheme.

individual plan with the local area coordinator. A central panel then approves the plan. People with disability can use the funds to employ support workers, but are responsible for all the legal requirements for employment (such as insurance) Direct payments must meet accountability requirements, including provision of receipts, monthly reporting and an annual review and acquittal.

To place that in context, around 8800 people used the LAC program altogether, so around 16 per cent of the LAC users were directly funded this way (Disability Services Commission, WA 2009, p. 32). To provide an even broader perspective on usage of this form of self-managed funding in Western Australia, there were around 21 000 users of CSTDA services in Western Australia in 2007-08 and \$363.5 million of CSTDA expenditure.

The number of people using LAC direct consumer funding has progressively fallen from 2004-05 to 2008-09 (from 1547 to 1374 or a reduction of around 12 per cent). There had previously been strong growth in the use of direct consumer funding (Disability Services Commission 2003, p. 20). The likely contributors for the reduction in take-up are:

- a policy goal to transfer high-cost, complex, self-managed cases to agency-managed or shared management arrangements (as described above). The purpose of the LAC program was to coordinate services and communities, not to offer de facto accountancy functions. Accordingly, the administrative functions associated with direct funding were reducing the time and resources for the coordination functions
- not accepting self managed program funding via the Combined Application Process, which is the dominant process for people to apply for any of a range of disability services (Disability Services Commission, WA 2008b, pp. 93–4)
- the relatively low profile of this option for funding. It was, for example, not disclosed as an option in the booklet on Local Area Coordination (Disability Services Commission, WA 2010), nor as part of the Disability Services Commission’s website about information for individuals, families and carers.⁴

Overall satisfaction levels with the LAC program (of which direct payments are only a part) are relatively modest — with only around 53 per cent of people being satisfied in 2007-08 (down 12 points on 2005-06 and down 25 points from 2003-04). More recently, a face-to-face interview with 100 people in 2009 found satisfaction levels had risen to ‘around two thirds’ (PriceWaterhouseCoopers 2010,

⁴ See <http://www.disability.wa.gov.au/forindividuals.html>, accessed at 23 July 2010.

p. 7).⁵ While relating to a broader set of services, in other jurisdictions satisfaction levels are typically around 75 per cent or higher (SCRGSP 2010, pp. 14.54–14.56). These results should not be taken as evidence of dissatisfaction with self-directed support, but about aspects of a particular program that includes one option for self-managed funding.

Overall, direct payments in the LAC program plays a relatively minor role in overall self-directed support in Western Australia, though some studies characterise it as *the* approach to self-directed support in that state (Chenoweth and Clements 2009).

Victoria

Victoria has implemented self-directed support through Individual Support Packages (ISPs), which give people control over a budget to direct at their planned needs (DHS Victoria 2009a). There were 14 379 clients receiving individual support and 4451 support plans completed in 2008-09 (DHS Victoria 2009b, p. 141). In its submission to this inquiry, the Victorian Government noted that in 2011-12, ISPs would make up 42 per cent of its total disability budget (sub. DR996, p. 8).

ISPs have a focus on community participation and strengthening informal supports. Participants can buy services delivered just to them or buy group-based services, such as a day service. Facilitators are available to help people develop a personal plan about their needs and goals and a funding proposal, but the person with disability or a supporter may take on this role if they wish.

A regional office of the responsible department assesses the funding proposal against the funding guidelines and the notional allocation. People are asked to re-submit proposals if they fail at this stage. The funding agreements must be reviewed at least every three years, but there is a capacity for more frequent reviews. These may be instigated by the person with disability or supporter if they wish to change their goals or plans, or if circumstances change (for example, a major transition point or as a result of changing disability), or by the Department of Human Services (for example, if the person frequently underspends their allocated budget).

People can only get a new ISP if they have a defined disability, need on-going support, are on the Disability Support Register (DSR) and meet the priority for

⁵ However, no actual numerical estimates were provided, and it is uncertain, given the wide confidence interval associated with the small sample involved, about the degree to which satisfaction rates have recovered.

access criteria. The DSR is the system used by the Victorian Department of Human Services to record the current need for on-going disability support by those currently not getting services. (It does not cover future needs, community support or respite services.) It is an indicator of unmet demand by those with current significant needs. The list is prioritised, with people with critical needs listed as having priority status to access services. There were around 2600 people at end June 2009 on the DSR, indicating the potential number of new clients of ISPs in a less rationed system.

The Victorian Government has introduced some constraints on how people may use individualised funding. Funds cannot be used:

- for gambling or anything illegal
- for directly employing staff, unless the person is involved in the Direct Employment Project Trial and have departmental approval. If that is not the case, staff must be employed by a service provider. However, a family member can be employed to provide personal support so long as they are employed by a service provider, does not live in the same dwelling and is subject to the same regulations as other paid carers (such as a police check). The requirement for a person to be employed by a service provider is not overly restrictive, as the Victorian system allows for providers that are not registered under the *Disability Act 2006*. These providers do not need to comply with the Act (for example, would not need to meet disability standards), there is no provision for complaints to the Disability Services Commissioner, and their conduct is not monitored by the government. Government may not permit use of such unregistered services if it considers the person to be vulnerable or needing specialist disability supports
- for spending on things normally purchased from income (like entertainment), though there are exceptions when a mainstream service would be cheaper than a specialised disability service, or where a positive social, health or wellbeing outcome could only be obtained by buying a normal good or service. In part, these constraints reflect the rules governing the Australian Government's tax and welfare system. The crux is that were individualised funding to be defined as 'income', then it would be subject to tax and would affect entitlements to Australian Government income transfers. We address this issue in chapter 8 and appendix F.

People funded under ISPs have three funding administration options. They can use any, or all of:

- direct payments, in which money is lodged into a separate bank account and is used to pay for the eligible services. The person with disability or their proxy must negotiate and arrange for services, check the quality of services, check and

pay invoices, and keep receipts and other records. Initially, direct payments were only feasible in some regions, but in 2010 were expanded to all of Victoria

- a financial intermediary service, which holds the ISP funding and pays the invoices for the services chosen by the person with disability, and keeps records and provides them to the client and to the government. The person must still negotiate and arrange services, check and authorise invoices that conform to the funding plan, and send them promptly to the intermediary
- a registered disability service provider, in which funds are transferred to a nominated provider. The provider delivers the bulk of needed services, maintains records and may act as agent for arranging to buy residual services from other providers (with input from the person with disability). This arrangement is seen as most appropriate when a given provider is likely to be the main source of services wanted by a person.

People can change providers if they wish, though, as is often the case with other suppliers (for example, utility services), a period of notice must be given. As an illustration, a person must usually give a registered disability service provider notice of two months before switching to another supplier, though it can be quicker if a supplier has regularly failed to provide a service.

At the end of each financial year, people must acquit their annual funding allocation and are able to carry forward unspent funds up to 5 per cent or \$1500 of the total allocation (whichever is the greatest). Continued under-spending may result in a review of the support and funding plan.

ISPs are approved regionally, but once obtained, a person can move with their allocated funding to another region. They may, however, have to re-negotiate all arrangements with providers if they do not supply services in the new region. If the person moves interstate, the ISP funding moves with them for a period of 12 months, and is subject to the rules applying to their use in that state.

South Australia

While there were some ad hoc arrangements for a few families in place beforehand, a more systematic approach to individualised funding started in June 2010 with a trial involving 50 people who were prior beneficiaries of services from Disability SA (Disability SA 2009 and Rankine 2010). (A second phase will involve the expansion of the system, based on an evaluation of the outcomes of the trial.) The trial phase involves no assessment process, since the cash value of the packages are based on estimates of the value of the participants' previous service entitlements. Cash is paid monthly in advance.

Given the newness of individualised funding in South Australia, the trial prescribes relatively rigid arrangements. Under the trial, Disability SA has provided each participant with a ‘self-management facilitator’, who will help participants and their support network develop a personal plan, which details how the funding will be used. (There are currently two facilitators for the trial.)

Participants can control the allocation of spending in three ways. They (or a legally recognised proxy) may:

- arrange and purchase services themselves, with encouragement to be innovative
- make the decisions about what to purchase, but pay an organisation to manage the financial arrangements.
- pay an organisation (a ‘host’ organisation) to meet the personal plan, with that agency arranging the services and managing the funds.

A participant is helped in managing their funding through training, resource materials, an enquiry service and their facilitator.

Participants must purchase any personal support type services from organisations registered on the Disability Services Provider Panel (which meet national standards). This would prevent a participant from paying a neighbour, friend or relative to help them get up in the morning, prepare a meal or drive them somewhere. Non-personal services and goods may be purchased from other organisations and contractors, but the participants must establish these have public liability insurance. Participants must meet with their facilitator once a month.

The personal plan must meet rules about what can be spent (for example, spending on alcohol and gambling are barred), and participants must account for any use of funds, with quarterly and annual acquittals of the funding. Participants must keep records of support and expenditure plans, receipts, invoices and relevant bank statements for seven years. Money must be lodged in a separate bank account and cannot be spent on items that a member of the community would normally be expected to pay for. Any unspent money must be given back to the Department of Families and Communities (DFC) at the end of each 12 month period, unless recipients receive written approval to keep them.

New South Wales

NSW is in the formative stages of self-directed support (Fisher et al. 2010), although it has some programs (mostly pilots involving small groups of people) that provide significant control to people with disability and their families (table D.3). Most involve an intermediary to organise the administrative aspects of self-directed

support, rather than making direct payments to the person or their family. The programs are:

- *The Attendant Care Program — Direct Payment model* is a small-scale program, that provides support and assistance to people with a physical disability aged 16 to 64 years who have the capacity to manage and direct their care workers. DADHC funding is transferred directly to approved clients who then take full responsibility for arranging and managing their care. Other than in exceptional circumstances, people cannot use direct payments to get a service from close relatives (any resident family member or any immediate family member and any resident family member). Payments are tax exempt after an ATO class ruling and the grant is GST free. In addition, the responsible Australian Government minister approved the direct funding model as an ‘approved scheme’ for the purposes of the Social Security Act, which means that direct payments were excluded from the social security income test and did not affect welfare payments (DADHC 2008, p. 17).
- *Community Participation — Self Managed model* is similar to the shared management model of Western Australia, but oriented towards young people with moderate to high support needs, who require an alternative to education/employment in the medium or longer run. An intermediary holds and manages the funds, employs staff on behalf of the client and meets any legal requirements. Funds are allocated based on assessed need. After drawing up a personal plan, the person determines how the funds are spent (subject to reasonable limits), and can choose and switch between intermediaries. The NSW Government only reimburses items covered by the plan.
- *Family Assistance Fund* provides small, non-recurrent grants for families with a child with disability. It is akin to the grants used in the ACT. It can be spent flexibly, such as on recreational activities for a child with disability and his or her siblings, but cannot be spent on basic items, like food and clothing.
- *My Plan, My Choice — Early Start* is a pilot program that commenced in the 2008-09 financial year, aimed at early intervention for children less than six years old with a developmental delay or disability. The family forms a personal plan for the child with assistance from an intermediary, and the family and the intermediary jointly implement the plan. The intermediary is responsible for overseeing the plan, setting up referrals, arranging and recording payments, and meeting any other statutory and regulatory guidelines set down by the government. There are few limits to permitted spending, except that people cannot use the funding for gambling, anything illegal, or for support from family or friends living in the same house. *Early Start* is part of a group of four pilot approaches to self-directed support, sharing common features, but involving people at different life stages. The other three programs — discussed below —

are *Extended Family Support, Life Choices and Active Ageing (Self-managed)* and *Older Carers*.

- *My Plan, My choice — Older Carers program* targets families where the carer is aged over 60 years old (45 years if Indigenous) and who is the primary carer of someone aged 25 years or older. The arrangements are similar to the Early Start pilot above with the carer and person with disability able to select staff and control their support package through an intermediary. The family gets additional funding, but may also bundle into a common funding pool any block funding they were previously getting.
- *Life Choices and Active Ageing — Self-managed model*, is oriented at adults with moderate to high support needs aged between 25 and 64 years old, who are living in the community or in supported accommodation and currently do not access a DADHC funded day or post school program
- *Extended family support* involves packages of up to \$50 000 per family, is tailored to the needs of families that are at risk of relinquishing a child with disability aged 0–18 years
- *NSW Younger People in Residential Aged Care (YPIRAC) Program* provides alternative accommodation and support services for some younger people (aged less than 50 years) with a disability (acquired after 18 years old), who are inappropriately living in, or at risk of entering, residential aged care. This program is Australia-wide, but is run at each state level. The person forms a plan (with assistance), which determines how resources are spent, but a specialised disability service provider delivers the services. The budget is projected to be around \$80 million over the five year funding period, including Australian Government funding (Urbis 2009, p. 7).

Queensland

Individualised funding — in the sense defined in chapter 8 — is in its infancy in Queensland, with block funding remaining the central funding approach. Funding is not generally made available to pay individuals or families directly for informal support.⁶ One recent study estimated that only around 10 people got direct payments (Fisher et al. 2010, p. 19).

⁶ <http://www.disability.qld.gov.au/support-services/funding/guidelines/funding-programs.html> at 26 July 2010.

Table D.3 Programs incorporating self-directed support

New South Wales

Program	Target group	Value	Places in pilot	Area	Roles	
					Planning	Purchasing
<i>My Plan, My choice — Early Start</i>	<i><6 years old</i>	<i><=\$8000 per place</i>	<i>20</i>	<i>SW Sydney local planning area Metro South Region</i>	<i>Intermediary</i>	<i>Intermediary (NGO)</i>
<i>Extended family choice</i>	<i>0-18 years old</i>	<i><= \$50 000 per place</i>	<i>41 families</i>	<i>Metro North and Hunter regions</i>	<i>Case manager</i>	<i>Purchasing broker (NGO)</i>
<i>Life choices and Active Ageing programs</i>	<i>25–54 and 55-64 years old respectively</i>	<i>Average was \$15 195 per place</i>	<i>89 by November 2009</i>	<i>State-wide</i>	<i>Intermediary</i>	<i>Intermediary OR client</i>
<i>My Plan, My choice — Older Carers program</i>	<i>Older carers > 60 years (and >45 for Aboriginal clients)</i>	<i><= \$50 000 per place</i>	<i>30 places</i>	<i>Northern Region</i>	<i>DADHC support planner</i>	<i>Intermediary (NGO)</i>
<i>Attendant Care Program – Direct Payment pilot^a</i>	<i>16–64 years old with capacity to employ own workers</i>	<i>Value equivalent to 15–70 hours assistance per week</i>	<i>18 recipients by October 2009</i>	<i>State-wide</i>	<i>Client</i>	<i>Client</i>
<i>Community Participation – self-managed pilot</i>	<i>School leavers</i>		<i>80 recipients</i>		<i>Intermediary with client</i>	<i>Intermediary</i>
<i>Family Assistance Fund</i>	<i>For families with children with disability aged <18 years</i>	<i>\$2000 max</i>	<i>4950 to November 2009</i>	<i>State-wide</i>	<i>Client with DADHC or DADHC funded case manager</i>	<i>Client</i>
<i>YPIRAC program</i>	<i>Mainly 18–50 years old</i>	<i>Level 1 <=\$29 000; level 2 <=\$8000</i>	<i>135 users in 2007-08</i>	<i>State-wide</i>	<i>Support planner with client</i>	<i>Specialist service provider</i>

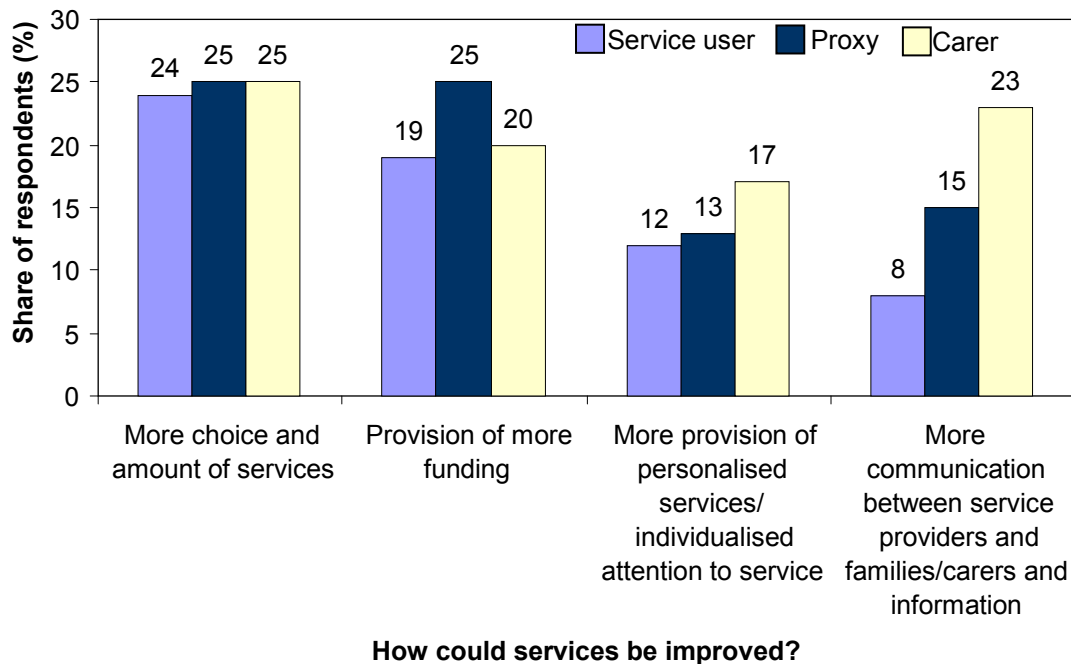
^a There is also an Attendant Care Program – Cooperative model, which resembles the shared management approach of Western Australia.

Sources: de Natris et al. (2010); Urbis (2009), Fisher et al. (2010); ADHC NSW (2008); Harwood (2009).

However, service providers would often attempt to take account of the preferences of the people they serve through meeting their personal plans. Moreover, at their own initiative, some have offered people control over their funding, such as Mamre, which allocates cash payments to 165 of its 200 families (Ward, trans., p. 402). In this sense, it can be important to distinguish between self-directed funding as a general option provided by government, and as an option determined by a service provider. Nevertheless, Mamre estimated that only around 5–10 per cent of family members with a disability were receiving individualised funding in that state (sub. 528, p. 16).

It was notable that in the 2009 Queensland disability satisfaction survey, people pointed to the desirability of more choice and more provision of personalised services (figure D.1).

Figure D.1 People want more choice and individualisation in Queensland^a
2009



^a Proxies are people who provide unpaid regular and sustained care to the person with the disability and responded on behalf of the service user. Carers are unpaid carers of disability service users. These two groups overlap.

Data source: Department of Communities, Queensland (2009).

However, there is some recognition of the value of self-directed support, exemplified by the Self-Directed Support Pilot Program. The small-scale pilot is

running for two years (2010 and 2011) and will involve up to 80 people and two overseeing service providers. The pilot is primarily for people who are 20–35 years old with an acquired physical disability (such as an acquired brain injury) in Brisbane and children aged 0–6 years old with a physical disability living on the Sunshine Coast (Queensland Disability Services 2010). The pilot is only directed at people without existing links to the community and without prior funding from Queensland Disability Services. The pilot centres on a person’s plan for life and provides a budget of \$4000 per annum. Service providers have a significant role in overseeing the trial, ensuring appropriate acquittal of money and supporting people in their plans and spending decisions.

Tasmania

Self-directed support in Tasmania is delivered principally through individual support packages (ISPs), which are portable funds that the client can shift from one provider to another. The ISP guidelines indicate that people are, *as far as possible*, to be *involved* in day-to-day management of their package (Disability Services, Tasmania 2008). This is less self-directed, and more a cooperative approach between government, service providers and the individual/family. Under these arrangements, people are given a ‘budget’ of hours, based on individual assessment, and this provides their service entitlement from an accredited service provider they choose. People may also ‘cash out’ their allocation (based on funds equivalent to the weekly allocation of hours) to purchase personal support while on holiday and to buy authorised respite services.

There is some trialing of direct funding through intermediary service providers, in which people with disability hire their own staff and organise the support roster, with an NGO managing the administrative aspects of direct funding, such as payment of staff (Fisher et al. 2010, p. 34). This is similar to the shared management approach in Western Australia.

There is also scope for people to create a business entity through which they channel ISP funding, allowing flexibility in the use of funding. However, these arrangements can be complex (usually involving a board of directors, treasurer and the other formal ways of achieving proper governance). Disability Services note that ‘the client will need to spend a significant amount of time administering their package’ (Disability Services, Tasmania 2008).

The Tasmanian Government has indicated that it plans to increase the use of self-directed support following a KPMG review of disability services in 2008.

Australian Capital Territory

As in Tasmania, the ACT implements some degree of self-directed support through ISPs. Block funding of service providers remains an important element of funding arrangements for people with disability.

ISPs are based on individual assessment, and are generally funnelled through a service provider.⁷ ISPs are offered in three ways:

- *Individually tied funding*, which allows individuals to make day-to-day decisions about the services they purchase, and to adjust services and service agencies as required. A specified amount of funding is paid to an auspice agency to purchase a range of services for an individual, consistent with their Individual Funding Plan, up to the maximum limit of each individual's Funded Support Plan. The funds are tied to that individual, and the individual may change their auspice agency. The auspice agency may charge administration fees of up to 10 per cent of the individual's package, and must provide receipts of spending every six months. An auspice agency usually purchases services from other agencies, however, in some circumstances an auspice agency may also be a provider of services. Disability ACT recovers unspent money at the end of each fiscal year, unless individual circumstances suggest otherwise. The individual or family cannot recruit and employ support workers. This form of ISP falls short of genuine self-directed support, but nevertheless gives consumers a relatively high degree of control
- *'Individualised funding'*, in which an agreed total level of funding is allocated to an agency for a specific individual, but where the service agency pools the funds with block funds and may allocate them to other individuals. Individuals may negotiate specific service requirements through a Funded Support Plan. While the term individualised funding is used, funds are not tied to the consumer, and the extent of tailoring and consumer power is limited
- *Individual grants*, which are small non-recurrent allocations for a specific period, but with considerable flexibility about how they are acquitted. They could include starting up a small business or individual support to help familiarise someone with a new recreational activity or accessing a community group. The idea is to stimulate innovative approaches. Grants are paid directly to an individual's bank account or by cheque. Clients must provide receipts for their spending. Their low value and non-recurrent nature means they are a weak form of self-directed support, similar to direct funding through LACs in Western Australia. The ACT Government has allocated \$300 000 to these 'Quality of Life' grants in 2010, with an expected 90 clients (Disability ACT 2010). To

⁷ DHCS ACT 2007, Individual Support Packages, Policy and Procedures, February 2007.

place this in context, the 2008-09 budget for disability services was around \$70 million (DHCS ACT 2009, vol. 2, p. 120).

ISPs can only be directed at spending that relates to the person's disability needs, be consistent with their plan, be cost effective and be 'reasonably justifiable in the public arena'. Items that would normally be spent out of ordinary income — such as food, consumer goods, entertainment, and rent — would not generally meet the spending guidelines.

Northern Territory

The nature of disability services in Northern Territory are nationally distinctive, reflecting:

- the small size of the territory's overall population, which means few providers and low competition between services
- the dispersion of the population, which means many remote areas needing services. There appears to be significant under servicing in these areas (KPMG 2006, p. 14)
- the disproportionate representation of Indigenous people with disability (KPMG 2006). It is estimated that 43 per cent of people with a severe or profound disability are Indigenous (whereas Indigenous people make up less than 30 per cent of the overall population) and there may be significant under enumeration. These higher prevalence rates mean a greater need to take account of cultural differences among the population with disability than other jurisdictions
- the fact that Indigenous people with disability face many other disadvantages and live in communities also experiencing widespread disadvantage. This means greater complexities in addressing problems, and greater problems in identifying service and policy priorities. As Fisher et al. (2010) observed: 'the disability service system still in development', and it is notable that the disability website has no document dated after 2008 and negligible information about what services are available
- the particularly blurred boundary between aged care and disability services, given that many Indigenous people enter the aged care system at ages below 65 years.

At the time of the KPMG review, most funding was block funded, with only around 10 per cent allocated to people through Individual Community Support Packages (ICSP) based on individual assessments. The main role of ICSPs was to 'fill gaps in

the Northern Territory Disability Service system with small and tailored packages' (DHCSNT 2008), rather than reflecting any particular goal for personalisation. ICSPs include the capacity for direct funding — which is paid and acquitted quarterly, and overseen by Disability Case Coordinators and Case Managers (with arrangements through Local Area Coordination now abandoned). The client is responsible for all administrative responsibilities for purchasing, managing expenditure and accounting. They have substantial flexibility in purchasing from mainstream providers and from friends and neighbours as carers. Direct payments account for something less than half of ICSPs (Fisher et al. 2010, p. 18).

Australian Government

While not typically seen as forms of self-directed support, the Australian Governments make several disability-specific payments that have all of the elements of self-directed support, although they are only available for carers (box D1). The three relevant and closely associated payments⁸ are:

- Carer Allowance (CA), which is a fortnightly payment for those caring for a child or adult with disability on a daily basis
- Carer Supplement (CS), which is a supplementary annual lump sum payment, available for those getting CA
- Child Disability Assistance Payment (CDAP), which is an additional supplementary annual lump sum payment, available for those getting CA.

The purpose of the first two payments has not been very precisely defined, with the Harmer Pension Review indicating that the CA is paid in 'recognition of the caring role' (Harmer 2009, p. 118). Despite this ostensible objective, the Harmer Review noted that people often used the CA to fund services needed by the person with disability. Three other reviews have also corroborated that its effective role is a payment to meet the extra costs of disability (Orima Research 2008, p. 13, SCFCHY 2009, p. 142 and Carer Payment (Child) Review Taskforce 2008). The purpose of the CDAP has been more explicitly specified as a payment that:

... can be used to assist families purchase support, aids, therapies, or respite that they require for their child with disability. Importantly, the payment will help carers to purchase the form of assistance that best suits the needs of the family. (FaHCSIA 2009a, p. 137)

⁸ The Australian Government makes several other disability-related payments to individuals, but these comprise income support related to the capacity to work (Disability Support Pension and Carer Payment) or are hypothecated to certain expenditures (for example, Mobility Allowance).

None of the above payments are means-tested, assets-tested or taxed, and the income associated with them do not reduce eligibility for other social security payments. This is again consistent with their role as a payment for the extra costs of disability, rather than income support.

Once government has approved eligibility, it requires no accountability for spending the annual collective allowances of close to \$4400, with people free to spend the money as they wish. Consequently, these disability allowances act as completely unconstrained forms of self-directed support.

Box D.1 Australian Government disability allowances

Carer Allowance (CA) is a non-means tested, non-taxed payment (set at \$106.70 per fortnight) for people caring for people with disability for at least 20 hours a week.

CA (Adult) is paid to any carer who provides daily care and attention to a person aged 16 years and over (including the aged), who has a substantial functional limitation. The care must take place in the home of the care receiver/s.

The Australian Government also pays CA (Child) to carers of people with disability less than 16 years old. However, payments are made only if the 'load' on the carer exceeds a given threshold as measured by a given assessment tool, or the child has certain specified medical conditions, or the carer receives Carer Payment.

In 2008-09, the Australian Government paid CA (Adult) to around 330 000 carers of adults (relating to the support of about 350 000 adults). Of the CA (Adult) carers, around half were providing support for adults aged less than 65 years of age. The Government paid CA (child) to around 120 000 of carers of children (relating to the support of about 145 000 children) (FaHCSIA 2009a, pp. 136–7).

Carer Supplement is an annual payment of \$600 dollars paid to people getting CA, while the Child Disability Assistance Payment is an annual payment of up to \$1000 for each child being cared for by a person receiving Carer Allowance.

In 2008-09, spending by the Australian Government for the three allowances was \$2.35 billion, covering all ages of people with disability receiving care (FaHCSIA 2009a, p. 297).

Sources: Centrelink (2010a,b,c) and FaHCSIA (2009a).