

Final Report
Funding and service options for people with disabilities

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Background

This report presents the findings from the *Funding and Service Options for People with Disabilities* research project, conducted in partnership with the Office of the Public Advocate Queensland, the Office of the Adult Guardian Queensland, National Disability Services, and Queensland Health.

The purpose of this research project is to provide foundational knowledge and evidence on the range of funding and service approaches for people with disabilities. This report is not a systemic review of research quality and individual program approaches, rather an extract of key trends in approaches. These key trends provide important guidance for developing and implementing the identified directions in funding and service delivery.

The project addresses the following research questions:

1. What are the current trends in funding and service provision for people with disabilities, including people with impaired decision-making capacity, and their families?
2. What are the features of the most effective approaches for funding services for people with disabilities and their families in Australia and internationally?
3. What internationally acknowledged standards could be adapted or developed by which to determine the most effective, equitable and just funding and service approaches in Queensland?
4. How might these approaches be implemented in practice in the Queensland context?

This report explores the research questions, to identify different approaches to funding and service and supports delivery, and the available evidence on their effectiveness, through the following methodology:

- A review of the research literature,
- An international search of different disability service systems, and
- Identification of internationally agreed standards for funding and service delivery to people with disabilities.

Introduction

This report presents the current international and national trends in approaches, and features of effective approaches, to both funding services for people with a disability, and service delivery for people with a disability. The Queensland context is compared with other Australian jurisdictions, and the United Kingdom (UK), Canada, the United States (US), Europe, and Scandinavia. Key international studies and Australian studies were reviewed, with a focus on reviews of multiple models.

Lord and Hutchison (2003) report on findings and themes from a Canadian study that investigated individualised funding (IF) projects from Canada, the US, and Australia. Emergent themes from the study included: values and principles mattered, a policy framework provided coherence and equity, infrastructure supports for individuals were separate from service system, facilitator–broker role differed from case management, allocation of individualised funds was designed to be equitable and accountable to the funder and person, and a ‘learn as you go’ philosophy maximised positive outcomes. The conclusions from this research project were that individualised support and funding, when embedded in the new paradigm of disability and community, build capacity of individuals, families, and communities.

Parmenter and Arnold (2008) recently reviewed national and international research, for the Victorian Department of Human Services, to identify and describe the key elements of community-based accommodation and support that provide the best personal outcomes for people with a disability. They recommended that a move from congregate facilities to smaller community-based settings is accompanied by different ways of planning and providing support; especially through processes that ensure that the lives of people are enriched with emphases upon individual needs, preferences and choices. They also recommended that the provision of IF, based on support needs should be expanded.

The overall emergent trends from the research are:

- Self-directed care/Self-determination/IF, and
- Independent living with services provided in the community

The key features of effective approaches to these trends, as identified from the research are:

- A good system for allocation of individualised funds
- Allocation of block funding to services, when implementing IF and support
- Local area coordination, so that local needs and preferences shape local services
- Implementation in phases
- Provision of infrastructure supports, which are separate from the service system
- Minimisation of bureaucracy
- Implementation of alternative quality systems
- Universal access: Increased use of mainstream services
- Use of best-practice models
- Utilising a blend of formal and informal supports

Current trends in approaches to funding and service and supports delivery

International

The introduction of the *United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol* (2006) marks a shift in thinking about disability from a social welfare concern, to a human rights issue. It recognises that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (United Nations, 2006).

During the latter part of the 20th century, the concept of disability moved toward a strong emphasis on personal rights and desired personal outcomes, and an awareness of the effects of discrimination and marginalisation on persons with disabilities (Schalock, 2004).

In policy systems internationally, there have been moves to a citizenship/inclusion approach, as presented in Figure A. below, particularly in Canada, Scandinavia, the United States and the UK:

Existing Service Approach	Disability Inclusion Approach
Eligibility based on diagnosis biomedical criteria	Eligibility based on impact of disability
Service/program-centered	Person-centered
"One size fits all" and "on/off" responses	Measured responses based on need
Fragmented service delivery	Integrated service delivery
Passive and residual measures (e.g. welfare)	Active measures (e.g. disability employment supports)

Figure A. Disability Inclusion Approach (Government of Saskatchewan, 2007)

Included in this shift, in the 1980s and 1990s, there was an active campaign by the disability movement for the right for disabled people to be given the cash to purchase their own support (Leece & Leece, 2006). IF of disability supports is viewed by many in the field as a mechanism for ensuring that the paradigm shift is grounded in genuine options and increased control for individuals and families. (Ontario Federation for Cerebral Palsy, 2000b).

Internationally there is a shift from the traditional model used to fund disability support services to an individualised approach with an increasing trend to direct-funding. The former relies more on the type of service and less on individual need, the latter identifies individual support needs, which in turn guide the

allocation of funding resources (Australian Institute of Health and Welfare (AIHW), 2002).

The alternative to traditional modes of funding and service provision for people with disabilities – to support people to make choices and to be included – goes under many different names, including person-centred services; self-directed support; person-directed service; independent living; consumer control; self determination; self-directed services; consumer-directed services; IF (IF). All alternative models are based on the same principle: if disabled people are to participate and contribute as equal citizens they must have choice and control over the funding and support they need to go about their daily lives (Glynn, Beresford, Bewley, Branfield, Butt, Croft, Pitt, Fleming Flynn, Parmore, Postle & Turner, 2008).

The key concepts to this new approach are defined for this paper as:

- **Self-determination/consumer-direction/self-direction:** a belief based on the understanding that people have both the right and responsibility to exercise control over the services they receive (Moseley, Gettings & Cooper, 2005).
- **Individualized Funding:** is a style of funding community services where funds needed to purchase required community services and supports go directly to the individual, based on a plan that is negotiated with government. Financial resources and a greater degree of decision-making power will thus be placed in the hands of people with disabilities and their personal networks (Advocates and Families from South Fraser, North Shore and Capital regions, 1998).
- **Independent living in the community:** definitions vary; however common themes relating to this value include consumer sovereignty, self-reliance, inclusiveness, and integration (Hanson, 2000).

Smith & Fortune (2008) argue that allocating funding at the person level enhances the capability to develop individualized support strategies, contributes to portability, and promotes individual choice. Managing funding at the person level hinges on developing funding methods that are service independent. The goal is to determine an amount of funding that attaches to the person and thereby is not contingent on the person's being slotted into a particular type of service.

In Scandinavia, the shift between the institutional and the community tradition of support has resulted in a citizen perspective towards persons with disabilities (Weinbach, 2004). In this perspective, the aim is to make services offered to the general public available for people with disability. In Europe, place-related funded systems of specialised assistance services are still in existence (Weinbach, 2004).

In the UK, IF arrangements such as direct payments have been implemented, underpinned by legislation, since 1996 (Weinbach, 2004; Leece & Leece, 2006). People with a disability can use the cash to purchase services directly including employing personnel to provide direct care (LDC Group, 2007). A number of recent reforms in the UK are aimed at increasing the use of IF, particularly direct payments, by implementing a new funding structure, whereby several funding streams will be brought together in the form of 'individualised budgets' (Leece & Leece, 2006.) Individuals will be able to choose whether to take these budgets as cash (direct payments) or as services. There are also proposals for new forms of support to help people currently excluded from direct payments, such as the use of 'agents' to assist people with severe cognitive impairments who are deemed unable to consent; and support to control their budget without the responsibilities of becoming an employer.

Research involving 38 individuals' experiences of direct payments revealed that most of the respondents appeared to be able to secure greater continuity of care with direct payments than they might have experienced previously through local authority-arranged provision (Mc Mullen, 2003). It was evident that direct payments have introduced a level of flexibility for many respondents that had not been enjoyed previously (Mc Mullen, 2003).

The first evaluation of the implementation of personalised approached to social care in the UK and the impact on users, support processes, workforce, commissioning and providers was recently published (IBSEN, 2008). The evaluation included a randomised controlled trial of almost 1000 service users across 13 sites where pilots of individual budgets were being trialled. The evaluation found that Individual budgets were used to purchase personal care, assistance with domestic chores, and social, leisure and educational activities. People receiving an Individual budget were more likely to feel in control of their daily lives, compared with those receiving conventional social care support. Little difference was found between the average cost of an individual budget and the costs of conventional social care support. The average weekly cost of an individual budget was £280, compared to £300 for people receiving conventional social care (IBSEN, 2008).

In North America, particularly in Canada, there is a much longer history of IF than in the UK. In the United States, Mosely, Gettings and Copper (2005) report that in 2002 some form of individual funding was in place in nearly three quarters of the 43 states they surveyed. Although there is great variation in its applications, IF is rapidly becoming a mainstream funding mechanism in the US.

A recent study by the Research and Training Centre on Community Living (2009) examined the extent to which states have implemented **both** individual budgets and consumer control over services for Home and Community based services. At the time of the interviews, 13 states had statewide availability of individual budgets and consumer control for at least some Home and Community based

services recipients. Eleven additional states had a consumer-directed option available as a pilot project to a limited number of people or available within a limited geographic area. Eight states reported that they were in final stages of development of a consumer-directed option.

From the perspective of the state administrators, themes related to success included (Research and Training Centre on Community Living, 2009):

- Not having to fit people into program-specific slots.
- Seeing people succeed after experiencing frustration with traditional services.
- Real change has occurred in people's lives.
- Hiring people of one's choice, with less staff turnover.
- Reaching more diverse service users.
- More efficient use of resources, and
- Collaboration between stakeholders, with increased participation by self-advocates.

Additionally, considerable impetus was given to consumer-directed services by changes in legislation that went into effect at the beginning of 2006 (National Council on Disability, 2008b). In early 2007, the Centres for Medicare and Medicaid Services issued a *Final Rule* to allow more Medicaid beneficiaries to be in charge of their own person assistance services, instead of having those services directed by an agency (Harrington, Ng, Kaye, & Newcomer, 2009).

Many of the advances in developing a consumer-directed, individualised approach have taken place in Canada. Virtually every province has some variation of IF underway, particularly in the areas of supports to people who have intellectual or physical disabilities (Advocates and Families from South Fraser, North Shore and Capital regions, 1998). For example, in Alberta, individualized funding has been in place since the mid-1980s, and in 1990, it became the official way for service delivery (Ontario Round Table on Individualized Funding, 2000b; Advocates and Families from South Fraser, North Shore and Capital regions, 1998).

In New Zealand, the Government began contracting in 2005 with a disability organisation to provide an IF service (Litmus Ltd, 2007). This is an administrative arrangement for some disabled people that allows them to hold, manage or govern their own needs-assessed disability support budgets.

Australia

Currently in Queensland, there is a combination of individual packages, as well as the traditional block-funding of services for people with disabilities, where services are funded to provide support to an aggregate of people with disabilities. The resources committed to the block-funded system do not generally enable or

measure individual outcomes as required by the Disability Services Acts in Australia (Bleasdale, 2001a; Parmenter and Arnold, 2008).

The 2003 Queensland State Government Funding Reform report also noted that non-government organisations ideally sought a mixture of block funding coupled with IF to cover organisational costs and individual costs. National Disability Services Queensland (2007) have also stated recently that most relevant for providers is block funding for fixed costs and individual funding for variable costs, reflecting the level and complexity of need as a major driver.

Disability Services Queensland (2007) report that in 2006-07 in Queensland, 19 300 people with a disability received a range of services. The AIHW estimates that in 2006, 3,578 Queenslanders were registered for disability support but did not receive any (AIHW, 2007).

Queensland introduced Local Area Coordination in 1988. Disability Services Queensland (2007) states that the Local Area Coordination program aims to provide information, promote inclusiveness in mainstream services, and support communities to be supportive of people with a disability.

Western Australia is the first of Australia's six states to adopt individualized funding. It has one of the simplest yet highly developed approaches to individualized planning and direct funding (Ontario Round Table on Individualised Funding, 2000a). Based on the *1993 Disability Services Act*, Local Area Coordination was developed to increase the self-reliance of people with disabilities, through the Individual Coordination Service. Individual Coordination relates to the provision of a range of supports and strategies through local area coordinators (LACs) who develop resources and support networks in local communities; provide information and link service users with local resources and support networks; and also provide IF to enable service users with disabilities and their families to choose and purchase their own supports and services directly.

The direct funding component of the program involves both untied (or discretionary) funding to cover one off or emergency situations, and tied funding agreements. Tied funding involves the development of an individual plan in conjunction with the Local Area Coordinator which is then approved by a central panel. Funds can be used for the employment of support workers and the service user is responsible for all the legal aspects of employment including workcover and the provision of a safe workplace (LDC Group, 2007).

Both funding streams are subject to strict accountability requirements which includes a signed acceptance of grant form, the provision of receipts for any payments made to, monthly reporting by users and an annual review and acquittal (WA Disability Services Commission, March 2003).

Planning is completely separate from services. LAC is considered to be a cost-effective option for achieving community-based support for people with disabilities and their family carers. The scheme is reported to be highly valued by people with disabilities and their families and serves to strengthen local support and friendship networks. Increasing numbers of people with disabilities and their families are expressing a willingness to plan and meet their needs without the use of funding for services from government systems. New forms of assistance such as information, strategies, templates and guides, as well as an outcomes-based, quality assurance framework are being developed (Disability Services Commission, 2007).

The Individual Coordination Service accounts for nine per cent (\$30.2 million) of the Commission's budget and 38 per cent (7,836) of service users. During 2006–2007, 7,836 service users were supported in the community through LAC. Of these, 1,521 service users received LAC Direct Consumer Funding. A total of \$10.3 million (three per cent of the Commission's budget) was paid as LAC Direct Consumer Funding. This represented an average cost of \$6,772 per service user.

In Victoria, a recent review of accommodation and support service for people with disabilities by Parmenter and Arnold (2008) recommended that the provision of IF based on support needs should be expanded. An evaluation of a recent Victorian trial indicates that direct payments were successfully used by all direct payment users in the trial (LDC Group, 2007). Direct payment users experienced benefits of great flexibility and control as a result of being able to negotiate the nature of the service provision directly with disability service providers and managing the expenditure of their funding in line with the goals of their funding plan and their changing needs. An outline of the direct payments process and the responsibilities of the various stakeholders are provided in Appendix A.

The Transport Accident Commission (TAC) in Victoria has a system of direct payments called Self Purchasing. It was developed by the TAC to promote client choice, control and autonomy over the services they receive. TAC clients are able to engage and direct disability service providers. Clients or their substitute decision-maker are required to enter into an individual funding agreement with the TAC. The agreement can involve self management by the client whereby funds are provided direct to the client and they purchase services in accordance with the funding agreement. The agreement can also involve broker assistance whereby the broker helps the client to purchase TAC funded services (LDC Group, 2008).

In New South Wales, ten people with physical disabilities trialled direct payments to employ their own support workers (Fisher & Campbell-McLean, 2008). In comparison with a control group, the evaluation found that people using direct payments had higher feelings of personal wellbeing, a greater sense of control

over their lives, more choice and a greater range of activities; better physical health; and improvements in pain and physical risk management.

Tasmania has a number of examples of successful IF arrangements. One example is that of D.G.Lewis Pty Ltd which is an independent company whose directors include an individual with disabilities (the person receiving support) and unpaid family and friends who act as personal advocates (Bleasdale, 2001b). D.G.Lewis Pty Ltd receives funds from the Department of Health and Human Services on behalf of specified individuals and manages the funds in accordance with individual needs for support and development. Originally established some years ago to provide a structure that would enable IF to be provided to one person with disabilities, D.G.Lewis Pty Ltd has since assisted a number of people with disabilities, often with the help of family and friends, to establish and maintain highly successful individually funded and tailored support arrangements.

The Senate Standing Committee on Community Affairs (2007) recommended that when reviewing the Commonwealth State and Territory Disability Agreement (CSTDA) that an examination of alternative funding arrangements be undertaken which specifically considers the issues involved with the introduction of alternative funding mechanisms, particularly IF.

Overall key trends in approaches

A range of international literature highlights the following trends in approaches, presented below (Kendrick, Bezanson, Petty, Jones, 2006; Lord & Hutchison, 2003; The Nucleus Group, 2002; Parmenter & Arnold, 2008; Powers, Sowers, & Singer, 2006; Robertson, Emerson, Hatton, Elliott, McIntosh, Swift, Krinjen-Kemp, Towers, Romeo, Knapp, Sanderson, Routledge, Oakes, & Joyce, 2007; Social Exclusion Taskforce, 2004; Weinbach, 2004):

1. Independent living with services provided in the community Providing a range of delivery methods at the local level that suits the needs of the individual for e.g. high levels of support provided within ordinary housing in the community. Kendrick, Bezanson, Petty, Jones (2006) state that high-quality community services must support social inclusion, i.e. not separating people from their natural communities. Separation deprives people of civic participation. Institutional social services have traditionally removed people from their natural communities to relatively segregated locations, which can result in lives of permanent exclusion.

2. Self-directed/consumer/person-directed/centred care, and/or/with IF. Providing increased autonomy and power in the hands of beneficiaries and informal caregivers through mechanisms such as cash payments or vouchers to purchase services (Nucleus Group, 2002). The literature suggests that person-directed services have a positive impact on factors such as quality of life, control,

productivity, unmet needs, use of preventative health care, and cost (Lord and Hutchison 2003; Government of Saskatchewan, 2007; Powers, Sowers, & Singer, 2006; Disability Reform Group, 2002).

Similarly, a range of literature highlights that individualised support and funding indicates an increase in positive outcomes for users of IF on measures of quality of life, satisfaction, control, independence, health care utilisation and satisfaction (Bleasdale 2001a; Conroy, Fullerton, Brown & Garrow, 2002; Dale, Brown, & Phillips, 2004; Glasby & Littlechild, 2002; Lord & Hutchison, 2003; Parmenter and Arnold, 2008; Standing Committee on Community Affairs, 2007; Stainton, 2006; Stainton, & Boyce 2004).

The 1997 Provincial Conference on IF endorses and statement of principles that define IF(North Shore Disability Resource Centre, 2005):

- IF provides the resources that each individual judges to be necessary for participation as a citizen in society
- IF is based on the needs of the individual as defined by the individual or trusted representatives
- IF dollars are paid directly to the individual or to support groups established by the individual
- IF dollars are portable within the State and across departments of Government.

No single model stands out as ideal according to the literature, so a range of options are needed, based on a change of focus from the service perspective to a person perspective (Parmenter & Arnold, 2008). Powers, Sowers, & Singer (2006) state that models are being developed that avoid the oversimplified notion that service users are either autonomous or non-autonomous, permitting both collaborative direction of services by individual and trusted others, and delegate autonomy by surrogates.

The structure for Governance in IF is:

- the role of the government: eligibility and allocation of money;
- the role of the individual or broker: needs articulation, assessment, planning, prioritisation, identification and negotiation of supports;
- contracted or directly employed/purchased: supports provision; and
- role of the individual: control over support.

This structure is presented in Figure B. on the next page (Bigby, 2007).

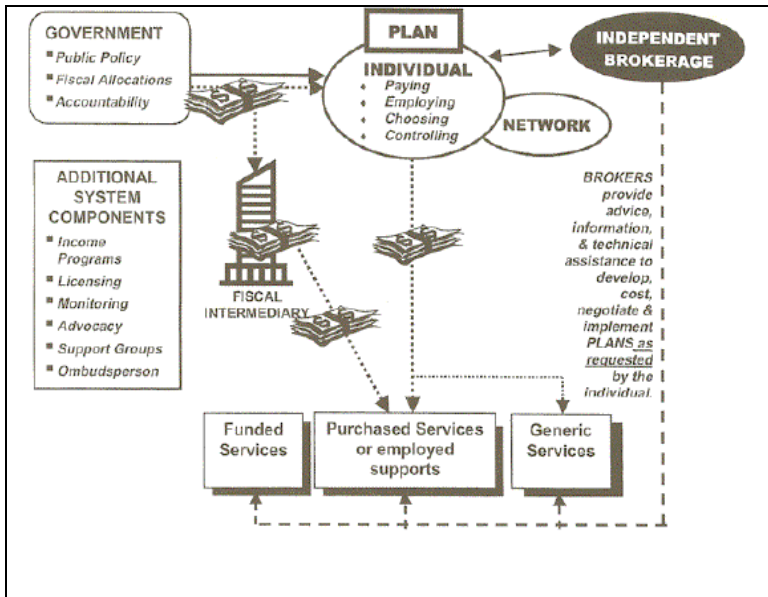


Figure B. Governance structure for IF (Bigby, 2008)

The inclusion of case managers/facilitators to plan, select and manage supports is recommended, starting at the planning phase (Dowson & Salisbury, 1999).

IF is a principle that enables a number of different models/types (Bleasdale, 2001a). Examples of these approaches include:

Direct Payments is a system whereby people with disabilities have the funds they require to purchase supports paid to them, and it is largely up to them which providers they use and which types of support they have access to. The money can be paid directly to the person, to purchase supports, and they are responsible for location, employment, management, accounting; or the money can go to a fiscal intermediary, such as a Microboard, to purchase supports as directed; as well as to do the administration and paperwork (Bleasdale, 2001b; Clements, 2008).

A Microboard is formed when a small group of committed family and friends join and form a non-profit society around a person who has particular needs for support (National Council on Disability, 2005). The group addresses the person's planning and support needs in a way that ensures maximum control by the person for whom it is created. Some jurisdictions have created Microboard associations to assist families. These associations provide development, support, and training.

Cash and Counseling: Although models vary, the essence of cash-and-counseling programs is that *Cash and Counseling* gives consumers a monthly allowance that they may use to hire workers, and to purchase care-related services and goods (Brown, Carlson, Dale, Foster, Phillips & Schore, 2007).

Consumers can get help managing their care by designating representatives, such as relatives or friends, to help make decisions. It also offers counselling and book-keeping services to help consumers and representatives to handle their program responsibilities.

In Control: This model was established in the UK in 2003. It provides a range of information and support to people with a disability and families about self directed supports, individual budgets and new ways of delivering funded support through processes of critical enquiry, dialogue and collaboration. It has been rapidly expanded to other countries and started in Australia in 2008.

Case Study - Direct payments in Canada

North Shore Disability Resource Centre, 2005:

IF program in British Columbia: Choices in Supports for Independent Living (CSIL)

The CSIL program is offered to consumers of home support services through the Health Authorities in each region of the province. CSIL was established in 1993 with the input of people with disabilities and is designed for individuals who wish to exercise more choice and control through purchasing and managing their own home support services.

Once an individual has been assessed by a case manager from the nearest office of their regional Health Authority and been approved for CSIL, the funding that would normally go to a service provider agency to provide the home support goes directly to the consumer. Currently this means that \$25.00/ hour of allowable home support is deposited directly into a separate bank account that is set up under the individual's name but specifying that it is for CSIL (for example, John Smith - CSIL) . Here is an idea of how it works in practice:

John is assessed as needing 4 hours of home support/day. This means \$100.00 of funding/day. Based on a 30-day month, \$3,000 will be transferred to John's CSIL account each month. Using this \$3,000 John will hire, manage and pay his own support workers to meet his care needs.

Under the CSIL program, individuals cannot use service provider agencies except in the case of emergencies. They must assume the responsibilities of being their own employer. Each Health Authority has a standard contract, which individuals or client support groups must sign and which is renewed on a yearly basis. Individuals who, because of their disability, cannot manage their support independently can still use CSIL if there is a group of family and friends who are willing to form a client support group. A client support group consists of a minimum of 5 committed individuals who form a non-profit society in order to provide the coordination and management of the CSIL option on behalf of the person with a disability. A third option for direct funding Under this program, individuals are responsible for all aspects of home support management except the payroll functions. These functions are handled by a designated agency.

Case Study - Microboard in USA

National Disability Council, 2005:

The Self-Directed Support Corporation (SDSC) model was established in 2001 by the Inclusion Research Institute (IRI). The SDSC model was created to adapt the concept of the Microboard to the legal, regulatory, and service delivery system for people with developmental disabilities in the United States. The U.S. adaptation was developed using existing service delivery components that are widely accepted in the disability community. The foundation of the SDSC model is six building blocks that interlock to form a foundation on which people with disabilities and their families can strive to build a life that offers real opportunities for security, dignity, and contribution. These building blocks are personal support; person-centered planning; responsive and flexible individual assistance; individual funding; transition of existing services; and community development. Supports are designed using the principles and tools of self-determination to meet the individual's unique support needs.

From a service perspective, the SDSC model and similar small boards serve as independent incorporated nonprofit entities, established to negotiate, receive funds, organize, and manage supports around one person and/or the person's family. In addition, the SDSC serves as a personal support circle. The state funds the SDSC directly. The SDSC is the employer of record and independently purchases the goods and services it needs, just as the members of an ordinary household would purchase the goods and services they need. The SDSC has complete freedom as to where and from whom it purchases goods and services. For example, if the SDSC wants to purchase payroll services rather than spending its time doing the payroll, it can purchase that service from a bank, a commercial payroll service, or a private bookkeeper, or it may join with other SDSCs to form a cooperative payroll service. If the SDSC doesn't like the service it is receiving, it can change the source at will, just as an ordinary family may change lawyers or change banks. An SDSC becomes the administrative body of the resources that the person with the disability requires. It differs from traditional support services because the board members (together, the provider) serve only one person. Because support services are provided to only one person, states may choose to be more flexible with regulations. However, an SDSC must follow the accounting requirements of both the Federal Government and the state government. It undergoes yearly audits to ensure accountability to both of these entities. It is subject to the same audits and reviews by state agencies as any other licensed service provider. It also must follow labor laws and nursing regulations. Currently, there are approximately 100 SDSCs (or some form of this model) across the United States. The numbers are growing rapidly, with about 75 more SDSCs in some phase of exploration or start-up.

Indirect Payment via Intermediary or Broker: Brokerage refers to a process whereby a person with a disability employs a person to assist them with the processes of planning, getting resources and then hiring and reviewing the quality of service providers (Bleasdale, 2001a). The function of brokerage, is separate from support provision.

Some people who require support may, for all sorts of reasons, prefer to receive their services from agencies funded by block grants, and it would be contrary to the values on which IF is based to deny them their choice (Dowson & Salisbury, 1999).

Figure C. below, from Dowson & Salisbury, 1999, shows the continuum of models of IF:


 <p>CONTROL WITH STATE FUND-HOLDER</p> <p>CONTROL WITH INDIVIDUAL</p>	Individual service costs identified, but only as accounting exercise within block-funded services.	ARRANGEMENTS WHICH DO NOT CONFORM TO THE PRINCIPLES OF INDIVIDUALIZED FUNDING
	Services costed and allocated individually, but assessed and controlled by fund-holder.	
	Standard allocation of vouchers issued to individuals for 'purchase' of services.	
	Individually determined credits which individuals can trade for services from authorized providers.	ARRANGEMENTS WHICH ARE MARGINALLY CONSISTENT WITH IF.
	Responsibility for service planning and funding requirements notionally passed to the individual, but overseen by 'broker' answerable to state fund-holder.	
	Individual allocation remains in hands of state fund-holder, but spent according to the person's requirements, subject to contractual constraints from state fund-holder.	ARRANGEMENTS WHICH ARE FULLY CONSISTENT WITH IF.
	Individual allocation passed to fiscal intermediary, to be spent according to the person's requirements, but subject to contractual constraints from state fund-holder.	
	Individual allocation of money passed to the individual, subject to binding conditions of use, with monitoring arrangements.	
	Individual allocation of money passed to the individual with no imposed conditions of use.	

Figure C.

Research shows that there are considerable benefits for users of direct payments, arising from greater flexibility, choice, independence, continuity of support, customizing of care packages and so forth (Carmichael & Brown, 2002; Clark, Gough, & Manfarlane, 2004; Commission for Social Care Inspection, 2004; Dawson, 2000; Leece, 2000 & 2001; Leece & Leece, 2006; McMullen, 2003; Stainton & Boyce, 2004). Individualized funding arrangements in which the funds themselves are handed over to the person (as in the UK Direct Payments system) offer the greatest level of control and freedom to the individual (Dowson & Salisbury, 1999)

Costs

Stainton (2009) reports that the evidence on cost and resource implication of IF is somewhat limited, and in his paper reviewing costs of schemes internationally, reports that the majority of evidence across jurisdictions supports better outcomes (cost/benefit) with IF over conventional systems without significant cost differentials. There is also some indication from a variety of studies that IF is either cost-neutral or cost-efficient, when compared to traditional ways of funding (Dawson, 2000; Stainton and Boyce, 2002).

Recently, research in the US conducted by Dale and Brown (2007), compared the cost of a consumer-directed model (Cash and Counseling) of personal care services or home- and community-based services, to traditional models of care. The findings showed that costs were generally higher under the introduction of the Cash and Counseling because those service users in the traditional system did not get the services they were entitled to. Compared with the treatment group, control group members were less likely to receive any services at all, despite being authorised to receive them, and traditional service recipients receive a lower proportion of the amount of care that was authorised. Additionally, the increase in cost from the traditional mode of service to the consumer-directed model was attributed to: increases in the number of recipients; agency worker shortages, particularly in rural areas; and reassessment procedures which made the treatment group more likely than traditional recipients to receive increases in their care plans during reassessment (Dale & Brown, 2007).

The Research and Training Centre on Community Living (2009) study states that most states have done little, if any, analysis of data, making accurate cost comparison data scarce and unwieldy.

The consumer-directed services in Texas are cost-neutral by design. In Texas, a study was conducted by the state Health and Human Services Commission on their consumer-directed model (Texas Health and Human Services Commission, 2004). The cost-effect analysis found that the consumer-directed option costs \$161.39 more per recipient per month than the non-consumer-directed option. Follow up study revealed that increased utilization of authorized services accounted for 60% of the cost difference. Adjusting for utilization differences, the cost discrepancy was reduced to \$65.96 per recipient per month.

The national evaluation of the Individual Budgets pilot programme in the UK found that the average gross value of an Individual Budget was £ 11, 450. This varied by service user group: £11 150 for people with physical disabilities; £ 18 610 for people with learning disabilities; £5 530 for people with mental health problems; and £7 860 for older people (IBSEN, 2008).

Vizel (2009) reports that figures for 2006-07 indicate that the vast majority of individual packages allocated in Victoria (77%) are smaller than \$10 000 per year for one individual and only 1% of all individualised support packages provided by the Department of Human Services exceed \$55 000 (Victorian Auditor-General, 2008)

Concerns related to IF/self-directed care

The literature has identified a range of concerns and/or barriers for stakeholders (Carmichael & Brown, 2002; Clark & Spafford, 2002; Clements, 2008; Commission for Social Care Inspection, 2004; Dawson, 2000; Dowson &

Salisbury, 1999; Ellis, 2007; Glasby & Littlechild, 2002; Hasler, 2003; Hasler & Zarb, 2000; ; Lomas, 2006; Leece & Leece, 2006; Maglajlic, Brandon, & Given, 2000; Nucleus Group, 2002; Pearson, 2000; Powers, Sowers & Singer, 2006; Spandler & Vick, 2005; Stainton, 2002; Stainton & Boyce, 2002 & 2004; Brown et al, 2007), as follows:

- **The “unbundling” of block-funded services, when implementing a new approach.** The establishment of both individual service rates and the accounting mechanisms necessary to track individual budgets and manage service billings is difficult for many systems.
- **Measuring and maintaining standards.**
- **Considering payment to family members.** Concerns persist about this issue, such as increasing the dependency between the carer and the person receiving care, and providing opportunity for abuse or overprotection
- **Ongoing service viability.**
- **Complexity of the system.** Person-directed and IF systems are not simple and can be more complex for individuals and their families to navigate. People with disability should be able to choose the level of self-sufficiency they need and are comfortable with, from traditional agency based services to self-management . Research, inadequate support for people to use cash payments, unnecessary paperwork and too much bureaucracy.
- **Uneven uptake across different groups** Several studies of direct payments have highlighted that users are younger, more disabled individuals with higher levels of benefit income, which reflects their disability. This is also linked to the issue of front line negative discretion in determining access, particularly social workers.
- **Dealing with crisis situations.** Another issue raised by service providers concerns how they will deal with crisis situations, with the implementation of individual budgeting arrangements.
- **The management of financial risk for service users.**
- **Making sure brokerage systems are effective.**
- **Accountability for spending of funds.** Concerns in several jurisdictions have included the overemphasis on surveillance that spending is for “correct” purposes countered by equally compelling arguments for strict accountability of tax payers money.

In summary, approaches to individualised funding have been the subject of a significant number of critical analyses and reviews to date. The next section of this report discussed features of *effective* approaches to funding and service delivery for people with disabilities that address the concerns above.

Features of *effective* approaches to funding and services and supports delivery

A range of international literature agrees on common features listed below, particularly relating to IF and support. (Bleadsale, 2001a & b; Cambridge & Ernst, 2006; Disability Reform Group, 2002; LDC Group, 2007; Lord & Hutchison, 2003; The Nucleus Group, 2002; Powers, Sowers, & Singer, 2006; Standing Committee on Community Affairs, 2007; Smith, 2001):

1. A good system for allocation of individualised funds, linked to person-centred planning for support needs. Person-centred planning is a process directed by the individual that is used to identify his or her strengths, capacities, preferences, and needs and the supports that will be provided to meet those needs. The person-centered planning document also provide the criteria against which the adequacy and appropriateness of services and supports are measured (Mosely, Gettings & Cooper, 2005). Smith & Fortune (2008) state that if funding does not reflect support needs, then it will be impossible to achieve critical goals for individuals.

Promising systems have been highlighted such as the creation of Adjudication panels that makes allocation decisions for funding and then releases the money to individuals. A system in Wyoming, called the DOORS system, which links specific needs to IF allocation, allows for making individual resource allocations on a person-by-person basis that are both flexible and portable (Smith, 2001). The central features of Wyoming's system are:

- An exemplar methodology (the DOORS system) for making individual resource allocations on a person-by-person basis, that are flexible and portable;
- Clear assignment of the authority to make decisions about services to planning team that supports each individual;
- The authority for individuals to select their own service coordinators;
- Adherence to the principle that individuals and families have free choice of service providers; and,
- Policies that encourage new providers stepping forward to offer supports to individuals (Smith, 2001).

The establishment of risk pools, service cooperatives, and flexible mechanisms for service redetermination hold promise for minimising customer' financial risk. Reviews of spending plans and monitoring of check requests and time sheets limited incidences of fraud, abuse of the funds, and abuse of consumers to a handful of cases.

IF provides an important accountability mechanism via the funded individual plan, to ensure that public tax dollars are being spent effectively/efficiently, thus reducing the need for expensive and external monitoring and accreditation schemes (Advocates and Families from South Fraser, North Shore and Capital regions, 1998. When the government approves the plan (developed by the person with a disability and his/her chosen supporters and advisors) the individual enters into a contractual agreement with government concerning the expenditure of the allocated funding. This contract commits the individual to spend the funding to meet *only* those needs that have been identified and budgeted for during the planning process.

2. Allocation of some block funding to build capacity of services, when implementing IF and self-directed support.

Canada's *Social Development Partnership Program* (SDPP) is a good example of this. SDPP (Human Resources and Social Development Canada, 2007) plays a role in furthering broad social goals through grants and contributions, to strengthen the capacity of the social non-profit sector.

Grants may be provided to national non-profit organisations to help increase their capacity in the areas of government, policy and program development, community outreach, organisations administration and management.

Western Australia also provides for the funding of set-up costs for option establishment for Individual Funding, for certain program areas.

It is generally accepted that somewhere between 75 - 80% of agency costs are related to direct staffing costs of serving individuals. Thus the concept of an 80/20 or 85/15 mixed funding model has emerged for consideration (Dowson & Salisbury, 1999; Young, 2000). In such a model, government block funds the agency's infrastructure costs (fixed costs) and individualizes the funding for the direct service to clients (variable costs). The other 80 or 85% of operating revenues are supplied to individuals.

Additionally, a possible response to the issue of providing for crisis funding is to either have a crisis component funded as a percentage of each individual plan, or to make a crisis budget available to agencies (or individuals) which could be quickly accessed via negotiations with government.

3. Local area coordination, so that local needs and preferences shape local services.

This approach is used currently in Sweden, the UK, Western Australia, Queensland, Australian Capital Territory, Northern Territory and some provinces in Canada (Nucleus Group 2002; Lord and Hutchison, 2003). In the UK, central government is increasingly moving towards giving greater freedoms and flexibilities at a local level. The UK has recently introduced Local Area Agreements (LAAs), where central government will be working to improve co-ordination with local authorities and local partners. It is thought that LAAs will simplify funding streams, help join up public services and allow greater flexibility for local solutions for particular local circumstances (Leece & Leece, 2006).

Chenoweth and Stehlik (2002), in an evaluation of the Local Area Coordination Pilot Program in Queensland concluded that the impact of LAC has been to safeguard people's preexisting capacities for independence and self-sufficiency and to further build supports around people that increases that capacity. They also identify that the LAC program represents one of the lowest budget items of DSQ; and that in comparison with other DSQ programs, LAC offers highly cost effective support.

4. Implementation in phases by using a particular amount of people or geographical area, with the use of independent pilot/demonstration sites.

Lord and Hutchison (2003) found that the most coherent implementation of policy utilised both piloting and phasing, which allowed maximum opportunity for evaluation, learning, and change. If a focus on training and the motivation of front-line support staff is taken, Initiatives are implemented quicker (Bleadsale, 2001a & b; Lord and Hutchison, 2003; Cambridge and Ernst, 2006).

The Federal Department of Health and Human Services issued a final rule in October, 2008, which provided guidance to States that want to administer self-directed personal assistance services through their State Plans for medical assistance. The State Plan option allows beneficiaries, through an approved self-directed services plan and budget, to purchase and control personal assistance services. The rule provides guidance to ensure beneficiary health and welfare and financial accountability (Department of Health and Human Services, 2008).

Case Study – Implementation in Canada

Advocates and Families from South Fraser, North Shore and Capital regions (1998)

Our proposal to implement *Individualized Funding* includes the following:

- Individualized Funding
- Information and Planning Support Centres (funded by business and civic groups)
- Crises Response Fund
- Re-negotiation of Global Budgets Currently held by Service Providers
- Contingency Funds for Service Dislocation
- Independent Evaluation: The evaluative framework should focus on outcomes identified by individual plans and be principle driven.

Government would provide developmental dollars for 25 people in each of 3 regions of the province at a cost of \$1.25 million per region (\$3.75 million total for the 3 regions; Median cost of \$50 000 per person.) These are individuals government would be required to support. In addition, 25 people per region would be assisted to convert their portion of global budgets, now held by community agencies, to Individualized Funding. Participants in either of these initiatives would be able to obtain information and practical planning supports throughout the process of identifying and meeting their needs through regionally-based Information and Planning Support Centres. Information and technical support to develop, negotiate and implement each individual's plan will be provided by regionally based Information and Planning Support Centres.

These *Centres*, funded by business and civic groups, would operate separate from government and service delivery agencies, and at the discretion of those individuals and families. These Centres would operate independently of government and service providers, be funded by business and civic groups, and would have a cross disability focus, zero rejection philosophy, an advisory (rather than decision making) role in people's lives, and be available over time as needed.

People converting global funding to Individualized Funding, may retain current service provider arrangements or choose new arrangements.

The individual (and chosen representatives) will develop and submit to government, a personal plan identifying needed services, supports and associated costs, that will be reviewed as circumstances warrant and renegotiated, if necessary. Individuals will provide periodic reports and accountability statements.

Government will retain authority to make decisions about fund allocation(s) and monitor their expenditure. A monthly total, representing the aggregate of *Individualized Funding* contracts signed by government for that period, will be electronically transferred to a recognized financial institution such as *VanCity Savings & Credit Union*. The institution will disburse funds to community service providers as directed by the individual's plan. Thus the Ministry will deal with a minimum number of established financial institutions for dispersal of funds.

5. Provision of Infrastructure supports (e.g. service brokerage; fiscal intermediaries; and case managers) separate from the service system.

The implementation of appropriate systems to assist consumers to manage their own funds must be separate from the service system. There are two major reasons for ensuring the independence of brokers from both service providers and government (Bleasdale, 2001b):

- brokers must assist the person with disability to conceptualise their needs and requirements, and help to develop a plan that is described from the person's

view, and not from the view of those who have services to fill (i.e. service providers and funding bodies);

- people with disabilities must have the option of hiring or not hiring a broker, and also have the option of dismissing a broker if they are not satisfied with her/his work.

This includes the role of brokers/facilitators as separate to case managers, which frees up services to focus on service delivery to the person rather than program and service issues. Manageable caseloads for service providers are another aspect, as intensive work such as one-to-one contact is often highly effective (Nucleus Group, 2002). It has been highlighted that case manager or facilitators are essential to help negotiate the system (Nucleus Group, 2002; Robertson, et al, 2007) with a capped caseload (e.g. 15-20).

Lord and Hutchison (2003) found that a broker, facilitator, or network builder was vital to the individualised process and was free of conflict of interest from service providers and government. Projects emphasised that not having facilitators attached to the service system enabled them to put all their energy into supporting the person and family as opposed to being concerned with program and service issues. Additionally, people with disabilities may need education and training in order to participate fully, for example financial literacy programs such as the US Federal Deposit Insurance Corporation Money Smart curriculum, that offer beneficiaries information and financial resources (National Council on Disability, 2008b).

Developments in IF in the UK recently have been directed towards increasing the uptake of IF arrangements by people with impaired decision making capacity. Legislative reform has been designed to remove policy barriers to people with impaired decision making capacity accessing IF options (Her Majesty's Stationary Office, 2008). Arrangements for people with impaired decision making capacity to be involved with IF include (Department of Health, 2004):

- allowing for direct payments to be made to a third party;
- the development of safeguards against the risk of abuse by third parties, such as independent advocacy services and decision making tools to show transparency in decision making; and
- the introduction of a range of options for supporting people with impaired decision making capacity to articulate their choices, and to manage the administrative arrangements of IF, through mechanisms such as: Independent Living Trusts; Independent Living Advisors; Advocates; and Care Managers.

Bigby and Fyffe (2009) state that mechanisms for supported or distributed decision making as well as more formal substitute decision making are central to the implementation of IF for people with intellectual disability so the processes used for making the range of choices necessary in a persons life are transparent.

It is also imperative that efforts be made to build capacity for people with a disability and families to develop a vision for how their life might be different and how change can be facilitated as well as the mechanisms of administration, accounting and decision making.

6. Minimising bureaucracy

The minimisation of bureaucracy for service users and their families assists in participation of people with disabilities. Kendrick, Bezanson, Petty, Jones (2006) state that Administrators should consider carefully risk management and restrictive, unnecessary control.

7. Alternative quality systems to those based solely on organisational frameworks.

The paradigm shift to individualised supports and person-centred planning has been accompanied by a shift in how we assess improvement and change (Ontario Federation for Cerebral Palsy, 2000). The new approaches to support are natural candidates for moving beyond traditional professional and managerialist outcome measures to more user-defined ones (Glynn et al., 2008). Gardner & Carran (2005) state that the state-of-the-art in quality measurement have moved beyond documentation of compliance with internal process and external standards and the tabulation of organisational process outcomes. Needs to be person-centred quality assurance based on responsiveness to the person serviced rather than compliance with process (Gardner, 2000)

The literature increasing highlights that quality of services needs to be determined by service users, with a service user outcomes focus (National Council on Disability, 2008a). Parmenter & Arnold (2008) note that there has been a shift from the quality of care focus, to a quality of life focus for service delivery, as presented in Table 1. below.

	Quality of care focus	Quality of life focus
Perspective	Provider	Person in his or her natural network
Interest	Process	Outcomes
Content	Management of care systems	Support and its effects on a personal life
Typical criteria for evaluation	Efficiency, cost-effectiveness, planning, consumer satisfaction	Long-term value-based outcomes on inclusion, personal development, and self-determination
Structures	Actual care systems only need improvement	Support needs to serve a person's case, even if this means that alternative structures have to be found

Table 1: Essential differences between a quality of care versus quality of life focus Parmenter & Arnold (2008)

Two sets of service standards that encapsulate an inclusion approach to people are presented below.

Victoria's new quality Framework

The Standards for Disability Services in Victoria (Standards) set out the expectations of better practice for the delivery of services and supports to people with a disability. In 2007, the Outcome Standards for Disability Services (Outcome Standards) were introduced into the Quality Framework. The Quality Framework maintains the standards introduced in 1997 as the Industry Standards for Disability Services (Industry Standards). Together these set out the expectations of better practice for the delivery of services and supports to people with a disability (Department of Human Services, 2009).

The Outcome Standards describe what is important for people with a disability as citizens. The Quality Framework identifies sixteen Life Areas. Each life area is defined by an outcome. Defining these outcomes enables a consistent understanding that services can support people with a disability to experience the same outcomes that are valued by the broader Victorian community (Appendix C). Examples of outcomes resulting for people include improved emotional well-being, economic circumstances, health, knowledge and skills, social status, and customer satisfaction (Department of Human Services, 2009).

The Industry Standards describe the systems and processes to support people to achieve outcomes and safeguard the rights of people with a disability, their family members and carers. A set of evidence indicators details the expectations for compliance with each standard and provide a level of consistency with other quality frameworks. These indicators include detailed descriptions of what services and supports actually look like against each standard (Appendix B).

In Alberta, Canada, the Council of Disability Services has the *Creating Excellence Together* (CET) standards (Alberta Association of Rehabilitation Centres, 2005). The CET standards are created around three major Areas:

- *Quality of Life* standards (based on feedback from service users), which are outcome based;
- *Quality of Service* standards, which are intrinsically inked to the *Quality of Life* standards, by looking at the role of staff who are closest to the individuals, and how those staff support the individual to achieve each of the *Quality of Life* standards; and
- *Organizational Framework* standards, in the areas of service delivery, human resources and strategic management that reflect current best practice. Each standard under Organizational Framework directly supports one or more of the *Quality of Life* standards (Appendix D).

8. Increased access to mainstream services, and increased capacity of mainstream services to respond to specialised needs.

In the same way that the general population use a variety of services and resources to maximise independence, so should people with disabilities. This includes targeted initiatives that work in partnership with universal and

mainstream provision. Mainstream public services can be used to reach out to disadvantaged groups, and be integrated with or provide a gateway to targeted or specialist services. Providing services within a 'universal' approach enables the provision of intensive help for the most disadvantaged clients without drawing particular attention to them, e.g. a 'windscreen' approach to delivering services, with universal services on one side and acute services on the other. This includes co-locating services and wrapping 'stigmatised' services into other provision (Social Exclusion Taskforce, 2004).

Dowson & Salisbury (1999) state that IF should allow people to obtain the support they require from whatever source suits them best, and to encourage creative use of funds - for example by making use of mainstream community services. Evaluation of some programs indicates that reductions in support costs under IF are often achieved in this way.

Bigby and Fyffe (2009) state that access to mainstream health, housing, transport, education, leisure and community services and community infrastructure is critical to the success of IF.

9. Best practice approaches underpinning the system and models of service delivery to maximise the outcome potential for service users (Kendrick, Bezanson, Petty, Jones, 2006).

10. Blended formal and informal supports

Informal supports can provide rich possibilities for meeting the needs of service users (Kendrick, Bezanson, Petty, & Jones, 2006). Examples include having a neighbour shop for groceries, or having a family member assist with cooking or grooming. The research evidence suggests that the quality of informal supports can be integral to a comprehensive package of supports (Nucleus Group, 2002). Bleasdale (2001b) states that the promotion of individual planning which enable the greater involvement of existing community, local and family resources, can lead to less reliance upon a specialist service sector.

International standards that could be adapted or developed for funding and/or support services/service delivery

There are limited international standards that provide guidance for funding services or for delivering services for people with a disability. Only *The Seattle 2000 Declaration On Self-Determination & Individualized Funding* (First International Conference on Self-Determination and Individualised Funding Attendees, 2000) has some principles for implementation of individualized funding (Appendix E).

The new United Nations *Convention on the rights of persons with disabilities and optional protocol* is a broad statement of human rights, covering a number of key areas such as accessibility, personal mobility, health, education, employment,

facilitation and rehabilitation. It provides a normative framework for social policy, without prescribing exact features of domestic disability policy.

Some work has been underway in Queensland through Queensland Advocacy Inc developing a set of human rights indicators for people with disability. The overall aim of this project is to make visible the relationship between the lived experience of persons with disability and the international human rights standards accepted by the Australian Government. These indicators are designed to be an objective measure of the degree to which persons with disability enjoy (or experience) a particular human right or freedom. This work could usefully inform future development of international standards for funding and support approaches for community living.

Discussion

Based on the work reviewed to date in this project, there are several recommendations for how to proceed further towards implementing new approaches. These include:

- policy and programs be developed and implemented that deliver funding for the disability sector via individual allocation, based on assessed need, with a variety of support mechanisms to enable individuals to control the spending of resources and the delivery of supports. Disability Services Queensland is currently developing new processes for determining need and allocating funding through its *Growing Stronger* initiative. The findings from this project may be a useful resource for further work in this area.
- The potential for expanding the LAC system that is currently in place in Queensland to address needs across the state warrants further investigation. This is currently available in regional, rural and remote areas but may have application in urban centres. The evaluations of existing WA LAC models would be useful in determining possible expansion strategies and which safeguards ensure better outcomes for people with a disability and families.
- The new Victorian model while still untested in the long term, should be further explored and reviewed.
- The rollout of IF approaches require a sound investment in building the capacity of people with a disability and families to vision, plan, manage and monitor supports and funding. This will require programs that develop ideas, knowledge and skills. These need to range from providing initial training and periodic review through to agencies that manage funding and resources on behalf of others.
- One way to trial initiatives in IF in Queensland, would be to establish an Innovative Options Initiative, whereby a number of approaches to IF would be piloted, tested and evaluated. This would be developed with the non-government sector in Queensland.

- It is also necessary to build the capacity of mainstream services, via education programs about the needs of people with disability and their families, or incentive programs

Conclusion

This report presents the current international and national trends in approaches, and features of effective approaches, to both funding services for people with a disability, and service delivery for people with a disability. The Queensland context is compared with other Australian jurisdictions, and the UK, Canada, the US, Europe, and Scandinavia. The report addressed the following questions: *What internationally acknowledged standards could be adapted or developed by which to determine the most effective, equitable and just funding and service approaches in Queensland?*

How might these approaches be implemented in practice in the Queensland context?

During the latter part of the 20th century, the concept of disability moved toward a strong emphasis on personal rights and desired personal outcomes. The research identified the overall emergent trends in funding and service options for people with disabilities are:

- Self-directed care/Self-determination/Individualised funding (IF) , and
- Independent living with services provided in the community.

The key features of effective approaches to these trends, as identified from the research are:

- A good system for allocation of individualised funds
- Allocation of block funding to services, when implementing IF and support
- Local area coordination, so that local needs and preferences shape local services
- Implementation in phases
- Provision of infrastructure supports, which are separate from the service system
- Minimisation of bureaucracy
- Implementation of alternative quality systems
- Universal access: Increased use of mainstream services
- Use of best-practice models, and
- Utilising a blend of formal and informal supports.

This whole field of funding and supports is rapidly changing and new models and approaches are constantly emerging. Some caution is perhaps warranted here. Many approaches are as yet untested and have not been fully scrutinised. The long term outcomes are also as yet unknown. As with any new policy there is likely to be unintended consequences that emerge over time. However, early

indications are positive. The research findings that are available are optimistic and suggest that these approaches are a way forward for the forthcoming decades.

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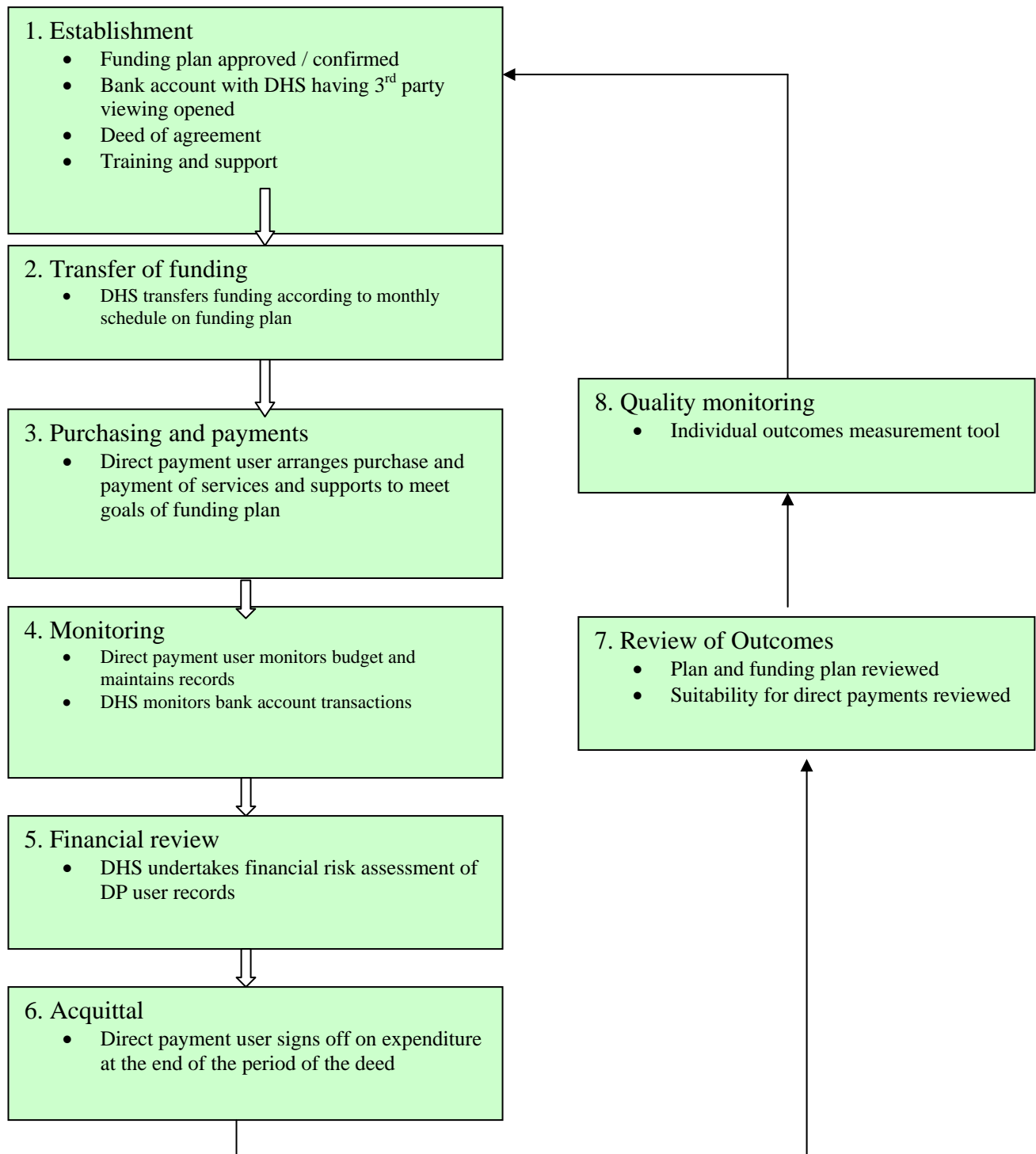
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Appendix A

Model of direct payments to be trialled in Stage 2, Direct Payments Project, Victoria (LDC Group, 2008)



Appendix A (con't)

Funding Administration Arrangements Roles and Responsibilities Victoria Department of Human Services (2008)

Function	Option		
	Registered disability service provider	Financial intermediary (FI)	Direct payments
Funding proposal	Person with a disability acknowledges conditions, role and responsibilities re funding allocation.	Person with a disability acknowledges conditions, role and responsibilities re funding allocation.	Person with a disability acknowledges conditions, role and responsibilities re funding allocation.
Agreement	DHS Service Agreement with disability service provider.	DHS agreement with FI and with the person or their representative.	DHS agreement with direct payments user or their representative.
Transfer of funding	Via Service Agreement.	Via Agreement to FI. Some regions currently provide the FI function.	Funding transferred to separate bank account established for purposes of direct payments.
Purchase or provision of services	Service provider provides services in consultation with the person with a disability based on the plan.	Person with a disability or representative arranges the purchase of services and approves invoices for payment by FI.	Direct payments user or their representative arranges purchase of services.
Monitoring	DHS monitors service provider. Service provider monitors budget.	FI provides information to the person so they can monitor expenditure against their plan. FI reports expenditure to DHS.	DHS monitors direct payments. Person with a disability or their representative is responsible for monitoring budget.
Quality	Person with a disability monitors quality of services. Service provider must comply with DS Quality Framework.	Person with a disability monitors quality of services including FI performance.	Person with a disability monitors quality of services.
Performance reporting	Service provider is accountable to DHS through DHS reporting/data collection.	FI is accountable to DHS through reporting and data collection and to person with a disability through reporting.	Person with a disability maintains records and is accountable to DHS. DHS undertakes reporting based on funding plan.
Review	Service provider responsible for ensuring support plan review. Includes consideration of funding administration arrangement.	Representative responsible for ensuring support plan review. Includes consideration of funding administration arrangement.	Representative responsible for ensuring support plan review. Includes consideration of funding administration arrangement.

(May change pending further development of the Financial Intermediary service model)

Appendix B

Victorian Standards and Indicators - (LDC Group, 2008)

Outcome Standards

Individuality - each individual has goals, wants, aspirations and support needs, and makes decisions and choices about their life

Capacity - each individual's abilities and potential are identified and encouraged

Participation - each individual is able to be part of his or her community

Citizenship - each individual has rights and responsibilities as a member of the community

Leadership - each individual has the opportunity to inform the way that supports are provided

Industry Standards

Service Access: Fair and equitable practices that are consistent with funding obligations, applicable legislation and purpose of the service are applied when managing and allocating resources

Individual Needs: Planning and support is tailored, flexible responsive and appropriate to the individual and addresses the core needs for which the individual sought support

Decision Making and Choice: Support options are planned, developed, implemented and reviewed in a manner that is responsive to the decisions, choices, and aspirations of individuals

Privacy, Dignity and Confidentiality: Privacy, dignity, and confidentiality is respected and maintained

Participation and Integration: Support options are planned, developed, implemented and reviewed in a manner that build opportunities for individuals to participate in the life of the community

Valued Status: Support options are planned, developed, implemented and reviewed in a manner that recognise the skills, abilities and potential of individuals and enable the achievement of valued roles in the community

Complaints and Disputes: Complaints and disputes are addressed promptly, fairly and respectfully without compromising services to the individual

Service Management: Management and governance practice is sound, accountable and consistent with current disability support policy and practice

Freedom from Abuse & Neglect: Supports are provided in safe and healthy environments that support individuals to exercise their legal and human rights

Evidence indicators

Sixteen life areas have been developed to assist service providers to focus on the things that are important to people with a disability and their family members and carers.

A suite of evidence indicators of the Outcome Standards has been developed for each of the 16 life areas. These evidence indicators describe measurable elements of practice that may be used to assess whether the support is in place to assist people with a disability achieve the outcome. These outcomes are reflective of those valued by the broader Victorian community.

Outcome Standard 1: Individuality	
Each individual has goals, wants, aspirations and support needs and makes decisions and choices about their life.	
Please note that the numbers on the left side of each indicator show how they will be cross-referenced with one of the 16 Life Areas in the Quality Framework for Disability Services in Victoria (2007).	
1.3	People with a disability are supported to identify, choose and realise goals that relate to their education, training and learning interests.
1.4	People with a disability are supported to understand about learning, development and education options and issues, such as further education, leadership and mentoring opportunities and volunteering.
3.1	People with a disability are supported to make choices and decisions about their life.
3.2	People with a disability are supported to identify, choose and manage their own daily and lifestyle routines.
3.4	People with a disability are supported to access an independent support person to assist them with decisions and choices.
4.3	People with a disability are supported to stay safe according to their needs and wishes.
6.1	People with a disability are supported to identify their own values, needs and reasons for seeking support.
6.7	People with a disability are supported to access information about other services and supports that may be able to assist them.
7.3	People with a disability are supported to use their preferred style, method or language when communicating.
8.1	People with a disability are supported to identify, choose and realise goals that

relate to their career and employment interests.
10.1 People with a disability are supported to live their lives in a manner that respects and supports their culture, language, religious and spiritual beliefs.
10.2 People with a disability are supported to maintain and share their life experiences, culture, language, celebrations, rites, music, history and all those things that give meaning to their lives.
10.3 People with a disability are supported to access information in community languages and culturally appropriate formats.
10.4 People with a disability are supported to use their preferred language when communicating.
10.5 People with a disability are supported to participate in arts and heritage activities, ceremonies and events that reflect their sense of personal and cultural identity and belonging.
10.6 People with a disability are supported to practise their cultural, religious or spiritual beliefs.
10.7 People with a disability are supported to maintain connections to family or cultural history and traditions.
10.8 People with a disability are supported to use their environments in a manner that supports and reflects their cultural identity and sense of belonging.
11.1 People with a disability are supported to identify activities and interests they enjoy.
11.2 People with a disability are supported to pursue hobbies and pastimes according to their interests and preferences.
11.3 People with a disability are supported to participate in recreational, leisure and sporting activities according to their interests and preferences.
11.4 People with a disability are supported to use their environments in a manner that reflects the activities and interests they enjoy.
12.1 People with a disability are supported to identify and realise priorities and goals to assist them exercise control over their living circumstances.
13.3 People with a disability are supported to participate in activities to regularly monitor and review their health and wellbeing.
13.4 People with a disability are supported to identify and realise personal goals to promote health and wellbeing.
15.2 People with a disability are supported to identify their financial priorities and budget constraints.

15.3 People with a disability are supported to choose and make personal purchases.

16.1 People with a disability are supported to identify and realise priorities and goals in relation to housing and accommodation.

Outcome Standard 2: Participation

Each individual is able to access and participate in their community.

Please note that the numbers on the left side of each indicator show how they will be cross-referenced with one of the 16 Life Areas in the Quality Framework for Disability Services in Victoria (2007).

2.1 People with a disability are supported to use facilities, resources and services in the community that reflect their interests and preferences.

2.2 People with a disability are supported to participate in a range of recreation, leisure and sporting activities in the community that reflect their interests and preferences.

2.3 People with a disability are supported to participate in a range of cultural events in the community that reflect their interests and preferences.

2.4 People with a disability are supported to experience a variety of social roles through membership and affiliation with cultural, recreational, leisure or sporting groups that reflect their interests and preferences.

2.5 People with a disability are supported to access educational opportunities in inclusive educational environments.

2.6 People with a disability are supported to access health services in the community.

2.7 People with a disability are supported to access information about their community.

5.1 People with a disability are supported to have contact with family and friends.

5.2 People with a disability are supported to extend hospitality to family and friends in their own homes.

5.3 People with a disability are supported to build new social networks.

12.4 People with a disability are supported to access natural areas and public spaces.

13.1 People with a disability are supported to participate in physical activity.

14.1 People with a disability are supported to access and use their

environments.
14.2 People with a disability are supported to experience personal mobility with the greatest independence.
14.3 People with a disability are supported to access mobility aids, equipment and assistive technologies and supports.
14.4 People with a disability are supported to access public transport.
16.2 People with a disability are supported to access a range of affordable housing options, including private rental, public housing programs and supported accommodation.

Outcome Standard 3: Capacity
Each individual has the ability and potential to achieve a valued role in the community.
Please note that the numbers on the left side of each indicator show how they will be cross-referenced with one of the 16 Life Areas in the Quality Framework for Disability Services in Victoria (2007).
1.1 People with a disability are supported to develop their life and social development skills.
1.2 People with a disability are supported to develop their artistic, creative and intellectual potential.
3.3 People with a disability are supported to access technology, aids, equipment and services that enhance their independence.
4.2 People with a disability are supported to understand what abuse and neglect is.
5.5 People with a disability are supported to understand issues that relate to healthy, constructive and respectful relationships, such as sexual health, family planning, parenting and domestic violence.
5.6 People with a disability are supported to access information about professional services aimed at promoting healthy, constructive and respectful relationships, such as counselling services, mediation and conciliation services and relationships skills courses.
7.5 People with a disability are supported to access information in formats that facilitate their understanding.
7.6 People with a disability are supported to access technology, aids, equipment and services that facilitate their preferred communication style.
7.7 People with a disability are supported to access advocacy organisations or

	individual advocates to assist them with communication.
8.2	People with a disability are supported to understand about employment options and issues, such as vocational training, volunteering, salary and conditions and workplace rights.
12.3	People with a disability are supported to access personal assistance, in-home, residential or community supports to assist them to live as independently as possible.
13.5	People with a disability are supported to understand about health and wellbeing issues, such as tobacco-related illness, the use of alcohol and other drugs, diabetes, sexual and reproductive health, nutrition and emotional wellbeing.
13.6	People with a disability are supported to access information about health professional services and supports, such as dentists, counselling, dietitians, allied health therapists and medical specialists.
15.4	People with a disability are supported to access information about consumer choice, such as shopping options, product advice and consumer protection.
15.5	People with a disability are supported to understand good financial management and budget practices.
15.6	People with a disability are supported to access information about affordable credit options, such as bank loans and mortgages.
16.3	People with a disability are supported to understand and access appropriately designed and located housing that enhances their independence.

Outcome Standard 4: Citizenship

Each individual has rights and responsibilities as a member of the community.

Please note that the numbers on the left side of each indicator show how they will be cross-referenced with one of the 16 Life Areas in the Quality Framework for Disability Services in Victoria (2007).

3.5 People with a disability own their own property and possessions.

4.1 People with a disability are not verbally, physically, sexually or emotionally abused, threatened, neglected or exploited.

4.4 People with a disability are supported to live in clean, safe and healthy home environments.

4.5 People with a disability are supported to access clean, safe and healthy support options.

4.6	People with a disability have their own space.
5.4	People with a disability are free to form consenting intimate relationships and express their sexuality.
6.6	People with a disability are supported to access an independent support person of their choice to assist them to choose supports.
7.1	People with a disability are supported to convey their ideas and opinions.
7.2	People with a disability are supported to express their feelings.
7.4	People with a disability are supported to access an accessible, transparent and documented system to lodge and resolve complaints and appeals.
8.3	People with a disability have access to promotion and career development opportunities.
8.4	People with a disability receive equal pay for equal work.
9.1	People with a disability are not discriminated against on the basis of gender, race, history, nationality, sexual orientation, personal identity, religious and spiritual beliefs and ethnicity.
9.2	People with a disability are treated with respect.
9.3	People with a disability are supported to exercise their rights and responsibilities in relation to accessing services and supports.
9.4	People with a disability are supported to exercise their rights and responsibilities in relation to personal privacy and dignity.
9.5	People with a disability are supported to exercise rights and responsibilities in relation to lodging a complaint or appeal.
9.6	People with a disability are supported to exercise their rights and responsibilities in relation to privacy and confidentiality of personal information.
9.7	People with a disability are supported to exercise their rights and responsibilities in relation to making decisions and choices.
9.8	People with a disability are supported to exercise their rights and responsibilities in relation to residential tenancy.
9.9	People with a disability are supported to access independent advocacy organisations or individual advocates.
9.10	People with a disability are supported to understand what to do if their rights are violated.
9.11	People with a disability are satisfied with the supports they receive to

exercise their human rights.
12.2 People with a disability are supported to access adequate and affordable food, clothing, energy services, medical care and social services.
13.2 People with a disability are supported to access, prepare and consume nutritious food.
15.1 People with a disability have access to an adequate income.
16.4 People with a disability are not isolated or segregated from the community.

Outcome Standard 5: Leadership
Each individual informs the way that supports are provided.
Please note that the numbers on the left side of each indicator show how they will be cross-referenced with one of the 16 Life Areas in the Quality Framework for Disability Services in Victoria (2007).
1.5 People with a disability are satisfied with the support they receive to experience lifelong learning and education.
2.8 People with a disability are satisfied with the support they receive to participate in the life of the community.
3.6 People with a disability are satisfied with the support they receive to experience individual choice and control over their life.
4.7 People with a disability are supported to understand issues that relate to staying safe, such as how to report abuse and/or neglect and occupational health and safety requirements.
4.8 People with a disability are satisfied with the support they receive to experience physical and emotional safety and be free from abuse, neglect and avoidable injury.
5.7 People with a disability are satisfied with the support they receive to experience healthy, constructive and respectful relationships.
6.2 People with a disability are supported to identify their own goals, priorities and long-term outcomes.
6.3 People with a disability are supported to explore a range of individual planning options and approaches.
6.4 People with a disability are supported to identify and choose options and approaches that may support them to achieve their goals or long-term outcomes.

6.5	People with a disability are supported to regularly monitor and review their supports.
6.8	People with a disability are supported to inform the development of policies, procedures and practice that relate to the delivery of service and supports.
6.9	People with a disability are supported to participate in the planning, development and monitoring of services and supports.
6.10	People with a disability are satisfied with the support they receive to choose their own supports and contribute to determining the manner in which supports are provided.
7.8	People with a disability are satisfied with the support they receive to seek, receive and impart information, ideas and opinions through their preferred communication style.
8.5	People with a disability are satisfied with the support they receive to access meaningful, rewarding and safe employment with just and reasonable conditions.
10.9	People with a disability are satisfied with the support they receive to express their cultural and linguistic needs and their sense of belonging, affinity and connectedness with others.
11.5	People with a disability are satisfied with the support they receive to experience a sense of social wellbeing through enjoyment of life and time for leisure and recreation.
12.5	People with a disability are satisfied with the support they receive to experience an adequate standard of living.
13.7	People with a disability are satisfied with the support they receive to experience the best possible physical, mental, emotional and social health.
14.5	People with a disability are satisfied with the support they receive in relation to moving freely in their environments and in the community.
15.7	People with a disability are satisfied with the support they receive to experience control over their finances.
16.5	People with a disability are satisfied with the support they receive to access adequate and appropriately located housing.

Appendix C

Victorian Standards for Disability Services – Life Areas for Outcomes Standards (LDC Group, 2008)

	Life Area	Outcome
1.	Always learning	People experience lifelong learning and education.
2.	Being part of a community	People participate in the life of the community.
3.	Being independent	People experience individual choice and control over their life.
4.	Being safe	People experience physical and emotional safety and are free from abuse, neglect and avoidable injury.
5.	Building relationships	People experience healthy, constructive and respectful relationships.
6.	Choosing supports	People choose their own supports and contribute to determining the manner in which supports are provided.
7.	Communicating	People seek, receive and impart information, ideas, opinions and feelings through their preferred communication style.
8.	Doing valued work	People experience meaningful and rewarding employment with just and reasonable conditions.
9.	Exercising rights & responsibilities	People exercise human rights.
10.	Expressing culture	People experience a sense of cultural identity and belonging.
11.	Having fun	People experience a sense of social wellbeing through enjoyment with life and time for leisure and recreation.
12.	How to live	People experience an adequate standard of living through exercising control over their living circumstances.
13.	Looking after self	People experience the best possible physical, mental, emotional and social health.
14.	Moving around	People move freely in their environments and in the community.
15.	Paying for things	People experience an adequate standard of living through exercising control over finances.
16.	Where to live	People experience an adequate standard of living through access to adequate and appropriately located housing.

Appendix D

Creating Excellence Together (CET) Standards –examples, Alberta Association of Rehabilitation Centres (2005)

Quality of Life Standards

Standard 1: Individuals have homes. Key indicators include

1. The individual indicates his preferences or the choices he has made have been honoured and supported (e.g., he is living where he wants to live and with whom he wants to live).
2. The individual indicates he has personal control in his home and is involved in household management and decision making.
3. The individual indicates he feels he has a good relationship with other household members, if there are any.
4. The home has a comfortable, lived-in appearance.
5. The individual has established day-to-day routines and indicates he has the flexibility to change them to suit his needs and desires.
6. The individual has a means of accessing his home whenever he wants (e.g., has necessary support, has his own key, knows the access code).
7. The home is personalized to match the individual's tastes.
8. The individual has formed and practises traditions (e.g. Thanksgiving, Christmas, Hanukah).

Standard 5: Individuals' rights are upheld. Key indicators include

1. The individual is aware of his legal rights and indicates that staff is supportive (e.g., the individual has voted if he wished to).
2. The individual indicates his religious or cultural beliefs and practices are respected and supported to the extent that he desires.
3. The individual is aware of his rights as an individual receiving service, and indicates that staff are supportive.
4. If his rights have been restricted, this has occurred with his full involvement, knowledge and informed consent.

Standard 6: Individuals achieve personal control. Key indicators include

1. The individual indicates she believes that she is in control of her life.
2. The individual expresses satisfaction with the opportunities provided for her to learn and acquire skills.
3. If the individual has or requires assistive technology and/or environmental interventions, she knows how to use them or is supported to use them.

Appendix D (con't)

Quality of Service

Standard 13: Individual are supported to have homes. Key indicators include

1. The service provider honours and supports the choices and preferences of the individual regarding where he is living and with whom.
2. Staff can describe the concept of "home."
3. Supports in the home are flexible enough to be adjusted based on the individual's changing needs and preferences.
4. Staff supports the individual to make decisions/guidelines about his home environment.
5. The individual is supported to make decisions about his daily activities around the home.
6. Staff respect and support the day-to-day routines and traditions of the individual.
7. The visibility of the service provider's support (e.g., materials, offices) is not overly intrusive or conspicuous.

Standard 17: Individuals' rights are upheld. Key indicators include

1. Staff are aware of the individual's legal rights.
2. Staff support the individual in exercising his rights (e.g. voting, religion, culture) to the degree that he desires.
3. Staff support the individual's legal right to be free from discrimination based on culture, religion, language, gender, etc., as well as discrimination based on physical or mental disability.
4. Staff are aware of the individual's rights as an individual receiving service.
5. The service provider has a strategy to teach the individual about his rights and responsibilities, and the rights of others.

Standard 18: Individuals are supported to achieve personal control. Key indicators include

1. Supports are in place to provide the needed encouragement for the individual to live as independently as possible.
2. The service provider gives the individual opportunities to learn new skills.
3. The service provider assists the individual in overcoming barriers to achieving personal control in areas such as transportation, finances, etc. This may include the provision of assistive technology or environmental interventions if appropriate.
4. If the individual uses assistive technology or environmental intervention devices, the service provider ensures that she has training and support necessary to fully use them.

5. If the individual uses assistive technology or environmental intervention devices, the service provider ensures that the equipment is maintained and in good working order.

Appendix D (con't)

Organizational Framework

Standard 26: The service provider has processes to ensure that the rights of individuals are protected. Key indicators include

1. The service provider is knowledgeable about the rights of individuals.
2. The service provider can demonstrate organizational activities that proactively protect the rights of individuals, which are separate from the appeal process.
3. The service provider has a written statement of the rights of individuals receiving services.

Standard 27: The service provider has a fair, reasonable and equitable process for addressing concerns and disputes. Key indicators include...

1. A dispute resolution process exists for individuals receiving service.
2. Documentation related to the formal dispute resolution process is maintained.
3. The dispute resolution process that is practised is congruent with the service provider's policy.
4. The service provider has an ongoing strategy to ensure that individuals are informed about and understand the dispute resolution process.
5. The Individuals clearly understand the appeal process, and can appeal any decision.
6. The service provider ensures that individuals expressing concerns or lodging an appeal are supported to do so.
7. Where appropriate, the service provider takes corrective action to prevent future occurrences of the situation that led to the concern or appeal.

Standard 28: The service provider has processes to protect individuals from abuse, and to report, review and follow up any allegations of abuse. Key indicators include...

1. The service provider has given information to individuals and their advocates about preventing, recognizing and reporting abuse.
2. The service provider implements policy in regard to abuse prevention, reporting and follow-up.
3. The service provider ensures that individuals who are reported to have been abused receive support.
4. Allegations of abuse are investigated and followed up according to provincial requirements.

Appendix E

Seattle 2000 Declaration on Self-Determination and Individualized Funding

- 25 The funding allocated to each person should be based on their individual need, not on pre-defined and arbitrary limits.
- 26 Individuals must be free to pay the providers of their choice, including family members.
- 27 Individuals must have full control over their supports, including the planning of supports, and choosing and directing their support providers.
- 28 People must have a choice of budgetary and administrative support services to assist them in using and tracking their individualized funding.
- 29 People must be given the opportunity and support to explore options and make their own choices of sources for forms of assistance such as brokerage, advocacy, and peer support.
- 30 Service providers and agencies must be encouraged to endorse and apply the principles of self-determination and individualized funding; and, in an expanded organizational role, to deliver supports that minimize dependency and strengthen partnerships with the larger community to address barriers to freedom and opportunity.
- 31 Individualized funding systems, support services, and technical assistance services must be designed and provided so as to ensure that their forms of communication, physical and environmental characteristics, and overall quality do not undermine their accessibility.
- 32 Individualized funding arrangements must be straightforward and easily understood by everyone.
- 33 Action must be taken to encourage the recruitment and employment of people with disabilities in the administration of individualized funding systems.