



HCSCC Supported
Decision Making
Interim Evaluation Report
August 2014

Community Matters Pty Ltd

Contents

Contents.....	1
Acknowledgements.....	1
1. Introduction	2
1.1 Introduction	2
1.2 Overview of the program.....	2
1.3 Participation.....	4
1.4 Evaluation focus and methodology	4
1.5 Structure of Report	6
2 Outcomes.....	7
2.1 Introduction	7
2.2 Outcomes for organisations.....	7
2.3 Outcomes for facilitators	9
2.4 Outcomes for decision-makers.....	11
2.5 Outcomes for supporters.....	14
2.6 Mechanisms of change	15
3 The SDM model.....	17
3.1 Introduction	17
3.2 How SDM differs from other person-centred approaches	17
3.3 Recruitment of decision-makers.....	19
3.4 Engagement and expectations of supporters and teams	23
3.5 Roles of trainee facilitators	25
3.6 Information and resources.....	25
3.7 Time, timelines and workloads	27
4 Training and mentoring	28
4.1 Introduction	28
4.2 Training Program for trainee facilitators	28
4.3 Mentoring	30
4.4 Community of Practice.....	32
4.5 Training for Managers.....	33
5 Future Directions	33
5.1 Refinements to the program for 2014-15.....	33
5.2 The program beyond 2015.....	34
5.3 The future policy and funding context.....	35

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1. Introduction

1.1 Introduction

In 2010-12, the Office of the Public Advocate (OPA) developed a model for Supported Decision-Making by people with disabilities. The model demonstrated significant benefits for people with disabilities including increased autonomy, increased capacity to make decisions, increased social capital and extended participation in society (Wallace, 2012).

In that project, all people with disabilities (known as ‘decision-makers’) were supported by a single Project Officer. This was not sustainable in the longer term. In 2013-14, the office of the Health and Community Services Complaints Commissioner (HCSCC) developed and piloted a model which trains and mentors other workers in disability services (known as ‘trainee facilitators’) to implement the model.

The original OPA Project Officer, Ms Cher Nicholson, was employed to:

- recruit agencies and workers to participate;
- develop and pilot a training program for trainee facilitators;
- mentor and coach trainee facilitators;
- establish and facilitate a Community of Practice for trainee facilitators;
- liaise with management in participating organisations.

Management support within HCSCC was provided by the Manager, Complaints Resolution Service, Ms Sandy Edwards. Community Matters Pty Ltd was contracted to undertake the evaluation of the pilot and to develop a research ethics application for a third phase of the project, to be undertaken in 2014-15.

1.2 Overview of the program

The project aims to train workers in disability agencies to establish and facilitate social support systems that support people with disabilities to make decisions. By doing so, people with disabilities can exercise a greater degree of control, authority and self-determination in their lives and be supported and respected in doing so. This puts into practice elements of the UN Convention on the Rights of Persons with Disabilities, and in the OPA pilot project, was demonstrated to improve quality of life and community engagement for participating people with disabilities.

The model is centred on a person with a disability (‘the decision-maker’) and one or more supporters. Supporters are drawn from the immediate family or social networks of the decision maker and commit to assist the decision maker to make decisions in areas of their own choosing.

Facilitators are workers in disability agencies. They:

- conduct particular processes to recruit decision-makers;
- support decision-makers to choose their supporters;
- assist with recruitment of supporters if required, and provide ongoing support to those supporters (some of whom must make significant shifts in previous beliefs and behaviours to be able to operate as a supporter);

1.3 Participation

Eight agencies or units were recruited to participate in the pilot phase. All agencies had had some exposure to the program through the OPA project. They included government and non-government agencies; large and relatively smaller agencies, and residential and non-residential services. The agencies were Leveda, Minda Inc., Strathmont (Northern Supported Accommodation Unit, DCSI), the Individualised Funding Unit, DCSI; the City of Playford; Cara Inc; and STAR (Skills Training and Resources) and Southern Area Mental Health Services (Uniting Care Wesley).

Larger agencies were invited to nominate two staff to participate as trainee facilitators and three smaller agencies were invited to nominate one participant. One agency withdrew during the training program: this was reported by HCSCC to be due to work-related constraints in that agency. Thirteen South Australian workers commenced the program. One withdrew during the training program and another at the conclusion of the training program. Two others did not withdraw, but for reasons described below, did not support a decision-maker and therefore cannot be considered to have completed the program. Nine trainee facilitators completed the program².

Each trainee facilitator was asked to recruit one or two decision-makers (people with disabilities) to go through the program. One trainee facilitator – who had been a supporter for a person with a disability in the earlier OPA project – supported three decision-makers; all others supported one each. A total of 11 decision-makers were therefore supported.

1.4 Evaluation focus and methodology

The evaluation of the HCSCC SDM project is being conducted in two phases: this evaluation of the pilot project, and a more detailed evaluation of the next round of implementation.

The overall purposes of the evaluation are to:

- Determine the circumstances in which the SDM project model is and is not effective.
- Identify the short term (for the pilot program) and medium term (for the subsequent evaluation) outcomes of the SDM Project for decision-makers, support people, facilitators and organisations.
- Identify the circumstances in which, and mechanisms by which, positive outcomes are or are not achieved, for decision-makers, support people, facilitators and organisations.
- Develop recommendations about the future of the SDM Project: whether and if so in what form it should be continued, and (if continuing) how its quality and sustainability might best be supported.

For the evaluation of the pilot project, the primary purpose is program improvement.

1.4.1 Evaluation questions

Over both phases, the evaluation seeks to answer the following questions.

- a) The program model:
 - To what extent are trainee facilitators able to engage decision-makers in the SDM approach? To what extent and in what circumstances are they able to engage and maintain the participation of support people, informal support networks and service provider organisations to support decision-makers – in their decision-making, and as a result of those decisions?
 - Should the SDM project be continued? If so, in what form and under what auspice?

² One NSW staff and two overseas staff participated in the training but are not included in this evaluation.

- What supports are required to ensure sustainability and continue to build the quality of the program in the longer term?
- b) Decision-makers:
- What outcomes for decision-makers are attributed to the program by decision-makers, their support people, and facilitators?
 - Are supportive networks maintained after active facilitator engagement has been completed?
 - Are positive outcomes maintained after active facilitator engagement has been completed?
 - What proportion of decision-makers 'graduate' to no longer requiring support or to needing lower levels of support?
 - What proportion of decision-makers achieves significant outcomes that have the potential to reduce costs for government (for example, moving to lower levels of support in accommodation, or gaining employment)?
 - Are there sub-categories of participants for whom the program is more, or less, successful? Why?
- c) For support people:
- What roles do support people undertake? How do these compare to the roles intended by the program?
 - What outcomes do support people identify for themselves from the program?
 - What costs (demands) do support people identify for themselves from the program?
 - What is the rate of turnover of support people?
- d) For trainee facilitators:
- What outcomes do facilitators identify for themselves from the program?
 - What costs (demands) do facilitators identify for themselves from the program?
 - Is there any turnover of facilitators? If so, for what reasons?
- e) For organisations:
- Does diffusion of innovation begin within organisations? If so, in what ways, in what sorts of conditions, and over what timeframes?
 - What costs and benefits do organisations identify for organisations and/or the sector?
- f) Project sustainability and direction:
- If the program should be maintained, where is it best located?
 - What is required to support ongoing implementation?

Not all of these questions can be answered in this evaluation of the pilot program. This is primarily because of the short time for which the project has been operating to date. For example, it is not yet possible to assess whether supportive networks or active decision-making are maintained once active facilitation has completed, and it is not yet feasible to assess whether diffusion of SDM practices begins within organisations. Nor was it possible in this round of the evaluation to collect information directly from decision-makers or supporters, because the short time frames precluded seeking research ethics approval for data collection directly from community members. However, information has been gathered in response to many of the questions, from the perspectives of trainee facilitators and organisations.

1.4.2 Methodology

This is a qualitative evaluation. Data was collected from 19 people (11 trainee facilitators and six managers across seven agencies; the SDM Project Officer and the HCSCC Complaints Service Manager) in 15 interviews. Where there were two trainee facilitators in an agency, they were interviewed together. Line managers of the facilitators were interviewed separately. In one agency the relevant manager had left the agency and the appropriate substitute was on extended sick leave, so no management interview was conducted.

Interviews were taped with the permission of respondents and transcribed for analysis. All respondents were advised that they could ask for the tape to be turned off at any stage of the interview and that anything said off tape would not be included in the report. Some respondents did request that the tape be turned off for small parts of the interview.

The analysis of the data might best be described as realist-informed. Realist evaluation (Pawson and Tilley, 1997; Pawson, 2013) seeks to explain whether, how, for whom, in what circumstances, in what respects and to what extent project has 'worked' or 'not worked'. Appropriate data is not available to undertake a full realist analysis but the logic of analysis that has been applied to the data that is available is realist. This includes identifying, where possible, differences in outcomes for different sub-groups; the 'reasoning' of those involved in response to the resources and opportunities provided by the program and how that has generated different outcomes (in realist terms, this is called a mechanism); and the factors in the context that seem to influence whether, for whom and how the program works.

1.5 Structure of Report

The report is structured in five chapters. This Introduction requires no further explanation. The second chapter addresses the reported outcomes of the project, for the participating organisations, the trainee facilitators, the decision-makers themselves, and supporters of decision-makers. The third chapter addresses aspects of the SDM model which attracted particular comment from respondents. The fourth chapter deals with the issue of training and mentoring for trainee facilitators and their organisations – the critical 'new element' of this phase of the program. The final chapter draws together the recommendations from the third and fourth chapters and discusses future direction for the program.

2 Outcomes

2.1 Introduction

As noted in the previous chapter, the HCSCC Supported Decision-Making (SDM) model is intended to work at multiple levels and to achieve different outcomes at those different levels. In this chapter, we summarise the outcomes for people and organisations at each level. Where possible, the contexts in which outcomes were and were not achieved are noted, as well as the mechanisms which appeared to generate both intended and unintended outcomes.

While the primary intended outcomes are for decision-makers, achieving those outcomes requires a whole sequence of intermediate outcomes to be achieved. This structure of this chapter follows that sequence of intermediate outcomes: organisations, trainee facilitators, supporters and decision-makers.

2.2 Outcomes for organisations

Six agency managers were interviewed for the evaluation. All identified that the principles and philosophy of SDM were strongly consistent with the principles and philosophies of their own agencies. In most cases, this was a significant reason for their participation in the project - although one manager said that they had not 'really known' at the beginning of the project that the fit would be as good as it turned out to be. This 'goodness of fit' is almost certainly one of the factors contributing to effective implementation of the project at agency level.

It was also one of the things that some managers identified as a benefit for the agency from their participation in the project. A couple suggested that it gave workers 'another tool' to implement agency policy. In a couple of other cases, it was seen as a tool for management to develop the skills of staff. For another, it was simply exposure to an additional way of working:

For [organisation], it'll be that we will look at the role of SDM in the options that we provide for people and we need to explore that further. ... So for us it's opened our eyes to a model that we knew nothing about. ... So definitely it's part of our consideration in how we move forward.

In a couple of cases, managers identified significant behavioural changes on the part of decision-makers. In the most outstanding case, this reduced the time that the decision-maker spent with senior administrative staff, increased the number of workers and carers who would work with him, reduced aggression and therefore administrative time doing incident reports.

one of them, ...he really needed a lot of intervention, ... we were putting a lot of effort into supporting this young fellow anyhow, ...- but the turnaround, and it may not be due to [the trainee facilitator's] intervention, but whatever's happened, that man's life's turned around. [Q: In what ways?] In an amazing way. Well he's a fellow who was getting into a lot of strife, serious, very serious things, ... when [decision-maker] had no say, he knew the best way to have a say was to do something so serious that people would step back and say we're just leaving you alone. ... what [trainee facilitator] did is he engaged this man, and they developed a fairly trusting relationship. He learned about what was important for him, or should I say to him. ... [He] found out all of the things that were in his head; what was worrying him, what he needed sorting out with, what problems he needed help solving, and helped him develop a framework for sorting things out. ...when [decision-maker] started to settle, he started to re-build relationships with people. ...he's got a more positive reputation, we're not reading terrible things about him anymore. If he's got a problem, he tells people. He knows how to fix it, he knows who to talk to.

...I think some of it's the work [trainee facilitator] did within the project about getting to know him, developing trusting relationships, helping him establish a good pattern of behaviour that helps him satisfy what he needs or wants. ... And now for [decision-maker], it's really timely because [change of accommodation is planned]. We can negotiate better with him. ... We're more ready to support him in the next part of his life, so that's really - it's been very good for him.

In this same case, the manager identified that the SDM project had changed the way a number of staff related with the decision-maker and a small but critical change in the organisation's focus in dealing with the decision-maker:

... people started talking with him, and ... establishing better relationships, and were more able to understand his speech ...[Q: Did his speech get a bit clearer when he was more settled?] No, I think we can understand him better because we're listening. He hasn't changed. In actual fact, the work [trainee facilitator] did probably didn't change him, it changed us.

You know, because institutions are mostly about what people need, but they're generally not about what people want, and that's the - it's only a fine change, but it's worth everything.

Some trainee facilitators also reported outcomes for organisations. In a couple of cases the change identified related to efficiency.

...it's a different way of working and obviously more efficient for us. Like if you can empower people to do things without relying on a service, that's what [management] want.

Because we're tapping into communities and we're tapping into supporters that are free to the person, you will find that a lot of the people that are constantly wanting to talk to the staff about issues, that have behaviours of concern, that aren't happy, that are whinging, you know, that take up a lot of time in the organisation, that families aren't happy, you know, I do think that this can do some people out of a job, and I don't mean that literally, that we'll...[free up the resources...]

A couple of organisations reported some flow-through effects to the skills and practices of other workers. In both cases, the effects were for workers who had become involved as supporters or team members.

... she's really latched onto it. ... It's almost like a tool for her to be able to give her the skills. ...I think in that program she probably just needed permission to be able to say 'we're doing this with him. Let's do this with him in the program.' Whereas before she was probably thinking, 'oh I'm going to do this, this and this' but didn't want to rock the boat ...

I'm actually finding one ...[staff member], is actually using it... I'm seeing massive changes in how she's dealing with the guys she's looking after. ...Giving them more of a voice and more options, more choices, more encouragement and more independence, and it's great.

The agency in which the program worked least well did not report positive outcomes for the agency. They reported being placed in difficult positions with families:

...it placed my staff and therefore me, [the organisation] in some quite awkward situations and trying to explain to families. More importantly, it was disappointing, ...we set, inadvertently, without knowing, families up with an expectation that then couldn't be met and that's not fair. That's not how we operate and there was angry families...

This created significant tensions in relationships between families and the organisation, between the trainee facilitators and the program Coordinator, and between the organisation and HCSCC. It also

caused significant stress for the worker most directly involved, described as resulting in a period of ill-health and sick-leave.

2.2.1 Agency contexts and the role of management

Although all agencies saw the SDM model as consistent with their existing philosophies, there were differences in the extent to which agencies were already implementing expressed wish decision-making. Differences in agency roles also meant that there were differences in the range of issues in client's lives to which they might apply the model. The strongest outcomes at agency level seemed to be reported where there was a close fit with the agency's intended direction, but still some distance to travel in terms of its implementation. This is of course predictable. Agencies who are closest to implementation have less 'room for improvement' while those who are furthest from implementation have more work to do in order to create change.

Having 'the right managers' involved as supervisors and supporters for trainee facilitators was clearly important to the outcomes achieved. The 'right' managers were already philosophically committed to maximising expressed-wish decision-making. They were also 'close enough' to trainee facilitators, in terms of line management, to be able to provide practical support such as reducing or restructuring other workloads to give workers time to work on the project. Where management was more distant, trainee facilitators reported a lack of direct engagement and support. In at least two agencies, there were changes in the managers most directly engaged in the project over time.

Manager perspectives also appeared to affect whether the project was seen as 'internal' or 'external' to the agency. Managers that saw it as a tool for change within the agency appeared more likely to restructure other workloads; those who saw it as external did not. Describing the reason why one potential staff member had declined participation in the program, a manager said:

One of them was her time commitments as a manager; she didn't get much release time to commit to things outside.

In another case, reallocations may also have been affected by agency size – small agencies have less flexibility to reorganise.

In larger agencies, it was also necessary to have a consistent understanding of the model across all levels of management.

...and that's one of the things we've identified internally ...that I think where we have tripped up a little bit has been the broad understanding across executive and that filtering down.

2.3 Outcomes for facilitators

Six agencies participated in the pilot program and each agency was intended to have two facilitators trained. However, two small agencies only recruited one facilitator, and in a third agency, one left the program relatively early. Nine facilitators completed the program.

Of the ten facilitators with significant engagement with the project, eight reported some level of learning outcomes for themselves. This included the facilitator who did not complete the program, who nonetheless reported significant learning from it.

There were a couple of experienced workers who reported very little learning as a result of the project.

...when I first started on the SDM I was told that it was going to be something totally new that had never been done before. I don't necessarily agree ... that I've been shown anything different

than I currently do. I think I was under the impression that it was going to be giving me more skills in people with more profound disabilities and that hasn't happened.

Others reported minor changes that were in line with their current practice.

In my work practice? I think it's just given me more tools...

I think it's made me a better teacher of self-advocacy... because it makes you push a little bit more. 'Remember, you can do this for yourself.'

Some noted a change from 'doing' to 'supporting others to do', but it was not clear whether this extended beyond the project.

Probably just restraint because we're so used to...having to do everything. It's quite refreshing to...sit back and kind of be the advice giver. ... it's more them doing it and then asking for help if they need it. So ... we're mentoring them while we're being mentored to do that.

I'm not as controlling. All evidence to the contrary [laughs]. There's a freedom in it. ... I learnt to step back, so the facilitator role has been good in that respect

For others, it was a more profound change in approach, involving asking different questions, listening differently to the answers, providing additional opportunities for clients to make decisions, and supporting them in developing the capacity to do so.

The main thing I would say is active listening. So on the weekend I spoke to ... two other people living in the [supported accommodation]. What they like, how they want us to support them.

...it's been an addictive thing to me. ...I was asking the other clients..."How would you like to do this one?" And if they say, "I don't know": Ding! No decision-making ability here. So I kept asking them, "Okay, ... what would you do if you don't know what to do? Are you going to ring me? Are you going to ring your dad? Are you going to ring your friend? How would you do it?" So I was always trying to get them to figure it out. So I was trying to facilitate. Not, 'This is the problem. This is the solution.' I can do it, but that wouldn't really change their life. The way I see it is how to change their life: Not to give them a solution.

Three workers identified changes to the ways in which they work with families.

I do try and work with the families, because sometimes the families are the ones that are stopping the client. ...And trying to work with the families... about getting them to understand that the reason it maybe should change is because why would anybody want their lives to stay exactly the same for the whole of their life. Why wouldn't we want extra exciting things to happen along the way? ... I try to talk to the families about thinking slightly different about ...their son or daughter.

Two workers identified changes to their own practice but also changes to their supervision or leadership style.

...with my work practice I'm more in tune now ... with the clients that I'm supporting... And also with the staff in team meetings, trying to get them to think about, ...you've been involved with them for a long time, what do you believe they would really, really like to do? Do you believe that that - ...all of them like going swimming? Do you believe that those whole three like going bowling? And then they'll go 'oh, they like it, but really [client] would prefer to do this'. ...So ...they start to think. And I said 'well I want you to think about not always taking them together, or thinking about what each individual would like to do. ...So really, it's kind of changed the way I'm working with people there.

I think just deciding that oh, people can be their own consent-givers a little bit. I'm always saying now, if staff come to me and say, 'can so-and-so do this?' 'Well ask them. Ask them, do they want to? Go and ask them'. ... We had another person that lives on the [supported accommodation] where I work. We thought that maybe some volunteers could come and go and play some soccer with them. I said to the volunteer coordinator, can you send some people over and they can meet him? He can select who he'd like to support him with that. So rather than just 'this is your person, this is the volunteer that's going to be with you', send a few over and this person can see that maybe there's someone that he's going to relate to or like more than someone else. ... So little things like that sort of creep into your practice I suppose.

Workers who were new (or relatively new) to the disability sector also identified improved knowledge.

I learned so much in that, particularly around dignity and risk versus duty of care ... I have learned a lot, it made me seek outside of the model. I did lots of other reading on other models and lots of conversations with [co-worker]

2.4 Outcomes for decision-makers

The project intended to recruit between 12 and 24 decision-makers, one or two per facilitator. Only 9 facilitators completed the program, and only one of them supported 3 decision-makers. Issues in relation to recruitment of decision-makers are described in section 3.3 below. A total of 11 decision-makers were recruited and supported.

Clear information about outcomes is available for eight of the decision-makers (the interview in relation to three decision-makers primarily discussed barriers to change). For three decision-makers, outcomes were either described by facilitators as 'small' (for example, extending skills for activities of daily living) or as not yet having been achieved, because of delays in the process. Even for these decision-makers, however, changes in relation to mood, self-esteem and focus were noted, and impacts on the understanding of other people were identified.

...it's just the little, tiny things that have happened. But those tiny things have happened have really kind of shaped the way that mum and dad look at his skills and then also the people in his day options look at his skills and what he's capable of doing for himself. So that little change is an impetus for bigger change, long term. It's a start. ...The making cup of hot chocolate at day options, making chocolate at home, packing his bag at home, doing things for himself at home, like, helping with the cooking. The ... big thing ... is now we're kind of looking at the money skills for him. So it's just those little things about doing stuff for himself. ... the thing is I noticed his behaviour when he sits in the meetings... I think it's now within himself. By doing those things for himself, ... - his dad even said, I think he realises now it's time for him to start stepping up a little bit and doing these things. That's what I've noticed in him; he's ready. That's what his dad - he's ready now. He's ready to take that next step forward.

In one case, the most significant changes related to communicating decisions. The agency in which the decision-maker resided had not known that the decision-maker had a way of communicating:

He actually went to school and he learned Makaton, he learned Key Word Signing which was something that we didn't know. There's something. He can communicate but, hello, we didn't know that. So we've started to do a lot of work around that. ... KnH have developed a communication book for [decision-maker] We're setting up some training where [decision-maker]'s going to train the volunteers that he spends time with, how to communicate with him. So he'll teach them his Makaton signs and his Key Word Signing with the help of his speech pathologist. We're also working on him going shopping for straws which is something he loves. Music has always been a big part of his life before he came here so we're starting to look at

maybe things in the community that he might be interested. We've had the community centre at [suburb] come to a meeting. They run Zumba classes and things like that he'll enrol in. So for [decision-maker] it's been probably a little bit more about him communicating his decisions. So, yeah, we're just at the stage where things are starting to happen.

For the other five decision-makers, more significant changes were achieved. Three decision-makers started formal courses and in two of those cases, also commenced voluntary work experience. One of those two also started volunteering with a local football club.

He started to study Certificate II Landscaping. ... But on the way back to our home, [he] told me that he would like to catch public transport by himself to go to school. So our next goal is to teach him how to catch bus to go to school and come back. ... He wanted to go to gym, we got the gym membership and Cher advised me to get volunteer friend from the gym who can help David to learn using the gym equipment. I spoke to the club manager and hopefully we may get some people for the internship who study to be the trainer, ... he will be going for the guitar lesson from next week. ...So we...decided to train [him] towards his goal to get a full time paid employment. For that, we tried to get some volunteer work ... in the mainstream. So we got somebody who can take David as a volunteer for him. Then while we are thinking about it, I also thought to send David to school to learn more. ...So that is why he is going to school. It will be four months' course and he just started it today. ...The other one is he wanted to support junior footy team. So I took David to ... Footy Club and we had a chat with the people up there. Many of them actually knew him... So then he's helping junior team. ...I've never seen any angry episode with [him] for a while. That's the other important thing.

One decision-maker had requested a particular day placement option which had no vacancies available.

...what SDM provided was an avenue through which there could be a next step and the next step was to go back and say, that's a no-go. What would you like instead and how about you have a chat to this other person?... Then it was also questions about well, if you're not doing that, what about maybe doing some volunteering? So then he went to [volunteering agency] ... So his networking circles have opened up more... ...We're not having many bad days from him. He seems more tolerant of his peer that he lives with....I think that's because he's out of his house more often. Even though he's got one-to-one support during the day to go out and about and do things, maybe the course is providing him with more stimulation. He's out of his house and he's more focused and ultimately... and he's got something else to talk to staff about, he's got something else to talk to his family about. So, yeah, he's a happier chappy.

The trainee facilitator attributed much of the process to the creativity and experience of the SDM Coordinator, who continued to ask questions and raise options when initial options could not be achieved.

Another person reduced work hours in order to take up other activities, including a recreational program, a fitness program, and learning to manage her own money: this person, who had recently moved into independent living with her sister (not as a result of this program) also learned to use public transport and to ride her pushbike to the local shops, re-established a previous social connection, and started organising and advocating on her own behalf.

Yeah she's made heaps of changes. She happened to be moving house into a new suburb when I was talking to her about it. ... She had quite a lot on her list. The first ... things were learning how to catch public transport from her new house to her work which she did really well. ... She's joined the council groups ... because she was ... worried about her fitness. So, yeah, they're going to this aqua aerobics program and have organised all the transport and taxis and whatever

they needed for that. ... She was doing two kind of short days at work ... She did add another day but then she decided she wanted to do this other [recreational program] in the community. So she changed that again. But it's good - it's been really good for her to go, oh, I can decide. I can go to my bosses and say actually I don't want to do that day anymore. I want to do this instead. ... I think she just needed a bit of confidence and to know that she could do these things. ... The other thing was the money thing. Her mum really manages her money ... So she's enrolled herself with a financial counsellor. She didn't even ring me about it or anything... ... She learnt how to ride her bike to the local shops so she can do that on weekends. She had an advocate from the past that she hadn't seen for a while so she kind of reconnected with her. She happens to live riding distance from her new house. So she's kind of picked up all her informal kind of things. ... I noticed her change in posture and expression. ... She has had issues with her new neighbour. He has music on at 2:00am and stuff and she'll go talk to the people who work with him. So she'll ring them and say he's doing it again. So she's quite - it's not like she's going to her mum or Disabilities SA worker and saying 'oh my neighbour', she's doing it herself.

Another decision-maker made a formal complaint to Disability SA in order to get a housing issue resolved (the issue is now being attended to); advocated on her own behalf for a say in selection of her new housemate; has successfully advocated for the introduction of a program for people new to her high school to make social connections; has organised to change from child to adult health care provision; is now self-motivated in relation to school work; and has established processes to find family members.

Then at school she actually suggested that she - there probably needed to be a program at [High School] for people like her, not just people with a disability but anyone who comes late into mainstream... where they haven't had time to develop friendships. That got taken to the student council and they think it's a fantastic idea, and they're developing a program. Too late for [decision-maker], but hasn't she made a difference? And ... she said she feels so good that she's had a voice and that she's going to help others, which is a big part of being proud of your life, that you're not only helping yourself but others. ... She wasn't doing her work at school. Now her teacher tells me that she's doing it without even being asked. And when I said to her 'why is that,[decision-maker]?', she goes 'I feel more confident.' And she actually likes the idea that she's going to be having a voice and presenting to people. So it's given her an incentive.

In most if not all cases, significant mental health and wellbeing outcomes were also identified. Most common were increased confidence, self-esteem and pride. However, one person was reported to be sleeping better and others as being happier, more goal oriented and more focussed.

He is now a bit more focused on what he wants to do. Before he took up his training, [he] didn't really know what to do when he wakes up in the morning. No goal and objective was there. Now he is onto something that he has a goal.

He was saying that he wasn't sleeping very well some nights and I felt that maybe that one possibility might have been that he wasn't stimulated enough during the day because he'd only got two days a week where he was at day options. So now he's got four days a week. ...when I went to see them this week he said he's sleeping better.

In two of the five cases, there were significant improvements in what had previously been quite problematic behaviour. Improved relationships, either with housemates or workers, were also identified in both these cases.

He used to get angry at staff very easy. But nowadays I think his problem-solving skills have been improved a lot ... We don't have many incident reports ... for a while now. ...he knows all the big bosses. He goes and talks to them every day. That was his routine. But nowadays he doesn't come to the admin building to stay with staff member. I think he is happy with himself at the

moment. ...I think the staff, they were very afraid ... to try new things with [him] because [he] could upset ... the staff, call them by names and ... threaten them... I think he has started to listen to the staff ...I think the agreement played a major role with [his] life. ...

It was notable that some of the most successful case histories reported to this evaluation involved larger changes by organisations. In one case, management had already created a new position for the trainee facilitator, giving him leadership responsibility for addressing systemic issues that were seen to contribute to undesirable behaviours on the part of the decision-maker.

And then [trainee facilitator] stepped up as the supervisor, which is why I created the role he went into, to try and sort this out and get this fellow on a decent track, and manage that part of the service a lot better, because it wasn't going well.

In other cases, trainee facilitators engaged other workers from the organisation, changing the ways in which they interacted with decision-makers, in order to facilitate change.

2.5 Outcomes for supporters

One of the aims of the SDM model is to assist supporters to learn the skills necessary to act as supporters. This round of evaluation was not able to interview supporters directly about the outcomes for them. However, trainee facilitators were asked about the outcomes they observed for supporters.

In one case, a decision-maker chose her sister – who also has a disability – as one of her supporters. The facilitator suggested that the sister was participating in some activities, was taking less responsibility for her looking after sister (thus enabling the decision-maker to take greater responsibility) and starting to consider making other changes as well

Well I just think even in meetings ...she's kind of wanting to do things for herself as well. ...So I think it's been a spin off for her to get her thinking as well... I think being in all those meetings she's kind of thought 'what can I do for myself' instead of worrying about that kind of position of power with her sister.

In at least three cases, facilitators reported that supporters had a new understanding of the capacity of the decision-maker which often contributed to 'a sense of relief' about the decision-maker's future. In each of these cases, the supporters were family members.

I think [supporter has] been really, I think, ultimately, relieved. ...I think it's taken some of that pressure off for her, in that she sees him making decisions and she sees him learning stuff from that too; the good and the bad. Yeah.

I found with my decision maker that her mother was doing a lot. I think her mum just felt like she had to. There wasn't anyone else. She couldn't really see the support. So when we got everyone in a room and did the agreement and all of that, I think it was just as powerful for mum as it was for her. Because she's like, well, I don't have to do all of this. When I'm not here, she'll be okay.

It's given them – 'Oh wow, there are all these people. Oh wow, actually we can help him do these things.' I don't know, it's given them a bit more of an understanding of what he can do if that makes sense.with the parents that I'm dealing with, they've kind of realised that their son's at a level now that there's more that he can do.

However there was also a case where somewhat different perspectives were presented by the manager and the trainee facilitator.

The family were thrilled. They never believed ... this gentleman had this in him. I think they have taken a step aside and [are] realising the gentleman is capable of making some decisions. Whereas previously he has been coerced and molly-coddled and managed. ... so they've seen another side to him that they have absolutely celebrated.

The facilitator reported, however, that some apparent progress on the part of the supporters was interrupted by a difficult patch for the decision-maker:

... certainly at the second meeting that we had, they seemed more positive. Then [Decision-maker] had a bit of a rough time so I think they've sort of reverted back to their original opinions of him.

This difference in perspective may reflect contact with the family at different points in time, closer contact with the family on the part of the facilitator, or simply a more optimistic view by the manager.

In other agencies, facilitators discussed the need to provide emotional support to families during the process.

The thing from the parents that I've kind of got is, because it's dad mainly that's the one that's there, ... - I had to remind him that this isn't having a go at you. This isn't about what you haven't done. You haven't had these opportunities before. ... don't think that you've done bad.

These workers believed that some supporters may need additional support to deal with the emotional challenges that the role created, but that would depend on the skills of the facilitator:

... maybe like a carers' group or something where they can go and kind of vent and there's other people in that situation type thing. . But, yeah, I think it would depend on the facilitators' skills.

Asked whether the project should create a specific network for supporters, they suggested that some would probably find it beneficial but others might experience it as “just another thing they had to do”.

For supporters who were not family members, increased confidence, and ‘learning to step back’ to allow room for people to make their own decisions were reported.

I'm seeing massive differences in the supporters. ... Well, one of the supporters, Heather ... she's actually seeing improvements, so it's boosted her confidence ... And the other supporter is learning to step back ... And that's growing her confidence, and she's been in this business for 38 years.

There were, however, also significant issues related to supporters: these are discussed in section 3.4 below.

2.6 Mechanisms of change

It is apparent that when the SDM model works, it has the potential to generate significant outcomes at a range of different levels. It is proposed, on the basis of the evidence here, that it does so through three primary mechanisms: challenging history; providing permission to try; and developing the skills to work differently. Each of these is described briefly below. The aim is to formalise hypotheses that can be tested more formally in the next round of the evaluation.

2.6.1 Challenging history

Family members, service providers and decision-makers themselves have established beliefs about the capacities of decision-makers and established routines to manage daily living. SDM provides evidence that the decision-maker has a wider range of capacities. This evidence assists all parties to change their perspectives and creates experiences of success.

This mechanism was originally developed in response to the following extract from an interview with two facilitators:

I think doing this has made us realise as well how many - like people with disabilities that we work with just have a lot of people in their life that limit their kind of world because 'well he can't do that. He doesn't do that. He can't do that, he's always done this.' Some of the parents were like, 'he doesn't need that. He does this, this and this and he loves it. You love it, don't you?... Our colleagues, we're trained to think about the possibilities and the abilities. But a lot of people working across in the more front line stuff, have that 'no he wouldn't be able to do that. This is what he does. He's always been like that.'

The facilitators originally described this as a barrier to recruitment of decision-makers, but then went on to describe ways in which the SDM model challenged assumptions about what was possible, built experiences of success, and changed the perspectives and beliefs of decision-makers and supporters. The phrase 'challenging history' was used to refer to challenging negative expectations and assumptions. The idea of 'clients having histories' that were in some way challenged or contradicted by the program was also independently by other workers in at least two other agencies.

2.6.2 Permission to try

The SDM model expects that some things will succeed and some will not. Acknowledging and accepting the possibilities of both success and failure gives both workers and decision-makers 'permission to try'.

This mechanism was again supported in a number of interviews with facilitators. The clearest example is contained in the following extract:

I spoke to somebody from his day option about him going [to a particular place]. 'Oh he couldn't do that. He's not smart enough to do that.' ... I suppose the supported [decision-making says]- 'give it a go'. It's kind of like more that thing, 'yeah it might not work, but ...'. it gives you more of that, we'll give it a go.

2.6.3 Skills to work differently

The SDM project provides direct training and/or support, structured to their particular roles, for facilitators, supporters and decision-makers. Outcomes are generated over time as all three parties develop skills and experience in the model.

The evidence for this mechanism has been discussed in sections 2.3-2.5 above. Training for facilitators is further discussed in chapter 4, below.

3 The SDM model

3.1 Introduction

The previous chapter has demonstrated that the SDM model can – when implemented by ‘the right staff’ with support from the wider agency, and in particular their managers – generate significant change in the lives of people with disabilities. In this chapter we turn to consider some of the issues associated with the model and its implementation. This is consistent with the ‘learning and improvement’ focus of this evaluation.

3.2 How SDM differs from other person-centred approaches

As noted above, one of the reasons that the SDM model appears to have worked as well as it has is because it is consistent with existing philosophies and intended directions of the organisations in which it has been introduced. In fact a number of the respondents interviewed for this evaluation struggled to distinguish exactly what it was that was different between the model and their existing practice.

Some agency managers in particular struggled to identify any significant difference between existing practices and the SDM program, with one suggesting that the lack of clarity about the differences had been ‘a major headache’

It's very interesting and I think that's been part of the one headache along the process; a major headache.

...on face value, no I don't think it is that different. My understanding of it is that it is attempting to create an environment for the person where decision-making can flourish... So that's no different really to what we're trying to achieve in a person centred way, ... because we have to check ourselves about our involvement in either overwriting someone's decision or influencing someone's decision. From a person centred point of view, it's about understanding individual and letting the individual make those decisions for themselves and our role is to create that environment, give them the information so that they can create and make those decisions for themselves. So I don't know the program well enough and haven't done the training to know how it stacks up against other person centred types of tools or programs to really give a definitive answer of that but that would be my sense of it

The manager quoted first above suggested that participation of a wider range of people served to constrain the power of workers or family members in influencing decisions.

Supported decision making perhaps takes away the variable of a person with a pre-conceived agenda from the decision-making process. ... It's not fully clear. It's more of about supporting the risk. Isn't it? Moving across that way. It's about enabling people outside of the providers to support those choices and to build those choices and lifestyles.

Two others suggested that SDM was a more structured way of approaching decision-making. Both saw that formalisation as a positive aspect of the program:

...this is a much more structured program with definite goals and outcomes and measurable outcomes

I think SDM is more focused around – no, focused isn't the right word. It's more formalised. What we do is quite informal. I think that formalisation is not a bad thing, 'cause it does push

the people we work with to genuinely understand the control and power they've got, and should have, over their lives. Yeah. So maybe we could actually do more to formalise that within our processes.

However, it was not only managers who struggled to define the differences.

One of the things I really struggled with and I did mention it in the training, what is the difference between this and advocacy and we couldn't come up with an answer because I saw a lot of it was advocating for the person... I see what the supporter does, that is probably slightly different to what I've done before, that there is an actual supporter person there that helps that person make decisions, [but I] still was struggling with what the difference was between that and advocacy.

At least one trainee facilitator and one manager (from different agencies) thought that the primary difference lay in the different balance struck between duty of care and dignity of risk.

... whether or not it's a duty of care thing or not. So they may be making decisions that their supporters may not agree with them but based on this model the supporter would have to support the person to do. Whereas I think person centred planning has more of a duty of care...

Other facilitators were able to describe the difference between their agencies' usual approaches and SDM. The following is a discussion between two facilitators in one agency:

Facilitator 1: What I find is having the agreement, it kind of gives it a bit more power almost.

Facilitator 2: But I think it also gives the supporters, whether they're parents or friends or other people in their lives, kind of that view of well they're doing this, they're doing the choices ... I don't know it's more in their lives and they're in the centre.

Facilitator 1: It's about them; they're the focus.

Facilitator 2: I feel like [existing model], like you were saying, sometimes it appears [people with disabilities] are more empowered than they actually are. I think that's because ... we go to the training and are given the information but it's not followed up in their lives. Because [worker] can't go around to everyone's house and make sure they're doing that stuff. So this is more like in their lives, in their community, in their wider circle, everyone's kind of on the same page and they're all supporting that.

In another agency, the facilitators agreed that the primary difference was between best interests and expressed wish decision-making

I think there's a lot of similarities, but I also think that a lot of the person centeredness is still in best interest.

For another person, the most significant difference lay in the methods used.

Do you know what the difference is for me now, after being through it, is that it's the essence that pins everything else together. It's the how you do it, okay? So you go and you set a goal setting meeting with someone, and you have these list of things, just like on the agreement. But then you kind of talk about them at a team meeting, where the client isn't there by the way, right, the client isn't there. ...And then you check on it, you know, every so often to see where you're going, and you tick that one off and that one's done. Now, with SDM you actually have a group of people, and this team grows and grows and grows. And instead of all these people being in silos they're actually this one great big team, and they're all there for my lady, team [decision-maker]. They are team [decision-maker], right? And they all know that whenever [decision-maker] says she wants to do something every one of them is going to say well I can help there, I can do this, I can do that. [Decision-maker], would you like me to do that? And it's all

what [decision-maker] wants, and they're just there to help her get there. And the focus is on community, or on somebody who isn't a paid worker. So whereas in the agencies it's very rarely - they don't even look there half the time. It's kind of like oh, we've got that here. We can do that. Or that person - we work with them. They can do that. It's not like well what's the alternative?

It is of course likely that the explanation for some of the variation in descriptions provided by workers and managers lies in the interview process, some in the fact that managers had less exposure to the program than facilitators, and some by different trainee facilitators having learned different things through the program. It was also the case that the *collective* description provided by trainee facilitators – that is, the sum of their descriptions across all the interviews – provided a thorough and accurate description of the ways in which SDM is intended to differ from existing practices. Nonetheless, the difficulty that many respondents had in defining the differences and the variation in elements suggests three things:

- that the differences between SDM and existing practice vary across organisations;
- that the differences between SDM and existing practice may not be as great, in some organisations, as was originally believed; and
- that the differences are not necessarily well understood by the organisations (and particularly by managers in those organisations).

This poses something of a challenge for the program. It is clearly necessary that facilitators and the organisations in which they work must understand the differences between SDM and their existing practices. Secondly, it is necessary to the credibility of the program that differences should not be oversold.

The answer to this challenge may lie in the use of participatory processes within the training program. That is, some initial description of potential differences will need to be provided. Beyond that, however, an active process of comparison between aspects of the model and existing practices in different organisations may serve several purposes. It may:

- assist individual trainees to understand the differences between their existing practice and that intended by the SDM program, and thus support their learning about how to adapt their own practice;
- heighten the awareness of participants of differences in practice within their own organisations, and between their own and other organisations, thus building their understanding of the sector;
- contribute to improved descriptions in resource materials developed by the program.

Recommendation 1

That participatory processes be used to develop resource materials that differentiate between SDM and other models of person-centred planning and person-centred decision-making. The resource materials should acknowledge the variety of models already in use and the differences in the balance between expressed wish and best interests decision-making across agencies.

3.3 Recruitment of decision-makers

There were a number of issues with recruitment and selection of decision-makers, including:

- Lack of response to invitations to attend the initial 'conversations' with people with disabilities;
- Families and/or service providers acting as 'gatekeepers' and consequently as barriers to recruitment;

- Inadequate information for decision-makers, families or services to enable informed decision-making about participation;
- In one agency, disagreement between facilitators and the program coordinator about the suitability of potential decision-makers for the program, in part caused by:
- Lack of clarity about eligibility for the program;
- In one agency, more decision-makers expressing interest than could be accommodated in the program.

There was also significant lack of clarity about actual selection processes. The process of selection was described by the program as 'self-selection'. However, wanting to participate did not guarantee selection: in a number of agencies, choices had to be made between numbers of people with disabilities who wanted to participate. Self-selection is therefore clearly not an adequate description of the process.

The three underlying issues to be resolved are methods for promotion of the program and recruitment of decision-makers; eligibility for the program; and selection processes.

3.3.1 Promotion and recruitment

The SDM model is described as being based on 'self-selection'. The prescribed model is that an open invitation should be distributed to clients of an agency inviting them to a meeting, in which a conversation is conducted who they trust to support them with making decisions and how they can think about who they trust to support them. Those who express interest are then invited to a second meeting and provided with information about the program, on the basis of which they can opt in to the program.

This process assumes either that the people with disabilities regularly attend the service (as in residential accommodation services or day programs) or that they have access to transport to attend the meetings – which often implies family support for transport. Unless workers or family members act as (unbiased) 'interpreters' of the invitation, it also implies sufficient literacy and comprehension to understand the invitation.

Respondents identified a number of problems with this model. In some cases other workers were perceived to be 'gatekeeping'; in others, where clients do not regularly attend the service (and particularly for services where clients are widely geographically dispersed), group meetings were difficult to organise.

the first advice we had was just to send out a general flier. So we did that, posted it, emailed and go no-one; zero. I think that is more of the staff's limiting. They would have read it and gone, 'none of our people would be interested in that or do it'.

...most of the clients live independently. ... So it was really a bit tricky for me to find out the best way to invite them and to give them a basic understanding why would they choose to be a ...decision-maker.

The information included in the flyer was not considered sufficient to overcome these potential barriers to recruitment.

But even saying that, the flier didn't actually go into what it was. It was like, does anyone use support and want to learn how to make decisions?

...at this stage we weren't actually allowed to use the words 'supported decision making'... We weren't allowed to put that on our invitation. It was just about talking, discussing, would you like to come back, "Yes". So I struggled with that because the mums were asking me questions...

As a result, in some agencies, much more active targeting of potential participants was required.

...we picked out a few people we knew of that we thought may be and we probably went there two or three times to have meetings. ... - instead of doing that general recruiting which didn't seem to work, to kind of think 'who might benefit from this?' and we'll go and meet with them and talk about it.

From the knowledge I got from the training, I tried to find out who could be the closest people I can select, out of the clients I see. And ... I selected about five persons; five to six persons.

...I made a list of all the participants who were currently on my case load ... who I guess I felt would, would benefit from perhaps having a supported decision making model in place. It wasn't always based on intellectual disability. There was one particular person on my list who I believed was in a situation where they had expressed interest in doing something but their carer had sort of got in the way ...

The balance to be struck is between the program intent – that there should be open access to the program and that participants should 'opt in' rather than being selected by workers – and the practicalities of accessing clients for different agencies in different circumstances. The usual solution to dilemmas of this kind is to be explicit about the principles involved (for example, 'open access' and 'opting in'), but to negotiate the methods to achieve them. While this may be a less significant consideration in the next phase of the program (which is limited to two agencies), it will become important again should the program expand in future.

Recommendation 2

That the program recognises the need for and value of tailoring promotion and recruitment processes to individual agencies. Principles for recruitment rather than methods of recruitment should be emphasised within materials and in training and support.

3.3.2 Eligibility and selection

Once the invitational process had been negotiated, some agencies ended up with more potential participants than there were spaces available in the program. Here, agency workers and the HCSCC selected the participants.

...obviously we couldn't take six of them, 'cause that would be a big task again. So we had to select one or two. So Cher and I discussed after that meeting ... who is really more in.. need of ... decision-making. ...And then we selected one.

This meant that there were instances of potential decision-makers wanting to participate in the program being denied access to the program, either because of lack of capacity in the program (facilitators were only supposed to support one or two decision-makers) or because the coordinator did not believe them to be appropriate. In the latter case, selection was in fact made by the project coordinator. This caused significant frustration and resentment for the agency, the facilitators, and the families of those who had expressed interest.

"Already having adequate support in place" was in at least one case given as a reason for excluding a potential decision-maker from the program. This suggests that 'level of existing support' was an implicit – but not explicit – criterion for selection. It might be noted here that 'having support in place' is not the same as 'having supported decision-making in place'. Respondents discussed a number of examples of decision-makers with well-intentioned families who were nonetheless not maximising or enabling either decision-making by the person with the disability or implementation of their decisions. (If – as must be expected at least in the short term - participation in the program

remains limited, there may be potential for a spin-off program in future, providing training and support for families who are basically 'on-side' about how to better support decision-making.)

During interviews for the evaluation, the right to make final selections of participants was described by HCSCC as being an HCSCC decision. However, this had not necessarily been apparent to the organisations during the recruitment phase of the project, and nor is it 'participant self-selection'.

HCSCC also apparently changed its position, over the course of the program, about whether the model was appropriate for supporting people with disabilities in making decisions about their use of disability funding. Given that there are already paid workers whose job it is to facilitate this decision, coordination and negotiation would clearly be required. However, it is likely that there will continue to be a sub-group of people who need the additional support that SDM provides to make those decisions or to avoid having family or other supporters unduly influencing those decisions. There may again potential for a spin-off program here, providing tailored support in relation to these decisions.

The program had clearly excluded people under Guardianship Orders. Clarity about the criterion is to be commended – but in fact, one participant from one agency was described by the agency as “having a Section 32” (Section 32 powers under a Guardianship Order provide legal authority to authorise the use of physical force). That decision-maker showed some of the most remarkable gains made in the pilot program. Further, some respondents argued that being under a guardianship order did not necessarily mean that people could not, and should not be supported to, make at least some decisions.

Recommendation 2

That the types of decisions that can be supported, the relationship to the guardianship system and the relationship between supported decision-making and advocacy be clarified for future rounds of the program.

The program clearly needs to be voluntary in the sense that decision-makers have to want to participate. However, this is not the same as self-selection. As awareness of the program grows and more decision-makers want to opt in, and for as long as capacity to provide support is limited, selection has the potential to become a bigger problem. It should be addressed transparently. There is a related issue here as well: should the initial meeting at which people with disabilities are invited to a general conversation about accessing support for decision-making actually be open to all, if the program will not have the capacity to provide support for all those who may wish to participate?

Recommendation 3

That clear eligibility criteria for the program be developed and documented. Written criteria should be available to agencies, facilitators, families/supporters and decision-makers. The eligibility criteria should include the program being voluntary (that is, 'opting in' should be one of the criteria).

Recommendation 4

That processes for selection of decision-makers should be documented and should be available to all parties.

In a related issue, there was some confusion about “when the model starts”. Trainee facilitators reported being told that the 'model doesn't start until the agreement is signed'. However, there were recommended processes for promoting the program, providing information to potential

decision-makers, and recruiting decision-makers and supporters – all of which happened before the agreement was signed. These activities influence who is recruited and their understandings of the program, and therefore should be recognised and treated as part of the program model.

Recommendation 5

That the program model be described as comprising multiple phases, including recruitment and selection, implementation and 'winding up'.

This issue is addressed further in section 3.6 below.

3.4 Engagement and expectations of supporters and teams

It is hardly surprising, in a new program model that relies on the engagement of a diverse range of community members, that some of the most significant issues experienced within the program related to those community members.

Issues were experienced in relation to recruitment, engagement and roles of supporters (those directly engaged in supporting decision-makers in the processes of decision-making) and of team members (those involved in assisting in the implementation of those decisions).

One relatively common problem was that many decision-makers have relatively limited social networks, which often resulted in them choosing family members as their supporters. However family members can experience conflicts of interest in the role.

[Q: What does it take for a supporter to be a good supporter?] Total objectivity, which I think when you're related to someone is really hard. When you're a parent or a sibling, or even a grandparent, I think it's really hard ... I feel it would be really hard for me, as a supporter, not to influence a person I was related to, to do what I wanted them to. Not because I'm mean or anything like that, or stupid. I've got their very best interest at heart, but I'm really going to encourage them to do what I want them to do, which is not necessarily what they really want to do.

They can't step from the parent role to the supporter role. ...It doesn't necessarily take a step backwards, but it takes a step sideways where they have to stop being the parent, you know, and try and protect. Instead sometimes [decision-makers] want to do something that they don't want them to do, which in a parent role is really difficult.

Family members also carry a long history of engagement with the decision-maker, which colours their perception of what the decision-maker is capable of doing.

He has got a colourful background and ... 'this is what happened last time' and they revert a lot back to history whereas I try and bring them into the today and tomorrow of what we can work towards. But sometimes it seems slow progress and you feel like you're getting somewhere and then he has a bit of a bad day. 'See? I told you. This is what he's like. That's not going to change.' ... I think what they struggle with ... losing the emotional baggage of his history. ...I think that when there's been some aggression in families, there sometimes a lot of work needs to be done to smooth things. ... I think they see it as their role in the decision maker's life. ...To make the decisions. I don't think they think that he can make decisions for himself.

In some cases, there were also difficulties reported in supporters and team members following through on activities that had been agreed in meetings.

...discussing it with Mum all together that this is the plan, this is how we're going to work. So that was goo ...but when you see them the fortnight afterwards ...that task hasn't been followed

through so that's not quite an empowerment thing. Now I'm not saying that Mum should do that, but who helps [decision-maker] do that when he's chosen his parent ... as a supporter?

The most commonly reported problem was inability of supporters and team members to attend meetings.

Yeah. And that was really one of the difficult parts, 'cause the team involves employment agencies, TAFE consultants, Mental Health Services, Deaf Can Do, and Community Livings. And to get them into the same time was a horrific job. ...

there was supposed to be a meeting in March [when trainee facilitator was away]. There was supposed to be a meeting then and that didn't happen. Why didn't it happen? I don't know whether one of the supporters couldn't make the meeting so that didn't go ahead. ...So once you open up to more people to be involved, it becomes like world war III trying to get everyone together.

– the more people that are on the team, it's like, oh, I could help with that, or ... I'm happy to work with that, but the people we invited didn't turn up regularly

But we've invited [decision-maker]'s dad along so many times; he just doesn't turn up. So how do you progress?

I've had massive issues with support. ... Arranged it with my decision maker's mum to be a support. She came to the first two meetings and then wouldn't answer phone calls, wouldn't answer text messages, nothing. So we've had to pull someone else in as a support. Someone from the service. One of the support workers. He's fantastic as a supporter, which is not the way it's meant to be, but that's how it's had to be. We've had no options. The sister was supposed to be involved. Nothing.

A number of facilitators reported particular difficulties getting agencies to reply to requests or to attend meetings. While all recognised that workers in other agencies have prior existing workloads and in some cases agency policies that restrict their capacity to attend external meetings, their lack of participation was a commonly-reported barrier to the model proceeding as planned.

Organising meetings was in some cases made more difficult by a restriction on the extent to which the program Coordinator could attend after-hours meetings. This in turn related to an expectation that the Coordinator should attend all team meetings, discussed in section 4.3 below.

Where team meetings worked well, there were clear advantages to the meeting process. One worker suggested that it became 'like a competition' to see who could offer help. However in other cases, the difficulties in arranging meetings became a clear impediment to progress. Clearly, this has the potential both to undermine the team process (as some members fail to participate, others become disheartened and withdraw) and to undermine the decision-maker's confidence and motivation to proceed.

It is not clear whether, or to what extent, alternatives to whole group meetings were explored. These might include, for example, increased use of communications technologies such as linking some team members in to a meeting by phone or holding meetings by Skype. Other options might include having a series of smaller meetings related to particular topics.

Recommendation 6

That a range of alternatives to full 'team meetings' be explored and developed, to ensure that the forward momentum of agreements is maintained.

In some cases, trainee facilitators effectively took on a coordination function rather than relying on meetings: this is discussed further in the next section.

3.5 Roles of trainee facilitators

There were clear differences in the extent to which trainee facilitators performed coordination, linkage and some support functions. In some cases, these roles were undertaken by supporters and facilitators acted primarily as advisors; in others, trainee facilitators were more active. Differences appeared to depend on a) the nature and extent of the disabilities of decision-makers; b) the nature and extent of their social networks (some decision-makers had extremely limited social networks); c) the extent to which supporters were active in recruiting and involving 'teams'.

Some trainee facilitators effectively fulfilled much of the role of a supporter – other than directly talking through decisions and their potential consequences – because the supporters were unable or unwilling to take on additional activities. In one case, however, a facilitator was reported to have been criticised for undertaking a function that, in the view of the program coordinator, “should” have been performed by a supporter. Both the trainee facilitator (who saw the function she had undertaken as being both role modelling and direct training for supporters) and some other trainee facilitators disagreed with this judgement.

There are three possible interpretations of this circumstance:

- that role expectations were clear and the facilitator did exceed the role (ie should not have been as active in supporting the decision maker-supporter dyad);
- that the boundaries or expectations for roles of facilitators and supporters were not clear enough; or
- that because the needs of decision-makers and capacities of supporters will vary, flexibility will be required.

It appears clear from this pilot round of the program that this latter is the case – the roles of facilitators and supporters will have to be flexible in order to accommodate the different circumstances of both decision-makers and supporters. The role of the program will be therefore need to encompass training facilitators in negotiating with supporters about where the boundaries of their respective roles will lie. In so doing, facilitators will need to recognise that their facilitation role is time-limited and seek to develop the capacity of supporters to gradually extend their role (as was clearly the intent of the trainee facilitator in the case above). This may imply either skills development for supporters, or extending the network of team members around a decision-maker so that a wider range of skills and resources are available within the team.

Recommendation 7

That the program recognises that the capacities of supporters will vary and that trainee facilitators be supported to negotiate the boundaries of supporter and facilitator roles as required.

3.6 Information and resources

The lack of written information about the program was the most common concern raised by facilitators and managers in the evaluation of this round. Concerns from families were also passed forward in some cases.

During the meeting the mum wanted more information and she wanted written information which we didn't give her, there was nothing in writing to give her.

Lack of written information contributed to confusion and frustration both for trainee facilitators and for families, while verbal information was described as 'overwhelming', too complicated and as being too much to remember. This latter concern related both to information for families and information for supporters.

I don't know whether the information that we were given ... was maybe too complicated for [supporters]. ... I sometimes felt that maybe the language ... was too complicated. I think ... when you're the leader of something you just think that everybody understands what you're talking about. I think that's not always the case.

It was suggested above that the SDM model should be developed and described as a three phase model: recruitment and initiation (covering all work up until the agreement is signed); implementation; and a final 'handing over' or 'moving forward' phase.

Each phase needs its own resource materials (see section 3.6 below) and facilitators (and potentially supporters) will require specific training for each phase.

Resources for recruitment will include information about the program for decision-makers; information for families or guardians; information for trainee facilitators; and information for workers in other agencies who may be requested to promote the program to others. If the program extends beyond the two agencies who will participate in the next round of the program, information for managers in new agencies will also be required.

While different groups may require slightly different information, overall the information should include:

- the aims of the program
- its underlying philosophies
- a brief description of the model
- eligibility criteria for decision-makers
- selection processes for both decision-makers and supporters, and
- program parameters (e.g. time-limited support, the sorts of decisions that are excluded, behaviours that are not acceptable).

Resources for the implementation phase should include clearer expectations for the roles of trainee facilitators and supporters and/or additional support for facilitators about negotiating the boundaries of the roles (see 3.5 below).

At the time data was collected for this evaluation, no facilitators had reached the stage of finalising an SDM agreement and no feedback was collected about the adequacy of resources and support for this phase of the program. However, time limited interventions always require clear processes for conclusion and where required, for transition to new processes of support. It is to be assumed, therefore, that resources and support to manage this phase of agreements will be required.

Several of the managers interviewed for this evaluation said that they would have liked additional information and training in order to more effectively support their trainee facilitators, to enable them to learn from other agencies in the program, and to enable them to plan for diffusion within their own agencies. This is addressed in section 4.5 below.

Recommendation 8

That the development of resource materials be a priority for the next phase of the program. Separate resources may be required for facilitators, program managers, decision-makers, and supporters.

3.7 Time, timelines and workloads

Three inter-related issues emerged from the interviews in relation to time, timelines and workloads. Firstly, there was clear agreement across all trainee facilitators that the SDM model requires more work, and therefore more time per week, than they had been advised would be required. One facilitator gave a detailed description of the work involved and estimated that in the early stages, around 6 hours per week can be required per decision-maker – three times what they had been advised would be required. Another facilitator in a different agency suggested it took around three hours per week on average, but could require 6 hours in particular weeks. The amount of travel time involved varied significantly across agencies. So too did the time required for communication with other agencies and coordination, which seemed to vary according to the role of the facilitator (variations in roles were described in 3.5 above). The time spent writing (emails to other agencies, writing up reports and so on) varied both because of agency expectations and different facilitators' ease of writing (in English. Not all facilitators spoke English as a first language). Facilitators generally agreed that this workload did reduce later as teams became more established.

Secondly, very few of the facilitators had their workloads in other areas reduced in order to accommodate the work required for SDM. Many of the facilitators already had complicated roles – for example, working in two roles within an organisation, working two jobs, or studying as well as working. The additional load became overwhelming for some and came close to precipitating withdrawal from the program for at least one facilitator.

Thirdly, the establishment processes involved – from recruitment and selection of decision-makers through recruitment of supporters to engagement of team members – were much slower than had been anticipated. This created a number of difficulties with completing the program within the time available and significantly increased stress levels for a number of facilitators.

These issues have both immediate implications for the next phase of the program and implications for its longer term sustainability. In the short term, the new trainee facilitators need more realistic expectations of the time required of them, and agencies need to ensure that other workloads are managed, and where necessary reduced, in order to give trainees the time to undertake the work required. In the longer term, more realistic expectations need to be incorporated in planning and further roll-out of the model. There may also be some scope to consider other ways of implementing aspects of the model in order to increase time efficiency.

[Q: How sustainable is it do you think to have it go...across the agency if you... have lots of staff working in that way?] It's a really good question. I guess we would want to see what this next round exposes in terms of if we're looking at six individuals, what are the commitments there around time and we've got an opportunity I think this time round to be wiser in measuring that and then evaluating that from there. I wouldn't be as bold as to say yeah, no, it's fine, we can do it, we have to be sensible about that and clever about the way in which we do it.

Recommendation 9

That all trainee facilitators in the next round be required to keep timesheets recording tasks undertaken and time required for the SDM program. That these time records be collected and analysed to inform refinements to the model to improve efficiency.

4 Training and mentoring

4.1 Introduction

Given that the purpose of the pilot program was to train workers in agencies as facilitators for SDM, the project had a significant commitment to capacity development for trainees. The primary capacity development strategies were:

- a four day training program conducted for two days per week over two weeks at the commencement of the program;
- individual mentoring, in which the program Coordinator demonstrated or attended and participated in all 'group based' activities (recruitment of decision-makers, meetings of supporters, decision-makers and 'teams', and presentations to agencies) for each trainee facilitator;
- a Community of Practice for trainee facilitators – monthly meetings including presentations by guest speakers and opportunities for trainees to share knowledge and discuss issues.

Each of these is discussed separately below.

4.2 Training Program for trainee facilitators

The SDM program required trainee facilitators to develop a range of skills and knowledge that their normal work roles did not require. What was new of course varied across facilitators depending on their work roles, previous training and previous work experience. Amongst learning aspects identified by respondents were:

- accommodating the shift from best interests to expressed wish decision-making;
- learning how to balance dignity of risk and duty of care when existing agency practices usually emphasised the latter over the former;
- learning new questioning techniques to support others (both decision-makers and supporters) in problem-solving;
- lateral thinking skills for problem-solving;
- improved listening skills;
- greater knowledge of the disability sector and the roles and practices of other agencies;
- greater knowledge of communities and the kinds of resources that might be available to support decision-makers outside of the disability sector.

The initial training program attracted more positive than negative feedback. Strengths of the program were seen to be hands-on practice, the involvement of the peer consultants, peer support and networking.

I learnt a lot because I [haven't worked in] this industry for long now. It would be less than four years. So I think I have learnt in many areas.

It was challenging and it was exhausting. It was I think exhausting. I think you had to put a lot of yourself into it. There was a lot of challenges, personally and professionally I think. Yeah so it was a very intense four days the workshop. [Q: So what sorts of things were challenging?] That you were with your peers from other organisations and you were to use your skill in working and communicating with people with lived experience and people with disabilities because we had the peer consultants come in where we got to practise some of our communication techniques and perhaps our listening skills. We were all professionals and we wanted to do well so that

could be a challenge. But it's actually really interesting and I think we learnt a lot by watching everyone else. Oh, how do they do that? So there was a lot of peer to peer learning.

I liked the fact that we'd got peer consultants to come in and give first-hand experience of their process and their path and how things had worked for them.

The training was really good. What I think I like most about the training and I think it's really important for those people with disabilities that can have a voice, that they have a voice and they tell us exactly how it is for them. Sort of warts and all stuff... it was full-on, head hurt at the end of every day

But for me it was very much a steep learning curve. There was a lot of stuff I learned in our training, particularly around working with the people, with the...peer consultants. So when they came and we did a lot role-play with them, that was, for me, very good because I'd never done that before

For one 'old hand', however, the peer consultant work was not a highlight.

Because there was too much of it, for me, and I just found, I found it a little bit patronising...In that we were asking them lots of things that, it was almost like they were on display, for me, I just didn't feel comfortable. It just didn't fit for me.

4.2.1 For whom was the training most and least effective?

As should be expected, there were marked differences in response to the training program for facilitators. The majority of participants enjoyed it. Almost all could describe what they had learned as a result of participating. Some found it challenging; others less so. A couple found it unnecessarily long and repetitive.

The difference in responses appears to relate to the previous experience of the facilitator and their attitudes to supported decision-making. The program appeared to be most effective for less experienced workers, whose personal beliefs were 'close to' the philosophy but whose practice was constrained either by organisational policies and procedures or by inexperience. Generally speaking, workers with more experience in the disability sector were more likely to report finding the training unnecessarily long.

I found it very repetitive. I think we saw the same video three times in the end. I think for me, being around a long time, it was a bit like, we're going over the same, similar stuff to what I have done in my training as well so for me it was not a lot of new stuff. The group that were doing it were a very good group. They were all clear and committed. I just found it a little bit cumbersome and boring, to be honest.

Another experienced worker was concerned that the training program had not equipped facilitators to undertake the role.

I expected to be able to go and do the course and come away knowing how to be a facilitator. How to run my meetings, how to meet up with the decision maker, look at creating a plan and working with the supporters. ...I would change the training. I would make the training so that by the time the facilitators have done their course, they are competent.

The same person was concerned that facilitators were not able to promote the model after having completed the training.

...maybe it's too strong a word but it was a case of 'well this is what the training should have provided us, so that we can then go and spread the word of SDM and have that understanding'. ...I don't know whether that's maybe something that could have happened within the workshops, the training, was that we had to actually present our understanding of SDM and then [Coordinator] could actually say, yes [trainee], I'm confident that you can go out and spread the word.

In one case (or perhaps two cases) it was not clear whether more experienced workers really did share the same view of SDM as the program. Very experienced workers can be harder to engage in training (because they have 'seen it all before') but may also find it harder to actually change practice, particularly if the required changes are subtle. They may also find it more challenging to 'get it wrong' in front of the group. This poses particular challenges for training programs and requires:

- very clear distinctions about 'what is different' between the new methodology and other similar methodologies. (This was not always clear for participants, even after completing the training). This also means being able to recognise and acknowledge that there are already existing practices that are genuinely person-centred and that the difference between these practices and SDM is not so much at the level of philosophy and values, but in specific processes such as engaging community members as supporters;
- very tailored opportunities to practice 'the thing that is different', rather than generic skills, with very specific feedback about performance of those particular skills or tasks;
- opportunities for skilled and experienced staff to extend their skills, perhaps by working together in small groups;
- recognition of the existing expertise of skilled workers (for example by using them as peer leaders within particular exercises).

Recommendation10

That consideration be given to structuring the training program to allow greater extension of skills for experienced workers.

Should the program continue beyond the next phase, future consideration might also be given to developing systems of recognition of prior learning for experienced workers.

4.3 Mentoring

The program incorporated a very strong element of mentoring of trainees by the program Coordinator. This included an expectation that the Coordinator would attend many recruitment meetings and apparently all team meetings, and (as noted above), make all presentations within agencies about the model.

This approach of course had advantages and disadvantages, and worked better for some trainees than for others. One of the significant disadvantages was that the requirement that the Coordinator attend all team meetings, along with (necessary) restrictions on the numbers of after-hours meetings that she could attend, caused delays in organising those meetings. This contributed to the timelines issue discussed in 3.7 above.

As might be expected, it appears that mentoring worked particularly well for less experienced and less confident workers.

In the beginning I think she did most of the talking, but then as the meetings went on she was taking a step back and she was letting me do it. And then she would only come in if she'd say oh Deb, do you mind if say something here? So I could see she was training me, and I was listening, and then she was letting me go, and then she'd come in when she thought something else needed to be said. The last couple of meetings I virtually ran the whole thing. So I think that she's a very good trainer, yeah.

Others thought it was useful having her in the meetings, but not necessary that she be there.

Q: Do you need her to be at all the meetings?

Trainee 1. I don't think so.

Trainee 2: I don't think so either. It's good having her there. ...Because maybe sometimes ... you might slip back into that okay, I'll do that, I'll do that, I'll do that ... She's good at reminding you that other people can do stuff. ... I've dealt with parents for ages so I'll do the reassurance kind of stuff. She'll be the giving them more of a push almost; she'll be the bad cop type of thing. So it's good in that way. ...She'll reframe some of the stuff really well. You'll be saying stuff and she'll go, okay, what about this? Then you go, oh, that's a good way.

However, some more confident workers found it overly restrictive. There were also a number of comments that suggested that the Coordinator sometimes 'took over' facilitating. In some cases, the trainees appreciated this as leadership, in others they did not.

That [Coordinator] is so skilled at what she does and to sit and watch her, okay, that's how you do it. ... She directs it. So she will say okay, now let's talk about this. She ... also asks very direct questions. ... she'll ask all the hard questions.

I feel like she spoon fed me every step of the way. ... It seems that [Project Coordinator] wanted to be involved every step of the way and that's not what I expected...But she's led the meetings that I've had, [she's] chaired as being the facilitator and not me.

Another facilitator suggested that she would have liked more opportunities to debrief after meetings, as distinct from having the Coordinator step in during the meetings.

In the long term, it is not feasible to establish a program model with multiple workers that depends on a single individual attending all meetings. While some degree of demonstration is undoubtedly useful, the development of skills by the trainees ultimately depends on them exercising those skills. Strategies to ensure that trainees can do so effectively may include:

- lengthening the training program so that trainees have greater opportunities to both practice and demonstrate facilitation skills during training;
- adopting the 'demonstrate, support, observe' model of mentoring – in which the trainer demonstrates a particular task once, supports the trainee to do it the second time, and observes and provides feedback the third time (and if necessary, subsequent times);
- changing mentoring practices – for example, reviewing session plans or debriefing on the telephone after meetings, rather than attending all meetings;
- using community of practice meetings to role play solutions to difficult issues that have arisen in practice.

Recommendation 11

That the processes used for mentoring of trainees be reviewed with a view to establishing a more sustainable model, with greater flexibility for negotiating mentoring strategies in response to the needs of individual trainees.

4.4 Community of Practice

The final element of the capacity building strategy was the establishment of a Community of Practice.

Attendance at the Community of Practice sessions was not particularly high. At least one respondent did not attend any sessions, and some others only attended a couple. In all cases, trainees suggested that lack of time and other commitments were the barriers to attending.

I haven't been to any of them because - I would love it but it's because I'm busy. That's the only reason why I haven't been because I've been busy.

A number of trainee facilitators commented that the guest speakers had been interesting and useful.

I've found them really good especially the people she's kind of - it's like free professional development which we don't get that much of. So to have that opportunity to go and listen to people... and they did speak about their areas but in relevance to SDM and how it might be used through what they do. I don't know it was really good to have PD and get out of the office.

However, they also (and perhaps more so) found the peer conversations useful:

Yeah and then we get to chat amongst ourselves about how is it going? What about this? What do you do when this happens? Yeah it's been really good.

I found the information sessions were very helpful, but you know what was really good, was staying in contact with the other people we trained with ... I enjoyed those first couple of weeks of intensive training. I think we formed relationships, and I wanted to keep those relationships going ... because ... everybody's client was different and they had different issues, and we were learning from each other. And I think we could support each other... One time we went we had some issues and we discussed it with the group,... we just said look, we've got some issues, can we please discuss this with the group at the end? And they were helpful to us

It's good to catch up to see how they're going because I know in the start we were all supposed to have two decision makers each and we were feeling like, with the recruitment, this isn't working. You feel like you're a bit discouraged. Why can't we get - and we ended up with one each. I was feeling like we haven't achieved it. ...But then I went to the first community practice and no-one had two to start with. So that made me feel a bit like, okay, other people are having the same. So it was good to have that support network of the process as well.

No suggestions for improvements to the Community of Practice meetings were offered by trainee facilitators. The fact that the program will operate in two agencies in the next phase offers some opportunity to increase attendance. Strategies may include alternating sessions between the two agencies, perhaps with a clear expectation that workers will at least attend the sessions at their own agencies; providing group transport from one agency to the other; and having managers attend the Community of Practice sessions.

4.5 Training for Managers

Managers identified that they would have benefited from additional training in the model, in order to best support trainee facilitators but also to better support diffusion of the model throughout the organisation.

Look I think having some training - whether that is a workshop type of training where they don't do the full blown program but have an understanding of what those people who are intimately involved and what their roles are et cetera - would be very useful. ...and giving people the information they need at various levels to understand exactly what the differences are between supported decision-making and other person centred initiatives that may be going on at the same time.

Recommendation 12

That a managers' training workshop be developed, providing greater depth of understanding than existing information sessions.

In some agencies, workers also suggested that managers required a better understanding of the program and in one case, suggested that better evaluation data might help 'bring the managers on board'.

... To us, okay he's making his chocolate and all that which is so huge for that person. But to our manager who's looking at 'Well you've spent this many hours...doing this. What's the benefit?' That's the gap that we find. [Q:...management don't understand what the progress is?] Yeah. ... How can we show that in data or wherever? How can we tap into that? How can we use that to bring in more money to the organisation and make it more viable?

5 Future Directions

5.1 Refinements to the program for 2014-15

The most significant refinements to the program have been outlined in the recommendations in Chapters 3 and 4 above. They are summarised here for ease of reference.

Summary of Recommendations

1. That participatory processes be used to develop resource materials that differentiate between SDM and other models of person-centred planning and person-centred decision-making. The resource materials should acknowledge the variety of models already in use and the differences in the balance between expressed wish and best interests decision-making across agencies.
2. That the program recognises the need for and value of tailoring promotion and recruitment processes to individual agencies. Principles for recruitment rather than methods of recruitment should be emphasised within materials and in training and support.
3. That clear eligibility criteria for the program be developed and documented. Written criteria should be available to agencies, facilitators, families/supporters and decision-makers. The eligibility criteria should include the program being voluntary (that is, 'opting in' should be one of the criteria).
4. That processes for selection of decision-makers should be documented and should be available to all parties.
5. That the program model be described as comprising multiple phases, including recruitment and selection, implementation and 'winding up'.

6. That a range of alternatives to full 'team meetings' be explored and developed, to ensure that the forward momentum of agreements is maintained.
7. That the program recognises that the capacities of supporters will vary and that trainee facilitators be supported to negotiate the boundaries of supporter and facilitator roles as required.
8. That the development of resource materials be a priority for the next phase of the program. Separate resources may be required for facilitators, program managers, decision-makers, and supporters.
9. That all trainee facilitators in the next round be required to keep timesheets recording tasks undertaken and time required for the SDM program. That these time records be collected and analysed to inform refinements to the model to improve efficiency.
10. That consideration be given to structuring the training program to allow greater extension of skills for experienced workers.
11. That the processes used for mentoring of trainees be reviewed with a view to establishing a more sustainable model, with greater flexibility for negotiating mentoring strategies in response to the needs of individual trainees.
12. That a managers' training workshop be developed, providing greater depth of understanding than existing information sessions.

While these recommendations are intended to be addressed in the next iteration of the program, other considerations are also necessary for the longer term.

5.2 The program beyond 2015

HCSCC has indicated that it will not be able to continue hosting the pilot program beyond the existing two year commitment.

As a complaints service, it is arguably not the most appropriate service provider in the longer term. One of the agencies noted that a family from this round of the program had considered making a complaint but was unsure of doing so because the program was located with the HCSCC.

And the families need to know because there's the perceived neutrality, they wouldn't know that it would be alright, it would be perceived as biased. So say the outcome of a complaint was, "Well you've got nothing to complain about", they're going to feel, "Well, that's because I can only complain to you". So I don't know that that's such a good thing.

If the program is to continue it will, therefore, be both necessary and appropriate to establish a new 'home' for the program.

The program requires a longer time frame in order to demonstrate the range of its effectiveness. It is clearly effective in increasing independence and quality of life in some circumstances. However, the pilots to date have been (necessarily and entirely appropriately) too small to establish either the boundaries of its effectiveness, to identify its true costs, or to determine whether it reduces service costs in the long term. This is not a criticism. Most new programs take at least three years to establish and 'bed down'. Programs which by their nature involve changes to practice by a range of other agencies and the wider community should be expected to take longer, and there is clearly room for further refinement of the model. While some of that refinement will take place over the coming year, it should be expected that further development will be required beyond that. By implication, any new host agency must be prepared to make a stable commitment over some years to the future development of the model. A larger staffing base (at least two project officers, with

appropriate management and administrative support) would provide a more sustainable base for that development.

It is likely to take a full year of negotiation and planning for a new base to be established. While it will impose additional demands to do so, it is strongly recommended that active negotiations be commenced as soon as possible. HCSCC might also consider the support that it could offer to the new host agency to facilitate that transition and to support the ongoing development of the program. This could include, for example, not just the transfer of policies and materials, but participation in an advisory group for the project

5.3 The future policy and funding context

The disability sector is undergoing major structural changes with the introduction of individualised funding and the National Disability Insurance Scheme (NDIS). The broader policy and funding context will of course influence the roles of agencies, the relationships between them.

One manager thought that the policy change was conducive to the introduction of SDM:

And the reason I say that is I look at service agreements, I look at the requests for quotations that are - you know, tenders that are coming out, they're all espousing the person centred approach and active support. I think for a lot of those things they're probably just words that don't mean an awful lot to people, ... And whilst you can just basically say well you know, they're just talking the talk for the sake of it being trendy, the bottom line is that it does create an air of difference.

Another suggested that the introduction of the right for people with disabilities to choose the services that they purchase from different agencies would increase competition and decrease cooperation between service providers, and may also decrease the number but increase the size of service provision agencies. Large for profit organisations would be likely to join 'the market', while non-government organisations would be likely to have to merge to remain viable. In this market, supported decision-making could be a competitive advantage, or it could simply be too expensive a model to operate competitively.

...because supported decision-making has got a cost to it - whether individuals will see the importance of buying that...

It is possible that the cost of implementation of SDM may be offset by cost-savings to agencies. Some respondents thought that the model may be cost-effective in the longer term, with a more intensive investment in the short-term reaping benefits through increased independence and decreased demands on service providers in the longer term. However, a longer term economic evaluation of the model will be necessary in order to establish whether – and if so, for whom and in what contexts – this is the case. As one manager suggested, it is too early to do that as yet:

It almost needs a social return on investment calculation done on it to try and work that through, and it would be near on impossible, because it's fairly embryonic.

Another manager thought that individualised funding would restrict the range of decisions that could be made by the person themselves.

It's a little bit like whether the new NDIA process is going to be similar to that, with the role of the area coordinators because they are the ones - that's what my biggest comment is about this - they are the ones that will be making the decisions about what the goals the person chooses are, in consultation with them of course, and if and when and how they will fund them. So supported decision making in that light is only one aspect...

It will also be necessary, therefore, to take this changing service landscape into account in establishing a new base for the program. If the model is to develop further, agencies will need to make decisions about how opportunities for supported decision-making are structured within their range of services, the range of issues or decisions in relation to which they could provide a service, and how the costs and benefits of supported decision-making are incorporated into their cost structures. The program itself would then need to be able to work alongside agencies which may have different service delivery and cost models and this may require increased flexibility in the model.