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Evaluation of Self-Directed Leadership Parents Creating Participatory Lives with Adults with Disabilities Part II: Methodology

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(Prepared for Parent to Parent Association, Queensland)

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 who 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 www.aiidd.org.au). An interview schedule was designed with open ended prompt questions (see Appendix D on www.aiidd.org.au). Probing was used to enable elucidation to facilitate the collection of thick data for analysis. Individual interviews were conducted with four 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 can be found in Appendix E on www.aiidd.org.au.

2. Information gathered in one focus group. Parents of adult children with disabilities 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 can be found in Appendix F on www.aiidd.org.au.
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 generalisation. 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. In Queensland, it has emerged, built relationships and drives networks that address gaps and weaknesses in existing, traditional service delivery organisations 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 ageing parents). Rather, it works metaphorically around, under or over obstacles (traditional pathways) to achieve innovative and workable solutions.

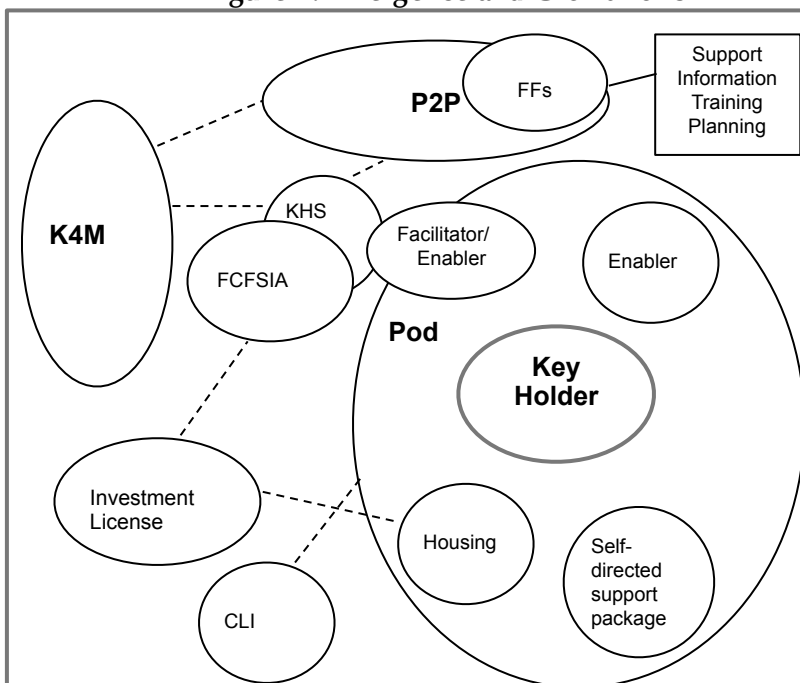
Figure 2 depicts the growth and emergent functioning of SDL. It also became apparent from the analysis that it was not simply a matter of SDL working around obstacles. SDL also predicts where obstacles may lie, pre-empts them and seizes opportunities that might arise by proactively placing themselves 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, 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 Finance and

Figure 2. Emergence and Growth of SDL



Social Investment, Australia (Foresters); A Key for Me Ltd. (K4M); and Key Housing Solutions (KHS). P2P is the nucleo-organisation, that is, where the SDL Model 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 and skill enhancement. It 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 of 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 that 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 that, 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 — proceeds from the provision of training to the then Department of Disability Services, Queensland (DDS) 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 www.aiidd.org.au), 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 DDS 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 DDS, 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 that informal or natural networks remained in tact. This led, in part, to the formation of 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 disabilities, 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 sync 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 an 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 assist with intensive and individualised planning.

'Key readiness', developed by the Strategic Director of P2P 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. P2P 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, we 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, with the sharing of 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 www.aiidd.org.au). 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 1 October 2009, 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 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 Family Action Planning Networks (FAPN) in P2P developed into a Pod in 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 effect 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 daughters 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, 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 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 practising 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 using 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. Under a licensing arrangement with Franklin Covey Pty Ltd., 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. 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 cultivating 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 *Self-directed Funding to the NICD Board* 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. 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 and Gloria's story in Appendix J on www.aiidd.org.au. 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 itself with necessary information, skills and supporting documents to take advantage of them. Likewise, alliance formation increases the resources available to it 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 ageing 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.

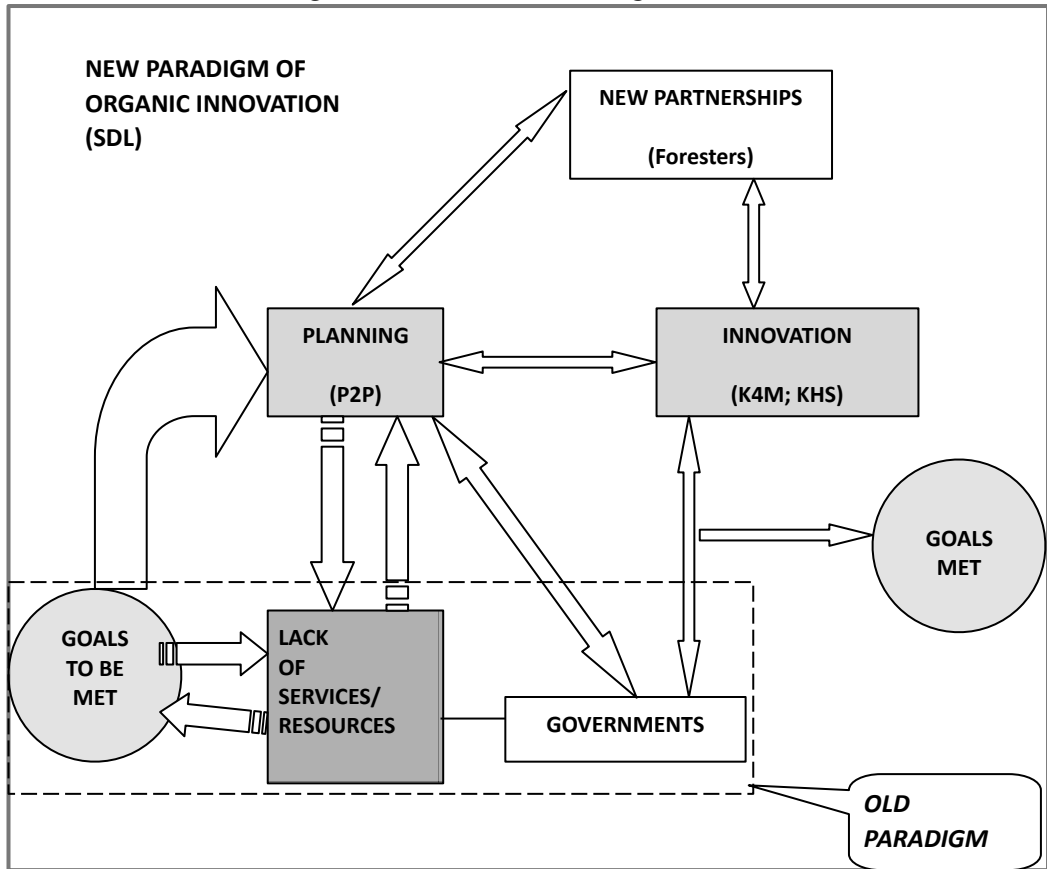
Figure 3. The Process of Organic Innovation

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-judgmental 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 a 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 that 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; 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 was 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.

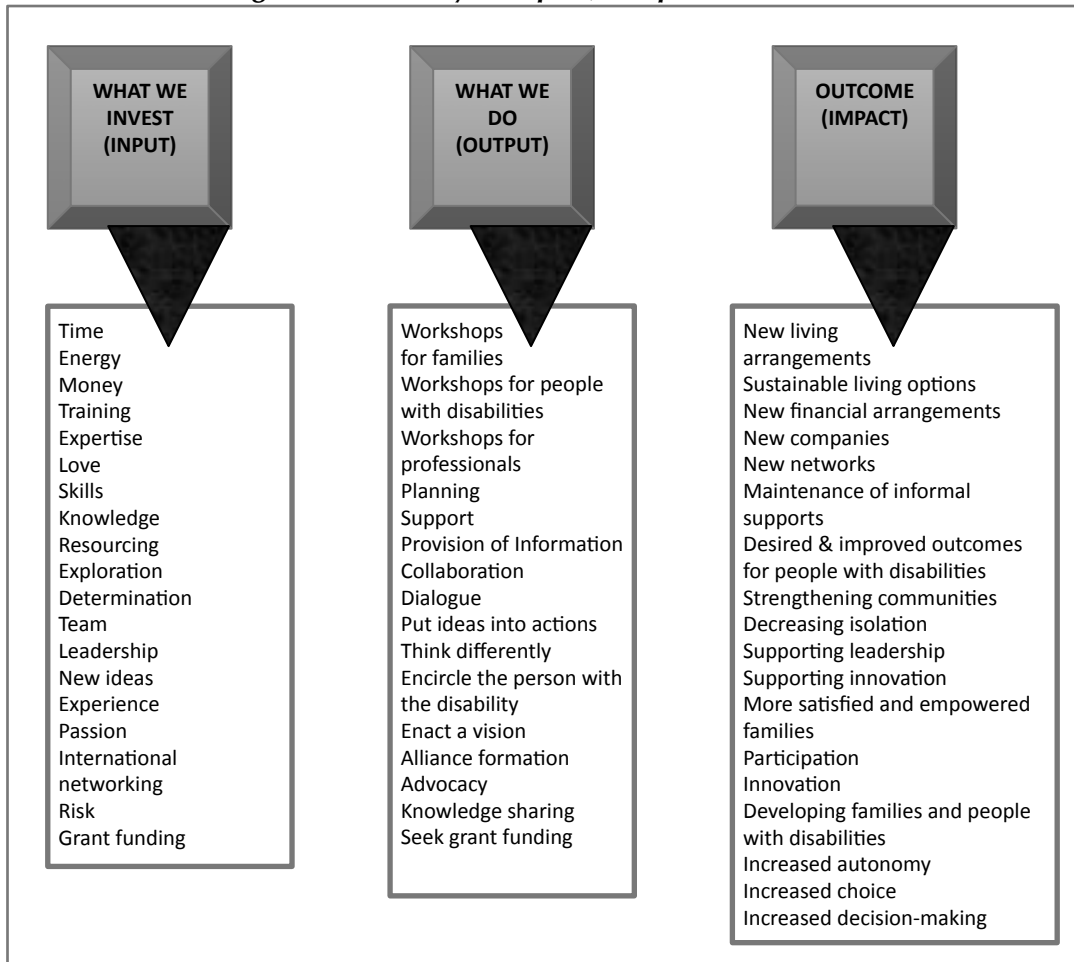
A number of inputs, outputs and outcomes have been identified in the analysis. These are summarised in Figure 4. Considerable time, energy and resources have been invested by families into their children's/family members' futures and finding new solutions despite the obstacles they have faced. As illustrated 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. It began with what only can be described as stitching bits and pieces of funding together with a 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:

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

Parents and families practising 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 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 23 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 judgmental 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 30 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 and sets it apart from other models reported in the literature:

- 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 and KHS have 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 ageing 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 and that 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 3,500 service evaluations in New Zealand and, since 2003, completed individual interviews, directly associated with the Disability Sector, of at least 1,600 support agency staff, 1,300 service users, 1,050 family members, 400 employers and 300 individuals involved in governance roles. These research activities provide and promote credibility regarding this approach. SAMS identifies that processes such as certification, routine audits and evaluation have a valid role, but that, in some

instances, they 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, interested in quality outcomes, a catalyst for innovation, and 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 lead 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 K4M and KHS to ensure positive outcomes are sustained as outlined in Figure 4 on page 29 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.

Please Note:

References: see in *Interaction* Vol 24#2 -- Evaluation of Self-Director Leadership, Part I: Literature Review.

Appendices: see on our website: www.aiidd.org.au