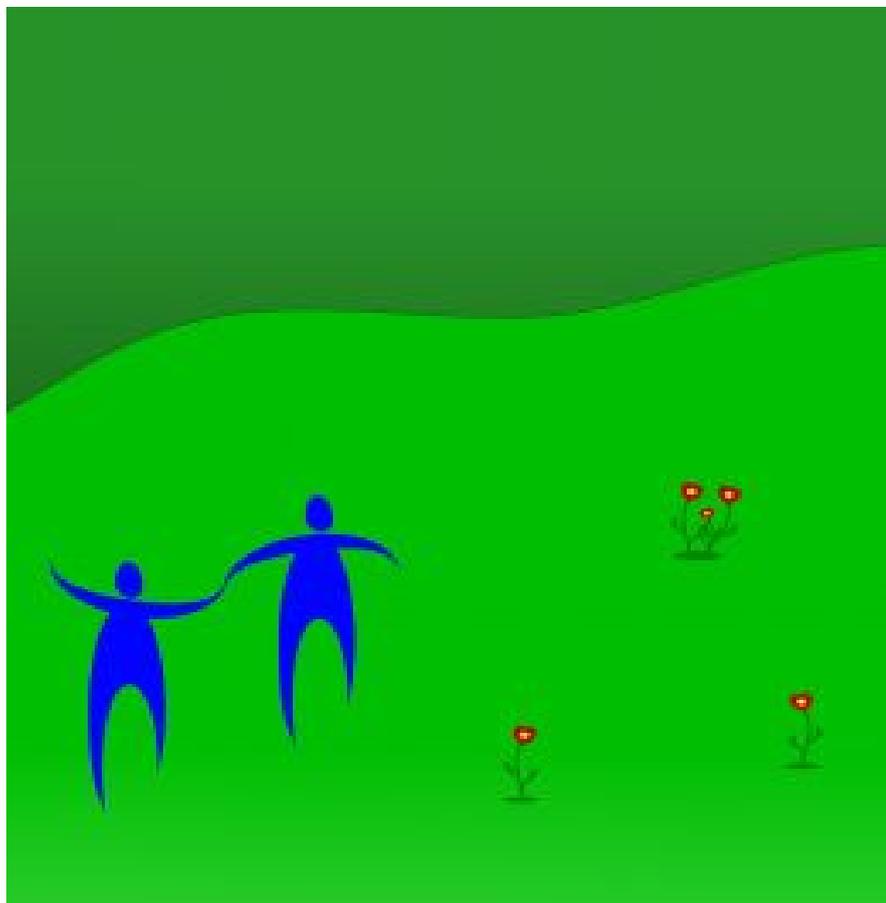


October 2010



EVALUATION

SELF-DIRECTED LEADERSHIP

Parents creating participatory lives with adults with disabilities



School of Human Services and Social
Work
Griffith Health Institute
Griffith University
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Contents

Contents	i
Definitions and Abbreviations of Key Terms.....	iii
Executive Summary	iv
Acknowledgments	vii
Background.....	1
Literature Review	2
Introduction and Summary.....	2
Current Trends in Approaches to Funding and Service and Supports Delivery...4	
Accommodation and Support Individual Funding Arrangements	9
Family Management of Services	11
International Research.....	14
Evidence from Australia.....	18
Barriers Related to Effectively Implementing Self-Directed Funding	23
Features of Effective Approaches to implementing Self-Directed Care and Individual Funding	25
Conclusion.....	32
Methodology.....	33
Evaluation Questions.....	33
Evaluation Design.....	34
Data and Method of Collection	34
Analysis	35
Strengths and Limitations.....	36
Ethical Issues	36
Findings	37
Self-Directed Leadership (SDL).....	37
Parent to Parent Association, Qld (P2P).....	38
A Key for Me Ltd (K4M)	42
Themes.....	47
What Motivates Us.....	47
Moving from Dependency to Leadership	48
Organic Nature of Innovation	51

Summary of Strengths, Weaknesses, Opportunities, Threats and Benefits ..	54
Discussion	59
Conclusion	66
Recommendations	67
References	68
Appendix A	78
Appendix B	79
Appendix C	80
Appendix D	81
Appendix E	83
Appendix F	86
Appendix G	89
Appendix H	90
Appendix I	100
Appendix J	102

Figures and Tables

Figure 1 <i>Mamre’s Family Managed Funds Process (Mamre Association Inc, 2009)</i>	20
Figure 2. <i>Emergence and Growth of SDL</i>	38
Figure 3. <i>The Process of Organic Innovation</i>	53
Figure 4 <i>Summary of Inputs, Outputs and Outcomes</i>	60
Table 1 <i>Personalised Residential Supports Framework (Cocks & Boaden, 2009)</i>	12
Table 2. <i>Essential Differences Between a Quality of Care Focus and a Quality of Life Focus (Parmenter & Arnold, 2008)</i>	31
Table 3. <i>Comparing SDL with Successes Identified in the Literature</i>	63

Definitions and Abbreviations of Key Terms

AIA	Investment arm of Foresters.
CLI	Community Living Initiative.
Enabler	Facilitators. Co-ordinates and provides infrastructure support to families and key holders in Pods. Provides practical and other support including connecting to community and developing and maintaining ‘circles of support’.
DCC	Disability and Community Care Services.
Doughnuts	Describes clear roles and responsibilities.
FAPN	Family Action Planning Networks – within P2P planning activities. Groups of families who want to create a legacy for their children and support and encourage them to leave home and live independently.
FF	Family facilitator (P2P) - facilitating support and planning activities with families and connecting the community – specific to local context and ‘agents of change’.
Foresters	Foresters Community Finance and Social Investment Australia (FCFSIA). Social Investment placing the capacity to create positive social outcomes into the hands of strong, sustainable, community organisations http://www.foresters.org.au .
IF	Individual funding.
Key Holder	The person with the disability who is part of a K4M
K4M	A Key for Me Ltd. Accommodation support agency using person centred management principles and designed to assist families to self-direct.
KHS	Key Housing Solutions. A community economic development corporation.
LAC	Local Area Co-ordination.
Pod	A term used to describe an independent, supported living situation. A network of services (formal and informal supports) is developed around the needs of an individual with a disability living in the community and supported by an Enabler – a ‘circle of support’. A network of families who provide peer support, informal and formal supports to key holders to enable them to live in their community. The family and individual are supported by a facilitator/ enabler. There may be several Pods in an agency according to interest or geographical location.
P2P	Parent to Parent Association, Queensland. Brings parents and family members together for mutual support and practical information, skill enhancement opportunities and planning activities. Funded by the Department of Communities. http://www.parent2parentqld.org.au .
SDL	Self-Directed Leadership Model. Parent-led leadership creating innovative, individual solutions.
Succession planning	A funding stream within the Disability and Community Services. Three Queensland organisations are funded, including P2P, to assist families to plan a desirable future for their family member with a disability. Actioning a vision of extraordinary possibilities, a mission of P2P’s succession planning activities.

Executive Summary

This evaluation was commissioned by Parent to Parent Association, Queensland, and undertaken by a team of researchers from the School of Human Services and Social Work, Griffith University. The purpose of this evaluation was to explore the *Self-Directive Leadership (SDL)* model; understand how it operates to achieve its objectives; identify its unique features, inhibitors and enablers; and its potential for replication.

The SDL is a parent-led collaborative development between families 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. 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 describes the movement led by parents that enables them to realise their own skills and knowledge and to mobilise their values and hopes of and for their sons and daughters into action by establishing and leading the networks and organisations that created individualised and context-specific 'life' choices for their adult children. The SDL can be understood by: evaluating its potential to meet the needs of families 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. 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.

Given the limited scope of the evaluation, the numbers of families involved and the stage of development of SDL, qualitative methods of inquiry were most suited to gathering information that would best respond to the evaluation questions and an interpretive phenomenological analysis was conducted to explore the lived experiences of a small group of participants (Smith & Osborn, 2003). The data corpus comprised information gathered from semi-structured interviews with key informants, a focus group, documents provided by key organisations and other text from relevant websites. Themes were identified during analysis and information was ordered into timelines to identify key focal points relevant to describing the development of SDL.

Themes identified in the analysis: *What Motivates Us; Moving from Dependency to Leadership*; and the *Organic Nature of Innovation* are presented in the findings and linked to the literature in the discussion section of this evaluation report. These themes provide an in-depth understanding of the SDL experience. The findings describe the development of parent-led organisations; Parent-to Parent Association, Queensland, (P2P), A Key for Me (K4M); and Key Housing Solutions (KHS) and how they have led to innovation. The SDL is organic. It has emerged, built relationships and drives networks that address gaps and weaknesses in existing, traditional service delivery organisations in Queensland and utilises funding opportunities that these systems also offer. Its emergence and development has been a bottom-up, rather than top-down process, that has proved fluid and dynamic in response to changing need and resourcing.

The SDL model was found to be innovative, developing in an organic yet proactive way that is effective in meeting the needs of the adults with disabilities and their ageing parents involved with SDL. Extensive planning, an important aspect of this evaluation, was conducted with people with disabilities and their families to support them to independent maturity and self-direction. Two major factors contributing to emergent leadership identities and self-directed practices evident during the analysis were a shared vision and the strong focus on planning.

SDL was identified during the analysis as flexible and responsive to the needs and desires of individuals and families and the local context which has allowed SDL to

develop consumer driven solutions that are unique. There are four factors that together are unique to SDL that sets it apart from other models reported in the literature. These are: the scope, depth, and breadth of planning that occurs in relation to organisational development and partnerships, and family and key holder preparation; a state-wide focus; and unique partnerships with government and financial sectors; and an ability to address isolation reported in the literature as a risk factor for families.

Enablers are the characteristics of SDL described throughout this evaluation that drive families towards innovative solutions while the most significant barrier to the future development of SDL and its replication. With funding and support, the replication of SDL is more than possible, it is desirable.

Recommendations are:

1. Fragmented funding arrangements have been identified as a threat and a barrier to SDL adding a level of complexity that could be eliminated with stable funding arrangements to support SDL activities.
2. Funding to support the Nice People Group currently run on a volunteer basis and other planning activities necessary for the development of people with disabilities.
3. Support to replicate the SDL framework in other regions.
4. Outcomes of dialogue between families, Foresters and Disability and Community Care Services that will support sustainability and expansion issues.
5. Opportunities for future research such as exploring short and long term outcomes for people with disabilities who have left home to live independently.

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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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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 supports delivery
- International and Australian research and practices
- 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 decision 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 recognizes 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 modes 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 customization 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
- is based on the needs of the individual as defined by the individual or trusted representatives
- dollars are paid directly to the individual or to support groups established by the individual
- 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).
- ***Individualized Funding:*** is 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 page 78.

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 the 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). Vizek (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 12.

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
1.1 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 investigates 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 organizations. These organizations acted as a "host" for the project. The specific terms of these hostings were negotiated between the families and the organizations concerned. Importantly, they could elect to leave the host organization and find another if they became dissatisfied with the hosting relationship.

Direct benefits of the project to families were (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 1000 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 are innovative and life-enhancing. However, achieving this potential in practice depends on a range of other factors, including changes in the routine practices and organizational 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 state-wide 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 into 'fit' into existing program-specific slots;
- Successful outcomes for people succeed 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 are 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. The state of 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:

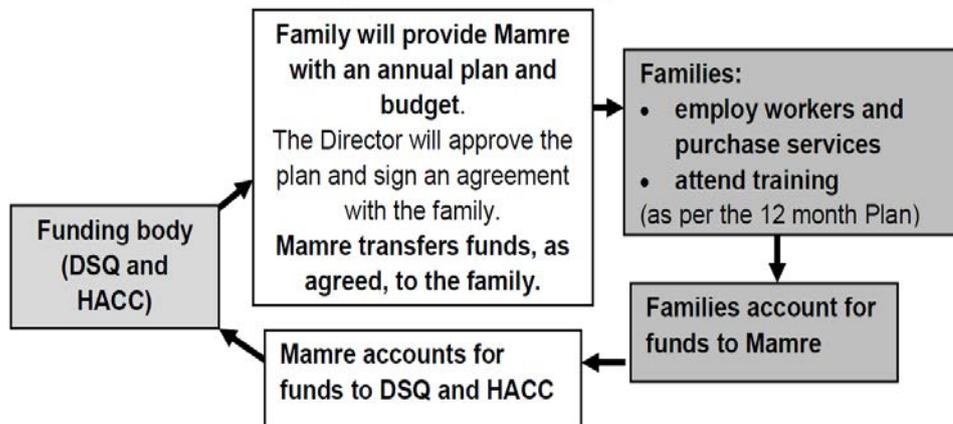
- Homes West Association Incorporated is a Brisbane-based service that works with eleven families to support twelve people with disabilities to live in a home of their own and to be included as active and valued members in their local community (Dyke, 2007).
- The Collective Action Group, is incorporated and has a hosting arrangement with a service provider to manage the legal and financial reporting to the Government, 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 family 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 20. 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 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, in two locations in Queensland (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; provide information and link service users with local resources and support networks; and also 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 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 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 on page 79.

In July 2007, a community organisation introduced a policy of self directed care and IF 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, 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 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*; expanded below (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 preexisting capacities for independence and self-sufficiency and build supports around people that increases that 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 were 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 a 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 have 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 31.

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 of 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 recourse to where it will produce the most benefit.

Methodology

Evaluation Questions

This evaluation seeks to answer the following:

1. Describe and understand SDL.
2. What are the unique features that distinguish SDL from other models?
3. Are there barriers and enablers to its success?

4. How well does SDL meet the needs of families and people with disabilities?
5. What is the potential for SDL be replicated in other regions?

Evaluation Design

Given the limited scope of the evaluation, numbers of families involved and stage of development of SDL, qualitative methods of inquiry were most suited to gathering information that would best respond to the evaluation questions. A qualitative approach is appropriate where little is understood about a phenomenon (Strauss & Corbin, 1990) and as SDL is in its embryonic stages an opportunity to develop knowledge about concepts and practices is presented using this method. Within-method triangulation (Denzin, 1989) was used, that is, semi structured interviews; a focus group; and text from websites and other documents as data sources for analysis. Purposive sampling was used to identify possible data sources. An interview was conducted with the founding Director of Parent to Parent Association, Queensland, to identify key stakeholders who may be willing to be interviewed and stakeholders who may be willing to participate in a focus group. An interpretive phenomenological analysis was conducted to explore the lived experiences of a small group of participants (Smith & Osborn, 2003).

Data and Method of Collection

The data corpus comprised:

1. Transcripts of semi structured interviews. Through purposive sampling, key informants that held knowledge or experience that could inform the evaluation were identified in a scoping interview with the founding Director of Parent to Parent Association, Queensland. Prospective participants were initially contacted via email containing an introduction and participant information, see Appendix C on page 80. An interview schedule was designed with open ended prompt questions, see Appendix D on page 81. Probing was used to enable elucidation to facilitate the collection of thick data for analysis. Individual interviews were conducted with 4 key consenting stakeholders representing key organisations connected to the SDL. These are Parent to Parent Association, Queensland (P2P); Disability and Community Care Services (DCCS), Department of Communities,

Queensland; and Foresters Community Finance and Social Investment Australia (referred to as Foresters). Interviews were recorded and transcribed. In some instances, follow up telephone calls were made to clarify particular information and extensive notes were taken. The Participant Information Sheet and Consent Form are attached as Appendix E on page 83.

2. Information gathered in one focus group. Parents of adult children with a disability involved in SDL were identified as potential participants in a focus group. A focus group provided opportunity for consenting participants to convey their stories in their own words while their reactions and interaction added richness that might be otherwise missed in individual interviews. Several broad, open ended questions were prepared to engage participants and keep discussions on topic while allowing open discussion and spontaneity. The focus group with three consenting participants was recorded and information summarised. Two participants were parents of adult children with disabilities active in SDL and members of the Key for Me Board and one participant was employed in two key roles – Facilitator for A Key for Me Ltd and Key Housing Solutions. Participant information Sheet and Consent Form are attached as Appendix F on page 86.
3. Documents provided by key organisations.
4. Information located on relevant websites.

Analysis

An interpretive phenomenological analysis was conducted as described by Smith and Osborn (2003). The transcripts and other textual material were read and reread several times to familiarise the researchers with the material, making notes of issues of particular interest. Patterns, threads, associations and disconfirming information were noted and some issues summarised taking particular note of the words and language used by participants. The data corpus was again reread to locate themes emergent in the analysis until saturation was reached. Themes were then clustered together to encapsulate important issues. The researchers' reactions and relationship to the material were noted and constantly compared to the data in order to make sense of participant's experiences. Themes included in the write up were those relevant to the evaluation questions and narratives of

participants' experiences. Information was also ordered into timelines to identify key focal points relevant to describing the development of SDL. Themes are presented in the findings and linked to the literature in the discussion section of this evaluation report. In this evaluation, rigour was addressed at each stage of the research process through constant comparison, reflexivity, member checking, being alert to disconfirming information, using multiple data sources and maintaining researcher self-awareness of their own subjectivity and influence on the analysis.

Strengths and Limitations

The strengths of SDL are examined through the appraisal of innovations, barriers and drivers, that is, the dynamic factors that contributed to its success or otherwise. A small number of informants enabled the gathering of rich data. The small number of informants, however, limits the capacity for generalisability. A particular strength lies in the capacity to capture a model of parent-driven planning, support and innovation during the process of actualisation. This enables a snapshot view analysis. The inclusion of the views of the individuals with disabilities would have further informed this evaluation but was beyond its scope. This is an area for future research and evaluation.

Ethical Issues

Ethics approval was granted by the Griffith University Human Research Ethics Committee and the evaluation was conducted in accordance with the *National Statement on the Ethical Conduct of Human Research (2007)*.

Due to the small number of informants and the potential to be identified, direct quotes that might identify participants will not be used in the write up of this evaluation unless permission was specifically granted. Rather, the individual narratives will be represented within themes identified during the analysis.

Findings

Self-Directed Leadership (SDL)

SDL describes the movement led by parents that enables them to realise their own skills and knowledge and to mobilise their values and hopes of and for their sons and daughters into action by establishing and leading the networks and organisations that created individualised and context-specific 'life' solutions for their adult children. A 'life' solution combines the flexible provision of housing, informal and formal supports that allows independent living in a person's own community in a sustainable and self-directed way.

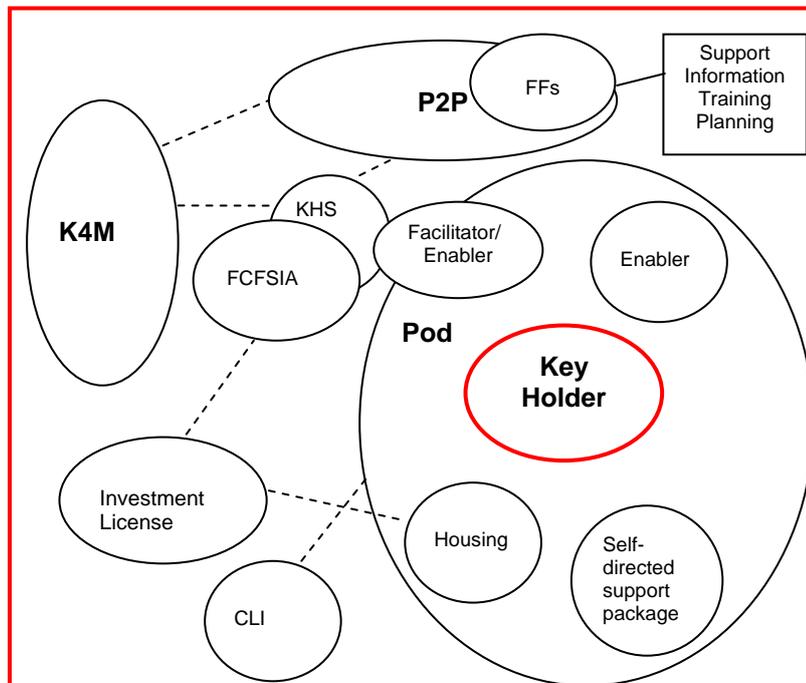
The SDL is organic. It has emerged, built relationships and drives networks that addresses gaps and weaknesses in existing, traditional service delivery organisations in Queensland and utilises funding opportunities that these systems also offer. Its emergence and development has been a bottom-up, rather than top-down process, that has proved fluid and dynamic in response to changing need and resourcing. This organic growth can be described as rhizomatous (Deleuze & Guattari, 1981), that is, like rhizomes (root systems), it is not deterred by barriers or obstacles to the desired goals (sustainable, inclusive, independent living and peace of mind for aging parents). Rather it works metaphorically around, under or over obstacles (traditional pathways) to achieve innovative and workable solutions. Figure 2 on page 38 depicts the growth and emergent functioning of SDL. It also became apparent from the analysis that it was not simply a matter of SDL working around obstacles. SDL also predicts where obstacles may lie, pre-empted them and seizes opportunities that might arise by proactively placing themselves in advantageous positions through personal and professional development, and by forming strategic alliances.

The following section briefly describes the emergence and development of the organisations depicted in  Figure 2 on page 38, the leadership model that enabled it, followed by the presentation of themes identified during analysis.

Parent to Parent Association, Qld (P2P)

Parent to Parent Association, Qld, (P2P), depicted in Figure 2, works in partnership with Disability and Community Care Services; Foresters Community

Figure 2. Emergence and Growth of SDL



Finance and Social Investment, Australia, (Foresters); A Key for Me Ltd., (K4M); and Key Housing Solutions, (KHS). P2P is the nucleo-organisation, that is, where the Self-Directed Leadership Model (SDL) began. P2P was formed in 1998 by a small group of parents of children with disabilities. It was established as a support and information agency for parents with children with disabilities and offers peer support; information; connecting families to other families, professionals, services and community; skill enhancement; and was funded in 2006 to provide succession planning. The mission of P2P as described on their website is: Families influencing society to recognise people with disabilities as valued contributing citizens.

The vision and dream of parents is that their children will:

- Love living where they live and who they live with
- Set new goals
- Make future plans and be confident in them

- Be independent
- Create their own lifestyle
- Have friends and community
- Fully participate – have meaningful engagement – work, holidays, recreation
- Ensure plans and support are active

Informants report that in the early days of its operation, parents would make contact with P2P and that the organisation was able to resolve a range of issues for families. With the progression of time and changing need, it is reported that facilitating change by responding to family need became increasingly difficult to the point where the organisation could offer little assistance with many of the issues that were presented. Resisting these limitations, driven by insider knowledge and the need for families to be supported to develop a vision and in planning activities, the Executive Director, P2P, led the development of the *Pathways to Possibilities* leadership and facilitation training with *Stronger Families* funding from the Department of Families, Community Services and Indigenous Affairs (FaCSIA). This was achieved via a sister organisation, Pathways to Leadership Ltd, a not-for-profit organisation to facilitate the leadership of families.

The *Pathways to Possibilities* course was based on a *Framework for Accomplishment* (Simpson, 1994) developed by O'Brien (1987, 1989, 1992, 2010) who had previously invited the founding Director of P2P to Georgia, US, to share ideas. This initiative emerged from this visit. The program was evaluated positively, clear recommendations were made (Whetstone, 2004) and seed funding sourced to roll out the training. As a result of the training, as reported by Whetstone (2004), sixty-six percent of parents reported feeling more confident and more able to negotiate with others in their community; eighty-seven percent found with more developed strategies they experienced service improvement and greater community involvement; eighty-three percent found evidence of increased recognition of contributions; half reported many opportunities to exhibit leadership and the other half reported some opportunities

The *Pathways to Possibilities Program* represents a key juncture in SDL as it supported and enabled the expansion of work already being conducted by families on a volunteer basis. It began with funding via Pathways to Leadership Ltd, 'a not-for-profit organisation, commissioned by the Department of Family and Community Services (FaCS) to develop and deliver the *Pathways to Possibilities Program* to communities in urban, rural, coastal and rural remote locations across Queensland' (Whetstone, 2004, p.1). Pathways to Leadership Ltd developed the five-day residential workshops that included a *Framework for Accomplishment*, *PATH* (Planning Alternative tomorrows with Hope, developed by O'Brien, Pearpoint and Forrest) Training, *Leadership* and *Integration*. The workshop participants were P2P families who had been working in that capacity with families across Queensland. The result was a roll out to develop leaders and partnerships in local communities during May and July 2005.

According to informants, parents who completed the course made positive changes in their lives, personally and organisationally meeting the objectives of the training. These objectives were: to build the capacity of families to advocate and plan; lead planning regarding their futures; build the capacity of professionals, services and communities to support people with disabilities and their families; and to develop a team of trained facilitators. Simpson (2004, p.11) describes what this transformative process meant for parents in the following excerpt.

...parents who have a family member with a disability move along a continuum of gaining skills and knowledge through life experiences, acquiring further skills and professional development through to becoming a professional trainer of professional personnel in the disability sector.

An important and innovative aspect of this training was the professional partnership model established by P2P during its inception (Simpson, 2004). Parents identified a professional from their local area. Parents and the identified professionals participated together in the five day live-in course, *Communication and Supporting Skills*. They returned to their local communities equipped to facilitate the course as needed. The commitment to building parent/ professional relationships was unique and innovative increasing capacity for relationships,

mutual support, understanding and appreciation of each others' skills. This led to new ways of thinking about support for people with disabilities and shifting the existing paradigm.

The P2P group who had completed the *Pathways to Possibilities* training (nine with nine professional partners) held formal organisational planning sessions to determine their future directions. P2P had been raising funds through successful grant applications and now proceeds from the provision of training to the then Department of Disability Services, Queensland, were reinvested in the development of parents. Family Facilitators, parents and professionals are offered training. Family Facilitators are developed via a suite of educational and development modules. P2P began to offer planning to families via PATH, see Appendix G on page 89, followed by the exploration of the work by Michael Smull, *Essential Lifestyle Planning* and *Person Centred Thinking* workshops.

Parents hoped for independence for their sons and daughters and inclusive living in their own community. Informants indicated that parents wanted a 'good life' for their children and were very clear about what this entailed, discussed in more detail later in the findings. The then Department of Disability Services, Queensland, became aware of P2P activities as some staff members were professional partners who had participated in the *Pathways to Possibilities Program* and wanted to know more. Following an invited presentation to the then Department of Disability Services, Queensland, it became evident to the five parents attending that despite being supported philosophically by the Department it was important for parents to invest in measurable support planning activities.

Subsequently, when P2P was invited to tender, it was one of three agencies successful in obtaining funding to develop individual plans with families. Person centred Essential Lifestyle Planning (created by Michael Smull) and futures planning were supported by P2P facilitators (Family Facilitators worked in a voluntary capacity prior to 2006). For visions to be realised, their sons and daughters would require access to family-driven agency and stable, affordable accommodation within their own communities to ensure informal or natural

networks remained in tact. This led, in part, to the formation A Key for Me Ltd (K4M) and Key Housing Solutions (KHS).

A Key for Me Ltd (K4M)

Families had been meeting informally since 2003 concerned about the impact of their own ageing on their adult children's futures and lack of success in accessing resources such as Adult Lifestyle Packages. As many of the adult children had low support needs, housing was identified as the most pressing issue. Experiences with the then Queensland Department of Housing, as identified by participants, meant their needs were unlikely to be met via traditional means. The provision of housing was too restrictive in relation to waiting periods and most particularly in terms of location. There would be no guarantee that a son or daughter could be housed in their own community where their natural networks could be maintained, that is, work, family and friends. In addition to maintaining relationships, employment and life satisfaction, parents felt maintaining natural networks was extremely important in ensuring personal safety and maintaining the community as a safe place in which the person can live.

In a rhizomatous action, parents in partnership with their allies created their own solution. K4M was formed in 2005 and registered as a limited liability company with not for profit status that met the requirements to receive funding from Disability Services, Queensland, in November 2007. Parents became board members, formalising new leadership roles. K4M aimed to provide support options for adult children with disabilities and their ageing parents. P2P acted as a support and contributed considerable resources such as a significant portion of a Family Facilitator's time in the three years of its formative stages. This assisted in the development of policies and procedures and meeting departmental requirements while allowing K4M to develop in its own way. This particular facilitator had prior experience in developing non government organisations. P2P still plays a supportive role. K4M provides parent-led support and infrastructure for parents as they move down the path towards self-direction. The philosophy of Janet Klees' approach to PATH planning (Deohaeko Support Network, Canada) relating to supporting families and recruitment was considered during this development. Families met weekly for approximately eighteen months. They were

motivated and enthusiastic and created their own learning culture. They accessed professional development opportunities provided by P2P as well as other sources such as conferences, courses by CRU and Values in Action. Families attended Person Centred Thinking, Person Centred Meetings, Person Centred Supervision and Person Centred Risk courses.

During the same period, Key Housing Solutions (KHS) was formed to enable the provision of housing stock in partnership with Foresters Community Finance and Social Investment Australia (Foresters), an ethical investment company. Foresters has a long track record of social investment and its structure enables private and organisational investors to directly contribute to positive social outcomes and receive a financial return on their investment. In partnership with parents, it provides expertise in relation to the design and delivery of social investment products. An investment lease was established to create a property portfolio while KHS will hold the lease of homes for people with disabilities (key holders). KHS is a community economic development corporation, a discrete dedicated accommodation agency. KHS was formed by families and their allies to improve access to affordable and personalised housing to people with a disability, as part of supporting their vision for a rich and meaningful life.

The then Executive Director of P2P had initially identified Foresters as an organisation that might have something to offer in terms of access to a different kind of capital to government grants and philanthropic sources. The collaborative partnership began with dialogue and, as reported by participants, there were no preconceived views on how they might work together or find solutions to the frustrations experienced by parents and the obstacles to their goals. Dialogue focused on building on strengths, increasing capacity and innovation. Participants described a developmental process that began in 2007 and continues currently. Initially, interactions focused on relationships and trust building, understanding the issues and gauging trustworthiness. This was particularly relevant given the financial nature of Foresters. The financial sector can be in tension with welfare concerns which makes the alliance of great interest. This period was followed by a design and development phase concerning technical, administrative and investment structures. Foresters also underwent organisational change in terms of

structure and corporate identity during this period. This next phase was implementation stage which is current. The relationship has moved from an informal to a more formal process. For Foresters, an idea has developed into a product which can be replicated elsewhere while parents and key holders (people with disabilities planning to leave home) in Queensland are closer to their goals. Foresters and KHS are currently engaged in conversation with Disability and Community Care Services about a capital grant investment that will be matched by private investment. The intention is for the aggregated funds to be used to purchase homes. This a new way of doing things for the public sector, is highly innovative, and presents new possibilities.

SDL is not solely concerned with making independent housing possible. Their leadership places a strong emphasis on planning using a person centred planning model where the goals and what key holders value is important. A number of person centred planning tools are used in practice including PATHS and Essential Lifestyle and futures planning. The emphasis on formal planning is an important aspect of both P2P and K4M. A Family Facilitator in P2P assists families in early and long term planning for future need – Futures Planning and Essential Lifestyle Planning. Families are offered individual and group opportunities (Family Action Planning Networks) to come together to plan a desirable future using person centred Essential Lifestyle planning. These networks brought parents together in local areas, aiming to connect them and maintain local alliances. Families complete 'A Key Readiness Evaluation' when planning for specific housing. This is a self assessment tool that guides families through the various processes involved in establishing long term, sustainable, independent accommodation and support. When families are moving towards being 'key ready', the P2P Family Facilitator and KHS, assists with intensive and individualised planning.

'Key readiness', developed by the Strategic director of Parent to parent in partnership with KHS and Foresters has the following components: a vision for the future; a vision of a home; personal (person centred) planning, provision of ongoing personal support; financial and estate planning; authority to make decisions; and safeguards and sustainability of accommodation and support needs. When families are 'key ready', KHS will make the final assessment and

provides approval for the purchase of a property. Foresters are then engaged in relation to their social investment role and a financial modelling of the lease with the tenant is undertaken to strike a balance between financial capacity and the needs of investors. Parents and Foresters are represented on the board of KHS.

The focus on planning and skill development extends to the future key holder (the person with the disability). Future key holders participate in regular self advocacy training, 'Having a Say' (Valid Self Advocacy Training), that concentrates on skills of decision making and self-responsibility. One group calls themselves the 'Nice People Group' who, it is reported, are very clear that 'if we are to leave home, they will need to learn these things', reflective of earlier commentary that emerged from a Shared Visions Conference where one attendee announced that he/she 'loved living with my mother but it's time I left home'. The Shared Visions conferences sponsored by the Department were reported to be energising, sharing ideas and knowledge.

Whilst families use person centred planning for their son or daughter's life, P2P also ensures that both families and individuals have their own plan. The families are able to articulate their dreams and visions and identify practical information that they will need when an individual leaves home. They are assisted in both formal and informal ways. These safeguards address what is important to the individual, important to families as well as providing important information concerning their needs to those providing supports.

As part of a key readiness assessment, future key holders, also complete an assessment framework process, 'A Vision of My Community Life', developed by P2P and designed to meet the criteria of the 'Key Readiness Evaluation', see Appendix H on page 89. The process described in this document assists people with disabilities to focus on their particular vision of their future life covering areas such as: what determines a rich and meaningful life for the individual; relationships and circles of support; what is important to the individual; the person's self perception – who am I?; keeping safe and healthy; support systems; staying in control of life; reviewing plans and managing budgets; dreams about what my home will be like; the next steps and an action plan.

When housing, supports and planning come together, a key holder can move out of home. The circle of care that surrounds him or her can be created around individuals, each having its own culture. An Enabler (family facilitator) is there to support and co-ordinate, supporting planning, decision making, independence and problem solving. The system is developing to where there will be a facilitator to support and develop Pod Enablers to ensure care, quality and safety standards; sustainability; support; and professional development. On the 1st October 2009, a K4M received funding from Disability Services, Queensland, for a three year pilot to enable young adults to live independently. To date, two key holders are now living independently with self-directed support through the Community Living Initiative (CLI), Disability and Community Services, Department of Communities, and self-directed budgets. The 'Vision for My Community Life' developed by P2P is also used to assist other individuals applying for CLI funding, who may not be part of a K4M.

It is the SDL that has through flexibility and responsiveness to their own and other families' needs created a vision for their sons and daughters, that is, coming to fruition through community leadership in its purest definition and through partnerships with key allies. As the SDL is a movement, its performative nature is the focus of this evaluation. It is the performance of its influence and the ability to translate innovative ideas into reality that has contributed to its rhizomatous growth and expansion to where it is today. The emergence of FAPN in P2P developed into a Pod in a K4M as one viable way of supporting sustainable independence that potentially achieves sustainable and more positive outcomes for the people involved.

A number of themes that lend insight into the factors which drive SDL and lead to its effectiveness in addressing the complex issues that affect parents with adult children with disabilities were identified during the analytical process. These are: *What Motivates Us; Moving from Dependency to Leadership;* and the *Organic Nature of Innovation.*

Themes

What Motivates Us

Overwhelmingly there is one factor that underpins all the activities of SDL and motivates these families. As described by one participant:

...parents had a palpable need to resolve seemingly unresolvable issues [and are driven by] concern about what will happen to their children when they are not around.

Parental love for their children and their desire to see them safe and happy as contributing individuals in their community propels SDL into action and is a state of being that cannot be replicated by any government service.

The path to self-direction, as identified during the analysis, is not necessarily an easy one. There are a number of fears with which parents have to deal on their own journey. They talk of learned dependency after years of involvement with traditional methods of service delivery and prior experiences with service providers; of being physically tired and anxious from the tasks of caring. Some parents are reported to feel trapped and would like their children to leave home yet feel guilty and question the legitimacy of these feelings. Some parents struggle over letting go of the authority and their role as primary carer and the need to redefine themselves differently. The greatest fears reported, however, are those related to their sons and daughter and their dreams and paths to independence. These concerns are about fear of failure and loneliness, and safety concerns such as emotional, physical, sexual and financial abuse.

An interesting process emerged during analysis. Through the processes of planning, training and the leadership of parents who have gone before them, parents can recognise these fears and manage, reduce or dispel them. They reported that it was during this process that many parents would begin to articulate future hopes seeking a sense of direction and a way to reach the goals they have

articulated. SDL provided this. Renewed hope was identified as an outcome in the analysis. One participant said:

I was beginning to think that the best place for my [son/ daughter] was going to be a retirement village with me or with other people with disabilities with a nurse in charge. I was thinking that would be the best and safest way. Now that is not even in my mind.

Hopes articulated were about a satisfying future for their sons and daughters. They hoped for fulfilling lives, to have a support network, community and friends encircling their sons and daughters and for their sons and daughters to articulate what they wanted and to be central to the planning process. Participants in this evaluation talked of the importance of communication, the support of P2P, the provision of an overarching structure (SDL framework), a shared vision, and families working together as integral to igniting hope and maintaining it and determination. They described the process as transformative where they initially had to think of new ways of doing things especially when confronted by challenges and, as reported, successful experiences, in turn, fuelled hope.

Moving from Dependency to Leadership

Hope strongly featured as the first step to developing new ways of thinking for parents, moving from away from past frustrations and resignation to recognising and building on their strengths and developing new skills – ‘moving from a tragedy model to a strengths focus’. Parents practicing SDL do not see themselves as recipients of services rather as leaders and creators of their own solutions. Options previously tried by some parents proved unsuccessful and ranged from independent to semi independent living yet the SDL framework has brought positive outcomes where other approaches have failed. This is linked in the analysis to peer support, increased family control, leading the decision making process and particularly the focus on training and planning. Two major factors contributing to emergent leadership identities and self-directed practices evident during the analysis were a shared vision and the focus on planning of which skill development is a part. A shared vision was repeatedly noted during analysis.

Planning, preparation, encapsulating and enacting a vision, and families engaging in professional development are core features of SDL and indicators of their success.

Participants articulated the importance of a shared vision for material and non material reasons. It was important to guide tasks and activities and to align the goals of partner organisations with SDL. A shared vision was also important to the maintenance of hope, determination, peer support and having the capacity to approach seemingly insurmountable differences in new ways. The commonality of issues and adhering to the same values ensured the group worked well together. The articulated vision placed the individual person in the centre highlighting what he or she wanted in their lives as most important. Parents were not going to rely on government to provide the answers or enact their vision and articulated the realisation that they would have to contribute in a range of ways, that is, by showing leadership and with other resources.

The heavy emphasis on planning and the attention paid to it is a key feature of SDL and important in the transition to leadership. A core premise to SDL is a belief that when families are given the right opportunities they can and do acquire the skills and can utilise planning tools to develop and maintain a sense of direction that helps them ensure the best and sustainable outcomes for their sons and daughters. Some participants in this evaluation reported that there are perceptions that parent driven activities are somehow less professional and invest in considerable amounts of training and focus on communication to counteract these prejudices and the assumptions inherent in them. As one participant said:

One of the positives is the parents' ability to realise what their own skills are. We do a lot of training and this is from people who are considered the best in the world at what they do.

Developing a learning and entrepreneurial culture and repeatedly exploring new opportunities for innovations that will enhance support for families is inherent to P2P's strategic development. P2P has experienced a bias towards perceptions that parent-led organisations are less professional yet has continued to implement

practices that seriously challenge these perceptions. From its beginnings, the organisation has focused on the provision of professional development to staff and families that is recognised for its quality. Ray Murray, the former Associate Dean of the Centre for Special Education, Auckland College of Education, has provided ongoing professional development. These include: the Communication and Supporting Skills training course for families to support other families; leadership modules; and The Seven Habits of Highly Effective leadership; under a licensing arrangement with Franklin Covey Pty Ltd. Person Centred Practice development has been facilitated by members of Michael Smull's Essential Lifestyle Planning Network from the US and by the staff of Helen Sanderson and Associates from the UK. Leadership development has been provided by Jack Pearpoint and Lynda Kahn from the Inclusion Network in Canada. P2P has kept abreast of innovation and provided opportunities for learning and exchange by building partnerships with like minded organisations across Australia and international alliances.

The UK experience highlighted the need to develop consumer-led organisations to assist individuals and families such as Self Direct (<http://www.selfdirect.org>), and to provide information and change management to service providers. The founding Director of P2P noted in a report to the NICD Board Self Directed Funding that during a visit to the UK in 2008 it became apparent that services were struggling with the idea of moving from a traditional model towards a self-directed response model. This suggests it is important to not only support training but to also invest in change management strategies.

Parents highlighted the importance of professional development and planning in taking themselves and their adult children on what can only be described as a journey to where independent living is a real possibility. In-depth planning using a range of tools and driven by P2P family facilitators, who are themselves parents, prepares them on a practical level and addresses very real fears such as safety concerns. Participatory learning activities based on adult learning principles are reported to have an empowering and life changing impact not previously experienced. Planning helped articulate what they wanted and how their son/ daughter/ family member could be supported and enable them to take planned risks with appropriate safeguards. Reported outcomes were increased autonomy,

choices, skills such as decision making and a general sense of ownership over what decisions were made and the effectiveness of those decisions. The other important aspect of planning and participation in certain skill development activities was the opportunity to form partnerships with professional allies. These partnerships engendered greater understanding, improved relationships and allied goals.

Planning is not simply about being prepared but has repeatedly led to new ideas and the embracing of possibilities that enable parent-leaders to make them possible. A K4M, KHS and the partnership with Foresters are examples of such innovation. PATH, Futures and Essential Lifestyle planning are supported by facilitators who have personally explored and experienced the benefits of person centred planning and developed the skills to practically action what they have learned. Parents make their own decisions and reshape their children's/ family members' and their own futures by doing so. For a parent's and family member's view of planning activities see Anne's story in Appendix I on page 100 and Gloria's story in Appendix J on page 102. Other personal accounts can be viewed on P2P website:

http://www.parent2parentqld.org.au/personal_stories/stories_index.php.

Informants also acknowledged the importance of the support and encouragement they have and do receive from other agencies such as the central and north coast offices of Disability and Community Care Services.

Organic Nature of Innovation

SDL, as it is reflected as a framework and in the organisations and networks it created, purposely set out not to design a service. These leaders did not want to be recipients of 'a service' as this returns them to a previous state typified by feelings of resignation, low expectations, frustration, powerlessness, passivity and sometimes anger. SDL represents a community, a community not formed in the first instance solely by geography. Rather, it has been formed by need, common experience, a shared vision and a passion to achieve the best outcomes possible for their family members.

There are several processes that characterise the performative aspects of SDL. It is a process of mutual influence where all are leaders and not subservient to any other or formal positions – it is about working together. Certainly people are at different stages in their journey towards self-direction and may contribute differently depending on roles. Influence wielded is multidirectional, influencing each other and bringing in those with other priorities, that is, partners such as Disability and Community Services and Foresters.

One unique feature of SDL is it is not simply about one intervention such as planning. SDL has created a complex array of connected interventions that is organic, dynamic and flexible. Responses are not fixed rather they are related to the context in which issues arise and which opportunities become available. While saying this, SDL is not reactive. Rather it maintains this flexibility through innovation, that is, new ways of thinking, pre-empting opportunities and barriers and arming themselves with necessary information, skills and supporting documents to take advantage of them. Likewise alliance formation increases the resources available to them and supports innovation.

The nature of SDL, as it emerged during the analysis, its relationships and how it engenders dialogue can only be described as organic. It has emerged, built relationships and drives networks that address gaps and weaknesses in existing, traditional service delivery organisations in Queensland and utilises funding opportunities that these systems also offer. Its emergence and development has been a bottom-up, rather than top-down process, that has proved fluid and dynamic in response to changing need and resourcing. This organic growth was previously described in this evaluation as rhizomatous, that is, like rhizomes (root systems). It is not deterred by barriers or obstacles to the desired goals (sustainable, inclusive, independent living and peace of mind for aging parents and family members). Rather it works metaphorically around, under or over obstacles (traditional pathways) by forming new relationships, generating new ideas and ways of working to achieve innovative and sustainable solutions. One process of achieving innovation organically is depicted below in Figure 3.

Figure 3. The Process of Organic Innovation

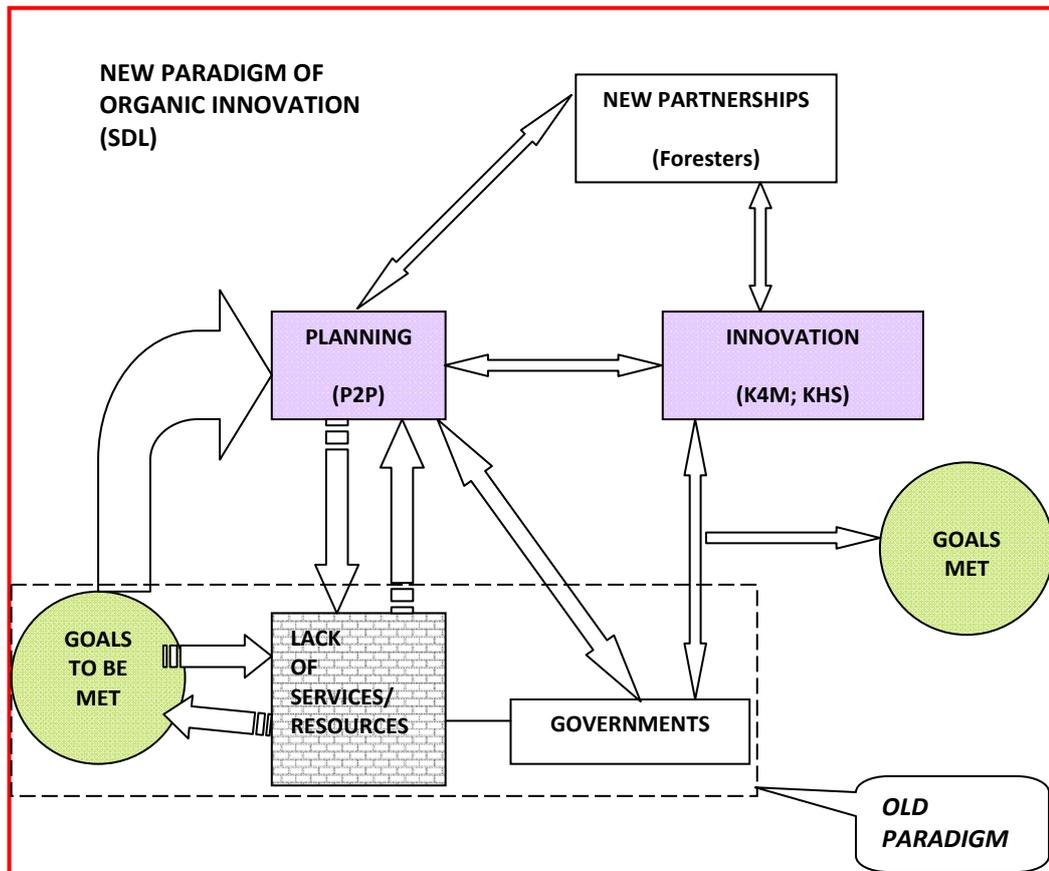


Figure 3 contrasts the old paradigm where parents and family members were hampered by obstacles such as inadequate services and support as service users and with no way out felt trapped and demoralised. A new direction that works around obstacles to find new and alternative paths, through planning (itself an innovation), new alliances and innovation is depicted in a new paradigm. Alliance formation appears to strengthen planning and goal attainment and increase opportunities for innovative practices. It is worthy of note that alliance formation is not limited to the local context. It extends to interstate and international alliances. It is along these networks that information, development opportunities, knowledge of best and most effective practices travel across borders and are absorbed into local practices.

Summary of Strengths, Weaknesses, Opportunities, Threats and Benefits

A number of strengths, weaknesses, opportunities and threats were identified by participants during a SWOT exercise and located in other data. Benefits for people with disabilities and their families were also identified by participants.

Many issues previously noted in this evaluation were clearly identified by participants to be strengths of the SDL approach and aspects that had considerable impact on the lives of families and the lives of the people with disabilities. These can be grouped as characteristics of the model, specific people/roles, and the consequences for the people involved.

Characteristics of the approach considered strengths by participants were person centredness, flexibility, a shared vision and values (as they pertained to the future of their children and family members) and a dedication that is described in the excerpt below.

We operate from the heart and therefore have the dedication and investment to remain committed.

The shared experience of dedication, peer support, non judgemental approaches and an openness to new ideas was highly valued. One of the features considered most important was the creation of boards (P2P and K4M) that were parent driven. This ensured a meaningful agenda and greater trustworthiness in activities as truly representative of the group. Family driven planning was core to the strengths of SDL particularly in relation to planning for future events and the prevention of destabilisation and managing risk. Healthy debate and opportunities to openly discuss issues were also noted to be a strength of SDL. Participants valued the work and expertise of people considered pioneers in SDL in Queensland and those in particular roles such as family facilitators in P2P and the facilitator in K4M who 'had the right people doing the jobs'. Networking and forming multiple alliances were identified as a strength in terms of staying abreast of research, best practices and innovations in international arenas. Participants also reported hiring the right people for carer roles was another benefit of SDL. Despite reports of a

recruitment crisis in Queensland, Parents indicated they had no difficulties in recruitment. They preferred carers with no previous experience in the field as they could then be trained to provide person centred care and not carry preconceived judgments or outmoded ideas from previous experiences into their new role.

The strengths grouped as consequences for families and people with disabilities include the strength and determination felt as result of peer support and planning, a resultant increase in resilience, and of particular note, the personal journey experienced as a result of involvement with SDL. This was described as:

...seeing our children differently...and seeing them thriving...self-direction and person centred planning looks at the key holder as a whole and reframes them in a more positive light, the parent or carer starts to believe that positive change can happen and as a result it often does.

This personal journey was also identified as a potential weakness, in that, it is not necessarily an easy process and does involve emotional risk as parents are required to leave their comfort zones. It was expressed by participants that in many ways some parents need to grieve over loss of previous roles. Yet the benefits were reported to far outweigh any discomfort in the process. An increased sense of autonomy and ownership over their futures and the benefits for them and their families as a result of independent living was greatly valued. Ultimately, for parents it was having real choices available to them.

The complexity of the system was raised as another potential weakness. Complexity was connected to the organic growth, the fragmented nature of funding arrangements, meeting multiple and complex needs in recognition that 'one size does not fit all' and 'there are no tick box solutions'. While saying this, complexity was considered to be inevitable while there was a focus on individual need which is a strength of this approach.

Due to small numbers of parents and increasing demand, burnout and the need for succession planning for organisational roles was identified as a risk. One participant described self-direction as emotional work. There is considerable

personal investment but also considerable reward. Although participating in SDL was identified as stressful associated with increased responsibilities, it was reported to be a different kind of stress to that experienced previously and one that was preferred. Overall, participants felt strengths far outweighed weaknesses and peer support and positive outcomes mediated stressors.

Other threats identified included concerns that demands on P2P, K4M and KHS might progress faster than capacity. K4M is currently actively working on the development of policies and processes to address this. There are also fears that as the work grows some parents might feel less connected to boards and less confident in making their voice heard. With expansion also comes some concerns that the very strengths of SDL such as a shared vision and values and the culture may be more difficult to maintain. Self-directed leaders participating in this evaluation felt, however, that the focus on planning, peer support, shared experiences, and the ongoing development of leadership within their ranks will be important in maintaining the strong value position and direction. It is also important to note, the SDL has placed considerable pressure on the infrastructure of P2P from time to time. Despite limited resourcing, it was the organisation's capacity to work together towards a shared and bold vision that enabled success and its ability to withstand the pressure.

Fragmented funding is also posed as a threat as are the bureaucratic requirements that accompany funding opportunities and reporting arrangements which pose additional burdens on the organisations. The continued goodwill of partners is essential. Participants identified that political climates have undergone change in Queensland moving towards a greater awareness and support of self-direction. This changing climate is echoed in overseas experiences where self-direction and person centred planning is increasingly considered best practice. Disability and Community Care Services recognise the value of SDL and are supporting innovation with funding such as CLI and engaging in dialogue with Foresters. It will be a significant threat to SDL if these innovations do not receive continued support. Lack of funding also means a portion of the work relies on volunteers. Facilitators were volunteers prior to receiving funding in 2006. Currently, the work with key holders, the Nice People Group, is reliant on

volunteers, a situation that threatens the stability of this work that is highly valued by people with disabilities and their families and important to achieving outcomes.

A significant threat identified by participants was societal attitudes towards disability, in other words: how their adult children are viewed; how people respond to them; access issues and opportunities for real participation; and how their needs are prioritised on government agendas; and the shortfall in traditional services' capacity to meet their needs.

Parents who participated in the evaluation identified that SDL works for them and other parents involved. Sustainability was a reality and participants did not question that outcomes achieved to date could be sustained with appropriate funding support. This certainty was derived from the strength of planning activities, decision making and problem solving mechanisms that had been devised to respond to individual crises and plan for futures and providing real choice. Participants named a number of opportunities in relation to the SDL model. These were related to more stable funding and the replication of SDL elsewhere that could be adapted to local contexts with some components directly transferable such as the Forester's products and planning tools.

A new federal workplace regulation, the New Modern Award, is an emergent threat to sustaining the best outcomes for people with disabilities living alone or with others in the community. Regulations designed for businesses to safeguard worker rights, *if applied to this sector*, would have implications for the provision of services to people living in communities where more flexible arrangements are often possible and preferred. To explain the implications in real terms a participant has given permission to use her example in this evaluation. Her daughter who has a profound disability and limited verbal communication, lives at home. Familiarity, routine and stable arrangements are important to her daughter. The new regulations if applied would mean it would no longer be possible for the same carer to assist her to go to bed, do a sleep over shift, then assist her to get up in the morning. The implications for this particular person and the impact on her behaviours and mood would be considerable. Her parent reports that this inflexibility would not support the best outcomes for her daughter.

Many of the strengths also have, in part, been identified as potential weaknesses. For example, the personal experience that drives them also has potential for burnout. There is evidence that SDL, as a proactive movement, appears to be able to identify weaknesses and potential threats and take actions to guard against them or minimise the impact. This again is a testament to the strength of planning activities undertaken in this framework and the support found in shared experience. Some threats are internal and relate to upholding a shared vision while many are external including funding and continued support from government. Opportunities identified such as replication create exciting new possibilities for people with disabilities and their families into the future.

Participants were clear about the benefits people with disabilities and their families experience as a result of SDL despite some challenges. Benefits most easily identified were those experienced by key holders. Informants reported significant change for their son/ daughter/ family members. These included 'being grown up' displaying a maturity not previously noted that were related to increased opportunities, independence, confidence, and new skills such as assertion and problem solving. Parents noted a sense of responsibility such as being houseproud, taking the initiative, caring for a pet and in one instance, fixing a tap, and trying new things in a planned and safe manner. It was reported that key holders had developed strong, connected, social relationships with each other and were maintaining the relationships in their local communities. Parents were proud of their children's growth and the strong sense of values associated with their new sense of responsibility. From their observations, their adult children were thriving.

The gaze of parents was focused squarely on the successes of their adult children and their achievements. It required deeper reflection for parents to begin to consider their own needs and gains in the process. On reflection, parents were able to identify the changes that had occurred in their lives. These were 'having space', less anxiety and more time for self care such as going on holidays. The participating parents acknowledged that though experience is individual, there is a considerable adjustment for parents who have spent many years in the carer role. There is potential for future programs to be developed to support parents with

transition issues, loss, and rediscovering a personal identity where being a carer or planning for their child's future are not the defining roles of their lives.

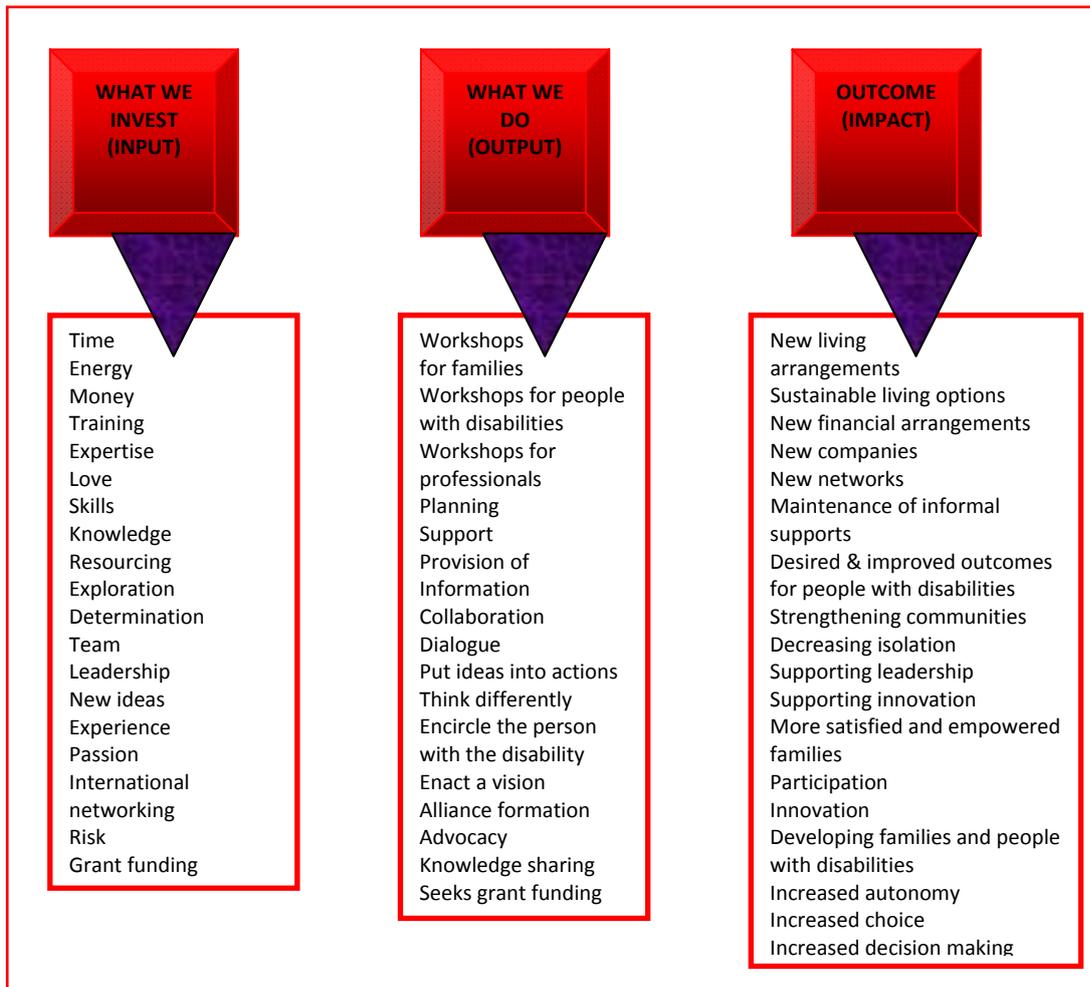
A number of inputs, outputs and outcomes have been identified in the analysis. These are summarised in Figure 4 on page 60. Considerable time, energy and resources have been invested by families into their children's/ family members' futures and finding new solutions despite the obstacles they have faced. As illustrated in Figure 4, SDL has produced a range of outputs and identified multiple benefits and improved conditions for people with disabilities and their families as a result of SDL.

Discussion

This evaluation aimed to describe and understand SDL; identify unique features that distinguish SDL from other models; identify barriers and enablers to its success; identify how well it meets the needs of people with disabilities and their families; and to gauge the potential for SDL to be replicated in other regions.

SDL was identified during the analysis as flexible and responsive to the needs and desires of individuals and families and the local context which has allowed SDL to develop consumer driven solutions that are unique. Its development can be described as organic, in that the innate flexibility enables them to work around obstacles rather than being deterred by them. They began with what only can be described as stitching bits and pieces of funding together with handful of people resolving issues as they arose. Determination and intimate knowledge of the personal experience of living with a disability that attracts a certain amount of stigma from the general community and the experience of parenting a child into independent adulthood has armed these families with the leadership required for self-direction.

Figure 4 Summary of Inputs, Outputs and Outcomes



Taylor et al (2008, p.195) highlights three key elements of community leadership. These are:

- Creating a common purpose of benefit to the community
- Bringing people together
- Balancing task and group process

Parents and families practicing SDL and the model for action created by them has not only developed organisations such as P2P, K4M, and KHS whose people are motivated and have the skills to work in partnership with Disability and Community Care Services and private organisations such as Foresters, it has also created a community. Networks of parents now extend across the state of Queensland. The common factor that drew families together in the first instance was concern for the

future of their children and dissatisfaction with the type and kind of services available to them that provided little in terms of raising their children to independent maturity. Housing availability and real choice about location and access to support packages were not guaranteed. Planning and skill development to prepare for remote possibilities of acquiring accommodation or care was impractical and parents/ families were very much stuck in the old paradigm described in Figure 3 on page 53 where there were few options for change.

Community leadership enabled families to develop a true sense of team where achieving participation became possible together. It is the strength of a group of leaders which is harnessed to enable the development of support and planning activities and effective organisations without isolating each other through excessive bureaucracy and rigid program areas. It is the sense of community and shared purpose that also defends against the isolation that is identified as an adverse aspect of self-direction in the literature (Williamson, 2006). Instead, the antithesis of isolation emerged strongly in the analysis. Parents and families felt connected through a shared vision and activities that brought mutual benefit reflecting the goals and outcomes that they seek. The striking aspect of SDL is that they do appear to have achieved the fine balance between task and process. Considerable attention goes to supporting parents on a journey to self-direction through support planning that has emotional and practical aspects delivered in a non judgemental or hurried environment. Ideas are developed and the systems are then put in place to support it.

SDL is a true community development approach. Beginning with dialogue, families define the problems and develop their own solutions differently to the planning and intervention that can be developed and implemented by governments. The focus on parents leading planning; the provision of infrastructure to enable real choice; partnership with the financial sector; and the unique alliance between government, Foresters and parents are the points of difference from other models nationally and internationally.

Key features of successful self-direction are identified in the literature review. These are listed in Table 3 on page 63 and are compared to the evaluation

findings related to SDL. As this comparison highlights, P2P, K4M and KHS have developed a range of successful features despite limited funding arrangements. There are two points worthy of note. Firstly, SDL do more than utilise existing services rather SDL has developed a framework that includes new partnership arrangements and has the infrastructure and resilience to respond to crises, based on intensive planning, that has been more difficult for other models of self-direction to achieve. Specific research such as a Canadian study by Lord and Hutchison (2003) supports the findings of this evaluation and reflects the benefits of SDL. They reported the importance of values and principles, an equitable and individually focused framework, a distinction between facilitation and broker roles, self-directed funding and 'learn as you go' flexibility optimised outcomes for people with disabilities and their families. Likewise, the US study conducted by the Research and Training Centre on Community Living (2009) identified elements that are also inherent to SDL that led to success. These included real change occurring in people's lives; hiring staff of one's choice; positive outcomes for people frustrated with traditional services; and greater collaborative efforts between stakeholders.

There are four factors that together are unique to SDL that sets it apart from other models reported in the literature. These are:

- The scope, depth, and breadth of planning that occurs in relation to:
 - Organisational development and partnerships
 - Family preparation
 - Key holder preparation
- State-wide focus
- Unique partnership with financial sector
- Ability to address isolation reported in the literature to be a risk factor for families

Table 3. Comparing SDL with Successes Identified in the Literature

Key Features of Success Identified in the Literature	Features of SDL
Self directed management of funds	An infrastructure developed to support the management of individualised funds
Allocation of block funding to services, when implementing self-directed care and individual funding	SDL is not a service and does not seek to be. P2P, K4M, KHS has developed from fragmented funding arrangements
Local area coordination, so that local needs and preferences shape actual services	The development of Enabler roles and Family Action Planning Networks enable this feature
Provision of infrastructure supports that are separate from the service system	Highly developed infrastructure support across P2P, K4M, KHS. Intentionally separated from service delivery
Implementation of alternative quality systems	Planning tools and goal setting instruments provide alternative methods of measuring quality rather than measuring the quality of business processes.
Use of mainstream services	Utilisation where appropriate to individual planning
Blend of formal and informal supports	Utilisation according to individual context and circle of support. Families are very involved
Focus on person and individual need and high relevancy to individual context. Transparent person centred planning	Person centredness and transparency strongly embedded in vision, mission and activities particularly planning
Consumer control	Family/ key holder controlled planning and decision making
Consumer directed	Parent/ family/ key holder led
Utilisation of existing community services	Utilisation of available services dependent on individual context/ circle of support
Use of facilitators/ network builder separated from service system	Family Facilitators – P2P Facilitator/ enablers – K4M
Supported decision making	P2P, K4M planning activities and workshops such as Nice Peoples Group
High level of family involvement	High level of family led planning and direction
Collaborative planning	Intensive and well developed planning, skill development and support through P2P.
Flexibility	Analysis supports high degree of flexibility present.
Capacity to respond to crises	Demonstrated resilience and planning -problem solving for crisis response and barriers

In terms of barriers and enablers, participants reported a positive political climate where efforts and innovation were currently being recognised and were hopeful that future barriers will be addressed through a dialogue and the mutual goal of meeting the needs of people with disabilities and their aging family carers. Enablers are the characteristics of SDL described throughout this evaluation that drive families towards innovative solutions. Cho (2007, p.31) identifies the factors that predict the effectiveness of human services organisations despite the multiple material dimensions against which effectiveness is often measured. Planning and goal setting processes and documentation provide alternative methods of quality measurement recommended in the literature that are more suited to community

driven activities than those which focus on measuring procedures and business outcomes. Factors for success identified by Cho (2007) are goal congruence, participation in decision making, culture, climate and management strategy. Alignment of partners and allies will ensure optimal outcomes.

A House of Representatives' Inquiry into quality and service provision to people with disabilities in New Zealand was conducted in 2008 (NZ HR, 2008). There were concerns regarding monitoring and auditing processes that focused on systems compliance rather than outcomes such as quality of life of the people actually receiving services. Disability Services' auditing processes moved instead towards developmental evaluation that shifts focus from systems to processes and encompasses measures such as a person: reaching their goals; making decisions about their own living arrangements; and access to services that foster independence and self determination. The evaluation concluded that: outcome focused evaluation processes were appropriate for disability standards; people with disabilities and their families had key roles in a measurement and monitoring process.

A model preferred by SDL is Standards and Monitoring Services (SAMS, <http://www.sams.org.nz>) operating in New Zealand since 1979. SAMS is an independent, charitable trust whose board members are family members and self-advocates. SAMS works nationally and internationally to promote service development through conducting evaluation, delivering training and undertaking research. SAMS created the Multi-Perspective (developmental) Approach (MPA) in 1994. This approach provides a framework for a range of stakeholders to work together using external evaluation as a forum for quality improvement. Since 1985 SAMS has conducted over 3500 service evaluations in New Zealand and since 2003, completed individual interviews, directly associated with the Disability Sector, of at least: 1600 support agency staff, 1300 service users, 1050 family members, 400 employers and 300 individuals involved in governance roles. These research activities provide promote credibility regarding this approach. SAMS identifies processes such as certification, routine audits and evaluation have a valid role, however, in some instances it can erode strategic, effective and efficient quality activities and service development in the disability sector. MPA

uses qualitative methods of evaluation and a partnership model, methodology consistent with principles of consumer focus, partnership, inclusion and equity. The SAMS MPA enables both a process and outcome focus where evaluators equitably represent multiple viewpoints and compare the outcomes. The attributes of a SAMS evaluation focus are: the effectiveness of desired policies, procedures and practices, the development of excellence, a catalyst for innovation, gathering experiences and opinions, individualised outcomes, obtaining information from all stakeholders, flexibility and inclusion. SDL is a partnership model, is interested in quality outcomes, is a catalyst for innovation, is flexible and inclusive.

SDL 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. It also describes a way of being, that is, leading self-direction 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. Though not necessarily an easy road, SDL is a preferred way of operating for families of people with disabilities who participated in this study.

The self directed and organic nature of SDL and its reflexivity and adaptability to local conditions means leaders can replicate the framework in line with the Queensland experience drawing on knowledge and products (such as planning instruments and those financial products provided by Foresters) developed specifically for Queensland and adapt them to local context and need. The framework can be transported, shaped by local conditions while keeping true to the core features and dynamic flexibility of SDL.

One important aspect of an interpretive phenomenological analytical approach is to understand a phenomenon at a deeper level. This understanding is reached by an awareness of the interaction between researchers and the phenomenon being studied during the analytical processes and the influence of the researcher on the process. The influence of the researchers on this analysis included pre-existing knowledge of research and practice experience in this field while admiration for the

women involved in SDL in Queensland who show spirit, ingenuity, highly developed organisational and leadership skills grew as the evaluation progressed. Their sense of connected community and capacity to work together, create new alliances and new ways of thinking is astounding given the lack of resources and high personal and professional demands.

Conclusion

SDL is unique and represents a new way of thinking about service delivery in Australia which has considerable benefits for people with disabilities, families and partnership organisations particularly governments. It is its autonomy, flexibility and organic nature, despite complexity, that enables it be both responsive to need and to problem solve both crises and future possibilities. It delivers positive outcomes for individual families and future possibilities are exciting. Local barriers to implementation in other regions, such as the 'unbundling' of block-funded services, bureaucratic accountability requirements and political will, may need to be addressed to enable replication of the SDL framework. Likewise, financial support for the work conducted by SDL is important to this crucial time in its development. Stable financial support that will not disrupt or change the very features that leads to SDL's success yet support the expansion and replication of a model that is effecting very real change in the lives of people by offering genuine choice is important to a planned and viable future.

Recommendations

1. Fragmented funding arrangements have been identified as a threat and a barrier to SDL adding a level of complexity that could be eliminated with stable funding arrangements to support SDL activities.
2. Recurrent funding for the continuation and expansion of a K4M and KHS to ensure positive outcomes are sustained as outlined in Figure 4 on page 60 in order to progress the self direction agenda.
3. Funding to support the Nice People Group currently run on a volunteer basis and other planning activities necessary for the development of people with disabilities.
4. Support to replicate the SDL framework and other local models in other regions.
5. Outcomes of dialogue between families, Foresters and Disability and Community Care Services that will support sustainability and expansion issues.
6. Opportunities for future research such as exploring short and long term outcomes for people with disabilities who have left home to live independently.

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Appendix A

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.

Appendix B

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 C

Dear (participant)

Parent to Parent, Queensland, has asked the School of Human Services and Social Work, Griffith University, to conduct an evaluation of the Self Direction Leadership model for families involved with the organisation. Mrs Julie Simpson has suggested that you are a key person who may help us understand the Self Directed Leadership model and be able to provide information important to this evaluation.

I have attached information concerning the evaluation for your perusal. If you are willing, I would like to ring you in a few days to provide an opportunity to answer any questions you might have and make an appointment for an interview if you are willing to participate in this evaluation. Your participation is totally voluntary. An interview is anticipated to take no more than 60-90mins. Please feel free to contact me in the meantime if there are any issues you would like to discuss. My contact details are 07 33821228 or p.fronek@griffith.edu.au.

This evaluation project will be conducted in accordance with the National Statement on the Ethical Conduct of Human Research (2007). If potential participants have any concerns or complaints about the ethical conduct of the project they should contact the Manager, Research Ethics on 3735 5585 or research-ethics@griffith.edu.au.

Kind regards

Dr Patricia Fronek

Appendix D

Key Stakeholder Interview Schedule Self Directed Leadership

Name of Interviewer:

Name of Interviewee:

Role and Organisation:

Consent Signed:

Collect any relevant policy and procedure documents from interviewee.

Interview Schedule (Semi structured interview)

1.1 Background

1. Can you describe your relationship/ role/ involvement with Self Directed leadership?
2. How long have you had this relationship/ role/ involvement?
3. How did you become involved with Self Directed Leadership?

1.2 Perceptions of Service Model and Integration

4. In a few sentences, could you please describe what you see are the main aims of Self Directed leadership? **OR** what is your understanding of Self Directed Leadership?
5. Can you explain the underlying philosophy of Self Directed Leadership to me?
6. (if relevant) How does this model fit into your service delivery approach/ model?
7. Thinking about the stage Self Directed leadership is currently at, what are some of the positives/ barriers you believe is helping or hindering Self Directed Leadership?
8. So far have there been any structural/wider changes to the way you deliver services to enable Self Directed Leadership?
9. Are there particular people (or the positions they hold) that help Self Directed Leadership achieve their goals?
10. How are new partnerships or alliances formed?
11. How are decisions made?
12. How are problems resolved?

1.4 Identifying/ Engaging Others

13. Thinking about the main target group of Self Directed Leadership, how has your service reached out to people in need of services/ support? What are the main facilitators/ barriers?
14. Are there groups that could be part of Self Directed Leadership that are missing or not engaged as well as they should? What could be done to better engage these groups?

15. Who are the main people you communicate with re Self Directed Leadership? And what this communication looks like – formal/ informal?
16. Which issues do you usually communicate about?

1.5 Outcomes and Summary

17. In your opinion, what are the benefits of Self Directed Leadership?
18. How do you think Self Directed Leadership changes lives?
19. In what ways do you think Self Directed Leadership works well?
 - e.g. Planning and goal setting; engaging the community; meeting individualised needs; decision making; filling gaps in services; collaboration; early intervention; support and education; governance
20. What does not work well?
21. To what extent is Self Directed Leadership organised around the wishes and needs of individual families?
22. How do you think this model works compared to other models?
23. Can you tell me how this model builds on or adds to the existing evidence base?
24. Where do you see Self Directed Leadership in five years time?
25. What does it need to do this?
26. Can you see Self Directed Leadership operating in other locations (can it be replicated)?
27. Can you direct me to any written information or other person who might be useful to this evaluation?
28. Is there anything else you would like to discuss?

Thank you for your time and valuable contributions to the evaluation of Self Directed Leadership.



Evaluation of Self Directed Leadership Conducted by Griffith University

Key Stakeholder Interviews

INFORMATION SHEET

Who is conducting the evaluation?

Dr Patricia Fronck and Professor Lesley Chenoweth
School of Human Services and Social Work, Griffith University

Why is the evaluation being conducted?

1. To evaluate Self Directed Leadership as an appropriate intervention for people with disabilities.
2. To evaluate its effectiveness in meeting the needs of families with adult children of disabilities.
3. To identify threats and barriers to the continuation to the continuation and replication of Self Directed Leadership.
4. To understand the model and how it operates to meet the needs of the client group.
6. To contribute new knowledge and evidence to the national social policy agenda.

What you will be asked to do

You will be asked to participate in an audio-taped semi structured interview, to be transcribed and later destroyed. The interviewer will ask questions of you pertaining to your knowledge of Self Directed Leadership and people with disabilities and their families.

The basis by which participants will be selected or screened

Key stakeholders have been identified by Parent to Parent, Queensland.

The expected benefits of the evaluation

The outcome of the evaluation will provide information to Parent to Parent about the model, identify barriers and opportunities regarding the future of the service. This can contribute to new knowledge regarding services for people with disabilities. The outcome of the evaluation will be published in a report provided to Parent to Parent and may be published in an academic journal.

Risks to you

Risks associated with participation in this evaluation are minimal. Attention will be

given to protect participant's identities in presentation of the evaluation findings.

Your confidentiality

Interviews: Once identifiable data has been collected, by way of audio-taped face to face interviews, participant identities will be protected but participating agencies will be named in the evaluation. The audio-tapes will be stored in a locked filing cabinet within the School of Human Services until transcribed. The audiotapes will be destroyed once transcribed and the transcripts will be stored in a locked filing cabinet within the School of Human Services for the period of time required by ethical standards.

Your participation is voluntary

Participation in the interviews for the Self Directed Leadership project is voluntary. Participants are free to withdraw from the evaluation at any time.

Questions / further information

Should participants have any further questions, or require further information, they can contact:

Dr Patricia Fronek

School of Human Services and Social Work

07 3382 1228

p.fronek@griffith.edu.au

The ethical conduct of this research

This evaluation project will be conducted in accordance with the National Statement on the Ethical Conduct of Human Research (2007). If potential participants have any concerns or complaints about the ethical conduct of the project they should contact the Manager, Research Ethics on 3735 5585 or research-ethics@griffith.edu.au.

Feedback to you

A report of the evaluation will be provided to Parent to Parent and be available to participants. Transcripts of the audio-taped focus groups will be made available to participants for verification upon request. All presentations of research findings will be made available to participants upon request. The report can be obtained by contacting:

Dr Patricia Fronek

School of Human Services and Social Work

07 3382 1228

p.fronek@griffith.edu.au

Privacy Statement:

The conduct of this evaluation involves the collection, access and/or use of your identified person information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. However, your anonymity will at all times be safeguarded. However, participating agencies may be identified. For further information consult the University's Privacy Plan at

www.gu.edu.au/ua/aa/vc/pp

Or telephone (07) 3735 5585.



Evaluation of Self Directed Leadership Conducted by Griffith University

Key stakeholder interview - Consent Form

Researchers:

Dr Patricia Fronek and Professor Lesley Chenoweth
School of Human Services and Social Work, Griffith University

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this evaluation will include participating in an audio-taped interview;
- I have had any questions answered to my satisfaction;
- I understand the risks involved
- I understand that there will be no direct benefit to me from my participation in this evaluation
- I understand that my participation in this evaluation is voluntary
- I understand that if I have any additional questions I can contact the evaluation team
- I understand that I am free to withdraw at any time, without comment or penalty
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and
- I agree to participate in the project.

Name _____

**Agency/
private citizen** _____

Signature _____

Date _____



Evaluation of Self-Directed Leadership Conducted by Griffith University

Focus Group

INFORMATION SHEET

Who is conducting the evaluation?

Dr Patricia Fronck and Professor Lesley Chenoweth
School of Human Services and Social Work, Griffith University

Why is the evaluation being conducted?

1. To evaluate Self Directed Leadership as an appropriate intervention for people with disabilities.
2. To evaluate its effectiveness in meeting the needs of families with adult children of disabilities.
3. To identify threats and barriers to the continuation to the continuation and replication of the Self Directed Leadership.
4. To understand the model and how it operates to meet the needs of the client group.
6. To contribute new knowledge and evidence to the national social policy agenda.

What you will be asked to do

You will be asked to participate in an audio-taped focus group, to be transcribed and later destroyed. The facilitator will ask questions of you pertaining to your knowledge of the Self Directed Leadership and people with disabilities and their families.

The basis by which participants will be selected or screened

All parents will be invited to participate.

The expected benefits of the evaluation

The outcome of the evaluation will provide information to Parent to Parent about the model, identify barriers and opportunities regarding the future of the service. This can contribute to new knowledge regarding services for people with disabilities. The outcome of the evaluation will be published in a report provided to Parent to Parent and may be published in an academic journal.

Risks to you

Risks associated with participation in this evaluation are minimal. Attention will be

given to protect participant's identities in presentation of the evaluation findings.

Your confidentiality

Focus Group: Once identifiable data has been collected, by way of audio-taped focus groups, participant identities will be protected by way of assigning pseudonyms in transcription. The audio-tapes will be stored in a locked filing cabinet within the School of Human Services until transcribed. The audiotapes will be destroyed once transcribed and the transcripts will be stored in a locked filing cabinet within the School of Human Services for the period of time required by ethical standards.

Your participation is voluntary

Participation in the focus group for the Self Directed Leadership project is voluntary. Participants are free to withdraw from the evaluation at any time.

Questions / further information

Should participants have any further questions, or require further information, they can contact:

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**Evaluation of Self Directed Leadership
Conducted by Griffith University**

Focus Group - Consent Form

Researchers:

Dr Patricia Fronck and Professor Lesley Chenoweth
School of Human Services and Social Work, Griffith University

By signing below, I confirm that I have read and understood the information package and in particular have noted that:

- I understand that my involvement in this evaluation will include participating in an audio-taped focus group;
- I have had any questions answered to my satisfaction;
- I understand the risks involved
- I understand that there will be no direct benefit to me from my participation in this evaluation
- I understand that my participation in this evaluation is voluntary
- I understand that if I have any additional questions I can contact the evaluation team
- I understand that I am free to withdraw at any time, without comment or penalty
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 5585 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and
- I agree to participate in the project.

Name _____

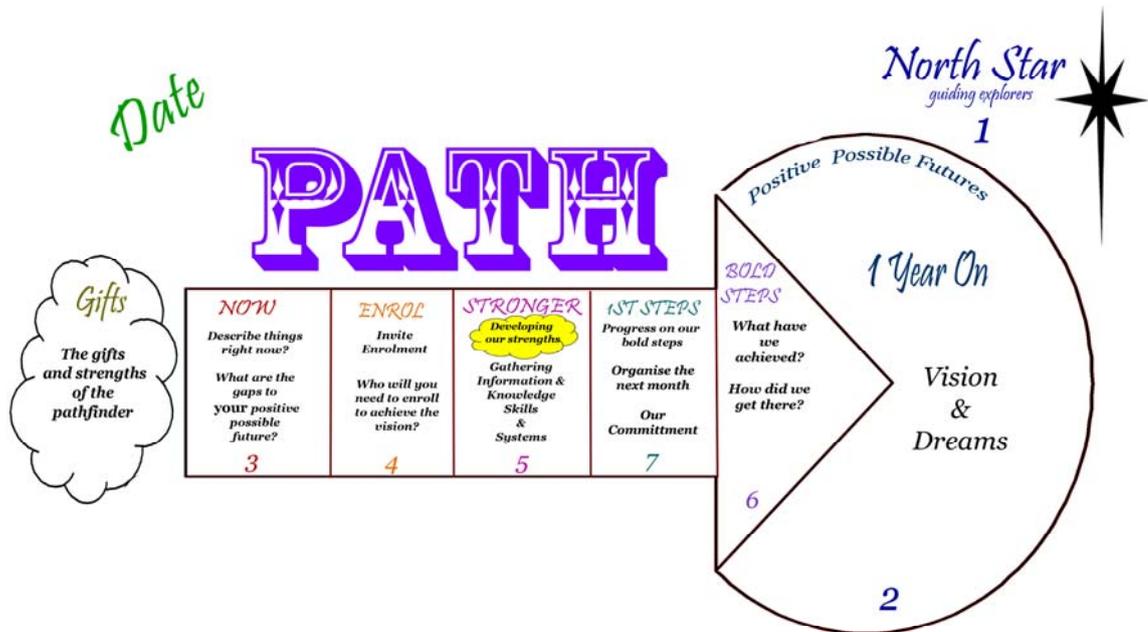
**Agency/
private citizen** _____

Signature _____

Date _____

Appendix G

PATH



From: J. O'Brien, J. Pearpoint, & L. Kahn The PATH and MAPS handbook.
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Appendix H

A VISION OF MY COMMUNITY LIFE Planning Template



Parent to Parent Association Queensland Inc.

Contact details

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©This template has been developed by Parent to Parent Association Qld Inc., adapted from Julie Simpson & Associates (1990); The Learning Community- Helen Sanderson & Associates; and Support Planning Cards, a publication of www.Shop 4 Support.com
www.Helensandersonassociates.co.uk; www.incontrol.org.uk

This guide/template has been developed to assist you to apply for resources, what you need to have a desirable future within your Community. The set of questions is provided to help your thinking and the positive, creative ways you can put on paper to action. The thoughts and answers you come up with using this template can then be used to action your plans.

At Parent to Parent we call this planning, and this can occur in 2 ways, one to one with a family or individual or in small groups of people. The following template questions have been designed to be used in groups or individually. As the funding application is asking the person with a disability the direct questions (in the first person), we have designed our own questions in the same way. Later on there are some questions which can be answered from the point of view of the parents or guardian.

A support plan is a useful and often powerful way of presenting ideas. It will need to detail how resources are going to be used and should include any supportive information or evidence you may have. As you go through this template you might find sections that you are unable to answer because these things are not happening in your life at this stage.

All these questions will need to be addressed in some way as eligibility will be influenced by these things occurring. If you are unsure you could contact Parent to Parent directly on the contact details given on the front page of this document.

So you might be wondering how the following questions can help you with your plan?

Telling your story will mean that people can get a better idea of who YOU (the Focal Person) are as an individual and this will be very important to articulate your planned use of resources

Writing the Plan

1) Your story

In this section you could write a short history of your life as a brief introduction about you. This may include information about your family life, where you are living at the moment, any hobbies or interests, social activities you enjoy. Also include any employment experiences, or voluntary work you might be doing. You might have favourite places you go to or like to travel to. Your story should have as much detail as possible so that other people reading it will get a good picture of who you really are, your spirit, heart and special gifts you have to share.

How will this help me with my plan?

People reading the plan will know a little about who you are as an individual.

2) A Vision of Your Life

This vision of your life is a story that will clearly show what a rich and meaningful life would look like to you. This needs to include your goals and dreams for the future the relationships, friends, places to go, your hobbies and passions, favourite places, things you enjoy doing and new things you are looking forward to doing, so it creates a picture for others to see.

How will this help me with my plan?

Your goals and dreams might include the people in your life, the friends you spend time with, the home you might like to live in. It could be the Job you want, or how much you are enjoying the job you have, and what this means to you, or whether you would like to find some part time voluntary work if you are not already doing so. What is your idea of contributing? It would be really helpful to talk about how you make your own choices and decisions and how you would like to be more in control of your life. This information will let others know the kind of life you are looking for and help you to work out how to make it happen.

- Include whether you would you like to live on your own or share with someone else? How does your family fit in with your plans? Would you like to live close to them so you can see them regularly?
- You can also describe the people you would like to have support you and have in your life apart from your friends and family. What kind of interests and personalities would they have, eg. Friendly, quiet and calm, lots of fun?
- What are the things you are good at? What kind of things give you pleasure? Are there any classes or hobbies you would like to start eg, painting or going to the gym or some other activity?. In this section you can use your imagination and talk about the kind of life you would like to have in the future. Include anything that is important to you.

3) Relationships and circles of support

This is about the family members and friends who support you to, and who will help you to live the life you want to live. Think about how they might support you and how often you will meet with them, maybe for coffee, or outings like the movies. Could they come over in the evenings for dinner or a takeaway? Are they able to help you with transport when you need it? Think about the connections and supportive people who are already involved with helping you, including those who may do so only occasionally. Everyone has a different idea of what a support circle will look like for them, so here are some suggestions if you do not already have a circle and you are thinking what it might be like for you.

- Who will help you to make important decisions? A table has been included for the contact details of people you know to be added into. Think about the people you contact regularly or even only sometimes, it will be handy to have and supporters can remind you to make contact if needed.
- Think of people you know who like to do the same things you do. People all have their own friends and connections who you could come to know in time. Are there people who know you well who you would like to become part of your support circle? It is really helpful to have a person in mind who you would like to run the get-togethers for you. This person could also ask others to become part of your network.
- If you do not have a circle, what would you like that to look like? How would you like it to work?

How will this help me with my plan?

Some of these questions will relate to the section about ways for you to stay in control of your life. Other questions will help you to think about who you want in your circle, what your circle may look like and how the people who are part of it can help you.

4) Gifts and Skills. What are your gifts, strengths and interests; what are the qualities people like and admire about you? Your passion and talents that allow others to know who you are?

How can it help me with my plan?

This helps to show who you are and how you express yourself as the unique person you are, in the way you want to live your life. It helps you reflect on how you can develop your plan in a way that builds on and uses your talents and gifts. You can use your interest, passions, gifts and skills to make new connections with other people, and to share your skills for working or volunteering.

- How do you demonstrate your qualities and how do you give back to your community?
- What opportunities are happening for you to do the things you enjoy?
- Your gifts and skills will link with the” **what is Important to me?**” section and this will be used in your action plan.

5) What’s Important to Me?

My story and my vision include some areas of what is important you. However the more information you give others, the better they will know how to support you to get the life you want.

- What matters to you? What is non-negotiable in your life-things that absolutely must be there?
- What makes you content and fulfilled? Not just what you need in your life.
- Who and what needs to be in your life for you to be happy?
- What things matter to you.
- Knowing what family occasions, holidays and some events are enjoyable to you. Who are some of the important people in your life that you may need help to catch up with? What are the things that give you pleasure?
- **Having people around me who have a good attitude and who like me for who I am, and who will give me opportunities to do what other people can do, be treated just like everyone else.**

How will this help me with my plan?

Other people will know the things that you really must have in your life to be happy and content. They will know what family occasions, holidays and events and places that are enjoyable and important to you. They will know what help you may need to have the things that are important to you in your life.

6) Keeping Healthy and Safe

The important part of this is finding a balance between assisting you to do and have what is important to you, without you being at risk or in danger. It provides information about any medical needs you may have, or the supports you may need in your home or out in the community.

How will this help me with my plan?

This information will need to be taken into account when working out how you want and need to be supported, including watching out for your health and well being. Challenges can often discourage us from attempting new things particularly when a person's health or safety may be at risk if they have medical issues, or a bit nervous about trying those new things they have been thinking about.

7) My ideal supporters

Here you can describe the type of person or people you would like to have around to support you. For example '*I like people who are friendly and listen to me when I have something to say*'; or '*I don't like people who try to boss me around*'. Another example would be '*I would like to have someone who likes the same movies I do so we can have fun together*' or '*I would like to learn to cook so it would be great if they were able to teach me*'. You can include as many qualities for as many activities as you can think of. Also think about how many people you would need around you to be able to do the things you want to do, for example, you might need 2 people to help you with household chores and one person to go out with.

How will this help me with my plan?

This will help you to find the people you want to have around you, so that some of the skills and things you like about them match up with some of the things **you** want to do in your home or in your community. This can link to your diary, calendar, budget and action plan to help get all the details you will need to complete your plan.

8) Staying in Control of My Life

In this part you will need to think about how you stay in control of your life.

- Do you have someone, either family or friends, who supports your decisions and respects your wishes to be independent?

- How will you make important decisions and who will help you?.

An example of being in control would be have a good medical plan and relationship with your doctor.

Another example of being in control would be that you choose the supporters you want.

Include any examples of experiences or situations in the past where you made decisions which allowed you to be in control.

How will this help me with my plan?

The things that help you stay in control will be listed, and the people you want to help you do this will know how to support you.

9) My Home

Whilst you may have already answered part of this question previously, in 'Vision of my life', in this section you can give more information on your ideal home. For example would you like to live in a unit or house?

- Where would you like to live?. Do you need it in a particular place to be close to family, or your work?
- How many bedrooms would you like to have? For example, more than one bedroom would be handy in case you decide to share with someone or so that you can have friends over to stay with you.
- Would you like to have a garden?
- Are there any particular furnishings you would like in your home?
- Do you need any special modifications or features to help to keep you safe in your home?
- Do you need to live close to public transport and shops?
- Include as many specific details as you can think of to create a picture of your home.

How will this help me with my plan?

This will give everyone a clear idea of what you want, who you may want to live with, and how your home will support you to live in and enjoy your community, go to work or volunteer, and be near the things you need to be near.

10) Reviewing Plans

People will want to re-look at their plan to add or change things. This can be done when needed. Sometimes it helps to put in some dates to plan ahead and to make sure you have the people you need to be there to assist you with your reviews.

How will this help me?

It will make sure you plan as often as you need, and that your plan is giving you what you need.

11) How are supports managed?

A budget will need to be created to link to a time table below. This outlines the hours of unpaid and paid support you may need, and how this will work in a practical way. The table is an example only and can be modified to suit your own needs or preferences.

How will this help me with my plan?

The number of hours and support can be calculated and included in a budget to show people exactly what you need to support you.

Weekly Calendar This timetable is an example only and can be adapted to suit.

	Monday		Tuesday		Wednesday		Thursday		Friday		Saturday		Sunday	
	Paid hrs	Unpaid hrs	Paid hrs	Unpaid hrs	Paid hrs	Unpaid hrs	Paid hrs	Unpaid hrs	Paid hrs	Unpaid hrs	Paid hrs	Unpaid hrs	Paid hrs	Unpaid hrs
AM- activity details		Work-		Lawn Bowls		Work-					House work, washing			Lawn Bowls
AM- activity assistance		A catches bus to & from work				A catches bus to & from work					2 hrs			
PM- activity details			Shopping Centrelink- 2 nd week Job									Lawn Bowls		Lawn Bowls
PM-activity assistance		Ten Pin Bowls- Mum drop me off	2hrs				Ten Pin Bowls- Mum drop off		Ten Pin Bowls- Mum drop off					
Evening details			Cooking, meal preps			Indoor bowls					Nice people Group			
Evening assistance		Volunteer bring home	2hrs				Volunteer bring home		Volunteer bring home		1.5hrs			
Overnight assistance	n/a		n/a		n/a		n/a		n/a		n/a		n/a	
Total hrs paid & u/paid for week			4								3.5			

This section below has been specifically requested by DS in the application

This section relates to the challenges table inserted on the last page of the Community Living application. This section is a requirement of the application and has to be completed. Challenges can often deter us from attempting new things particularly when a person’s health or safety may be at risk if they have medical issues. The table has been designed to look at these challenges and then come up with helpful, positive ways or ideas to help reduce the worry associated with the challenge. Examples in the table have been given to help understand how best to fill out this section.

Below are some examples of how to complete this section. It is important that you think of all the challenges you might face when you move into your own home, and then make plans or have safeguards in place to prevent or minimise problems from occurring.

Challenge	Plan/safeguard
You become sick/this may relate to a medical condition you have	Have a list of emergency numbers close to the phone
	Your supporters know what to do if you have a specific medical condition
A fire in the unit	Required fire alarms installed
	A Fire blanket is located in a designated place
	(Name) knows the fire drill and emergency exits

Appendix I

Anne's Story

http://www.parent2parentqld.org.au/personal_stories/documents/Anne%20Story.html

(accessed 24th October 2010)

I recently joined Parent to parent Association Queensland Inc at the Yandina office, and was immediately invited to attend the Workshop on Person Centred Practice. This was all new to me so I just turned up with no expectations and open to receive what information I could acquire to help me with my son who is 10 and has Down syndrome.

Well, I was so impressed by the presenter Michelle Livesley, from Helen Sanderson and Associates in England. Her visual presentation and group activity style was just fantastic. She had my attention the whole time with her beautiful English accent and her professional and organized presentations with clear visual support from the Agenda, the group activities implementing blue sky thinking, through to objectives and results we wanted to achieve. Michelle displayed a clear path of information which I could take in. There was a wide range of participants being parents and professional organizations responsible for carers. I felt the information was related to us and met individual needs, for our children or staff.

I was so excited about the information that I came back for the third day on Friday as I originally was invited for two days. I felt totally relaxed and able to contribute and so did all the other participants. Some were parents and others were professional employed people. So there was a different prospective to discuss and learn throughout the workshops.

My first day was on Community Connections and this was followed by a second day on the topic. The tools presented were on what is in the community and what does the community mean to me. The purpose was to see, try and reflect on tools and exercises which help us to support people to make connections and friendships in the community. I felt equipped to use the tools following the course with exercises like the community mapping and capacity mapping, and staff matching. Another strategy was a hand out of the star exercise, about hopes and dreams.

The third day was to explore risk using person-centred approaches to help people to achieve the changes they want to see while keeping risk in perspective. We looked at how does your organisation manage risk now? Then ways to spend more time defining the problem so that the solution is evident, simple but important research.

Since the workshops Parent to Parent has helped me write a plan for my son's future, with actions that I am now putting in place. Next week I am attending another workshop on Person Centred Thinking, I just want to know more.

Appendix J

Gloria's Story

http://www.parent2parentqld.org.au/personal_stories/documents/Gloria%20Story.html

(accessed 24th October 2010)

When my sister passed away 3 years ago in June 2004 she left a huge void in our lives, not only did we have to deal with the passing of our loved one we suddenly became Guardian of her daughter who has a disability.

It's all very well to grow up with someone but it's very different to suddenly be responsible for her life and future welfare.

We didn't know where to start; we had no idea what was available for someone with a disability and how we would manage if we did find something. We went into panic mode.

Our family member had led a very sheltered existence, rarely accessing the community, henceforth having very limited people skills.

I just did not know where to turn to, then along came my neighbour and friend who is the Local Group Network and Family Facilitator for Parent to Parent.

She suggested that I might like to participate in a Planning Positive Pathways workshop that was about to begin in my local community, which she would be facilitating.

Through the process we would be working towards planning a desirable future for our family members. I was very happy to join the group as I felt I had nothing to lose and everything to gain.

It proved to be the turning point in our lives, not only did it provide me with immeasurable insight into my and my family members psyche, it also gave me the self confidence to know I can do this and do it well.

The course was one day a week over 5 sessions and during that time it put me in a position where I had to really dig deep and cast aside the fact that this is my

family member I'm dealing with and learn to look at the woman instead. I learned many things about not only my family member but myself also during that time.

My ongoing association with the Local Group Networker for Parent to Parent has been invaluable by way of support and guidance, someone to listen to me and help me through the hard times.

The greatest satisfaction I have from doing the course is seeing the results of the plan being implemented into my family members new life and witnessing the change in this person who has now become a beautiful, capable and socially confident woman living life to the full, a life that in the past was not even a dream, it was totally non-existent.

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Focusing on her Gift's, Capacities, Strengths and Interests gave us the means to developing a plan that will sustain her future and quality of lifestyle.

I have since with my family member participated in other Planning processes Parent to Parent has to offer and have found them to be a great way of organising thoughts and creating a desirable, visible plan for the future of my family member.

I am very happy with the outcomes.

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2010



