Evaluation of the Supported Decision Making Phase 2 (SDM2) project: Final report

Prepared for:  
NSW Trustee and Guardian with the NSW Public Guardian

May 2017

Christiane Purcal, Trish Hill, Kelley Johnson, Rosemary Kayess

**Acknowledgements**

1. Thank you to the SDM2 project team, the project participants and their supporters for their contributions, advice and comments.

**Research Team**  
Professor Kelley Johnson, Ms Rosemary Kayess, Dr Christiane Purcal, Dr Jane Bullen, Dr Trish Hill, Associate Professor Leanne Dowse

1. For further information:  
   Rosemary Kayess +61 2 9385 7800, [r.kayess@unsw.edu.au](mailto:r.kayess@unsw.edu.au)
2. Social Policy Research Centre
3. UNSW Arts & Social Sciences   
   UNSW Sydney NSW 2052 Australia
4. T +61 2 9385 7800
5. F +61 2 9385 7838
6. E [sprc@unsw.edu.au](mailto:sprc@unsw.edu.au)
7. W [www.sprc.unsw.edu.au](http://www.sprc.unsw.edu.au)

© UNSW Sydney 2017

The Social Policy Research Centre is based in Arts & Social   
Sciences at UNSW Sydney. This report is an output of the *Supported Decision Making Phase 2 (SDM2) Evaluation* research project, funded by NSW Family and Community Services, NSW Trustee & Guardian and the Public Guardian.

Suggested citation:

Purcal, C., Hill, T., Johnson, K., & Kayess, R. (2017). *Evaluation of the Supported Decision Making Phase 2 (SDM2) project: Final report (SPRC Report 14/17)*. Sydney: Social Policy Research Centre, UNSW Sydney. <http://doi.org/10.4225/53/59c490b3e83a2>

Contents

[Brief summary 1](#_Toc492033339)

[Executive summary 2](#_Toc492033340)

[1. Introduction to SDM2 project evaluation 8](#_Toc492033341)

[Part A: The Financial Decision Making Program and its implications 11](#_Toc492033342)

[2. FDM Program overview 11](#_Toc492033343)

[2.1 Intended outcomes of the FDM Program 11](#_Toc492033344)

[2.2 Financial management policy context 11](#_Toc492033345)

[2.3 FDM Program recruitment 12](#_Toc492033346)

[2.4 FDM Program activities 13](#_Toc492033347)

[2.5 Summary of FDM Program 14](#_Toc492033348)

[3. Methodology for FDM Program evaluation 15](#_Toc492033349)

[3.1 FDM Program evaluation questions 15](#_Toc492033350)

[3.2 Data collection methods for FDM Program evaluation 15](#_Toc492033351)

[3.3 Analysis of FDM Program evaluation data 17](#_Toc492033352)

[3.4 Limitations of the FDM Program evaluation 17](#_Toc492033353)

[4. Profile of FDM Program participants 19](#_Toc492033354)

[5. Outcomes for decision makers in the FDM Program 20](#_Toc492033355)

[5.1 Financial decision making capability 20](#_Toc492033356)

[5.2 Financial decision making authority 24](#_Toc492033357)

[5.3 Relationship with NSWTG 26](#_Toc492033358)

[5.4 Summary of outcomes for decision makers 27](#_Toc492033359)

[6. Outcomes for supporters in the FDM Program 28](#_Toc492033360)

[6.1 Identifying effective support practices 28](#_Toc492033361)

[6.2 Learning about NSWTG processes 30](#_Toc492033362)

[6.3 Project resources 31](#_Toc492033363)

[6.4 Suggestions for future projects 31](#_Toc492033364)

[6.5 Summary of outcomes for supporters 31](#_Toc492033365)

[7. Implementation of the FDM Program 32](#_Toc492033366)

[7.1 Planning of the FDM Program 32](#_Toc492033367)

[7.2 Recruiting decision makers and supporters 32](#_Toc492033368)

[7.3 The nature of financial supported decision making 33](#_Toc492033369)

[7.4 Provision of resources to support financial SDM 33](#_Toc492033370)

[7.5 The role of program staff 33](#_Toc492033371)

[7.6 Summary of FDM Program implementation 34](#_Toc492033372)

[8. Implications for individual FDM support 35](#_Toc492033373)

[Part B: The Training Program and its implications 37](#_Toc492033374)

[9. Training Program overview 37](#_Toc492033375)

[9.1 Intended outcomes of the Training Program 37](#_Toc492033376)

[9.2 Training Program activities 37](#_Toc492033377)

[10. Methodology for Training Program evaluation 38](#_Toc492033378)

[10.1 Training Program evaluation questions 38](#_Toc492033379)

[10.2 Data collection and analysis for Training Program evaluation 38](#_Toc492033380)

[11. Training Program activities and participants 40](#_Toc492033381)

[12. Outcomes for service providers in the Training Program 42](#_Toc492033382)

[12.1 SDM training workshops 42](#_Toc492033383)

[12.2 Community of Practice 43](#_Toc492033384)

[12.3 Summary of outcomes for service providers 43](#_Toc492033385)

[13. Implementation of the Training Program 45](#_Toc492033386)

[13.1 Implementation of the SDM training workshops 45](#_Toc492033387)

[13.2 Implementation of the Community of Practice 46](#_Toc492033388)

[13.3 Summary of Training Program implementation 47](#_Toc492033389)

[14. Implications for service provider training 48](#_Toc492033390)

[15. Conclusion to SDM2 project evaluation 49](#_Toc492033391)

[Appendix A Literature review 51](#_Toc492033392)

[Appendix B SDM2 project outcomes and indicators 66](#_Toc492033393)

[Appendix C Program logic model for the SDM2 project 67](#_Toc492033394)

[Appendix D Demographic data of decision makers 68](#_Toc492033395)

[Appendix E Decision maker survey responses 71](#_Toc492033396)

[Appendix F Governance structure of the SDM2 project 74](#_Toc492033397)

[References 75](#_Toc492033398)

List of Tables

[Table 1 Methods and sample sizes for the FDM Program evaluation 17](#_Toc492033432)

[Table 2 Methods and sample sizes for the Training Program evaluation 38](#_Toc492033433)

[Table 3 Training Program activities 40](#_Toc492033434)

[Table 4 Training feedback survey responses 42](#_Toc492033435)

[Table 5 SDM2 project outcomes and indicators 66](#_Toc492033436)

[Table 6 Decision makers by age group 68](#_Toc492033437)

[Table 7 Decision makers by gender 68](#_Toc492033438)

[Table 8 Decision makers by disability 69](#_Toc492033439)

[Table 9 Decision makers by location 69](#_Toc492033440)

[Table 10 Decision makers by accommodation 69](#_Toc492033441)

[Table 11 Decision makers by NDIS registration 69](#_Toc492033442)

[Table 12 Decision makers by source of income 70](#_Toc492033443)

[Table 13 Decision makers by assets 70](#_Toc492033444)

[Table 14 Reported confidence at beginning of project (number of decision makers) 71](#_Toc492033445)

[Table 15 Effect of the financial literacy training 71](#_Toc492033446)

[Table 16 Changes in confidence 71](#_Toc492033447)

[Table 17 Assessment of project information 72](#_Toc492033448)

[Table 18 Perceptions of financial management order at the beginning of the project and change at the end 72](#_Toc492033449)

[Table 19 Confidence to talk with NSWTG at beginning of project and change at end of project 72](#_Toc492033450)

[Table 20 Relationship with NSWTG: beginning of project and changes 73](#_Toc492033451)

Glossary

**ADHC** NSW Ageing Disability and Home Care

**CoP** Community of Practice

**CSO** Client Services Officer

**FACS** NSW Family and Community Services

**FDM** Financial Decision Making

**NDIS** National Disability Insurance Scheme

**NSWTG** NSW Trustee & Guardian

**PG** NSW Public Guardian

**S71(2)** Subsection of the NSW Trustee & Guardian Act 2009 (see definition in section 2.2)

**SDM** Supported Decision Making

**SDM2** Supported Decision Making Phase 2

**SPRC** Social Policy Research Centre, UNSW Sydney

**UNCRPD** United Nations Convention on the Rights of Persons with Disabilities

Brief summary

The Supported Decision Making Phase 2 (SDM2) project was a pilot program funded by NSW Family and Community Services (FACS) and undertaken by the NSW Public Guardian (PG) from January 2016 until June 2017. It consisted of two components: first, the Financial Decision Making (FDM) Program worked with 33 people with cognitive impairments (‘decision makers’) who had financial management orders, as well as their chosen supporters, to identify and support financial decisions, and the FDM Program also organised financial literacy training for the decision makers; second, the Training Program delivered workshops on Supported Decision Making (SDM) to hundreds of service providers and established an SDM Community of Practice (CoP) for networking and practice development.

PG commissioned the Social Policy Research Centre (SPRC) to evaluate the SDM2 project. The evaluation used mixed methods including program data collection, interviews, surveys and focus groups. This report presents the evaluation findings.

In the FDM Program, most decision makers valued the opportunity to learn financial skills through an individual approach. Effective decision making support included trust, responsiveness to the person’s needs, and access to relevant information. Most decision makers wanted more responsibility for their finances, and some achieved their goals, usually because program staff intervened with the NSW Trustee & Guardian (NSWTG). Some supporters developed greater awareness of the decision makers’ capabilities. Implications for future individual FDM support are:

* Ongoing FDM support, facilitation and advocacy for decision makers appears essential. It could be considered as part of NDIS packages or through funding for advocacy services.
* Financial literacy training for people with disability could be made readily available and delivered in accessible formats. Supporter training could help manage conflicts of interest and increase knowledge of SDM processes.
* NSWTG could make its processes more accessible and transparent, incorporate SDM principles into its practice, and provide opportunities for people to build financial skills and manage parts of their estate.

In the Training Program, most service providers found that taking part in training workshops and in the CoP increased their capacity to assist people with cognitive impairment to make their own decisions. The high demand for Training Program activities indicates that further funding might help to build skills among service providers and embed SDM within organisations.

The evaluation evidence points to the need for a funded body – an agency, service or co-ordinating group – that can promote and develop SDM with services, people with disability and their families in NSW.

# Executive summary

This report presents the findings of an independent evaluation of the Supported Decision Making Phase 2 (SDM2) project. It was an 18-month pilot program funded by the NSW Government Department of Family and Community Services (FACS) and undertaken by the NSW Public Guardian (PG). The SDM2 project was based on recommendations from an earlier SDM pilot project in NSW, run by FACS with PG and the NSW Trustee & Guardian (NSWTG) as partners. The SDM2 project aimed to add to the knowledge gained in that and other pilots. In addition, it sought to explore SDM in relation to financial issues for people with disability, in particular people with cognitive impairment who were subject to financial management orders.

Supported decision making by people with disability has become an important issue both nationally and internationally. Supported decision making as articulated in Article 12 of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) recognises the legal capacity of all persons with disability, and places an obligation on governments that have ratified the Convention, such as Australia, to provide the support necessary for people with disability to exercise decision making in their lives and to be able to express their will and preference in making such decisions. Article 12 places emphasis on governments to take all appropriate and effective measures to ensure equal rights of people with disability, including control of their own financial affairs.

The project

The SDM2 project was part of the NSW Government’s Ready Together reform and was made up of two components. The first involved an SDM pilot that focussed on supporting financial decision making (FDM) by people with cognitive impairments, the FDM Program. Most of the people participating in the pilot – called decision makers – had financial management orders with NSWTG. Program staff worked with them and their chosen supporter individually to identify and support financial decisions, and they offered financial literacy training to the decision makers. The second component was the Training Program, which offered a range of workshops on supported decision making (SDM) for service providers and established a Community of Practice (CoP) for networking and practice development around SDM. While staff from the FDM Program and Training Program components worked together when possible, the two parts of the SDM2 project were implemented separately and are therefore discussed separately in this evaluation report.

Methodology

The evaluation was conducted alongside the SDM2 project, from January 2016 until June 2017. The methodological approach incorporated inclusive research principles to prioritise the experience of people with disability. People with disability were included in the evaluation team, and inclusive data collection methods were used in interviews and surveys.

The evaluation aimed to answer the following questions:

* 1. How effective was the SDM2 project in:
     + supporting people with cognitive impairment to successfully manage parts of their estate, where possible
     + enhancing the financial literacy of research participants with cognitive impairment
     + increasing the capacity of service providers and the community to assist people with cognitive impairment to make their own decisions?
  2. What are the implications for:
     + supporting people with cognitive impairment to make decisions about their lives
     + efforts to embed SDM within the policy and practice of support organisations?

Data collection methods included a brief literature review, program data collection, interviews, surveys and focus groups. Consistent with the evaluation brief provided by the funder, the evaluation focussed mainly on the FDM Program, with a secondary emphasis on the Training Program.

Part A: FDM Program

Participants and activities

The FDM Program succeeded in recruiting 33 people with cognitive impairment who had financial management orders. Most were from metropolitan Sydney, and there was little cultural diversity, possibly due to difficulties in recruitment and time constraints. Generalisations from the group should be made with care. The fact that the decision makers chose primarily service providers as their supporters suggests they had small social networks. The main criterion for selecting a supporter seemed to be a trusting and previous relationship. Supporters were not expected to meet any attributes other than being chosen by the decision maker.

Due to a relatively long recruitment process and time limitations of the program, decision makers participated for three to seven months. Program activities were based around the three-way relationship between a decision maker, a supporter and a program staff member as an external facilitator. Program staff engaged with decision makers and supporters about how they could be supported to make financial decisions. This included building rapport, exploring and implementing financial decisions, arranging financial literacy training if the decision maker was interested, monitoring, reflecting, and providing SDM resources and contacts.

Outcomes for decision makers

The data about financial literacy skills and training indicates that most decision makers valued the opportunity to learn budgeting, setting priorities and saving. The data also shows that an individual approach to training was important to address the unique circumstances of each decision maker, including their support needs and life situations.

It appears that effective support in this project included trust, responsiveness to the decision maker’s needs and circumstances, and access to relevant information. Building trust took time, which needs to be recognised in SDM approaches. Responding to the decision maker’s needs and preferences required flexibility in deciding who could be considered as an effective supporter. The decision maker’s consideration for choice of supporter also needed to include safeguards against potential conflicts of interest.

Most decision makers in this project wanted more responsibility for their finances, and for many, this was the reason they agreed to participate. Some achieved their goals, and in some cases this happened because program staff intervened with the NSWTG on the decision maker’s behalf. The successful advocacy provided by the program staff suggests that skills in this form of advocacy would be useful for supporters and decision makers and that access to NSWTG processes could be improved. Promoting supported decision making is consistent with provisions under section 39(b) of the NSWTG Act 2009.

Decision makers found the financial literacy training useful in giving them new skills and information, and most valued the information provided by program staff and supporters. At the end of the project, the majority did not report a marked increase in confidence in managing financial issues, possibly due to the short time frame. While some reported effective relationships with the NSWTG, others expressed concerns over difficulties in contacting relevant staff or obtaining financial decisions.

Outcomes for supporters

Most supporters indicated that their views about what made effective support had not changed as a result of the project. They outlined factors that contributed to good support relationships, such as regular, respectful communication; listening carefully; adequate time; tailoring financial goals; and activities that fostered confidence. The project also provided supporters with the opportunity to think more broadly about networks of support and ongoing support arrangements. A few noticed improved relationships with decision makers and a greater awareness of the decision makers’ capabilities. Supporters found the program staff helpful, especially in providing insight into NSWTG processes and facilitating communications with NSWTG. Some supporters who were service providers indicated they would use the project resources for other clients in the future. Several supporters expressed the need for advocates for decision makers.

Implementation of the FDM Program

The FDM Program provided some effective support for participants, and program staff felt that more could have been achieved with more time. The pilot revealed challenges of developing a financial supported decision making project. These included difficulties in recruiting people with cognitive impairment through the use of NSWTG files, and problems in finding supporters when the person with cognitive impairment did not have someone they could ask. The importance of program staff in providing advocacy and intensive face-to-face support to decision makers and supporters was evident.

|  |
| --- |
| Implications for individual FDM support   * Accessibility of NSWTG processes:   Decision makers and supporters expressed difficulties in communicating their needs to, and receiving a response from, NSWTG, and they requested assistance from program staff to advocate on their behalf. This indicates that NSWTG could streamline communication mechanisms and develop more transparent processes for the benefit of its stakeholders. Processes relating to financial management orders could be made more accessible to people with disability, along with necessary information about their financial situation, their rights and responsibilities.   * Involvement of NSWTG:   The FDM Program occurred while NSWTG underwent a major restructure of its staffing and service delivery model. This limited the intended reach of the project into the agency. The findings of this evaluation indicate that training for NSWTG staff to incorporate the principles of SDM into practice may be important to implement the UNCRPD focus on SDM.   * Role of facilitators:   It appears from the evaluation findings that developing a trusting relationship with the decision maker and being able to translate financial decision making intentions into practice does require ongoing support and in some instances advocacy. Ongoing resource provision for the facilitation role is important and could be considered as part of NDIS funding.   * Providing opportunities for decision making:   The project showed that people with cognitive impairment can increase their capabilities in making financial decisions when given the opportunity to gain knowledge and skills and to practise their learning. The project activities also increased some supporters’ awareness of SDM, indicating that similar future projects may have merit. The findings indicate the importance of NSWTG providing opportunities for people with orders to manage parts of their estate in concert with skill building.   * Choice of supporters:   Decision makers in the project were enabled to choose their supporters, and most chose family members or service providers. This led to various concerns and potential for conflicts of interest. Developing a group of people with financial expertise who are available to lend financial decision making support may provide a solution, and so may funding for advocacy services for the role of financial supported decision making, especially in light of the implementation of the NDIS.   * Financial literacy training:   There appears to be a need for financial literacy training to be readily available and accessible to people with disability. The experience of the FDM Program indicates that the financial literacy sector needs to develop further to meet the demand for skills development of people with cognitive impairment, and that recognising financial skill development in NDIS packages would be beneficial. Additional training in financial literacy for supporters would provide a safeguard for both parties given the sensitivity of financial issues |

Part B: Training Program

The Training Program activities included SDM information sessions, a one-day ‘Introduction to SDM’ workshop, Train the Trainer workshops and a Community of Practice (CoP) group. The information sessions and workshops reached hundreds of service provider organisations and staff in metropolitan Sydney and several regional centres. While the CoP was confined to the Sydney and adjoining regional areas, it attracted a relatively large, diverse and stable group of service providers.

Outcomes for service providers

Findings across the various data sources are consistent, indicating service providers found that participating in training and in the CoP increased their capacity to assist people with cognitive impairment to make their own decisions. A large majority of training workshop participants said the information was relevant to their work, increased their awareness and understanding of SDM concepts and strategies, and that they were likely to apply the training in their practice. CoP members appreciated the networking, peer support and information sharing opportunities of the group. Embedding SDM within organisations appears to be a longer term process, involving policy, procedural and practice changes and more tailored training aimed at a deeper application in day-to-day practices including, for example, how agencies perceive and deal with risk.

Implementation of Training Program

The Training Program seems to have developed successful implementation strategies, including broad preparatory consultations, tests of training materials and flexibility in delivering the training. A suite of training approaches – including workshops, shorter presentations and collaboration with other agencies – appears to have ensured wide reach and relevance to different contexts. The Public Guardian, in partnership with FACS during 2017-2018, will develop further resources and training, e.g. an e-learning program, after the end of the project.

The CoP was organised around its members’ preferences for content and format, which seems to have led to sustained engagement by a core group and visits from other service providers. The Training Program staff worked towards sustainability of the group from the beginning. With more project resources, similar groups could be set up in regional centres.

|  |
| --- |
| Implications for service provider training   * The need for service provider training:   The high demand for training in SDM reflects that service providers acknowledge both the importance of SDM and the need to be skilled in supporting client decision making.   * Sustainability of service provider training:   The project indicates that a group of people who are skilled in SDM, have knowledge of the sector and can co-ordinate training and support for service providers would be helpful to sustain momentum in sector capacity building around SDM. Program staff expected that the Information Support Team at the Public Guardian would continue to roll out SDM training in a limited way.   * Community of Practice:   Such a networking group seems an effective way to disseminate information and help service providers to build SDM skills and capacity. Given the demand demonstrated in this project, an investment in setting up regional groups in the future appears useful. |

Conclusion of SDM2 project evaluation

The evaluation evidence points to the need for a funded body – an agency, service or co-ordinating group – that can promote and develop SDM with service providers, people with disability and their families in NSW. This is particularly important in relation to financial decision making, which is fundamental to other life decisions. The evaluation indicates that people with disability need the opportunity to obtain accessible and relevant information as well as training in financial decision making and the process of SDM, and that supporters and advocates need opportunities to learn skills in SDM. This seems particularly relevant in the context of NDIS implementation as people with disability have increasing possibilities to exercise choice and control in their lives. Change takes time and resources but may be cost effective in reducing the workload of government organisations currently involved in SDM and financial management.

# Introduction to SDM2 project evaluation

Supported decision making by people with disability has become an important issue both nationally and internationally. Supported decision making as articulated in Article 12 of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) recognises the legal capacity of all persons with disability and places an obligation on governments that have ratified the Convention, such as Australia, to provide the support necessary for people with disability to exercise decision making in their lives and to be able to express their will and preference in making such decisions. This involves a shift from traditional forms of decision making where decisions for many people with disability were made by others based on their welfare and best interests. Article 12 places emphasis on governments to take all appropriate and effective measures to ensure equal rights of people with disability, including controlling their own financial affairs.

The recognition of legal capacity and the promotion of supported decision making (SDM) involve a profound shift in culture and thinking. A body of literature has developed that has sought to clarify the nature of supported decision making (see for example Committee on the rights of persons with disabilities, 2014; Gooding, 2015; Arnstein-Kerslake & Flynn, 2015). The literature indicates that there are challenges in translating the theory of SDM into practice, particularly when working with people with cognitive impairment, which has motivated a series of SDM pilot projects in Australia (Appendix A).

The Supported Decision Making Project Phase 2 (SDM2) project was an 18-month pilot program funded by the NSW Government Department of Family and Community Services (FACS) as part of the NSW Government’s Ready Together Growth reform. The project was undertaken by the NSW Public Guardian (PG), with NSW Trustee & Guardian (NSWTG) and FACS as program partners, which formed part of the project’s governance structure (Appendix F). The SDM2 project ran from January 2016 to the end of June 2017.

The SDM2 project aimed to add to the knowledge gained in previous pilots and also sought to explore SDM in relation to financial issues for people with disability, in particular people with cognitive impairment who were subject to financial management orders. Financial SDM has not been a focus of other Australian pilots nor has it had a strong emphasis in overseas trials (one exception is an Israeli report, Bizchut, 2015). The current project also had a training component designed to increase the knowledge and skills of service providers in SDM more broadly, not just in financial decision making.

Hence, the SDM2 project was conceived in two parts:

* The Financial Decision Making (FDM) Program aimed to determine the practical implications of applying SDM to financial decision making with people under financial management by helping them develop their support and build their capability to make financial decisions.
* The Training Program developed and delivered training and resources for non-government organisations, disability advocates and private guardians to incorporate SDM principles into policy and practice.

This project was particularly timely in Australia as several factors have recently led to policy revision in relation to the rights of people with disability and a particular focus on the issue of supported decision making.

Article 12 of the UNCRPD approach to legal capacity is in contrast to existing approaches within legal and financial regulatory systems. In relation to financial issues, institutions and administrators have seen the management of risk as their primary duty to customers and clients, rather than enabling decision making rights. The need to better understand how supported decision making on financial issues may occur is therefore important. The SDM2 pilot project and its evaluation seek to add to the evidence base about how the UNCRPD can be implemented in practice.

The National Disability Insurance Scheme (NDIS) is based on individual planning and support for people with disability, including individual budgets. This places emphasis on SDM in relation to general as well as financial decision making. People with disability participating in the NDIS will be involved in making decisions that have a financial context, or will be directly involved in the financial administration of their disability support plans. Therefore it was timely to consider the application of supported decision making to financial decision making.

Financial decisions are often seen as more significant and their outcomes of greater consequence for individuals than many other forms of decision making. Concerns about undue influence, risk and harm, and possible conflicts of interest tend to be acute in relation to financial decision making. This is particularly the case with people with cognitive impairment, where there may be additional difficulties in ascertaining clearly the individual’s will and preference.

There has been little research on the application of SDM to financial decision making. Internationally, the report by Bizchut, (2015) a legal advocacy organisation for people with disability in Israel, considers the potential use of existing legal and regulatory mechanisms to maintain autonomy and address decision support needs and issues of risk, rather than the appointment of a financial manager. Its findings emphasise the need for further exploration in Australia.

The SDM2 project aimed to build on findings from an earlier SDM pilot project in NSW, run by FACS with PG and NSWTG as partners, which addressed SDM in general (Westwood Spice 2015). Its evaluation pointed to the need for providers to become more skilled at decision making support and in assisting people with decision making impairment. Broader service system development was viewed as necessary in order to drive and facilitate the uptake and best practice of SDM in the context of the NDIS. The evaluation also found that there was a need to develop supports to assist people under financial management to take greater responsibility for their own financial decision making, and specifically recommended that a further trial be undertaken with NSWTG clients. The SDM2 project sought to address the recommendations of the previous pilot by focussing particularly on financial decision making by people with cognitive impairment and by developing training and capacity building for organisations supporting people with disability.

The SDM2 project occurred during a time of significant restructuring within the NSWTG.

This report provides the findings of an independent evaluation of the SDM2 project undertaken by the Social Policy Research Centre. A draft description of the project provided by the program staff from the Public Guardian was incorporated into the report. In line with the brief from the funder, the evaluation focussed on the FDM Program, while the Training Program was a secondary part of the evaluation.

The evaluation was conducted alongside the SDM2 project over 18 months, from January 2016 till June 2017. The evaluation methodology outlined in this report was approved by the UNSW Australia Ethics Committee, approval number HC 16260. More detail about the methodology can be found in the evaluation plan (Bullen et al. 2016).

The methodological approach incorporated inclusive research principles to prioritise the experience of people with disability (Walmsley and Johnson, 2003; Fisher and Robinson, 2010). People with disability were included in the evaluation team; and inclusive data collection methods were used in interviews and surveys.

The evaluation design was based on a program logic model developed by PG (Appendix C). A program logic model articulates the elements of a program and their relationship as well as the program’s wider context (McLaughlin & Jordan, 1999; Pawson, 2006). In this evaluation, it provided a framework to understand SDM2 project processes and the impact of project initiatives on intended outcomes for participating people with cognitive impairment, supporters and service providers.

The evaluation findings for the two discrete parts of the SDM2 project are presented consecutively: Part A of this report presents the evaluation findings for the FDM Program and Part B for the Training Program.

# Part A: The Financial Decision Making Program and its implications

# FDM Program overview

This section provides an overview of the FDM Program, including its intended outcomes, its policy context, recruitment and activities.

## Intended outcomes of the FDM Program

The FDM Program’s intended outcomes were:

* People with cognitive disability (decision makers) under financial management be supported to successfully manage parts of their estate, or larger parts than before.
* People with cognitive disability, including those whose funds are subject to a financial management order, be able to undertake financial literacy training to enable them to take greater control of their finances.
* Agencies and other suitable persons be supported to gain skills and to perform a facilitating role for decision makers and supporters with financial decision making.
* The NSWTG will have a mechanism in place to enable people with financial management orders to increase self-management of their affairs.

A detailed table of outcomes and indicators is in Appendix B.

## Financial management policy context

The FDM Program worked primarily with people with a financial management order. The NSW Guardianship Act 1987 and the NSW Trustee & Guardian Act 2009 provide the legislative framework for the making of orders. The NSW Supreme Court, NSW Civil and Administrative Tribunal (NCAT) (previously the NSW Guardianship Tribunal) and the Mental Health Review Tribunal (previously by order of Magistrate), all have the power to make financial management orders. An order can be made for a person if they are deemed by the court or tribunals to lack the capacity to manage their finances. An order can include all or part of a person’s estate and can appoint a private person as a financial manager or the NSWTG as an independent financial manager as a last resort.

Many of those considered for the FDM Program had been given an s71(2) authority. This is a provision of the NSW Trustee & Guardian Act 2009, where the financial manager can delegate some or all of the person’s decision making responsibility back to the person. It is a way of enabling a person with a financial management order to have more independence for managing their money and financial affairs. It can also be an effective mechanism for enabling them to develop and demonstrate their financial management capability. The program was to work with people and their supporters to see if they could be granted s71(2) authorities if they did not have them or, if they did, to extend their scope.

Although financial management orders can be limited in duration, most are indefinite in length having no review date. While there is some scope for the NSWTG to terminate orders if a person has gained capacity to manage their finances, in most cases, people who wish to resume responsibility for their finances need to apply to the court or tribunal that made the order for it to be reviewed. Although it was not the role of the program to assist decision makers to seek reviews of their orders, this was of significant interest to several participants.

The Act also includes principles that are consistent with those of supported decision making. Section 39 of the Act sets out the principles by which the NSWTG implements financial management orders. Section 39(b) requires that the freedom of decision and freedom of action of people under a financial management order should be restricted as little as possible. The general principles also include provisions that the views of people under a financial management order should be taken into consideration, in relation to the exercise of the NSWTG’s functions, and that they should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs.

## FDM Program recruitment

The program had access to the client database of the NSWTG, and 817 client records were reviewed. It was intended that participants in the program would have an s71(2) authority or be eligible to have one. Subsequently, as the program experienced difficulties in recruiting participants, this criterion was relaxed and people with potential to develop their decision making or financial capability were also considered.

Program staff contacted 147 NSWTG clients or their stakeholders to discuss their potential participation; 33 consented to participate. Most were based in the Sydney metropolitan area, with a small cluster located in regional NSW (Newcastle and Mid North Coast). Program participants were called ‘decision makers’ and all had the NSWTG appointed as their financial manager. The program attempted to recruit people who had a private financial manager but none chose to participate. Two people who did not have an order were recruited but exited the program early. Some decision makers had s71(2) authorities.

Out of the 33 decision makers, 24 chose and identified supporters. Program staff had decided that it was for the decision maker to determine who they wanted to support them, given the importance of trust in supported decision making relationships. The supporter was not expected to meet any other requirements or attributes. Of the 24 supporters, 14 consented to participate in the program. Decision makers without a supporter could participate if they were willing for the program facilitator to try and find them a supporter. As experienced by other Australian supported decision making pilots (Appendix A), recruitment of decision makers and supporters was difficult and time consuming. Twelve decision makers chose to exit the project before it ended for various reasons (section 7.2); 21 remained to the end.

Depending on when they were recruited or chose to exit, the program worked with decision makers and supporters for periods of between three and seven months, between June 2016 and March 2017.

## FDM Program activities

The program activities were based around the three-way relationship of a decision maker and supporter resourced by an external facilitator as described in the previous NSW pilot (Westwood Spice, 2015). The program’s four staff members had regular face-to-face and phone contact with decision makers and supporters, at least every few weeks. Program staff engaged with decision makers and supporters about how they could be supported to make financial decisions. While contact sessions were largely determined by the wishes of the decision maker and/or supporter, generally program activities included the following:

### Meeting the decision maker and building rapport

Program staff engaged in multiple meetings and phone calls with decision makers to discuss their expectations of the project and complete an entry questionnaire to establish baseline data. Program staff also established the person’s communication needs.

### Exploring decisions and current experiences of managing money

Program staff discussed with decision makers which financial decisions they wished to make or which possible changes they wished to make around involvement in their money management. If a decision was carried out during the project, the decision makers could then revisit one of their other decisions or explore further decisions.

### Exploring supports

Program staff asked decision makers to define their own support needs and what good support meant to them. If the decision maker had elected a supporter, program staff discussed the decision with both the decision maker and supporter. Program staff also provided information to the decision makers and supporters, including a resource kit with an extensive list of resources on supported decision making and financial literacy. In a few cases, program staff tried to refer decision makers to support services for support when needed, but this was largely unsuccessful.

### Providing financial literacy training

Program staff also offered decision makers financial literacy training. If this was undertaken, staff consulted with the decision maker, supporter and financial literacy trainer to ensure training was appropriate for their needs and expectations. In total, 19 decision makers were referred to financial literacy training: 10 undertook training with two mainstream providers, and nine decision makers completed training with two disability services which provide programs designed for people with disability. Due to decision maker preference and the difficulty in arranging training in groups, training occurred one-to-one, except where training was provided to one small group.

Content was tailored to the need of the individual, from the provision of basic numeracy and money skill development through to budget planning, managing savings and investments, and contract and debt negotiation. Program staff, trainers and decision makers liaised regularly to ensure that training content and delivery met the decision maker’s needs; changes, further training or referral to other services were arranged if needed. Trainers provided feedback on course outcome to decision makers and the project, and in some cases provided certificates of achievement or letters outlining course content and skills learned.

### Monitoring the decisions

Program staff maintained regular contact with decision makers and their supporters to monitor their decisions. At times, there was a delay in the progress of a decision due to illness or life events. This meant that the implementation of a decision did not always maintain momentum.

### Reflection

Program staff reflected with the decision maker and their supporter (separately and together) about decisions. This often took the form of a discussion where both parties explained what happened before the decision was made, what support was provided before and during the process, the decision maker’s satisfaction with the support and the process, and how they both felt about the outcome. Program staff highlighted aspects of the process that aligned with supported decision making principles, such as the supporter only providing as much help as required or the decision maker articulating their positive feelings of empowerment or recognition of the right to make the decision. Where decision makers were not decision-ready, program staff had targeted conversations with them about how the principles of supported decision making related to their supports and their lives.

## Summary of FDM Program

The FDM Program involved the development of a supported decision making pilot that focussed on financial decision making by people with cognitive impairments. Most of the people participating in the pilot had financial management orders with NSWTG. Program staff worked with them and their chosen supporter individually to identify financial decisions, provide resources and support in making decisions and reflect on the process of financial decision making. Financial literacy training was offered to decision makers in the project, and this occurred mainly on an individual basis.

# Methodology for FDM Program evaluation

## FDM Program evaluation questions

Considering the goals of the SDM2 project and its program logic model, the FDM Program evaluation aimed to answer the following questions:

* 1. How effective was the FDM Program in:
* supporting people with cognitive impairment to successfully manage parts of their estate, where possible
* enhancing the financial literacy of research participants with cognitive impairment
* increasing the capacity of the community to assist people with cognitive impairment to make their own decisions?
  1. What are the implications for supporting people with cognitive impairment to make financial decisions about their lives?

## Data collection methods for FDM Program evaluation

Data collection methods included a brief literature review, program data collection, surveys, interviews, case studies and observation. Sample sizes for the various methodologies are in Table 1.

### Literature review

SPRC conducted a brief literature review focussing on evaluations of other Australian supported decision making projects and indicators of best practice. The review informed the selection and design of data collection tools and provides a comparative reference for the findings of this evaluation. The literature review is in Appendix A.

### FDM Program data collection

Program staff collected **demographic information** such as the numbers and socio-demographic characteristics of people with cognitive impairment participating in the trial; their sources of income, assets, debts and housing arrangements; financial management arrangements; reasons for participation; numbers of supporters and service providers; and the number and types of contacts and activities related to decision making support during the evaluation data collection phase.

Program staff also prepared **participant summaries** for each decision maker in the project. The summaries included project goals for the person, project inputs such as actions initiated or resources provided, any observed outcomes, and the staff member’s assessment of the project’s efficacy for each person.

Finally, an **observations log** contained staff comments and experiences relating to recruitment, decision maker characteristics, decision maker relationships with NSWTG and project processes. Program staff de-identified all program data before providing it to the evaluators for analysis.

### Surveys with decision makers and supporters in the FDM Program

SPRC assisted with the design of a short **survey** that program staff conducted with decision makers and supporters at the beginning and end of the project. The survey asked decision makers about confidence in managing their finances and the quality of their relationship with NSWTG, while supporters were asked about their perceived role in supporting the decision maker. Both groups also answered questions about their expectations and experiences of the FDM Program. The surveys contained quantitative and qualitative questions. Program staff provided the completed, de-identified surveys to the SPRC for analysis.

### Interviews, case studies and observation in the FDM Program

SPRC conducted in-depth, qualitative **interviews** with six decision makers and their supporters. Interviews occurred soon after participants had joined the project (between September and November 2016) as a baseline to seek their views on what they expected from participating. Follow-up interviews took place at the end of the project (February and March 2017) about participant views on the project’s efficacy in increasing decision makers’ capability and authority in financial decision making.

Program staff invited all project participants to take part in the evaluation. Three decision maker–supporter pairs took part in both rounds of interviews, and a further three pairs who had joined the project later took part in the second round only. All interviews occurred face-to-face in Sydney, except for one telephone interview with a supporter. Interview methods with decision makers, including the consent process, were inclusive and adjusted to the communication preferences of the person. They included communication assistance from supporters, simplified questions, pictures, yes-or-no questions for people who did not communicate verbally, and observation.

Program staff undertook three **case studies** of decision makers, consisting of a detailed description of the person’s background, their activities and engagement in the project, any facilitators and barriers to achieving project outcomes, and other observations by the facilitator. These case studies were de-identified and made available to SPRC for analysis.

The evaluators gained additional data from decision makers by observing a participant **group session** organised by the project team. During a half-day meeting, nine decision makers took part in financial literacy training activities and gave feedback on their experience of the project, all in a group setting.

Three **program staff** from the FDM Program took part in in-depth, qualitative interviews with the evaluators at the end of the project about their views of the project, its achievements and challenges, and implications for future, similar projects.

Table Methods and sample sizes for the FDM Program evaluation

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Method** | **Decision makers (N=21)** | | **Supporters (N=23)** | | **Early exit participants (N=12)** | **Program staff (N=5)** |
| **Round** | | **Round** | |  |  |
| **1** | **2** | **1** | **2** |
| Demographic information | 21 | |  | | 12 |  |
| Participant summaries | 21 | |  | | 12 |  |
| Surveys | 16 | 16 | 8 | 7 | 111 |  |
| Interviews | 3 | 6 | 3 | 6 |  | 3 |
| Case studies |  | 3 |  |  |  |  |
| Observation of group session |  | 9 |  |  |  |  |

Source: PG program data; 1 total number of entry and exit surveys available from decision makers and supporters who exited the project early

## Analysis of FDM Program evaluation data

1. Most data were qualitative and analysed thematically with reference to the evaluation questions. Quantitative demographic and survey data were analysed using Excel and SPSS. Data from the various sources and research methods were triangulated where possible.

## Limitations of the FDM Program evaluation

1. Due to practical reasons and resource constraints, program staff collected program and survey data after attending a two-hour training workshop by the evaluation team that covered interview techniques, case study methodology and ethical research conduct. Quality control occurred also through regular phone conversations between staff and evaluators, data checking by evaluators and triangulation of data collected by both teams.
2. The size of the project participant group (decision makers and supporters) and the corresponding interview sample were relatively small, which limits the statistical significance of the evaluation findings. However, the qualitative interviews yielded rich experiential data. Combined with the participant summaries, case studies and reflections from program staff, the data enabled a comprehensive assessment of process issues, of outcomes for participants, and of suggested implications for future projects and financial supported decision making in general.
3. Due to budget limitations, face-to-face interviews outside of the Sydney metropolitan area were not possible, and telephone interviews with people with cognitive impairment would have been inappropriate. This precluded interviews with the decision makers who lived in regional areas.
4. The project had a relatively short funded lifetime of 18 months. This, combined with difficulties in recruiting participants, meant that some participants were included late in the project, limiting the time for supported decision making and the evaluation of some of the outcomes for individuals.
5. The policy and administrative context of the project placed limitations on its development, particularly in relation to recruitment of participants for the FDM Program. Program staff had anticipated that they would work closely with NSWTG during the project. However, the NSWTG’s internal restructure meant that staff were focused on organisational changes and had limited options for working with the FDM Program. Further, the project began at a time when the NDIS was rolled out in Western Sydney and in some rural areas of NSW. Engaging with services in these areas proved difficult as staff were focussed on transitioning to the NDIS. Project management decided to avoid regions where the NDIS was being implemented, leading to a reduction in possible participants.

# Profile of FDM Program participants

1. Demographic and administrative data about the 33 decision makers collected by program staff is provided in detailed tables in Appendix D.
2. The age profile of the decision makers encompassed a broad range, with a third in the 46-55 year age bracket. The gender composition of the group slightly favoured men, with 20 men and 13 women in the group. A significant number had complex and multiple support needs, including intellectual disability and mental illness. Nearly all the decision makers had been born in Australia and all spoke English at home as the main language. Few decision makers identified as having culturally and linguistically diverse or Aboriginal and Torres Strait Islander backgrounds. Most of the decision makers (26) lived in the Sydney metropolitan area. The housing arrangements of the decision makers were diverse and encompassed private and community housing, group homes and boarding houses.
3. Five of the participants indicated that they were registered with the NDIS. Most received income only from Centrelink benefits (23 decision makers), while the others had some combination of benefits, wages income and investments. Sixteen decision makers had only bank savings as assets, while 13 had other assets, including investments, shares, property and superannuation. Three decision makers had debts, which included financial estate loans, debts to friends and debts to the government.
4. Nearly all (30) decision makers had a direct financial management order, with the NSWTG being the manager, with only one decision maker having a private manager. Nine decision makers had an s71(2) to manage some portion of their income. One-third of decision makers indicated that they used Centrepay. Eighteen of the decision makers said at the beginning of the project that they were interested in financial literacy training, and 15 were interested in assistance with revocation of financial management orders, while nine were interested in both.
5. Twenty–three of the decision makers had a supporter, and for over half of this group (13), the supporter was their service provider. Other supporters were family and friends, and often this was a pre-existing decision support relationship. Those who did not have supporters were asked if they wished to be referred to a supporter. In the one case where this occurred, this was a referral to an advocacy service.
6. In summary, the project succeeded in recruiting people with cognitive impairment who were under financial management orders. However, the group was relatively small, most were from metropolitan Sydney and there was little cultural diversity, possibly due to difficulties in recruitment and time constraints. Generalisations from the group should be made with care. The fact that decision makers chose primarily service providers as supporters suggests they had a small social network. As mentioned previously (section 2.3), supporters were not expected to meet any attributes other than being chosen by the decision maker.

# Outcomes for decision makers in the FDM Program

1. As outlined in section 3.1, this evaluation aimed to explore how effective the FDM Program was in:

* supporting people with cognitive impairment to successfully manage parts of their estate, where possible
* enhancing the financial literacy of research participants with cognitive impairment.

1. A detailed list of the intended project outcomes is in Appendix B. This section first examines outcomes in relation to financial decision making capacity, and then considers financial decision making authority and the decision makers’ relationships with NSWTG. This section draws on data in the entry and exit surveys for decision makers and supporters, the interviews with the decision makers and supporters where available, and the participant summaries and case studies prepared by program staff. Quantitative data from the surveys is reported in Appendix E.
2. Decision makers had varying levels of participation in the project relating to their personal goals and circumstances. Some decision makers participated in financial literacy training, some had identified supporters who also participated in the training, and all had contact with program staff who provided them with information and other forms of support. The discussion of outcomes below should be read with an appreciation of the impact of the diversity of personal contexts and circumstances that may have affected participation in the project and relationships with supporters.
3. Sixteen decision makers responded to questionnaires at both the beginning and the end of the project. Their minimum length of participation in this project was just over three months, while the longest time period was just over seven months, with an average of around five months. The relatively short time period may have affected opportunities for change and the achievement of outcomes for decision makers. This project had data for a relatively small sample of decision makers and supporters, and while the analysis below reflects the outcomes for these specific decision makers, no broader generalisations should be drawn to the population of people in similar circumstances.
4. An additional, unanticipated outcome of the project was that specialist communication assessments were made for some decision makers to ascertain their capabilities with regard to decision making. In one case, this process led to a greater understanding by service workers of the communication style and capabilities of the decision maker and for SDM to be used. In another case, this involved specialist assessments which identified that communication about will and preference was difficult and therefore, decisions relating to finances would generally be substitute decisions.

## Financial decision making capability

### Financial literacy skills and training

1. At the beginning of the project, 10 of the 16 decision makers who completed the survey expressed confidence in asking for help with money, and 11 were confident in managing their money to the extent that they currently did so (Table 14). Decision makers spoke of ‘spending money wisely’ and prioritising bills and other essentials. Decision makers who reported less confidence in asking for help with money expressed reasons such as:

'because I don’t want to seem like I’m a dummy and I don’t understand these things'. [DM12]

1. Ten of the decision makers reported that they would like help with managing their money, such as financial literacy training, while five indicated that they did not want help. The decision makers outlined a range of reasons as to why they would like to undertake the financial literacy training, including learning more about maths so that they could do the shopping on their own and wanting to learn more about budgeting and how to save. For some, this included being able to demonstrate financial literacy skills to the NSWTG to access more funds or work towards expanding their involvement in managing their funds with an s71(2) or revoking their financial management order. Among the five people who indicated that they did not want financial literacy training, reasons given included that they already had the skills or had adequate support.
2. Many financial literacy training sessions were conducted one-to-one, either because of decision makers’ expressed preference or because arranging group training for a diverse, dispersed range of program participants was impractical. Those who did participate in group training sessions enjoyed or preferred this format, highlighting the need to tailor any training to the individual’s circumstances and preferences. In other cases, where participating in training sessions was not possible for a range of reasons, decision makers were sent materials, such as money management tools, to assist with their financial literacy.
3. Decision makers and supporters noted that the level and focus of the financial literacy training was often appropriate to the specific context:

[It] taught me how to divide my money into different sections and how to budget correctly and what I can save and not save… Set it out simply in simple steps so I understood [DM2]

1. A few decision makers found the courses too easy and expressed interest in participating in additional training in more advanced courses.
2. When asked what they learnt in the financial literacy training, decision makers reported that it had helped them focus on distinguishing between needs and wants, and that they had learnt to compare prices and look for bargains and specials. Around half of the decision makers who completed the surveys also reported that it had been helpful to track their spending – either by collecting receipts or through an app. Identifying priorities and setting aside money for savings or saving goals were other elements of the training reported as helpful by around half of these decision makers.

…. stretch out me money through the week… It made it a lot more easier and I could work out my budget a lot shorter. [DM18]

I’ve learnt to save a bit more and when I go shopping look for specials. [DM30]

1. While around half of the decision makers who completed the surveys reported that they had successfully started saving money, one of the challenges was that some decision makers had constrained incomes, and therefore the possibilities for engaging in choice and decision making and saving for bigger items were limited. In some cases, the training helped the decision makers identify that when they spent significant proportions of their income on one item, such as cigarettes or eating out, this might be limiting their overall spending and saving possibilities.
2. Feedback from decision makers and supporters regarding the financial literacy training was generally positive. Most decision makers (12) reported that it had helped them and that they thought that they made decisions differently since the project started (Table 15):

Because of the FL training. It helped me to understand things better [DM31]

Well (financial literacy trainer) told me to look at needs basis and I do that…[DM26]

I plan. I prioritise. I think it through a bit more [DM26]

1. In summary, the data about financial literacy skills and training indicates that most decision makers valued the opportunity to learn budgeting, setting priorities and saving, and that a flexible approach to training was important to address the unique circumstances of each decision maker, including their support needs and life situations.

### Changes in decision making confidence

1. Most decision makers reported at the end of the project that their confidence levels to ask for help with their money had stayed the same. Based on the data provided in the entry and exit questionnaires, a small number of decision makers reported increased or decreased confidence levels at the end of the project (Table 14). The scales for confidence levels were different between the entry and exit questionnaires, which may have affected the responses, so this data should be interpreted with caution. The short time frame for the project should also be taken into account, as well as the small sample size.
2. In the qualitative data, just under half of the decision makers and their supporters reported changes in confidence about managing money as an outcome of the financial literacy training, for example:

It increased my confidence with money and going to the shops. [DM11]

1. For a few decision makers, the increased confidence had spill-over effects in increasing confidence in their ability to learn more generally and their interest to undertake further courses. A few decision makers and supporters reported that undertaking the project and the training had had a positive effect on the decision maker’s self-esteem:

I feel a lot more confident and my knowledge has improved. It lifted up my spirits and I feel better about myself. [DM20]

I believe she is a more confident person now, not just money wise, but in making decisions about life. [S30]

1. In one case, a supporter noted that the scheduled meetings with program staff and trainers were important, as they resulted in the decision maker developing routines to prepare for appointments. In a few other cases, especially in the group sessions, decision makers described that they were proud to be sharing stories with others and helping others, for example:

We help other people that are in the same boat as us helping them to depend on themselves. [DM16]

Nearly all of the decision makers (15) reported that the project had met their expectations, while one was unsure. When asked about whether the information provided by the project was useful, most said it was very useful (7) or useful (7). In the other two cases the decision makers had not received any information. All decision makers found talking with program staff very useful or useful (Table 17).

It was really good and built my confidence up. I like to participate in courses and improve my knowledge and show people that I can make decisions despite my disability. [DM20]

1. In summary, most decision makers found receiving project information and talking to program staff useful. At the end of the project, few reported a change in confidence to manage their money, which may be related to the short timeframe of the project.

### Identifying effective support

1. Not all decision makers had supporters for this project. Among those who did, they had a range of reasons for choosing their supporters. In some cases supporters were trusted family members or friends, while for others they were services workers with whom they had good rapport and trusting relationships.
2. Reasons for wanting support and practices of support were complex and unique to each situation. One decision maker reported that she preferred not to have a supporter:

because I prefer to be independent and responsible. [DM26]

1. A few supporters indicated that they did not attend the financial literacy sessions as they felt it was better for the decision maker to attend on their own. Decision makers outlined a range of factors that they considered to have helped in the support relationship, which included:

* being offered choices or options
* visual aids - putting money in an envelope for different things, setting up an expenses book with receipts
* having the opportunity and encouragement to “just try it out”
* comparing prices and quotes
* information and discussions
* no criticisms or arguments - relaxed
* getting tips to take on board
* being “straightforward” and “very understanding of where I am coming from”.

1. Decision makers also noted what did not work in selecting supporters or in providing support, indicating inconsistent application of supported decision making principles among supporters:

It would have been very helpful had they listened to what I wanted. [DM2]

I like when they give me advice but I don’t like when they tell me what to do. [DM23]

1. All the decision makers reported that it was very useful or useful talking to the program staff about the supports they needed to make decisions about their money, for example:

At first I wasn’t sure, but now I feel more confident about getting more advice from you guys as you know what you are talking about. [DM31]

1. Program staff indicated that sometimes their role in the project crossed over into that of a supporter, for example when the chosen supporter was not present at a scheduled meeting and the facilitator supported the decision maker to make a decision.
2. Decision makers’ suggestions for future projects included having more group activities and getting to meet more participants, that the project could be longer and provide more information and that more organisations could be involved in the project, like government departments.
3. It appears effective support in this project included trust, responsiveness to the decision maker’s needs and circumstances, and access to relevant information. Building trust takes time, which needs to be recognised in supported decision making approaches. Responding to the decision maker’s needs and preferences requires flexibility in deciding who can be considered as an effective supporter. The decision maker’s consideration for choice of supporter also needs to include safeguards against potential conflicts of interest and financial abuse.

## Financial decision making authority

1. At the beginning of the project nearly all (14) of the decision makers indicated that they thought it was ‘very important’ to manage their own money, and this had increased to all 16 decision makers at the end of the project.
2. At the beginning of the project, nearly half (7) of the decision makers indicated that they were not happy about having a financial management order, four had mixed feelings and four reported that they were happy. While most decision makers had not changed their feelings about having a financial management order, nearly one third of the decision makers (5) reported a negative change in how they regarded their order (Table 18). These decision makers all reported that they were ‘not happy’ about their financial management order at the end of the project. This may be because gaining more financial literacy skills or confidence had created greater dissatisfaction with their lack of control or because the constraints of the situation became more apparent in the financial literacy training.
3. As reflected in Table 18, the decision makers reported diverse perspectives on having financial management orders. Around half of the decision makers who responded to the surveys expressed frustration at NSWTG processes. A few decision makers reported that they did not know how much money they had, and some indicated that they would like to know. One decision maker identified being under the financial management order as being attached to stigma:

It doesn’t look good to others to be under management. …Don’t want to be treated like a financial invalid. I want to be treated with dignity and respect. [DM27].

1. While less than half of the decision makers indicated that they appreciated the support and protection of the NSWTG, this too sometimes came with mixed feelings:

When I really needed them I appreciated them a lot but now I don’t really want them. [DM23]

Good thing but I don’t want it. It’s working for me but I hate the process. [DM27]

1. Decision makers talked about demonstrating the capability to save and manage bills to the NSWTG in order to support their case for a review of their financial management order. One decision maker used the project to expand their involvement in managing bills, while for another, it was part of the evidence used when their s71(2) was reviewed. In one case, a decision maker was given a three-month trial to manage more bills as part of the first step towards applying for an s71(2) and then revoking the financial management order.
2. Program staff provided decision makers and supporters with information and advice about NSWTG processes, and if necessary, referral to advocacy services or different support services. In one case, program staff facilitated a meeting with NSWTG, which resulted in the decision maker gaining access to more of their funds and a trust account for bigger purchases.
3. Decision makers had a range of reasons for wanting to revoke their financial management orders. One was that they did not wish to engage with NSWTG, another that it was too restricting, and others felt that they had the capability to manage their own affairs but did not know how to go about the process of revoking the financial management order. As one supporter indicated, it was less that the project helped to make the decision but rather that it helped the decision maker implement the decision. As the decision maker states:

I am grateful for the information that you [project worker] provided on dealing with the Trustee and the information you provided to the tribunal on my involvement in the project. It helped to get rid of the Trustee…It was good to get information on what I needed to do to change my situation and to have my sense of dignity and citizenship recognised. [DM15]

1. A key goal for a few decision makers was to revoke the financial management order, and when this was achieved they exited the project early. In one such case, the decision maker reflected on the effect of not making financial decisions on a habitual basis and said:

Now I have to do things with my money like deal with my investments and bills which the Trustee used to look after, I am learning more just by doing it. I guess if you don’t have to do it you don’t need to remember how to do things and you either don’t learn or you forget. [DM21]

1. In summary, most decision makers in this project wanted more responsibility over their finances, and for many this was the reason they agreed to participate. Some achieved their goals, and often this happened because program staff intervened with the NSWTG on the decision maker’s behalf, for example by arranging a meeting, facilitating direct communication, or clarifying the decision maker’s situation and needs to NSWTG. The successful advocacy provided by the program staff suggests that access to NSWTG processes could be improved. Promoting supported decision making is consistent with the provisions under section 39(b) of the NSWTG Act 2009 (section 2.2)

## Relationship with NSWTG

1. At the beginning of the project seven decision makers reported confidence in contacting the NSWTG about money and financial matters, and the same number reported little or no confidence (Table 19). Reasons expressed for lacking confidence included logistical factors, like not knowing who to call, and negative previous experience:

The Trustee makes me feel like I’m stupid and that I can’t spend my money wisely. [DM 20]

1. Levels of confidence to contact the NSWTG were the same for most of the decision makers at the end of the project, while three reported increased confidence (Table 19). A few decision makers who reported confidence in contacting the NSWTG noted frustrations with organisational processes in that:

You have to wait a long time to talk to someone. [DM26]

Don't like talking to a machine and that is all I get when I ring up. [DM12]

1. Several decision makers requested support from the project in negotiating with NSWTG as they had found it difficult to get responses from the agency on their own.

Similar to the statements about confidence, five decision makers described their relationship with NSWTG as good at the beginning of the project, four said it was not good and the other seven variously described it as mixed, indifferent or average (Table 20). The majority of decision makers reported no change in their relationship with NSWTG in the course of the project, while two said it had improved and one, that it had worsened (Table 20).

1. Relationships with NSWTG are mediated through client services officers (CSOs), and decision makers reported both positive and negative experiences with the CSOs. In one case a request from the decision maker to meet with the CSO was declined, and a few decision makers and supporters expressed frustration with having different CSOs respond to their queries and not being able to meet personally with them, for example:

Sort of happy as they pay the bills but I would like to be able to meet my client services officer and we could sit down and talk about things. [DM20]

The Trustee’s not very good about giving out any money for anything. … They’re not always easy to deal with and they have this very difficult situation that every time you go to them there’s some new person in charge of your account. … I don’t know how [decision maker] would deal with them on her own. I don’t know how she’d get started with them. It’s a very difficult process to deal with the NSWTG. [S5]

1. In contrast, one decision maker, who had a good relationship with their CSO, felt the project provided the opportunity to examine their financial management order more closely, and they decided that they were happy with the current situation, which involved managing small amounts of their money but not all:

I like managing what I have but I am glad that the Trustee manages the rest. It would be too much for me if I had to look after everything. [DM33]

1. Other project work and research has been about supported decision making in general, not specifically about financial decision making. The NSW system separates substituted financial decision making from other areas of guardianship, and therefore the focus of this project on financial decision making offered an opportunity to identify barriers that people experienced when dealing with the NSWTG. The data indicates that decision makers’ relationships with NSWTG were mixed, depending on their circumstances and their relationship with their CSO.

## Summary of outcomes for decision makers

1. This project revealed that three quarters of decision makers (12) found the financial literacy training useful in giving them new skills and information. While few reported a marked increase in confidence in managing financial issues, almost all decision makers (14 out of 16) valued the information provided by program staff and supporters during the project. The majority expressed a desire to take on more financial responsibility or to have their financial management order revoked. While about half reported effective relationships with NSWTG, others expressed difficulties in contacting relevant staff or obtaining financial decisions.

# Outcomes for supporters in the FDM Program

1. This evaluation also considered how effective the SDM2 project was in:

* increasing the capacity of the community to assist people with cognitive impairment to make their own decisions.

1. In this section, the analysis focuses on the outcomes for supporters of the decision makers in the project, as a proxy for community outcomes. The data used to explore this question was based on the entry and exit questionnaires for supporters and, where available, the entry and exit interviews with them. As outlined in Table 1, eight supporters provided responses to entry questionnaires and seven to the exit questionnaires. Interviews were conducted with three supporters at the beginning and six at the end of the project. The small sample size of supporters should be borne in mind when interpreting the comments outlined in this section.
2. As noted in section 5.1.3, decision makers had a range of reasons for choosing their supporters, and they also had different types of relationships with them. This section reviews supporters’ perspectives on what contributed to and was challenging in effective support practices and outcomes for decision makers. The section also explores supporters’ experiences in learning about NSWTG processes, their use of, and perspectives on, the project resources and suggestions for future projects.

## Identifying effective support practices

### Successes and challenges

1. Supporters outlined a range of reasons why they thought they had been chosen for the role, including trust, rapport and pre-existing support relationships. When asked about their views of their role in supporting decision making, supporters generally provided a response within a person-centred approach, saying that they were to: educate decision makers about their rights and empower them to make decisions, ‘believe in them to find their own answers’ and offer them the opportunity for making gradual changes and dignified risk taking. A practical aspect of their role included contacting the NSWTG on their behalf.
2. Supporters had a range of views as to what worked and was helpful in providing support for financial decision making. Recurring themes were:

* providing information about choices and options and explaining the consequences of different choices
* regular communication that was respectful, honest and non-judgmental, for example, ‘life coach-style questions around decisions to help [the decision maker] arrive at [their] own conclusion’.
* listening carefully and asking questions in different ways to ensure that there was a consistent answer
* consistent reminders and prompting about decisions
* adequate time for decision makers to reflect on decisions
* approaches and activities that fostered confidence, including setting short-term goals so that decision makers could experience success
* tailoring goals to interests
* the use of practical examples and the need for practical information, such as how to deal with NSWTG and other agencies
* practical experience for decision makers, such as going to banks or shopping, and supporting decision making in those environments.

1. Challenges reported by supporters in providing the support included:

* being very busy and lacking time to provide support
* experiencing conflicts of interest and managing those by careful and transparent accounting practices and possibly by having a team of supporters
* managing the anxiety levels of decision makers around financial practices and decisions
* assisting the decision makers to see the full picture
* being concerned about risks in decision making.

Supporters also indicated that if they were concerned about decisions, they would aim to try to put safety provisions in place:

That’s a difficult one isn’t it because there’s always that balance between it’s their money and obviously you want to keep them safe. [S16]

1. While supporters did not indicate that their views about what made effective support changed as a result of the project, a few had clear views of what effective support entailed:

Someone who’s not going to actually tell them what to do. Let them make their own mistakes…. Just give him all the tools – give them the tools that they need, and then ultimately let them make the decision. [S13]

Part of developing a good relationship with my clients is being able to challenge them on some of their choices so that if I think that a choice or decision presents problems I will tell them, but in the end it is for me to act on what they want. [S15]

1. One outcome of the project seemed to be an emerging awareness among supporters of the value of setting up a network of supporters around the decision maker, for example among support staff. This might involve advising staff of aspects that they could remind the decision maker about in their day-to-day interactions. One of the challenges related to continuity of support in group homes and other situations where staff changed according to shifts.
2. Another concern raised by supporters – both family members and service workers – was around what happens when the supporter leaves and someone else is required to take over that role. One supporter talked of referring the decision maker:

to a financial counsellor who provides literacy training primarily so he has a connection with someone to whom he can talk about his finances in the future. [S15]

### Awareness of decision makers’ capabilities

1. While most supporters indicated that there had been no change in their relationship with the decision maker as a result of the project, others noticed changes that they attributed to the project, for example:

Yes, he is more inclined to come and chat about what he would like to do with his savings. [S13]

I think the project maybe made it [the relationship] a bit stronger. I think it got stronger. Because I did actually leave most of the work to [decision maker] for her project except a couple of times she had to come in with her homework and that was fine, she just asked me and I just helped her. [S30]

1. Supporters indicated that they learnt new things about the capabilities of the decision makers, which made them reflect about their own practices:

I was really surprised at what [decision maker] actually knew about money. I didn’t think he had any concept at all about money. … I think I learnt more about [decision maker] than the project, to be honest. [S13]

Being part of the project and seeing [decision maker] being asked questions around how he manages his finances and how I support him with his finances has made me reflect on my practices more and if there is more I can be doing to support [decision maker] and my other clients too. [S16]

## Learning about NSWTG processes

1. Supporters were interested in gaining a greater understanding of how to support people in their relationship with NSWTG. Supporters generally commented positively on the role of program staff in providing information and support, especially in relation to NSWTG processes and facilitating communication with NSWTG:

It was useful in gaining an insider understanding to [NSWTG] particularly of the new structure, finding out who to speak to in [NSWTG] and getting assistance at negotiating their processes. I’ll use that info again in future cases where I need to negotiate on behalf of a client who has [NSWTG]. [S15]

1. Supporters also identified the need for decision makers to have advocates to help negotiate the complex processes involved in managing their finances, including their relationships with NSWTG. Similar to the decision makers, several supporters expressed frustration in dealing with NSWTG. One supporter had interpreted the role of the project as one of advocacy:

I mean the purpose of this project my understanding was that they would work as our advocate to approach the guardianship which they did. They facilitated the meeting. Without that meeting nothing would have happened. [S12]

1. Other supporters who were service workers but also potential advocates identified the conflict of interest in their relationship with the decision maker:

I'd love to advocate for her and to try and somehow find out how much … money she has. I don't think that's something I can do, I think I need to talk to [manager]… Yeah it's a bit difficult, because I don't know if I'm allowed to know how much money [decision maker] has. [S7]

## Project resources

1. Among the seven supporters who responded to the exit questionnaires, four did not engage with or use project resources, while the three other supporters did. The latter indicated the resources were useful. They would use the resource kit with other clients in the future, and they wanted to be informed about future workshops:

I think I can take a lot from the project and help other customers in strategies to help them save money and work towards their goals … because they have a disability, a lot of people turn around and say, “He can’t manage his money.” And it’s like… no – I would daresay half the people who have their money managed could learn how to manage their money, and how to save … [S13]

## Suggestions for future projects

1. Suggestions for improvements for future projects from supporters included that some supporters believed more training sessions would have helped their decision makers, while others suggested more group activities and workshops. Following up the one-on-one financial literacy training with written materials could also assist some decision makers. Other suggestions included some structured support for supporters and perhaps shorter training sessions for some decision makers.
2. An additional comment about future projects was that it would be beneficial for decision makers to have support and training around negotiating with banking institutions and with the NSWTG.

The training would have to be - particularly we’re talking about the Public Trustee here - … that they are able to have a conversation with somebody and tell them their needs, what the money is required for … I’d like to see it perhaps taken a bit further as I said, so that they actually go to the financial institutions and deal with the person … and then seeing how they handle it. … it’s all about the practicality of it that really works. [S5]

## Summary of outcomes for supporters

1. While most supporters indicated that their views about what made effective support had not changed as a result of the project, they outlined factors that contributed to or hindered good support relationships. The project also provided them with the opportunity to think more broadly about networks of support and ongoing support arrangements. A few supporters noticed changes in their relationship with the decision maker that they attributed to the project. These changes included improved relationships with the decision makers and a greater awareness of the decision makers’ capabilities. Supporters found the program staff helpful, especially in providing insight into NSWTG processes and facilitating communication with NSWTG. Supporters also highlighted the need for advocates for decision makers, and some supporters indicated they would use the project resources for other clients in the future.

# Implementation of the FDM Program

1. The FDM Program recruited people with cognitive impairments who had financial management orders (decision makers) along with their chosen supporters and worked with them to increase the capacity of the decision makers to make independent financial decisions. This section reports on the successes and challenges in implementing the project and how staff addressed the challenges. The process analysis below is based mainly on evaluation interviews with FDM Program staff and an observation log compiled by staff. This data was complemented and triangulated with qualitative data from project participants and the evaluators’ observations.

## Planning of the FDM Program

1. All program staff were experienced in working with people with disability and had worked in SDM or as Guardians. Project implementation included the following steps:

* recruitment of participants with financial management orders using NSWTG client files
* discussion with participants about choice of supporters for the project and discussion with chosen supporters
* provision of a resource kit and other relevant information to support the SDM process
* definition of program staff roles in supporting participants through the project
* identification of financial literacy programs which were relevant and accessible to decision makers
* development of entry and exit questionnaires for participants and supporters.

1. While the planning was carefully undertaken, with successive steps, one staff member commented that a more action research-based form of planning may have been useful. Such an approach could have enabled more flexibility and learning from early stages of the project to then be used in its implementation. They felt this would have been particularly appropriate given the short time frame of the project.

## Recruiting decision makers and supporters

1. Recruiting decision makers from assessing NSWTG client files and then contacting people who met the project criteria proved more time-consuming and less effective than program staff had anticipated. In part, this was due to the restructure of NSWTG, which meant that there was limited opportunity to engage staff in the project.
2. As in some previous pilots (Appendix A), the SDM2 project encountered difficulties in finding people who were interested in participating. Whenever individuals did express an interest, meetings and discussions were held to explain the project and to choose a supporter. This often took several weeks and only sometimes led to participation.
3. The project team then tried a different recruitment strategy, approaching organisations providing services to people with cognitive impairments to see if clients might be interested. Again, this proved time-consuming, and while senior managers in some organisations showed interest, staff on the ground seemed more difficult to engage because of time constraints and concerns about possible conflict of interest. Workshops on SDM with staff and encouragement to become involved had little success.
4. As a result, fewer people than expected became participants in the project. One program staff member commented that, in retrospect, it may have been more productive to base the project in service organisations, which would also have allowed capacity building within the organisation and the promotion of a stronger SDM culture.
5. About one-third of decision makers exited early from the project. Reasons included difficulties with maintaining contact between program staff and decision makers, precarious housing arrangements, mental illness, a family or personal crisis, lack of time to participate in the project, or gatekeeping by supporters or family members. Some exited early because they had achieved their project goal to get their financial management order revoked.
6. The project also encountered difficulties in finding supporters. When the person chosen by the decision maker was a service provider, the supporter or their organisation sometimes voiced concerns about potential conflict of interest. In one instance, a service stated that their policy would not allow staff to become involved in decisions about the finances of their clients. Another issue with paid staff as supporters was that staff might change roles or leave their employment, interrupting the continuity of the support relationship. This happened several times in the project.

## The nature of financial supported decision making

1. Program staff commented that financial supported decision making could be more fraught than other types of decision making, due to, for example, anxiety about managing finances, concerns that the ‘right’ decisions were expressed, possible conflicts of interest, and the difficulties of implementing decisions even when they had been made.
2. Program staff found that some supporters were concerned about their role because money was involved and also because their expectations of the decision maker about financial knowledge and capability to make decisions were low. More time than the project allowed was often needed to work with both the decision maker and their supporter to adopt SDM practices.

## Provision of resources to support financial SDM

1. While staff developed and provided a resource kit about SDM to supporters and decision makers, all program staff agreed that individualised resources were also needed. Program staff considered face-to-face engagement and phone contact with decision makers and supporters, as well as the teaching and mentoring provided, as primary in conveying knowledge and learning about SDM, and written resources as secondary. Decision makers and supporters needed resources primarily for practical information to deal with NSWTG, banks and other agencies.

## The role of program staff

1. As in some previous projects on SDM (Appendix A), the role of program staff was important. Staff found that they needed to have face-to-face conversations with both supporters and decision makers and that these conversations proved useful both in changing attitudes of supporters towards decision makers and in increasing the decision makers’ awareness of their rights.
2. Program staff also found that they performed an advocacy role at times, particularly in discussions with NSWTG on the decision maker’s behalf. Since program staff knew the NSWTG system and culture, they were able to undertake negotiations that would have been difficult for the decision maker or supporter. Program staff attempted to engage advocacy services, but their involvement was constrained by a lack of resources.
3. These experiences indicate a need for individuals or organisations to undertake a facilitating role in developing financial SDM capacity on a personal level and in supporting contact with government agencies such as NSWTG.

## Summary of FDM Program implementation

1. The FDM Program component of the project provided some effective support for participants, although program staff felt that more could have been achieved with more time. The pilot revealed challenges of developing a financial supported decision making project. These included difficulties in recruiting people with cognitive impairment using NSWTG files and problems in finding supporters. The importance of program staff in providing advocacy and intensive face-to-face support to decision makers and supporters was evident.

# Implications for individual FDM support

1. SDM is an important factor in the implementation of the UNCRPD and the achievement of rights, choice and control for people with disability. Financial SDM is particularly important because other life decisions rely on the capability of individuals to decide how their financial resources are used. The SDM2 project involved a financial SDM pilot with people with cognitive impairments who had financial management orders, the FDM Program. Since this was one of the few projects so far focussing on financial decision making, the findings from the evaluation provide important evidence and implications for future work in financial SDM.
2. **Accessibility of NSWTG processes:** The evaluation findings indicate that processes relating to financial management orders could be made more accessible to people with disability. Many decision makers and supporters in the FDM Program found it difficult to speak to people in NSWTG, and they often did not know what they needed to do to have their request responded to. Moreover, participants did not always have the necessary information about their financial situation, nor did they always understand their rights and responsibilities. In the project, supporters and decision makers requested assistance to advocate with NSWTG to communicate their needs and receive a response. The evaluation findings show that NSWTG could streamline communication mechanisms and develop more transparent processes for the benefit of its stakeholders.
3. **Involvement of NSWTG:** The FDM Program occurred while NSWTG underwent a major restructure of its staffing and service delivery model, which limited the capacity of NSWTG staff to engage with the project. The SDM training for NSWTG staff intended as part of the project did not occur, although development of content for such a course in collaboration with NSWTG began before the project finished. The findings of this evaluation indicate that the project would have benefited from deeper engagement of frontline NSWTG staff. The project experience also indicates that engagement of NSWTG staff with the principles of SDM (to promote capability and autonomy) is critical in increasing the likelihood that people with a financial management order will take on more responsibility of their affairs. The implication is that training might be developed for NSWTG staff to incorporate the principles of SDM into practice. Such training, engagement and the embedding of SDM into NSWTG processes would be important for the implementation of the UNCRPD focus on SDM.
4. **Role of facilitators:** As in previous pilots on SDM, the importance of the presence and support of program staff, in this case from the Public Guardian, was acknowledged. Program staff provided written resources to supporters and decision makers throughout the project. While these were of some assistance, qualitative findings indicate that people learned more from face-to-face conversations and interactions. This was time-intensive for program staff, and at the completion of the project it was uncertain how this form of support could be offered on an ongoing basis. It appears from the evaluation findings that developing a trusting relationship with the decision maker and being able to translate financial decision making intentions into practice does require ongoing support and in some instances advocacy. Program staff felt that the current service sector was not in a position to provide ongoing support of this nature. While advocacy, financial literacy and NDIS-funded services all may have a role in promoting capability development and autonomy of people with disabilities, those services would be unable to provide the open-ended involvement that may be required. The project showed there is a need to determine what facilitation will look like for SDM in the future and how it will be resourced.
5. **Providing opportunities for decision making:** The project showed that people with cognitive impairment can increase their capabilities in making financial decisions when given the opportunity to gain knowledge and skills. It also seems important that they have the opportunities to use newly acquired skills in practical situations, e.g. at the bank or while shopping, in order to reinforce their learning. The project activities also increased some supporters’ awareness of the decision maker’s capability.
6. While such success may require intensive project engagement, this appears worthwhile as people might gain more choice and control and require less restrictive financial management orders. The findings indicate the importance of NSWTG providing opportunities for people with orders to manage parts of their estate in concert with skill building. S71 authorities are mechanisms to do just that, and chances for people to make use of this mechanism could be optimised.
7. **Choice of supporters:** The project decided to enable decision makers to choose their own supporters. They chose mostly family members or trusted service providers, which indicates the sensitive nature of financial decision making and the small networks of some people with disability. The project revealed tensions with both choices, mostly around potential conflict of interest. Some family members felt uncomfortable in supporting their loved one to make financial decisions; they held particular views about their family member’s capacity to make decisions, or they were concerned about a future conflict of interest. This latter issue also applied to service providers who became supporters. Other issues brought up by service providers included shortage of time and lack of consistency or continuity in staff availability.
8. This project, similar to other pilots, found the recruitment of supporters difficult. Developing a group of people with financial expertise and who are available to lend financial decision making support may provide a solution to some of the conflicts experienced by supporters in this project. However, the project also indicated that advocacy services were constrained by resources. It seems that funding for the role of financial supported decision making is important to ensure the availability of SDM for people who lack other support options, especially in light of the implementation of the NDIS. There appears to be a role for NDIS funding for this purpose.
9. **Financial literacy training:** People with disability participating in the project found the financial literacy training highly valuable. There appears to be a need for this form of training to be readily available and accessible as it might help people to learn relevant financial skills and exercise more choice. Project experience showed that the financial counselling and literacy sector provides mainstream financial literacy services that some people with cognitive impairment may be able to access, but there were few financial literacy programs specifically targeted at people with cognitive impairment. Program staff found that specialised providers already struggled to deal with the demand for their services. The experience of the FDM Program indicates that the financial literacy sector needs to develop further to meet the demand for skills development of people with cognitive impairment, and that recognising financial skill development in NDIS packages would be beneficial. Additional training in financial literacy for supporters would provide a safeguard for both parties given the sensitivity of financial issues.

# Part B: The Training Program and its implications

# Training Program overview

1. This section provides an overview of the Training Program, specifically its intended outcomes and its activities.

## Intended outcomes of the Training Program

The intended outcomes of the Training Program were that:

* Non-government organisations providing support to people with disability in NSW are able to deliver decision making support to people with disability and have clear guidelines against which to measure their performance.
* People and organisations providing decision making support form and maintain a ‘community of practice’ to continue to support and develop supported decision making practice and knowledge.

1. A detailed table of outcomes and indicators is in Appendix B.

## Training Program activities

1. The Training Program component of the SDM2 project was delivered by a team of three full-time staff, comprised of one project manager and two project officers. The Training Program worked with service providers to increase their awareness and capacity around supported decision making, mainly through a one-day training workshop delivered around the State and regular meetings of the Community of Practice (CoP) group. The CoP group was established in Sydney, as a forum for peer support and networking around SDM. Non-government disability support providers and disability advocacy organisations took part in all activities, while the CoP also included members from NSW Government departments and agencies. Additional Training Program activities were: short information sessions, the development of a suite of SDM resources, and a Train the Trainer workshop.

# Methodology for Training Program evaluation

## Training Program evaluation questions

1. Considering the goals of the SDM2 project and its program logic model, the Training Program evaluation aimed to answer the following questions:
   1. How effective was the SDM2 project in increasing the capacity of service providers to assist people with cognitive impairment to make their own decisions?
   2. What are the implications for efforts to embed SDM within the policy and practice of support organisations?

## Data collection and analysis for Training Program evaluation

1. The evaluation used the following data sources to assess project outcomes for service providers: feedback surveys from the training sessions, reports of CoP activities and attendance, observation of a CoP session, and focus groups with CoP members. Interviews with program staff provided contextual data. Sample sizes are in Table 2.
2. The perceived impact of the supported decision making training workshop was evaluated through a brief, anonymous training feedback survey. Training Program staff designed the survey with advice from the evaluators and administered it at the end of the one-day training workshops. The survey asked participants how useful they found the training in assisting them to understand and incorporate supported decision making into their own practice and, where relevant, their organisation’s policies and procedures. Training participants could also suggest changes or additions to the training.
3. Regarding the CoP, program staff provided reports of the group’s activities and attendance to the evaluators. In February 2017, the evaluators observed a regular meeting of the SDM Community of Practice group. As part of the meeting, the evaluators conducted focus groups with the participants about how successful this initiative had been in developing supported decision making practice and knowledge. Due to the size of the meeting, two focus groups were held simultaneously, with 16 participants in total.
4. Two of the Training Program staff members took part in in-depth, qualitative interviews with the evaluators at the end of the project about their views of the project, its achievements and challenges, and implications for future, similar projects.
5. Table 2 Methods and sample sizes for the Training Program evaluation

|  |  |  |
| --- | --- | --- |
| **Method** | **Program staff (N=2)** | **Service providers (N=3871)** |
| Interviews | 2 |  |
| CoP focus groups |  | 16 |
| Training feedback surveys |  | 328 |

1 number of service providers who participated in the one-day training workshop

1. Qualitative data from all methods were analysed thematically with reference to the evaluation questions. Quantitative survey data were analysed using Excel and SPSS, and data from the various sources and research methods were triangulated where possible.
2. The evaluation of the Training Program was a secondary focus of the research and therefore involved less data collection and analysis than the evaluation of the FDM Program. Due to practical reasons and resource constraints, program staff administered the training feedback survey and subsequently provided the collated data to SPRC for analysis. SPRC verified the data collation by checking against the completed surveys. Quality control also occurred through regular phone conversations between program staff and SPRC evaluators and triangulation of data collected by both teams.

# Training Program activities and participants

1. Training Program activities reached hundreds of service provider organisations and staff across NSW (Table 3). The centrepiece of the Training Program component of the SDM2 project, the one-day ‘Introduction to SDM’ workshops, was delivered according to requests. Some workshops were offered to individual providers, others in specific locations so representatives from various organisations could attend. In total, 20 workshops were attended by 387 people from 99 organisations.
2. Most information sessions about SDM were held at the beginning of the project, with staff testing training formats and materials. The sessions lasted between 10 minutes and three hours, and many were held at provider forums organised by National Disability Services (NDS), the peak body for non-government disability service organisations. Experiences and feedback from information sessions resulted in the design of the one-day workshop. ‘Train the Trainer’ built on the ‘Introduction to SDM’ workshop and was targeted at providers who wanted to deliver the SDM training to other workers or to families.
3. Locations of Training Program activities were diverse, with a good proportion of sessions held in regional centres: Coffs Harbour, Orange, Wagga Wagga, Ballina, Gilgandra, Grafton, Shoalhaven and Wollongong.
4. Table 3 Training Program activities

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| 1. **Type of training activity** | 1. **Location** | 1. **Number of sessions** | 1. **Number of organisations by:** | | 1. **Number of participants by:** | |
|  |  |  | 1. **Location** | 1. **Activity type** | 1. **Location** | 1. **Activity type** |
| 1. Information sessions | 1. Metro | 1. 13 | 1. 186 | 1. 442 | 1. 673 | 1. 12701 |
| 1. Regional | 1. 10 | 1. 256 | 1. 597 |
| 1. Introduction to SDM workshops | 1. Metro | 1. 12 | 1. 40 | 1. 99 | 1. 230 | 1. 387 |
| 1. Regional | 1. 8 | 1. 59 | 1. 157 |
| 1. Train the Trainer workshops | 1. Metro | 1. 1 | 1. 9 | 1. 19 | 1. 13 | 1. 24 |
| 1. Regional | 1. 1 | 1. 10 | 1. 11 |
| 1. **Total** |  | 1. **45** | 1. **560** | | 1. **16812** | |

Source: PG program data until 31 December 2016; 1 There is likely double-counting as people would have attended both a 10-minute information session and a 2-hour workshop at the NDS provider forums; 2 The actual number is likely smaller due to double-counting at the information sessions, and also because people may have attended an information session, an introduction workshop and/or a train the trainer workshop.

1. Initial invitations to the Community of Practice group went to known providers in the field, but anyone with a professional interest could join. The group met every two to three months in Sydney, a total of five meetings between May 2016 and February 2017. Commonly, more than 20 people attended, mostly from the metropolitan area but also from surrounding regions. The group was diverse, including NGOs that were community service providers or specialist disability providers, advocacy organisations, Aboriginal service providers, university researchers and government agency representatives.
2. Meetings were organised and facilitated by Training Program staff and originally scheduled for two hours but increased to three at the request of the CoP members. Each meeting included project updates, sharing of news and events, opportunities for networking, and a focus on an SDM practice topic such as supporter engagement, reflective practice or communication support. The CoP group also started an online forum to enable communication among members between meetings.

# Outcomes for service providers in the Training Program

1. This section considers the evaluation question for the Training Program outlined in section 10.1.

## SDM training workshops

1. The one-day training workshop titled ‘Introduction to Supported Decision Making’ was the Training Program’s main activity. It was intended to give workshop participants a basic understanding of key SDM concepts as well as strategies for how to apply the concepts and address challenges. It included discussions about decision making principles, rights, steps and a practice framework, SDM strategies and communication support, and practical case studies.
2. Of the 387 people who attended the one-day training workshop, 330 – or 85 per cent – completed a feedback form. Their ratings were overwhelmingly positive (Table 4). In each question, more than half chose the highest possible score, and more than a further one-third chose the second-highest score. Conversely, in each question less than 10 per cent of participants ticked any of the two lowest options.
3. Table 4 Training feedback survey responses

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1. **Responses** | 1. **Questions** | | | | | | | |
|  | 1. Was the training relevant to your work? | | 1. Did it increase your awareness and understanding of SDM concepts? | | 1. Did it increase your understanding of SDM strategies and processes? | | 1. Will you likely apply it to your practice? | |
|  | 1. N | 1. % | 1. N | 1. % | 1. N | 1. % | 1. N | 1. % |
| 1. 11 | 1. 0 | 1. *0* | 1. 1 | 1. *0* | 1. 1 | 1. *0* | 1. 0 | 1. *0* |
| 1. 2 | 1. 2 | 1. *1* | 1. 18 | 1. *5* | 1. 18 | 1. *6* | 1. 1 | 1. *0* |
| 1. 3 | 1. 35 | 1. *11* | 1. 110 | 1. *33* | 1. 125 | 1. *38* | 1. 34 | 1. *10* |
| 1. 4 | 1. 122 | 1. *37* | 1. 201 | 1. *61* | 1. 183 | 1. *56* | 1. 124 | 1. *38* |
| 1. 5 | 1. 171 | 1. *52* | 1. N/A | | 1. N/A | | 1. 170 | 1. *52* |
| 1. **Total2** | 1. **330** | 1. ***100*** | 1. **330** | 1. ***100*** | 1. **327** | 1. ***100*** | 1. **329** | 1. ***100*** |

Source: PG program data until 31 December 2016; 1 Responses were on scales from negative to positive, with 1 being the most negative response, and 5 being the most positive. The answer scales varied between questions. Questions 2 and 3 had only 4 response options. 2 Percentages may not add up to 100 due to rounding error.

1. The answers to the open-ended questions in the feedback survey confirm that service providers found the training helpful for both their professional and their organisational practice. Many participants described how they would use what they had learned in the future, e.g. ‘listen and observe clients’, ‘apply principles to planning’, educate and support staff’ or ‘be unbiased and consistent’. General comments were almost entirely positive, praising the workshop as well structured and informative, and the trainers as engaging and friendly. Few people made critical remarks, such as ‘it’s a very long day’ or ‘too simplistic’. Some participants suggested improvements to the workshop, such as including more information on guardianship and legalities. Some asked specifically for more information on how to support families to shift their thinking or how to deal with cultural differences.
2. Training Program staff said that some participants expressed concern during the workshop about how they could implement SDM within their organisations given time and resource constraints. But the trainers also received positive feedback where participants had used selected material from the workshop to train staff, or they had modified their practice in unanticipated ways.

## Community of Practice

1. The Community of Practice (CoP) group had been intended as a forum for practitioners to exchange ideas, resources and information, to provide mutual support and to build SDM knowledge and capacity in the sector. These aims seem to have been achieved for those who participated. In the two focus groups conducted for the evaluation, CoP members were unanimous that they enjoyed and valued:

* the networking opportunities at the meetings
* sharing resources, such as SDM tools
* peer support, such as discussing their practice challenges and strategies
* developing SDM knowledge together.

1. For example, one CoP member said:

I’ve felt that two years ago anybody in this space was very isolated, and it was hard to know whether you were heading in the right direction or not, or whether your challenges were similar to others’. So, I found [the CoP] extremely valuable …. It brought a lot of people together and growing together.

1. While the CoP seems to have helped members to develop their own SDM capacity, embedding SDM within their organisations sometimes appeared difficult. Many practitioners felt that they needed to effect a significant culture change among colleagues who were used to substitute decision making. CoP members said they used basic strategies such as asking colleagues to talk to the person with disability directly rather than their family member, or they workshopped with staff how to show the family member respect while letting the person with disability make the decision. One CoP member said they had updated internal processes to include SDM principles, for example letting young adults sign consent forms themselves rather than parents on their behalf. Some CoP members wanted more training for their organisation and had asked the CoP facilitators to come and deliver their one-day SDM workshop.

## Summary of outcomes for service providers

1. Findings across the various data sources are consistent, indicating that service providers found participating in the training and in the CoP group increased their capacity to assist people with cognitive impairment to make their own decisions. A large majority of workshop participants said the information was relevant to their work, increased their awareness and understanding of SDM concepts and strategies, and that they were likely to apply the training in their practice. CoP members appreciated the networking, peer support and information sharing opportunities of the group. Embedding SDM within organisations appears to be a longer term process, involving practice changes and more training for staff to shift from substitute to supported decision making.

# Implementation of the Training Program

1. The Training Program staff developed separate implementation strategies for the training component of the SDM2 project, which encompassed SDM training workshops and the CoP group. The implementation strategies were intended to maximise project resources, utility for service providers and impact of the training within the short timeframe of the project. The process analysis below is based on evaluation interviews with Training Program staff as well as CoP focus groups and observations conducted by the evaluators, complemented and triangulated with qualitative data from training feedback surveys and the evaluators’ observations.

## Implementation of the SDM training workshops

1. Implementation strategies for the training workshops involved:

* broad initial consultation with experts and agencies in the field, including service providers and advocacy groups – to establish need within the sector and capacity of staff to attend, and to clarify the scope of the training (46 consultation interviews and five group consultation sessions were conducted)
* testing training formats, components and materials – during the information sessions and short workshops, and during consultations
* rollout of the one day ‘Introduction to SDM’ workshop across NSW
* maintaining flexibility in training format and delivery – e.g. when requested, deliver short information sessions rather than the full workshop or deliver the one-day workshop over two days; stagger delivery in the regions to be outside the immediate NDIS rollout phase when service providers would be saturated with information
* developing the ‘Train the Trainer’ workshop – to help extend SDM practice within organisations or to families, and create sustainability
* collaboration with the financial SDM part of the project – while both parts operated separately, regular meetings provided opportunities for sharing experiences and resources; and Training Program materials were used to inform supporters about SDM principles
* providing learning resources for wider use – e.g. as part of a TAFE course or an NDS e-learning package
* promoting SDM principles within Government agencies – e.g. deliver the workshops to Public Guardian staff and develop an e-learning package for NSWTG staff in the future.

1. It appears that these strategies were successful. Given the strong interest in training courses (section 11) and the positive feedback from participants (section 12.1), the workshops seem to have engaged the sector and raised awareness of SDM. Staff felt that the long initial consultation period and testing of workshop materials and formats had paid off, leading to an unexpectedly high demand for the ‘Introduction to SDM’ workshop. This high demand prompted a six-month extension of the project.
2. Staff dealt with several challenges in implementing the workshops. Private guardians and financial managers had been among the intended target groups, but their response to invitations was negligible. Program staff instead tried to reach them in other ways, for example through NSWTG and Public Guardian newsletters. Discussions occurred about developing an e-learning package or conducting a webinar for Private Guardians as they are dispersed throughout NSW. Staff anticipated that this initiative would be acted upon by the Information Support Team at the Public Guardian.
3. Similarly, the Training Program had intended to train NSWTG service centre staff in SDM, but this was not taken up as anticipated. Program staff thought the reasons were disruption within NSWTG due to its restructure as well as staff and time constraints. The Training Program was developing an e-learning package for NSWTG staff on SDM and how it relates to their work as substitute decision makers, complemented by a face-to-face session with the staff. This work was planned to be continued by the NSWTG Learning and Development arm and the Public Guardian’s Information Support Team after the end of the project. The e-learning package may also be made available to Private financial managers with relevant modifications to content. Program staff anticipated this training would be rolled out in July 2017.
4. Other challenges for the Training Program related to transferring SDM knowledge to different locations and support needs. Within the project’s time and resource constraints, staff managed to hold the ‘Introduction to SDM’ workshop in several regional areas, attracting high attendance. Mental health and aged care providers showed interest in receiving SDM training, and while there were not enough resources to adapt the training from its original focus on people with cognitive impairment, the Training Program team collaborated with the Mental Health Coordinating Council (MHCC) and addressed mental health and ageing issues as much as possible in the workshops.

## Implementation of the Community of Practice

1. Implementation of the CoP involved setting a clear purpose, inviting organisations who program staff knew were operating in the field, and at the first meeting establishing terms of reference, which were based on discussions among the group about its purpose and preferred format. Training Program staff organised and facilitated the meetings, but group membership and structure remained open and also changed over time. Meetings became longer upon member request (section 11), and membership fluctuated somewhat around a stable core group.
2. CoP members appreciated both the consistency of the core membership – which they said deepened relationships – and the flow-through of other organisations, which brought new ideas and information. The Training Program staff’s facilitation style was regarded as open and inclusive, and the resulting camaraderie was seen as an antidote to increasing competition among organisations.
3. The main limitation of the CoP appears to be its metropolitan focus. Setting up a CoP in regional areas was precluded by funding and time constraints of the SDM2 project. However, Training Program staff observed that connections among participants in regional areas had continued after the ‘Introduction to SDM’ workshop.
4. Sustainability of the CoP was a concern from the beginning as there would be no paid facilitator from the SDM2 project after June 2017. Training Program staff raised this issue from the first meeting onwards and discussed succession planning in the group in several meetings before the end of the project. When data collection for the evaluation ended in February 2017, the group was planning to have a rotating chair. The online CoP forum, which was established as a networking and information sharing tool, was also intended to help sustainability. To that end, it was hosted by one of the CoP members on their website.

## Summary of Training Program implementation

1. The Training Program seems to have developed successful implementation strategies, including broad preparatory consultations, tests of training materials and flexibility in delivering the training. A suite of training formats – including workshops, e-learning resources and collaboration with other agencies – appears to have ensured wide reach and relevance to different contexts.
2. The CoP was organised around its members’ preferences for content and format, which seems to have led to sustained engagement by a core group and visits from other service providers. The Training Program staff worked towards sustainability of the group from the beginning. With additional project resources, similar groups could be set up in regional centres.

# Implications for service provider training

1. **The need for service provider training:** The high demand for training in SDM reflects that service providers acknowledge the importance of SDM, the need for a shift in culture from substitute decision making and ‘best interests’ to enabling choice and control in the lives of people with disability and the need to be skilled in supporting client decision making. Interest in training was evident in both metro and regional areas.
2. **Sustainability of service provider training:** The introductory workshops on SDM were well attended and attracted positive feedback from participants. The Train the Trainer workshops offered opportunities for capacity building within organisations. Given the relatively short duration of this project, this kind of work might benefit from being made sustainable. The project indicates that a group of people who are skilled in SDM, have knowledge of the sector and can co-ordinate training and support for service providers would be helpful. The move by program staff to embed SDM in existing TAFE courses seems a positive step, but it would require further development to be fully effective.
3. Program staff expected that the Information Support Team at the Public Guardian would continue to roll out SDM training in a limited way. They hoped that, if future law reform results in a move from the Public Guardian to a Public Advocate, there may be more emphasis on community education to promote SDM.
4. **Community of Practice:** Participants valued the networking and information-sharing opportunities that the CoP group offered. Such a group seems an effective way to disseminate information and help service providers to build SDM skills and capacity. With the SDM2 project’s conclusion, and the consequent loss of a paid group co-ordinator, efforts were being made to continue the initiative. An investment in continuing the facilitation of the CoP group as well as setting up regional groups in the future would appear useful.

# Conclusion to SDM2 project evaluation

1. This evaluation sought to examine the effectiveness of the SDM2 project in relation to the SDM training offered to service providers and in relation to changes in financial decision making by participants in the pilot.
2. The evaluation of the SDM2 project aimed to ascertain the project’s effectiveness in relation to the following issues:

* supporting people with cognitive impairment to successfully manage parts of their estate, where possible
* enhancing the financial literacy of research participants with cognitive impairment
* increasing the capacity of service providers and the community to assist people with cognitive impairment to make their own decisions.

1. The evaluation findings indicate that time constraints and recruitment challenges limited the effectiveness of the FDM program component in supporting people with cognitive impairment to manage their finances. There was evidence that some people gained skills in setting priorities for spending, confidence in managing some of their financial matters and power in decision making. The evaluation showed that more time and advocacy would be needed for people to achieve changes in their financial management orders.
2. People who took up the opportunity to develop financial literacy skills found the training useful. The need for tailored and accessible financial literacy training was evidenced in the evaluation findings.
3. The high demand for service provider training and the positive response to the workshops during the project demonstrated that service providers have a need for developing skills and knowledge around SDM. This was confirmed in the positive development of the CoP.
4. Further, the evaluation aimed to explore the implications of the project in relation to:

* supporting people with cognitive impairment to make decisions about their lives
* efforts to embed SDM within the policy and practice of support organisations.

1. Regarding the FDM program component, there was evidence that both decision makers and supporters found the conversations and particularly the role of the program staff as facilitators useful. It is not yet possible to ascertain long-term effects of the pilot, but at the end of the project, decision makers did give consistent accounts of increased reflection about their finances and some evidence of increased skills and confidence in relation to financial issues. The project also demonstrated that some supporters had a positive attitude change in how they saw the decision makers’ capability to manage financial issues.
2. The training program and CoP success indicate demand by service providers to develop skills in supported decision making and a need to build capacity in service organisations. Embedding SDM training in TAFE courses seems to provide a sustainable way of developing such capacity, and a resource kit and an online information sharing forum were welcome initiatives that could be further developed.
3. The evaluation findings indicate an opportunity for the NSWTG to develop processes that are more accessible to people with disability and have a stronger emphasis on supported decision making. This intended part of the project could not be undertaken within its duration. However, the NSWTG already has opportunities to embed SDM principles in practice through use of mechanisms available in policy, such as s71 authorities.
4. Within the constraints of this project, some issues arose in relation to both SDM generally and financial SDM in particular. The evaluation evidence points to the need for a co-ordinating group that can promote and develop SDM with services, people with disability and families in NSW. This is particularly important in relation to financial decision making, which is fundamental to other life decisions.
5. The evaluation indicates that people with disability need the opportunity to obtain accessible and relevant information and training in financial decision making, and that supporters and advocates have opportunities to learn skills in SDM. FACS has taken the lead in NSW in promoting SDM and funds a range of projects. With the cessation of government disability services in NSW, there is space for a funded agency or service to take on the role of promoting SDM. This seems particularly relevant within the context of the NDIS implementation, as people with disability have increasing opportunities to exercise control and choice in their lives. Change takes time and resources but may be cost effective in reducing the workload of government organisations currently involved in SDM and financial management.

###### Literature review

1. This brief literature review has been prepared for the evaluation of phase two of the Supported Decision Making Project commissioned by the NSW NSWTG. It focuses on evaluations of Australian supported decision making projects and indicators of best practice. The review will inform the selection and design of data collection tools and provide a comparative reference for the findings of this evaluation.

Background

1. The background to both the initial SDM pilot and the SDM2 pilot is the recognition, both in Australia and overseas, of the importance of decision making support in the lives of people with cognitive impairment. While decisions were previously made largely by governments, services and families, people with disability now have increasing influence over the decisions that are made about them, for example through substitute decision making mechanisms. As well as daily decisions and lifestyle choices, already of critical importance in forging one’s life, the policy environment in Australia is changing, with increasing reliance on individualised funding and self-directed supports, especially in the context of the development of the National Disability Insurance Scheme (NDIS).
2. As a result, more people with disability can be in a position where they are making major decisions about large-scale and far-reaching issues impacting on their lives. People may need support for making such decisions due to intellectual disability, communication difficulty, acquired brain injury, stroke (Pachet, Allan, & Erskine, 2012), or mental illness (Gooding, 2013). Australian research has found significant deficits in appropriate and effective support for decision making (C. Bigby & Tait, 2004; Dowse, 2009; Fisher et al., 2010).
3. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) sets the framework within which the pilot is occurring. Article 12 enshrines the recognition of legal capacity for people with disability, with obligations on governments to ensure that people with disability will be supported to exercise their legal capacity. Any support mechanism should ensure that the will and preferences of people with disability are ascertained, their views heard, and their decisions reported and respected (Byrnes et al., 2004; Dinerstein; French, Dardel, & Price-Kelly, 2009; Kayess & French, 2008). Having ratified the UNCRPD, Australia has an international obligation to ensure this intent is translated into practice.
4. In accordance with these broad requirements, ADHC’s policy (ADHC, 2012) identifies issues relevant to supported decision making, such as the primacy of the client’s input into decision making, and the presumption of capacity unless there is a factual basis to doubt it, together with detailed procedures to be followed in the case of need for support.
5. Government trials of supported decision making projects have so far been or are being conducted in South Australia, the ACT, New South Wales (phase 1) and Victoria (Office of the Public Advocate, 2014). A trial has also been initiated in Western Australia. Queensland is undertaking significant work in the area but has not conducted a trial.

South Australia

1. The South Australian Office of the Public Advocate (OPA) conducted two trials of a rights-based model of supported decision making, either as an alternative to guardianship or for people who have a disability but where guardianship had not been considered (early intervention). The first trial (2010-2012) was supported by a single project officer and aimed to develop a model for decision making. A preliminary in-house evaluation of this trial was conducted (Office of the Public Advocate South Australia, 2011), followed by a final independent evaluation (Wallace, 2012). It was found that SDM could be used for decisions about accommodation, lifestyle and health decisions, acknowledging that these decisions could have financial implications (Wallace, 2012).
2. The second trial was conducted in 2013-14 and 2014-15, using a model that trained workers in disability agencies to implement supported decision making (Community Matters Pty Ltd, 2014, 2015).

First trial

1. The first trial initially tested and refined the service model, and then broadened the model’s implementation. Twenty-two people were referred, with eight signing SDM agreements. The preliminary evaluation (Office of the Public Advocate South Australia, 2011) supported the use of SDM and led to refinements in practice during the remainder of the trial. These refinements included that participants became clients of the OPA and were covered by a statement of rights, including confidentiality; that consent would be sought to share information with relevant providers; and that the safeguarding strategies of the project would be based on the UN Convention, with the decision to proceed with a SDM agreement being up to the participants, although the facilitator could decline to proceed if they had professional misgivings about harm to the client.
2. The final evaluation (Wallace, 2012) involved an expansion of the trial to involve 26 SDM agreements. It found that SDM brought benefits for most participants and was both a companion process and a viable alternative to substitute decision making for people who were initially under Guardianship orders, with people using SDM demonstrating that they no longer required Guardianship.
3. The report flagged the following issues for future development of SDM:

Model:

* The initial document outlining the SDM model needed to be updated to a manual.
* The role of the supporter is crucial but not necessarily straightforward, and access to volunteer supporters was needed when a trusted person from the circle of the participant’s family and friends was not available.
* The project co-ordinator played a role in advocacy and case management and this was viewed as positive. The original approach had involved a separate monitor role, which was responsible for making sure that the process was consistent with the participant’s wishes. However, the project co-ordinator came to also assume the monitor role, and meetings between the project and OPA senior staff filled the role of the monitor. The evidence was that this work did help participants enact their wishes, and the evaluation suggested the role of monitor be reassessed when the project was enacted in the community. A case management role was also required during SDM, and the evaluation suggested the supporter role may need to be further developed to incorporate this when self-managed and self-directed funding became more widely used.
* The evaluation noted there was no legislative basis for SDM. The evaluation noted a number of suggestions, as well as that the Public Advocate was responsible for recommending legislative reform.
* The Public Advocate also had a role in integrating SDM principles into self-managed and self-directed funding.

Training/Perceptions of SDM:

* Training and support for supporters should continue on a needs basis, in addition to information provision.
* The project highlighted an ongoing issue of service provider conflicts and concerns about perceived risk and participants’ perceived capacity to exercise SDM. Adequacy of service provision was also suggested as a related issue. SDM challenged accepted approaches among some providers, although others did respond to participant wishes. The evaluation suggested a need for continued development of knowledge and skills about person centred and rights based approaches disability service design and delivery, and the role of SDM.
* There was a need for a change in management strategy focussed on educating relevant services, the wider community as well as the disability community.

Second trial

1. The trial initially involved 11 decision-makers. The (interim) evaluation (Community Matters Pty Ltd, 2014) made a number of recommendations which were accepted:

Eligibility and recruitment:

* That the program recognises the need for and value of tailoring promotion and recruitment processes to individual agencies. Principles for recruitment rather than methods of recruitment should be emphasised within materials and in training and support.
* That clear eligibility criteria for the program be developed and documented. Written criteria should be available to agencies, facilitators, families/supporters and decision-makers. The eligibility criteria should include the program being voluntary (that is, ‘opting in’ should be one of the criteria).
* That processes for selection of decision-makers should be documented and should be available to all parties.

Resource materials:

* That participatory processes be used to develop resource materials that differentiate between SDM and other models of person-centred planning and person-centred decision making. The resource materials should acknowledge the variety of models already in use and the differences in the balance between expressed wish and best interests decision making across agencies.
* That the development of resource materials be a priority for the next phase of the program. Separate resources may be required for facilitators, program managers, decision-makers, and supporters.

Model:

* That the program model be described as comprising multiple phases, including recruitment and selection, implementation and ‘winding up’.
* That a range of alternatives to full ‘team meetings’ be explored and developed, to ensure that the forward momentum of agreements is maintained.
* That the program recognises that the capacities of supporters will vary and that trainee facilitators be supported to negotiate the boundaries of supporter and facilitator roles as required.
* That all trainee facilitators in the next round be required to keep timesheets recording tasks undertaken and time required for the SDM program. That these time records be collected and analysed to inform refinements to the model to improve efficiency.

Training:

* That consideration be given to structuring the training program to allow greater extension of skills for experienced workers.
* That the processes used for mentoring of trainees be reviewed with a view to establishing a more sustainable model, with greater flexibility for negotiating mentoring strategies in response to the needs of individual trainees.
* That a managers’ training workshop be developed, providing greater depth of understanding than existing information sessions.

1. The second trial was conducted with changes to the implementation. Ten trainee facilitators and ten decision makers participated, although two decision makers withdrew because of ill health. The evaluator conducted interviews and focus groups with decision makers, their supporters, trainee facilitators and other staff (Community Matters Pty Ltd, 2015).
2. The evaluation found that the project did generate change and that the adaptations made in the second phase successfully addressed problems identified in the first phase. The project was effective under the following circumstances:

* decision makers had sufficient cognitive capacity, a mode of communication, adequate mental health, an interest in making changes in their lives, and time to commit to the project
* at least one committed supporter can be identified within the time frame for the project
* there is stability in facilitator and/or a back-up facilitator is available
* facilitators are appropriately supported both in practical and emotional terms by the program and by their own agencies.

1. The evaluation identified circumstances and mechanisms for positive outcomes:

* for decision-makers ‘voice, choice and control’ were key. The evaluation found that voice can be exercised when processes for deliberation are established and when intended audiences ‘listen for meaning.’ Choice can be exercised when there are real options to choose between, and when an active, lateral problem-solving approach is exercised, supported by a social capital mechanism where networks available to supporters and facilitators are used to extend access to community options. Control can be exercised when decision-makers have developed a level of confidence and self-efficacy and when other stakeholders (family members, organisations) release control that they have traditionally held. This in turn requires genuine acceptance of the concept of ‘expressed wish’, belief in the capacity of decision-makers to develop skills and competencies, and willingness to rethink some aspects of traditional risk management policies;
* for facilitators, development of new knowledge and skills, role modelling and reflection were linked to positive outcomes;
* for supporters, important factors included ‘seeing is believing’, new learning in relation to expressed wish and community organisations, and the emotional satisfaction of supporting someone about whom they care. These operate when all other stakeholders in the program, but most particularly trainee facilitators, are actively fulfilling their program roles;
* for organisational outcomes, mechanisms included diffusion of innovation, operating at least in part through ‘seeing is believing’, and senior leadership support which provides both financial resources and moral authority for the program.

1. Recommendations from the second phase were:

Future development and funding of SDM:

* The SDM project should be continued and expanded.
* Participating organisations in this second phase of implementation should collaborate in seeking external funding to continue and expand the SDM project.
* All participating service provision organisations should continue to be required to fund the salaries of their participating staff.
* Independent cost-benefit modelling for the SDM project should be undertaken as a matter of priority. This should comprise both direct costs and benefits and social return on investment analyses for non-material benefits, for agencies, workers, decision-makers and supporters.
* If and when subsequent rounds of the SDM project are conducted, a cost-benefit analysis (i.e. actual costs and benefits) should be included in the evaluation.
* A business development plan should be developed to cover a three- to five-year period. This should include sustainable funding systems, processes for diffusion within and across organisations including high quality promotion and marketing materials, staffing structures that can expand with the program, continued adaptation and development of the program itself including cultural adaptations, and evaluations (including economic evaluations) that are tailored to the changing needs of the program over time.
* HCSCC should lead a process to identify and secure an appropriate agency to operate as the ‘base’ for the program over the next 3-5 years.
* A clear strategy for expansion to a further two agencies should be developed, and planning and preparation for their involvement should be undertaken concurrently with the next (internal only) round of training. (Note that the recommendation of ‘two agencies’ here is intended to limit the rate of expansion to manageable levels: many new projects ‘fail’ at the point of expansion because they do not have good quality processes for managing ‘scaling up and scaling out’.)
* A range of fee for service opportunities should be explored, and costings be developed such that those services both cover their own costs and contribute to the core operations of the program.
* Consideration of cultural adaptations to the program should be included in the business development plan.

Promotion:

* That strategies for accessing different market segments, and appropriate funding mechanisms for different market segments, be developed.
* Development of high quality promotional materials for the program should be included in the early stages of the business development plan.

Model:

* That the program continue to refine the program implementation model.

Training:

* That a strategy for diffusion of SDM within agencies be developed, involving strategies for awareness raising across senior management, middle management, and service providers; continued participation in SDM for all ‘graduate’ facilitators; and maintenance of processes to train and mentor new cohorts of trainee facilitators.
* That the initial training program for phase 3 of the SDM project be led by the internal liaison staff from phase 2 of the program, with support from the Program Coordinator, and that those personnel operate as the mentors for trainee facilitators within their own agencies.
* That participating agencies consider separating the roles of trainer/mentor and internal liaison, involving different staff in the two positions. That all participating agencies (including HCSCC) consider the implications, potential and feasibility of developing a new ‘buddy’ role in the program.
* That a job and person specification for the role of trainee facilitator be developed, supported by recommended selection processes.
* That options for accreditation of training for facilitators (in the first instance) and trainers/mentors be explored. Explorations should include consideration of impacts on costs and income generation for the core operations of the program.

ACT

SDM for people with disability

1. A formal relationship based supported decision making model, developed by the Julia Farr Foundation in partnership with the South Australian Office of the Public Advocate, was trialled in the ACT (ACT Disability Aged and Carer Advocacy Service, 2013). The project took the South Australian trial as a starting point, and sought to add to the understanding of how formal supported decision making (SDM) might be accessed by a cohort of people with a broader range of decision making impairments and different support needs, such as those with complex communication needs, and those whose social isolation prevented them from identifying a natural decision support relationship. People needing support to make financial decisions were also included in the project.
2. Three service providers were involved in the project, with one identifying six people living in supported accommodation who were under a guardian order, and who were interested in supported decision making (decision makers). The other two organisations held an information session for care workers and managers, and a forum for older parents respectively.
3. Each of the six participated in a series of one-to-one conversations to ascertain their expectation to be engaged in decision making, their experience as decision makers and their approaches to decisions. They explored concepts such as choice, trust, the right to decide, risk, support for decision making and recognition as a decision maker. The decision makers were involved in a five-stage supported decision making process with an emphasis on developing rapport between the monitor, decision maker, and once identified, supporters. The role of the monitor was to facilitate the creation of the supported decision making agreements, oversee the relationship and provide coaching support where necessary.
4. The project found that the model used was effective, but also that there was a need for a spectrum of decision making supports from formal to informal, and encompassing people with disability along with family members and others involved. The report also identified a key area of future work, which is to explore how supported decision making models should respond to the needs of people living with mental illness or psychosocial disability and the needs of frail older people, particularly those experiencing dementia.
5. The report made a number of recommendations:

Model:

* That support to develop decision readiness be provided for individuals, families and care workers.
* That supported decision making programs provide responsive flexible models of decision support tailored to individual needs.
* That supported decision making programs recognise and accommodate individual needs around timeliness.
* That supported decision making programs further develop a range of decision supporter models, including freely given known supporters, volunteer introduced supporters and professional support.
* That any supported decision making initiative include a paid monitor role to oversee and coach decision makers and decisions supporters.
* That decision support be provided to people to enable their will and preference to be heard in substitute decisions that are being made by others.
* That a review of guardianship legislation in the ACT be progressed as a matter of priority.
* That the ACT Government continues to fund decision support programs which enable people to avoid or minimise guardianship and administrative orders.
* That close relationships between individual advocacy and supported decision making initiatives be integral to the development of decision support.

Training:

* That a training program be created that recognises the role of care workers as a decision making resource for people with disability and promotes the care workers’ capacity to fulfil this role.
* That training programs for care workers highlight the limitation of guardianship to important and increasingly specific decisions, and provide information to empower care workers to advocate on behalf of those they support.
* That community based education programs which facilitate cultural change are implemented as part of a broader supported decision making agenda.
* That support for decision making encompasses capacity building resources for care workers, families and family guardians, in addition to capacity building for individuals.
* That decision making support programs recognise that supported decision making agreements may have multiple purposes for the decision maker and that the documents therefore need to be flexible to meet individual needs.
* That an approach be made to the ACT Civil and Administrative Tribunal (ACAT) to fund the development of easy English materials that describe the responsibilities and limits of guardianship under the current legislation.

SDM for people with psychosocial and intellectual disability

1. A further ACT project focussing on SDM for people experiencing psychosocial and intellectual disability was undertaken and evaluated in 2013-14 (Rea & May, 2014). There were five participants. The project coordinator’s role included working with people in the decision maker’s life through mentoring and training to ensure they recognised the person’s right to decide, identifying volunteer decision supporters and providing professional decision support where volunteer support was not available or the decision maker preferred support by the coordinator.
2. The project had positive outcomes, with decision makers gaining experience in being supported to decide and recognising their right to decide, and support workers, family and others being more able to recognise the right to decide and approaches that support or limit this right. There was a greater recognition that:

* the values and attitudes of people who interact with the decision maker were more important than the person’s functional capacity in access to and experience of decision-making
* a whole-of-community approach is needed where everyone has a potential role in decision support
* a range of support options and expertise is needed
* introduced support relationships are not necessarily effective or efficient: a range of factors limited volunteer commitment and some decision makers preferred a professional supporter because of greater skills, knowledge and investment in the relationship
* professional decision support can be an accessible and sustainable model, and paid peer workers may also form part of this model.

1. The key findings of this report were:

Perceptions:

* The capacity of this group of people with cognitive impairment is poorly recognised and not well supported (decisions made do not reflect capacity but values and attitudes of others). As a result, there needs to be investment in the sector as well as in the wider community to create change.
* Decision making skills can be learnt.
* The decisions of people in this group are highly limited by institutional values, support imperatives, clinicians and other professionals. There is a real need to ensure broader cultural change to ensure people are meaningfully engaged in creating the life of their choosing.
* There is a widely held belief that decision making is too risky for this cohort, underpinning the need to promote understanding of values, and responsibilities, particularly of care workers and guardians.
* Our community, in general, is yet to fully appreciate shifts in the ways in which functional decision making capacity is understood. To ensure that all people are able to exercise their right to decide, the premise that all people have some capacity to engage in decision making, even with support, needs to be better understood and more broadly respected by the community at large.
* There is a need for more investigation into how people who are actively experiencing mental illness might be supported to make decisions, including decisions about how they are to be treated when they are unwell. More recognition is needed that capacity is decision-specific and that people retain capacity to make some specific decisions even when unwell.
* There is a need for more work with families, particularly to ensure that people with disability are able to access and drive planning opportunities under the NDIS. Additional work is also needed in relation to supported decision making and guardianship. Supported decision making can be used consistently with the Guardian and Management of Property Act to ensure least restrictive practise and the will and preference of the protected person. However, subjectivity around what might constitute a ‘significant decision’ proved an ongoing impediment to decision makers engaging as many decisions as they could, and as far as they could.
* There is a need to undertake more work around how people who experience intellectual as well as psychosocial disability can be supported to engage in advance planning.

Model:

* Freely given support continues to present problems for sustainability and accessibility where there is social isolation, a lack of willing volunteers, or limited engagement of decision makers in volunteer support relationships. Professional support was able to fill these gaps. Additionally, the complexity and sensitivity of some decisions makes freely given support less tenable. Professional support was able to bring additional expertise in the context of complex decision making. The project reinforced the need for a spectrum of support options to be available which cater to the needs of different individuals.
* There was clear demonstration of SDM improving outcomes for individuals in medical settings, including mental health treatment.
* Professional decision support is effective. It builds capacity of individuals disenfranchised from decision making, and it builds expectation and skill to be engaged in the decisions that are important to them.
* Professional decision support is able to respond to critical decisions as they arise, with supporters being able to advocate for recognition of the decision makers capacity and right to exercise this capacity.
* Professional decision support is an effective way to build appreciation that all people have the right to decide and that this right can be exercised with support, regardless of a person’s functional capacity. The authority of a professional supporter adds weight to challenging long held, institutionalized, at time paternalistic values and practices around safety and risk, rights and responsibilities, functional capacity, equality and participation.
* Professional support can create as well as respond to need, creating potential for people who are socially isolated, or whose lives are closely governed by others, to experience decision making with support.
* Through professional, support individuals were able to demonstrate their capacity to make and fulfil decisions. This was is a powerful current for cultural change.
* Secondary supported decision making given in day-to-day life by those who share the lives of people with disability is an effective way to develop experience, expectation and skill of decision makers. With training and mentoring, those who share the lives of people with impaired capacity can play an effective decision support role using the rights based principles of decision support.
* Professional decision support is the preferred model for some consumers.
* Training works because it builds the capacity of the community at large to support decisions and it contributes to cultural change. Training which is delivered through an intensive action learning model is more likely to result in changed practices within workplaces.

1. The report recommended:

* a two-tiered response to developing capacity in the community and individuals for involvement in decision support: developing community capacity through training and systemic policy development and developing individual capacity through one-to-one support
* funding for a project manager to build individual and community capacity for SDM through training, professional decision support, oversight for voluntary support, policy development and social policy input.

NSW

1. In 2013/2014 the NSW Department of Family and Community Services, Ageing Disability and Home Care (ADHC) (a joint initiative with the NSWTG [NSWTG] and the Public Guardian [PG]) conducted a small pilot project that aimed to explore what supported decision making might look like in practice in the NSW context (Westwood Spice 2015). It involved 26 decision makers and focused on how supported decision making relationships work; what tools and resources are useful; and what issues may need to be considered for the broader application of a supported decision making framework.
2. The initial stage of the pilot focused on developing concepts, definitions and resources and establishing governance arrangements. This was followed by a recruitment of pilot participants from both ADHC programs and the NSWTG (decision makers) and supporters, and testing of materials and approaches with decision makers. Program staff from ADHC acted as facilitators. Each decision maker was invited to nominate a supporter/s and a decision to focus on. Facilitators provided information, training, coaching and mentoring with decision makers and supporters. They also conducted a workshop in February 2014 with both decision-makers and supporters.
3. An evaluation of this pilot (Westwood Spice 2015) used an action research approach to investigate the following questions:

* Did the intervention work to establish new ways for people with a disability to exercise SDM to direct their services and supports?
* Were the pilot tools/resources useful in assisting SDM in decision makers and supporters?
* Did the training activities increase awareness and understanding of SDM?

1. The evaluation found that the use of supported decision-making processes enabled individuals to make more of their own decisions and to make these in new areas. The overall number of decision makers who now made most or all of their financial decisions increased considerably. However, for the group under financial management, changes to the number of financial decisions were insignificant. The evaluation found that this result suggested that greater availability of supported decision making processes could reduce demand for financial management, but that it was difficult to return control to individuals who had been subject to financial management.
2. The evaluation found that further work was needed to develop supports to assist people under financial management to take greater responsibility for their own financial decision making. Decision makers had low literacy levels, and with the exception of an Easy Read booklet, the written tools and resources were of limited assistance to the decision makers, although they were of value to facilitators. The role of the facilitator was of key importance and written resources did not reduce the need for this role. Recommendations included ongoing support for and mechanisms to promote the adoption of SDM; additional development, promotion and dissemination of the SDM framework developed for the pilot; revision of the tools and resources produced for the pilot; and broader service provider and community education sessions about SDM. In addition, the report identified challenges in finding supporters, and also in attitudes and skills of carers and supporters.

Victoria

OPA's Supported Decision Making Program

1. The Victorian Office of the Public Advocate (OPA) conducted an 18-month supported decision-making trial from October 2013 to June 2015 (Office of the Public Advocate, 2015a). The project aimed to:

* explore and develop a service model connecting trained volunteers with socially isolated people wanting support to make decisions
* promote participants’ dignity and autonomy by facilitating their decision making
* create a formal and structured arrangement to assist and build the participants’ decision-making capacity
* build a skilled volunteer team to provide support and build participants’ capacity to make decisions
* explore whether substitute decision making can be replaced by support for decision making (Office of the Public Advocate, 2015a, 2015c).

1. Prior to the release of the external evaluation of the project, the Office of the Public Advocate identified the following learnings:

* Volunteers require commitment to the participant’s right to make decisions; commitment to developing a respectful and trusting relationship; patience to develop the relationship and to learn about the participant’s life and goals before decision making and problem-solving; and patience and perseverance with the slow systems and responses around the participant.
* Support for decision-making is a time-consuming and resource intensive process.
* A barrier to decision-making or implementation of decisions often appeared to be limited interest by staff in the participant as a person and/or in exploring their wishes and potential goals and decisions.
* Limited resources, e.g. time, staff and training, were further barriers.
* For some participants, the relationship with the volunteer appeared to have contributed to their sense of identity and autonomy.
* Decisions would not have caused application for a form of informal substitute decision-making.
* Supported decision making is an area of unrecognised and/or unmet need.
* Decision making worked well with substitute decision-makers because they were better informed about the participant’s wishes and could advocate for them (Office of the Public Advocate, 2015a).

1. An external evaluation (Calnin, 2016) was recently released. The evaluation found that SDM brought benefits to participants, volunteers and OPA itself.
2. Implementation of the project was supported by:

* the qualities of the volunteer supporters, including an interest in and commitment to the rights of people with disability, good communication and interpersonal skills, an understanding of the disability service system, and relevant skills and abilities including the ability to work collaboratively with the project coordinator
* the support and training offered by OPA
* the flexibility in decision making depending on the participant, for example researching options and impacts related to the decision, building rapport and trust with participants who had not identified a specific decision to make and working alongside the guardian where one had been appointed to help them understand people’s preferences and needs.

1. Identified challenges for implementation were:

* external factors: systems, processes and people from the broader disability sector that restricted decision making (including arrangements intended as protections) and family members who found it difficult to relinquish their decision making role
* ending the supportive relationship between the volunteer and the person they supported due to the 12-month limit of the pilot project and resource limits
* the definition and clarity of the role of the volunteer supporter, in particular to what extent it was necessary or appropriate for the volunteer to engage in advocacy.

The OVAL Project

1. In September 2015, OPA began the OVAL Project, a 12-month collaborative supported decision-making project with the Victorian Advocacy League for Individuals with Disability Inc (VALiD) (Office of the Public Advocate, 2015b). The project aims to recruit, train and match volunteer supporters in Victoria's Barwon South region with 60 socially isolated people with decision-making disability who wish to receive support with decision-making about their National Disability Insurance Scheme (NDIS) support plan. Volunteers will assist participants to build their capacity to make autonomous and informed decisions about their NDIS support plan.
2. The OVAL Project is funded by the National Disability Insurance Agency (NDIA), which has identified that further development is required for people with disability to assume significant choice and control over their lives. The OVAL Project will also develop a ‘model of practice’ for supported decision making for scheme participants, which include resources and tools for participants and supporters.

La Trobe Living with Disability Research Centre

1. The La Trobe Living with Disability Research Centre conducted a study of a trial in Victoria with a small number of people with mild to moderate cognitive disability and good enough verbal communication skills to take part in an interview (Christine Bigby, Whiteside, & Douglas, 2015). The study was part of a larger project, *Supported Decision Making and guardianship: building Capacity within Victoria*, being undertaken by the non-government organisation Scope and its partners, and funded by the Legal Services Board.
2. The study found overall support for the broad concept of supported decision making from participants, including those with cognitive disability, but multiple dilemmas and tensions in practice. The report highlighted the need for further research in this area, particularly in relation to ‘what works’ in support for decision making for people with cognitive disability.

Methodology and data collection tools

1. The studies reviewed varied in their scope and focus, and also in their methodology. Key features are:

* Most studies used qualitative interviews and/or focus groups as either the main tool or the only tool and were used with decision makers, staff, supporters and services.
* Studies included demographic and recruitment data in varying detail.
* Some tools intended for decision makers (such as a written questionnaire, journal and recorded interviews) did not succeed because they were not appropriate to participants’ communication needs. Oral (face-to-face or by telephone) surveys were used in some research.
* In NSW, surveys and feedback sheets were used with service providers and an activity log/diary was used with senior policy officers and project officers.
* Surveys of facilitators, services and families were used to assess outcomes and views. In one case, an intended survey of facilitators was not pursued because numbers were low.
* In some studies, observation was used as a tool through attendance in project meetings and general observations of decision making.

Conclusions

1. Supported decision making involves a paradigm shift in the way in which people with disability are positioned in their communities. This is a new approach in Australia, and there has until now been no specific supported decision making project concerned with financial decision making alone. Financial decision making is complex and for people with disability may be subject to conflicting agendas by those who support them. The current pilot project is therefore important in adding to existing knowledge of good practice.
2. While some of the findings and recommendations of the small number of evaluations of Australian trials may be specific to particular sites, some key best practice themes do emerge:

* the need for recognition of and a commitment to the shift in how people with disability are positioned
* the need to see people with disability as having legal capacity and to be aware of the provisions of Article 12 of the CRPD, particularly the importance of acknowledging will and preference of the decision maker
* the need for development of knowledge and skills related to SDM among services, professionals and families, who may initially not accept SDM, as well as in the community more generally
* the need for appropriate promotion and resource materials about SDM for supporters, facilitators and decision makers, including easy English material describing SDM and the responsibilities and limitations of guardianship
* the need for clear program documentation, e.g. on eligibility criteria and processes
* the need for some flexibility in decision making supports that respond to individual needs, including researching options and impacts of decisions, and decision support to enable the will and preference of people to be heard where substitute decisions are being made by others
* the need for a paid role to oversee and coach decision makers and supporters
* the availability of professional decision support where needed due to factors such as isolation, shortage of volunteers or decision maker preference
* the need for care in selecting and training facilitators and supporters has been shown across the projects
* the use of volunteers provides an interesting model that may be of use in the current project
* the importance of decision makers being involved in the process and being provided with appropriate support which recognises their particular life situation, needs and preferences are issues which need to be emphasised
* the need for capacity building and leadership within organisations as well as adequate resources to enable this to happen.

1. A range of data collection tools has been used in evaluations of SDM. Successful tools include:

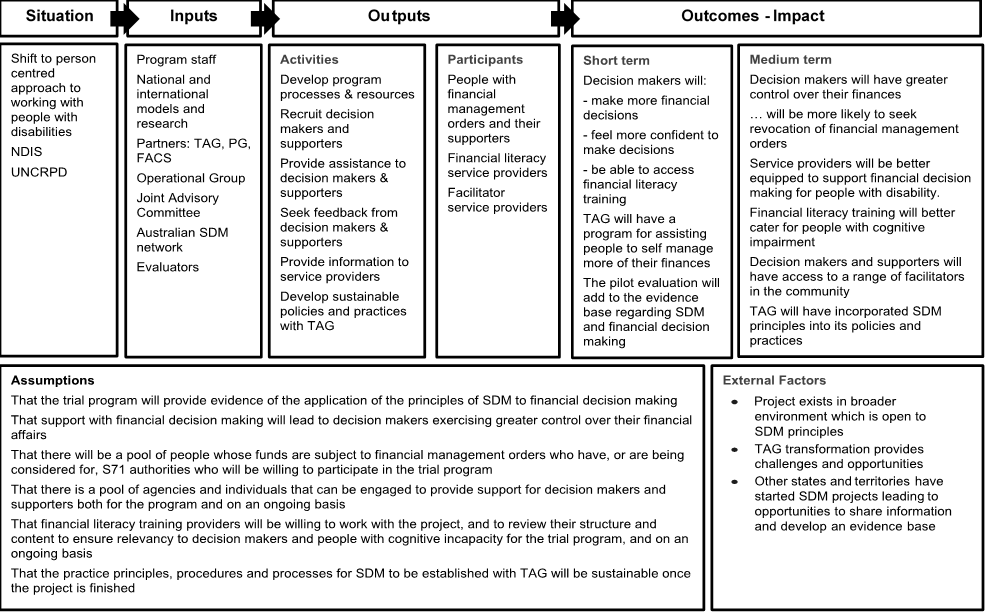
* program data, including demographic information
* qualitative interviews/focus groups were used for all involved including decision makers, supporters, providers, families and staff
* where numbers permitted, written questionnaires and surveys and activity logs/diaries were successful with staff, supporters, services and families but not with decision makers. Oral surveys were successful with some decision makers
* observation of decision making and project meetings was used in some evaluations.

###### SDM2 project outcomes and indicators

Table SDM2 project outcomes and indicators

|  |  |  |
| --- | --- | --- |
| **Project outcomes (short & medium term)** | **Indicators** | **Data sources** |
| A sample of people under TAG are supported to successfully manage parts of their estate where possible. | Decision makers in the project are making more decisions about their finances reflected e.g. by granting of s71(2) authorities.  Decision makers in the project are accessing financial literacy training.  Decision makers in the project are planning for, or have submitted, applications for revocation of financial management orders.  Decision makers in the project have increased the number and types of FD being made and implemented by decision makers with support.  Decision makers in the project report an improved relationship with TAG, and an increase in confidence in dealing with TAG.  No. of supporters reporting decision makers’ DM capacity has improved.  Decision makers in the project show increased confidence to make decisions.  Decision makers in the project show increased ability to articulate their needs and wants. | Program data (de-identified)  Program data  Program data  Program data, participant interviews  Program data, participant interviews  Interviews with supporters  Interviews with decision makers  Interviews with decision makers |
| Increased capacity of service providers to assist people with cognitive impairment to make their own decisions. | Increased knowledge, ability and confidence of service providers and the community to assist people with cognitive impairment to make their own decisions. | Training evaluation survey, focus group |
| Better understanding of how SDM is best embedded within the policy and practice of organisations. | Increased understanding of service provider organisations of how to embed SDM within their organisation’s policy and practice. | Training evaluation survey, focus group |

###### Program logic model for the SDM2 project



###### Demographic data of decision makers

1. According to the demographic data collected by program staff, 33 decision makers participated in the program, of which 14 were recommended and the other 19 were identified by program staff through the NSWTG client records. Eighteen of the decision makers indicated that they were interested in financial literacy training, 15 were interested in assistance with revocation, while nine were interested in both.
2. The majority, 29 of the decision makers, were aged 55 years or under, with one third (11) in the 46-55 years age bracket (Table 6). Slightly more men (20 decision makers) participated in the program than women (13) (Table 7). Nearly all the decision makers (30) had been born in Australia, and all spoke English at home as the main language. One-third (11) of the decision makers identified as Australian, two identified as Aboriginal and Torres Strait Islander and three as having a CALD, background while the rest (17) did not record a self-identified cultural background.
3. Table 6 Decision makers by age group

|  |  |  |
| --- | --- | --- |
| **Age group** | 1. **n** | 1. **%** |
| 18-25 | 1. 7 | 1. 21.2 |
| 26-35 | 1. 6 | 1. 18.2 |
| 36-45 | 1. 5 | 1. 15.2 |
| 46-55 | 1. 11 | 1. 33.3 |
| 56 and over | 1. 4 | 1. 12.1 |
| **Total** | 1. **33** | 1. **100.0** |

1. Table 7 Decision makers by gender

|  |  |  |
| --- | --- | --- |
| **Gender** | 1. **n** | 1. **%** |
| Male | 1. 20 | 1. 60.6 |
| Female | 1. 13 | 1. 39.4 |
| **Total** | 1. **33** | 1. **100** |

Around half the decision makers had an intellectual disability, another one-third indicated they had a mental illness, and 15 per cent had a brain injury (

1. Table 8). The majority of decision makers who participated in the program lived in the Sydney metropolitan area (26), while the other seven decision makers lived in regional areas (Table 9). The housing arrangements of the decision makers were quite diverse: nearly one-third (10) lived in Housing NSW Accommodation, one-quarter (eight) lived in private rental homes, five lived in groups homes, four in boarding and lodging houses and three with family and friends. The others lived in their own home or community housing (Table 10).
3. Table 8 Decision makers by disability

|  |  |  |
| --- | --- | --- |
| **Disability** | 1. **n** | 1. **%** |
| Brain Injury | 1. 5 | 1. 15.2 |
| Intellectual Disability | 1. 17 | 1. 51.5 |
| Mental Illness | 1. 10 | 1. 30.3 |
| Other | 1. 1 | 1. 3.0 |
| **Total** | 1. **33** | 1. **100.0** |

1. Table 9 Decision makers by location

|  |  |  |
| --- | --- | --- |
| **Location** | 1. **n** | 1. **%** |
| Metropolitan | 1. 26 | 1. 78.8 |
| Regional | 1. 7 | 1. 21.2 |
| **Total** | 1. **33** | 1. **100** |

1. Table 10 Decision makers by accommodation

|  |  |  |
| --- | --- | --- |
| **Accommodation setting** | 1. **n** | 1. **%** |
| Boarding or lodging house | 1. 4 | 1. 12.1 |
| Family Friends | 1. 3 | 1. 9.1 |
| Group Home | 1. 5 | 1. 15.2 |
| Housing NSW | 1. 10 | 1. 30.3 |
| Private rental | 1. 8 | 1. 24.2 |
| Other | 1. 3 | 1. 9.1 |
| **Total** | 1. **33** | 1. **100.0** |

1. Five of the decision makers indicated that they were registered with the NDIS. Another 17 said that they were not registered and for 11 decision makers, their NDIS status was unknown (Table 11).
2. Table 11 Decision makers by NDIS registration

|  |  |  |
| --- | --- | --- |
| **NDIS registered** | 1. **n** | 1. **%** |
| Yes | 1. 5 | 1. 15.2 |
| No | 1. 17 | 1. 51.5 |
| Unknown | 1. 11 | 1. 33.3 |
| **Total** | 1. **33** | 1. **100.0** |

1. Most of the decision makers only received income from Centrelink benefits (23 decision makers), while six had some combination of benefit and wages income and four had income from investment, with or without benefits (Table 12). Sixteen decision makers had only bank savings as assets, while 13 had other assets, including investments, shares, property and superannuation (Table 13). Only three decision makers had debts, which included financial estate loans, debts to friends and debts to government.
2. Table 12 Decision makers by source of income

|  |  |  |
| --- | --- | --- |
| **Income** | 1. **n** | 1. **%** |
| Centrelink benefits | 1. 23 | 1. 69.7 |
| Benefits and wages | 1. 6 | 1. 18.2 |
| Centrelink benefit and Investment or investment/rental income | 1. 4 | 1. 12.1 |
| **Total** | 1. **33** | 1. **100.0** |

1. Table 13 Decision makers by assets

|  |  |  |
| --- | --- | --- |
| **Assets** | 1. **n** | 1. **%** |
| Bank savings | 1. 16 | 1. 48.5 |
| Other | 1. 13 | 1. 39.4 |
| Missing | 1. 4 | 1. 12.1 |
| **Total** | 1. **33** | 1. **100.0** |

Notes: ‘Other’ includes some combination of these assets: savings, investments, shares, property, and superannuation

1. Nearly all (30) of the decision makers had a financial management order with the NSWTG as the manager, and one decision maker had a private manager. Nine decision makers had an s71(2) to manage some portion of their income. For 14 decision makers, the management order related to their allowance only, while for others it referred to pension and wages. One-third of decision makers (11) indicated that they used Centrepay (a free and voluntary service to deduct bills and regular expenses from Centrelink payments).
2. Twenty-three of the decision makers had a supporter in the SDM2 project, and for over half of this group, the supporter was their service provider (13 decision makers). Other supporters were family and friends. For the majority (22 decision makers), this was a pre-existing decision support relationship. Those who did not have supporters were asked if they wished to be referred to a supporter. In the one case where this occurred, this was a referral to an advocacy service.

###### Decision maker survey responses

1. Table 14 Reported confidence at beginning of project (number of decision makers)

|  |  |  |
| --- | --- | --- |
|  | 1. **How confident are you to ask for help with your money?** | 1. **How confident are you to manage [money]?** |
| Little or no confidence | 1. 2 | 1. 0 |
| Somewhat confident | 1. 4 | 1. 3 |
| Confident | 1. 10 | 1. 11 |
| Unknown |  | 1. 2 |
| **Total** | 1. **16** | 1. **16** |

1. Table 15 Effect of the financial literacy training

|  |  |  |
| --- | --- | --- |
|  | 1. **Do you think the money management training helped you?** | 1. **Do you think you make some financial decisions differently since the project started?** |
| Yes | 1. 12 | 1. 12 |
| No | 1. 1 | 1. 4 |
| Unsure | 1. 0 | 1. 0 |
| N/A | 1. 3 | 1. 0 |
| **Total** | 1. **16** | 1. **16** |

1. Table 16 Changes in confidence

|  |  |  |
| --- | --- | --- |
|  | 1. **How confident are you to ask for help with your money?** | 1. **How confident are you to manage these things?** |
| Positive change | 1. 3 | 1. 2 |
| Same | 1. 12 | 1. 11 |
| Negative change | 1. 1 | 1. 3 |
| **Total** | 1. **16** | 1. **16** |

1. Table 17 Assessment of project information

|  |  |  |
| --- | --- | --- |
|  | 1. **How useful was the information provided by the project?** | 1. **How useful was talking to program staff about your money and the support you need to make decisions about your money?** |
| Very useful | 1. 7 | 1. 7 |
| Useful | 1. 7 | 1. 9 |
| Not Useful | 1. 0 | 1. 0 |
| N/A | 1. 2 | 1. 0 |
| **Total** | 1. **16** | 1. **16** |

1. Table 18 Perceptions of financial management order at the beginning of the project and change at the end

|  |  |  |  |
| --- | --- | --- | --- |
| 1. **How do you feel about having a financial management order?** 2. **Beginning of project** | | 1. **How do you feel about having a financial management order?** 2. **End of project** | |
| 1. Happy | 1. 4 | 1. Positive change | 1. 1 |
| 1. Mixed | 1. 2 | 1. Same | 1. 10 |
| 1. Indifferent | 1. 2 | 1. Negative change | 1. 5 |
| 1. Not happy | 1. 7 |  |  |
| 1. Unsure | 1. 1 |  |  |
| 1. **Total** | 1. **16** | **Total** | 1. **16** |

1. Table 19 Confidence to talk with NSWTG at beginning of project and change at end of project

|  |  |  |  |
| --- | --- | --- | --- |
| 1. **How confident are you to contact NSWTG to talk about your money and financial affairs?** 2. **At beginning of project** | | 1. **How confident are you to contact NSWTG to talk about your money and financial affairs?** 2. **Change at end of project** | |
| 1. Little or no confidence | 1. 7 | 1. Positive change | 1. 3 |
| 1. Somewhat confident | 1. 2 | 1. Same | 1. 13 |
| 1. Confident | 1. 7 | 1. Negative change | 1. 0 |
| 1. Unknown | 1. 0 |  |  |
| 1. **Total** | 1. **16** | 1. **Total** | 1. **16** |

1. Table 20 Relationship with NSWTG: beginning of project and changes

|  |  |  |  |
| --- | --- | --- | --- |
| **How would you describe your relationship with NSWTG?**  **Entry questionnaire** | | **How has your relationship with NSWTG changed since you have been a part of the project?** | |
| Good | 1. 5 | Improved | 1. 2 |
| Mixed | 1. 4 | No change | 1. 13 |
| Indifferent | 1. 1 | Got worse | 1. 1 |
| Average | 1. 2 |  |  |
| Not good | 1. 4 |  |  |
| **Total** | 1. **16** | **Total** | 1. **16** |

###### Governance structure of the SDM2 project

The SDM2 project was based at, and led by, the Public Guardian, with NSW Trustee & Guardian and FACS as program partners.

It was overseen by an Operational Group whose members had governance or previous project experience, and who met monthly to review progress and give input into project direction. The Operational Group was convened and chaired by the Public Guardian and included representatives of the project’s funder and partners – FACS (1 person), NSWTG (2), PG (3) and a representative of the Justice Department Diversity Services branch. One of the representatives had been involved in the previous SDM pilot project run by FACS in 2013-14.

The SDM2 project also received sector and consumer advice from a Joint Advisory Committee. The NSW Ombudsman’s office convened the committee, provided secretarial support, including refunding member expenses and organising a participation worker to support the attendance of members with an intellectual disability. The Joint Advisory Committee met every three months. It was made up of:

* 2 people with intellectual disability
* 1 person with brain injury
* 1 person with psychosocial disability
* 1 parent of a person with high support needs in disability supported accommodation
* 1 former representative of the NSW Disability Council who has a disability
* 2 disability advocates (one resigned at the end of 2016)
* 1 disability speech pathologist
* 1 representative of National Disability Services
* 1 NDIS representative
* 1 representative of FACS
* 1 representative of ADHC

# References

1. ACT Disability Aged and Carer Advocacy Service (2013). *Spectrums of Support: A Report on a project Exploring Supported Decision Making for People with Disability in the ACT*. Canberra: ADACAS.
2. Arstein-Kerslake, A. and Flynn, E. (2016). The general comment on article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law. *The International Journal of Human Rights* 20(4): 471-490.
3. Bigby, C., & Tait, S. (2004). Evaluation of the independent review of a major life decision affecting people who have an intellectual disability. *Psychiatry, Psychology and Law* 11(2): 202-213.
4. Bigby, C., Whiteside, M., & Douglas, J. (2015). *Supporting People with Cognitive Disabilities in Decision Making - Processes and Dilemmas*. Retrieved from Bundoora, Victoria: <http://arrow.latrobe.edu.au:8080/vital/access/manager/Repository/latrobe:37677>
5. Bizchut (2015). *Alternatives to guardianship in financial affairs.* Bizchut: The Israeli Human Rights Center for People with Disabilities.
6. Bullen, J., Johnson, K., & Purcal, C. (2016). *Supported Decision Making Project, Phase Two Evaluation: Evaluation Plan*. Sydney: Social Policy Research Centre, UNSW Australia.
7. Byrnes, A., Conte, A., Gonnot, J.-P., Larsson, L., Schindlmayr, T., Shepherd, N., . . . Zarraluqui, A. (2004). *Disabilities: A Handbook for Parliamentarians.* Switzerland: United Nations.
8. Calnin, G. (2016). *Evaluation of the Supported Decision Making Pilot Project Report*. Melbourne, Victoria: The Victorian Office of the Public Advocate (OPA).
9. Committee on the rights of persons with disabilities (2014). *General comment No. 1. Article 12: Equal recognition before the law.* UN CRPD.
10. Community Matters Pty Ltd. (2014). *HCSCC Supported Decision Making Interim Evaluation Report*. Canberra: Health and Community Services Commissioner.
11. Community Matters Pty Ltd. (2015). *HCSCC Supported Decision Making Program 2014-15*. Canberra: Health and Community Services Commissioner.
12. Dinerstein, R. (2012). Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: the difficult road from guardianship to supported decision-making’. *Human Rights Brief* 19(2): 8-12.
13. Dowse, L. (2009). “Some people are never going to be able to do that”. Challenges for people with intellectual disability in the 21st century. *Disability & Society* 24(5): 571-584.
14. Fisher, K. R., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., . . . Thompson, D. (2010). *Effectiveness of Individual Funding Approaches for Disability Support, Occasional Paper No. 29, Canberra: Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)*. Retrieved from <http://www.fahcsia.gov.au/about/publicationsarticles/research/occasional/Pages/op29.aspx>
15. Fisher, K. R. & Robinson, S. (2010). 'Will policy makers hear my disability experience? How participatory research contributes to managing interest conflict in policy implementation'. *Social Policy and Society* 9(2):207-220.
16. French, P., Dardel, J., & Price-Kelly, S. (2009). *Rights denied: towards a national policy agenda about abuse, neglect and exploitation of persons with cognitive impairment*. Sydney: People with Disability.
17. Gooding, P. (2013). Supported decision-making: a rights-based disability concept and its implications for mental health law. *Psychiatry, Psychology and Law* 20(3): 431-451.
18. Gooding, P. (2015). Navigating the flashing amber lights of the right to legal capacity in the United Nations Convention on Rights of Persons with Disabilities: Responding to major concerns. *Human Rights Law Review* 15(1): 45-71.
19. Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review* 8(1): 1-34.
20. McLaughlin, J. A., & Jordan, G. B. (1999). Logic models: A tool for telling your program’s performance story. *Evaluation and Program Planning 22*(1): 65-72.
21. Office of the Public Advocate (2014). *A journey towards autonomy? Supported decision-making in theory and practice A review of literature*. Retrieved from The State of Queensland (Department of Justice and Attorney‐General): [www.publicadvocate.qld.gov.au](http://www.publicadvocate.qld.gov.au)
22. Office of the Public Advocate (2015a). *OPA Supported Decision Making Pilot Project*. Paper presented at the ASID SDM Symposium 2015.
23. Office of the Public Advocate (2015b). Supported Decision Making. Retrieved from <http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making>
24. Office of the Public Advocate (2015c). *Supported Decision Making Pilot Project description.* Retrieved from <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/supported-decision-making/59-supported-decision-making-pilot-project-description>.
25. Office of the Public Advocate South Australia (2011). *South Australian Supported Decision Making Project: Report of preliminary "Phase I"*. Retrieved from batch1376447055\_phase\_1\_supported\_decision\_making\_project\_evaluation (1).pdf
26. Pachet, A., Allan, L., & Erskine, L. (2012). Assessment of fluctuating decision-making capacity in individuals with communication barriers: a case study. *Topics in Stroke Rehabilitation* 19(1): 75-85.
27. Pawson, R. (2006). *Evidence-based policy: A realist perspective*. Thousand Oaks, CA: SAGE Ltd.
28. Rea, K., & May, F. (2014). *Self–Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual Disability*. Retrieved from Canberra: <http://www.adacas.org.au/decision-support/ADACAS_recommendations_SDM_psychosocial_and_intellectual_disabilty.pdf>
29. United Nations (2006). *Convention on the Rights of Persons With Disabilities*. NY: UN.
30. Wallace, M. (2012). *Evaluation of the Supported Decision Making Project*. Retrieved from batch1376447055\_final\_supported\_decision\_making\_evaluation.pdf
31. Walmsley, J. and Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures.* London: Jessica Kingsley Publishers.

Westwood Spice (2015). *My Life, My Decision: an independent evaluation of the Supported Decision Making Pilot*. Sydney: NSW Department of Family and Community Services