

**Evaluation of the
Supported Decision Making Project**

**Office of the Public Advocate
November 2012**

Margaret Wallace



Muirgen Nominees Pty Ltd
consulting services

Contents

| | |
|--|----|
| 1. Executive summary | 4 |
| 2. Background to the Supported Decision Making project | 6 |
| 3. Evaluation methodology | 12 |
| 4. Findings | 15 |
| 4.1 Recruitment | 15 |
| 4.2 Participant experiences of Supported Decision Making | 17 |
| 4.2.1 Johnny | 17 |
| 4.2.2 Rosanna | 20 |
| 4.2.3 Alex | 22 |
| 4.2.4 Kathleen | 24 |
| 4.3 Supported Decision Making project; participants, supporters and services | 28 |
| 4.3.1 Participant profile | 28 |
| 4.3.2 Participants | 31 |
| 4.3.3 Supporters | 35 |
| 4.3.4 Services | 37 |
| 4.3.5 Services and the project exit strategy | 40 |
| 4.4 Non-participants in the project | 42 |
| 4.5 Participant safeguards | 42 |
| 4.6 Supported Decision Making as an alternative to guardianship | 43 |
| 4.7 Peer worker | 46 |
| 4.8 Other impacts of the project | 47 |
| 4.8.1 Information | 47 |
| 4.8.2 Resources | 48 |
| 4.8.3 Social capital | 49 |

| | |
|--|----|
| 5. Further development of the Supported Decision Making model | 50 |
| 5.1 The Supported Decision Making Practice Manual | 50 |
| 5.2 Training and Support | 50 |
| 5.3 Supporters | 51 |
| 5.4 Case management and advocacy | 51 |
| 5.5 Supported Decision Making and service providers | 53 |
| 5.6 Supported Decision Making Agreements and legislation | 54 |
| 5.7 Supported Decision Making Agreements and self-managed funding | 55 |
| 5.8 Developing a change strategy | 56 |
| 6. Conclusions | 57 |
| 7. Appendices | 58 |
| 8. References | 71 |

1. Executive summary

The United Nations Convention on the Rights of Persons with Disabilities promotes equal recognition before the law and supported decision making for all people with a disability, including people with an intellectual disability.

The South Australian Supported Decision Making service model enables people with a cognitive disability to make decisions, themselves, about their accommodation, lifestyle and health. They do this with supporters, who give information and talk through options and consequences before a final decision is made.

The Supported Decision Making research project operated from the Office of the Public Advocate from late December 2010 until October 2012. The M.S. McLeod Benevolent Fund and the Office of the Public Advocate funded the project.

This evaluation report is in several parts. It provides background to the project. It includes a section on findings from the evaluation, with particular attention given to the experience of the project participants and their supporters. The report includes four stories from people with disabilities who were participants in the project. It also includes a section on issues to consider in the further development of Supported Decision Making in South Australia.

Issues for further consideration that emerged from the project's implementation are the:

- further refinements of the service model
- future place of Supported Decision Making as a statutory option
- place of Supported Decision Making in emerging models of self-managed funding.

The Supported Decision Making project has demonstrated that there were specific benefits to most of the participants. These were seen in their increased confidence in themselves and in their decision making. There was evidence of improvement in decision making skills. Participants described

the growth in their support networks. Many reported that they felt more in control of their lives. Participants gave evidence that they had increased their engagement with the community, either through expanding their options or through making decisions that changed their circumstances.

Supporters reported positive changes. They reported on increases in supported decision making in the lives of the participants, changes to the way they considered decision making with the participants, and positive improvements in the nature and quality of their interpersonal relationships.

The evaluation gives evidence that Supported Decision Making was both a companion process and viable alternative to substitute decision making for participants who were initially on Guardianship Orders.

2. Background to the Supported Decision Making project

The United Nations Convention, *The Rights of Persons with Disabilities*, defines the rights of people with disabilities and recognises, among other areas, ‘the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.’¹ Article 12 of the Convention, Equal Recognition before the Law, requires states to develop ‘appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.’² The United Nations Convention promotes equal recognition before the law and Supported Decision Making for all people with a disability, including people with an intellectual disability.

The Office of the Public Advocate in South Australia began exploring the implications of this Convention in 2009.

Development of the Supported Decision Making project

The Office of the Public Advocate developed an alternative to substitute decision making, called Supported Decision Making. Supported Decision Making provides a way for people with a disability to exercise their legal right to make their own decisions where possible, and to access support to do so, rather than having decisions made for them through formal or informal substitute decision making. The Office of the Public Advocate developed Supported Decision Making as a non-statutory element of a stepped model for decision making, in which Supported Decision Making takes its place as a less restrictive option than substitute decision making. (See Appendix 1)

The Julia Farr M.S. McLeod Benevolent Fund funded a research project proposal put forward by the Public Advocate in 2010. The project had two

¹ *South Australian Supported Decision Making Project Report of Preliminary ‘Phase 1’*, Office of the Public Advocate South Australia in collaboration with the Julia Farr M.S. McLeod Benevolent Fund, June 2011.

² *Convention on the Rights of Persons with Disabilities*, The United Nations, 2007.

component parts. One was to develop a service model for decision making, the other was to develop the model within a research framework. The service model was to be developed, put in place and its impact evaluated.

The South Australian Supported Decision Making Committee was established in 2010. It was formed under the provision of the Guardianship and Administration Act 1993 Section 21(3), which allows the Public Advocate to set up committees to provide him with advice in areas relevant to his functions. This Committee was also known as the Project Control Group. In this report it is called the project Committee.

The project Committee developed the Human Research Ethics Committee proposal, which was given approval in December 2010. The project Committee overseeing the project's development and implementation saw external accountability to the Ethics Committee as integral to the implementation of the research, as a way of ensuring safeguards for the potentially vulnerable participants. The proposal also defined the scope of the research, that is, a trial in two phases. The first phase was intended to test the applicability and refine the service model. Phase 2 broadened the implementation of the refined service model.

The membership of the project Committee included people with lived experience of disability as well as academics, advocates/guardians, a legal practitioner and senior staff from the Office of the Public Advocate. (See Appendix 2)

The terms of reference for the project guided the work of the project Committee. The terms of reference include the project objectives, which are to:

- advance the implementation of Article 12 of the United Nations Convention for the Rights of Disabled Persons: 'Equality in the Law'
- provide assistance to individuals to exercise autonomy and self-determination over their lives through personal decision making
- develop resources and assistance tools for people who may provide decision support (such as family, carers, friends, circles of support)

- develop Supported Decision Making options that may serve as a guardianship alternative (consistent with the Office of the Public Advocate’s role of exploring and using alternatives, where these help reduce reliance on formal Guardianship)
- promote and develop new systems of Supported Decision Making, within guardianship practice, so that the use of substitute decisions is limited wherever possible, even for those with a statutory Guardian.³

The Supported Decision Making model developed by the project Committee focused on the roles of the participant, the supporter and the monitor. It also developed the Supported Decision Making Agreement (SDM Agreement). (See Appendix 3)

Participants

The person using support to make decisions, the participant, would indicate that they wanted to be part of the project and identify which decisions they wanted support to make. The participants would identify the people they wanted as supporters. The participants also needed to understand and accept that they would make their own decisions, rather than the decision being made by their supporters. They were able to end the agreement at any time.

Supporters

Supporters for participants would be drawn from existing circles of trusted family and friends. Supporters were also expected to undertake the role willingly and be well informed about the participants’ goals. They also needed to commit the time needed to undertake the support role and to assist the participants to make their decision known.

³ Adapted from the Terms of Reference; adopted March and July 2010, OPA Annual Report 2009 -10

Monitors

A monitor would be a person who could keep oversight of the process as it unfolded and to act as a point of reference should the SDM Agreement stop working effectively. The Committee saw this role as part of the safeguards necessary for the project to operate ethically.

The SDM Agreement records the participants and their supporters and the areas for decision making. The SDM Agreement was accompanied by information about Supported Decision Making. As well, it was used as the device to formally include participants in the project.

The project Committee determined that the project would focus on two groups: an Alternative to Guardianship group and an Early Intervention group. The recruitment criteria defined potential participants as people with an intellectual disability, or acquired brain injury or neurological disease. The areas of life in which Supported Decision Making could be used focussed on accommodation, lifestyle and health decisions, consistent with the areas that may be included in a Guardianship Order, while acknowledging that decisions in these areas could have financial implications. However, the project Committee decided that the scope should be limited to areas not covered by financial Administration Orders under the relevant legislation.

The project Committee approved information sheets for potential participants and their supporters, the SDM Agreement and the evaluation framework. It also approved the skill set for the project co-ordinator and the need to include two more people with lived experience of disability on the project Committee.

The Committee planned to meet every four to six weeks to give oversight and guidance to the project, as it was implemented.

Phase 1 of the Supported Decision Making project

The project co-ordinator was appointed in November 2010.

Phase 1 targeted the recruitment of 10 participants to the project. Eight SDM Agreements were in place by the end of this phase, from 22 referrals to the project.

In this phase, the project Committee considered the role of community organisations as a source of voluntary supporters should the person who wanted to use Supported Decision Making also experience social isolation.

Phase 1 trialled the use of Supported Decision Making alongside existing Guardianship Orders.

Although no one with a mental illness was recruited to the project in this phase, several were referred to the project. The project Committee decided to exclude people with dementia, or mental illness as a primary diagnosis, from the trial.

The project co-ordinator developed pictograms through one of the agencies involved in the project. These were developed because there were some people who were not able to read the existing materials about Supported Decision Making.

The project Committee was asked by the Human Research Ethics Committee to consider the role of police checks for all supporters as a way of ensuring the participants' rights to safety. The position adopted by the project Committee, and accepted by the Human Research Ethics Committee, was that, as both the participant and the supporter make the decision to be part of the SDM Agreement, in the context of a trusting relationship, a primary safeguard was in place. The project co-ordinator and the role of the monitor were seen as additional safeguards to the participants. Volunteers would be required to have police and reference checks. The participants in the project were also given information about the Office of the Public Advocate's Complaints Policy, which they were able to use.

Reports on the project's development and on Phase 1 of the project were included in the Annual Reports of the Public Advocate in 2009-2010 and 2010-2011. These reports included descriptions of the research project and the project Committee structure. The reports also explored the philosophical underpinnings of the project and make reference to international models in use or development. The 2009-2010 report also includes the stepped model of decision making, which places Supported Decision Making in a continuum of practice.

The in-house evaluation found that SDM Agreements can be put in place and can be used. The in-house evaluation also found the experience of developing and using SDM Agreements was positive for participants and supporters. In addition, the in-house evaluation found that the small scale trial provided information about Supported Decision Making, which helped people with a disability to make a decision about proceeding to an Agreement. It also found that the project co-ordinator's role was to both facilitate the decision to participate and to be a resource for supporters as they developed in the role.

Developing a Model of Practice for Supported Decision Making was written on the basis of Phase 1, in June 2011. This report captured the experience of Phase 1 of the project and was intended to provide background information to establishing SDM Agreements. The report was posted on the Office of the Public Advocate's website.

Phase 2 of the Supported Decision Making project

The implementation of Phase 2 occurred from June 2011 until the end of the project's funding period, November 2012.

In Phase 2, the project co-ordinator continued recruitment of participants and their supporters, maintained the project database and developed and implemented an exit strategy for project participants and their supporters.

The project Committee continued to meet and provide guidance to the project's implementation.

3. Evaluation methodology

Phase 1 of the project was the subject of an in-house evaluation, which was completed in June 2011. The Phase 1 report contains information about the aims of the research project trial and about the kinds of decisions made in the project. It also includes information about the participants and their SDM Agreements and responses to the telephone survey administered as the basis for the evaluation. It includes information about anticipated changes to the model in Phase 2. The evaluation report was forwarded to the UN Committee on the Rights of Persons with Disabilities and the funding body.⁴

The purpose of the external evaluation was to assess:

- how well the new service model of Supported Decision Making is being implemented and delivered; whether the aims, anticipated outcomes and its anticipated general benefits for people living with disability have been met; and identify any unanticipated consequences
- the outcomes and specific benefits of Supported Decision Making for people living with disability related to community inclusion, autonomy and personhood
- the experiences and perspectives of people living with disability about the impact of Supported Decision Making on their lives.⁵

The original evaluation plan for the external evaluator was to provide both process and outcome evaluations. As part of the background to the planned process and outcome evaluations, the evaluator interviewed most members of the project Committee (85%) and two Guardians from the Office of the Public Advocate. The process component of the evaluation was provided through verbal reports at the Project Control Meetings, where they were relevant, following a recasting of the evaluation parameters.

⁴ *South Australian Supported Decision Making Project; Report of the Preliminary "Phase 1"*. Office of the Public Advocate South Australia in collaboration with the Julia Farr M.S. McLeod Benevolent Fund, June 2011.

⁵ Adapted from the *Evaluation Service Brief and Tender*. Office of the Public Advocate South Australia, February 2011.

The external evaluation focussed on the impact of the Supported Decision Making service model for people living with disability and the experience and perspectives of people living with disability about the impact of Supported Decision Making on their lives.

Quantitative data was collected and recorded by the project co-ordinator, while the evaluator collected qualitative data. Both sources have been used in this evaluation. A series of interview questions were developed for the evaluation. They were used as the starting point for discussion. (See appendix 4)

Participants in Phase 2 of the project gave consent to be involved in the evaluation, as part of their agreement to participate in the project. Those in Agreements from Phase 1 of the project were asked to give consent to participate in the evaluation. In addition, a number of people approached to adopt Supported Decision Making, who did not go ahead, gave consent to participate in the evaluation. The project co-ordinator maintained consent records. All the people interviewed gave consent.

Information was gathered using interviews with participants (53%) and their supporters (27%), and with staff from three services. Some of the interviews were recorded, with the permission of the interviewees.

The interviews with participants were arranged in parallel with the review meetings conducted by the project co-ordinator. (These meetings monitored progress for participants in achieving their decision making goals.) Other, more direct, methods of contact had not resulted in a schedule for the interviews. This refined process allowed for participants to reconnect the evaluation within the Supported Decision Making project context. The interviews took place with the interviewer and participant and interviewer and supporter in the main. If the participant wanted the supporter present, that occurred. On one occasion, the supporters, the project co-ordinator and others who had had some involvement in the Supported Decision Making process for the particular participant, were all involved in the discussion.

The project co-ordinator developed and maintained a database about recruitment and participation to the Supported Decision Making project. This information was available to, and has been used in, the evaluation.

The evaluator also attended most project Committee meetings and could therefore contribute to both the process evaluation and receive information relevant to the final evaluation of Phase 2 of the project.

The evaluator accessed background papers and the reports generated by the first phase of the project and other general source materials in the area of Supported Decision Making.

All information generated through the project about participants is de-identified in the evaluation. The evaluator was also bound by a confidentiality agreement in relation to people involved in the project.

This evaluation does not have the remit to report on project management in terms of governance, budget management, human resource management or the extent to which the project infrastructure was fit for purpose for the Supported Decision Making project. The Office of the Public Advocate managed these matters internally.

A preliminary evaluation summary was presented to a planning workshop held by the project Committee in July 2012. This report was used as the basis for discussion about the future of Supported Decision Making in South Australia. The outcomes of the workshop are in the hands of the Office of the Public Advocate.

This evaluation report was submitted to the project Committee in November 2012.

4. Findings

4.1 Recruitment

The project Committee sought approval for Phase 1 of the project for up to 10 participants, which was given on 3 December 2010. An extension was given to include a further 5 people on 17 June 2011. The second approval (9 September 2011) allowed for 20 participants in each of the Alternative to Guardianship and the Early Intervention streams of the research project.

Ten participants were recruited in Phase 1 of the project. There were 7 women and 3 men in this group. By the end of Phase 1, one of the participants had died, and another had withdrawn.

Early in Phase 2, a further 15 participants were recruited, 10 men and 5 women. Thirty-seven people had been contacted and interviewed at this stage. Of those, 2 later withdrew, because of changes to their circumstances. By May 2012, 52 people had been recorded as having been contacted and 26 SDM Agreements were in place for 14 women and 10 men. Two other participants had died before the end of the project.

The target groups for recruitment were people with an intellectual disability or acquired brain injury and people who might otherwise be under a Guardianship Order. All of the participants fitted the selection criteria for the project, that is, all were adult people with a disability, who did not have mental illness as a primary diagnosis or degenerative dementia, had not been assessed as experiencing abuse or neglect, or were not at the centre of significant conflict among family and friends.

All of the participants made the decision to be part of the project themselves.

The project began with the project co-ordinator seeking referrals from services and the Guardians in the Office of the Public Advocate. Work with the service providers involved providing information to the service providers, then following up with a series of information meetings and then individual meetings with people who were referred by the agency or service to the project. Ten organisations were contacted in the first three months of the

project. This led to 16 referrals from non-government agencies and to 13 from government agencies for a possible group of 10 in the Phase 1. This recruitment model was used in Phase 1 and for part of the Phase 2 expansion.

However, this process did not lead to enough suitable people being nominated for the project, once they were assessed against the selection criteria. The process was also time intensive. By the end of 2011, only 51% of those people referred to the project co-ordinator, and recorded on the project spreadsheet, had proceeded to an SDM Agreement.

The project co-ordinator then developed a model based on meeting potential participants in the places where they worked. She gave information to the organisation and then arranged a series of meetings, inviting people to come and find out about Supported Decision Making. The first session gave the information and a second meeting, one-on-one with those who expressed interest, was then held. Any further meetings with potential participants were held, as required, to finalise the SDM Agreement.

Participants self-selected to be part of the project using this method of recruitment.

Several of the participants were of non-English speaking background and all spoke English. None of the participants were Aboriginal.

A further recruitment phase began in early 2012, following the decision that the Alternative to Guardianship stream in the planned project would lapse. (See section 4.5 for a discussion of this matter)

The success of this new method of recruitment indicates that Supported Decision Making should have multiple entry points. This does not exclude the role of agencies in recommending the process to their clients. The refined model did provide a community based point of access to the project. It also ensured increased personal autonomy, through the participants' decisions to seek information about Supported Decision Making.

4.2 Participant experience of Supported Decision Making

This section of the report tells the stories of four participants and their experiences of the Supported Decision Making project.

4.2.1 Johnny

Johnny was 61 years old when he joined the Supported Decision Making Project in Phase 1. His Guardian in the Office of the Public Advocate referred him to the project. He was referred as a possible candidate for the Alternative to Guardianship stream of the project. He was under a Guardianship Order and an Administration Order when he first began as a participant in the project. He received the Disability Support Pension.

Johnny was in a nursing home, recovering from a stroke and other illnesses, when he began in the project. He wanted to leave the nursing home. The nursing home staff members were worried that if he left, he would not get enough support to maintain his health. When he was negotiating his SDM Agreement, he said that he wanted to have several decisions in it: he wanted to move to independent living, manage his health, get back to volunteering and spend time with his family. Johnny's Guardian was ready to support Johnny's involvement in the Supported Decision Making project and see how it went. The Guardian was prepared to support the revocation of the orders in six months time, if Johnny did well under the new regime.

Johnny called on two friends to be his supporters. One was an old friend, the other a friend of his son's. Johnny's son had died recently and his son's friend wanted to help support Johnny, who was deeply distressed. The supporters understood his wishes and supported them being achieved. Johnny described his relationship with one of his supporters: 'I ring a lot to talk things over.' He said about his other supporter that he, Johnny, had recently 'backed off a bit because I didn't need so much help.' One of the supporters involved Johnny in his own family life.

Johnny's first start at making his own decisions did not go as smoothly as hoped. Initially he made impulsive decisions about his desire to live in independent accommodation: 'I didn't get it quite right'. The project co-ordinator, who also acted as an advocate with Johnny and other

participants, helped Johnny find accommodation. That in itself caused some problems, as Johnny would be required to accept more help from service providers than he thought was necessary, in order to access accommodation options.

A place was found, although the service provider wanted some formal support involved. Johnny's two supporters were accepted as volunteers for the organisation and could then continue to be included in his life, as well as meeting the necessity for formal points of contact for the service provider. Johnny arranged for local council support to do his shopping and some housekeeping. He negotiated with his accommodation service to have a pet, after he had organised evidence in support of his wish. He involved himself in the life of his community, through an 'open door' policy, as he described it. He also organised some social events and joined the residents' committee.

Johnny found himself briefly at odds with the terms of his accommodation, when he broke the terms of his accommodation agreement. He then consistently complied with extended terms on his accommodation.

He became a volunteer, as he had hoped, working with homeless men and in the gift shop of a public hospital. He kept to his regular commitments and extended his responsibilities. He used public transport to do this, using a walking frame to aid his mobility. Johnny also kept the staff at the nursing home informed about his progress. He took over responsibility for his shopping.

Johnny used the decision-making diary that had been developed as part of the project infrastructure. In it he recorded the decisions he wanted to make, his analysis of the benefits and drawbacks to the decision and the outcomes of the process. His diary records that he decided to contest a phone account he believed was wrong. One of his supporters worked with him on this decision. He recorded that he was 'quite satisfied' with the outcome of the decision to take action, and it resulted in a significant refund. Johnny used his skills to negotiate with power suppliers, make complaints that were upheld and negotiate repairs in his accommodation.

He used the Supported Decision Making process to make decisions about how to manage relationships that did not support his chosen goals or to maintain relationships that were good for him. One example is his delight in the result of him writing to an old friend to re-establish contact: 'X rang on [date]. Will see him Friday!'

At Johnny's 6 month review, previously agreed between the participant, the Guardian and the project co-ordinator, both his Guardianship Order and his Administration Order were revoked.

Johnny achieved all he wanted from his SDM Agreement, except his hope to visit family interstate. Sadly, Johnny's chronic condition deteriorated and he died before he could use the train ticket he had saved for and bought for his interstate trip to see members of his family.

Johnny's sister said that his involvement in the project 'saved his life and made his life worth living again as he was his own boss.' His friends thought that Johnny had achieved a level of happiness in the last eighteen months of his life.

Johnny was proud of his involvement in the project and promoted the benefits of Supported Decision Making in his own life: where he volunteered, at his accommodation, to service providers and to his family and friends. '[I] feel confident. [I] get confidence from having people believe I could do [these things]. A large percentage of people didn't expect me to survive, didn't recognise [that I could]. One said six weeks and you'll be back. That was nearly a year ago.'

'2012 is great. I am content with my lifestyle and what I do.'

'I help promote the service because I have come so far in such a short period'.

Perhaps most importantly for him, he was able to reconnect with his family before he died.

Johnny's experiences of Supported Decision Making highlight the need for time to be given to the development of decision making skills and confidence.

4.2.2 Rosanna

Rosanna was 20 years old when she began in the Supported Decision Making project in Phase 1. She was referred to the project by the staff at the Special School she attends. Rosanna received the Disability Support Pension. Her supporters were her mother and her sister, both of whom have disabilities themselves.

Rosanna's goals centred on her transition from school to post school life. She wanted to leave school, but wanted to be able to be more independent and have something meaningful to do when she left.

Rosanna's experience of Supported Decision Making has involved her family, especially her mother and sister. Families SA and Disability SA were also involved with the family, and were working to strengthen the family's capacity. The focus on decision making processes and Supported Decision Making became an important part of the family's way of life, dealing with the decisions they faced.

Rosanna decided to leave her school program part time and attend TAFE. This followed on from Rosanna having a very positive work experience at the front desk on the school. Rosanna, who had previous experience of TAFE, and her mother and sister, enrolled in Certificate 1 Computer, English and Maths courses, and they all took part in a child development course.

One of the benefits of being in the Supported Decision Making project was the way it allowed and encouraged family members, in their role as supporters, to be part of 'official planning' with Rosanna.

A granny flat has been partially fitted out for Rosanna, which gives her much greater independence: 'It is big stuff, going into [my] own flat.' Her bedroom is fully functional, but she has to 'get off her chair and crawl to the kitchen' as it is not yet accessible to wheelchairs. Disability SA is supporting these improvements. Rosanna has made decisions about her own life, in its context, and has developed a healthy eating plan, given up smoking and joined in activities in her great area of interest, motor sport. Her family believe that now Rosanna 'has a voice, a powerful voice.'

Rosanna spends 3 days a week at school, and 1 session at TAFE a week. She has completed her Duke of Edinburgh Award. She has learned how to buy things, how to budget and pays her own bills. Now she is saving for an iPad. The family, and in particular Rosanna, now use voice recognition dictation software and screen reading software. This has significantly reduced her isolation as Rosanna and the family can now email and use the Internet. Rosanna has participated in the Service to Youth Council Helping Young People Achieve and is in contact with the Julia Farr leadership program. School personnel believe that Rosanna now 'shows great leadership [in] the class.'

Rosanna has taken action on her own and other people's behalf. She has written to the Honourable Kelly Vincent about the lack of access to swimming for people with a physical disability and believes that now she has a better understanding of issues for people with a disability. She brings things to people's attention and people now go to her for help. Staff at the school believe that Rosanna is 'much more confident now' and that she has 'grown in maturity and in her approach to life.' They see that she no longer waits for other people to make her decisions and is more independent.

The school held a parent information evening about Supported Decision Making, where the project co-ordinator informed them about the project. There was a high level of interest, but the project had reached its goal numbers and so extra participants could not be included. However, the school sees the process of Supported Decision Making as so useful, it is basing its transition program on it.

The family now use the process of Supported Decision Making for their own decisions, including ones made by Rosanna. This has been of great benefit to the family: '[This] has helped us heaps.' '[We know] how to fit the decision into life...' The family worked as a team and felt more confident about tackling everything in a different way by using the Supported Decision Making process.

One decision has been to develop a plan with Rosanna, who said ‘knowing that there is a plan in place if something happens to mum has been a huge, gianormous weight off my shoulders.’

There are several things on Rosanna’s decision plan that have not been achieved yet. One is to drive a car, and she is still working on that. The other is how to approach toileting, which, in her words, is ‘a major thing’ for ‘going out and about.’ Her time at TAFE is limited because the site does not have a sufficiently trained staff member, although facilities are on campus. If she is eligible to attend for longer, and even at the four-hour sessions, Rosanna is dependent on a member of her family to attend with her. She hopes that self-managed funding will help her find a solution to this barrier to her wider participation in the life she wants.

Rosanna’s experience highlights that making a decision to act does not always mean the decision can be achieved. While this is true in every life, for people with a disability, external and institutional barriers can unnecessarily confine a person’s achievement of their goals.

4.2.3 Alex

Disability SA referred Alex to the project in Phase 1. Alex has an Administration Order on his Disability Support Pension, imposed because of previous debts. He was 41 when he became a participant in the project, in the Early Intervention stream. Alex is a widower and has a 12 year old son.

He had become homeless and moved to the city: ‘everything was falling down.’

Alex and his son stayed with a friend, who also became his supporter. Alex was a problem gambler and his supporter gambled often.

Alex wanted to change his gambling, as part of his SDM Agreement. He went to gambling and financial counselling, which the project co-ordinator negotiated on his behalf, once Alex made the decision to attend. Alex is no longer behaving as a problem gambler. Alex was also able to make

arrangements to manage his debts and therefore resolved outstanding civil actions against him.

Parenting was another issue Alex had identified where he wanted to use Supported Decision Making. After some difficulties in Alex and his son's capacity to manage together, his son went to live with his grandparents, where he had supportive networks of family and friends. Alex has reported that this was a good decision, for his son and for him. He maintains contact with his son and sees him in school holidays.

Alex also wanted to make decisions about finding a permanent relationship. This was an unpredictable process for him, at the beginning of his growth in Supported Decision Making. He was surprised when decisions he had made, without talking or thinking them through, did not work out as he had hoped. His supporter and Alex met with the project co-ordinator for a run through of the process again, concentrating on the need to identify the benefits and drawbacks before making a decision. He has continued to practice this approach and is using it when he makes contact with possible female friends. He says that it is fun now and it is not so serious an issue: 'I am doing it differently now.'

Alex has continued his counselling and is using harm minimisation as his guiding approach to managing his decisions. He is now living in and maintaining his own accommodation, an area where the advocacy role of the project co-ordinator helped Alex achieve his wish. He has progressed from a disability service sponsored fitness program to maintaining his own regular involvement in a gym. He works full time and is very pleased with his savings. He has decided to continue to use his Administration Order, rather than apply for it to be revoked, because he sees it as both a support and a protection for him to keep to the improvements he has made in his life. He is now debt free, feels he can support his son better within the framework of the Order, and can save for a holiday.

Alex said '[It's] better, I know how to do things now. I can do things. I have noticed changes. I reckon it's good I can do things and make my own decisions now.'

Alex's experiences also highlighted areas for further development. He found that maintaining relationships with his disability workers was hard, as he had 5 changes of staff while he was in the program.

As well, Alex's supporter withdrew from the process, for a mixture of reasons. One was that Alex's choices were creating some distance between their previously shared experiences. In response to this situation, the project Committee explored the role that voluntary supporters, drawn from community service organisations, could play when a person wanting to use Supported Decision Making, was also socially isolated. However, this promising beginning did not result in an agreement between Alex and the volunteer. The project co-ordinator took on the role, once this, and other options, were exhausted. Alex wanted this arrangement and formally agreed to it. This agreement provided continuity through to the end of the project.

The role of the supporter is integral to the Supported Decision Making model. The supporter is the trusted friend or family member who willingly takes on a more formal role, helping to get information about options and being a sounding board before the person makes the decision. This is difficult for people who are socially isolated, as Alex's experience shows. Alex now talks things over with a number of people, his counsellor, the gym staff and his disability workers. But none of these people can be his supporter.

Alex's says that he can use the process himself: 'I can do it. It is a different way of looking at it, a different angle.' However, his experience does highlight that learning and practising decision making skills with a trusted person is a necessary component of Supported Decision Making.

4.2.4 Kathleen

Kathleen was 74 when she became a participant in the project in Phase 1. She was under an Administrative Order and was on the Disability Support Pension. She joined the project in Phase 2.

Kathleen lived with a close friend who became her supporter. Her friend has a son who lived in the same house with them. Kathleen's husband was in a

nursing home and was under an Administration and Guardianship Order: '[I] can't see my husband. It is so hard. [It] all feels down.'

Proceeds from the sale of the couple's house were managed through the Administration Order. Kathleen used aged mental health services, somewhat reluctantly, and had nursing support for her health conditions.

Kathleen's most urgent area for decision making was to find independent accommodation: 'I just long to get into my own little house. When I am tired I can just sit down. I can read a book. I think it is a dream that will never come true.' Kathleen believed that she was on a list for accommodation. She did not believe that she would be able to purchase a home, and, in any case, she thought that rental would be a good stepping stone to her 'dream.'

Kathleen's supporter was finding it a strain to have Kathleen living in her house, when she herself had her own serious health problems and the tensions between Kathleen and her supporter's son led to disputes at home. Kathleen's supporter was careful to say that she was not Kathleen's carer. Rather she was a trusted friend who helped with some things, for example, helping to manage Kathleen's medical appointments. She said that Kathleen 'gets worked up', wondering 'who else is coming.'

Kathleen and her supporter believe that using Supported Decision Making 'helps to make things clearer', 'gives me a little bit of security about what to do,' 'helps me be the person I want [to be]' and does 'support decision making.' Kathleen said that she tried writing down her decisions, but did not use the project diary. She said that now she 'thinks about it before saying yes.'

As part of her role of monitoring progress with the decisions the participants want to make, the project co-ordinator met regularly with participants and their supporters. In certain circumstances, the project co-ordinator also acted as an advocate for participants, in order for them to achieve their expressed wish. In this case, the project co-ordinator checked on Kathleen's progress on a housing list, to find that she was in fact not on it at all. She was placed on the list.

Kathleen's husband died two weeks after she moved into her new accommodation. Kathleen was very distressed by his death: she had hoped that he could visit or come and live with her. A long standing friend of the family attended Kathleen's husband's funeral. He volunteered to be Kathleen's ongoing informal supporter, as he felt he owed her a great deal. He said that she had been like a parent to him when his own mother died. (Kathleen's supporter withdrew from the role after the interviews because of her own circumstances. The project co-ordinator took that role until the end of the project.)

Kathleen's exit strategy discussion included her supporter (the project co-ordinator) a person from Aged Mental Health Services, a person from the Royal District Nursing Service, Helping Hand and the person who has said he will act as Kathleen's informal supporter into the future. That meeting took place in Kathleen's new house. Some modifications had already been made, with rails installed in the shower. Services will make an assessment for other modifications that may be required.

Responsibilities for ongoing support were negotiated. They included connecting Kathleen to a local clinic that specialises in her medical condition, retaining her nursing services, financial counselling to establish her utilities payments now that she responsible for them, and accessible contact information for the people she will need to work with. She has support to change the provider for her meals. She has discussed making out a Medical Power of Attorney and an Enduring Power of Attorney and a will. Kathleen was looking forward to having her dog door installed so she can have her much longed for pet.

Kathleen is still grieving and adjusting to living on her own. Plans have been made to connect her with Red Cross and St John's. Kathleen also uses Lifeline. She has support to renew her love of tapestry.

Kathleen's experiences show that sometimes the circumstances surrounding both the participant and supporter are complex and stressful. Without the capacity for informed advocacy as part of the repertoire of skills in another party, external to the situation, this situation would not have

resolved in ways that meet the expressed wish of the participant. Kathleen's experience and that of her initial supporter, show that managing a range of service providers, in particular should the advice be inconsistent or inaccurate, can also be stressful in complex circumstances.

4.3 Supported Decision Making project: participants, supporters and services

4.3.1 Participant profile

The largest disability group recorded amongst the participants was Acquired Brain Injury (50%) and 2 of this group had another disability. Intellectual disability was the second largest group recorded (38.5%), with 4 of this group having another disability. People with Autism Spectrum Disorder were 8% of the participants. The remaining participants recorded a range of other disabilities.

The participants clustered mainly in 2 age groups: 20 – 29 years and 50 – 59 years.

The next largest groups were of a similar size: 30 – 39 and 40 – 49 years.

One participant was 18, the youngest person in the project, while the oldest person was between 70 – 79 years old.

Fifty-six percent of the participants were female.

All of the participants were either on a pension or on the Disability Support Pension and 38% of the participants also earned a wage.

A number of agencies referred potential participants to the project. They included Disability Services SA, Orana and Circle of Support. The Office of the Public Advocate referred 20% of the participants into the Alternative to Guardianship stream of the project.

However, the largest group (44%) were self-referred, that is, they chose to attend information sessions and adopt Supported Decision Making.

Participants had a variety of accommodation, ranging from living with their family (36%) and friends, to group housing, aged care, South Australian Housing Trust, a shared house and private rental.

Guardianship and Administrative Orders

Two of the participants began their time in the project with both a Guardianship Order and an Administration Order. The Office of the Public

Advocate referred both of these people to the project. In one case, both of the Orders were revoked once the participant had established his capacity to manage within the Supported Decision Making process. In the other case, the participant experienced an episode of significant mental illness and was no longer able to participate in the trial. The Guardianship and Administration Orders were therefore maintained in these circumstances.

Fifty-two percent of the participants had an Administration Order when they began in the project. Three participants (11.5%) had their Administration Orders revoked entirely, and one partially, as a result of them adopting the Supported Decision Making process.

Supporters

All of the participants, except one, had supporters who were either friends or family members at the time their Agreements were signed. The project co-ordinator became the only supporter of one participant when other options had been explored and had not worked. She was also a supporter for a short time for another of the participants.

The areas identified for decision making within the project mirrored those used in Guardianship Orders, that is, health, accommodation and lifestyle choices.

Accommodation

Data kept by the project co-ordinator shows that accommodation was a significant area for a number of the participants. A move to more independent living arrangements in either private or Housing Trust accommodation featured strongly as an expressed wish for half the participants. One wanted to be able to execute repairs on her home, while another wanted to move from residential into group housing. Several of the participants indicated that they wanted to move from their shared housing into accommodation that afforded them more privacy.

Health

Medical treatment was identified by 32% of the participants as an area for decision making. Others wanted to improve their overall health, for example, manage their weight and make decisions about their medication. One participant wanted to manage toileting as a prelude to exercising her wish to engage more broadly in her community.

One of the participants used her SDM Agreement to determine the level of medical intervention that she wanted, during her terminal illness. The existence of the SDM Agreement allowed medical staff to follow her expressed wish. Her supporter also acted as her advocate. This is an example of person's wishes being enacted on the basis of the test of 'reasonably ascertainable evidence.'⁶

Lifestyle

Participants identified a range of areas in which to make lifestyle decisions. The largest group expressed the wish that they wanted to make decisions about their relationships. Others wanted to decide on a holiday and make it happen, or improve their feeling of security, or resolve legal or Centrelink issues. Several of the participants wanted to make choices about work, training and day options.

⁶ *HREC Application Phase 1*. Office of the Public Advocate South Australia, November 2010, p 15.

The findings in the following sections of the report, 4.3.2 - 4.3.4, are based on interviews with the participants, their supporters, the project co-ordinator and service providers.

4.3.2 Participants' experiences of Supported Decision Making

Most of the participants put forward a view that Supported Decision Making had worked well. There is evidence that the process improved both their confidence in making their own decisions and their confidence in the decision making process.

'[It] opened my ideas.'

'I am more independent - I talk about [things] more.'

'I set my goals.'

'We talked about a better way to find a relationship and that helped. It was in the early stages [of the project]. I am doing it differently now.' ' Now I know how to do things I want to.'

'It helped me make some decisions. I am saving for a trip to [interstate capital]. [My supporter] got information for me.'

'I make my own decisions, using pros and cons. [It is] useful with my mother. The process is working with my mum. It's different. We never talked this way before.' 'I have confidence to make decisions, even if [it is a] mistake.'

'I thought decision making would help me. I needed something to help me instead of other people making decisions for me. I like to make my own decisions on my future.'

There is evidence that participants improved their decision making skills and some expanded the area in which they want to make decisions.

'It made me think before I do. Now I think, what do I want this for.'

'I make decisions in social things and my health. [There's] been some really good sessions with Mum. Mum and Dad use pros and cons.' 'I had illnesses since [I've been]

on the project and need medication. I decided that if I feel sick the best place for me is [hospital].’

‘I used it when talking to the doctor about surgery.’ This person’s supporter said that ‘It has helped 110% in decision making. She has related [Supported Decision Making] into family life and [her daughter’s] schooling. It has opened her eyes in handling [her daughter’s] behaviour.’

‘Decision making’s been great. [I’ve] achieved goals. And I have more trust at work.’

‘I now have people who understand, recognise and appreciate what I say and how I do things.’

A supporter described new strategies for decision making that one of the participants used after adopting Supported Decision Making: ‘He can now say, I will call back or I will talk about this with you later. This gives him time to think.’

Explicit confidence in their rights was less apparent in participants. However, there is implicit evidence of self-determination.

‘It helped me get back on my feet. I can’t rely on other people to make decisions all my life.’

‘I have learned to say no. I am happier ...’

Some participants experienced a growth in personal empowerment.

‘[I am] trying to sort my friends out.’

‘I have come so far in such a short period.’

‘I have a voice, a powerful voice because of [the Agreement]. I don’t have to wait on or look to other people to make the decisions.’

‘My kids have noticed a big difference in me. [My daughter] said she is so proud of me. It made me cry.’

'I get my independence. I think for myself - I feel good about making decisions. It's my new life. [I have] confidence in myself that I never had before. I didn't used to speak my opinions.'

'Now I do my own shopping, look after myself. I am feeling good. Not as depressed.'

'I go to [the] problem now, take advice. I'm thinking properly for myself. Life's not too hard. There are people who can help me, and sometimes you've got to ask for help.'

Three of the participants reported that they felt some frustration about the extent to which their wishes were or could be achieved.

Two of these participants wanted to make decisions about their financial affairs, because they needed money to enact some of their goals, one for travel and the other for more independence about how to use his money. The intersection of areas covered by Supported Decision Making principles and practice and Administration Orders was a problem for both these participants.

'My brother and sister don't know about the [SDM] Agreement and so it hasn't helped. I hate asking for money from my brother and sister. They have all [my] money.'

'The Public Trustee won't help. They only give you food money.' '[They are] not really rights: decision making is not respected. So far it hasn't worked.'

(As these participants progressed with Supported Decision Making this situation changed. See section 4.3.)

Another participant expressed a different form of frustration with his life.

'My feelings are angry. I don't want to be there. Maybe there will be light at the end of the tunnel. I feel free when I talk to... (his supporter). I feel a little bit scared because my [family] will be upset if my decisions work [for me]. My brain tells me I am a man... they think I am a baby.'

There was some evidence that participants experienced an increased ease in transacting personal business.

'[Having a supporter] helps. I have difficulty in processing information and I need people.'

'I sent an email looking for an explanation about... The explanation made me feel better.'

'I got a laptop and internet working using [my] money from the Public Trustee. I pay my bills and they are starting to let me get what I want... I am spending better now. The Public Trustee is helping me get to my goals.'

'We talk about what are the most urgent [bills] when paying accounts. I do direct debit now.'

4.3.3 Supporters' experience of Supported Decision Making

One of the supporters made explicit reference to the legal rights of participants to make their own decisions: '[I have] learned skills about [her] rights.'

Some of the supporters said that they approached the role with new ideas.

'[It] has opened my eyes.'

'It's been an eye opener. I have learned along the way.'

All of the supporters who participated in the interviews could trace changes in the way the participants approached decision making, and, for some, it had made a difference in their perception of some one they had known only in more informal contexts.

'[I can] see now that there is a potential for ... to get her needs met. She can be more independent. I am letting her make decisions and she will voice her own opinions now, speaks her mind a little more about health and accommodation. She picks out her own clothes. She's got her own voice.'

'She is more opinionated about what she wants to do. I really enjoy that.'

'I can see [he] has got stronger.'

'This has made a lot of difference. He can run [his] house on his own and pay bills now.'

Increased adult interaction and developing and maintaining positive relationships were evident from the information gained at interviews.

'[My supporter] is my trusted friend.'

'I am a trusted friend, not a carer.'

'They communicate with me, are concerned for me.'

'I have a team supporting me'

'We feel OK about going on [as supporters]. We have a friendship that will last. We love him.'

There was some evidence presented to the evaluation about the impact of the relationship between participants and supporters on the relationships with parents or carers. One of the participants positively described the way that he now talked with his mother, when she was in the role of supporter, as being completely different. Another made reference to the way she talked now with her mother and father about her decisions. In several cases the participants and supporters talked of the extension of Supported Decision Making into the way they take on family decisions, or in the way they manage interpersonal relationships.

In many cases a parent or close family member is also the supporter. In those cases, the supporters who were interviewed talked about the impact of Supported Decision Making on their relationship with the supported person and the different perceptions they had gained through the explicit change in their role, when acting as a supporter.

'[I] think about things a bit differently – what does she want? I [present] alternatives now: do it a different way.'

'I see her differently. I let her go.'

'It is important to consult [her] about holidays, as opposed to believing her capacity to decide is conditioned by communication, as [she] is non-verbal.'

Several supporters who were interviewed commented on the struggle they had to sustain themselves in the role. Some had complicated issues in their own lives: 'sometimes it hits me like a bolt of lightning, you've got all these worries.' Others found the behaviour of the participant a challenge as they adjusted to the new role as decision maker. These supporters commented on the mentoring role undertaken by the project co-ordinator: they felt that she had supported them as they worked out how to respond and had helped their motivation.

'It makes it different, talking to [her]. It helps to make things clearer.'

'I can talk to [her] about how to go about things' (referring to a 'rough patch' in their relationship with the participant).

Some tension can arise when a supporter is not a member of the participant's family. There were several examples given when the participant's family did not endorse the participant's wish. One of these participants is now working with both his supporter and disability worker so that he can act on the decision he has made. This highlights potential tensions as participants exercise a greater degree of autonomy in their decision making.

4.3.4 Services' experience of Supported Decision Making

Three services were interviewed as part of the evaluation. One was an employer, another a government disability agency and the other provides resources for independent living. Each of these had contact with potential or actual participants in the project.

One organisation's relationship to the project was straightforward and involved one participant, although a potential participant had also briefly been employed in the facility. The manager reported that the participant had shown a 'huge difference' once he had begun on the project. The participant had been working there for about 18 months before joining the project. He had previously been 'withdrawn' but developed the confidence to speak to two people about being his supporters. The manager said that she and the project co-ordinator worked well together to put a team around the participant. This involved connecting the participant with local health and psychological services and the Public Trustee. This enabled the participant to develop his interpersonal skills, including his decision making, and he is now succeeding better at his work, 'a right hand man', with some management responsibilities. The manager and staff monitored and rewarded progress in the work place with promotion. The participant is now able to sustain important family relationships. He now manages his own transactions with the Public Trustee.

Building trust between the participant and the manager and the project co-ordinator was an important component in the process. The manager also reported that the project co-ordinator built skills in this person's supporters, as they developed in their role.

This agency did developed a support team, with the project co-ordinator, to respond directly to the individual and his wishes. The manager knew about the role of the supporters. She thought that the direct support provided by the participant's expanded network led to a more consistent and measured approach to decisions.

Staff members from the state government disability agency saw benefits in the Supported Decision Making process, for example, in transitioning from a Guardianship Order. The 2 staff members interviewed suggested that 1 of the people that they knew, who had been referred to the project, was an 'ideal' candidate for the project, because she could 'make decisions with support, she understands what's best for me.' The particular strength of the process from their point of view was that the SDM Agreement gave the participant 'formal approval, a piece of paper, that said somebody is going to listen to me... it restores power.'

They also expressed some concern about two other referrals to the project. These two referrals did not lead to successful participation in the project. These staff members believed that the vulnerability indicators that they use in their work to decide on required levels of support should be included in any decision for a person to be referred for Supported Decision Making. They believed that a future program would benefit from tighter eligibility criteria to reduce any inappropriate referrals.

Information from the third agency indicates that the three participants in the program who were involved in the Supported Decision Making project each derived benefited from the experience. In the case of the person whose money was managed by family members, the SDM Agreement, on 'OPA letterhead' gave him increased confidence to negotiate successfully with his family about his financial needs. He was able to pay for an important piece of medical equipment as well as fund a holiday. He was also able to identify

other decisions he wanted to make about his financial independence and has started working with his supporter towards having those decisions enacted. For another person from this agency, the SDM Agreement was used to develop a health care plan, which involved the participant, the agency (where the staff member acted as a supporter) and the person's general practitioner. In this case, the supporter also acted as a case manager.

The SDM Agreements were seen as having real advantages. They gave legitimacy to the participants to express their views and have conversations. The process underpinning the SDM Agreements also allowed for conversations that would not have otherwise occurred. One of the staff members from the agency said that 'it gives permission and opens up an opportunity ... to start with the person and to be more personal. We can exchange information.'

The SDM Agreement also led to a useful dialogue between a number of sources of support for one of the participants. For the other, the supporter believed the process led to 'self-pride in making decisions. It did lots for him, about his confidence and his sense of his own competence.'

The staff member from this service saw application for other clients with intellectual disability, because 'going through step by step and considering all the options would be beneficial. It is a really good way to go.'

There is insufficient evidence from these sources to argue that, generally, service providers adopted a more person centred approach and increased accountability to the person living with a disability. However, the reports to the project Committee indicate that while some service providers were at odds with some of the decisions made by the participants, they changed their positions over time. This occurred as the process unfolded and it could be seen that the participants were able to manage both the consequences of their decisions and the benefits that accrued to them. This has also led in some cases to increased knowledge, skills and acceptance of Supported

Decision Making as a methodology that could be used. Some have indicated that they would now refer people to the project should it continue.

The project co-ordinator engaged with service providers in her role as supporter for 1, and then 2, participants. She also worked with a number of supporters to access services for participants, when it was appropriate, in order to achieve the decision making goals they had set. This engagement, from the point of view of the participants, highlighted gaps in service planning and provision. As well, the project co-ordinator, in her role as advocate, found that in several other cases, the participant, while a registered client of a service, had not received any contact from them for some years.

4.3.5 Services and the project exit strategy

The project co-ordinator developed a strategy for exiting the project, focussed on the participant maintaining Supported Decision Making processes once the project had finished. Each of the project participants applied the model to their own circumstances and worked with supporters, the project co-ordinator and relevant services to do so. The intention of the strategy was to link participants and their supporters to services and resources already in the community and to maintain networks of connection. The project co-ordinator found that the smaller disability specific organisations she contacted were active participants in this process. While the benefit of this initiative is clear for the project participants, it also indicates that sections of the service community have connected with Supported Decision Making principles and practices and see them as beneficial.

Twenty agencies were involved in the exit strategy for the project. They were from both the non-government and government sectors, and three of them involved multiple sites. They ranged from Disability SA, the Public Trustee, to nursing and aged care service (for example, RDNS, Helping Hand), employment sites (for example, Orana, Bedford Industries), skills development (for example, CARA and Minda Supported Employment, which

includes skills development and training) and accommodation services (for example, Balyana). All of these services have had some experience with the project, have been provided with information about Supported Decision Making and some have made undertakings into the future about their continued involvement with individual project participants.

4.4 Non-participants in the project

Four of the people who registered interest but did not go ahead to an SDM Agreement were interviewed.

Each of these people indicated that they were at ease with their decision not to take part in the project and that they did not know of anything that would have altered that choice.

Of those 4, 1 respondent said she was interested in the Supported Decision Making project but her closest support, her brother, did not respond to her requests to be her supporter. She said too that, as she was moving house at the time, she needed support to move, not to do the project. She also reported that a decision about her work place was made around the same time on the basis that '[family member] and [family member] said it would be easier to go from [her house] to work.'

Another person, who attended the meetings but did not proceed to an SDM Agreement, thought in retrospect that the reason she did not join was because she 'didn't need it.' The third respondent agreed with this point of view.

The other respondent said that her mother 'wouldn't do it.' This person's involvement in the project meetings at the employment service led to a complaint to her service provider about being involved in any activity without parental consent. Some members of the Committee thought that it was important that parents/carers were informed about the invitation to join in the Supported Decision Making project. Others thought that rights centred, self-selection and meeting the project criteria were the main considerations.

4.5 Participant safeguards

In line with the UN Convention and good practice, the Supported Decision Making project took steps to ensure that participants would not be at risk of being exploited, abused or having undue control exercised on them. The project operated within the frameworks of Human Research Ethics Committee Approval for the project.

A range of safeguards was put into place.

Participants in the project had the right to make a complaint, using the Office of the Public Advocate's Complaints Policy.

The role of monitor was included in the Supported Decision Making practice model and was based on overseas experience. It was intended that this person would maintain oversight of both the process and the decisions made using it, and thereby be one of the participant's safeguards.

The Committee considered the place of police checks in Supported Decision Making practice, in the light of potential supporters' concerns about the practicalities of obtaining them. The option to request a police check was maintained, but it was not mandated for all supporters.

The evaluation has no evidence that any participant used the complaint mechanisms open to them. There was no evidence of exploitation, abuse or of undue control.

4.6 Supported Decision Making as an alternative to guardianship

The project was originally conceived as having two streams of 20 people, an Early Intervention stream and an Alternative to Guardianship stream. Early Intervention was defined in 2 ways, those who are young adults and people who have been recently diagnosed as having an acquired brain injury or neurological disease. The Alternative to Guardianship stream was designed to include people who would otherwise be under a Guardianship Order, if it were not for the opportunity to be in the Supported Decision Making project. This stream was seen as consistent with current, relevant legislation.

In Phase 1, 15 people were interviewed who may have met the criteria for the Alternative to Guardianship stream. The Office of the Public Advocate referred them. The interviews led to one person having an SDM Agreement. The ability to give consent in the circumstances of each individual was one of the areas where judgement had to be exercised and this meant that many of the initial referrals did not meet the project's recruitment criteria around consent. By the time recruitment to the project ended (May 2012), there

were three people from the Alternative to Guardianship stream with SDM Agreements in place. The original proposal for this stream of the project was for 20.

When the project was first conceptualised, it was believed that referrals to the project would flow naturally from the work of the Guardians in the Office of the Public Advocate and from the Guardianship Board. However, the project Committee had reports from the project facilitator about the difficulties of recruitment into this stream of the project.

In Phase 1, the project co-ordinator interviewed a number of the Guardians. Their recorded responses show some ambivalence to the concept of Supported Decision Making. There was a strongly held belief that Guardians already operate within the principles of Supported Decision Making, as they are obliged to operate in the basis of the principles defined in section 5 of the Guardianship and Administration Act 1993: for example, ‘... consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter if he or she were not mentally incapacitated...’ This led to some confusion about the differences, and potential overlap, between Supported Decision Making and Guardianship. From the point of view of the Supported Decision Making project, the locus of decision making is different from that of a Guardian: the participant is the decision maker in the Supported Decision Making model.

The Guardians interviewed by the evaluator saw some potential in Supported Decision Making for those people who might otherwise be considered for guardianship, or as a system that could operate alongside guardianship. However, concerns about risk were also expressed and about the boundaries between the informal Supported Decision Making processes and the legal expectations of guardianship. Although they could see the point of Supported Decision Making as a useful option for people with disabilities, potential guardianship was not seen as necessarily the point at which those options would, in the main, be apparent. Acceptance of the role of informal, non-statutory Supported Decision Making as a relevant option for Guardians was questioned: their work is focussed on their statutory

obligations and responsibilities. The early stages of project implementation also drew into sharp relief the different perceptions of responsibility in several complex cases, and the recruitment criteria did, in the end, exclude those people from the project.

The issue of risk for potential participants was discussed at the project Committee meeting of July 2011, as the level of scrutiny around risk had emerged as a theme of the project's implementation. The project Committee believed that decisions that involve risk were important. One project Committee member believed that 'the risks are worth it for the freedom of self-managing.' Calibrating risk and safety was seen as a function of informed choice exercised by the participant, and by extension, the supporter: as another project Committee member said decisions must include the 'dignity of risk and of its consequences.'

The project co-ordinator worked initially across both streams of the Supported Decision Making project. However, the demand for advocacy and, in some circumstances, case management with people already on SDM Agreements, as well as the expectation to recruit into the Alternative to Guardianship stream, were intensive pressures on her workload. Appointing a Guardian to take the lead in this stream of the project was considered. This did not eventuate. Along with other factors, the project infrastructure did not appear to be sufficiently developed to support this stream of the project to its conclusion of 20 participants.

The decision was made to stop recruitment into this stream of the project and from then on the project co-ordinator recruited using the criteria for the Early Intervention stream.

The target of 20 participants in the Alternative to Guardianship stream was not met in the project.

This has implications for any re-conceptualisation of the model. Should Supported Decision Making continue to be seen as a viable alternative to Guardianship, the experience of the project points to the need for a considered process, within the processes and structures of guardianship, to identify potential users of Supported Decision Making, and the need to

clarify, at a public and formal level, the boundaries and intersections between Supported Decision Making and guardianship.

The project did demonstrate that, where criteria are clear and the relationship between Supported Decision Making and guardianship is delineated, Supported Decision Making is a viable alternative to Guardianship. It has shown that Supported Decision Making can build capacity to the extent that existing Guardianship Orders were revoked.

4.7 Peer worker and the service model

The project included a peer worker from September 2011. The role was initially as a volunteer, supporting recruitment. She was later employed as a casual, part time peer worker. It was intended that the peer worker would assist participants and service providers to understand the concept of Supported Decision Making, be a role model for potential participants, and share her skills and experience in Supported Decision Making with participants. The peer worker had previous experience as a supporter in the Supported Decision Making project.

In her capacity as a volunteer, she had access to information and some on the job training in the principles and practices of Supported Decision Making. It was hoped that as a peer worker, she might be able to fulfil the role of supporter to one of the participants. This did not happen, as the participant did not, in the end, accept her in that role, as she had not previously been part of his network.

The peer worker took part in a number of exit interviews and participated in project Committee meetings from her appointment as a volunteer, until the end of the project.

It was reported to the project Committee that the peer worker's role did support recruitment.

The function of peer workers in a Supported Decision Making model should be examined as part of the next stage of development of Supported Decision Making.

4.8 Other impacts of the project

4.8.1 Information

Data about the full range of service providers involved in the project as a whole was not routinely recorded. However, in the first stage of the project, the project co-ordinator provided information sessions about Supported Decision Making to 15 agencies that have a focus on disability. The project exit strategy involved 20 agencies.

The project was included in the national broadcast of ABC Radio's AM program on 27 December 2011. It included interviews with two of the participants who described their experience with the project and the difference they felt it had made in their lives. The broadcast informed the audience about the existence and purpose of the Supported Decision Making project.

The process of implementing the project has led to a spread of information about Supported Decision Making. Many agencies were informed about it as part of the recruitment and exit strategy elements of the project. Some had more detailed involvement, as they worked to implement the participants' wishes.

The work of the Supported Decision Making project has become known interstate. The Victorian Office of the Public Advocate participated in the development of the South Australian model, working with the project Committee, as it refined the project and its parameters. The Public Advocate, the project co-ordinator and, on one occasion, the project peer worker, have presented the project to interstate workshops and to interstate colleagues who are developing their own responses to Article 12 of the United Nations *Convention on the Rights of Persons with Disabilities*. Victoria and New South Wales, and the Australian Capital Territory are currently developing Supported Decision Making models that are informed by the South Australian experience.

4.8.2 Resources and materials for the project

The Office of the Public Advocate developed a *Model of Practice for Supported Decision Making* in June 2011.⁷ The document describes the basis of Supported Decision Making in some detail and goes on to outline the nature, purpose and scope of the SDM Agreement. It defines the roles of the three categories of players in the project; participants (the supported person), supporters and monitors. The paper also describes a number of reasons people may find Supported Decision Making of benefit to them. It outlines the governance arrangements for the project. It defines the areas for specific practice guidelines to be developed and defines the limits and constraints of various roles; the supporter, the project co-ordinator, and the supported person.

Phase 2 further developed practice in, for example, the areas of recruitment and the applications of facilitation, advocacy and case management to decision making.

The project generated a number of support materials aimed at gaining consistency in the project's operation. These included the template for baseline data collection and a series of questions designed to explore the circumstances of a potential participant's current decision making practice. An information sheet about the project was also made available to potential participants. A template to record the SDM Agreement was also available for participants under a Guardianship Order as well as those who were not. Both templates allowed for the supported person to state their choice of supporter and monitor. The Agreements recorded the areas for decision chosen by the supported person. The Guardianship Order form included a reference to the participant's ability to make a decision in an area covered by an existing order, as well as allowing for the Guardian to take final responsibility while the order is in place, taking into account the terms of the SDM Agreement. The Agreement could also be used if an order were revoked. (See Appendix 5)

⁷ *Developing a Model of Practice for Supported Decision Making*, Office of the Public Advocate South Australia in collaboration with the Julia Farr M.S. McLeod Benevolent Fund, June 2011.

The information sheet and agreement were also made into a pictogram format.

The project co-ordinator developed a Work Flow Chart for the project. (See Appendix 6) The elements of this chart indicated the separate steps that were taken to make a SDM Agreement, as well as the steps taken to establish and maintain the project.

All of these materials are transferrable to any expansion of Supported Decision Making.

4.8.3 Social capital

There was consistent evidence from the project that Supported Decision Making built social capital for participants and supporters. The basis of the selection of the supporter was a trusted family member or friend. This was, of itself, an affirmation of the role of interpersonal trust in people's lives. The project demonstrated many examples where social networks and social support were expanded or improved through Supported Decision Making, for example, in the participants' experiences described in the stories in section 4.2.

Some people's experiences showed an increase in their integration into their community, through participation in training, through the use of standard technologies to manage personal affairs and to communicate, and through their involvement in community based activities, such as, gym and volunteering.

The participants' experiences also demonstrate that there was a sense of reciprocity for some of them and their supporters. Several supporters indicated that they had wanted to give back to people who were important in their lives. As well, one of the participants said of his supporters that he was glad to 'be there, supporting them', while acknowledging the value their support had for him.

5. Future development of Supported Decision Making

The project Committee has decided that it will continue in a different form once the project is finished. It has decided that it will set up Working Groups to focus on particular issues and areas for further work. This section of the report discusses a series of issues for the Committee's consideration in the further development of the service model and its ongoing implementation.

5.1 The Supported Decision Making practice manual

The Office of the Public Advocate developed a *Model of Practice for Supported Decision Making* at the end of Phase 1. The document included information about how the roles in the project would operate.

The Model needs to be updated to a manual, taking into account the developments in practice learned through the later stages of the project and on reflection. This could include a flow chart outlining the steps in an SDM process, information about finding a supporter if there are not obvious choices to the person who wants to use Supported Decision Making and information about the various roles as they apply in a model that is redefined by the project experience, and the reconceptualising of the rights and roles of people with a disability.

5.2 Training and support for Supported Decision Making

Supporters reported that they felt the benefit of having support while they developed their own skills, as a supporter. Training and support for this, as opposed to providing information about Supported Decision Making, was provided on a needs basis in this project, as the relationship with the project co-ordinator enabled her to be aware of individual circumstances.

Access to this sort of support may continue to be necessary, if the relationship of participant and supporter is to be maintained and developed.

5.3 Supporters

The Supported Decision Making project has demonstrated that the role of supporter is crucial to the success of the participant in undertaking Supported Decision Making. However, it has also demonstrated that it is not necessarily a straightforward role to undertake.

Two of the participants did not have a supporter who fitted the definition, that is, a trusted person from the circle of the participant's family and friends. These participants were, to varying degrees, socially isolated.

The project Committee spent some time on developing a community based model, through developing relationships with service clubs. This did not lead to any one agreeing to become a supporter, although one person volunteered and then withdrew herself from the process. Both these participants reported that Supported Decision Making had helped them sort out their lives and they wanted to continue using the process. This benefit depended on them having the project co-ordinator for all or part of the project as their supporter.

It is likely that some people who would want to use the Supported Decision Making process will not be able to, because of their social isolation. Access to volunteers will need to be in place, so that people, who want to take up the option, can.

5.4 Case management and advocacy

One of the sources of success for participants and their supporters in this project was the role played by the project co-ordinator in both advocacy and case management.

Advocacy was included in the role of supporter, that is, in communicating the person's wishes.⁸ In practice, the project co-ordinator often acted as advocate for the participant, that is, took on the role of someone who supports and encourages a person to exercise his or her wishes and rights.

⁸ *Developing a Model of Practice for Supported Decision Making*, Office of the Public Advocate South Australia in collaboration with the Julia Farr M.S. McLeod Benevolent Fund, June 2011.

A supporter reported that the project co-ordinator had acted as a case manager for a participant, and that the co-ordinator's experience in the disability sector was integral to the participant achieving his wish.

It is not possible on the information available to the evaluator to assess the extent to which the exercise of this role led to wishes being achieved. It is clear, though, that for a number of participants, the role of advocate was entirely necessary for a person to achieve their wishes and goals. When the project co-ordinator was also the supporter, actions she took on behalf of the participant, brought matters to the attention of service providers. These matters had not previously been addressed.

The role of the project co-ordinator also involved case management, for example in the exit strategy, through which she co-ordinated ongoing support services for and with the participant. This indicated that one of the strengths of the project was the project co-ordinator's well-developed knowledge of the sector, which helped participants and supporters 'navigate the maze.' Participants and supporters may not have this knowledge of 'the maze.' One of supporters said that she learned better how to approach agencies, because of the work of the project co-ordinator. Another supporter described her role as occasional case manager, and believed that it was an important component in achieving the intent of the SDM Agreement.

It may be that decisions identified by future users of Supported Decision Making will not require this knowledge. However, most of the participants in this project did. The extent to which these functions need to be included in a refined model needs to be assessed.

The original concept of the monitor and supporter intended a separation of responsibilities, with the monitor acting as a guarantee that the process was working for the wishes of the participant. Once the project co-ordinator assumed both roles, this distinction could not be maintained. Practice support meetings between the project co-ordinator and Office of the Public Advocate senior staff became the de facto monitor of the process for participants. There is only evidence from the evaluation that the work undertaken by the project co-ordinator with the participants was to help

enact their expressed, and recorded, wish. The role of monitor in the service model will need to be re-assessed for its applicability in processes which, when in the community, will not operate of necessity within a human research, ethical framework.

The advocacy and case management roles undertaken by the project coordinator led to successful decisions that were enacted by most of the participants in the Supported Decision Making project.

The extent to which Supported Decision Making processes in this project required a case management role, calls into question the extent to which the process can be 'free standing'. Do supporters need to be able to case manage, as well as support the person, as well as be their advocate when that role is required? It could be argued that the Supported Decision Making project, as it was designed, privatises the case management role. The need for these functions in the project operations, gives insight into the role that may need to be developed when self-managed and self-directed funding becomes more widespread. The roles will need to be articulated into the role of supporter as it is further developed.

5.5 Supported Decision Making and service providers

Along with many other sources, including the Productivity's Commission's 2011 report, information provided to the evaluation continues to call into question the extent to which person centred, rights based and least restrictive practices are the primary principles on which advice and action in the disability sector are based.

The process of implementing the project revealed conflicts about the participant's perceived capacity to exercise more autonomous decision making. There are anecdotes reported to the evaluator, which indicate that concern about risk may over ride alternative choices. Gaps in service provision were also brought to the attention of the evaluator. To a certain extent, the Supported Decision Making project provided a challenge to some accepted practices and to the conventional wisdom that can operate in this culture.

On the other hand, some service providers did develop options based on the wishes of the participants. For example, information from some participants was included in a revision of an independent living training program. In this example, the program was changed considerably, reflecting what the participants saw as their needs, rather than what had been assumed previously.

The intersection of Administration Orders for financial matters and Supported Decision Making emerged as a theme for some participants. In some cases, it is clear that improved decision making skills led to some participants being able to interact with increased authority with the Public Trustee, and for the organisation to respond with increased flexibility.

Supported Decision Making cannot of itself provide the leverage for the scale of change required to achieve person centred and rights based services in a service system that has to manage within the constraints of fragmentation and the levels of service demand. However, the experience of Supported Decision Making does illuminate an ongoing issue of some concern to the participants and their supporters. These examples support continued attention to increasing the knowledge of, and skills in, person centred and rights based approaches to the design and delivery of services in this sector, and the role Supported Decision Making can play in this.

5.6 Supported Decision Making Agreements and legislation

At the end of the project, the SDM Agreements in place as part of the project, lapse. There is no formal or legislative basis for the SDM Agreements, or the use of the process, into the future. Several options for legislative reform were canvassed through the life of the Supported Decision Making project. Some of the ideas put forward were:

- including key concepts and principles of Supported Decision Making in existing legislation
- including presumption of capacity in legislation

- recognition in the law of the role of supporters and their responsibilities
- mandating Supported Decision Making as a statutory option
- expanding statutory options for guardianship.

There is a growing body of international experience in this area, as well as trial programs in development in several states and territories in Australia, which can continue to inform the work of the Committee.

Recommending legislative reform is part of the responsibility of the Public Advocate, as the role continues to advocate for rights based disability legislation and least restrictive practices for people with a disability.

5.7 Supported Decision Making and self-managed funding

The Productivity Commission's report, *Disability Care and Support*, includes references to the 'need to build some people's confidence in exercising power and to provide supports that give people more control.'⁹ Choice of provider through to managing a cash service budget are opportunities canvassed in the National Disability Insurance Scheme, to be launched in South Australia in July 2013. (In South Australia it will begin with young children and grow to include older children as the 3-year program is implemented.) There is a role for Supported Decision Making in the emerging models for self-managed and self-directed funding. As this shift in direction grows in its momentum and impact, Supported Decision Making has a clear place in the future growth in personal autonomy envisaged by this reform.

The Public Advocate has a role in integrating the principles and practice of Supported Decision Making into the arena of self-managed and self-directed funding.

⁹ *Disability Care and Support*. Productivity Commission, 2011, p 356.

5.8 Developing a change strategy

Any further development of Supported Decision Making should sharpen the focus on change management. This project demonstrated that the objectives of trying to deliver a new service model, develop practice and generate cultural change through one mechanism needs further consideration.

Both the Committee and one of its working groups should focus on change management and the strategic actions that will be required, at various levels, to broaden the uptake of Supported Decision Making.

The Committee may need to consider its membership in light of this and consider the resourcing required to undertake the task.

There is evidence that participants in the program have been advocates for extending Supported Decision Making to other people. The role of people with disabilities on the Committee should include a responsibility to participate in the development, and perhaps the delivery of, any information strategy, as well as having an impact on any further models for exercising Supported Decision Making.

Part of a change strategy should focus on educating services that are particularly relevant to the application of Supported Decision Making. It should also focus on the community more widely, including the disability community.

The change strategy should connect the positive outcomes of the project to increasing the impact of Supported Decision Making on both people with a disability and on services. It should also focus on creating the platforms that give the process legitimacy in the wider community.

6. Conclusions

South Australia is the first state in Australia to implement a service model based on Supported Decision Making. The project has therefore broken new ground and gives a documented example of an innovation in implementing the United Nations Convention for the Rights of Persons with Disabilities.

The project has demonstrated that Supported Decision Making can be a powerful mechanism to affirm the right of people with disabilities to make decisions and therefore exercise their legal capacity. The 26 participants in the project, and their supporters, have shown ways in which Supported Decision Making can give a voice to people with a disability about their own lives and how they want to live them. The experience of Supported Decision Making has increased people's exercise of autonomy and self-determination.

The project has demonstrated that Supported Decision Making can work alongside guardianship, and that people using Supported Decision Making can demonstrate that they no longer require a Guardianship Order.

The project provides evidence that Supported Decision Making can change people's lives.

7. Appendices

Appendix 1: Stepped model for decision making

Appendix 2: South Australian Supported Decision Making
Committee membership

Appendix 3: Supported Decision Making Agreement

Appendix 4: Questions used in the evaluation

Appendix 5: Supported Decision Making Agreement for people with a
Guardianship Order

Appendix 6: Work flow chart

Appendix 1: Stepped Model of Supported and Substitute Decision Making

This Stepped Model was revised in 2010 (as illustrated on the last page of this appendix). This model provides context to both the Supported Decision Making trial and helps in recognising gaps in what is available now and might be considered for future legislative reform.

The 2010 version is more generic than our first attempt at charting the model in 2009. It expands on different forms of supported and substitute decision making and unlike last year's model is not specific to South Australia.

Not all definitions are agreed in the literature (for example some authors use the terms Assisted and Supported Decision Making interchangeably) but this model can be used as a useful schema.

Autonomous Decision Making: At the top of the stepped model is autonomous decision making. Even when decision making is autonomous most of us will choose to seek advice and support from others when making an important decision, and at times share decision making with others. For this reason decision making can be seen as “interdependent” as opposed to independent.

Assisted Decision Making: While definitions vary, in assisted decision making a person is regarded as having legal capacity, but requires assistance to collect information to make a decision. This can be communication assistance – for example a person who has had a stroke and may need to communicate with a special device. Perhaps for this reason Assisted Decision Making is commonly piloted by Speech Pathologists. For people who have an intellectual disability Assisted Decision Making may require information to be presented clearly in plain English with the use of diagrams if needed. Assistance can be provided by anyone including service providers. While it may be helpful to have an agreement this is not absolutely necessary.

A non-statutory Supported Decision Making agreement: The appointment of a supporter is made by the person needing support. The person must want to have support making decisions, and have a trusting relationship with someone who will be their supporter. The person also must be able to cancel an agreement at any time if they are unhappy with its operation. Agreements can also specify a third person – a “*monitor*” – who can check to ensure that the agreement is operating as it should.

Without a specific law, an agreement acts as a record of the person’s wish to receive support from another. It will not give the supporter any additional standing, and a supported person will not be obliged to use the agreement.

This will be the type of agreement used in the South Australian Supported Decision Making trial described earlier in this Annual Report.

A statutory Supported Decision Making agreement: This has most of the same features as a non-statutory agreement, but in jurisdictions that have Supported Decision Making laws, this legal recognition has advantages in safeguarding the supported person, and giving a special status to supporters.

A legislated form of agreement can create obligations on the supporter to act in the interests of the supported person, and also give their role legal recognition so that health services and community agencies can share information directly with supporters. Legislation can also include protections from liability for supporters and other parties assisting a person to make decisions provided that such actions are not in breach of the supporter’s duty to the supported person.

A supported person is expected to use the agreement – if they wish to make decisions outside it then a person should cancel the agreement. The agreement is a significant document that cannot be ignored.

A tribunal appointed Supported Decision Making arrangement: Unlike the agreements already described, a person would not have the option of ending an agreement unilaterally as only the tribunal has the power to do this, and would be required to seek support in making decisions while the agreement is in place.

Representational Agreement: Such agreements are intended primarily to provide Supported Decision Making, and a person appoints their supporters through signing an agreement document as described previously. However, representational agreements also permit the supporter to make a substitute decision if the supported person is unable to make a decision themselves – for example, if the person became unwell and is in hospital. This model, as practiced in British Columbia allows for both supported and substitute decision making.

A tribunal appointed Co-decision maker: This is an arrangement used in Alberta. If an adult needs support with decisions a co-decision maker can be appointed by a court. The co-decision maker, who is usually a family member or close friend, and the adult, need to agree on major decisions. If there is a disagreement the decision of the adult (not the co-decision maker) takes precedence. If the arrangement is not working it may be followed up by the Public Guardian to determine if another person should be appointed co-decision maker or another form of decision making support is required. In Victoria, the Office of the Public Advocate in that state has called for the creation of co-decision maker appointments.

Autonomous Decision Making

No assistance or support required, but assistance, support and advice may be sought by an individual

Assisted Decision making

In coming to an autonomous decision a person requires assistance with collecting information, explanation of alternatives or communication

Supported Decision Making Agreement (non statutory model)

An agreement indicates a person's wish to receive support. A person can end this agreement at any time. A person is not required to use the agreement.

Supported Decision Making Agreement (statutory model)

An agreement indicates a person's wish to receive support. A person can end this agreement at any time. A person is expected to use the agreement unless cancelled. Law creates obligations on the supporters

Supported Decision Making Appointment (statutory model - appointment by tribunal)

A person is required to use support. A person cannot end the support agreement (role for tribunal)

"Representation agreement" – supported and substitute decision making (statutory model)

A person can end this agreement at any time. A person is expected to use the agreement unless cancelled. Law creates obligations on the supporters. Substitute decision making permitted

"Co-decision maker" Guardian appointed as joint decision maker with person by tribunal (statutory model). Substitute decision maker (guardian) and the person themselves need to agree on each decision

Private Guardian appointed by a tribunal

Public Guardian appointed by a tribunal

Increasing care and protection and increasing intervention by the state

Equal Recognition Under the Law

A Stepped Approach to Supported and Substituted Decision Making:

Illustration of available and potential new models



Now used in SA.



Can be used in SA. Not routinely available.



Model from other jurisdiction which would require law reform to operate in SA

Autonomy and Self determination

Appendix 2: Membership of the Supported Decision Making Committee

The committee met regularly through the life of the project.

John Brayley, the Public Advocate, chaired the Committee. Its members were Tiffany Bartlett, Ian Bidmeade, Margaret Brown, Margie Charlesworth, Dianne Chartres, Ian Cummins, Julie-Anne Harris (OPA), Helen Mares (OPA), Graham Mylett, Elly Nitschke (OPA), Dell Stagg and Robbi Williams (Chief Executive, Julia Farr Group).

The project co-ordinator, the evaluator, and later, the peer worker, were present at the meetings.

Barbara Carter, from the Victorian Office of the Public Advocate, was a commentator in the development of the project model and participated by phone in early meetings of the project Committee.

Appendix 3: Supported Decision Making Agreement

SUPPORTED DECISION MAKING AGREEMENT

(Office of the Public Advocate SA 2010-2012)

Date

.....

I choose

.....
name, relationship

.....
name, relationship

to be my **supporter(s)** and assist me to make decisions.

I trust them to help me make decisions about:

- where I live
- who I spend time with
- what I do (work / study/ activities)
- my health
-
-

I trust them to help me make decisions about:

I want my **supporter(s)** to assist me by *(for example)*

- Providing information in a way I can understand.
- Discussing the good things and the bad things that could happen.
- Expressing my wishes to other people
-
-
-

I accept to be a **monitor** who will keep track of how things are going with my supported decision making.

I agree to be a supporter and assist make his/her own decisions when he/she asks me to.

I agree to monitor supported decision making by and let the Supported Decision Making Project Co-ordinator know how things are going.

We will review this agreement by
month and year

Any person in this agreement can stop being involved in the agreement by letting the Supported Decision Making Co-ordinator know.

This agreement does not cover decisions about finance or assets.

This agreement will not operate after 31 October 2012.

| | |
|-----------------------|-------------|
| | |
| <i>name</i> | <i>date</i> |
| | |
| <i>supporter</i> | <i>date</i> |
| | |
| <i>supporter</i> | <i>date</i> |
| | |
| <i>monitor</i> | <i>date</i> |
| | |
| <i>Cher Nicholson</i> | <i>date</i> |

Supported Decision Making Project Co-ordinator

The Supported Decision Making Project Co-ordinator is Cher Nicholson. She can be contacted by telephone on (08) 8342 8200 or by e-mail: *nicholson.cher@agd.sa.gov.au*

Appendix 4: Evaluation questions

All of the questions were used as the basis for discussion.

1. Participants and supporter interview questions

- 1.1 How long have you been in the SDM program?
- 1.2 What are the good things about being in the SDM program?
- 1.3 Talk to me about decisions you have made with your supporter.
- 1.4 Supporters: what techniques do you use to support decision making?
- 1.5 Supporters: Which decisions does the participant make with your support?

2. Questions for those who chose not to participate in the SDM program

These questions are a guide to conversation with the people who have chosen not to participate in the program and who have given consent to be contacted by the program evaluation.

- 2.1 Why did you not continue your involvement in the SDM program?
- 2.2 Was there any reason in particular?
- 2.3 Who made the decision not to go ahead with your involvement in the trial?
- 2.4 Would you want to participate if we did something differently?

3. Interview questions for service providers

- 3.1 Which criteria have you used for referring potential participants to the program?
- 3.2 What ongoing role do you have with the participants once they are in the program?
- 3.3 What does your experience with the program tell you about its strengths and weaknesses?
- 3.4 How has your involvement in the program impacted on your views about person centred service systems for clients?

4. Interview questions for project Committee members

4.1 Process evaluation

4.1.1 Program environment: what are the characteristics of the program environment for the SDM trial program?

4.1.2 Program design: what are the main elements of the SDM program design?

4.1.3 What do you see as the main tasks/priorities and scope of effort involved in implementing the SDM program?

4.1.4 Does the process for program implementation work smoothly?

4.1.5 What is your analysis of the successes of the program at this stage?

4.1.6 What issues do you see emerging as ones the project Committee will need to address?

4.2 Outcome evaluation

4.2.1 What do see as the practical lessons learned so far from putting theory into practice in the SDM program?

Appendix 5: Supported Decision Making Agreement for those under a Guardianship Order

SDM AGREEMENT UNDER GUARDIANSHIP ORDER

Date

.....

I choose

.....
name, relationship

.....
name, relationship

to be my **supporter(s)** and assist me to make decisions.

I trust them to help me make decisions about:

- where I live
- who I spend time with
- what I do (work / study/ activities)
- my health
-
-

I want my **supporter(s)** to assist me by *(for example)*

- Providing information in a way I can understand.
- Discussing the good things and the bad things that could happen.
- Expressing my wishes to other people
-
-
-

I accept to be a **monitor** who will keep track of how things are going with my supported decision making.

Guardianship Order Details: Date Review date

Terms : Full or Limited: to accommodation health lifestyle

I agree to be a supporter and assist make his/her own decisions when he/she asks me to.

I agree to monitor supported decision making by and let the Supported Decision Making Project Co-ordinator know how things are going.

We will review this agreement by

month and year

Any person in this agreement can stop being involved in the agreement by letting the Supported Decision Making Co-ordinator know.

This agreement can be used to make decisions not covered by the Guardianship Order. It can also be used to reach a decision which is covered by the Guardianship Order, however the guardian has final responsibility for decision making in those areas. The guardian will take into account an SDM decision in making their decision. This agreement has full effect after the Guardianship Order is revoked.

SDM agreements will not operate after 31 October 2012.

This agreement does not cover decisions about finance or assets.

.....

name *date*

.....

supporter *date*

.....

supporter *date*

.....

monitor *date*

.....

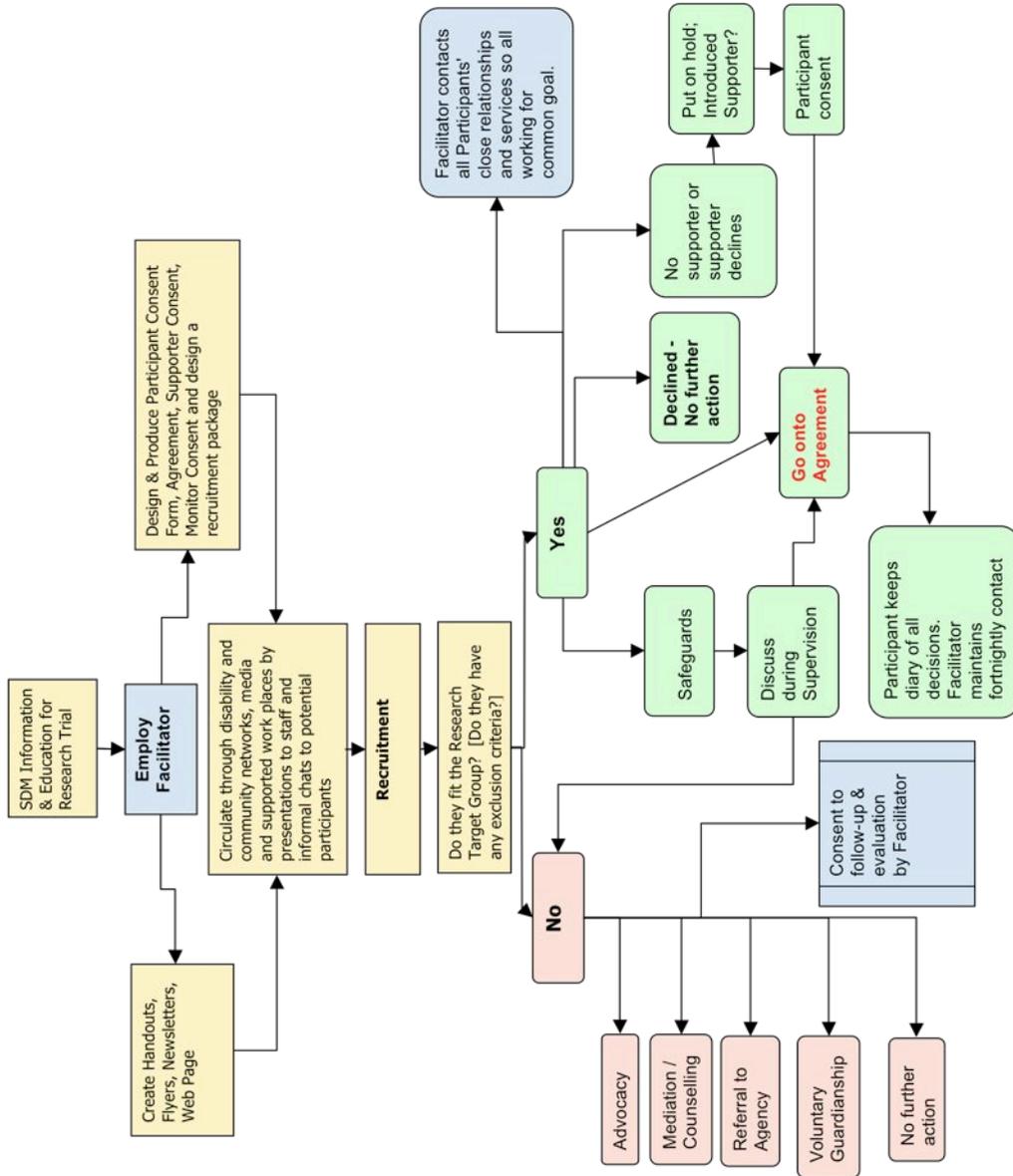
Cher Nicholson *date*

Supported Decision Making Project Co-ordinator

The Supported Decision Making Project Co-ordinator is Cher Nicholson. She can be contacted by telephone on ((08) 8342 8200) or by e-mail on nicholson.cher@agd.sa.gov.a

Appendix 5:

Work Flow Chart



8. References

Annual Report. Office of the Public Advocate South Australia, 2010.

Annual Report. Office of the Public Advocate South Australia, 2011.

Carter, Barbara. *Adult guardianship: Human rights or social justice?*
Journal of Law and Medicine (2010) 18 JLM 143 © 2010 Thomas Reuters
(Professional) Australia Limited.

Chartres, Dianne. *To investigate supported decision making practices, capacity building strategies and other alternatives to guardianship*. The Winston Churchill Memorial Trust of Australia, 2011.

Convention on the Rights of Persons with Disabilities, The United Nations. 2007.

<<http://www.un.org/disabilities/default.asp?id=259>> 16.2.11.

Developing a Model of Practice for Supported Decision Making Background information to assist the facilitation of agreements. Office of the Public Advocate South Australia in collaboration with the Julia Farr M.S. McLeod Benevolent Fund, June 2011.

Disability Care and Support. Productivity Commission, 2011.

HREC Application Phase 1. Office of the Public Advocate South Australia, November 2010.

South Australian Supported Decision Making Project Report of Preliminary 'Phase 1'. Office of the Public Advocate South Australia in collaboration with the Julia Farr M.S. McLeod Benevolent Fund, June 2011.

Supported Decision Making Update. Office of the Public Advocate South Australia, August 2011. <<http://www.opa.sa.gov.au/publications>> 3.9.12.