Developing capacity to self direct?
It’s a day to day thing

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Introduction
Traditionally services and supports for people with a disability have been delivered by service providers in facility based organisations through block funding from government. In Victoria in the past ten years the trend has shifted. Funding and support for people with a disability has become increasingly individually tailored, offering more choices through flexible approaches that are built around the individual (Department of Human Services 2001). Funding mechanisms, policies, service and support models have been developed by Government to implement these approaches. In Victoria these are referred to as Self Directed Approaches (SDAs) and are defined as approaches that intend to, “...put the person at the centre of the action and focus on the person’s aspirations, lifestyle, choices and goals” (DHS, 2012). Principles of choice and self determination underpin these approaches making way for greater involvement of people with a disability in planning and managing their supports and services. Underpinning these approaches is an expectation that people with a disability and their informal support networks will actively participate in the planning and assessment processes and direct if not manage the supports and services they receive.

Internationally SDAs have been implemented for a number of years leading to what Lord & Hutchinson (2003) refer to as a “paradigm shift [that] reflects a move away from institutional services and professional control towards an emphasis on self-determination and community involvement” (p. 71). However, much of the research and policy development work has been on funding and management mechanisms. Less attention has been paid to the way people with a disability, and in particular people with an intellectual disability and their supporters including family and other informal supports develop their capacity to participate in and use these approaches.

This report is about a project that sought to build the capacity of people with an intellectual disability, day services staff and families of people with an intellectual disability to use SDAs.

Background
The Victorian State Disability Plan 2002-2012 (DHS, 2002) set goals for increasing individualisation of supports and services and improved community access and inclusion for
people with a disability. A sub goal was to reorient disability supports so that people with a disability could exercise more choice over supports and services; the reorientation of day services was one component of this broader goal. The 2010 Enhancing Sector Capacity Initiative (ESCI) focussed attention on this. It had two strands; Leadership in Reorientation of Day Services (LIRDS) and Leadership in Self Directed Approaches (LISA). LISA funding was provided to ten day services to develop innovative practices to implement SDAs and to partner with DHS to lead the overall transition in the sector. LIRDS funding was provided to each region to establish a working group with broad representation to enhance the capacity of CEOs of organisations to lead the transition to SDAs and to support families to understand options available to their family member through these approaches.

In the Eastern Metropolitan region an existing network, the Eastern Disability Services Network (EDSN) undertook the role of the regional LIRDS working group. It was funded by LIRDS to achieve the following outcomes:

- CEOs and Day Service Managers have an understanding of the philosophy and issues associated with self-directed approaches and an outcome based approach to quality monitoring;
- CEOs and Day Service Managers have the capacity to undertake the organisational and individual planning necessary to implement self-directed approaches;
- CEOs and Day Service Managers have the capacity to lead the organisational, cultural and practice change necessary to implement self-directed approaches;
- Supporters of people with a disability have an increased awareness of the options available through self-directed approaches and ISPs and how to access them.

A reference group with representatives from Disability organisations and advocacy groups was established to develop a proposal to meet the fourth outcome. This reference group developed the following two strategies:

- Develop a local champions approach to building the capacity of people with disabilities and their supporter within each day service in the region;
• Use a local area/place based approach to bringing people with disabilities and/or families together to grow their capacity in directing their own supports (EDSN, 2010).

From these strategies the group developed a set of expected outcomes they named Key Performance Indicators;

• Develop regional expertise in Capacity Building for supporters of people with disabilities in leading/determining their own planning and supports;
• Build family/supporter capacity and participation in SDA (Self Directed Approaches).
• A Capacity Building (families) champion is identified and developed to lead the work of each EMR day service in developing family capacity.
• A group of approximately 10-12 people, family members or supporters of people with disabilities, are identified and developed to provide family to family peer support in developing family capacity.
• Community forums held providing families with information about self directed approaches, local service providers and service types, opportunities to connect with families from the same communities (EDSN, 2010)

The agreed goal for the reference group was that people involved would develop their capacity to participate in SDAs and could become mentors for their peers so they could also develop their capacity. At an early reference group meeting the researcher employed to undertake the project sought to find out what the reference group understood by this goal; the following questions were posed to the group,

• Where are we starting from? – what knowledge/skills/experiences do people already have?
• Where do you want to get to? – what knowledge/skills/experiences do people need to have?
• How will we/they know when they are there?
• What will support the ongoing development and sharing of capacity to direct own services?
The discussion that followed indicated questions such as this had not necessarily been discussed before and there was not an agreed position on these points. There was a silence when the first question was asked, “What does building capacity mean?” Further facilitation of the discussion resulted in the emergence of some key themes.

- it is about more than information about funding and the ‘how to’;
- whatever happens there should be an establishment of collaborative relationships between services, people with a disability and families;
- self does not mean on your own;
- building capacity is an ongoing task.

The reference group members acknowledged it was not clear what the starting point was, that little had been done to establish what people with disabilities, family members and staff knew and were doing or what they needed in order to ‘participate in’ SDAs. The question of championing was also raised as this was a key strategy identified by the group for the project.

In summary people agreed the project should be talking about ‘mentoring’ rather than championing and being a mentor meant that people could be a resource to each other. One reference group member said “I want to get others to be interested in this”. This discussion indicated the reference group themselves needed time to reflect on what they were expecting of participants in the project and what their own understanding of capacity building was.

A review of the LIRDS and LISA aims (DHS, 2010) also suggested there were a number of assumptions underpinning these initiatives. Specifically that ‘cultural change’ was needed within the sector to reorient day services, that change would occur through increasing the leadership capacity of CEO’s and day service managers and that increased knowledge about SDAs would enable people who support people with a disability to reorient to SDAs. People with a disability were not named as key stakeholders in these initiatives, suggesting an assumption that they would be the beneficiaries of the changed culture rather than proactive change agents. A further assumption suggested by the timelines was that cultural change could occur within a twelve month period and that there was a readiness in terms of willingness and resources for families to champion SDAs. Most importantly perhaps was the assumption that SDAs were new and different from what people had been used to. Notably, the framework provided by the Intellectually Disabled Persons Services Act (1986) and the approaches used by services over the past two decades are underpinned by similar principles.
as those articulated in SDAs; choice, control, community inclusion and self determination. It has primarily been the way services and supports are funded that has changed, but initiatives like the LIRDS and LISA focus strongly on broad scale changes and reorganisation in the disability day sector suggesting adoption of SDA’s requires stakeholders to learn new skills to operate within this service and support environment.

This paper describes an action research project that aimed to build the capacity of people with an intellectual disability, families of people with an intellectual disability and staff from day services in Victoria to participate in SDAs. The paper details the experiential learning method used in this project and reports on the findings, including the efficacy of this approach to supporting people with an intellectual disability, staff and families of people with an intellectual disability to build their capacity to effectively use SDAs.

**Method**

Although the existing strategies set out by the EDSN reference group were the starting point for this project it was agreed during the establishment phase that these would be reviewed. The key aim was to establish and work with three groups to build their capacity to use SDAs. The three groups were; people with a disability currently using funded services, families of people with a disability using services and staff working in services. The method proposed emphasised that to be successful the work would have to be guided by the groups and depend on their engagement with and progress towards self determined goals. A Participatory Action Research framework was used (Rapoport 1970) with an emphasis on collaboration between the participants and the researcher (Fisher et al 2007). Rather than predetermining the project outcomes this approach developed a space for participants to come together and, consistent with adult learning principles, determine for themselves, what they wanted and needed to do to build their capacity. The project focussed on facilitation of this process and reflected on the learnings and outcomes as they emerged through the group work.

The key question for the project was: What strategies assist people with a disability, families who have a family member with a disability and staff from disability day services to develop their individual and combined capacity to participate in SDAs? The following section describes the study design and implementation of the project.
Design
The study had four phases; 1. Recruitment; 2. Data collection - survey/ survey based interviews. 3 Facilitated group meetings 4. Analysis. The research phases were interwoven rather than linear and the analysis was iterative. This approach is represented in the following figure:

Figure 1 Research process

Recruitment
Nine people with a disability, nine staff from disability services and nine family members of people who used services in the Eastern Metropolitan region were recruited by members of the reference group using an information flier (Appendix 1). Recruitment of people with a disability also included an information session at a local self advocacy network meeting. The recruitment period was from December 2010 to June 2011, with the more focussed recruitment occurring from April to June 2011. The numbers of participants in all groups fluctuated over the course of the project. There were a number of issues with recruitment that are discussed in the sections below that give a detailed account of the work with each group.

Surveys/survey based interview
Initial data was collected using a survey (Appendix 2). Staff completed this survey prior to the first facilitated meeting and returned it via email, the survey was used with family members as the basis for the initial phone discussion held prior to the first meeting. For
people with a disability the survey was used as the basis for the first part of the first facilitated meeting. The survey/survey based interviews collected background information about the participants, in particular their reasons for being interested in learning more about SDAs and information about their current knowledge and awareness of SDAs. This information was used to inform the facilitated group work.

**Facilitated group meetings**
Each group participated in two group meetings, facilitated by the researcher and attended by a representative from the reference group, held between September and December 2011. Initially it had been proposed that the groups would combine early in the process and work together on shared goals. This did not occur primarily because as the meetings progressed each group indicated they needed more time together to explore their shared experiences before joining with the other groups to establish shared goals and actions. All meetings were audio taped and used as the key data for reflecting on the group processes and the issues and aims discussed.

These facilitated meetings were the central activity of this project and could be framed as an intervention. The researcher used their knowledge of SDAs and skills as a facilitator to lead the participants through a process of learning, sharing their own experiences and identifying goals for building their capacity to use SDAs.

**Process and Analysis**
A reflective group work approach was used in these ‘meetings’. Ideas generated from each meeting were reviewed by the researcher, summarised and used as the starting point for the subsequent meeting. Reflections sent to the researcher by email from participants and from the reference group members were also used to inform the ‘next steps’ and to understand how the groups were progressing. A cumulative analysis process was applied throughout the project using the *Double Loop* learning approach developed by Argyris & Schon (1996) and applied in a range of learning environments over the past decade (see Blackman, Connelley & Henderson 2004). This learning approach enables learners to reflect critically on some of the underlying factors that might be impacting on change; beliefs, the validity of these within the context of the problem and development of strategies to critically question and address these underlying issues. The participants were guided through this learning process in the...
facilitated group meetings; the researcher asked questions and posed ideas that challenged the group members to go beyond ‘describing’ their experiences to questioning and critiquing the issues raised by their experiences.

The following section outlines the work of each group and the key themes that emerged.

**Detailed account of work with each group**

**People with a disability**

The recruitment process and its outcomes raised a number of issues about supporting people with an intellectual disability to participate in work that impacts on their lives. Many of the services people were recruited through did not take an active approach to informing people about the project, nor were people supported to understand what the project was about and how they could participate.

The reference group member with an intellectual disability determined that an additional strategy was needed apart from circulating information about the project through services (Appendix 3). He suggested that he and the researcher present at the September meeting of a local self advocacy network. Over fifty people from a range of day services across the region attend these meetings each month supported by workers from services. The forum is arranged around the interests of the group and facilitated by VALID. At the September 2011 meeting guest speakers from the RSPCA were talking about pet ownership and care. This presentation went over time leaving five minutes for the SDA project to be presented. The reference group member with an intellectual disability was very disappointed about this experience; he also had to leave early because staff from his day service indicated the bus was leaving.

With assistance from a VALID staff member, nine people were able to express interest in participating. The nine people; six men and three women were from four different day services, one man identified as ‘independent’ meaning he did not use any particular day service. They were all adults whose primary disability was an intellectual disability.

Unfortunately prior to the first meeting one person was withdrawn by their parent who indicated that their adult child would not understand the work and they did not want them to get involved in client councils or other similar groups. The other people from this service
who had expressed interest in the project were not given adequate support to attend the meeting. The staff contact person had been on leave and the people with a disability had not been informed of the upcoming meeting. One other person did not attend because the meeting date clashed with a pre-arranged work commitment and no clear reason was given why the two people from the other day service did not attend.

At the first meeting three people from the one service attended including the reference group member with an intellectual disability. Given the poor attendance the staff representative from this service suggested they could identify additional participants who would be interested in the work. This service was nearby to the meeting venue. Two additional people, both women with an intellectual disability joined the group. All five members; three women and two men aged between 32 and 46 years were from the one service. In retrospect there were some advantages to this as the people knew each other well, they worked on the client council together and were used to talking about issues and sharing ideas and experiences with each other.

**Facilitated group meetings**

Two meetings were held one month apart. The meetings were carefully facilitated to achieve three things; provide accessible information about SDAs; create opportunities for people to share their own ideas and thoughts and to facilitate participants to question and reflect on the key concepts of SDAs in relation to their own lives. At the first meeting the researcher went through the consent process with each participant and completed the survey based interview. The meeting then explored what day services provided for the participants, what they did outside their day service, what they understood about SDAs and what else they needed to know or would like to find out and how? The concept of being a mentor for other people with an intellectual was also explored. At the second meeting people focussed much more on sharing their own experiences, hopes, aspirations and the challenges they faced in being able to self direct. This was facilitated through a group discussion about the key concepts embedded in self direction; having a say, making choices, being heard. The group also watched the DVD ‘Whose life is it anyway’ focusing on the stories of adults with an intellectual disability who, through self directed approaches, had been supported to live independently, work in supported employment, participate in sports and have one-to-one support for daily living. This DVD acted as a catalyst for the group members to reflect further
on their own situations and to articulate their disappointment that they were not ‘self
directing’ in the same way as the people on the DVD; in particular that their often expressed
wishes were not acted on.

At the end of the first meeting the participants agreed they would like to talk to their peers at
their day service about what they had talked about in the meeting and there could be some
benefit in exploring the ideas about having a say, being heard and expressing your ideas in a
client council meeting. The participants reported back at the second meeting they had done
this and after the second meeting agreed they would like to go to other services and talk to
staff and people with a disability about what they had done in the meetings.

Overall, the meetings with this group resulted in some clear reflection about self direction in
the participants’ lives and an increase in their awareness about what the concept could mean
in practice. However, it also led to a realisation by the members that they were not self
directing. A key issue of concern for these participants was the idea of managing money or
funding and their view that they were not able to do this. Underpinning the issues discussed
and reflected on in these meetings was a clear lack of self determination and decision making
by these participants with a strong sense they would like to make more decisions for
themselves and be listened to when expressing their preferences. These themes are discussed
in more detail in the findings section below.

The following diagram summarises the approach used, the key themes that emerged and the
action ideas generated by the group.
Family members

Eleven family members representing nine day services were recruited. Each person received an information flier about the project and was asked to make an expression of interest via a reference group representative (Appendix 1). This recruitment process began in December 2010 and spanned several months. In July 2011 verbal consent was gained for the researcher to contact the participants. Initial contact was made with each participant in August 2011 by which time one person indicated they had forgotten about nominating for the project and had work commitments that would prohibit them from participating and another person was no longer available due to holiday arrangements. Five of the 11 participants were recruited in August 2011.

A survey based initial interview (Appendix 2) was conducted by phone interview with each participant. This interview collected information about their family member with a disability, current knowledge about SDAs and discussed their reasons for wanting to participate in the project. In some instances these phone discussions went for an hour with family members...
providing a detailed overview of their history of involvement with the disability services system and the current and past experiences negotiating funding, supports and services. All participants were keen to meet face to face with other family members saying they had few opportunities to do this and services rarely organised such forums.

All family member participants had children who were adults ranging in age from 19 to mid 40s. Most identified that their children had an intellectual disability, with two also noting their child had Autism, and one noting mental illness as the primary disability. All their family members’ with a disability currently used disability day services with one also using disability residential services. Four noted that they accessed an Individual Support Package (ISP) and this funding was primarily used for in home support to provide respite for the family or to enable the person to live independently in one case. ISPs were also used to support their family member to access the community and to meet costs of transport and therapy.

**Facilitated group meetings**

Two focus group meetings of two hours duration were held with the family member participants at a community house in the outer Eastern region; the first was held on November 17, 2011 and the second on December 8, 2011.

At the first meeting participants shared information about their family member and their experiences over the years with disability supports and services. The focus of this meeting was for participants to get to know each other, to explore each other’s experiences of service use and where relevant SDAs. Another aim was to discuss ideas about developing their own capacity to use SDAs and to explore the idea of being mentors for other family members.

Themes from this first meeting and information from the survey based interviews were developed by the researcher and summarised for the group (See Appendix 4). These points were used as a starting point for the second meeting. As with the first meeting the participants wanted to talk to each other about their experiences and to reflect on what kinds of obstacles they had faced and how in some instances they had overcome these. In general though the second meeting was focussed mainly on further clarification of what was possible if using SDAs and how family members might get access to the best possible options for their sons and daughters. Participants indicated the most useful activity for further developing their
capacity to participate in SDAs would be to have more facilitated group discussions, possibly at a service level but there would be benefits to having ‘across service’ groups like this one.

Overall the discussions at these meetings were about challenges people faced gaining access to services, getting adequate funding for services and knowing what was available and how to access it. Most had heard of or were already accessing a flexible package, mainly ISPs but also talked about Futures for Young Adults and Linkages which they did not recognise as being related to SDAs. One participant described in detail how they were ‘completely self managing’ their son’s ISP, outlining the range of supports and services they had purchased and how they managed the funding, including how they independently developed and submitted the ISP and did the financial acquittal. In response to this others reflected they would not have the skills and knowledge for such an undertaking and would not have the time needed to self manage. Participants reported the most beneficial outcome for them from attending the meetings was hearing each other’s experiences, ‘picking up ideas’ from what others were doing and realising that there were many ways to ‘self direct’. However it was clear they did not have access to information, the source and type of information each had received differed and often gave inconsistent messages and in general they felt they were ‘in the dark’, unsure of what was possible or expected of them. Only one participant indicated they were already acting as a mentor through participation in government reference groups and through a peer support program being developed by DHS. None of the other members were interested in mentoring and did not feel they had enough information, skills or the requisite experiences of self directing to mentor others.

The following diagram summarises the work of the family member group.
Staff

Ten staff (seven women; three men) from eight disability day services participated in the project. The recruitment phase spanned several months. Consent was given for the researcher to contact staff in July 2011, by this stage two people had decided to withdraw from the project. Of the remaining eight only seven participated in the whole project; one person indicated that they would be participating however this person did not attend either meeting.

The organisations represented those that provided more traditional day services as well as ones that had developed flexible programs and supports. All staff participants however, reported they had some knowledge of SDAs. Two participants worked in an organisation they described as being ‘well down the path’ of SDAs while another noted in their organisation ‘they were doing it’. The remaining participants worked in services they described as being ‘more traditional day services’. All but one participant held positions of responsibility including; coordinator, senior staff member, family liaison coordinator.
Facilitated group meetings

Responses from the survey were used as the starting point for the first meeting. In addition, this meeting aimed to bring staff together to share their experiences of facilitating SDAs and to establish some individual goals for increasing their capacity to do this. The meeting also provided an opportunity for staff to critically question the underlying factors that impacted on their capacity to facilitate SDAs in their organisations.

At the first meeting participants were asked to consider what they wanted to achieve from their participation in the project, what they saw as the existing ‘resources’ they had at their disposal to achieve this and what they needed to move further towards their goal. The responses were categorised into philosophical, opportunities and knowledge and skills (Appendix 5). The resources available to them for meeting these goals were categorised as staff/personal; staff/knowledge and skills and organisational. A summary of this work was collated and emailed to participants along with suggestions on how they could progress these goals. The expectation was participants would choose one goal and implement it before the next meeting where they would share with their peers the processes they used and the outcomes. The second meeting was held one month later; only four participants attended this meeting. They gave an overview of what they had implemented in between meetings and reflected critically on the barriers and challenges they faced in developing their own capacity and mentoring their peers to develop their capacity to facilitate SDAs. These approaches are summarised below.

Each participant had tried a slightly different approach including:

- Making time to talk to the people they support and find out from them how the idea of SDA had been used in their support
- Looking for self direction in the programs people were doing; thinking about tools to enhance choice making to go beyond a ‘wish list’ of activities
- Developing a link with a parent who participated in the family member group – considering co-facilitating a workshop with other parents
- Reflection on current approaches asking if they were ‘self directed’ or ‘family directed’ or ‘staff directed.’
Most participants also noted they were looking at what had been done ‘in the name of SDAs’ and considering whether this had led to better outcomes for the person; socially, being included and contributing in their lives.

Capacity of staff to implement SDAs was reported as being dependent on ‘how far along the way’ their organisations were in implementation. Participants thought that more reflection was needed to critically question what was being called SDAs and they needed to ‘partner with family members and people with a disability to facilitate SDAs.

The work with the staff member participants in summarised in the following diagram.

**Findings**

Earlier in this report it is noted that there were a number of assumptions underpinning the LIRDS and LISA initiatives. These assumptions were; that cultural change was needed; people with a disability and family members could and should ‘champion’ self directed approaches and the approaches that are called ‘self directed’ are new, so people need to ‘learn’ about them.
The following section is organised to discuss the findings in relation to these assumptions and the goals of the reference group that oversaw this project.

**Building Capacity**

An important part of the project was finding out what people understood about SDAs. It was clear with all three groups there was diverse and varied knowledge about SDAs and this knowledge was experiential; what people had learned from their own or others’ experiences. Few of the staff or family members had accessed formal information, and where they had they reported it was confusing. Only one family member reported they were able to ‘completely self manage’ and had primarily used information from the DHS website to find out what was possible. The people with a disability had very little ‘formal knowledge’ about SDAs and had been given very few opportunities to access information or participate in activities/forums that would increase this knowledge. The participants in this project were a somewhat different cohort to those who have been ‘championing’ SDAs through sharing their own stories through workshops run by advocacy groups (see VALID Keys to Success training) and person centred planning organisations.

Building capacity from diverse and varied starting points was likely to require individual definition. The project adopted a group process based on the view that people could gain from sharing their ideas and experiences and could build individual if not collective strategies for building their capacity from facilitated group work. It was clear from this approach that people did have capacity to learn and understand about SDAs but they were lacking information and their experiences had led them to believe SDAs were not for them or were out of their reach.

**Understanding SDAs – staff and family members**

Staff and family members saw funding and changes to individual funding arrangements as the key component of SDAs. They understood that funding could be used to pay for activities or supports for the person, rather than the person going to a service that in turn would determine what people would receive. They understood that there was some level of flexibility in the way the money could be used and were aware that planning had to occur with the person and/or their family/and or other supporter and it should cover the whole of a person’s life.
Family members had very different experiences from staff of SDAs. They had some experience of the processes for accessing funding but most relied heavily on services to inform them about what was possible. One family member was, in their words, “Completely self directing everything”. This family member talked at length about their experience of SDAs and what they had achieved for their child outlining a ‘package’ that enabled 1:1 support at a day service, funding to purchase a vehicle, to pay for therapy and for 1:1 support in the community. Other members of the group had been somewhat overwhelmed by this story as most had access to smaller packages, had waited in some instances up to five years to get one, had limited use of funds for 1:1 support at home that had been used mainly to give them some respite and time away from caring for their family member with a disability. Most also shared stories of difficulties accessing adequate funds to meet their needs, and having to spend a large amount of time planning and organising support. The reflects findings from an Australian study of individualised funding programs (Fisher et al., 2010), that found families or other supporters are significantly involved in arrangements for people with cognitive impairments and the funding provided is rarely adequate to meet the varied and sometimes complex needs of this group. Family members also reflected on their role saying they expected to be consulted and involved and sometimes they would be doing this without their son or daughter having input, but they would be doing it in the best interest of their adult child. This raises an important point about the decision making process and the question of formal supported decision making in SDAs. Most also indicated that they would not be able to self manage because of the limited time, resources and skills including computer skills, financial management skills and the confidence to deal with the system.

Understanding SDAs – people with a disability

All of the people with a disability, apart from the reference group representative were unfamiliar with words ‘Self Directed Approaches’. The discussion about SDAs was facilitated by talking to people about what they did in the lives and what helped them do these things; such as going to a day service, living at home or in supported accommodation, doing house work and doing things in the community like voluntary work and attending a men’s group. The group then talked about what a disability service does for them, they talked mainly about staff and how they helped them do things like setting up client council and
going out in the community to places such as a community house to learn literacy. They also talked about centre based programs like cooking. Summing up this discussion they said:

Well.....it means looking at the individual and what they want to do (P1)

Teaching other people what is right and wrong and helping other people (P2)

I reckon for me I want to become a leader(P3)

The idea of self directed planning was also discussed. One person talked about how their plan was developed, “I have an individual program plan..my mum my key worker ......me with assistance from [name of worker]...but mainly me” (P2). Another noted that they did not have a plan they just “took each day at a time”.

Funding was a key issue. When the question of self directing funding was discussed it was clear that managing money was a big issue. Three participants talked about the support they got for budgeting and that they did not make their own decisions about money with family members managing their finances for them. Two participants had a clearer idea about what self directing funding meant, one was on the project reference group and the other had attended a conference where SDAs were discussed. They said, “It means about getting more money” (P1) and “It means directing it to what you want to” (P2). After this discussion the researcher asked what people knew about the idea of self directed support, P2 responded:

We know someone who comes to [day service] but not all that often and he gets Self Directed funding and sometimes one of the staff at work worked with him once didn’t she [P1 and P3] and I might mention his name [....] and he comes to[day service] sometimes and does other things other times.

This is an example of the experiential knowledge that people have, but also reflects the way words and concepts on their own, or even expressed more plainly, are unlikely to be understood by people like those who participated in this group. To gain an understanding of these concepts and to engage with the ideas, people need time to work through what they know with support to link the ideas with their own and other’s experiences. At the end of this session participants considered what they needed or wanted to know more about to better understand SDAs and help others understand them. The conversation went straight to money
and the difficulties people had managing money, getting the opportunity to manage money and to be ‘allowed’ to make decisions about their money. One participant said, ‘I don’t know if I told you or not but I have trouble with my money’

Summary
Participants had varied knowledge and experience of SDAs. Most gained this knowledge experientially, with some accessing information that was available through websites or information developed by services. Most family members were working from their own experiences and acknowledged that getting together with other families had ‘opened their eyes’ to what was possible. Staff were somewhat limited in their knowledge by how their organisations were implementing the ideas associated with SDAs, few indicated that they had learned about SDAs through training or attending conferences. For people with an intellectual disability the key to understanding SDAs was having time to hear about what they meant and to relate this to their own lives and the lives of people they knew.

Mentoring
All three groups rejected the idea of being mentors for their peers. They recognised the benefits of sharing ideas and learning from each other’s experiences. However they felt they did not have the breadth of experience, and in some cases, particularly for family members, the motivation and time to share their experiences with others. Their goals were more personal and individual. Only the people with an intellectual disability suggested they might formally share what they had done with their peers and possibly staff in other services, however the group work with them uncovered inconsistencies between their own experiences and what policy suggests SDAs are about.

People with an intellectual disability
The people with an intellectual disability recognised that they were seen as people who could be ‘leaders’; three members of the group talked about leadership and self advocacy courses they had completed, and all five members of the group belonged to the client council at their day service. Therefore they expected that they could and would talk to other people including peers and families about self directed approaches, however, this process revealed that despite being able to ‘spread the word’ if it was given to them, they were not able to do this from their own experience.
The people with a disability raised some important points – in particular that it is hard for them to ‘champion’ SDA when in their own lives they feel they have not been listened to and that they have not been able to ‘self direct’ to get some very important things actioned for them eg moving into a more independent living situation; accessing further education; using public transport. This discussion was excellent and indicated that we have to work carefully with people when asking or inviting them to be spokespeople about enabling policy - making room for people to express their personal experiences and perhaps supporting them to achieve these. (Field notes)

The group work process gave each person an opportunity to reflect on what self direction really meant or could mean for them and each person found in fact they had little self direction in their own lives without which they could not truly ‘mentor’ others to participate in SDAs. The reference group observer in this group noted that people were ‘constrained and contained’, primarily by their disability and what people like family members and support staff perceived they could do. The process of the group work did however increase their awareness of what self direction meant.

So for (P1) when in a moment he experiences around him friends who are speaking simply and openly about their heartfelt desires, and it’s OK he takes the risk, and with huge difficulty opens up about his own unfulfilled hopes as well. (Fieldnotes)

Further reflection on what people can achieve through SDAs was facilitated by watching the DVD ‘Whose life is it anyway’ and seeing what the people with a disability in the DVD had achieved. The participants immediately spoke up about their own hopes and the challenges they faced being heard in their lives once the DVD had finished.

P4 wants to catch public transport but their guardian won’t allow it because they once got lost

P5 wants to live independently and is ‘saving’ to do this. Their family have told them they can when they has ‘saved enough money’. This participant spoke often about the problems they had with budgeting and the limited opportunity they had to budget.
P2 wants to study but has been told by their mother it is too expensive. During the group discussed they realise they could use funding that they currently use for day services to attend a course but says their mother will not agree

P1 through the group work was able to articulate that he wants to move out of shared supported accommodation, they have apparently said this many times in planning but nothing has happened about it

The group meetings gave this group access to information and time to consider their own experiences in relation to others. Although this enabled them to identify that they wanted to experience self direction in their lives, they indicated very clearly they would like to talk to other people about SDAs, in particular other people with a disability at their own services and other services. One participant suggested they go to a neighbouring day service and ‘do what we had done’ in the facilitated group meetings, another suggested they also might consider talking to staff in their services and others about the kinds of things they had found out during this project.

**Family and staff**

Family members were hesitant to consider mentoring or championing SDAs and similarly to the people with a disability indicated they needed more time to ‘get the best they could’ for their sons and daughters before they would talk to others about how to do it. They recognised the value in meeting together and talking about what was possible, sharing information and experiences, and through facilitated discussions reflecting on some of the challenges they faced and how these might be addressed. They suggested that ongoing meetings would be helpful and talked about the benefits in learning from each other. Some of the things they suggested such groups might achieve were very similar to the aims of family advocacy groups, however none of these participants were members of this type of group.

The one family member who was already self managing funding did not attend the second session recognising their experiences were very different from the rest of the group. However this family member did offer to share more information with this group or other groups if requested. Despite what seemed to be an overwhelming task managing their child’s funding and support packages, working full time, and being involved in many government led reference groups and forums about SDAs, this person remarked on how they valued the
opportunity to participate in these forums. Most other family members however, felt left behind, incapable of self managing, and as they had not achieved what this person had, would have little to share with others.

There is currently a strong emphasis on people telling their stories to illustrate the benefits of SDAs. This project suggests that people do benefit from sharing their experiences and that experiential learning is effective. It raised a concern however, that people may be led into this role before they have adequately considered their own needs. Whilst a different recruitment process might have had more success in recruiting family members who were ‘ready’ and ‘able’ to mentor, it is unlikely that the majority of family members have such readiness. It is worth considering the experience of this project that carefully facilitated group work can provide a safe and supportive forum for people to consider their own experiences in relation to others who have a similar ‘starting point’. Such an approach could build their capacity to participate in SDAs. The family member group noted that despite this approach being a somewhat ‘old fashioned’ way of doing things, it had worked well. They indicated a strong interest in continuing to meet together, expanding the group or developing their own groups in their services. All of these options have merit; however they require resourcing, particularly through careful facilitation.

The staff group identified that their capacity to facilitate SDAs was dependent on the way their organisations were implementing them. They recognised the resources they had within their organisations, with one staff participant noting they “did not need to know everything about implementing SDAs” because they had a manager who did this very well. What they considered important was good team work at the organisational level so such resources were used. Staff training was also noted as important, in particular the group suggested that all staff needed to understand the philosophy of SDAs and know how to reflect this in their practice. There was some frustration felt by some of the staff participants that they would be trying to mentor others who themselves did not see implementation of SDAs as their role. One manager discussed the importance of recruiting staff who understood these principles and providing a robust staff training program that built on these principles and were addressed in staff appraisals. Most of the staff recognised the principles were not new, that they should be the basis for all practice and where there were new approaches and processes it was important that someone in an organisation could communicate these clearly to people
with a disability and families. They noted however that all staff did not need the same level of knowledge of SDA processes.

Summary
All three groups reflected the importance of learning by experience and sharing these experiences, most importantly the group work indicated that central to the success of SDAs is how people with a disability are considered and how they are brought into the process. Whilst family members had different ideas about their adult child’s capacity to participate, they agreed there was a need to fully understand their preferences. One parent said that what they were able to give was love and what they wanted was to be trusted and to be able to trust others who were involved in their child’s life, they felt able to express this in the group. Another parent noted through this process he had learnt what the ‘self’ part of self directed meant; that his son would not be expected to work this out for himself and it could be managed as a partnership between his son, himself and the service. All three groups recognised that services played an important role in SDAs and they were an important resource to people with disabilities and their family members for learning about and accessing SDAs. In summary these groups valued a collective and networked approach rather than one that expected individual leadership or mentoring.

Conclusions
There were a number of limitations to this project; in particular it worked with a small number of people who were not recruited to be a representative sample. Findings from the project therefore cannot be generalised, however as a qualitative study it was able to richly describe and learn from the processes employed, in particular the facilitated group work and the reflective analysis of what was shared in these meetings.

There was not enough time to fully develop these groups or to support them to develop individual and/or collective aims to build their capacity to participate in SDAs. The assumption that people are ready, willing and able to build their own capacity and mentor others to do this was challenged in this project. Participants needed time and carefully facilitated forums first, to consider their own experiences and then decide how through their experiential knowledge they might be able to build their own capacity and participate with others to do the same.
The experiences of these groups suggest that whilst SDAs are being presented as new and different requiring broad scale changes to service models most people are focussed, as they always have been, on getting the best for themselves, for their family members or the people they support from the system in which day services still occupy an important place. SDAs do offer flexibility and research suggests they can lead to more choice, control and self determination, however there are also shortfalls. In particular, people with a disability and, as the literature suggests, family members in the case of people with a cognitive disability are expected to participate more, manage more and make more decisions (Fisher et al, 2008). This project found there are challenges for each group in doing this. The following field notes reflect some of these issues in particular for people with an intellectual disability:

*Probably many people with a disability will not be seen as capable of self directing by their families and will therefore have difficulties even beginning the process. For people with a [intellectual] disability to participate (in anything) they need clear information, given more than once, regular discussions/reminders about what they have expressed an interest in doing and the implications of participating? That ‘supporters’ need to be able to advocate for people with their families – but this is best done slowly, gently (i.e not at the last minute). That organisations still have some way to go in understanding how to ‘be beside’ people with a disability through processes that are available to people to participate – communication, commitment, clarity etc is needed within organisations (field notes).*

More does need to be done to ‘bring people along’ in understanding and using SDAs. This project suggests that one way of doing this is through carefully facilitated group work that provides information, enables sharing of experiences and uses experiential knowledge to ground the learning in people’s real life experiences. This needs to be done over time and in locally based groups, possibly facilitated by services. It also suggests there is a need to link family members into family advocacy groups that can provide objective and independent advice and possibly a group where these issues can be further addressed. Self advocacy for people with an intellectual disability also has a place in supporting people with an intellectual disability to build their capacity to participate in and better understand SDAs. The self advocacy sector needs resourcing and informed development to be able to support people to have their say about their lives through SDAs.
References


Appendix 1 Information sheet Families and staff

2009/10 Enhancing Sector Capacity Initiative

Leadership in Reorientation of Day Services Initiative (LIRDS) Eastern Region

Information for Participants/Mentors – family & staff

This project is part of a bigger program that wants to make sure people with a disability are involved in planning and having a say about what they want to do in their lives. It is also about working with day services to see how they can support people in this and with families to make sure they know about and can participate in these approaches.

In this project we are interested in working with families, people with a disability and day service staff together to:

- Learn about what self directed approaches are
- Share ideas, experiences, skills and what you already know
- Share ideas about ways of having a say about what people want and finding ways to get there
- Develop new ideas about planning for and using supports and services
- Learn through what other people have done
- Be a resource to other families, staff and people with a disability in the Eastern Region through the project and into the future

We already have some families and staff who have said they are interested in being involved in the program. We are still looking for some more and are also looking for people with a disability through the Eastern Client Network to get involved.

Patsie Frawley from LaTrobe University is going to be working with us on this project. She will be getting in contact with people who have said they are interested and we will all be getting together sometime to talk more about it.

If you have any questions or are interested in being involved, please contact

Stuart Findlay on: Ph: 9857 0289 or Mob: 0458 034 600 or

Email: stuart.findlay@edar.org.au
Appendix 2 Survey

1. Please fill in your name and contact details

Name: 

Address 1: 

Address 2: 

City/Town: 

State/Province: 

ZIP/Postal Code: 

Country: 

Email Address: 

Phone Number: 

2. Why are you involved in this project?

☐ I have a family member with a disability

☐ I am a person with a disability

☐ I work with people with a disability

☐ Other

3. What do you think is meant by Self Directed Approaches?

☐ People can choose what kinds of things they want to do and get whatever help they need to do it

☐ After a person has a plan they get the funding they need to do the things they want and a
support service to help them

☐ Funding can go directly to the person with a disability so they can choose their services and supports

☐ People with a disability manage their own lives

4. What are some other things you know or have heard about Self Directed Approaches?

5. Where have you got information about Self Directed Approaches from?

☐ The day service you are connected with

☐ A staff person at the service

☐ The Department of Human Services website/brochure or person from DHS

☐ Another family member/person with a disability

☐ Other

6. This diagram shows the parts that together make up Self Directed Approaches. Circle any that you think you need to know more about

7. What do you think you need to be able to use Self Directed Approaches?

☐ Information all in one place/one booklet/brochure

☐ A staff person from the service to be able to go to whenever we have questions

☐ To meet with others who have experience and can help us worth things out

☐ Other ........................................................................................................................................................................

Thank you for filling out this survey. Please return it to Patsie Frawley in the addressed envelope or call Patsie on 94793041
Appendix 3 Plain English information sheet

Leadership in Reorientation of Day Services Initiative (LIRDS) Eastern Region

Information for Participants/Mentors – family, staff and people with a disability

This project is part of a bigger program that wants to make sure people with a disability are part of their own planning and having a say about what they want to do in their lives. It is also about working together with day services to see how they can support people and their families to plan for themselves.

In this project we would like to work together with families, people with a disability and day service staff to:

- Learn about what self directed approaches are
- Share ideas, experiences, skills and what you already know
- Share ideas about ways of having a say about what people want and finding the best ways to make these ideas happen
- Think about new ideas for planning and using supports and services
- Learn through what other people have done
- Help other families, staff and people with a disability in the Eastern Region through the project and into the future

We already have some families and staff who have said they are happy to be part of the program.

We are still looking for some more families and staff to be a part of the program.

We are also looking for people with a disability through the Eastern Client Network to be part of the program.
Patsie Frawley from LaTrobe University is going to be working with us on this project. She will be getting in contact with people who have said they want to be part of the program and we will all be getting together sometime in August to talk more about it.

If you have any questions or are interested in being involved, please contact Rick Ruiu on: Ph: 94164003 or Email: rick@valid.org.au

OR

Adam James: Ph: .................
Appendix 4 Family meeting feedback

Self Directed Approaches – Family Mentors group

December 8, 2011

Summary of information gathered from the first group meeting (17/11/11)

Experiences of the group

Our discussion at the last meeting raised a number of points that show that in general families did not have a clear understanding about what Self Directed Approaches means nor was there evidence of uniform use of Self Directed Approaches by families.

Most families understood that there were different funding streams available; in this group people were accessing a range of these including Linkages, Futures for Young Adults, Individualised Support Packages and My future My choice.

There was agreement that using Disability Services in Victoria at the moment did not mean the same thing for all people – individuals have access to different supports and services and that essentially this is what current policy enables. What seems to be difficult however is knowing what is available, knowing how to access what is available and knowing how to get help to do this and from whom. There was a general consensus that accessing Case Managers was difficult and having a Case Manager did not necessarily mean you would have better access to what was available, however for some people getting access to available funding and support was dependent on a ‘good case manager’ at the time.

In general it seems that ‘what you get’ is dependent on: who is giving you the information and how much they know; your own capacity to find out what is available using available resources that are somewhat confusing; the information that your current service providers are giving you about changes to funding, supports and services and for some, the case you can make about the severity of your need.

What is needed?

- More opportunities to meet with other families to share what people are doing – to learn from each other
- Clearer information from the Department about what is available – it is like a maze at the moment and very hard to understand
- For services to be consistent in the information they are providing families - services are an important intermediary between the Department/Policy and families
- Access to other groups that could provide advocacy, information and support

What next? People were going to choose whether to continue to attend these meetings. We also discussed sharing email addresses/contact details so people could connect up with each other. Future actions will be discussed but might include services supporting family networks to continue this work.
Appendix 5 Staff meeting feedback

SDA Staff Mentors - Eastern 13/10/11

What you have embarked on

You have agreed to be a staff mentor on the Eastern Region Self Directed Approaches project. This means you are going to spend some time thinking about how you can help make Self Directed Approaches work in your service and how you can support other staff, service users and family members to develop their understanding, skills and knowledge.

This is an ‘Action Project’ - that means you need to direct it - it is a ‘Self Directed’ project for staff! This means that after we do some work together you need to think about what we did, choose some actions to take, take them and use the group to share the outcomes and help work out any issues that you might encounter. You can choose things you want to do on your own or you can share them with the group and see if everyone wants to do the same thing. Use the email list to communicate with each other.

There is a family mentor group and a mentor group for people with a disability. They will be doing the same things you do and the three groups will come together when everyone is ready.

What we did today

- You met other staff members from other disability organisations who are also being staff mentors.
- You found out a bit about what other services are doing
- You watched a DVD called ‘Whose life is it anyway’ that people working on SDAs in Southern region developed
- You talked about what you understand SDAs to be
- You developed a list of goals for you to reach and that are needed to make SDAs work
- You developed a list of resources that you or your organisations have or need to make SDAs work

What’s Next?

Attached is the list of Goals and Resources you developed at today’s meeting.

1. Choose at least one goal
2. Work out what you (either on your own or with others in the group) can do to start working towards this goal
3. Develop your ideas and get started.
4. Keep some notes about what you have done or want to do – you might want to plan a new resource, get staff together at your work place and share the DVD, have a session with your manager and learn from them about SDAs
5. Think about the resources you have listed and see which of these you can use and/or might need to develop some more to help you reach the goal.

### Goals

<table>
<thead>
<tr>
<th>Philosophical</th>
<th>Opportunities</th>
<th>Knowledge and skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desire for there to be more ‘us’ and less ‘them’</td>
<td>Network with other agencies and provide a possible collaborative approach to SDA</td>
<td>Understanding of how to move forward at our service</td>
</tr>
<tr>
<td>For the people we support to have a more purposeful and meaningful life</td>
<td>Work closely with families</td>
<td>To have a clear understanding on how self directed approaches work so I can mentor staff and families</td>
</tr>
<tr>
<td>Staff that ‘get it’</td>
<td>Get mentoring/support on how to approach and guide individuals to be more Self Directed</td>
<td>Get information to improve self directed approaches at our service</td>
</tr>
<tr>
<td>Participants doing what they want when they want</td>
<td>Share knowledge – what are other services doing?</td>
<td>To be an active listener to the family and individuals that are mentors</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Have a better understanding of what people want</td>
</tr>
<tr>
<td></td>
<td></td>
<td>What a variety of approaches can offer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The ability to inform people especially families about the benefits of SDAs</td>
</tr>
</tbody>
</table>

### Resources:

<table>
<thead>
<tr>
<th>Staff – personal</th>
<th>Staff – experience/knowledge</th>
<th>Organisational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimistic nature</td>
<td>Experience as a parent and staff member</td>
<td>Team leader has a wealth of knowledge on SDA</td>
</tr>
<tr>
<td>Self satisfaction in work I do</td>
<td>Knowledge that SDAs are valuable</td>
<td>Organisation has already set systems in place for SDA</td>
</tr>
<tr>
<td>Fresh perspective – offer new ideas and challenge the ‘blockers’</td>
<td>Have worked with young man using an SDS – proven benefits</td>
<td></td>
</tr>
<tr>
<td>Passion</td>
<td>Experience moving from traditional approach to community and SDA</td>
<td></td>
</tr>
<tr>
<td>Belief it can work</td>
<td></td>
<td></td>
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</table>