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Published

2010

Journal Title

Interaction

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Evaluation of Self-Directed Leadership: Parents Creating Participatory Lives with Adults with Disabilities Part 1: Literature Review

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October, 2010

(Prepared for Parent to Parent Association, Queensland)

Background

The evaluation, conducted over three months by Griffith University, was funded by Parent to Parent, Association, Queensland to inform future planning and development. A preliminary interview was conducted with the Strategic Director of Parent to Parent Association, Queensland to determine the purpose and scope of the evaluation. A literature review provides a context, based on contemporary research, for the evaluation of the *Self-Directed Leadership (SDL) Model*.

The SDL is a parent-led collaborative development between parents of adult children with disabilities, people with disabilities, and grassroots, private, not-for-profit and government organisations, to create parent led, local solutions for sustainable, participatory, independent living. The SDL is not a service. It can be described in two ways. Firstly, it is a framework for addressing the long-term needs of people with disabilities and their families, organising the responses to people's needs around them through intensive planning and development. Secondly, it describes a way of being, that is, leading self-direction in Queensland rather than simply undertaking tasks. It is a way of describing an approach that builds on a strong community development and leadership value base, and a belief that the full participation of people within their own communities is possible. SDL is driven by Queensland parents and families who, in partnership with their sons or daughters and other organisations, create local and sustainable independent 'life' solutions. Ann Ingamells describes the underlying conceptualisation that energises SDL in the following excerpt:

[Community development]...positions community members (rather than workers) as the primary actors, beginning with the poorest, most marginal, disadvantaged or those most affected by adverse policies. Change is pursued through relationships and through the transformative process of dialogue. The practices include equipping the actors for their role in change and creating the kinds of structures that enable and sustain participation and bottom up

agendas and decision-making...The method at the core of this approach begins with the horizontal linking of person to person, group to group... (Ingamells, Lathouras, Wiseman, Westoby and Caniglia, 2010, p.3)

This evaluation focuses on the efforts of a group of parents with adult children with disabilities living in Queensland, Australia. It is the actions of these parents, that is, the setting of their own agendas, decision-making, alliance formation and innovation that have created new possibilities for their sons and daughters and changed their own futures as parents of adult people with disabilities.

The evaluation seeks to explore the SDL; how it operates to achieve its objectives; its unique features; identify inhibitors and enablers; and its potential for replication. The SDL can be understood by: evaluating its potential to meet the needs of parents and their adult children with disabilities; and locating the unique position it occupies in the range of self-directed personal support models reported in the literature that include carer support, individualised and self-managed funding and accommodation for people with disabilities. The following section reports on this literature.

Literature Review

Introduction and Summary

The purpose of this literature review is to provide a research-informed context for understanding, mapping and evaluating the *Self-Directed Leadership (SDL) Model*. A particular focus on identifying barriers and enablers to implementing innovative person-centred, self-directed personal support models that include carer support, individualised and self-managed funding and accommodation for people with disabilities and their families is central to this review. This report is not a systematic review of research quality and individual program approaches; rather, key trends in effective approaches are identified. These key trends provide important guidance for developing, implementing and evaluating innovation.

The Queensland context is compared to other Australian and international jurisdictions, with a particular focus on the United Kingdom (UK), Canada and the United States (US), where self-directed care models have been operating for approximately thirty years. Key international and Australian studies published in the last fifteen years were reviewed and the following issues identified:

- Current trends in approaches to funding and service and support delivery
- International and Australian research and practice
- Accommodation, support and individual funding arrangements
- Family managed care
- Barriers related to effectively implementing self-directed funding
- Features of effective approaches to implementing self-directed care and individual funding arrangements

In western countries, there has been a move away from funding traditional disability support services towards individualised, self-directed care. This trend represents a shift from one where expertise is held exclusively by professionals and decisions are made by those organisations responsible for funding programs to individualised

approaches where service users are experts in their own lives and considered able to make decisions about those issues that directly affect them. Traditional models emphasise the type of services to be delivered rather than focus on individual need. Contemporary models place emphasis on the identification of individual support needs that, in turn, guide the allocation and delivery mode of financial and other resources (AIHW, 2002).

A number of barriers to the successful implementation of self-directed care and individual funding models that emerged from the literature are:

- The “unbundling” of block-funded services
- Developing, measuring and maintaining quality standards
- Direct payment to family members (requiring new systems)
- Complexity of systems required for implementation and maintenance
- Financial accountability
- Dealing with crisis situations and complaints management processes
- Isolation of informal carers
- Lack of access to information and support by service users
- Limited choice and supports relating to the availability of services in local areas
- Funding availability and adequacy of that funding.

The key features of effective approaches to self-directed care and individual funding models are:

- An effective system for the allocation of individualised funds
- Allocation of block funding to services when implementing individual funding and support
- Local area coordination ensuring local needs and preferences shape local services
- Provision of infrastructure supports that are separate from the service system
- Implementation of alternative quality systems
- Increased use of mainstream services
- Utilisation of blended formal and informal supports

Current Trends in Approaches to Funding and Service and Supports Delivery

During the latter part of the 20th century, perspectives on disability placed a stronger emphasis on personal rights, desired personal outcomes, and an awareness of the impact of discrimination and marginalisation on people with disabilities (Schalock, 2004). In this decade, the introduction of the *United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol* (2006) cements the shift from thinking about disability as a social welfare concern to a human rights issue. The Convention recognises that disability results from interactions between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (UN, 2006). Article 19 of the Convention states that:

State Parties recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

In Canada, Scandinavia, the US and the UK, there have been policy changes that reflect citizenship and inclusion approaches. The disability movement, particularly important to this paradigm shift, led an active campaign in the 1980s and 90s for the right of people with disabilities to self-manage cash payments to purchase their own support (Leece & Leece, 2006). Self-directed management of disability support is viewed by many in the field as a mechanism for ensuring that change reflects genuine options and increased control for individuals and families (OFCP, 2000). A body of international literature highlights a number of trends, presented in the section 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):

Independent living with services provided in the community: The provision of a range of delivery methods at the local level that suits the needs of the individual, such as high levels of support provided within a person's home in their own community. Kendrick et al (2006) state that high-quality community services must support social inclusion, that is, enabling people to remain in their communities as separation deprives them of civic participation, a basic right. Institutional social services have traditionally removed people from their natural communities to relatively segregated locations, which can result in lives lived in permanent exclusion. Specifically, self-directed care enables people to live in the ways that *they* choose rather than being subjected to eligibility and suitability assessments and the provision of particular services that match preconceived practitioner assumptions about a person's needs and lifestyle (Spandler, 2004).

The alternative to traditional models of funding and service provision for people with disabilities are those models that support people to make choices and to be included. These models are known by many names, including: person-centred

services; self-directed support; person-directed service; independent living; consumer control; self determination; self-directed services; consumer-directed services; and individualised funding. Each alternative model is 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). These include 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).

Models of self-directed care and individual funding are reported to lead to an increased use of instruments that measure quality of life, satisfaction, productivity, healthcare utilisation and unmet needs of people with disabilities and their families (Bleasdale 2001a; Conroy, Fullerton, Brown & Garrow, 2002; Glasby & Littlechild, 2002; Lord & Hutchison 2003; Dale, Brown, & Phillips, 2004; Stainton, & Boyce 2004; Government of Saskatchewan, 2007; Powers, Sowers, & Singer, 2006; Stainton, 2006; Disability Reform Group, 2002; Standing Committee on Community Affairs, 2007; Parmenter & Arnold, 2008). This research also shows that there are considerable benefits for people with disabilities and their families under these models. These benefits arise from greater flexibility, choice, independence, continuity of support and the customisation of care packages (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). Individualised 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). There is also some indication that self-directed care is either cost-neutral or cost-efficient, when compared to traditional funding models (Dawson, 2000; Stainton & Boyce, 2002; Stainton, 2009).

The 1997 Provincial Conference on Individualised Funding endorses a statement of principles that define models of self-directed care (North Shore Disability Resource Centre, 2005). A model of self-directed care is one:

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

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

- ***Self-directed care***: 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).

- **Individualised Funding:** a style of funding community services where funds needed to purchase required community services and supports are provided 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 families and personal networks (Advocates and Families from South Fraser, North Shore and Capital regions, 1998).

The key goal is to determine an amount of funding that attaches to the person and thereby is not contingent on the person's 'fit' into a particular type of service. There are limited international standards that provide guidance for self-directed care and individual funding. Only *The Seattle 2000 Declaration on Self-Determination & Individualized Funding* (First International Conference on Self-Determination and Individualised Funding Attendees, 2000) offers principles for implementation, see Appendix A on www.aiidd.org.au

The structure for governance in self-directed care and individual funding defines:

- *the role of the government:* eligibility and allocation of money;
- *the role of the individual or broker:* Brokerage refers to a process whereby a person with a disability employs a person to assist them with the processes of planning, obtaining resources and then hiring and reviewing the quality of service providers (Bleasdale, 2001a). The function of brokerage is separate from support provision;
- *needs articulation, assessment, planning, prioritisation, identification and negotiation of supports;*
- *contracted or directly employed/purchased:* supports provision; and
- *the role of the individual:* control over the purchasing and nature of support.

Self-directed care and individual funding principles enable a range of models/types (Bleasdale, 2001a).

- **Direct Payments** is a UK system whereby people with disabilities have the funds they require to purchase supports paid to them, and the freedom to decide which providers they use and the nature of support they receive. The money can be paid directly to the person to purchase supports; and the person is responsible for location, employment, management and accounting or the money can be paid to a fiscal intermediary, such as a 'microboard', to purchase supports as directed and administer the program (Bleasdale, 2001b; Clements, 2008). A microboard is formed when a small group of committed family and friends join and form a not-for-profit society around a person who has particular support needs (National Council on Disability, 2005).
- **Cash and Counselling:** Although models vary, the essence of cash-and-counselling programs in the US is that service users receive 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). Service users can obtain advice and practical assistance to manage their care by designating representatives, such as relatives or friends, to help make decisions. The Cash

and Counselling model also offers counselling/support and book-keeping services to assist service users and representatives in the self-management of 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 disabilities and their families about self-directed programs, individual budgets and new ways of delivering funded support through processes of critical enquiry, dialogue and collaboration between the funder and the service user (In Control, 2010). This model has rapidly expanded to other countries and emerged in Western Australia in 2008 linking with existing services and people with disabilities and their families (Williams, 2007).

Powers, Sowers, & Singer (2006) highlight that models are being developed that avoid oversimplification, that is, the polarisations of service users as either autonomous or non-autonomous. Instead, collaborative relationships between individuals and trusted others or surrogates when planning the nature and direction of services recognises, legitimises and manages the complexities inherent in these practices.

Accommodation and Support Individual Funding Arrangements

Historically, accommodation for people with disabilities who have complex health needs have been limited to institutional and medicalised settings (Epstein-Frisch, van Dam & Chenoweth, 2006). 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 disabilities. They recommended that moves from congregate facilities to smaller community-based settings be accompanied by different approaches to planning and support provision, especially through processes that ensure that the lives of people are enriched. They emphasised individual needs, preferences and choices. They also recommended that the provision of self-directed care and individual funding, based on support needs, should be expanded.

The research on housing for people with complex needs supports an argument for increasing individually funded support (Bleasdale, 2007). The notion of self-directed care and individual funding is gradually becoming a hallmark of successful housing and support arrangements, and is an integral part of the inclusive disability services paradigm. The capacity for negotiation on behalf of an individual appears to widen the scope of accommodation options and leads to innovative practices in the provision of both formal and informal supports. A self-directed care and individual funding approach to accommodation support, when effectively applied, ensures supports and housing respond to the unique needs of individuals located within their communities (Williamson, 2006).

With particular reference to the evaluation of direct payments in the UK, Riddell, Pearson, Jolly, Barnes, Priestley, & Mercer (2005) argued that self-directed care and

individual funding have the potential to make a major contribution to social justice for people with disabilities by translating the principles of independent living into practice. Independent living in the new disability paradigm context means 'having *choice* over where and how to live, and who provides assistance and *control* over when and how that assistance is provided' (Carmichael & Brown 2002, p. 805 as cited in Bostock, Gleeson, McPherson & Pang, 2004).

The move toward self-directed care and individual funding means that more service users would have the ability to determine their own accommodation and support needs, creating the need for more complex housing and support solutions and innovative methods of establishing and delivering these programs within communities. A diverse and flexible community care landscape is better equipped to meet the individual accommodation and care needs and choices of service users thereby enhancing social inclusion (Bostock et al., 2004). Vizel (2009), however, cautions that the move away from specialised group housing for people with disabilities to generic housing in the private sector may reinforce the vulnerability of people with intellectual disabilities to various forms of exclusion in the private housing market where there is insufficient support to assist in the integration process.

Cocks and Boaden (2009) conducted the Personalised Residential Supports Project (PRS) in Western Australia, with the aim of providing information on the nature, purposes and outcomes of personalised and individualised residential supports from the perspectives of key stakeholder groups, including people with disabilities, family members and service providers. The main findings are presented as a framework featuring nine themes that define and describe personalised residential supports. These themes: *Assumptions; Leadership; My Home; One person at a Time; Planning; Control; Support; Thriving and Social Inclusion*; provide a blueprint for understanding such models and the negotiation of complexity inherent in their practice and are outlined in Table 1 on page 13.

An evaluation of the Victorian Accommodation Innovation Projects that facilitates independent living for people with disabilities was conducted in early 2007 to determine whether the projects were achieving key outcomes for their participants (Fyffe, McCubbery & Bigby, 2008). Achieving long-term housing and support arrangements for people with disabilities and their families were found to depend on many things: locating rental or other forms of suitable housing; diverse contributions from friends and community members; planning where to live; assistance with moving to new living arrangements; developing independence and problem solving skills during and following a move; and perhaps planning for a later move (Fyffe, McCubbery & Bigby, 2008).

Family Management of Services

The values of self-directed care and individual funding approaches are also based on an acknowledgment that people with disabilities, and their families, advocates and carers are in the best position to define and determine how their own needs are met (Williamson, 2006). Not uncommonly, the authority of professionals, bureaucrats and others in roles of authority, tend to overshadow the expertise of families, who

have a 'natural' authority that goes a long way in reducing this imbalance of power (Kendrick, 1995). Kendrick (1995) argues that reducing the imbalance of power depends on families appreciating their natural authority and a willingness to act on it.

Table 1 Personalised Residential Supports Framework (Cocks & Boaden, 2009)

| |
|--|
| Theme 1: ASSUMPTIONS |
| .1 People with complex and high support needs can live in their own home |
| 1.2 It is not necessary for people with disabilities to live together |
| 1.3 Personalised residential supports can occur without a person having to live independently or alone |
| Theme 2: LEADERSHIP |
| 2.1 The leader/s holds and acts upon a clear vision and strong ideas |
| 2.2 At least one key person provides the leadership necessary for the arrangement to be created and endure |
| Theme 3: MY HOME |
| 3.1 The person has a clear personal stake, such as ownerships or secure tenure, in the home |
| 3.2 The person engages in typical home forming practices, roles and responsibilities |
| Theme 4: ONE PERSON AT A TIME |
| 4.1 The person's 'voice' is central to the arrangement |
| 4.2 The arrangement is designed around the unique identity of one person |
| 4.3 There is an intentional avoidance of 'grouping' people with disabilities together |
| Theme 5: PLANNING |
| 5.1 All planning activities maintain a central focus on the person |
| 5.2 People in close relationships are involved appropriately |
| 5.3 Planning includes a long-term outlook |
| 5.4 Planning includes an emphasis on safeguarding positive elements and addressing areas of risk |
| 5.5 Considerable ongoing time and effort is spent in planning. |
| 5.6 Ongoing processes of internal and external review occur |
| Theme 6: CONTROL |
| 6.1 The person, and/or those in close relationships, determines his/her own lifestyle and personal affairs |
| 6.2 Self-determination for the person is central to the relationship |
| 6.3 The person, and/or those in close relationships, has considerable influence in governance of the arrangement |
| Theme 7: SUPPORT |
| 7.1 The overall arrangement is flexible |

| |
|--|
| 7.2 The agency involved is creative and responsive |
| 7.3 There is a balance of formal and informal supports |
| Theme 8: THRIVING |
| 8.1 The person's lifestyle and general wellbeing are enhanced |
| 8.2 The person acquires a range of valued roles at home and in the community |
| 8.3 There are many opportunities for growth and development |
| Theme 9: SOCIAL INCLUSION |
| 9.1 Some relationships are close and enduring |
| 9.2 The person has a rich and varied social network |
| 9.3 There are opportunities for participation in a variety of community settings |

The Australian study by Ottmann, Laragy and Haddon (2009) that evaluates a Victorian self-directed care and individual funding program presents the experiences of twelve families caring for a dependent family member. This study lends further support to claims that self-directed care and individual funding increases service user satisfaction with care arrangements and produces better care outcomes. Indeed, the potential benefits of self-directed care and individual funding for people with disabilities and their carers are considerable, and service users were very satisfied with the flexibility, sense of control and achieved outcomes. The sense of empowerment service users experienced as a result of self-directed care and individual funding were highlighted. Moreover, the formation of informal support groups added to this sense of empowerment as it provided families with additional encouragement and assistance. The fact that families no longer had to negotiate with case managers enhanced their sense of autonomy and independence.

Neely-Barnes, Graff, Marcenko, Weber and Warfield (2008) conducted a study of family involvement in decision-making for people with developmental disabilities in the US. They found a strong correlation between family involvement in decision-making and the level of services provided and satisfaction with those services. Service users whose family members were highly involved received more services than service users in other families. In addition, when family members were highly involved, families and service users experienced more family member satisfaction than others.

Buchanan's (2006) study investigated the effects of self-directed care and individual funding on the empowerment of parents/carers of people with intellectual disabilities in Western Australia. The results indicate that four dependent variables – collaborative planning, availability of paid supports, funding availability and control of funding plans – are significant predictors of the empowerment of parents/carers within the Western Australian *Direct Consumer Funding* model. The results also show that there are five predictors of satisfaction with funding within this model. These are: information availability; sufficiency of funding; availability of paid supports; funding availability; and the control of funding.

Kendrick (2001) reports on the Massachusetts Family Governed Flexible Family Support Projects in the US. Family Support Projects, initiated by groups of families, were formed and largely governed by these same families. The projects were typically governed by some sort of overseeing committee whose members were elected from the families who were the project's "membership". Almost universally, these projects were not incorporated. They typically entered into what were distinctive "hosting" or auspice arrangements. These commonly took the form of semi-autonomous, internal "mini-projects", within the legal framework of existing not-for-profit organisations. These organisations acted as a "host" for the project. The specific terms of these hostings were negotiated between the families and the organisations concerned. Importantly, they could elect to leave the host organisation and find another if they became dissatisfied with the hosting relationship.

Direct benefits of the project to families were that (Kendrick, 2001):

- the projects affirmed the value of families;
- families were not as isolated;
- families were recipients of highly relevant and very needed family support;
- the families had virtually no direct bureaucratic involvement with the funder;
- the families could personally define, invent and improvise "family support"; and
- the families' cultural and linguistic contexts were respected and proved influential.

International Research

Lord and Hutchison (2003) report on findings from a Canadian study that used document analysis, case studies and cross-site analysis to investigate ten of fifteen of the most promising self-directed care and individual funding projects from Canada, the US and Australia. They identified that: values and principles mattered; a policy framework provided coherence and equity; supports built into infrastructures for individuals were separate from service systems; facilitator–broker roles differed from case management roles; allocations of individualised funds were designed to be equitable and accountable to the funder and persons; and a flexible 'learn as you go' philosophy maximised positive outcomes. This research concludes that self-directed care and individual funding embedded in the new paradigm of disability and community builds the capacities of individuals, families and communities.

In Scandinavia, the shift from the institutional tradition to the community provision of support has resulted in a citizen perspective towards people with disabilities (Weinbach, 2004). From this perspective, services offered to the general public are made available equally to people with disabilities.

In the UK, self-directed care and individual funding arrangements, such as direct payments and individualised budgets, underpinned by legislation, have been in operation since 1996 and, by late 2010, the Right to Control gave persons with disabilities greater control over decisions that affected their day to day lives (Weinbach, 2004; Leece & Leece, 2006; Davey, Fernandez, Knapp, Vick, Jolly, Swift, Tobin, Kendall, Ferrie, Pearson, Mercer, & Priestley, 2007; Office for Disability Issues, 2009). Individuals can choose between arrangements that involve direct payments (cash) or services. New forms of support for people currently excluded from direct

payments, such as those with severe cognitive impairments deemed unable to consent, are proposed through the use of 'agents'. The role of an agent is to support people in the control of their own budgets eliminating the need for the person to become an employer with all the associated responsibilities.

Semi-structured interviews with thirty-eight individuals from thirty-three local areas across England were conducted to identify strengths and weaknesses of access to direct payments. Most of the respondents revealed that they were able to secure greater continuity of care with the direct payment models than what they had previously experienced through local authority-arranged provision (McMullen, 2003). Their findings showed that direct payments introduced a level of flexibility for many respondents that had not been enjoyed previously (McMullen, 2003).

The first formal evaluation of the implementation of self-directed care and individual funding approaches to social care in the UK and the impact on service users, support processes, workforce, commissioning and providers, was published in 2009 (Glendinning, Challis, Fernandez, Jacobs, Jones, Knapp, Manthorpe, Moran, Netten, Stevens, & Wilberforce, 2008; Rabiee, Moran & Glendinning, 2009). A randomised controlled trial was conducted on almost 1,000 service users across thirteen sites. It was reported in the findings that where individual funding models were being trialled, individual budgets were used to purchase personal care, assistance with domestic chores, and social, leisure and educational activities. People receiving individual budgets were more likely to feel in control of their daily lives compared to those people receiving conventional social care support via traditional models. Little difference was found between the average costs of an individual budget (£280) and a conventional social care support package (£300) (Glendinning, et al., 2008). The findings, supported by rigorous methodology, contribute to a growing body of evidence that show an individual budgets approach is innovative and life-enhancing. However, achieving this potential in practice depends on a range of other factors, including changes in the routine practices and organisational culture of adult social care services and ensuring service users have access to appropriate documentation and support (Glendinning, et al., 2008; Rabiee, Moran & Glendinning, 2009)

There is a much longer history of self-directed care and individual funding in north America, particularly Canada, than in the UK and Australia. In the US, Mosely, Gettings and Cooper (2005) reported that in 2002 some form of self-directed care and individual funding was in place in nearly three quarters of the forty-three States they surveyed. Although there is great variation in their applications, self-directed care and individual funding models are rapidly becoming mainstream funding mechanisms in the US.

A US study involving interviews with forty-two State directors of developmental disabilities services conducted by the Research and Training Centre on Community Living (2009) examined the extent to which US States have implemented *both* individual funding and self-directed care in Home and Community Based Services. At the time of the research, thirteen States had statewide availability of individual budgets and service user control for at least some Home and Community Based Services recipients. Eleven additional States had self-directed options available as

pilot projects to limited numbers of people or within limited geographical areas. Eight States were in the final stages of developing self-directed options. From the perspective of the State administrators, successes included the following (Research and Training Centre on Community Living, 2009):

- Not expecting people to ‘fit’ into existing program-specific slots;
- Successful outcomes for people who previously experienced frustration with traditional services;
- Real change occurring in people’s lives;
- Hiring staff of one’s choice, resulting in less staff turnover;
- Reaching a more diverse range of service users;
- More efficient use of resources; and
- Greater collaboration between stakeholders.

Considerable impetus for self-directed care and individual funding of services was provided by legislative reform effective from early 2006 in the US (National Council on Disability, 2008b). In 2008, the US federal Department of Health and Human Services issued a ‘Final Rule’ that provided guidance to the States regarding allowing more Medicaid beneficiaries to take charge of their own personal assistance services rather than remaining reliant on services directed by agencies (Department of Health and Human Services, 2008; Harrington, Ng, Kaye, & Newcomer, 2009).

Canada has led the way in the expansion of self-directed care and individual funding. Virtually every province has some variation of self-directed care and individual funding models underway, particularly in the areas of supports to people with intellectual and/or physical disabilities (Advocates and Families from South Fraser, North Shore and Capital Regions, 1998). For example, in Alberta, self-directed care and individual funding has been in place since the mid-1980s and, in 1990, it became the official method of service delivery (Ontario Round Table on Individualized Funding, 2000; Advocates and Families from South Fraser, North Shore and Capital Regions, 1998).

In 2005, the New Zealand government began contracting with disability organisations to provide a self-directed care and individual funding services (Litmus Ltd, 2007) and has, more recently, introduced Local Area Coordination to aid the transition to self-directed care and individual funding (Office of the Associate Minister for Health, 2010).

Evidence from Australia

Currently in Queensland, Australia, there is a range of funding models in operation. These include self-directed care and individual funding models as well as the traditional block-funding of services for people with disabilities where services 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 & Arnold, 2008). National Disability Services Queensland (2007) stated that block funding arrangements with fixed costs are most relevant to providers while individual funding arrangements with variable costs are more relevant to individuals reflecting

the level and complexity of need as the major driver for the type and level of support provided. Queensland introduced Local Area Coordination (LAC) in 1988. Disability Services Queensland (2007) states that the LAC program aims to provide information, promote inclusiveness in mainstream services and enable communities to support people with disabilities.

In Queensland, some models of self-directed care and individual funding have been established through negotiations with Disability and Community Care Services (DCCS) and individual service providers and/or people with disabilities and their families. In these models, DCCS either pays the money to the service provider who will administer the money according to the person's and/or their families' needs, or pays the money directly to the person or family who have become incorporated as a company, which creates a legal entity separate from its members. The funding and support are either self-administered or external providers are hired to do some of this work. Some examples are:

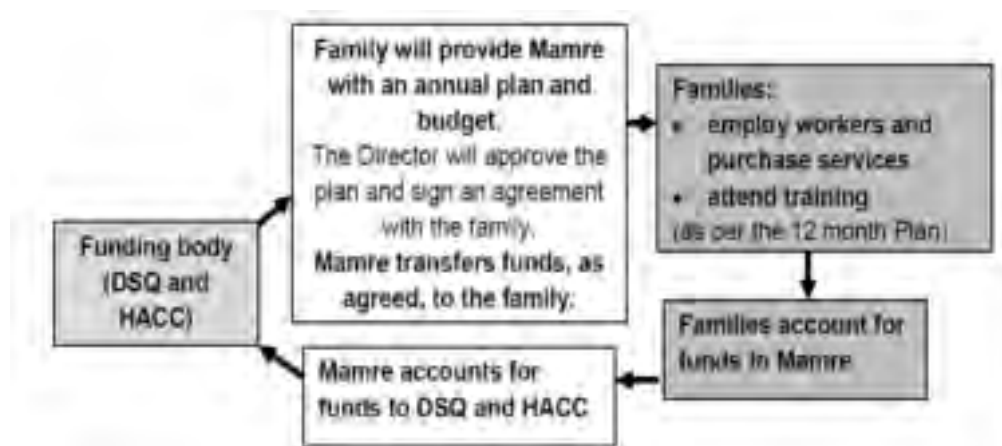
- Homes West Association Incorporated is a Brisbane-based service that works with eleven families to support twelve people with disabilities to live in a home of their own and to be included as active and valued members in their local community (Dyke, 2007).
- The Collective Action Group is incorporated and has a hosting arrangement with a service provider to manage the legal and financial reporting to the Government. It has been successful in gaining funds to establish an innovative project which enables the personalised support arrangements for ten people with disabilities (Collective Action Group, 2007).
- Family Managed Funds are funds provided by DCCS and the Home and Community Care Program (HACC) that are transferred from the Mamre Association Incorporated to families with members with disabilities (Mamre Association Inc, 2009). Mamre devolves the responsibility for the management of all or part of the funds to families. Mamre requires each family to use the funds in accordance with the guidelines of DCCS and/or HACC and the annual plan, including accountability for the expenditure of the funds in accordance with the family's plan and Mamre's guidelines, see Figure 1 on page 19. Families identified the lack of services for self-directed initiatives. Mamre in response to this auspices Bespoke.

DCCS has recently introduced a pilot program for 2010–2011, called the Self-Directed Brokerage Funding Model – a brokerage model of individual funding. This is currently being piloted in two locations in Queensland for children with a disability aged 0-6 years and their families and carers and young people aged 20-35 years with an acquired physical disability (Disability Services Queensland, 2010).

The data corpus of a study conducted by Fisher, Gleeson, Edwards, Purcal, Sitek, Dinning, Laragy, D'Aegher, & Thompson (2010) included information gathered from questionnaires and interviews with policy officials, service providers, and people with disabilities and their families and carers in Australia. They concluded that self-directed care and individual funding appeared to be successful in achieving its aim of person-centred disability support. People with a range of disabilities reported a

high level of control over their individualised support and a general feeling that their services were arranged around their needs.

Figure 1 Mamre's Family Managed Funds Process (Mamre Association Inc, 2009)



Western Australia is the first of Australia's six States to officially adopt self-directed care and individual funding. It uses one of the simplest yet highly developed approaches (Ontario Round Table on Individualised Funding, 2000). Based on the 1993 *Disability Services Act*, LAC 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 who develop resources and support networks in local communities to provide information and link service users with local resources and support networks and to provide individual funding to enable service users with disabilities and their families to choose and purchase their own supports and services directly. The individual 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 LAC 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 worker's compensation cover and the provision of a safe workplace (LDC Group, 2007). Both funding streams are subject to strict accountability requirements that includes a signed acceptance of grant form, the provision of receipts for any payments made, monthly reporting by service users and an annual review and acquittal (Disability Services Commission, 2003). Planning is distinct 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 outcomes-based, quality assurance frameworks 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 self-directed care and individual funding based on support needs should be expanded. An evaluation of a Victorian Government trial indicates that direct payments were successfully utilised by all service users involved in the trial (LDC Group, 2007). Direct payment service users experienced benefits of greater 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 B (see on www.aiidd.org.au).

In July 2007, a community organisation introduced a policy of self-directed care and individual funding based on the funds provided by the Victorian Department of Human Services (DHS) either as "block" funding or as an Individual Support Package (ISPs). In effect, this provided a separate budget account for each service user upon which they could draw for services and activities provided by the community organisation (Craig & Cocks, 2009). Ottmann, Laragy and Haddon (2009) conducted the first Australian longitudinal study and reported on the experiences of twelve families with a self-directed care and individual funding disability programme implemented by a community organisation in Melbourne, Australia. The study lends further support to claims that self-directed care and individual funding increases service user satisfaction with care arrangements and may produce better care outcomes. Indeed, the potential benefits for people with disabilities and their carers are considerable, and service users were very satisfied with the flexibility, sense of control and achieved outcomes, and the sense of empowerment they experienced as a result of self-directed care and individual funding were highlighted.

The Transport Accident Commission (TAC) in Victoria uses a system of self-directed care and individual funding 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-makers 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 offers a number of examples of successful self-directed care and individual funding arrangements. One such example is that of D.G. Lewis Pty Ltd which is an independent company whose directors include an individual with a disability (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 (DHHS) 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 individual funding to be provided to one person with a disability, 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 self-directed care and individual funding support arrangements.

Barriers Related to Effectively Implementing Self-Directed Funding

Williamson (2006) states that in designing and maintaining self-directed care and individual funding models, acknowledgment of and safeguarding against barriers and challenges increases the likelihood of achieving quality outcomes for people with disabilities and their families. The development of safeguards addressing these weaknesses is crucial for the sustainability of self-directed care and individual funding programmes (Ottmann, Laragy & Haddon, 2009).

A range of concerns and/or barriers for stakeholders in the implementation of new systems of self-directed care and individual funding are identified in the literature (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). These are as follows:

- *Changing systems.* The “unbundling” of block-funded services, including the establishment of both individual service rates and the accounting mechanisms necessary to track individual budgets and manage service billings, are problematic in many systems;
- *Quality systems.* Measuring and maintaining quality standards;
- *Risk.* Governments’ consideration of payments to family members. Concerns such as increased dependency on the carer by the person receiving care, and an

increased risk for abuse or overprotection made possible by increased dependency persist around this issue;

- *Complexity of the system* itself. Self-directed care and individual funding systems are not simple and can be difficult for individuals and their families to navigate. People with disabilities should be able to choose the level of self-sufficiency they need and are comfortable with ranging from traditional agency based services to self-management. Inadequate support for people to use cash payments, unnecessary paperwork and excessive bureaucracy persist;
- *Responding to crisis situations* – particularly important during the implementation of individual budgeting arrangements;
- *Financial risk*. The management of financial risk for service users;
- *Fiscal accountability*. 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;
- *Isolation* and lack of access to information and support.
- *Access to adequate funding and respite*. Laragy (2009) reported that self-directed care and individual funding did not overcome all difficulties and that inadequate funding and no available respite were major concerns for most families. While all self-managing families in this study were highly satisfied with outcomes achieved, they universally spoke of the difficulties and demands of accessing information about services and community opportunities.
- *Documentation and carer support*. Rabiee, Moran and Glendinning (2009) and Glendinning, et al. (2008) reported on the experiences of and outcomes for early UK service users of *Individual Budgets* and highlighted the importance of access to appropriate documentation and support to ensure the life-enhancing potential of self-directed care and individual funding.
- *Alienation*. Fisher et al (2010) reported that one service provider raised a concern about individual packages alienating people with disabilities from the traditional disability service system and the social opportunities it (the traditional system) provides. Some of the challenges in providing quality outcomes purported in self-directed care and individual funding include isolation (Williamson, 2006). Ottmann, Laragy and Haddon (2009) suggests that carers may experience an accumulative effect, that is, over time, they may experience an increased sense of isolation and lack of support as a result of their involvement in the self-directed care and individual funding programme.
- *Availability of choices/supports in local area*. For people in need of care and support, choice is only possible if the services they want to purchase are readily available, of good quality, and have the capacity and in-built flexibility to respond to choice (Carr, 2010). Local markets in many areas, particularly rural areas, still provide only limited choice to people.
- *Adequate funding availability*. Positive outcomes for people with disabilities and their families rely on a sufficient level of funding to address their particular needs and a funding model that is flexible enough to provide the appropriate mix of informal, mainstream and specialist support (Laragy, 2009; Fisher et al., 2010).

In summary, approaches to self-directed care and individual funding have been the subject of a significant number of critical analyses and reviews to date, sufficient to provide a clear picture of the benefits of such models despite barriers and challenges to implementation. It is important that people with disabilities and their families are aware of and provided with the appropriate level of support when making decisions and addressing these challenges. Evidence supports the capacity of people with disabilities and their families in making these choices. The next section of this report discusses features of *effective* approaches to self-directed care and individual funding for people with disabilities and their families that address the concerns above and highlight the importance of innovations generated by people with disabilities and their families.

Features of Effective Approaches to implementing Self-Directed Care and Individual Funding

There is general agreement in the literature on the common features of successful self-directed care and individual funding models. These (expanded below) are *transparent person-centred planning; capacity building, local area co-ordination; provision of infrastructure supports; alternative quality systems; increased access to mainstream services and increased capacity of mainstream services to respond to specialised needs; and blended formal and informal supports* (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):

- *Transparent person-centred planning.* An effective and transparent system for allocation of individualised funds, linked to person-centred planning is required. Person-centred planning is a process directed by the individual that is used to identify his or her strengths, capacities, preferences, and needs congruent with the services that will be provided to meet those needs. A person-centred planning document provides the criteria against which the adequacy and appropriateness of services and supports are measured (Mosely, Gettings & Cooper, 2005). Smith and Fortune (2008) state that if funding does not reflect support needs, then it will be impossible to achieve critical goals for individuals. The establishment of risk pools, service cooperatives and flexible mechanisms for service redetermination hold promise for minimising financial risk that can be experienced by service users. Reviews of spending plans and monitoring of cheque requests and time sheets limited incidences of fraud, abuse of the funds and abuse of service users to a handful of cases (Smith & Fortune, 2008).

The funded individual plan provides an accountability mechanism that ensures public tax dollars are spent effectively/efficiently thus reducing the need for expensive, external monitoring and accreditation schemes (Advocates and Families from South Fraser, North Shore and Capital Regions, 1998). When governments approve plans (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.

- *Capacity building*: Part allocation of total block funding to build capacity of services when implementing individual funding 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 non-profit organisations to increase capacity in the areas of government, policy and program development, community outreach, organisational administration and management. The Western Australian model also provides funding for set-up costs in certain program areas.

It is generally accepted that somewhere between 75-80% of agency costs are related to direct staffing costs. Thus the concept of an 80/20 or 85/15 mixed funding model has emerged for consideration (Dowson & Salisbury, 1999; Young, 2000). In such models, governments block fund the agencies' infrastructure costs (fixed costs) and individualises funding for direct services to clients (variable costs). The other 80 or 85% of operating revenues are supplied to individuals. One possible response to the issue of crisis funding provision is to either opt for a funded crisis component built into each individual plan, or to make a crisis budget available to agencies (or individuals) via negotiations with government that can be quickly accessed.

- *Local area coordination* (formal or informal) to ensure 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 & 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, where central government will be working to improve co-ordination with local authorities and local partners. It is thought that Local Area Agreements will simplify funding streams, help connect public services and allow greater flexibility for local solutions and particular local circumstances (Leece & Leece, 2006). In an evaluation of the LAC Pilot Program in Queensland, Chenoweth and Stehlik (2002) concluded that the impact of LAC has been to safeguard people's pre-existing capacities for independence and self-sufficiency and build supports around people that increases this 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 cost effective support. In the UK study of direct payments, Priestley, Jolly, Pearson, Ridell, Barnes and Mercer (2007) found that the prospects for implementation appeared to be enhanced where there was long-standing service user-led support for direct payments from the disability community combined with strong political commitment from the purchasing authority. A locality or regional approach to housing and support would create a means to concentrate knowledge and

expertise so that smaller groups and individuals do not need to replicate the learning, rather simply seek advice (Fyffe, McCubbery and Bigby, 2008)

- *Provision of Infrastructure supports*, such as service brokerage, fiscal intermediaries, and facilitators/ case managers, that are separate from the service system. The inclusion of facilitators/ case managers to plan, select and manage supports is recommended, starting at the planning phase (Dowson & Salisbury, 1999).

The implementation of appropriate systems to assist service users 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 assist people with disabilities to conceptualise their needs and requirements and help to develop plans that are described from the person's view not from the perspective of those who may have conflicting obligations, that is, to service providers and funding bodies;
- people with disabilities must have the option of hiring or not hiring particular brokers and the option of dismissing a broker if they are not satisfied with her/his work.

The roles of brokers and facilitators are identified as separate to case managers in the literature. These distinctions free services to focus on service delivery to the person rather than on program and governance issues, such as financial reporting requirements. Manageable caseloads for service providers are important as intensive work such as one-to-one contact is often highly effective (Nucleus Group, 2002). It has been highlighted that case managers or facilitators are essential to help negotiate systems (Nucleus Group, 2002; Robertson et al., 2007) and that capped caseloads of a maximum of fifteen to twenty is important.

Lord and Hutchison (2003) found that a broker, facilitator or network builder was vital to the individualised process and was free of conflicts of interest from service providers and governments. Projects emphasised that separating facilitators from 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 to participate fully, for example, financial literacy programs such as the US Federal Deposit Insurance Corporation Money Smart Curriculum offers beneficiaries information and financial resources (National Council on Disability, 2008b).

Legislative and policy reform in the UK has been directed towards increasing the uptake of self-directed care and individual funding options by people with impaired decision-making capacity (Her Majesty's Stationary Office, 2008). Arrangements that enable people with impaired decision-making capacity to be involved with self-directed care and individual funding include: allowing 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 ensure transparency in decision-making; the introduction of a range of options for supporting people with impaired decision-making capacities to articulate their choices; and to manage the administrative arrangements of self-directed care and individual funding (Department of Health, 2004).

Bigby and Fyffe (2009) state that mechanisms for supported or distributed decision-making, as well as formal substitute decision-making, are central to the implementation of self-directed care and individual funding for people with intellectual disability so that processes used for making the range of choices necessary in a person's life are transparent. It is also imperative that efforts be made to build capacity for people with disabilities and families to develop a vision for how their life might be different and how change can be facilitated in conjunction with mechanisms of administration, accounting and decision-making.

- *Alternative quality systems* to those designed for bureaucratic organisations. The paradigm shift to self-directed care and individual funding has necessitated a shift in how improvements and change are assessed (Ontario Federation for Cerebral Palsy, 2000). The new approaches to support are natural candidates for transcending traditional professional and managerialist outcome measures to measures that are service user-defined (Glynn et al., 2008). Gardner & Carran (2005) state that the state-of-the-art in quality measurement has moved beyond documentation of compliance with internal process and external standards and the tabulation of organisational process outcomes. Instead, person-centred quality assurance responsive to the person rather than compliance with process is preferred (Gardner, 2000). Outcome measures must be designed that take into account not only subjective and objective quality of life indicators but also outcomes measured against the individual's own goals (Bigby & Fyffe, 2009). The literature increasingly highlights that the quality of services must be determined by service users with a service user outcomes focus (National Council on Disability, 2008a). Parmenter & Arnold (2008) describe a shift from the quality of care focus, to a quality of life focus for service delivery, as presented in Table 2 on page 27.

The Standards for Disability Services in Victoria outlined expectations for better practice for the delivery of services and supports to people with disabilities. In 2007, the Outcome Standards for Disability Services were introduced into the Quality Framework. Examples of positive outcomes for people include improved emotional well-being, economic circumstances, health, knowledge and skills, social status and customer satisfaction (Department of Human Services, 2009).

Table 2. Essential Differences Between a Quality of Care Focus and a Quality of Life Focus (Parmenter & Arnold, 2008)

| | 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 |

- *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 integrate with or provide a gateway to targeted or specialist services.

Dowson & Salisbury (1999) state that self-directed care and individual funding should allow people to obtain the support they require from whatever source suits them best and to encourage creative use of funds such as making use of mainstream community services. Evaluations of some programs indicate that reductions in support costs under self-directed care and individual funding 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 self-directed care and individual funding.

- *Blended formal and informal supports.* Informal supports can provide rich possibilities for meeting the needs of service users (Kendrick et al., 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 is integral to a comprehensive package of supports (Nucleus Group, 2002). Bleasdale (2001b) states that the greater the involvement of existing community, local and family resources, the less reliance there is upon a specialist service sector.

Conclusion

This literature review presents the current international and national trends and features effective approaches to funding services and service delivery methods for people with disabilities. 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 toward self-directed care and individual funding combined with independent living and services provided within a person's own community.

Self-directed care and individual funding shifts focus from specialised group housing for people with disabilities towards generic housing in the private sector to increase independence, choice and community integration (Vizel, 2009). No single model stands out as ideal in the literature, so a range of options are needed (Parmenter & Arnold, 2008). The full range of public and private, large and small housing development possibilities needs to be considered for people with disabilities (Fyffe, McCubbery & Bigby, 2008).

Barriers to the successful implementation of self-directed care and individual funding that emerged from the literature are:

- The “unbundling” of block-funded services;
- Measuring and maintaining standards of quality;
- Payment to family members;
- Complexity of systems;
- Accountability for spending of funds;
- Dealing with crisis situations;
- Isolation and lack of access to information and support;
- Availability of choices and supports in local area; and
- Funding availability and amount.

The key features of effective approaches to self-directed care and individual funding, as identified from the research, are:

- A good system for allocation of individualised funds;
- Allocation of block funding to services, when implementing self-directed care and individual funding;
- Local area coordination, so that local needs and preferences shape local services;
- Provision of infrastructure supports that are separate from the service system;
- Implementation of alternative quality systems;
- use of mainstream services; and
- Utilising a blend of formal and informal supports.

Successful models are reliant on innovation and the resources generated by people with disabilities, their families and communities and the commitment and goodwill of governments in redirecting their resources to where it will produce the most benefit.

to be continued

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Acknowledgments

The research team would like to acknowledge the support and guidance received from those people in Parent to Parent Association, Queensland who have generously given of their time and resources, particularly the Strategic Director, Julie Simpson, who made this evaluation possible. We would also like to especially thank those stakeholders including: Parent to Parent Association, Queensland; A Key for Me Ltd; Key Housing Solutions Ltd; Foresters Community Finance and Social Investment Australia; and Disability and Community Care Services, Department of Communities; who agreed to be interviewed or participate in the focus group despite demanding schedules and multiple obligations. We greatly value their shared insights and expertise that made this evaluation possible. The *Self-Directed Leadership* evaluation has provided a unique opportunity to work collaboratively with industry partners.

We would also like to acknowledge the environmental and infrastructural support provided by the School of Human Services and Social Work, the Griffith Health Institute, and Griffith University, and to thank the research and administrative staff for their work on this project.

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NOTE: Part II: Evaluation Findings and Discussion will be published in the next issue of *Interaction*, 24#3.