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NSW GOVERNMENT
Family & Community Services
Ageing, Disability & Home Care

My life, my decision

An independent evaluation of the Supported Decision Making Pilot

April 2015

By Westwood Spice for the Department of Family and Community Services
April 2015

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Acknowledgements

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Special thanks are due to the Senior Policy Officers, ADHC, and Project Officer, ADHC, for their generosity and time in both meeting with members of the evaluation team and organising access to decision makers and supporters. Above all, we would like to thank the individual decision makers who willingly shared their experiences with us.

Abbreviations and terms

The following is a list of abbreviations and terms that have been used in this report.

Abbreviation	Meaning
ADHC	Ageing, Disability and Home Care
ALRC	Australian Law Reform Commission
CRPD	United Nations Convention on the Rights of Persons with Disabilities
Decision maker	A person with a disability who made decisions in the pilot. Also referred to as participant (see further comment at section 3.2)
Facilitator	The role of the Senior Policy Officer or Project Officer when working directly with decision makers and supporters
NDIS	National Disability Insurance Scheme
Participant	A person with a disability who agreed to take part in the SDMP. Also referred to as the 'decision maker'
PG	Public Guardian
SDM	Supported Decision Making
SDMP	Supported Decision Making Pilot (also referred to as the pilot)
Supporter	A person nominated by the decision maker to assist them to make decisions
NSWTG	NSW Trustee and Guardian
WWS	WestWood Spice
Project Officer	The Project Officer was a facilitator in the pilot
Senior Policy Officer	Project Coordinator. The Senior Policy Officer was a facilitator in the pilot

1 Executive summary

"The human rights-based model of disability implies a shift from the substitute decision making paradigm to one that is based on supported decision making.[1]"

Supported decision making (SDM) is the process of assisting a person with disability to exercise their legal capacity to act on an equal basis with others. Support generally involves the assistance of trusted others and encompasses practical elements such as assistance with communication or providing information in accessible formats. SDM processes are designed to build the capacity of the person and their supporters to enable a person to make their own decisions and improve their quality of life.

The NSW Department of Family and Community Services, Ageing Disability and Home Care (a joint initiative with the NSW Trustee and Guardian [NSWTG] and the Public Guardian [PG]) conducted a small-scale pilot project in 2013/2014 to explore what supported decision making might look like in practice in the NSW context.

1.1 Design and conduct of the pilot

The aims of the pilot were to learn:

- more about how supported decision making relationships work
- what tools and resources are useful
- what issues may need to be considered for the broader application of a supported decision making framework.

The pilot also aimed to develop and evaluate education material to raise the awareness of key stakeholders and the general community about supported decision making.[2]

The first phase of the pilot focused on the development of concepts, definitions and resources. This included a program logic for the pilot, a supported decision making framework and the following resources:

My life, my decision. A booklet for the supported decision making pilot

Designed for participants (also known as decision makers), this booklet was available in two versions (Standard English and Easy Read).

Supported Decision Making Pilot Handbook 2013

This handbook was for people supporting people with a disability to make decisions and for family, carers and service providers, whether or not they were taking on the role of supporter.

Tools and Resources Kit

This was a compendium of reading material, tools and worksheets drawn together in a folder from local and overseas sources. Website links to additional information, with

1 http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en (Clause 3)

2 P5 ADHC Supported Decision Making Pilot Methodology February 2013

similar information to that contained in the Tools and Resources Kit, were also in the Pilot Handbook and My Life My Decision booklet.

The second phase of the pilot tested these materials and approaches with people with disability and their supporters working on real decisions selected by the individuals.

There were 26 participants (known as decision makers) who joined the pilot, nine of whom were under financial management with the NSWTG (identified for Section 71 approval). Six withdrew during the pilot. All decision makers were drawn from the Cumberland Prospect area of the then ADHC Metro North region of Sydney. This region was selected because it had diverse demographic and service delivery features and contained the head offices of the NSWTG and the PG.

Thirteen decision makers lived in the family home, one in public housing with drop-in support and the remaining 12 in some form of residential accommodation, mostly group home.

The project was managed within ADHC by a full-time Senior Policy Officer, and a part-time Project Officer was added to the team once recruitment was underway. These staff acted as facilitators to project participants.

Over the course of the pilot, 19 people acted as supporters to 16 of the pilot decision makers; of these 19 supporters, 10 were paid service providers, seven a family member, one a friend, and one person was a paid advocate. The pilot facilitators acted as the supporters for another six individuals. Four individuals exited the pilot without a supporter ever being nominated.

1.2 Pilot evaluation

WestWood Spice was engaged to evaluate the pilot. The objective of the evaluation was to assess the effectiveness of the SDMP. There were three key questions:

1 Did the intervention work to establish new ways for people with a disability to exercise SDM to direct their services and supports?

2 Were the pilot tools/resources useful in assisting SDM in decision makers and supporters?

3 Did the training activities increase awareness and understanding of SDM?[3]

Did the intervention work to establish new ways for people with a disability to exercise SDM to direct their services and supports?

The pilot demonstrated that the use of supported decision-making processes enabled individuals to make more of their own decisions and to make these in new areas.

Over the life of the pilot there was an increase in the number of decisions made by decision makers for themselves. There was a wide variety of decisions worked on during the pilot, ranging from day to day decisions such as going on an outing or buying new shoes to major decisions such as moving house.

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Nine decision makers said they were making decisions in new areas since joining the pilot (six in financial areas, one in living arrangements, one to go on a holiday, one with fitness and one with what they wore).

The most significant impact was in the area of financial decision making. Financial decision making was the most common area where people indicated they wanted to make more of their own decisions before the pilot. Two-thirds of decision makers said that they now made most or all of their financial decisions compared to one in five at the beginning of the pilot. However, amongst the nine NSWTG decision makers, only three (one-third) reported an increase in financial decision making. This could suggest that if supported decision making processes are more widely available to individuals, there may be a reduced demand for financial management. However, once having become subject to financial management, it is more difficult to return control to the individual.

More work needs to be undertaken to develop supports which can assist individuals who are under financial management to take greater responsibility for their own financial decision making. This could include further investigation of the barriers which prevent individuals under financial management from exercising supported decision making.

Supporters reported a positive change in the way the decision maker was making decisions for 15 decision makers. Examples included: the decision maker is now more focussed on the decision making process and seeing it through; the person is less compulsive about decisions and more considered and they have greater confidence about making decisions and asking for help. It was also noted that the pilot is a good reminder to the decision maker about the process of making good decisions.

Whilst decision makers reported an increase in their confidence levels with making decisions, this was not substantiated by supporters. Overall the supporters reported the decision makers were slightly less confident making decisions.

Although the pilot design did not include formal agreements between individual decision makers and their supporters, informal agreements were used on two occasions. In both cases, these were to assist supporters to recognise the capacity of the decision maker to be an active participant in the decisions that they were making and to clarify roles and responsibilities.

Were the written pilot tools/resources useful in assisting SDM in participants and supporters?

It was anticipated that the written resources would reduce the need for face-to-face facilitation but this was not the result. The pilot demonstrated that the written tools and resources were insufficient to enable supported decision making. The pilot demonstrated that the facilitator role was crucial to the achievement of supported decision-making. Facilitators needed to spend significant time working on a 1:1 basis to support both decision makers and supporters to progress the decisions which had been identified for the pilot.

"Making decisions for yourself can give you insights into the consequences of your actions".

Chantelle* chose her group home keyworker as her supporter. Part of her income is managed by the NSWTG. The facilitator and financial manager initially visited Chantelle at home with her supporter where Chantelle noted that she tended to impulse buy.

While Chantelle 'shopped' at the chemist, her medications and other items she purchased were put on a tab and paid for by the NSWTG. Chantelle decided she wanted to pay her own chemist bill. The facilitator worked with Chantelle, her chosen supporter and the NSWTG to make this happen. Together a plan was developed. Chantelle negotiated with the chemist to receive her bill fortnightly. This made it easier to budget than monthly. Chantelle started paying her account in cash. Chantelle came to see that buying toiletries and other non-medical items at the chemist was more expensive than buying them at the supermarket. She changed to purchase these items at the supermarket and saved money as a result. Chantelle is keen to look at other areas in her life where she might be able to make more decisions for herself, and perhaps save even more money!

**Name changed*

Despite the considerable work that went into the creation of the tools and resources, generally, decision makers and supporters reported that they provided limited assistance. This may have been exacerbated by low literacy levels amongst the decision makers. The exception was the Easy Read booklet which appeared to serve as a focal point and added legitimacy to the supported decision making process for some decision makers. The facilitators used a number of the individual tools in the resource kit but felt that as a package the material did not have an overall coherence to guide the user to the appropriate tool for the decision or issue at hand. Nevertheless, the written resources were used extensively by the facilitators and they referred to them regularly to guide them in specific questions that arose in the decision making process.

Did the training activities increase awareness and understanding of SDM?

It was envisaged that the pilot would provide three types of training activities: face-to-face training with decision makers and supporters; formal group training with decision makers and supporters; and formal group training with service providers, particularly those in the Western Sydney District of ADHC.

The pilot training activity that was most successful was the face-to-face training provided by the project team to the decision makers and supporters. This facilitation was mostly in the form of 1:1 support with decision makers and supporters.

The SDM Team facilitated one workshop for both decision makers and supporters during the pilot.

With respect to the broader formal education sessions, only one of these was conducted.

1.3 Data limitations

It should be noted that there are a number of limitations to the SDMP and the evaluation which restrict the extent to which the findings can be generalised:

- the small sample size of decision makers and supporters
- the range of circumstances which were tested
- the limited timeframe of the pilot, exacerbated by recruitment difficulties
- different people involved in the collection of data from baseline through to follow-up/ final interviews
- the relative complexity of some of the concepts to be measured , for example, level of control over one's life, changes to areas of decision making and levels of satisfaction and confidence in decision making
- Some decision makers had a support person during the evaluation interviews and some did not. This impacted on the level of detail of information which was available to the evaluation.

1.4 Barriers and enablers of SDM

In the main, the barriers to supported decision making were not intrinsic to the specific decision maker but to others around them, the general life circumstances of people with a disability such as social isolation (leading to difficulties with supporter recruitment), lack of power and familiarity with making decisions, low expectations by others, power imbalance and conflict of interest in relationships and the length of time that it takes for someone to be supported to become 'decision-ready'.

Key enablers were the assistance provided by facilitators, 1:1 support and training of decision makers by a trusted individual, the availability of supporters, the time available in the pilot to work thoroughly through the decision making process, the education and training of people in the supporter role and the flexibility to use facilitators directly as supporters when needed.

The pilot demonstrated that it was possible to enhance the legal capacity of a number of people with disability to make their own decisions and deliver on the intent of article 12 of the UN Convention to recognise their legal capacity.

Recommendations

The report makes a number of recommendations which are summarised below.

Ongoing support for SDM

1 That ADHC consider implementing ongoing mechanisms to promote the adoption of SDM. This could include:

- 1.1 Ongoing access to capacity building for people with disability through dedicated SDM facilitator positions.
- 1.2 Provision of 'train the trainer' opportunities for service providers, similar to that undertaken in South Australia.
- 1.3 Development of training opportunities specifically targeting potential supporters.
- 1.4 Creation of a website to allow easy access to the range of tools and resources compiled for the pilot.

2 That the PG considers implementing ongoing mechanisms to promote the adoption of SDM. This could include:

- 2.1 That the PG utilises SDM processes as the starting point when making decisions for individuals who are appointed under guardianship.
- 2.2 That consideration be given to trialling SDM processes in respect of individual applicants prior to an application for guardianship proceeding to the Guardianship Tribunal.

3 That the NSWTG considers implementing ongoing mechanisms to promote the adoption of SDM. This could include:

- 3.1 Further investigation into the development of supports to assist individuals who are under financial management to take greater responsibility for their own financial decision making.
- 3.2 Conducting an additional SDM trial for another cohort of current NSWTG clients suitable for section 71 approval.

SDM Framework

4 That ADHC consider further development, promotion and dissemination of the SDM framework developed for the pilot:

- 4.1 The SDM framework developed by ADHC be expanded to recognise the need for flexible support arrangements, including family members, paid supporters and advocates.
- 4.2 That the framework recognise the need for dedicated supporter time.
- 4.3 That the framework further expand information about the potential for conflict of interest for a paid service provider or family member acting as supporter and provide examples of how to manage this conflict.

Tools and resources

5 That ADHC undertake revision of the tools and resources produced for the pilot:

- 5.1 The pilot handbook be expanded to include a detailed discussion of implementation of SDM.
- 5.2 Implementation issues are included in the decision maker handbooks.
- 5.3 Provide access to the resource materials in a more user-friendly format for example, web accessible.
- 5.4 Consider an audio version of the easy read SDM handbook or video alternatives.
- 5.5 Consider the production of a number of one page fact sheets about SDM.

Training activities

6 That ADHC considers undertaking a range of broader service provider and community education sessions about SDM.

2 Introduction

In mid-2012, the NSW Department of Family and Community Services (ADHC) began planning a pilot project to be conducted in 2013 to explore what supported decision making might look like in practice in the NSW context. The pilot was a joint initiative of ADHC, the NSW Trustee and Guardian (NSWTG) and the Public Guardian (PG). The evaluation of the pilot project was contracted to Westwood Spice (WWS) in late 2012.

Since the pilot began, the imperative to go down the path to supported decision making has been strengthened with clarification by the UN that it believes that there is no place for substitute decision making under Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

This first section of the report provides a context for the pilot. It explores the term 'supported decision making', discusses the drivers for supported decision making in NSW and gives examples of initiatives elsewhere.

2.1 What is supported decision making?

Decision making can be defined as the process of making choices among possible alternatives. Supported decision making assumes that all individuals have capacity to make their own decisions which means decisions are made on the basis of the person's will and preference. This can also be described as their 'expressed wishes'. This is in contrast with the 'best interests' frame which is used in substitute decision making; which may or may not always accord with the person's expressed wish.

Supported decision making is the process by which people with disability are able to exercise their legal capacity to act on an equal basis with others. Support generally involves the assistance of trusted others and encompasses practical elements such as identifying and weighing up options, assistance with communication or providing information in accessible formats. SDM processes are designed to build the capacity of the person and their supporters to enable a person to make their own decisions and improve the quality of life.

The Capacity Toolkit describes supported (assisted) decision making as follows:

Assisting or supporting, someone to make a decision means giving them the tools they need to make the decision for themselves. It is about supporting them to make their own decision and in doing so, safeguarding their autonomy.[4]

The Department of Human Services (Vic) says:

Supporting decision making refers to when people with a disability, notably those with complex needs, cognitive and/or communication requirements are assisted to understand, consider and communicate their choices.[5]

4 P147 Attorney General's Department (2008) Capacity Toolkit Parramatta NSW

5 Department of Human Services (2012) Supporting decision making: A guide to supporting people with a disability to make their own decisions

2.2 The context for supported decision making

There are compelling reasons to understand supported decision making and what this might look like in practice at all levels of government - state, national and international, as well as in the non-government sector and in the community. These reasons include Australia's commitment to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the implications of the CRPD for law reform in Australia and current reforms to disability service provision in both NSW and Australia.

United Nations Convention on the Rights of Persons with Disabilities

Internationally, the United Nations Convention on the Rights of Persons with Disabilities (set out in Article 12 that people with disability should have equal access to the law and equal opportunities to exercise their legal rights. Australia ratified the Convention in 2008. The full text of Article 12 of the CRPD can be found at Appendix 3.

The recent (11 April 2014) UN General Comment on Article 12 says:

The human rights-based model of disability implies a shift from the substitute decision making paradigm to one that is based on supported decision making.[6]

It goes further to suggest that practices such as guardianship must be abolished to ensure that full legal capacity is restored to persons with disabilities on an equal basis with others. It makes a distinction between 'mental capacity' and 'legal capacity' and notes that impaired decision making capacity requires that support be provided in the exercise of legal capacity but that legal capacity itself cannot be extinguished. In safeguarding legal rights, a 'will and preference' paradigm must replace the 'best interests' paradigm (Clause 18). It further states that:

The development of supported decision making systems in parallel with the maintenance of substitute decision making regimes is not sufficient to comply with article 12 of the Convention.[7]

Australian Law Reform Commission (ALRC): Inquiry into Equality, Capacity and Disability in Commonwealth Laws

In July 2013, in light of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Australian Governments' commitment to the National Disability Strategy, (this includes 'rights protection, justice and legislation' as a priority area for action), the Australian Law Reform Commission began examining laws and legal frameworks within the Commonwealth jurisdiction. This examination considers whether such laws and frameworks deny or diminish the equal recognition of people with disability as persons before the law and their ability to exercise legal capacity and considers what, if any, changes could be made to Commonwealth laws and legal frameworks to address these matters.[8]

Supported and substituted decision making are within the scope of the inquiry. Following an earlier issues paper, a discussion paper was released in late May 2014.

6 http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en (Clause 3)

7 Ibid (Clause 24)

8 www.alrc.gov.au/inquiries/legal-barriers-people-disability

The discussion paper proposes the adoption of national decision making principles (i.e. dignity, equality, autonomy, inclusion and participation and accountability). It suggests a new model for supported and fully supported decision making at a Commonwealth level, underpinned by the will and preferences of the individual. It further suggests withdrawal of the Australian government's interpretive declaration in relation to article 12, finding that the continuing reference to 'substitute' decision making in the declaration may be an impediment to reform.

Living Life My Way and Ready Together

On 3 July 2013, the Minister for Ageing and Disability Services released *Living Life My Way*, a framework to guide the expansion of opportunities for people to exercise greater choice and control over their supports in preparation for their transition to the National Disability Insurance Scheme (NDIS).[9]

This extends the delivery of person centred supports and individualised funding arrangements for people with a disability living in NSW begun under *Stronger Together 2*. The *Living Life My Way* framework expands opportunities for people to have individualised funding arrangements, including the option of self-management of their own funding.[10]

Ready Together: a Better Future for People with a Disability in NSW, released 3 December 2013, brings supported decision making to the fore with its underpinning of person centred approaches and access to Support Planners and Ability Linkers. Individuals are assisted to make decisions about their services and supports and their linkages to the community.

The importance of individual control in decision making has been strengthened in the updated NSW Disability Services Standards 2012 which place people with disability at the centre of decision making and choice about their supports and services. Decision making, choice and individual needs are now merged into one standard – Standard 3 Individual outcomes. An important practice element of this standard is the requirement for service providers to recognise the importance of risk taking and enable each person to assess the benefits and risks of each option available to them and to trial approaches even when they are not in agreement. Service providers are also required to make every effort to enable a person to make a decision or assist families, carers or advocates to come to an agreement before a substitute decision maker is engaged.

Disability Inclusion Act 2014 (NSW)

The *NSW Disability Inclusion Act* was introduced in NSW Parliament as a Bill on 27 May 2014 and passed into law on 14 August 2014. The *Disability Inclusion Act 2014* replaces the *Disability Services Act 1993*.

The Act recognises the CRPD and its human rights principles and has a strong, outcomes-focused approach to making communities more accessible and inclusive for people with disability, as well as equipping people with disability, service providers

9 www.adhc.nsw.gov.au/about_us/strategies/life_my_way

10 www.adhc.nsw.gov.au/__data/assets/file/0007/280276/ReadyTogether_booklet_web.pdf

and the NSW Government for the transition to the NDIS. Amongst the general principles of the Act is the following:

> *(5) People with disability have the same rights as other members of the community to make decisions that affect their lives (including decisions involving risk) to the full extent of their capacity to do so and to be supported in making those decisions if they want or require support.*

National Disability Insurance Scheme (NDIS)

NDIS, the new National Disability Insurance Scheme, commenced on 1 July 2013 in four trial sites across Australia, including in the Hunter, NSW. In NSW, the scheme will roll out progressively from the trial site to the rest of NSW beginning in 2016 for completion by July 2018.

The NDIS recognises the vision that Australia is an inclusive society that enables people with disability to fulfil their potential as equal citizens. The objects of the *NDIS Act (2013)* include the provision that the NDIS is to "enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports".[11]

The Principles of the Act include:

> *People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity (Principle 8).*

Decision making by the individual with a disability is at the core of service design and delivery under the NDIS. Supported decision making processes are thus likely to have a significant role to play as the NDIS is scaled to full implementation.

Guardianship Act 1987 (NSW)

Currently in NSW, for major life decisions a person is either deemed to have full capacity to make decisions independently or to lack capacity to make decisions independently; there is no middle ground. In the latter, a substitute decision-maker (guardian or financial manager) can be legally appointed to make decisions on their behalf. NSWTG can also be appointed as a financial manager by the Supreme Court. The Public Guardian can be appointed under the *Guardianship Act 1987* where there is no other suitable person able or willing to take on the role of guardian.

Guardianship is usually limited to specific domains (for example, accommodation, health care, services, medical and dental consents) and is time-limited. The principles of the legislation support the least restriction of the freedom of the person as possible, the encouragement of self-reliance and places emphasis on the importance of consideration of the person' s views. These are not inconsistent with a SDM approach. However, legally, it is the guardian who assumes full responsibility for the decision/s made and decisions are made in the best interests of the person. This may or may not align with the person's expressed wishes.

11 Object 1(e) National Disability Insurance Scheme Act 2013 http://www.comlaw.gov.au/Details/C2013A00020

NSW Trustee and Guardianship Act 2009 (NSW)

The NSWTG was established on 1 July 2009 by the *NSW Trustee and Guardian Act 2009* merging the former Office of the Protective Commissioner and the Public Trustee NSW.

Financial management can be limited to parts of a person's estate (Section 40, *NSW Trustee and Guardian Act 2009*) NSWTG has the authority to authorise a client to manage a specific portion of their financial affairs under Section 71 of the NSW Trustee and *Guardian Act 2009*.

2.3 Other supported decision making initiatives

Interest in alternatives to substitute decision making existed prior to the advent of the CRPD. In Alberta, Canada, where the concepts of guardianship and substituted decision making originated in the late 1970's other legal mechanisms (based on presumed capacity) have been implemented, such as Supported Decision-making Authorisation.[12] In British Columbia, Representation Agreements under the *Representation Agreement Act* have been in place since 1996.[13]

At the time of the commencement of the NSW pilot, South Australia (SA) was already piloting supported decision making with 26 individuals and a similar trial using the SA model was underway in the ACT for six individuals. The South Australian trial has now moved on to another phase of training, mentoring and coaching disability service workers to run supported decision making processes. There is further work being undertaken in the ACT and new pilot projects in Western Australia and Victoria.

12 www.qp.alberta.ca/1266.cfm?page=A04P2.cfm&leg_type=Acts&isbncln=9780779737468&display=html humanservices.alberta.ca/documents/opg-guardianship-form-opg5557a.pdf

13 www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/BC_Rep_Agreements.authcheckdam.pdf

3 The design and conduct of the pilot

The pilot was a joint initiative of ADHC, the NSWTG and the PG and was conducted in the then Cumberland Prospect area of the ADHC Metro North region of Sydney. The Metro North region was selected because it had diverse demographic and service delivery features and contained the head offices of the NSW Trustee and Guardian and the Public Guardian.

The design of the pilot was informed by both program logic and a supported decision making framework document.

3.1 Aim of the pilot

The Supported Decision Making Pilot aimed to develop, trial and evaluate a supported decision making framework, tools and training resources for people with disability, their families, carers, advocates and service providers.[14]

It was anticipated that the pilot would provide an opportunity to learn:

- more about how supported decision making relationships work
- what tools and resources are useful
- what issues may need to be considered for the broader application of a supported decision making framework.

3.2 The decision makers (pilot participants)

In keeping with the person-centred and rights-based philosophy which underpins supported decision making, the staff undertaking the pilot made a decision to refer to the pilot participants as 'decision makers'. To the extent that the clarity of the document is maintained, this evaluation report has adopted this term.

3.3 Program Logic

A Program Logic was developed to show the design of the SDMP pilot. See Figure 1 overleaf. Program Logic presents the inputs, outputs and outcomes of a program and the (presumed) causal links between them. Program Logic is used to:

- articulate a program's intended outcomes
- make assumptions explicit about the causes of change
- test those assumptions, by providing a framework for monitoring and evaluation.

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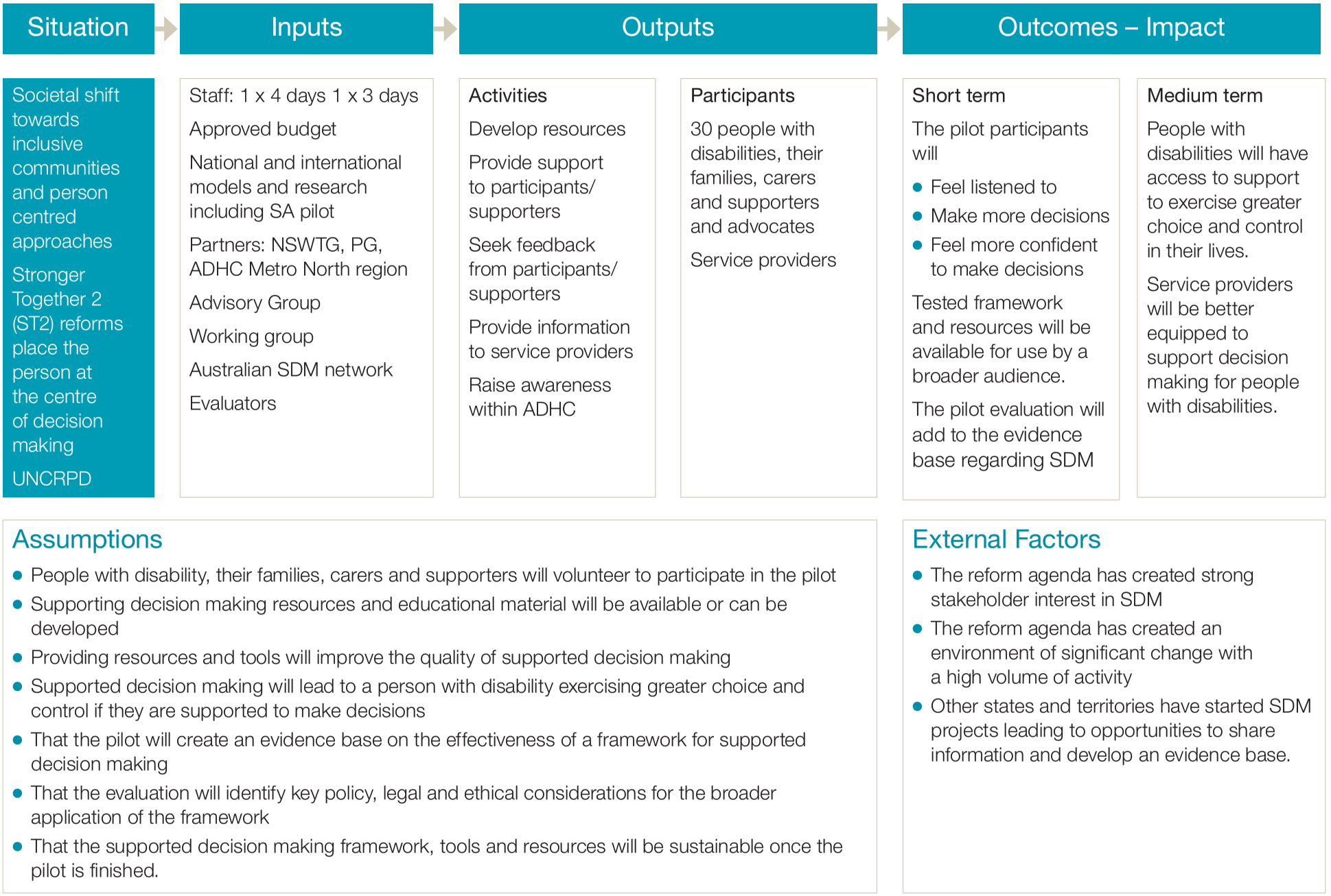
Figure 1: SDMP Program Logic



3.4 The Framework

The rationale for supported decision making and the pilot was laid out in the Supported Decision Making Framework (Framework) developed by ADHC in the planning stages of the pilot.[15] The Framework acknowledged that supported decision making is an emerging concept in Australia and internationally and a variety of models and approaches have been developed.

It described decision making as a continuum with independent decision making at one end and substitute decision making at the other. The Framework suggested that many aspects of supported decision making have already been built into current NSW Government policy. The next step is to establish supported decision making as common practice and raise awareness of it in the wider community.

3.4.1 Supported decision making principles

The Framework describes the core principles of supported decision making as:

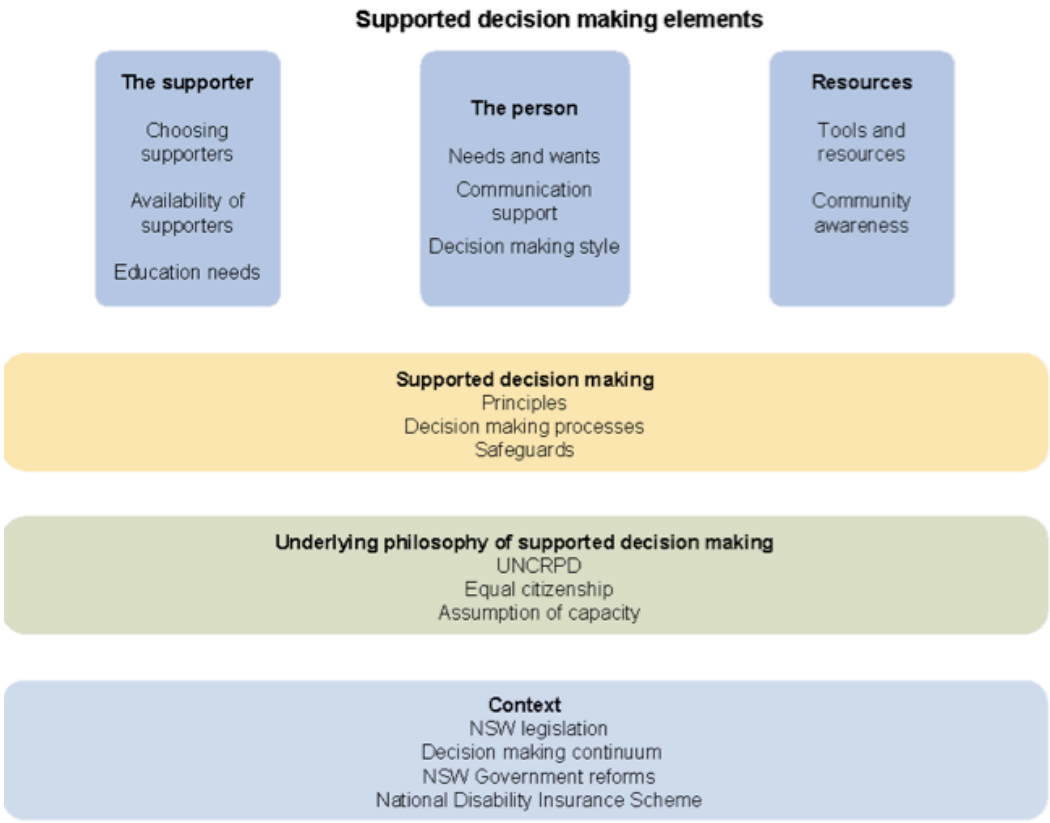
1 Every person can express their will and preferences.

2 person with disability has the right to make decisions.

3 A person with disability can expect to have access to appropriate support to make decisions.

Figure 2 shows the elements of supported decision making as described in the framework.

Figure 2: Elements of supported decision making



15 Supported Decision Making Framework Draft 2013.

3.4.2 Use of formal agreements

In contrast to the South Australian model, an early decision was made that the NSW pilot would not have any formal agreements between the individual participant and their supporter/s. This was to avoid a quasi-legal approach and to recognise the possibility that different people may provide support in different life domains.

Notwithstanding this, informal agreements were used by pilot facilitators on two occasions to assist with decision maker/ supporter relationships.
(See section 7.3.11.)

3.5 Project staffing and activities

The project was managed by a full-time Senior Policy Officer and a part-time Project Officer was added to the team once recruitment of the pilot participants was underway.

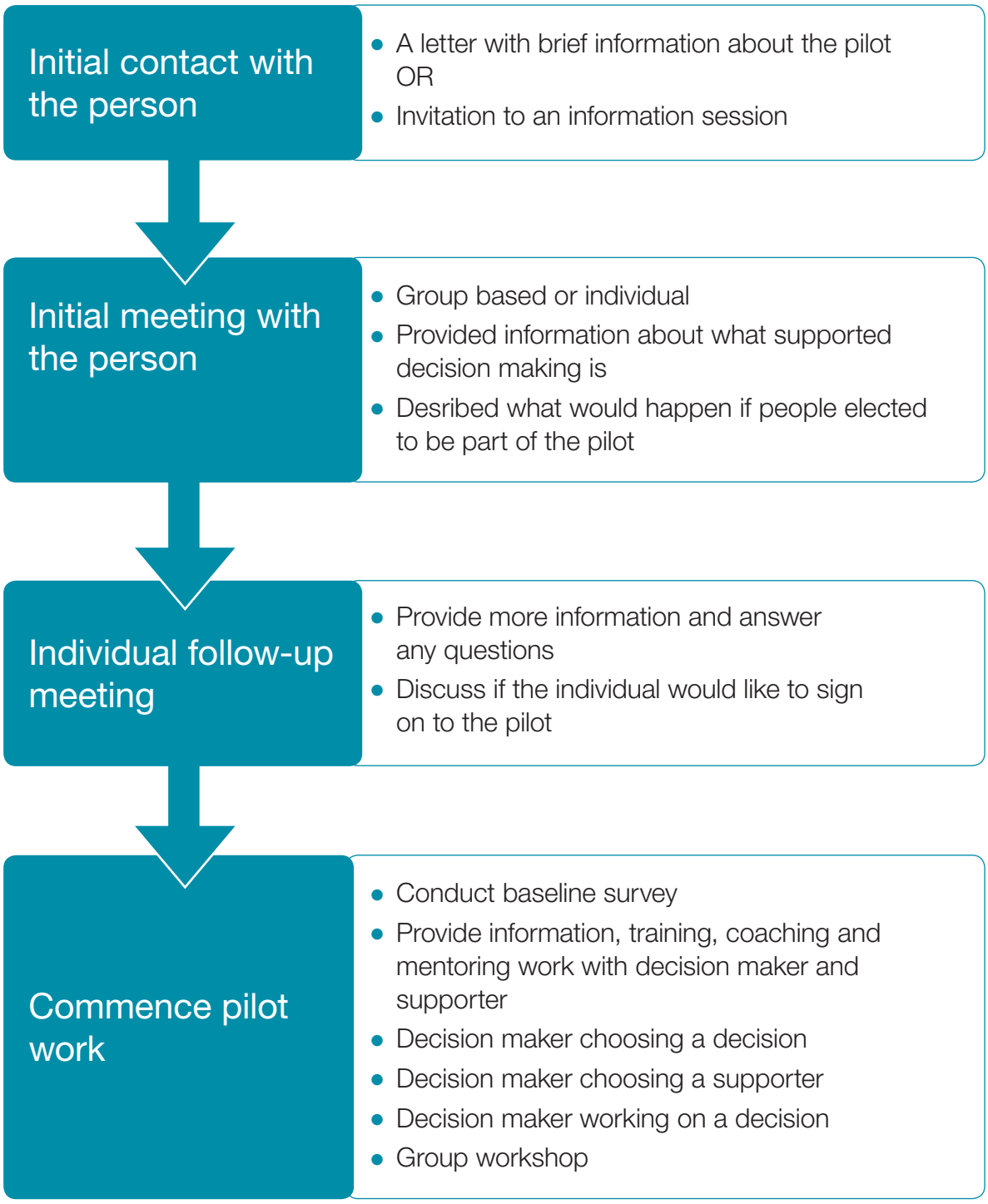
Over the life of the pilot, there were three core staff involved. The initial Senior Policy Officer ('Coordinator'), left approximately one year into the pilot (November 2013) and was replaced. The Policy Officer, joined the pilot in July 2013 and remained for its duration. Each individual is very experienced in working with people with disabilities, and has familiarity working in both the government and non-government sectors.

The first phase of the pilot focused on the development of concepts, definitions and resources (the pilot methodology, program logic and supported decision making framework) and the establishment of governance arrangements.

The second phase recruited decision makers and supporters and tested materials and approaches with them with project staff acting as facilitators. Decision makers were invited to nominate a supporter/s and a decision to work on during the pilot. Facilitators used the time whilst a supporter was being identified to educate decision makers about SDM. Facilitators also developed and delivered training and information to a number of service provider and ADHC audiences.

Figure 3 below provides an overview of the Facilitator role.

Figure 3: Flow chart of Facilitator's role



3.5.1 Workshop

The SDM Team facilitated one three hour workshop in February 2014 for both decision makers and supporters. A workshop scheduled earlier in the pilot (November 2013) did not proceed as no one was able to attend on the selected date.

The evaluators conducted a focus group with supporters as part of the February workshop program.

The program included:

- background information on SDM, rights of people with a disability, person centred approaches, and the NDIS
- guest speakers – a decision maker and her supporter (daughter/ mother)
- guest speaker – ADHC planner - person centred tools
- quiz on SDM – for decision makers
- evaluation with Westwood Spice – for supporters.

The following attended:

- 15 decision makers
- 9 supporters.

3.6 Written tools and resources

In addition to the facilitator resource, an important aspect of the pilot was the development of written resources which could be used by decision makers and their supporters to help make decisions. There were three components:

My life, my decision. A booklet for the supported decision making pilot

This booklet was designed for decision makers and was available in two versions (Standard English and Easy Read).

Supported Decision making Pilot Handbook 2013

This handbook was for people supporting people with a disability to make decisions and for family, carers and service providers, whether or not they were taking on the role of supporter.

Tools and Resources Kit

This was a compendium of reading material, tools and worksheets drawn together from local and overseas sources. The booklets also contained links to websites with additional useful material and tools.

These three resources were distributed by the facilitators to decision makers and supporters. Decision makers received their preferred version of the My life, my decision booklet, and supporters received the SDMP Pilot Handbook and Tools and Resources Kit.

The facilitators also created other individualised resources for decision makers to assist in the education process of SDM. This included the adaptation of existing tools,

such as Helen Sanderson's Important To/ Important For. A very simple tool created was drawing a line down a sheet of paper and listing positive and negative aspects of an option in each column; and then repeating the exercise for each option in a decision. The options could then be compared and weighted to help the person make a final decision.

3.7 Participants (decision makers)

The pilot aimed to recruit up to 30 decision makers (aged between 18 and 64 years); 20 decision makers from ADHC programs and 10 from the NSWTG.

3.7.1 Financial management participants (decision makers)

The intention to recruit 10 NSWTG decision makers was based on there being little research on models for supporting financial decision making which addressed concerns and potential risks[16] for individuals under financial management.

NSWTG decision makers were to be eligible for Section 71[17] approval for management of a proportion of their estate and to be given support to make their own decisions in respect of this component of their estate.

3.7.2 Recruitment activities

The implementation of the supported decision making pilot proceeded more slowly than originally anticipated principally due to difficulties in recruiting decision makers.

There was a low level of response to initial invitations. Additional recruitment activities included direct approaches to service providers, a mail out to the school leavers group in Cumberland Prospect and discussions with the PG. Once an individual expressed initial interest in the pilot, it took time to get to know each person and their family members and explain the purpose of the pilot. Two to three visits were required to introduce a pilot and reach a stage where the participant could consent.

A total of 26 decision makers enrolled in the pilot (including nine NSWTG decision makers). Participant recruitment ceased in January 2014. Participant numbers were boosted considerably in October and November 2013 when nine individuals at the day program provider were recruited following a presentation by pilot staff at the service users committee. In November 2013 it was decided to extend the pilot timeframe until 30 June 2014. (Appendix 1 provides detailed case studies for two of the participants and Appendix 2 gives a summary for the remainder).

The final participant cohort comprises a diverse group of individuals. As it has transpired, this has been a strength of the overall pilot allowing the exploration of SDM with a variety of circumstances and individuals.

16 Decisions around finances or assets were not included in the South Australian pilot

17 NSWTG has the authority to authorise a client to manage a specific portion of their financial affairs under Section 71 of the NSW Trustee and Guardianship Act 2009. This can be implemented under a trial basis. www.tag.nsw.gov.au/verve/_resources/FM_Fact_Sheets_18_What_is_a_section_71_2012.pdf

3.7.3 Decision maker withdrawal

Of the 26 decision makers who signed up to the Pilot, six (23%) withdrew. That is, they ceased their involvement prior to completing a follow-up or final survey interview with the evaluators.

The reasons for withdrawing from the pilot for these six were:

1 Person relocated interstate and effective communication with the person was not possible over the phone.

2 Participant not very interested in engaging with SDMP team, House Manager informed the facilitator the person was able to make his own decisions and is very busy with a new job, girlfriend, and community access activities.

3 Participant informed she no longer wanted to be involved in the Pilot shortly after her mother declined to be her supporter.

4 Participant did not formally withdraw, but became increasingly disinterested in engaging with the pilot, and would not spend more than a few minutes with the facilitator.

5 Since moving to her new group home, the participant was receiving a lot of support from staff at house and support planner about making decisions and working towards these and so didn't see any benefit to being in the pilot.

6 Participant and her supporter couldn't identify any decisions to work on, and the participant indicated she was happy with the support she was receiving around decision making from her family and service provider.

3.8 Supporters

Most individuals joined the pilot without having a supporter identified. A number of individuals had difficulty identifying an appropriate supporter/s. In the case of six decision makers, the pilot project staff shifted their role from one of facilitator to act directly as a supporter for the person. This flexibility in the implementation of the pilot meant that these individuals were able to remain in the pilot and access supported decision making. This also allowed pilot staff a direct opportunity to explore the role of supporter.

Even though a decision maker and supporter considered that they already were practising SDM, facilitator feedback pointed to positive changes.

"The facilitator worked with the decision maker and her supporter on a decision to go to a shopping mall. Despite fears from the supporter over her safety, the person was able to clearly express her decision and articulate how she would get to the mall and the safeguarding measures she would take, which she later did. The decision maker's involvement in the pilot may have contributed to this outcome."

3.8.1 Supporter withdrawal

There were no formal withdrawals of supporters during the pilot. However, there were 18 supporters at baseline, and 16 at follow-up. One supporter (paid staff person) who had been sharing the supporter role relinquished this to the second supporter who as the participant's keyworker had more contact with him. Another participant's supporter who was no longer involved at follow-up reported the participant had become estranged from them.

3.9 Service provider education

It was initially envisaged that the pilot would provide formal training sessions to service providers, particularly service providers in the Western Sydney District of ADHC associated with pilot decision makers. However, only one formal training session was undertaken (in June 2013). This was due to demands on facilitator time for recruitment, supporter and participant facilitation and the need for facilitators to act directly as supporters for some individuals. There were also limited opportunities to present formally.

3.10 Governance

Both the pilot and the evaluation were supported by a Working Group, comprising representatives of ADHC central office and ADHC Metro North region, the PG, the NSWTG and a representative of people with disability. An Advisory Group provided input and oversight to the pilot. The Advisory Group had a broader membership base, including a representative from the Public Advocate in South Australia, an ethicist and stakeholder representatives from the Guardianship Tribunal, NSW Council for Intellectual Disability, the Brain Injury Association of NSW, Carers NSW and a Non-Government Organisation (NGO) service provider.

3.10.1 Advisory Group

The terms of reference stated the Advisory Group was responsible for the provision of expertise on the development, implementation and evaluation of the pilot, including:

- recommendations regarding appropriate agency participation in the project
- high level business advice and recommendations
- expertise and advice on decision making, disability and other related issues
- feedback on the development of the framework and other associated material
- feedback on the specifications for the evaluation of the project.

3.10.2 Working Group

The terms of reference for the Working Group gave them responsibility for overseeing the development, implementation and evaluation of the pilot. This included:

- monitoring the overall progress of the project and achievement of project outcomes
- providing feedback on the development of the framework and other associated material

- providing feedback on the pilot methodology as developed in consultation with the independent researcher
- approving the selection of appropriate decision makers based on the agreed methodology
- providing advice on the specification for the evaluation of the project.

A combined workshop of Working Group and Advisory Group members was held in November 2012 to finalise the Supported Decision Making Pilot framework, sampling and implementation and discuss key questions on methodology for the evaluation of the pilot. The Working Group met frequently during the development stage of the pilot. There were three meetings of the Advisory Group during the life of the pilot.

3.11 Consent

Participation in the pilot was voluntary. A participant information sheet (Standard English version and Easy Read version) and supported decision making pilot consent form (decision maker and supporter version) were developed. These addressed both participation in the pilot and the evaluation. An explanation tailored to the needs of each individual was also provided to decision makers by the facilitators to ensure that each participant had an understanding of their participation in the pilot and the evaluation. All decision makers and supporters participating in the pilot signed the consent form. (Copies of the information sheet and consent form are at Appendix 5.)

4 The evaluation

4.1 Objectives of the evaluation

The objective of the evaluation was to assess the effectiveness of the supported decision making pilot. There were three key questions:

1. Did the intervention work to establish new ways for people with a disability to exercise SDM to direct their services and supports?
2. Were the pilot tools/ resources useful in assisting SDM in decision makers and supporters?
3. Did the training activities increase awareness and understanding of SDM?[18]

The relationship between the pilot and the evaluation was that the pilot was testing the SDM framework, tools and processes (doing it) and the evaluation was assessing if these worked.

4.2 Methodology

The overall evaluation process is shown in Figure 4 Baseline information about decision maker characteristics was gathered through the recruitment process by the facilitators.

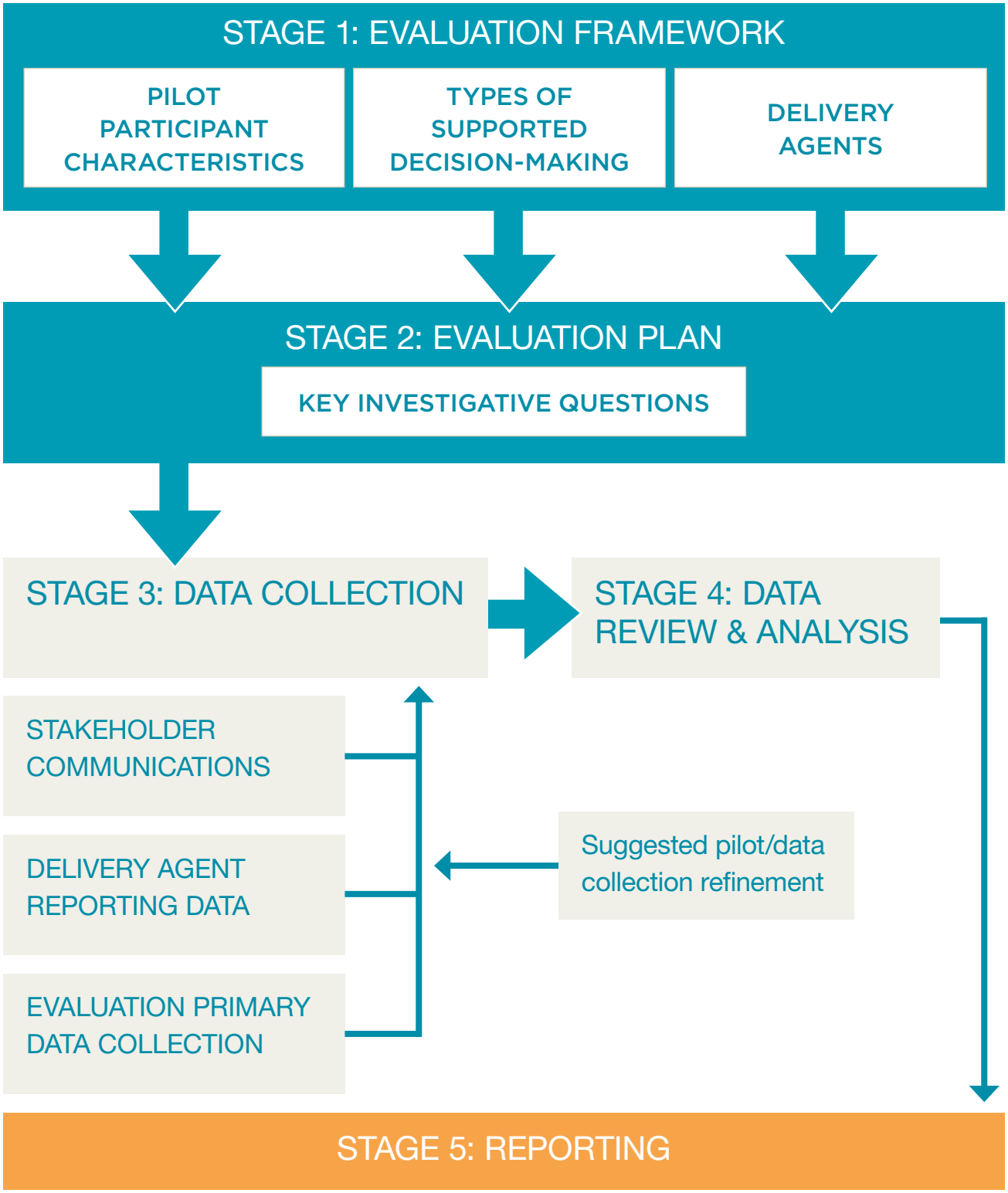
In light of the exploratory nature of the pilot, the evaluation adopted action research practices[19] so that future actions could be guided by experience as the pilot unfolded. The working party was used as a forum to reflect on progress and the ADHC pilot project team completed a monthly reflections log answering the following questions:

- What has been working well this month?
- What have been the challenges? What should I change (if anything) as a result of these?
- What has surprised me?
- Other comments/ observations.

18 P8 final supported decision making pilot evaluation framework and plan February 2013

19 Key questions for each stage of the Action Research Cycle are as follows:
- PLAN: What do we want to do?
- ACT: What did we do?
- OBSERVE: What happened?
- REFLECT: What does this mean?
- REPLAN: What do we want to do as a result?

Figure 4: Evaluation process



4.3 Key evaluation questions

The key evaluation questions were structured into a Results-based Accountability (RBA)[20] framework and these guided the content of baseline and follow-up interviews.

Table 1: Evaluation questions

RBA measures and overarching evaluation questions	Evaluation questions

QUANTITY – HOW MUCH WAS DONE?
 	
Did the need for the tools/ resources increase or decrease for the participants during their involvement in the pilot?
 	
Were any additional (unforseen) resources required during the pilot?
	• How were people supported during the pilot?
	  ◆ How were supporters sourced?
	  ◆ What roles did supporters play?
	  ◆ What methods were used to provide support?
	  ◆ Were different supporters used for different decision types?
	• How much training was provided/ to whom? (e.g. # of training sessions conducted/ whom for?)
	• What tools were made available/ to whom?

QUALITY – HOW WELL DID WE DO IT? Are the tools/ resources useful in assisting SDM in participants and supporters? Did the training activities increase awareness and understanding of SDM?	• What was the profile of participants using SDM? What barriers were there to using SDM? • What is the participant view/ experience/ satisfaction with SDM? • What is the support person/ group's view/ experience/ satisfaction with SDM? • What is the experience/ view of service providers? • What is the experience/view of ADHC? • How effective/ useful were the decision making tools/ training/ resources? For whom? • Have any ethical, policy and legal issues emerged?

20 Mark Friedman (2005) Trying Hard is Not Good Enough

RBA measures and overarching evaluation questions	Evaluation questions

EFFECT – WHAT CHANGE DID WE PRODUCE?
 	
Has the intervention worked to establish new ways for people with a disability to exercise SDM to direct their services and supports?
	• How many and what type of decisions were made using SDM?
	  ◆ Was there an increase in the number/ proportion of decisions made by participants?
	  ◆ Did participants make decisions in any new areas where they have not made decisions before?
	• Were there any other outcomes for participants? (Ratings of greater independence/ empowerment/ choice?)
	• Have any new models to support financial decision making emerged?
	• Have service providers increased their understanding and awareness of SDM? Have service providers made any changes to their practices as a result of the pilot?

4.4 Evaluation instruments

A number of instruments and questionnaires were developed to gather data for the evaluation. These are listed at Appendix 4. Each tool was extensively reviewed by ADHC and the working party; however, the small numbers and difficulties with recruitment of decision makers meant that tools were not pilot tested with participants.

Surveys were administered to decision makers and supporters to facilitate ease of data collection and recording. Baseline information was collected at the time of pilot sign-up and follow-up interviews were undertaken 12-16 weeks later.

Interviews included open-ended questions and a conversational style adjusted to the individual's circumstances and communication skills. Some participant interviews were undertaken with support from others.

The 12 weeks' timeframe for follow-up was only used as a guide. All decision makers, except for those who had withdrawn (six individuals) completed a follow-up interview and those who joined the pilot prior to end August 2013 were also provided the opportunity to participate in a final interview.

4.5 Other data sources

The evaluation was informed by a number of additional data sources. This included a comprehensive review of the facilitators' case notes for each decision maker[21] and interviews with key stakeholders.

Stakeholder interviews have been conducted with:

- SDMP Senior Policy Officers x 2
- SDMP Project Officer
- A/Manager Safeguards & Individualised Options, ADHC
- A/Assistant Director, Advocacy and Policy - Public Guardian
- Individual guardians for decision makers who were under the PG
- A/Assistant Director NSWTG
- 3 x day program provider Disability Services Managers.

21 The evaluators attended the offices of ADHC to undertake the case notes review.

5 Decision maker (participant) characteristics

5.1 General profile information

The recruitment processes resulted in 26 confirmed decision makers (pilot participants). There were 16 females and 10 males. All 26 completed consent forms and baseline participant interviews. Six withdrew during the pilot. There were two decision makers who were Aboriginal and two who were born in non-English speaking countries (India and Lebanon). Almost all decision makers spoke English at home (23/26), with the remaining three speaking Indonesian, Arabic and Lebanese respectively.

Table 2 below gives an age profile of the decision makers.

Table 2: Participant age details

Age Group	#	%
16-24yr	9	35%
25-34 yr	7	27%
35-44 yr	5	19%
45-54yr	4	15%
55-64 yr	1	4%

5.2 Disability, communication and literacy

Whilst information about disability was collected at the baseline, understanding of the literacy and communication skills of the decision makers emerged over time as the facilitators engaged with individuals.

Table 3: Participant disability, communication skills and literacy

PRIMARY DISABILITY	#	%
Intellectual	22	84%
Acquired Brain Injury	2	8%
Not disclosed	2	8%
COMMUNICATION	**#**	**%**
Verbal	22	85%
Verbal with support (Assistance from a person familiar with the decision maker was required to facilitate verbal communication)	4	15%
LITERACY (based on information gathered in file note review)	**#**	**%**
Can Read	9	35%
Easy English	3	12%
Non-reader	2	8%
Unable to determine from file notes	12	46%

5.3 Residential situation and daytime activities

As can be seen in Table 4 below, more than half of the decision makers lived in the family home. 80% had some daytime activity, most commonly a day program.

Table 4: Residential and daytime activities

LIVING ARRANGEMENTS	#	%
Family home	13	50%
Group home <7 residents	9	34%
Residential accommodation > 7 residents (1 x Nursing home)	2	8%
Public housing with drop-in home support	1	4%
Living arrangements not disclosed	1	4%
DAYTIME ACTIVITIES	**#**	**%**
Day Program	10	38%
PT/ FT Work	3	12%
PT Work + Day Program	5	20%
Transition to Work program (TTW)	2	7%
School	1	3%
No formal daytime activity	5	20%

5.4 Legal substitute decision makers in the lives of the decision makers

While there was a specific target in the pilot to recruit up to 10 individuals who were under financial management, there was no similar target with respect to guardianship. Whether or not an individual was under guardianship was no impediment to pilot participation. Due to the difficulties which the pilot had experienced in the timely recruitment of participants, the PG nominated possible participants. This resulted in the inclusion of five of the decision makers who had a current guardianship order. There were nine decision makers who had a financial management order.

6 Supporter characteristics

6.1 Supporter general profile information

The identification of a supporter was not a prerequisite for decision maker entry into the pilot. As is discussed in more detail later, not all decision makers had a supporter.

Nineteen people acted as supporters to 16 of the pilot decision makers. Eighteen of these supporters completed a baseline supporter interview. Table 5 below gives a summary of the major demographic characteristics of supporters.

Ten decision makers did not have a supporter. Four of these decision makers withdrew, and six had pilot facilitator act as their supporter. The supporter information which follows relates only to supporters recruited to the pilot, not to the facilitators.

Table 5: Supporter numbers, language and age

TOTAL SUPPORTERS	**19**	**14 Female (74%)**	**5 Male (16%)**
#s who completed baseline survey	18	16 participants had a supporter, with two having more than one supporter.	
#s who completed follow-up survey	16	One person continued to have 2 supporters (his mother and key-worker).	
Aboriginal or Torres Strait Islander	**0**		
CALD (non-English speaking background)	10 (52%)	This was largely a function of the high proportion of paid staff who acted as supporters. Of those who gave details: Arabic (1), Russian (1), Indian (1), Hindi (1), Ghana (1), Polish (1).	
Age Group	**Supporters ranged in age from their early 20's to -mid 60's**		

6.2 Supporter relationship to decision maker

In the table below it can be seen that the most common supporter relationship was as a paid service provider.

Table 6: Supporter relationship to decision maker

RELATIONSHIP TO DECISION MAKER	#	%
Paid service provider	9	48%
Parent (or step-parent)	7	37%
Sibling	1	5%
Paid advocate	1	5%
Friend	1	5%
TOTAL	19	100%

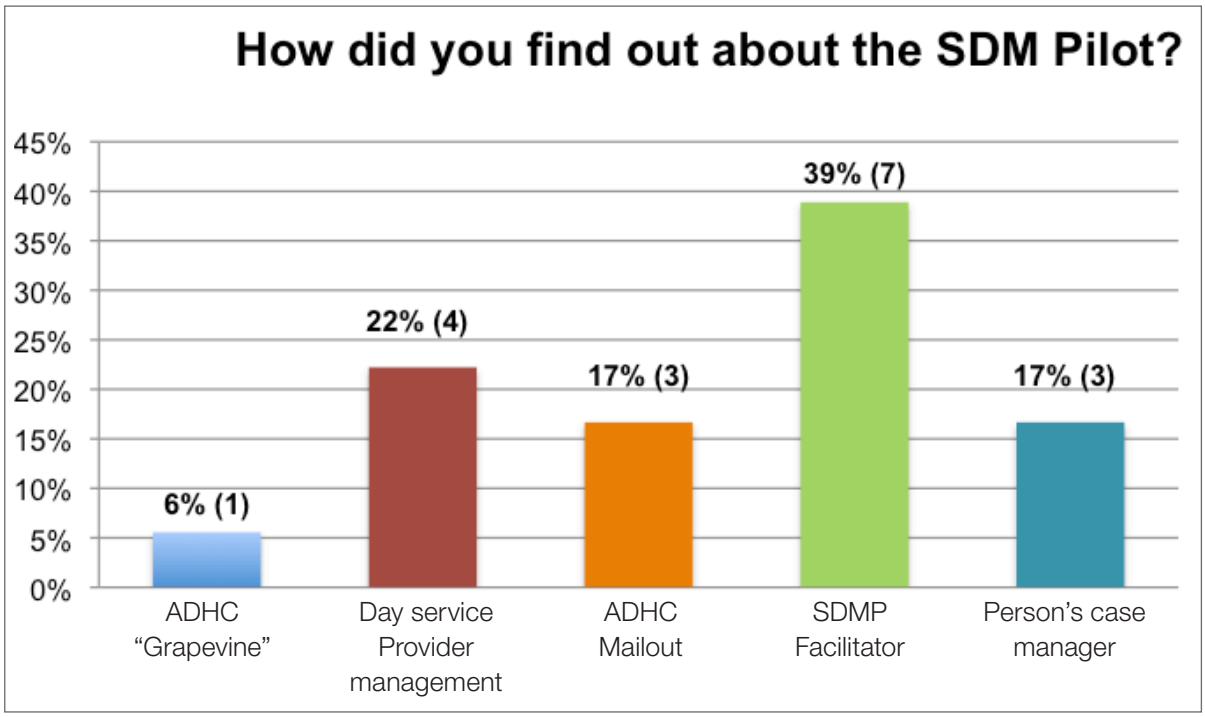
6.3 Supporters' legal appointment as substitute decision makers

Only two supporters had ever been appointed as a legal guardian and two as an enduring guardian. Similarly, only one person reported being appointed as a financial manager. No one reported being appointed as a power of attorney for someone. Over a third (six) reported they made medical or dental substitute decisions as the 'Person Responsible' for another person. Typically, these supporters were the parent of a participant.

6.4 Supporter introduction to the pilot

The most common way supporters were introduced to the pilot was through face-to-face contact with a pilot facilitator following a phone call. Usually this occurred when facilitators were actively recruiting to the pilot through promotional visits to services. Staff who work with the day program provider were informed about the pilot through their manager or team leader. Figure 5 shows the range of ways supporters found out about the pilot.

Figure 5: How supporters found out about the pilot



6.5 Supporter recruitment processes and difficulties

Choosing a supporter was often one of the first decisions made by decision makers, with assistance from a facilitator. Finding supporters proved to be more challenging than expected. In six instances, the facilitators acted directly as supporters. This is a fundamental issue for supported decision making, for without a supporter there can be no 'supported' decision making.

Supporter issues are explored in more detail in the discussion section of this report.

7 The findings

This findings section provides information about why decision makers joined the pilot, the understanding of supported decision making from participant and supporter perspectives, changes to decision making over the course of the pilot, the role of the facilitator, service provider training and feedback from the supporter focus group.

7.1 Reason for joining the pilot

Decision makers reported joining the pilot for a range of reasons. They were given a list of reasons to choose from, and could select more than one if they wished. Eleven decision makers answered the question and on average, each gave two answers. Nearly all (10/11) said they wanted to make more of their own decisions. Over half said they wanted to have more recognition of and support for the decisions they make, and to have more choice and control over their services and supports. See Figure 6 below.

Decision makers were also given the opportunity to report in their own words why they joined the pilot.

Why I joined the pilot:

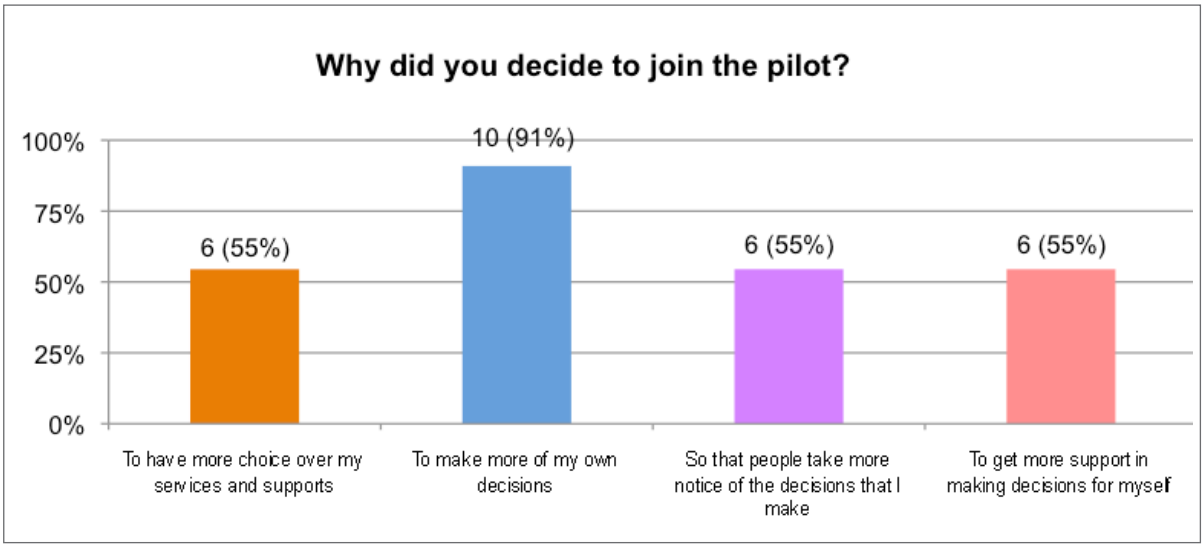
"Of course I want people to take more notice of the decisions that I make. I want my money please."

"Dunno ... I'm 43 I want to be treated like my age. I know what to do."

"To learn about money and my budget."

"To help me make the right decision at times. To be confident about my decisions."

Figure 6: Reasons why decision makers joined the pilot



7.2 Expressed understanding of SDM

7.2.1 Decision maker views

Overall, decision maker understanding of SDM increased in detail and depth during the pilot.

On each occasion the decision makers were formally interviewed they were asked to describe in their own words their understanding of SDM.[22] Variables which impacted on the quality of the answers included the person's comprehension of the question, and whether or not there was a support person present at the interview.

At baseline, the majority of decision makers (17/26) were able to provide some response to the question, particularly after prompting; with the remaining nine indicating that they did not know what SDM was. There was however a significant range in the level of understanding of SDM.

At follow-up, a similar proportion of decision makers (13/20) gave a response indicating that they understood what SDM was. In comparison with baseline, definitions were more accurate and sophisticated, with some decision makers also mentioning the types of supported decisions they had been making.

22 For some individuals, this meant that they were asked three times: at baseline, 12 weeks after joining the pilot (or following a decision) and at the final interview. For others who started later they were asked at baseline and follow-up. For those who withdrew, they were only asked at baseline.

Examples of participant understanding of SDM

Participant 1

Baseline: "Not sure."

Follow-up: "Making our own decision and having choices and other people can't make decision for me."

Participant 2

Baseline: "They don't make your decisions for you but they see if they agree or don't agree."

Follow-up: "Making a big decision, and staff supporting you."

7.2.2 Supporter views

Supporter understanding of SDM increased in detail and depth during the course of the pilot, including after the workshop. This reflects the success of the educative component of the pilot as supporters were provided with the opportunity to discuss SDM regularly (e.g. with the facilitator, attend a focus group) and to be involved in actual application of the principles and processes of SDM with the participant.

When supporters were formally interviewed (at both baseline and then again at 12 weeks or following the participant making a decision), they were asked to describe in their own words their understanding of SDM.

At baseline, supporters in general were able to articulate what SDM entailed, at least in part. Only one supporter stated they did not know what SDM was.

Some supporters' descriptions included identifying the need for placing limitations on full SDM.

Table 7 illustrates the change in understanding of SDM over the course of the pilot for three supporters.

Table 7: Examples of the change in supporter understanding of SDM over time:

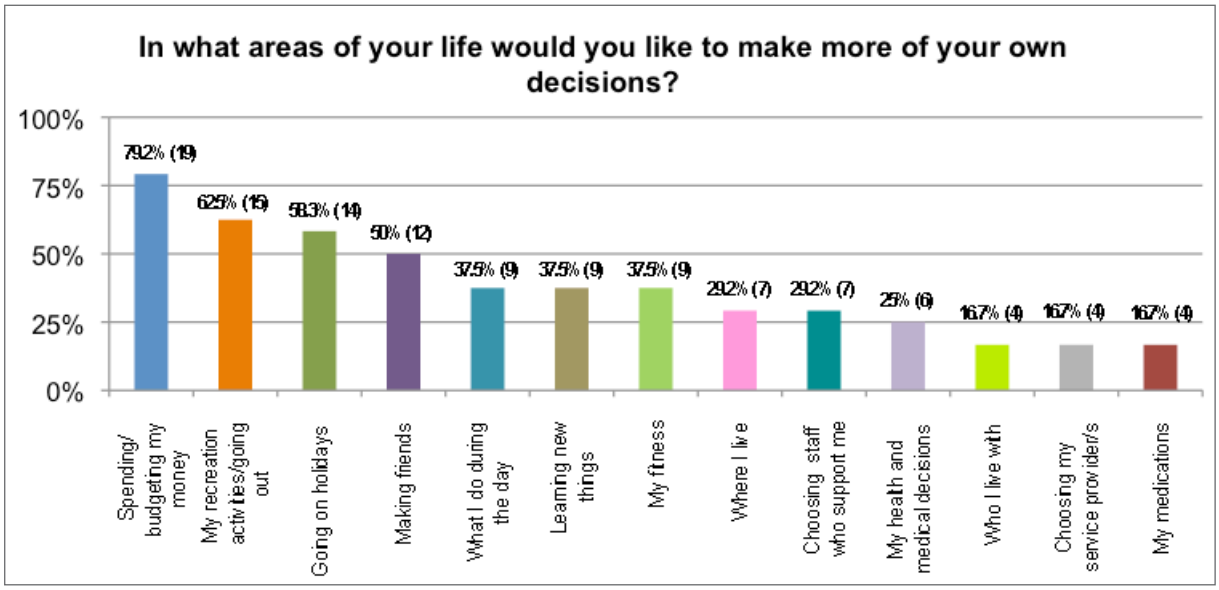
	Baseline	Follow Up
Supporter 1	It is about supporting independence and about the person making the decision.	Guidance for someone to help them make financial and life decisions. Needs to be done in a way they still feel in control of the decision. They also have to have a real understanding for decision making for it to be of benefit to them.
Supporter 2	Help the person make appropriate decisions that make sense and are in the person's best interest. Otherwise it would be pizzas and McDonalds.	It's about helping Participant X express some of the things they would like to be able to do and exploring how to make these things happen.
Supporter 3	Help Participant X achieve their goals, make their own decisions and help them do what they want to do.	The person I support wants to do something and sometimes they are not able to do everything by themselves and I'm the person who supports them as much as I can remembering that you need to leave them to do as much as THEY can.

7.3 Changes to decision making during the pilot

7.3.1 Areas of life where decision makers would like to make more decisions

Decision makers were asked at baseline in what areas of their life they would like to make more of their own decisions (selected from a given list). The results are shown in Figure 7 below (24/26 respondents). On average, decision makers nominated five areas.

Figure 7: Areas of life decision makers wanted to make more of their own decisions



Amongst the nine decision makers who have their money managed by NSWTG, seven identified that they wanted to make more decisions in the area of finances and budgeting.

7.3.2 Areas in which decisions were actually made (new/ same)

At baseline and follow-up/ final, the decision makers were asked how many of their own decisions (a few, some, a lot, all) they made across four life domains:

1. Day-to-day (e.g. what to wear, eat).
2. Big decisions (e.g. where to live, work).
3. Medical decisions (e.g. go to doctor, take medicine).
4. Financial decisions (e.g. what to buy, how much to save).

Over time, an increase in the number of decisions the decision makers were making is evident, across all the domains. The most significant changes were in the area of financial decision making. This is the area in which almost 80% (20) decision makers identified as wanting to make more decisions at baseline. See Figure 8, Figure 9, Figure 10 and Figure 11 below.

Figure 8: Day-to-day decisions

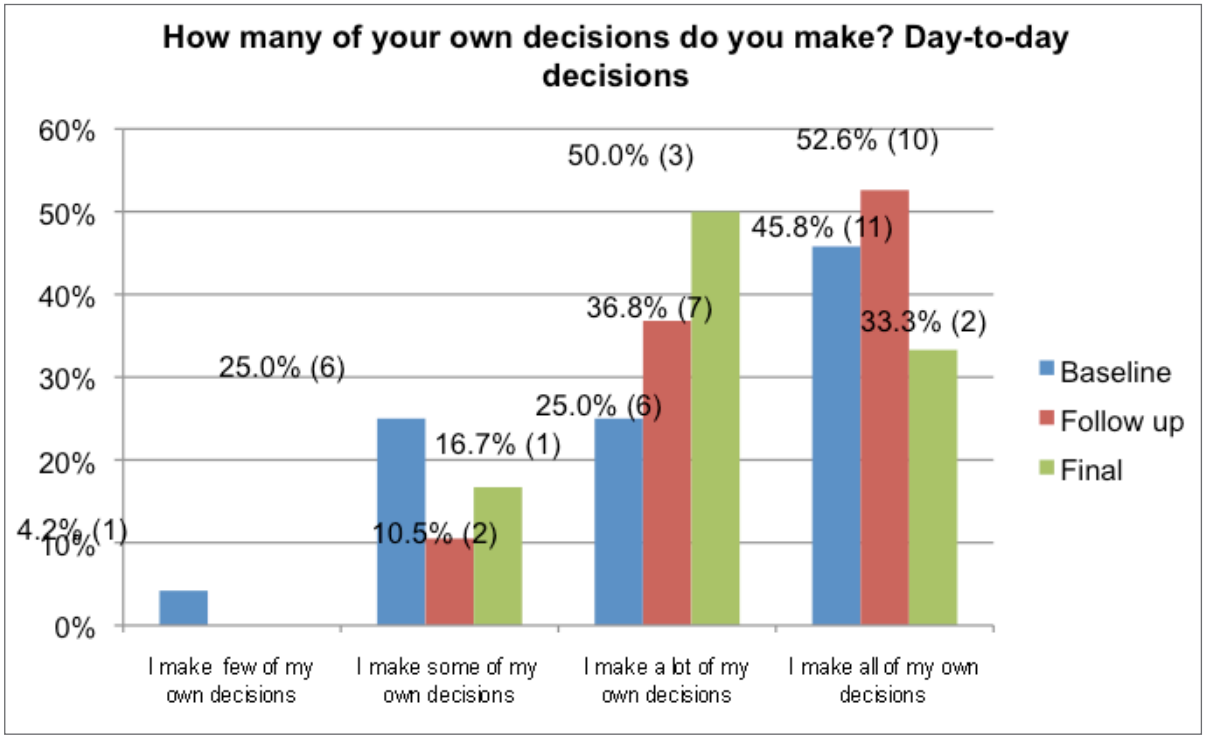


Figure 9: Big decisions

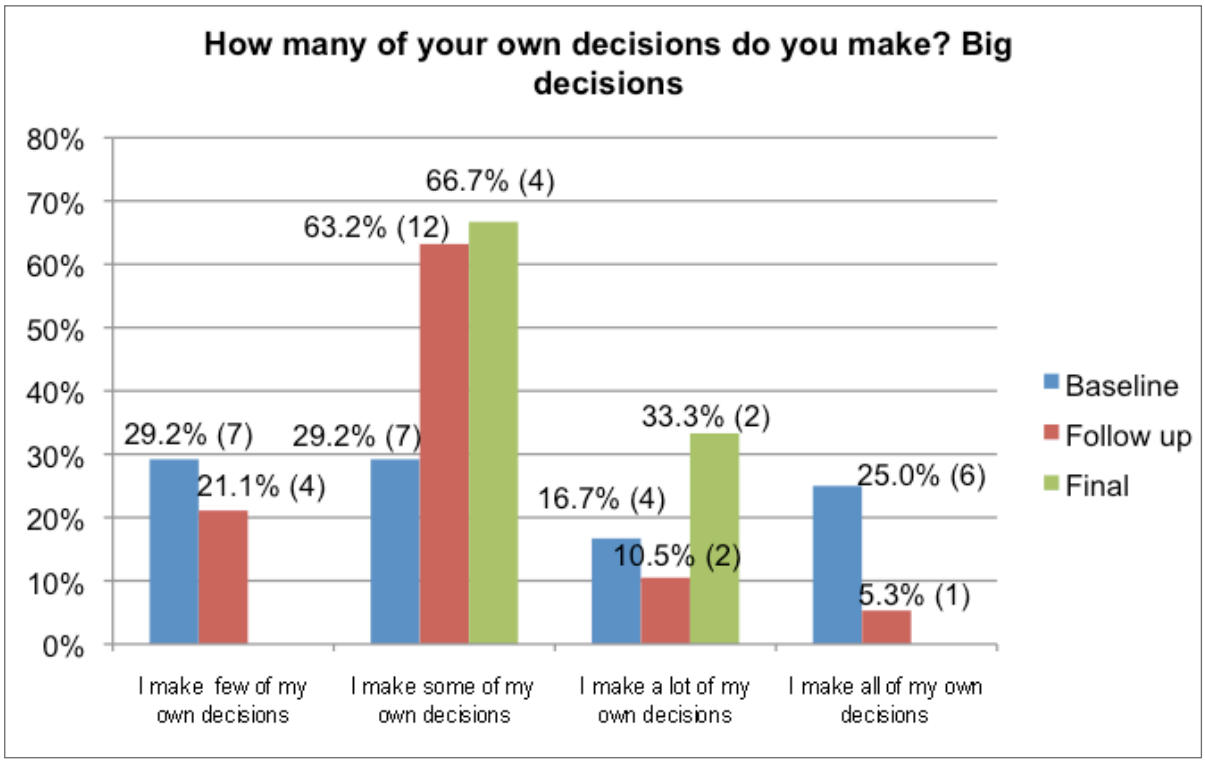


Figure 10: Medical decisions

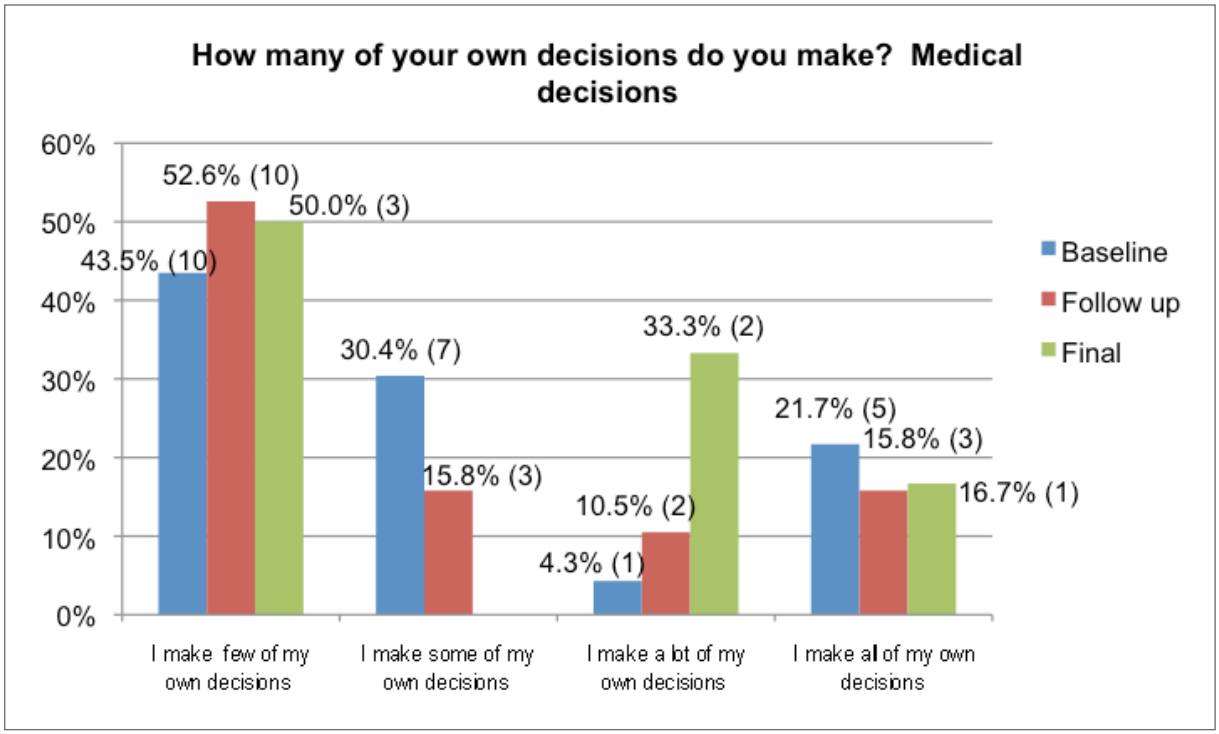
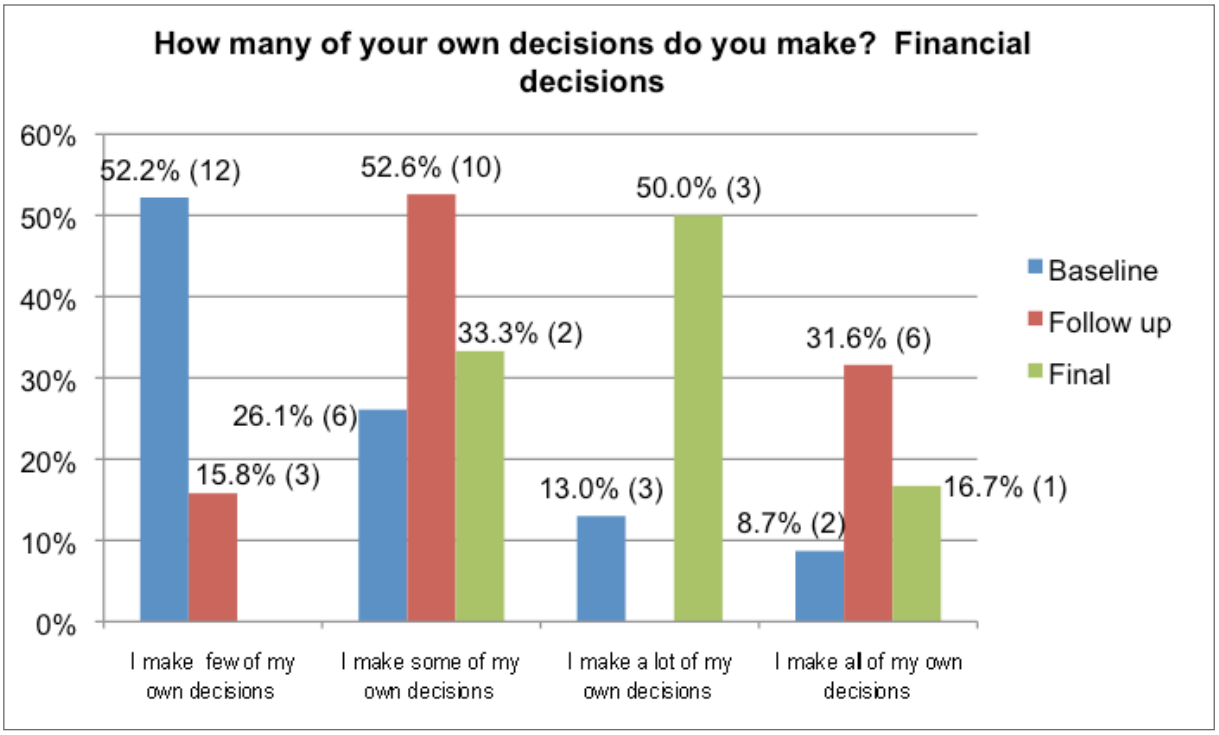


Figure 11: Financial decisions



7.3.3 New areas of decision making

Decision makers were asked at follow-up and final interviews to indicate in what areas they were making more of their own decisions, and if any of the areas they identified were new areas of decision- making. Almost half of the decision makers (9) identified new decisions making areas since joining the pilot:

- Budgeting/ Finances – 6
- Living Arrangements – 1
- Going on Holiday – 1
- Recreation/ Going Out – 1
- Fitness – 1
- What I wear – 1

> **"It's too early for me to have lots of examples, but I am definitely making more of my own financial decisions now, and thinking of the different ways to make those types of decisions."**

The most significant area of change was again in the area of Budgeting/ Finances, with six people identifying this was a new decision area for them. Two of these were from the NSWTG group of decision makers.

7.3.4 Decision makers with NSWTG as financial manager

Of the nine decision makers who had NSWTG appointed, three reported an increase in the number of financial decisions they were making, one a decrease, three no change and two did not respond. Refer to Table 8.

Table 8: NSWTG decision makers and financial decisions

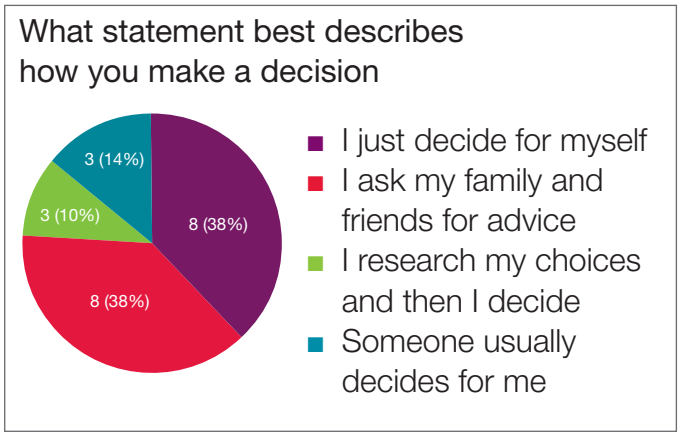
Decision maker	Baseline	Follow up	Final	Overall change
Person 1	Few	All	Some	Increase
Person 2	Few	Some	Some	Increase
Person 3	Few	All	NA	Increase
Person 4	Few	NA	NA	NA
Person 5	Some	Some	NA	No change
Person 6	Some	Some	NA	No change
Person 7	A lot	Some	A lot	No change
Person 8	All	Few	NA	Decrease
Person 9	No answer	No answer	No answer	NA

7.3.5 How the decision makers make their decisions

Decision makers were asked at baseline how they make their decisions. They were given a list of options and also had the opportunity to use their own words.

The Figure 12 below illustrates the range of responses for those who answered the question (21/26).

Figure 12: How decision makers make their decisions



Examples of responses:

"Family give guidance and direction."

"By telling the staff. Sometimes I don't tell the staff and they get worried. Sometimes ask staff and members (house mates) for assistance."

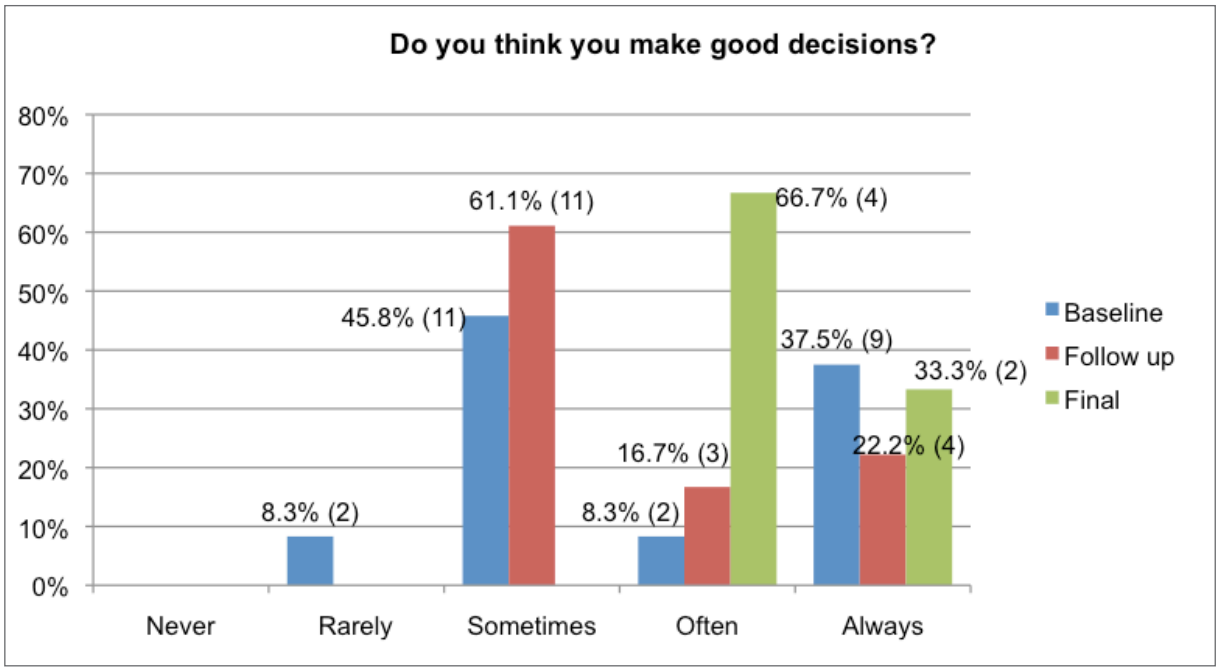
"Someone at home decides for me - mum or grandma."

7.3.6 Do you think you make good decisions?

Decision makers were asked at baseline, follow-up and final interview if they thought they made good decisions. There were 24 responses at baseline, 18 at follow-up and six at final interview. While there was no significant overall increase in the decision makers' view that they made good decisions, fewer decision makers indicated that they 'never' or 'rarely' made good decisions at follow-up and all six decision makers at final interview said they often or always made good decisions. See Figure 13 below.

These results need to be considered in light of the views of both the facilitators and the evaluation team view that it was not always possible to adequately explain the concept of a 'good decision' to some decision makers.

Figure 13: Do you think you make good decisions?



7.3.7 What makes it difficult for decision makers to make decisions

Decision makers reported a decrease in the 'things' that make decision making difficult for them during the course of the pilot.

What makes SDM difficult?

"Thinking about the pros and cons and impact on my family."

"It upsets others. Some decisions may not be right."

"Sometimes decisions are easy sometimes they are hard. Previously when it's been hard it's been about other people's influence."

In response to the baseline question: "What things make it difficult for you to make your own decisions?" About one-third (eight) said they were not sure or did not know, five said there were no difficulties, whilst another two reported they had difficulties with

the financial aspect of decisions (e.g. getting money from the NSWTG to implement a decision, understanding how much things cost). Others reported barriers to decision making due to mobility or communication difficulties and decision making not always being easy because others disagreed with the decision.

At follow-up and final interviews, decision makers were asked to report if there was anything that stopped them from being able to use SDM or any particular difficulties experienced during the pilot. The overwhelming response was 'no'.

7.3.8 Overall changes to how decision makers make their decisions

Decision makers

The majority of decision makers reported that they had changed the way they made their decisions since being in the pilot. At follow-up, three-quarters (15/20) said they had made changes while a quarter (5/20) reported they had not changed the way they made decisions. Of those who had made changes, responses ranged from examples of specific decisions they have made through to observations (sometimes confirmed by their supporter) about changes in their process of making decisions. For example, the decision maker is more aware they have choices and they now initiate support from family or staff to assist them with making a decision.

Changes to decision making:

"I am thinking more deeply about how to make my decisions and different ways of getting a result."

"The pilot has helped Participant X be more focussed on his decisions." Comment from a supporter during follow-up interview.

Supporters

Supporters were also asked whether they had noticed any changes to the way the decision maker was making decisions since being in the pilot. Twenty five percent reported no change, and 75% that there had been a positive change. Reasons cited for the positive change included: the decision maker is now more focussed on the decision making process and seeing it through; being less compulsive about decisions and more considered; is more confident about making decisions and asking for help; and the pilot is a good reminder to the decision maker about the process of making good decisions.

7.3.9 Confidence in decision making

Decision makers

There was an overall increase in the decision makers' level of confidence in their decision making during the course of the pilot, with all decision makers reporting that they were either quite confident or very confident in making their own decisions at follow-up and final interview. No one rated themselves as not confident whereas three decision makers were not confident at baseline.

There were four decision makers who did not answer this question, as the concept of decision making confidence was too difficult to convey.

For the six individuals where the facilitators acted as supporters:

- one person reported an increase in confidence in their decision making from 'quite confident' to 'very confident'
- one person reported a decrease in confidence from 'very confident' to 'quite confident'
- one person reported 'very confident' at baseline and follow-up
- one person was not able to comprehend the concept being asked
- two people withdrew before follow-up data was collected.

Supporters

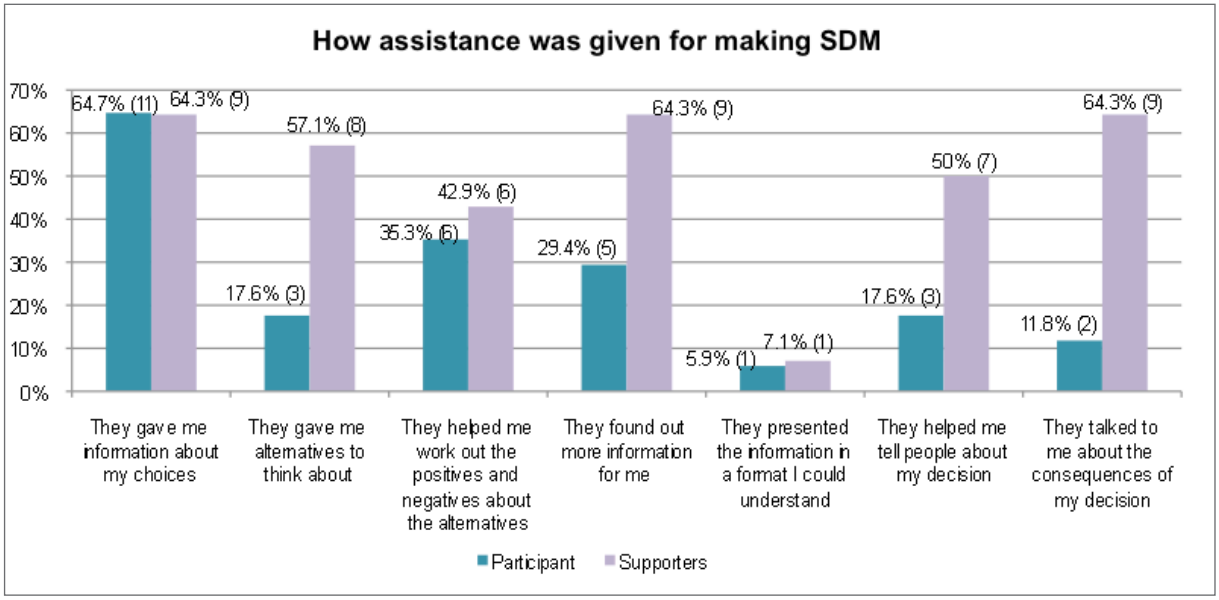
Supporters were asked at baseline and follow-up to rate the level of confidence they thought the decision maker had in their ability to make their own decisions. Overall the supporters reported the decision makers were slightly less confident to make decisions. In contrast, the decision makers themselves reported they had become more confident. The difference between the supporters and the decision maker's responses over time could relate to several possibilities such as:

- decision makers exposure to SDM processes increased, the complexity and intricacies of decision making became a reality and supporters had more awareness of this
- supporters are only reflecting their views about another person's confidence level.

7.3.10 How the supporters assisted in the decision making process

Both decision makers and supporters were asked how assistance was provided in making the decision/s. As can be seen in Figure 14, there were a range of ways the decision maker was assisted as reported by both parties. There was a high level of agreement between decision makers and supporters about the provision of information but on most other measures, the supporters perceived they provided more assistance than the decision makers felt they received. This data does not include the six decision makers where the facilitators acted as supporters.

Figure 14: How assistance was given for SDM



7.3.11 Use of agreements in assisting the decision making process

As discussed earlier (3.4.2), the pilot design did not include formal agreements between individual decision makers and their supporters. However, informal agreements were used on two occasions. A brief written agreement outlined the role of the decision maker and their supporter, their expectations of each other, and what to do if they had a disagreement. These agreements were informal, situation-specific and helped make explicit the supported decision making processes for these individuals. An example of one of these agreements is provided at Appendix 6.

In both cases, the agreements were generated based on the needs of the supporter rather than the needs of the decision maker. The agreements were used to strengthen supporter recognition of the capacity of the decision maker to be an active participant in the decisions that they were making. These agreements were intended as a reference point to remind the supporters of their role and provide guidance on how to implement supported decision making.

7.3.12 Decision makers level of control over their lives

The evaluation team asked whether involvement in the pilot led to an increase in the level of control decision makers felt they have over their life. On each occasion the evaluation team met with the decision maker, they rated the level of control they have of their life on a scale from 0 to 10 (where 0 represents no control and 10 complete control).

Not all decision makers provided an answer to this question. However, some ratings were received from 20 decision makers and comparative ratings are available for 12 individuals as shown in Table 9 below. This illustrates the degree of change to the control each reported over the course of the pilot. Five reported an increase in control, there was no change for three and four a decrease. There was an overall increase in the percentage of people who reported a level of control of five and above when compared to the baseline data, with initial ratings of five or lower showing the most increase.

Table 9: Degree of control decision makers feel they have over their life

Decision maker	Baseline	Follow up	Final	Difference
Person 1	10	10		0
Person 2	10	10		0
Person 3	10	6	9	-1
Person 4	10	2		-8
Person 5	8	8	7	-1
Person 6	8	10	10	2
Person 7	7	6		-1
Person 8	6	6	7	1
Person 9	5	10		5
Person 10	5	5		0
Person 11	3	5		2
Person 12	2	5		3

7.3.13 Specific decisions worked on during the pilot

No limit was placed on the nature of decisions that could be explored during the pilot. The decision makers could choose to work on simple or life changing decisions.

Table 10 below provides a list of decisions worked on by each of the decision makers. This has been drawn from both interview data and facilitator file notes.

Ten of the decision makers did not expressly identify a decision to work on during the pilot, despite various options being explored with the facilitator. There was a higher likelihood of withdrawal from the pilot when a decision had not been identified.

Table 10: Actual decisions identified to be worked on during the pilot

Decision Making Area	Decision (paraphrased)
Day-to-day	Going on an outing for the day To buy a new pair of shoes To become more independent Spending more time alone at home Getting a mobile phone to use To have more control over what I eat To go to a horror movie Going for a walk around the block by myself when agitated
Big decisions	To get a job To do a course at TAFE To get a driver's licence To make more decisions about my money Go on a holiday involving a flight (to Gold Coast) To buy a new DVD/ video player To go on an ABBA cruise holiday Going on a holiday To get a tattoo To get a girlfriend To lose weight To manage money better To move out of home
Medical and health decisions	Nil (While no medical or health decisions were specifically the subject of the SDMP, a number of decision makers made these types of decisions during the pilot.)
Financial decisions	To purchase an iPAD, Assistance to use the iPAD To purchase a computer Money and budgeting skills Budgeting for and paying own chemist bill
No decisions made	Ten (or 38%) of the decision makers did not expressly identify a decision to work on during the pilot, despite various options being explored with the facilitator

The short time-frame of the pilot limited opportunities to implement many of these decisions, for example, an annual holiday. However, at the end of the day, a system of support for decision making must also consider the implementation of decisions that are made and any need for support with implementation. (There is further consideration of implementation in the discussion section of this report.)

7.3.14 Decisions worked on that were not specific to the pilot

As identified in the case note file review process, almost half of the decision makers were working on other decisions in addition to those decisions identified as being specific to the pilot. Examples of these are illustrated in Table 11.

Table 11: Example of decisions worked on that were not specific to the pilot

Decision Making Area	Decision (paraphrased)
Day-to-day	Increasing contact with family
	Independent travel training to the Mall
Big decisions	Moving to Qld to live in an aged care facility closer to daughters
	To move out of group home and into the home of a family member
	Deciding whether to plead guilty or not to a Police charge
	Changing Transition to Work service provider
	Moving out in to a group home from the family home
	Deciding where to go on a holiday
	Deciding whether to get a paternity test
	Having leg surgery
	Taking major medications
Financial decisions	Increased involvement in NSWTG budgeting
	Purchase of a new wheelchair

7.4 Role of the facilitator

The role of the facilitator ended up being more flexible than first envisioned, with more 1:1 decision maker support than anticipated. Interview, case note, discussion and reflection log feedback makes clear that facilitators played an active and at times intensive role with each participant in the pilot.

This was particularly so for those six without an identified supporter where a flexible approach enabled the facilitators to progress decision making for these decision makers by taking on the supporter role. In this role, a challenge for the facilitators was walking the fine-line between being a supporter and becoming ‘quasi’ case managers.

A major component of the facilitator's role was the provision of information and training on a 1:1 basis with both decision makers and supporters.

Much of the learning of the pilot comes directly from the facilitators' experiences from working with individual decision makers and supporters and the issues which arose are explored in more detail in the discussion section of the report.

7.4.1 Level of contact with the decision makers and supporters

Based on the review of case notes, on average, each decision maker received almost eight hours face-to-face contact with a facilitator (each visit was estimated at 1.25 hours). This amount of time was even higher when the facilitator was also the person's supporter, with some decision makers receiving in excess of 16 hours of direct support.[23] Direct support included initial face-to-face meetings with the decision maker (and supporter) to introduce concept of SDM and discuss issues related to the decision maker and follow up support.

In addition to the direct contact with decision makers, the review of the case notes reveals a range of other activities undertaken by the facilitators for each individual.

Activities included:

- follow-up phone calls with potential supporters
- phone calls to supporters arranging visits to decision makers and specific issues as they arose
- phone calls and emails to services to make referrals on behalf of the decision makers (for example, referrals for communication assessments, respite, courses)
- creating individualised resources for decision makers to assist in training about SDM.

There were up to 35 calls/ emails made in respect of an individual decision maker.

7.4.2 Feedback from decision makers and supporters on role of the Facilitator

The evaluation team asked decision makers and supporters about their experience working with the facilitators. The response was overwhelmingly positive, with comments made about the helpfulness, approachability and knowledge of the facilitators being made by both groups. There was no distinguishing question for decision makers where the facilitator had also acted directly as the supporter, but in the case of these six individuals, facilitators reported that they had built positive relationships and rapport.

23 These times are likely to be an underestimate as not every interaction with the decision maker or supporter was recorded.

7.5 Service provider training

At the conclusion of the only service provider formal training session undertaken, nine service providers completed an evaluation form. Six of these providers included an email address which enabled the evaluation team to send a follow-up survey three months later. There were only two responses to the follow-up survey.

Immediately following the information session, all nine respondents gave the session an overall rating of 'good'. Comments were that it was 'easy to understand', 'informative' and 'presented good ideas'. With respect to self-rated understanding of supported decision making before and after the session, on a five point scale, three people indicated that their understanding had improved by two points, two by one point and four people rated no change. Two thirds indicated that they would be definitely or likely to use supported decision making in their work as a result the session.

At follow-up, both respondents indicated previous experience with supported decision making – through individual service plans and goal setting and day-to-day encouragement of individuals to make choices. The most useful concept from the information session was described as:

"Knowing that it is available to everyone so everyone regardless of disability can make decisions."

Difficulties in implementing supported decision making were described as:

"Always difficult as you never know who is really driving the decision."

A potential solution was described as ensuring that staff are trained to "try to allow decisions and not to influence the process".

7.6 Workshop and focus group feedback

As mentioned in 3.5.1, a workshop and focus group was conducted in February 2014.

Supporters were asked to provide feedback on the workshop and focus group by completing an evaluation form (see Appendix 7). Feedback was provided by seven of the nine who attended.

The overall feedback from the supporters was positive. The opportunity to share experiences with others and the presentation by the participant and her supporter (mother) were the two aspects people enjoyed the most about the session. The most common suggestion for improvement was more time, with people commenting some of the sessions were a bit rushed.

The majority of the supporters (5/7) reported they received enough information to meet their needs as a supporter. Of the two who responded they didn't, only one gave an explanation, stating they would have liked more information about the implications of a participant's decision on family and other clients.

Supporters were asked to nominate the most important skill for a supporter. These were the responses:

- being able to listen and support the decision maker
- undertaking advocacy on behalf of the decision maker, effective communication skills, active listening, Work, Health and Safety (WHS) awareness
- common sense and skilful communication
- patience, understanding and love
- to listen and always use open ended questions
- to involve the person 100% with each decision making occasion
- a person centred approach, respect, privacy and confidentiality.

Supporters were asked to rate their understanding of SDM prior to the focus group session and their understanding following the session, on a scale of 1-5 (where 1 was 'knew nothing' and 5 'knew a lot'). The most common baseline rating of 3 or 4 is a likely reflection of the fact that most supporters had been in their role for a number of weeks or even months before the focus group. Notwithstanding this, as can be seen from Table 12, there was a notable increase in the supporters' understanding of SDM as a result of the session for six of the seven supporters.

The average level of understanding before the session was 3.2 and after the session 4.7.

Table 12: Supporter understanding of SDM before and after the Focus Group

	Before the session	After the session	Change
Supporter 1	3	5	+2
Supporter 2	4	5	+1
Supporter 3	3	5	+2
Supporter 4	3	5	+1
Supporter 5	4	5	+1
Supporter 6	1	3	+2
Supporter 7	5	5	0

In the specific focus group session with supporters run by the evaluation team as part of the workshop, supporters were asked to discuss their experiences of the pilot to date and to comment on aspects of the pilot. The topic areas and responses of supporters are below.

Benefits of the pilot

- Some supporters have witnessed an increase in the decision maker expressing (and initiating) their opinion about what they want to do
- Some decision makers are making more decisions about smaller day-to-day aspects their life
- Some decision makers have an increased awareness of their independence and how beneficial this can be for them
- Decision maker is now making choices 'from the heart'[24] rather than choices about things that actually aren't that important to them
- Some supporters commented they already take the position of SDM in their interactions with the people they support.

Difficulties with the pilot

- Need to consider the potential impact of the participant's decision on the carer/ supporter when assisting the decision maker towards a decision
- SDM is very 'person-centred' which is good, however the decision maker needs to be made aware/ educated of possible implications for others when making a decision
- Particular decisions have the potential to impact aspects of the participant's life – relationships, family members, health (e.g. decision to smoke, not take medications)
- Supporters who are paid carers have to manage the conflict that arises when a participant identifies a decision they want to make that the family doesn't agree with. This conflict can negatively impact how effectively the supporter can support the participant as they don't want to 'rock the boat'
- Supporter needs support themselves to be able to support the decision maker effectively
- Some decisions/ goals the person identifies can be completely unrealistic so it's a matter of working with the person to identify achievable goals – there is a skill in being able to do this
- Supporter needs to be aware of the context of the decision the person is working towards – e.g. if a decision maker has identified they want to make a decision about going on a holiday but the participant actually has no money then this is not going to be achievable.

Feedback on the project team

- Very client-focused
- Good at identifying new approaches to assist the decision maker and supporter to identify and work towards making a decision
- Have been beneficial in clarifying what the role of the supporter is and their scope of responsibilities.

24 Actual words of the supporter.

Written resources

- 'Skimmed through' and don't really refer to
- One decision maker legally blind so print material of no use
- The 'pros' and 'cons' resource is helpful
- Useful resource was – 'Blue Sky Thinking' – encourages the person to think outside of the box when identifying decisions
- Some commented they hadn't received any resources and requested on the day to have them (these were provided).

Sustainability of the pilot

- Sustaining an environment that is supportive of SDM is the key and this will come down to staff having the relevant skills/ experience in SDM as well as support from management team.

8 Other stakeholder views

8.1.1 The Public Guardian

Five decision makers in the pilot were individuals who had a PG appointed. The appointed guardians worked closely with the pilot facilitators and identified supporters where these existed. In four cases, this included the PG accompanying the facilitator to the participant's house to introduce the person or to subsequent meetings.

The general consensus was that supported decision making had been very valuable and the techniques it uses were not inconsistent with current approaches used by the PG when seeking the views of the person.[25] A key learning, however, was that it did take time to properly enact supported decision making processes, particularly where major decisions were involved, such as changes to accommodation. (See Tanya's detailed case study.) The resource cost associated with providing this time was also noted.

Other key issues identified by the PG were:

- The helpfulness of the involvement of a supporter – this assisted in confirming views and gave confidence that the decision was really what the person wished.
- The importance of the development of a level of trust between the decision maker and the supporter, especially for bigger decisions.
- The difficulties of identifying a supporter for some decision makers who were socially isolated. A suggestion was that service providers might be able to assist individuals to identify non-paid supporters.
- The difficulties for decision makers in overcoming a range of influences, for example, differing views of service providers, overcoming history and stereotypes about people with a disability, overcoming everyone else's opinion, experiences of a lifetime of having to abide by everybody else's opinion as well as the individuals lack of familiarity with making decisions and power imbalances.
- The need for training for all of those involved with the participant; day-to-day staff in particular may not be supportive – the process of supported decision making may be seen as too much of a 'hassle'.
- A need for widespread cultural change so that supported decision making is taken seriously in the community. It was noted that a formal guardianship order, whilst being the antithesis of SDM, brings a formal legitimacy which creates authority for the decision maker.

Although the pilot was small-scale and the number of individual decision makers who were under guardianship even smaller, the success of supported decision making for these individuals suggests that SDM could be used in future to target people who would otherwise have a Guardian.

25 Nevertheless there is a clear legislative difference in terms of the status of the person's views when there is an appointed substitute decision maker.

8.1.2 NSW Trustee and Guardian

Nine decision makers in the pilot had the NSWTG appointed to make decisions about their finances. The evaluation team was particularly interested in finding out how SDM could be used in conjunction with financial management, and asked the NSWTG representative "What are the key elements needed for SDM to be used when there is a financial manager appointed?"

Key issues identified by the NSWTG were:

- The decision maker having a support person to assist them with identifying what decisions they would like to make regarding their money, to communicate these decisions with NSWTG and to provide support with day-to-day budgeting strategies, is essential in ensuring there is consistent and meaningful engagement of the person with their financial decisions.
- If the decision maker has basic money skills this increases their ability to have input in to decisions about their finances.
- There is a significant need for people to receive money skills/ budgeting training before they can engage in the decision making process regarding their money. This training is not currently within the scope of NSWTG services and needs to be sourced from external services.

8.1.3 Day Program Provider

Apart from the supporters who were employed by the participating day program provider, three people at the management level provided feedback on the pilot. The evaluation team was particularly interested in whether there had been any broader impact on the organisation as a result of several of their service users and team members being part of the pilot.

In summary, the day program provider management reported:

- no difficulties using SDM in the organisation
- an increased awareness and understanding of SDM as a result of the pilot
- the SDM handbook/ booklet and toolkit were found to be useful
- there was a ripple effect due to the pilot, for example – discussing SDM in service user committee meetings and staff and management meetings; witnessing the positive impact of the pilot on decision makers such as more confidence for one decision maker to discuss what he wants with his family and 'opening up his communication' with others
- planned changes to how the day program provider supports its service users as a result of the pilot, for example, increased involvement of service users in the development of the program plan and sharing the information about SDM amongst other service users and team members.

9 Discussion

This section discusses the key learnings from the pilot and identifies the implications of these for any broader adoption of supported decision making processes going forward.

9.1 'Decision readiness'

'Decision readiness' not only means that an individual has a decision/s on which they wish to work and a supporter available to them, but also that they have the knowledge and skills to make a decision.

To reach this point, facilitators in the pilot were required to invest considerable time working 1:1 with each decision maker to build their capacity to be decision ready. Supporters too required mentoring in how to assist in this capacity building.

"Supporters have a key role to play in helping individuals to weigh up their choices."

David* is in his early 30s and is eager to move out of his parents' home and live in a group home. David's supporter (and mother), Lisa, believed that for David to make an informed decision he needed to better understand the consequences of moving. David agreed to write a list of his rights and responsibilities thinking about the differences between living at home and living in a group home. This was done by drawing a line down a piece of blank paper and simply thinking about what the move would look like. Five months later, after several sessions with his supporter and facilitator, David repeated the exercise. David's second list was much more detailed. He was able to see the marked improvement in his ability to think through his decision by comparing the two lists he had made. This has provided David with a transferrable skill, enabling him to better communicate his preferences.

**Name changed*

The final sample contained a wide diversity of decision makers at various stages of 'decision readiness'. Some had difficulty identifying supporters (see supporter section below). To be effective, facilitator support needed to be delivered face-to-face. Additionally, many decision makers had limited literacy and communication skills. Work was required to identify a decision for consideration. Individuals required training and support to develop the confidence and skills to enable them to make their own decisions. Even after a number of months, some individuals were unable to identify a decision on which to work, however the project team saw that more decisions were being made outside of the pilot boundaries. It was interesting to note that there was a decrease in the number of decision makers who said that they made good decisions over the course of the pilot. It is likely that this is due to increased awareness and experience of what is involved in making an informed decision.

Implications

1. Facilitator support was required to assist individuals to be 'decision ready'.
2. 'Decision readiness' takes time.
3. There is a need for 1:1 training by skilled individuals (facilitators/ supporters) to support individuals to be 'decision ready'.
4. Decision makers may have a more realistic understanding of the decision making process after experiencing supported decision making.
5. The person's communication needs and style need to be established and accommodated as a first step to SDM.

9.2 The need for flexible supporter arrangements

A variety of supporter arrangements were put in place by decision-makers, including family members, paid supporters (staff of a service used by the decision maker), facilitators acting directly as supporters and in one case, an advocate.

9.2.1 Identifying a supporter

The difficulties encountered in identifying suitable supporters were not anticipated, although given the limited availability of natural supporters, this is not surprising.

This is a fundamental issue for supported decision making, for without a supporter there can be no 'supported' decision making. For individuals who do have family members actively involved in their lives, choosing a family member as a supporter would seem to be a self-evident logical choice. If SDM is to be implemented at scale then this would be the obvious place to start.

The facilitators tried not to influence an individual's decision about possible supporters but explored with individuals who in their networks might be able to take on this role.

Some individuals invited declined to be supporters because they felt they were already implementing supported decision making practices.

"Getting to know the person and the impact of important relationships in their life is an important part of being able to provide appropriate support."

We look to Michael*, a young man who likes to spend time with friends and family and values his relationships highly. Michael, like many young men, wants to develop his independence and self-reliance. Michael chose a paid supporter and started to think about ways to become more independent, such as learning catching the bus to his day service and exercising by walking around the block by himself. Concerns were expressed by other people in Michael's life about the risks to Michael travelling unaccompanied on the public bus. Michael's paid supporter felt the pressure of balancing Michael's wants and needs with those being expressed by other people in his life. Whilst the UN convention clearly sets out that people with disability should be afforded the right to make their own decisions, the reality of implementation in practice can be far more difficult, especially when a person's decision may impact heavily on those around them. In Michael's situation – whilst he wanted to catch the bus to his day service this would not have been possible without the support of other people in his life. As a result the decision was put on hold. While, the option was available to Michael to continue to look at this decision, he decided to work on other decisions. It is the assumption of the facilitator that Michael's desire to maintain good relationships with other people in his life is more highly valued than his desire for independence.

**Name changed*

9.2.2 Paid supporters

The willingness of paid staff to act as supporters was beneficial in assisting almost half of the individuals in the pilot to access supported decision making. Individual choice and staff and organisation receptiveness combined to make the process of supported decision making successful for these individuals.

This suggests the potential need to build the capacity of disability service providers to become a source of facilitators or supporters. For individuals, especially those without family, this meant they were able to access supporters with whom they had a pre-existing relationship, and to act on their preferred supporter preferences.

The pilot showed that being a supporter required a definite commitment of time. Facilitators identified that the managers of group home staff within service provider organisations did not always recognise the need or importance for group home staff to have dedicated one-on-one time with decision makers to discuss SDM.

Some staff felt the time pressures of the supporter role and would have preferred having more time supporting the decision maker and the recognition of this from management. If SDM is to be adopted more broadly, there needs to be recognition of the time implications for service providers where staff take on the role of supporter.

While recognising the usefulness of paid staff supporters, the pilot team was also mindful of the potential for conflict of interest when paid service providers are acting as supporters. In some instances the pilot encountered difficulties when it came time to implement decisions which had been made by the decision maker because of family members who did not support the decision. (See Section 9.9.2 Conflict of interest.)

"It can't be assumed that family members will wish to take on the supporter role."

Jenny* is a young woman with a great sense of humour. Sometimes her 'pranks' went too far and created challenges for her carers and others. Jenny took medication to calm her moods, and understood why it was needed. Jenny's mother declined to be a supporter in the pilot. The facilitator saw this as a missed opportunity. Jenny eventually chose a support worker to be her supporter, and work was done to assist Jenny to see the consequences of her decisions (actions). For example, because she sometimes decided to grab the steering wheel, she was not allowed to sit in the front seat of the car. Toward the end of the pilot Jenny's mother sought engagement with the facilitator and some work was started on supporting Jenny's decision to get a tattoo and have a party.

**Name changed*

9.2.3 Facilitators as supporters

Without the flexibility to have used facilitators as supporters, 25% of decision makers would have been unable to participate in supported decision making. This suggests that any system of SDM requires the capacity to access supporters who are not already part of the networks of individuals who require support with decision making. The emergence of facilitators as supporters in the pilot was organic rather than planned. This required a considerable investment of time in getting to know the individual, their preferences, communication styles and decision making styles.

9.2.4 Family members as supporters

Decision makers commonly nominated family members as their preferred supporter. Not all family members were willing to take on this role. The withdrawal of one participant from the pilot corresponded with the decision of her mother to decline to be involved in the pilot.

Trusted close relationships which an individual may have with a family member can be beneficial to the supported decision making process. Notwithstanding this, the pilot showed that in reality family members were not always a natural fit. Some family members did not wish to take on the role; in other situations, family members did not support the person's desire to make more of their own decisions.

Sometimes there was conflict of interest with family members as supporters.

Three individuals who withdrew from the pilot did so because they were already satisfied with the level of (informal) support they were receiving around decision making from family members.

9.2.5 Supporter readiness and training

In the same way that individual decision makers needed assistance to be 'decision ready', supporters too, required assistance with their role.

Most training for supporters occurred during 1:1 engagement between the facilitator and the decision maker/ supporter. As well as facilitators providing ongoing training, coaching and support in these sessions, supporters also came together in the workshop. The workshop was well received by the supporters and was an opportunity for them to share information and experiences. There was a general sense that it would have been beneficial to have held multiple workshops and for these to have started earlier in the pilot.

Implications

1. Some individuals will be unable to identify their own supporters and will need access to an appropriate mechanism through which to find supporter/ supporters.
2. Some individuals will choose to rely on paid service providers for the provision of support in SDM.
3. The supporter role requires an investment of time and where the supporter is a paid service provider, specific provision needs to be made for the provision of dedicated supporter time.
4. Where a supporter is previously unknown to the individual, there will need to be an upfront investment of time to develop a trusting relationship.
5. Access to an 'independent' supporter can be helpful for some individuals, for example using an advocate.
6. Supporter readiness and training may be a factor in the willingness of family members to take on the role of supporter.
7. Targeted training about supported decision making to increase familiarity with supported decision making principles and processes may assist family members and others to take on the role of supporter.
8. The potential for conflict of interest needs to be recognised (and appropriate mechanisms enacted) to deal with the conflict where a family member or a paid service provider is a supporter. (See 9.9.2 below.)

9.3 Limits to decision making

The pilot showed a number of ways in which a person's choices were limited. These included restrictive family attitudes and lack of interest in supported decision making, rhetoric around supporting the growing independence of family member with a disability but resistance in practice and a tendency (most notably among service providers) to prioritise duty of care over dignity of risk. In other situations, cultural norms in the family environment influenced decision outcomes. (See Abdul's story in text box.) Supporters sometimes felt a protective need to stop decision makers from making decisions they considered risky. This can deny the person the right to take risks. (See 9.9.1 below.)

"Balancing dignity of risk and duty of care is a challenging part of the supporter role."

Abdul* enjoyed living in his group home but sometimes became angry and would leave the house and walk to a local park to cool off. He always returned. Staff at the home feared Abdul would be hit by a car on these walks and, for his own safety, wanted to prevent him walking alone in the streets. The facilitator worked on the decision with Abdul and with his keyworker, who was also his supporter. Abdul clearly articulated how to cross the road safely (look both ways and cross if there were no cars). His supporter noted that the park was close and there was only one road to cross, and the road was not busy. The facilitator encouraged the supporter and staff at the group home to consider Abdul's right to go for a walk when he chose to, whether he was angry or not and suggested reviewing Abdul's road crossing skills for any additional training needs. Helping the person to manage risk and to carry risk is hard but necessary work.

**Name changed*

Implications

1. Supported decision making will require more than education and training and will need to address attitudes and mindsets of both family members and service providers who may potentially take on the role of supporter.
2. Modelling and mentoring (such as that undertaken by the facilitators in the pilot) can assist with both training and attitude change.
3. Balancing dignity of risk and duty of care will require consideration of appropriate safeguards. (See 9.9.1 below.)

9.4 Financial decision making

The NSW pilot was distinctive in that it specifically included a sample of decision makers who were under financial management. The pilot findings demonstrated that area of financial budgeting and decision making was one of broad interest across the whole cohort of decision makers, not just the NSWTG sample.

This interest was manifest in the reported changes to decision making which occurred over the course of the pilot. Whereas at baseline most decision makers reported they made few of their own financial decisions, by follow-up over half of the sample now made some of their financial decisions. However, the outcomes amongst the NSWTG group remaining at follow-up showed a lower level of increase in financial decision making. (Only two individuals reported an increase.)

Implications

More work needs to be undertaken to develop supports which can assist individuals who are under financial management to take greater responsibility for their own financial decision making.

There needs to be further investigation of the barriers which prevent individuals under financial management from exercising supported decision making.

"Big decisions can sometimes mean the need for more support with day-to-day decisions."

Many participants made a decision to get healthy or to increase their fitness. This goal is common amongst the general population and is often set as a vague goal with no specific decisions about how to implement it. Many participants still wanted to make the decision, however the day to day implementation proved to be more difficult for some participants, as is often true in the broader community. For this reason many participants needed support with the smaller day to day decisions and reminders of their commitment to their bigger health and fitness decision. This can be seen clearly in the example of Kerrie* who indicated that she would like to lose a significant amount of weight (10+ kg). Kerrie further detailed this goal stating that she was going to improve her diet and increase her level of activity. Kerrie was supported to trial a few different fitness activities (Zumba, the gym, dance class, walking to and from work) and was then supported to set up a routine in which her preferred activities were encouraged. Kerrie now walks to and from work a few days per week, sees a personal trainer once per week and has a gym membership. Kerrie is enjoying her increased level of fitness and is starting to see the benefits of her hard work on the scales. She is motivated by her personal trainer and is given a new bead for her charm necklace when she loses a kilogram. Kerrie is thinking about ways to improve her diet but admits that junk food is a big weakness!

**Name changed*

9.5 Decision making vs. goal setting

Decisions can be large or small, straightforward or complex. Deciding whether to catch a bus or a taxi is a different matter from deciding where to live. A SDM approach can assist individuals to take responsibility for their own decisions whatever the level of impact. In the domain of providing an alternative to statutory substitute decision making, the focus is on major lifestyle decisions such as services and supports, where to live, financial management and health. While some decisions worked on during the pilot were of this nature, including one person who moved house, others were day-to-day, for example seeing a film. Decision makers learnt from the experience of making decisions and a number of individuals were making decisions in more areas of their life than before they joined the pilot.

"Simple resources can make a big difference."

Carla* recently had a lengthy admission to hospital for leg surgery. During her admission she was physically restrained by staff and twice transferred to a mental health unit. Carla and her supporter felt that Carla's bad experience at hospital was mostly about hospital staff not understanding how Carla could be best supported. The hospital had Carla's support plan but it was a large document and was misplaced by staff. In response - with guidance of the SDMP facilitator and assistance from her supporter - Carla decided to write a one page story that she could give to hospital staff the next time she needed to go to hospital. This might help them to give her the support she needed. Carla adapted the 'important to/ important for' tool to write her story. It told the story of who she was, why she might become anxious, and how best to support her if she did become anxious. She felt it would give her more control over the support she would get the next time she is in hospital. Carla and her supporter are thinking about other situations in which the tool may also be used.

**Name changed*

"Making decisions for yourself can give you insights into the consequences of your actions".

Chantelle* chose her group home keyworker as her supporter. Part of her income is managed by the NSWTG. The facilitator and financial manager initially visited Chantelle at home with her supporter where Chantelle noted that she tended to impulse buy.

While Chantelle 'shopped' at the chemist, her medications and other items she purchased were put on a tab and paid for by the NSWTG. Chantelle decided she wanted to pay her own chemist bill. The facilitator worked with Chantelle, her chosen supporter and the NSWTG to make this happen. Together a plan was developed. Chantelle negotiated with the chemist to receive her bill fortnightly. This made it easier to budget than monthly. Chantelle started paying her account in cash. Chantelle came to see that buying toiletries and other non-medical items at the chemist was more expensive than buying them at the supermarket. She changed to purchase these items at the supermarket and saved money as a result. Chantelle is keen to look at other areas in her life where she might be able to make more decisions for herself, and perhaps save even more money!

**Name changed*

Supported decision making processes can play a key role in goal setting and support planning but goal setting and support planning themselves are not necessarily supported decision making. Furthermore supported decision making processes can be equally used for every day decisions. An important element of decision making is that the decision is implemented. (See discussion at 9.6 below.) Much of what

happens in goal setting are plans, ideas and dreams. The implementation of some of these big ideas can involve many smaller contributory decisions along the way.

A goal setting process can be person centred without embracing SDM.

Implications

1. Experience with supported decision making can lead to more involvement in decision making in other areas of an individual's life.
2. Dissemination of the principles of supported decision making as well as information about processes which are helpful will be needed to enact attitudinal and practice changes amongst stakeholders who provide supports to people with a disability and the broader community.

"Seemingly simple decisions can be made complex when there is a lack of support available to work through and implement decisions."

Mandy* lived in a group home with drop in support. She made a decision to get an iPad and her financial manager approved the cost. Mandy had limited natural supports and chose her keyworker as her supporter to buy the iPad. The facilitator worked with Mandy and the keyworker around implementing the decision. Mandy took initiative by getting a quote and later found another cheaper quote. Her supporter and other staff at the group home reported a number of obstacles: they were too busy, there were greater priorities for Mandy, the supporter went on holiday, there was a concern that Mandy would lose the iPad.

*Name changed

9.6 Implementation of decisions

An important part of any decision making is the implementation of the decision once it has been made and the opportunity to learn from the consequences of the decision. Some decisions which were made during the pilot were of a longer-term nature and the pilot timeframe was too short to examine their implementation. The Pilot Handbook only briefly addressed implementation and it is not addressed at all in the companion handbooks for decision makers.

Implementation is an important concern and many supporters indicated that they did not have the time to assist with the implementation of decisions. This was particularly real for those supporters who were in paid service provision roles.

The role which others play in putting a decision into practice was an area of challenge for the pilot. In some situations supporters felt that they did not have the 'authority' to assist with implementation (for example, one decision maker had a wish to get a tattoo, would have needed his parents 'involvement' to carry this out).

This was echoed by the words of one facilitator:

> *"One of the difficulties I've had is getting other people on board – staff, families, service providers, case managers etc … I think this is partly to do with our ability to communicate the benefit of SDM to others."*

Some individuals in the pilot encountered external blockages to implementation of their decisions as the result of power imbalances between individuals who could not effectively advocate for themselves and service providers who exercised choice and control. In other instances, some pilot participants chose not to proceed with their decision as they feared it would damage their relationships with significant others who had indicated their opposition to certain decisions.

This suggests that supporters can face dilemmas about where and when not to intervene to guide decision makers in the implementation of their decisions. There were some instances where a decision maker did not want to involve others such as key family members, despite implementation of the decision needing their involvement.

Implications

1. SDM needs to include support for the implementation of decisions which are made.
2. Weighing up choices and the impact on others should be part of training in supported decision making.
3. The resource materials about supported decision making should provide additional advice and suggestions about implementation.

9.7 Resources and tools

The NSW Pilot developed written tools with an expectation that these tools would stand in for the face-to-face contact with facilitators. However, the experience in the pilot did not bear this out. Despite the considerable work which went into the creation of the tools and resources, in general they appeared to have provided limited stand-alone assistance to decision makers and supporters. One contributing factor could have been the low literacy levels amongst the decision makers. The exception was the Easy Read booklet which appeared to serve as a focal point and provide legitimacy to the supported decision making process for some decision makers. The facilitators reported that a number of the individual tools in the resource kit were particularly helpful (see David's and Carla's stories) but that as a package, the volume of material was overwhelming. The resources and tool kit would have benefited from an introductory section which summarised when each tool might be used and for some tools which were interrelated- in what order they should be used. Resources which were able to be tailored to individuals were most effective.

Implications

1. Provide access to the written resource materials in a more user-friendly format e.g. web accessible.
2. Consider an audio version of the easy read SDM handbook or video alternatives.

3 Consider involving/ getting advice from a range of therapists (e.g. speech pathologist, occupational therapist) in the development of individualised resources, as well as from those who are closest to the participant.

4 Streamlined resources such as fact sheets may be more attractive to time-poor supporters and others.

9.8 The role of facilitator

Facilitators played an instrumental role in the pilot. Leaving aside the specific situations in which the facilitators acted directly as supporters, the facilitators remained key enablers of the SDM process. They introduced the concept of supported decision making to participants, assisted with the establishment of decision maker/ supporter relationships, cemented the legitimacy of SDM, provided role modelling, training and access to tools, and guided and engaged other individuals who had a role to play in decision implementation.

While the facilitators had limited opportunity to play a broader education role with service providers, the experience with the service providers involved in the pilot showed the importance of this.

Implications

1 Facilitators play a crucial role in enabling SDM.

2 The role of facilitators in the broader education of service providers needs to be recognised.

9.9 Ethical, policy & legal issues

The pilot raised a number of ethical, policy and legal issues.

9.9.1 Duty of care and dignity of risk

The issue of balancing dignity of risk and duty of care has been described in 9.3 above. While service providers may have a risk averse culture, some individuals might need access to specific training and skill development which will enable them to safely undertake a proposed activity. Having received the training and acquired the skill will provide confidence both to the person and to others that they can exercise the necessary skills. In the case of Abdul, a real life assessment of his road crossing skills, and provision of additional training and shadowing as needed may have avoided the whole question of duty of care and dignity of risk.

Having said this, however, the issue of dignity of risk and duty of care is a very real one and needs to be identified, acknowledged and addressed. In the absence of this, an individual may not be able to exercise their own decision making rights and their power and control is compromised.

The pilot faced an ethical dilemma with a decision maker who had Prader Willi syndrome and who wished to make more decisions about their food intake. This is a situation in which the rights of the individual to make their own decisions need to

be considered alongside the clear need to include adequate safeguards. Supported decision making presented an opportunity to think about ways to balance these to increase the opportunities which the decision maker could have to make some decisions around their food intake, for example in taking a greater role in food choices for particular meals.

9.9.2 Conflict of interest

Conflict of interest is an issue which needs to be identified and managed where it exists. In some cases, the wishes of an individual and of their family may diverge. In others, the operation of a service program may not allow for an individual's preferences to be accommodated.

The views of others on decision outcomes and the need to balance personal relationships and decision choices were issues faced by decision makers in the pilot. In most cases decision makers chose to preserve relationships instead of pursuing a decision that their supporter didn't agree with. The choice of a decision maker not to communicate a decision to a parent who it was anticipated would disapprove was respected by their supporter. However, as this individual would need to be involved in the implementation of the decision, it did not proceed.

There are positives and negatives to the selection of supporters from amongst the ranks of family members and from independent sources. In the former case there is the potential for conflict of interest between the family member's own position on a particular decision and that of the decision maker; in the case of the latter, scope for conflict between the supporter and members of the decision maker's family.

9.9.3 Legal implications

On the legal front, the pilot presented a number of opportunities to explore the adoption of supported decision making alongside existing legal substitute decision making arrangements, primarily guardianship and financial management. Supported decision making processes which were enacted worked well. However, where there was a guardian in place, the guardian reported that the time taken to make decisions was greater than would have been anticipated if supported decision making was not in place.

The experience of the NSWTG decision makers in the pilot suggests that more financial literacy skill development may have supported increased financial decision making. The NSWTG would also need to be satisfied about these competencies.

Implications

1. The issue of dignity of risk and duty of care needs to be identified, acknowledged and resolved.
2. The potential for conflict of interest needs to be identified and managed where it exists.
3. Adoption of supported decision making processes for individuals who are under formal guardianship will require more coordination between the individual and their supporter and their guardian/ financial manager. There is a time implication for this.

The current legislation provides that NSWTG as a substitute decision maker, ensures the prudent financial management and the minimisation of risks in relation to an individual's funds. This can present some barriers in relation to supported decision making. However the current legislation does allow NSWTG the flexibility of authorising an individual to manage part of their estate. This is where competencies are relevant. As a substitute decision maker, in granting an authority to the individual to manage part of their estate, NSWTG need to be satisfied that the individual has the necessary ability/ skills to make those financial decisions.

9.10 Cultural considerations

While the process of supporting individuals around making more of their own decisions worked well for all individuals, irrespective of cultural background, the need for cultural sensitivity is required not only at implementation but also during the decision making process. As SDM is intended to be driven and tailored to the person, it can take account of different cultures and family norms. For instance, if it was the family practice/culture that the father made the decisions for the family, non-family supporters needed to be aware of this, respect it but still seek ways for the person to express their views and be involved in the decision making.

Implications

1 Supporters require cultural awareness sensitivity when supporting an individual from another cultural background.

10 Conclusions

The pilot demonstrated that SDM could be successful for a diverse group of people with a disability and varied support needs and circumstances.

In the area of financial decision making, in particular, the decision makers who were under financial management were included in light of their potential to take responsibility for much of their day-to-day financial decision making. Overall however, those under financial management reported insignificant changes to the number of financial decisions they made for themselves. Nevertheless, across all of the other decision makers, individuals were making more of their own financial decisions. This was the most common area in which people had indicated they wanted to make more of their own decisions before the pilot.

Individuals showed increases in confidence and sense of control in their own lives and were making decisions in areas where they had not made decisions before.

The barriers to SDM were largely not due to the person's disability but to the lack of supports that were immediately available to them. Circumstances of social isolation, lack of power and unfamiliarity with making decisions, low expectations by others, power imbalance in relationships and the need for investment of time within which to do SDM all create challenges for SDM.

Key enablers were 1:1 support and training with a trusted individual and the time available to work thoroughly through the decision making process, together with role modelling, mentoring and training of people in the supporter role and a shift in the 'mindset' of the broader service system providing services to the individual.

All of this serves to underscore the intent of article 12 of the UN Convention to accord people with a disability, their right to have their legal capacity recognised. In the words of Professor Patricia O'Brien[26] "to listen deeply to people." The path to the achievement of this requires action on the part of service system working on the fronts of both broad community education and cultural change and "one person at a time".

26 www.cds.med.usyd.edu.au/news-a-information-66/videos/153-prof-patricia-obrien-speaks-at-the-ihc-symposium-in-nz

11 Recommendations

Ongoing support for SDM

1 That ADHC consider implementing ongoing mechanisms to promote the adoption of SDM. This could include:

1.1 Ongoing access to dedicated SDM facilitator positions.

1.2 Provision of "train the trainer" opportunities for service providers, similar to that undertaken in South Australia.

1.3 Development of training opportunities specifically targeting potential supporters.

1.4 Creation of a website to allow easy access to the range of tools and resources compiled for the pilot.

2 That the PG considers implementing ongoing mechanisms to promote the adoption of SDM. This could include:

2.1 That the PG utilises SDM processes as the starting point when making decisions for individuals who are appointed under guardianship.

2.2 That there be consideration given to trialling of SDM processes in respect of individual applicants prior to an application for guardianship proceeding to the Guardianship Tribunal.

3 That the NSWTG considers implementing ongoing mechanisms to promote the adoption of SDM. This could include:

3.1 Further investigation into the development of supports to assist individuals who are under financial management to take greater responsibility for their own financial decision making.

3.2 Conducting an additional SDM trial for another cohort of current NSWTG clients suitable for section 71 approval.

SDM Framework

4 That ADHC consider further development, promotion and dissemination of the SDM framework developed for the pilot:

4.1 The SDM framework developed by ADHC be expanded to recognise the need for flexible support arrangements, including family members, paid supporters and advocates.

4.2 That the framework recognise the need for dedicated supporter time.

4.3 That the framework further expand information about the potential for conflict of interest for a paid service provider or family member acting as supporter and provide examples of how to manage this conflict.

Tools and resources

5 That ADHC undertake revision of the tools and resources produced for the pilot:

5.1 The pilot handbook be expanded to include a detailed discussion of implementation of SDM.

5.2 Implementation issues are included in the decision maker handbooks.

5.3 Provide access to the resource materials in a more user-friendly format for example, web accessible.

5.4 Consider an audio version of the easy read SDM handbook or video alternatives.

5.5 Consider the production of a number of one page fact sheets about SDM.

Training activities

6 That ADHC consider undertaking a range of broader service provider and community education sessions about SDM.

Appendix 1: Case studies

Two comprehensive case studies are provided in this section to give an overview of the total experience of these individual pilot decision makers.

'Tanya'[27]

Profile:

Tanya is a woman in her early forties who has Down Syndrome. She communicates verbally and is able to read basic English. She resides in a group home with other residents and receives drop-in support daily. Tanya attends supported employment during the week and is actively involved with her local church on the weekend. She is under the guardianship of the PG and her finances are managed by the Trustee and Guardian (NSWTG).

Tanya signed up to the pilot in August 2013 and was referred to the pilot internally through ADHC.

Supporter:

A staff person was initially identified as a supporter. Later in the pilot, Sophie, who is a friend of Tanya's from church, took on the role of supporter for her second (major) decision.

Decision making:

Tanya identified a decision she wanted to work on in the pilot soon after joining. She wanted to buy an iPad and have assistance in learning how to use it. Due to time constraints reported by the initial supporter, the facilitator became actively involved in assisting her to implement the decision.

At the time Sophie became Tanya's supporter, it was because she was also looking at the option of moving to another group home. Therefore, the staff person and the facilitator acted as Tanya's supporter for the iPad decision and Sophie as her supporter for the accommodation decision.

At baseline, Tanya reported she made few decisions in the area of finances/ budgeting and big decisions, that she made most of her decisions regarding day-to-day activities and some of her own medical decisions. She stated she was 'quite confident' in making her own decisions and when she needs assistance asks staff or family to help her.

When asked what she thought SDM means, she reported "I like to spend my own money". Tanya said she joined the pilot to "learn about money and my budget". When asked whom she would like as her supporter she named a few of the staff that work with her at the group home, including her keyworker.

At follow-up, three months after her commencement in the pilot (November 2013), Tanya could not articulate what SDM means but she had the Easy Read Booklet on hand and referred to it. She said she had not made any changes to the way she makes decisions

27 Name changed

but stated she does not like it when people "take over for me" and make decisions for her. Tanya still did not have an iPad and because of this was understandably not sure if she was satisfied with the decision she had made just yet. She identified the facilitator as the person who was working through the decision with her.

When asked who her supporter was she named her keyworker even though this person had declined to be her supporter in the pilot. Tanya reported she now makes all of her own day-to-day decisions (an increase since baseline), only a few of her big decisions (no change from baseline), all of her own financial and budgeting decisions (increase from baseline) and was not sure about her medical decisions (whereas as baseline she claimed she made some of her own decisions in this area). Tanya thought she made good decisions 'sometimes'.

Tanya engaged well with the Easy Read booklet and told that she found it very useful, particularly the worksheet in it. She and the facilitator spent time working through the booklet together.

During the time from November to when the final interview was conducted in April 2014, several significant changes occurred for Tanya. Her supporter, Sophie joined the pilot, she was presented with an opportunity to move to a more suitable group home and she purchased her iPad.

At the final interview, Tanya said SDM means "I can do things myself" and she confirmed she had made some changes in the way she makes decisions, citing the people who assist her. She said she now feels more satisfied with her decision to buy an iPad as she now has it. But she is not yet completely satisfied as she still needs someone to assist her to connect to the internet. Tanya reported she 'often' makes good decisions ('sometimes' at follow-up) but on the day the evaluation team met with her was unable to comprehend the concept of level of confidence and rating the control she has over her life, therefore these were not recorded.

Sophie supported Tanya through the decision to move house. Sophie was the only supporter in the pilot who was a friend and not a service provider, family member or professional advocate. Sophie viewed her role as "helping Tanya to look at all the options for her (moving to another house) and making sure she understands all the options available to her and makes the best decision for herself." Sophie's active involvement in assisting Tanya with the decision to move, included talking to her about what is involved in moving house, taking her to look at churches in the area and helping her to become familiar with the area. Sophie reported both she and Tanya were satisfied with the decision for Tanya to move. Sophie was asked by the Public Guardian for her view on Tanya's proposed move.

The facilitator had extensive involvement with Tanya. This involved for example, visits to Tanya at home around 10 times which represented approximately 16 hours of face-to-face time, the sending and making of over 30 emails/ phone calls (including to the OPG and NSWTG) following up issues in relation to Tanya. The facilitator was instrumental in coordinating an approach between the house staff and NSWTG to ensure the iPad was affordable and ultimately purchased.

Observations by the facilitator and the evaluation team:

- SDM works but it takes time.
- Simple tools can be useful in facilitating decision-making.
- Having a committed supporter and being 'person centred' contributes to the achievement of SDM.
- A facilitator can assist with complex decisions, especially when the supporter is not familiar with government processes or has limited time or confidence and there is considerable coordination required.
- The concept of a 'supporter' and the allocation of this role can sometimes be a bit blurred. A number of stakeholders acted as supporters to individual decision makers in a quite fluid way. For example, stakeholders using SDM principles were central to the success of the accommodation decision in the case study above. These principles were reinforced by the facilitator at the group meetings with the participant.
- This case study showed the decision maker's ability to make a complex decision once the support to make the decision was available.
- Even though a decision maker may not be able to articulate the benefit of SDM, it is nevertheless beneficial.
- Outcomes are facilitated when all stakeholders are around the table and with the person during the decision making process.
- There can be resistance to the provision of SDM training/ additional skills by the service provider
- It is time intensive when the facilitator also acts as a supporter.

'Naomi'[28]

Profile:

Naomi is a woman in her early twenties who has Prader Willi Syndrome. She communicates verbally (both in English and her language of origin) and is able to read and write, including completing the follow-up survey independently on the computer. Naomi lives at home with her mother and older brother. She attends a disability day program five days a week.

Naomi signed up to the pilot in late November 2013. She found out about the pilot through a presentation at the service user committee at her day program.

Supporter:

Naomi took a couple of months to identify who she would like as her supporter, over several regular meetings with the facilitator to explore her options. She eventually chose her day program keyworker, 'Belinda', who agreed to support her.

Decision making:

Naomi identified two decisions she wanted to work on:

1. To decide what she eats.
2. To have Flexible Respite so she can go to see a 'horror' or 'scary' movie.

Changes to decision making:

At baseline, Naomi said she makes some of her own day-to-day decisions, a lot of her 'big decisions' and only few of her medical or financial/ budgeting decisions. She said she was 'very confident' in making her own decisions and makes good decisions 'sometimes'. She rated the control she feels she has over her life (on a scale of 0-10) as seven. When asked who helps her make decisions she mentioned her mother but was unable to say how she assists. She reported experiencing difficulties in making her own decisions in the area of what she eats, advising that others decided for her.

The reason Naomi joined the pilot was "to make more of my own decisions" but she was not sure who she would like to have as her supporter.

Five months after she joined the pilot, Naomi articulated what SDM means as "making our own decisions and having choices and other people can't make decisions for me". She described the benefits to being part of the pilot as: "I can make my own decisions and I get to have choices". She reported her confidence level of making her own decisions as 'very confident' (no change from baseline) and said that there were no areas of her life where she was making new decisions. The level of control she felt she has over her life remained the same.

At follow-up Naomi had not yet been to a scary or horror movie, but an implementation plan was developed: the facilitator identified flexible respite options and the supporter assisted Naomi to submit an application for the respite. She reported she was 'satisfied' with the decision she had made to go to the movies.

28 Name changed

In relation to the SDM resources, Naomi reported she had received the Handbook and the Toolkit but was not sure about the others. She described the resources she did receive as 'extremely useful' and liked the Handbook in particular. She offered no suggestions as to how the resources could be improved.

Belinda (her supporter) reported she assisted Naomi to make the decision about going to the movies by giving her alternatives to think about, finding out more information and talking to her about the consequences of her decision. She reported a change for Naomi since being part of the pilot as now deciding "on what she wants to do" and noted since being in the pilot Naomi is now assisting others in making decisions (through a committee). Belinda rated Naomi's satisfaction level with the decisions as 'satisfied', which is consistent with Naomi's self-rating.

The facilitator visited Naomi at least five times, which represented approximately six hours of face-to-face time. In addition, the facilitator sent/ made between five and ten emails/ phone calls following up issues in relation to Naomi (including seeking advice from Prader Willi Clinic at RPA) and made at least two phone calls to her supporter.

Observations by the facilitator and the evaluation team:

- Naomi identified one of the decisions she wanted to make as being able to eat whatever she likes. Naomi has a diagnosis of Prader Willi, meaning, among other things, she is unable to control her craving for food (Prader Willi Syndrome Association of Australia www.pws.org.au/)

If left unsupervised, someone with Prader Willi can eat a life-threatening amount of food, and are at much higher risk of associated health concerns such as obesity and related problems. So Naomi's decision regarding her eating posed significant ethical dilemmas for those involved in her support, including the facilitator. To what extent should someone with a significant medical diagnosis be able to make decisions that potentially place their health and wellbeing at significant risk? What is the role of the supporter in assisting the person in their decision making when the decisions can have detrimental impacts on their health? Where does dignity of risk end and duty of care take over? Are there other ways to offer some choices in respect to food intake while retaining the needed guidance, for example in taking a greater role in food choices for particular meals?

- Naomi's decision to go to a 'horror' or 'scary' movie appears straight-forward. However, as the day program she attends does not provide 1:1 support, a referral for Naomi to receive 1:1 support from a paid service (during a respite placement) was necessary. This meant that Naomi had no control over the timing of the implementation of the decision. Although Naomi eventually followed through with an application for respite, with assistance from her supporter, the application was unsuccessful, so at the time of writing, the decision has still not been implemented.

Appendix 2: Decision makers

The tables below provides a brief profile of the 17 decision makers (both those who remained in the pilot and those who withdrew) who have not been profiled in the main part of the report or in Appendix 1.

Decision makers who remained in pilot	
DMA	DMA joined the pilot in July 2013. DMA is a man in his early forties who has an intellectual disability and mental health issues. He resides in a group home with other males, and works a nine-day fortnight in supported employment. NSWTG manage his finances. He chose his house keyworker and team leader as his supporters, and expressed interest in wanting to learn more about making his own decisions, particularly in the areas of going on holiday/ recreation/ budgeting and finances. He reported he is not confident in making his own decisions and rated the level of control he has over his decision making as '4'. He identified a holiday on a plane and buying a new DVD player as the decisions he wanted to work on in the pilot. His supporters noted DMA had become more confident in approaching staff for support in decision making. At follow-up and final interview DMA reported an increase in his confidence making decisions and he said he was making more decisions in the four areas he had nominated.
DMB	DMB joined the pilot in July 2013. She is a woman in her early fifties who has an intellectual disability and resides at home with her mother, who was also her supporter for the pilot. At baseline she reported she was very confident in making her own decisions and felt very supported by her mother, sister and niece. She said she would like to make more decisions about her finances and get to know more people. Both of these were achieved during the pilot. She appointed her niece as her Enduring Power of Attorney and increased the number of social activities she was attending.
DMC	DMC joined the pilot in August 2013. She is a young woman in her early 20s who resides at home with her mother, father and siblings. She attends TTW one day a week and TAFE four days a week. DMC demonstrated a sophisticated understanding of SDM from the outset, stating her reason for joining the pilot as "exposure and confidence around choices when I still have the support of my family. There will be a time when family will not be available." She chose her father to be her supporter and from the information available to the evaluation team she had a positive relationship with her father and the family had a natural approach towards SDM. Over the course of the pilot her confidence in her decision making increased.

Decision makers who remained in pilot	
DMD	DMD joined the pilot in August 2013. She is a young woman who had just left school and has an intellectual disability. She lives at home with her mother and father. DMD attends a TTW program five days a week. Her supporter was her mother. She said at baseline she makes good decisions but that it is her parents who make most of her decisions. The main change her supporter identified in DMD during the pilot was her confidence to tell others her preferences on day-to-day issues, such as what to wear and what clothes she would like to buy. The facilitator noted she enjoyed working with the Easy Read booklet.
DME	DME joined the pilot in November 2013. He is a 16 year old male with an intellectual disability who resides in a group home with other young males and attends school. DME is a Young Person Leaving Care (of the Minister). During the pilot the PG was appointed as his substitute decision maker and NSWTG as his financial manager. His keyworker was his supporter. DME made the decision to look for work, and he worked on this decision with his supporter throughout the pilot. At follow-up he reported he was dissatisfied with his decision as he still had not secured a job. There was no change in his answer regarding his confidence in making his own decisions ('very confident') and in the level of control he feels like he has over his life (10).
DMF	DMF joined the pilot in November 2013. He is a young man in his late teens/ early 20s who has an intellectual disability. During the pilot he moved from a group home to a community housing unit with drop-in support. DMF was unable to identify someone he wanted as a supporter so the facilitator took on the role. His finances are managed by NSWTG. He reported at baseline he felt he had complete control over his life except when he was at the group home, where he felt he had no control. At follow-up he reported a marked decrease in the level of control he has over his life to 2, even though he had moved out of the group home. This could have been because he had a couple of people unofficially living with him whom he wanted to move out but they were refusing and because his finances continued to be managed by NSWTG and he was clear he wanted to have control of his finances.

Decision makers who remained in pilot	
DMG	DMG joined the pilot in December 2013. He is a man in his late 20s/ early 30s who has an intellectual disability (Down Syndrome) and limited verbal communication. He resides in a group home. His mother and day program keyworker were both his supporters in the pilot. DMG attends a day program five days a week. He did not want to engage with the evaluation team for the follow-up interview. He did not identify any specific decision to work on in the pilot. The facilitator identified early on that his communication skills were a significant barrier to him being able to express his wishes and choices. The facilitator made a referral for a communication assessment
DMH	DMH joined the pilot in September 2013. She is a young woman in her late teens/ early 20s who has an intellectual disability. At baseline and follow-up she was living at home with her father and step-mother and her younger sister. Later, she moved out after a disagreement with her family to reside with her boyfriend in his public housing property. Her step-mother was her supporter until she moved out. She identified at baseline wanting to make a decision about which TAFE course to do. She reported being very confident in her ability to make decisions but said she does sometimes make the 'wrong' decisions which get her in to 'trouble'. At follow-up she noted she was making more of her own decisions regarding her money, and she was 'quite confident' with making her decisions. However she did comment the pilot has helped her "turn my life around" (following a recent brush with the law).
DMI	DMI joined the pilot in September 2013. He is a man in his late 40s/ early 50s who has an intellectual disability. He lives in a group home and has regular contact with his family. NSWTG manage his money. He attends a day program two days a week. The group home team leader was his supporter. He joined the pilot to learn more about his money and to make more of his financial decisions. At both baseline and follow up reported he makes 'some' of his own financial decisions. No specific decisions were worked on during the pilot, however he did report an increase in decision making confidence during the course of the pilot.

Decision makers who remained in pilot	
DMJ	DMJ joined the pilot in October 2013. She is a young woman in her late 20s/ early 30s who has an ABI. At the time of joining the pilot she was living in a group home. NSWTG manages her finances and she has the Public Guardian appointed to assist in making some of her lifestyle decisions. She attends a day program four days a week and is very independent in regards to her travel and managing her weekly routines. At baseline she nominated several areas of her life she would like to make more of her own decisions, including finances. Due to difficulties identifying a supporter, the facilitator took on the role. At follow up DMJ said she had made the decision to go on a holiday, however there was no evidence the decision had progressed passed being an idea. She stated there had been no change to her decision making during the pilot, and she "has always been strong willed and made my own decisions". DMJ had made the decision, against the advice of house staff and without her guardian's knowledge, to move out of the group home and into the home of her 'cousin'. This decision was also made without the involvement of the facilitator.
DMK	DMK joined the pilot in December 2013. He is a young man in his late 20s/ early 30s who has an intellectual disability. He lives at home with his parents and attends a day program five days a week and has an active social life. He stated he joined the pilot as he wanted someone to talk to him about his choices, and identified wanting to become more independent, whilst at the same time concerned about how this would be possible due to his physical disability and sight impairment. DMK chose his father as his supporter. It is evident that throughout the pilot that his father gained a new appreciation for how DMK could be supported to make his own decisions. He made several decisions regarding increasing his independence, and commenced working on them during the pilot.

Decision makers who withdrew	
DML	DML joined the pilot in November 2013. He is a young man in his early 20s residing in a group home with other residents. DML chose not to disclose the nature of his disability. Although he signed the consent form to be part of the pilot, at baseline he said he had not yet made the decision to be in the pilot. He was unable to identify a supporter so the facilitator took on this role. The file review demonstrated DML was not very interested in engaging with pilot team and did not identify a decision he wanted to work on. The house manager informed the facilitator that DML could make his own decisions and that he was very busy with a new job, girlfriend and community access activities. DML withdrew from the pilot in January 2014.
DMM	DMM joined the pilot in October 2013. He is a man in his late 40s who has an Acquired Brain Injury (ABI) as the result of a stroke and is also sight impaired. DMM identifies as being of Aboriginal or Torres Strait Islander descent. He was residing in a nursing home in Sydney when he joined the pilot. The decision he wanted to work on was going on an outing of his choice. At baseline he said he was quite confident in making his own decisions and if he needed assistance he could talk to his daughters interstate. DMM withdrew from the pilot after four months as by then, he moved to an aged care facility interstate to be closer to his daughters (he made this decision outside the pilot). Ongoing communication with pilot staff was difficult as this was best done face-to-face so DMM exited the pilot. His decision to choose where he went on an outing was not implemented, though he was taken on an outing to an alternative destination. The service responsible for taking him were not aware of the destination DMM had decided. This highlights the need for good communication between all players needed to enact a decision.
DMN	DMN joined the pilot in June 2013. She is a woman in her late 50s who has an intellectual disability and resides at home with her family. DMN attends supported employment three days a week, and a day program two days a week. She reported at baseline she was not confident in making her own decisions and that her family usually make decisions for her. She chose her sister to be her supporter and thought the pilot would help her to learn more about making her own decisions. When the evaluation team visited her to follow-up, her family indicated DMN no longer wanted to be part of the pilot because DMN and her supporter couldn't identify any decisions to work on. DMN indicated she was happy with the support she was receiving around decision making from her family and service provider.

Decision makers who withdrew	
DMO	DMO joined the pilot in October 2013. She is a woman in her late 20s/ early 30s who has an intellectual disability and lives at home with her mother and grandmother. She attends a day program five days a week. She chose her mother to be her supporter, who initially agreed, but then declined. The facilitator then took on the supporter role. However, after her mother declined to be further involved, DMO's interest in the pilot decreased and despite time spent discussing with her she did not identify any decisions she wanted to work on and disengaged.
DMP	DMP joined the pilot in October 2013. She is a woman in her early 40s with an intellectual disability. DMP identified a couple of people she would like to be her supporters, however neither of these people were contactable. She had recently moved to a new group home and was being supported with decision making in new areas of her life (e.g. managing money, recreational activities, family contact) by house staff and the support planner independent from pilot involvement. She decided to withdraw from the pilot as she was satisfied with the level of support she was already receiving with her decision making.
DMQ	DMQ joined the pilot in October 2013. She is a woman in her late 30s/ early 40s who has an intellectual disability. She lives at home with her parents and siblings and speaks a language other than English at home. DMQ identified her mother as her potential supporter. Her mother was initially interested in being involved in the pilot but when the facilitator discussed with her in detail what the role would involve, she declined. DMQ then informed the facilitator she no longer wanted to be involved in the pilot.

Appendix 3: Article 12 UNCRPD

Equal recognition before the law

1 States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2 States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3 States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4 States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5 Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Appendix 4: Tools

Table 13 lists the tools which were developed for the evaluation.

Table 13: List of Evaluation Instruments

Ref	Stakeholder	Ref	Tool	Purpose	Timing
1	Decision maker	1.1	Participation and consent form	Confirm informed consent to participate in pilot and evaluation	On recruitment
		1.2	Pre – pilot interview (baseline)	Template summary of data collected from decision makers about current decision making practice , access requirements	On recruitment
		1.3	Post – pilot survey	Face to face or telephone interview to establish impacts	Following significant decision or at 12 weeks from recruitment
		1.4	Exit survey/ final interview	Face to face or telephone interview to establish impacts	At exit from pilot or at pilot conclusion
		1.5	Focus group	Feedback on process and tools	Held 21/02/14
2	Supporter	2.1	Resources feedback form NOT USED	Feedback on tools	Project manager issues at end of training process
		2.2	Resources/ training impact interview	WWS interview to explore impact of intervention	12 weeks or post significant decision
		2.3	Focus group	Feedback on process and tools	Held on 21/02/14

Ref	Stakeholder	Ref	Tool	Purpose	Timing
3	Senior Policy Officer/ Project Officer	3.1	Client status report	# clients active in program	Monthly report to WWS
		3.2	Training package report	# training packages/ processes delivered by stakeholder type (participant, supporters, service providers)	Monthly report to WWS NOT USED
		3.3	Activity log/ diary	Document type and nature of supports provided Track changes and decisions to project plan to inform action learning	Ongoing log reviewed at Working party meetings; June/ July and Sept/Oct
		3.4	Version controlled handbook	Track manual holders and changes to tools	Ongoing NOT USED
		3.5	Session summary	Date, time, participants and contact emails/ phone numbers Consent to be contacted	Following recruitment to pilot or after information session
4	Service Provider	4.1	Session feedback ONE SESSION ONLY	Feedback immediately following information session	Feedback sheet issued at session by project manager
		4.2	Session impact	Determine impact of training	Online survey by WWS administer survey following session 12 weeks
		4.3	Baseline survey to be undertaken by ADHC	Current decision making practice	NOT UNDERTAKEN
		4.4	Conclusions interview	Individual or group interview to seek views at conclusion of pilot	Pilot conclusion DAY PROGRAM PROVIDER ONLY

Appendix 5: Information sheets and consent forms

Ageing, Disability and Home Care, Department of Family and Community Services
Supported decision making pilot - participant information February 2013

Supported decision making pilot

This fact sheet is about the supported decision making pilot, a joint project of Ageing, Disability and Home Care, NSW Trustee and Guardian and the Public Guardian. It tells you things you need to know about and agree with if you want to be in the pilot. You can ask for help to read and understand this information.

Our aim

Our aim is for people with disability to make more of their own decisions and for supporters to have the skills, confidence and resources to make this to happen. We want to find out what kinds of support can help people with disability to make their own decisions.

The pilot will test a supported decision making framework and resources for people with disability, their families, carers, advocates and service providers.

About the pilot

The pilot will run from March 2013 to March 2014. About 30 people with disability who receive support from Ageing, Disability and Home Care or other disability services will be involved in the pilot, along with their families, carers and supporters. Some people will also be under the financial management of the NSW Trustee and Guardian.

Evaluation

When you join the pilot we will ask you to also be part of the evaluation. The pilot is being evaluated by WestWood Spice, an organisation independent of Ageing, Disability and Home Care, NSW Trustee and Guardian and the Public Guardian. Their team will collect information from you about your experience of supported decision making. They will also ask what you thought about the books and resources used in the pilot.

WestWood Spice will write a report about the pilot early in 2014. We will give you a copy of their report and tell you what we learned.

Read the WestWood Spice evaluation fact sheet for more information. You can also look at their website www.westwoodspice.com.au.

NSW GOVERNMENT Family & Community Services Ageing, Disability & Home Care

Contact: Melanie Oxenham
Phone: 9377 6467
Email: Melanie.Oxenham@facs.nsw.gov.au

Your involvement

If you want to join the pilot, we will talk with you about the information in this fact sheet and make sure that you understand what it means. The pilot is not right for everyone, and it is important that you can understand and agree to be involved.

As a volunteer in the pilot and the evaluation, you decide how much you want to be involved. You can decide how much contact you want to have with us. When we telephone or email, or ask to set up a meeting, you can let us know whether this is ok with you.

You can stop your involvement at any time without any problems. Leaving the pilot will not affect the services or support that you may be getting. If you decide to leave the pilot we will talk to you about your decision and try to resolve any concerns or difficulties you had with the pilot. We can also refer you to other services or supports if you need help with support or decision making.

Contact us

The people on the Supported Decision Making Pilot team are:

Melanie Oxenham, Senior Policy Officer, Ageing, Disability and Home Care
Phone: 02 9377 6467
Email: decisionmakingpilot@facs.nsw.gov.au

The people on the WestWood Spice evaluation team are:
Sue Warth, Senior Consultant
Alison Plant, Senior Consultant

What will happen during the pilot

When you first join the pilot, we will meet you to talk about supported decision making and how it might work for you. You will be invited to an information session where you will learn more and meet other people involved in the pilot. We will give you some handbooks and resources to use. We will collect some information about you, like your age, the type of services and support you get.

After you have been in the pilot for about three months, WestWood Spice will talk with you about the decisions you are making, how you are being supported and what resources and information you are using. Because we are learning as we go, we might ask you to fill in a survey or come to a group to discuss your experiences. It is up to you to decide if you want to do these things and you don't have to answer questions or go to meetings.

You can talk to us if you have any concerns or questions about the pilot, the handbooks that we give you or your supported decision making arrangements. We are not linked to your services or support and we cannot find funding or services for you, advocate for you or influence the way another agency is providing support to you.

Protecting your privacy

When you join the pilot, we will ask you to agree that we can collect information about you and what happens during the pilot. Ageing, Disability and Home Care and WestWood Spice will make sure all personal information is kept secure and confidential. Any written information will be kept in locked storage available only to the people working on the pilot. Electronic material will be kept in an electronic folder secured with a password only available to the people working on the pilot.

Using your information

In their evaluation report WestWood Spice will not use your name, address or any other information that could identify you. Without identifying you, they might write about:

- comments that you have made about the pilot
- examples of the types of supported decisions you have made
- your age or cultural background
- the types of services you use.

Some of this information might also be used by the pilot team for presentations at conferences or seminars.

After the pilot

In the last few weeks of the pilot, we will meet with you to talk about your involvement and how you and your supporters want to work together in the future. We will not contact you again after this. You can keep the handbook and any tools we give you during the pilot.

Using information from the pilot, we will revise the supported decision making handbooks and resources. You will be able to see the final documents on the Ageing, Disability and Home Care website.

WestWood Spice will write an evaluation report about the pilot. We will send you a copy of the report, and tell you what we learned.

Complaints

If you are not happy with the way we do things in the pilot, you can contact Ageing, Disability and Home Care to make a complaint by telephone 9377 6000 or email servicembx@facs.nsw.gov.au.

NSW GOVERNMENT Family & Community Services Ageing, Disability & Home Care

Contact: Melanie Oxenham
Phone: 9377 6467
Email: Melanie.Oxenham@facs.nsw.gov.au

Ageing, Disability and Home Care, Department of Family and Community Services
Supported decision making pilot – introduction for participants February 2013

Supported decision making pilot

What is supported decision making?

Everyone has the right to make their own decisions and to be in charge of their lives. Decisions are choices you make every day about your life. Decisions could be about what to do each day, where to live or what to spend money on. Some people might need help to make decisions. Getting help for decisions is called supported decision making. It happens when you ask someone in your family, a friend, advocate or carer to help you. You could get help to find information, think about the good and bad things that could happen, or tell other people what you have decided.

What is the supported decision making pilot?

A pilot means trying new things. The supported decision making pilot is about how people with disability can get more help to make their own decisions. We have put together some books with ideas about how people with disability can make decisions. We would like people to join the pilot to try out the books and tell us about how they make decisions.

What will I do in the pilot?

If you join the pilot, we will come and meet with you and the people who help you make decisions. We will ask you how you make decisions and what could help you make more decisions for yourself. We will give you some books with lots of ideas and tools you can try out when you make decisions. We will meet you again later to see how things are working and to talk about any decisions that you have made. You can keep the books and any other tools we give you during the pilot. You can leave the supported decision making pilot any time you like. You do not have to tell us why you are leaving.

Pilot evaluation

WestWood Spice is an organisation which is helping us with the pilot. WestWood Spice will ask you about how you make decisions in the pilot. They will write a report about the pilot when it is finished. We will tell you what the report says and give you a copy.

How can I find out more?

You can talk to Melanie Oxenham about the Supported decision making pilot. You can ring Melanie on 9377 6467 or email decisionmakingpilot@facs.nsw.gov.au.

NSW GOVERNMENT Family & Community Services Ageing, Disability & Home Care

Contact: Melanie Oxenham
Phone: 9377 6467
Email: Melanie.Oxenham@facs.nsw.gov.au

Family & Community Services
Ageing, Disability & Home Care

Supporter Consent Form: Supported Decision Making Pilot & WestWood Spice evaluation

I have talked to _____ about the Supported Decision Making Pilot (Pilot) and evaluation by WestWood Spice (Evaluation).

- ☐ WestWood Spice can contact me to discuss my involvement in the Pilot, for example:
  - the decision making support I have given
  - my view about Pilot resources, including written materials and the role of the Pilot's facilitators/trainers.
- ☐ I know that some information about me may be included in the evaluation report, including:
  - my relationship to the person I support (e.g. parent or carer)
  - observations made by the Pilot team
  - the support I have given to the participant.
- ☐ My personal details – such as my name and other identifying information – will not be disclosed in the evaluation or other reports. This is to ensure my privacy is maintained.
- ☐ Information about me will not be given to anyone else unless I give consent.

Name _____

Signature: _____

Date: _____

Ageing, Disability and Home Care, Department of Family and Community Services NSW
Level 5, 83 Clarence Street, Sydney NSW 2000 | **T** (02) 8270 2000 | **TTY** (02) 8270 2167
Translating and Interpreting Service 13 14 50 | ABN 82 016 305 789 | www.adhc.nsw.gov.au

Family & Community Services
Ageing, Disability & Home Care

Consent form
Supported Decision Making Pilot
Evaluation by WestWood Spice

Tick the boxes that apply to you.

I have talked to _____ about the pilot and the evaluation.

☐ I have read the Supported Decision Making Pilot Fact Sheet.

☐ Someone read the Supported Decision Making Pilot Fact Sheet to me and explained it.

☐ I know what the fact sheet says about the pilot and the evaluation by WestWood Spice.

☐ The pilot team can call me to talk about my decisions and the people who help me.

☐ WestWood Spice can have my name and phone number so they can talk to me about:
- my decisions
- the help I get with my decisions
- what I thought about the toolkit.

☐ I can decide if I want to:
- come to meetings
- fill in forms about the pilot or the evaluation
- leave the pilot at any time
- be part of the evaluation

☐ I know that some information about me may be included in the evaluation report, like:
- my age
- the type of services I use
- if I am male or female

My name and personal details will not be in the report.

Ageing, Disability and Home Care, Department of Family and Community Services NSW
Level 5, 83 Clarence Street, Sydney NSW 2000 | T (02) 8270 2000 | TTY (02) 8270 2167
Translating and Interpreting Service 13 14 50 | ABN 82 016 305 789 | www.adhc.nsw.gov.au

Family & Community Services
Ageing, Disability & Home Care

- ☐ Information about me will not be given to anyone else unless I say it is ok.
- ☐ I agree to be part of the Supported Decision Making Pilot and the evaluation by WestWood Spice.

Name:_____

Signature:_____

Someone signed this form for me. The person who signed was:

Name:_____

Signature:_____

I had help to fill in this form. The person who helped me was:

Name:_____

Signature:_____

Date:_____

Appendix 6: Example of an agreement between a decision maker and their supporter

Department of Family and Community Services

Supported Decision Making Agreement
17th December, 2013

I, decision maker, choose supporter, my sister, to be my supporter and assist me to make decisions. I like having supporter as my supporter.

I want to make decisions about:

- My social life
- My money
- Getting a job
- Buying a laptop, computer or iPad
- Doing community service
- Going on a holiday

Supporter will support me by:

- Teaching me new things
- Showing me everything
- Talking to me
  - Especially about the good and bad things about the choice I could make

If we don't agree

- We will try to fix it
- I will try to explain to them about what I am wanting to do
- They will explain to me why they don't agree
- We will take some time out to stop and think about it and then talk about it the next day
- Try to make a deal

Name
Decision Maker _____ Date _____

Name
Supporter _____ Date _____

Name
Facilitator _____ Date _____

Appendix 7: SDMP focus group evaluation form

Venue: Conference Room, Level 2, 93 George St, Parramatta

Date: 21 Feb 2014

Your name (optional): _____

Your views

Overall, how would you rate today's information session?

☐ Poor ☐ Fair ☐ Good ☐ Excellent

Why did you give this rating? _____

_____

Before this session, from one to five, how would you rate your understanding of supported decision making?

(Knew nothing) 1 2 3 4 5 (Knew a lot)

After this session, from one to five, how would you rate your understanding of supported decision making?

(Know nothing) 1 2 3 4 5 (Know a lot)

Will you continue in the role of supporter as a result of this session?

☐ Definitely ☐ Maybe ☐ No ☐ N/A

Did you get enough information about the SDM Pilot to meet your needs?

☐ Yes ☐ No

If No, what would you like to know more about? _____

_____

What do you think is the most important skill for a supporter to have? _____

_____

What has been most useful about today's session? _____

_____

How could today's session be improved? _____

_____

About you

Can the evaluators contact you to follow-up? Please give contact details (email and phone). _____

_____

Notes

Notes

NSW GOVERNMENT

Family & Community Services

Family and Community Services

www.facs.nsw.gov.au

3477 FACS 210415