Spectrums of Support

A Report on a project Exploring Supported Decision Making for People with Disability in the ACT.

ACT Disability, Aged and Carer Advocacy Service

September 2013

ADACAS
ADVOCACY

ACT Disability, Aged and Carer Advocacy Service (ADACAS) asserts, promotes and protects the rights and responsibilities of people with disabilities, people who are older and people who are caregivers. We vigorously advocate for and with vulnerable people who have a disability, are older, or their caregivers so that they may exercise their rights as citizens, live valued and dignified lives in the community and pursue their dreams.

ADACAS acknowledges the Ngunnawal people as the traditional owners of the land on which we work.

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Executive Summary

Supported decision making is grounded within the United Nation Convention on the Rights of People with Disability (UNCRPD). This convention acknowledges that people with disability have the same rights as those who do not, to be enjoyed on an equal basis with others. This includes the right to personal autonomy through choice, participation in all aspects of civil society and equality before the law. The convention represents a cultural, identity and legal shift, casting people with disability not as passive subjects in need of protection, whom things are done 'to' and 'for' but as bearers of rights and active agents in their own lives.

DisabilityCare Australia, with its key imperative to deliver choice and control over supports and services, will bring Australia closer to fulfilling its responsibilities under the UNCRPD, which it ratified in 2012. For the first time in their lives many people participating in the scheme will have the possibility of becoming active in making decisions about the services and supports they need to fulfil their vision of a good life.

In June 2012 ADACAS accepted an opportunity, created by Disability ACT, to explore supported decision making in the lead up to the launch of DisabiltyCare Australia the National Disability Insurance Scheme. As decision making is central in the delivery of the scheme, the project examined what supports people whose decision making capacity is impaired, or simply not recognised, may need to access and realise the opportunity for self-determination promised within DisabiltyCare Australia and beyond.

Universally what was discovered was that each person's capacity for self-determination was limited, not by their ability to make a decision, but by the support they received to exercise decision making.

The project set out to explore one particular model of supported decision making, set against the socio-cultural context in which decisions are made. While the efficacy of this model was confirmed, the project outcomes also recognised the extent to which support for decision making needs to exist on a spectrum, from formal to informal, and encompassing people with disabilities along with those who share their lives. Some people may need only a little support to access information or weigh up a decision. Others, however, will need to access more comprehensive support, including support to understand decision making, build expectations that they will be involved in the decisions that are important to them, or consider the possibilities for decision support, even before they identify a decision and work towards its fulfilment.

Many of those engaged in the project enjoyed very limited opportunity for self-determination, with lives largely lived within the service sector and governed by the values and decisions of others, including families and care workers. The project illustrated that, for

this group, support for decision making is also about creating cultural change that normalises active participation by people with disability in decision making, and by extension access to decision support, and builds the capacity of people who share their lives to enable participation in decision making on a day to day basis.

For Australia to fulfil its responsibilities under the UNCRPD, a spectrum of decision support responses need to become as mainstream as ramps, automatic doors and braille on ATM machines and be viewed as fundamental accessibility issues that are rights rather than additional extras in the life of a person with disability. Decision support responses must therefore be freely available to all people on the basis of need, rather than meted, rationed or only available to those lucky enough to have them included in DisabilityCare Australia support packages. This paper proposes a comprehensive decision support response which encompasses universal, primary and tertiary initiatives that lead to a cultural change in societies' approach to decision making and increased self-determination for people with cognitive disability.

While each of the decision makers in the project shared many elements of support, what featured overwhelming, was the need to establish decision support tailored to individual need and the role of the formal project in generating cultural change among family members, support workers, guardians and the wider community.

This project has demonstrated that both formal and informal supported decision making actions do create change for individuals, families, the service system and more broadly in the community. There is now clear evidence that supported decision making initiatives are valuable and enable people with disability to be active decision makers who can exercise choice and control over the decisions that affect their lives.

This project focused on working with people with cognitive disability to enable their decision making through support and has made significant advances on the model developed and trialed in South Australia. We now have a clearer picture of the spectrum of support that needs to be available to ensure that people with cognitive impairment can be active decision makers in their own lives. The project also provides a basis for further work. In addition to the recommendations presented, a key area of work remains in exploring how supported decision making models should respond to the needs of people living with mental illness or psychosocial disability and the needs of frail older people, particularly those experiencing dementia. Supported decision making has the potential to increase the opportunities and rights of people in both of these groups to be active decision makers.

Recommendations

1. That support to develop decision readiness be provided for individuals, families and care workers.

2. That a training program be created that recognises the role of care workers as a decision making resource for people with disability and promotes their capacity to fulfil this role.

3. Training programs for care workers highlight the limitation of guardianship to important and increasingly specific decisions, and provide information to empower care workers to advocate on behalf of those they support.

4. That community based education programs which facilitate cultural change are implemented as part of a broader supported decision making agenda.

5. That supported decision making programs provide responsive flexible models of decision support tailored to individual need.

6. That supported decision making programs recognise and accommodate individual needs around timeliness.

7. That support for decision making encompasses capacity building resources for care workers, families and family guardians, in addition to capacity building for individuals.

8. That supported decision making programs further develop a range of decision supporter models including freely given known supporters, volunteer introduced supporters and professional support.

9. That decision support programs recognise that supported decision making agreements may have multiple purposes for the decision maker and that the documents therefore need to be flexible to meet individual need.

10. That any supported decision making initiative include a paid monitor role to oversee and coach decision makers and decisions supporters.

11. That decision support be provided to people to enable their will and preference to be heard in substitute decisions that are being made by others.

12. That an approach be made to the ACT Civil and Administrative Tribunal (ACAT)to fund the development of easy English materials that describe the responsibilities and limits of guardianship under the current legislation.

13. That a review of guardianship legislation in the ACT be progressed as a matter of priority.

14. That the ACT Government continues to fund decision support programs which enable people to avoid or minimise guardianship and administrative orders.

15. That close relationships between individual advocacy and supported decision making initiatives be integral to the development of decision support.

Aim

The ACT Supported Decision Making Research Project has been aimed to explore the application of the formal, relationship based supported decision making model, developed by the Julia Farr Foundation in partnership with the South Australian Office of the Public Advocate, to people living within the ACT[1]. The overarching purpose has been to understand how people with a decision making impairment or whose decision making capacity is undervalued, might be supported to make more decisions.

While the ADACAS project took the South Australian trial as a starting point, it sought to add to our understanding of how formal supported decision making (SDM) might be accessed by a cohort of people with a broader range of decision making impairments and different support needs. This included people with complex communication needs, and those whose social isolation prevented them from identifying a natural decision support relationship. People needing support to make financial decisions were also included in the project.

The project was framed within the broader socio-cultural circumstance in which decisions are made. This framework identified some of the values and attitudes that enable or prevent access to decision making by people with disability, especially in relation to potential uptake of the model. The project has been undertaken in the lead up to the 2014 launch of DisabilityCare Australia in the ACT and was funded by Disability ACT.

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[1] Office of the Public Advocate South Australia, *Supported Decision Making*, at http://www.opa.sa.gov.au/cgi-bin/wf.pl?pid=&mode=cd&file=../html/documents//11_Supported%20Decision%20Making

Background

The UNCRPD, Supported Decision Making and DisabiltyCare Australia

Supported decision making is grounded within the UNCRPD [2]. This convention acknowledges that people with disability have the same rights as those who do not, to be enjoyed on an equal basis with others. This includes the right to personal autonomy through choice, participation in all aspects of civil society and equality before the law.[3] The convention represents a paradigm shift, casting people with disability not as passive subjects in need of protection, whom things are done 'to' and 'for' but as active agents of their own lives. Legal capacity is a universal right under the UNCRPD. Denial of the presumption of that capacity is discrimination. So too is denying a person of the supports they need to give effect to that presumption of capacity.

DisabilityCare Australia, with its key imperative to deliver choice and control over supports and services, will bring Australia closer to fulfilling its responsibilities under the convention, which it ratified in 2012.   For the first time in their lives, many people participating in the scheme will have the possibility of becoming active in making decisions about the services and supports they need to fulfil their vision of a good life.

The centrality of decision making to the practice of the scheme raises the question of how those whose decision making capacity is impaired, or simply not recognised, will access and realise this opportunity. Finding practical responses to this question is paramount so that old 'protective' values and decision making regimes are not transferred into the new scheme. While the scheme rules accommodate for guardians and substitute decision makers, the priority must be for as many people as possible to exercise their right to self determination, including those understood to have impaired decision making capacity. If the scheme is to deliver choice and control, then substitute decision making must be last resort, implemented only when all other options have been exhausted.

There are some answers within the framework of the UNCRPD, where disability due to decision making impairment does not undermine a person's right to choose. The convention recognises that some people will need support to exercise their right. It identifies as the responsibly of the States the establishment of mechanisms that provide for as much support as is necessary for people to exercise their right to decide. This is called supported decision making.[4]   Within this framework there are significant distinctions between legal capacity, which is a universally granted right, and decision making capacity,

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[2.] United Nations General Assembly, 13 December 2006, *Convention on the Rights Peoples with Disability*, http://www.un.org/disabilities/default.asp?id=259
[3] United Nations, *Enable: Chapter 6: Implementing the Convention: Legal Capacity and Supported Decision Making,* http://www.un.org/disabilities/default.asp?id=242
[4] Ibid,

which is skill that can be learnt and developed with experience and support.[5]   This distinction facilitates what Bach and Kerzner identify as a shift away from deficit based models, used to deny people's decision making right. The question of how much capacity to decide a person holds is recast to become a question of how much support is needed to enable that person to exercise their right to decide.

When understood in these terms support for decision making is an access tool, with the potential to facilitate participation and break down barriers. For those with a decision making impairment decision support should be understood in the same way that we understand existing access tools, such as wheel chair ramps, braille and communication aides. With the establishment of DisabilityCare Australia, what the UNCRPD has identified as the State's responsibility to effectively ensure that those citizens who require decision support are able to access it, is in the spotlight. Imagine, for a moment, the construction of a DisabilityCare Shopfront that lacked wheelchair accessibility. While not as visible as a concrete ramp, decision support is as essential as an access tool for those with decision making impairment.

There is, of course, a circular, 'chicken and egg' scenario here. DisabilityCare Australia is about delivering choice around support. However, for those with decision making impairment, either real or perceived, support will be needed to access that choice. What that support might look like is the subject of this project. Worldwide there have been a range of responses that inform the project. Alberta, Canada implemented a formal, legislated supported decision making agreement.[6] More recently Ireland has identified essential principles for a proposed Capacity Bill developed through broad collaboration with non-government stakeholders including people with disability, older persons, and those experiencing mental health issues and acquired brain injury.[7] The South Australian Supported Decision Making Research Project, completed in 2012, explored non-legislative, relationship driven supported decision making.[8]

How the Australian Government might respond to the need for support for decision making, ensuring all citizens are able to enjoy full and equal benefit of DisabilityCare Australia, may well be exemplified by the diversity of approaches to decision support around the world. Each of these, with their own valid model, illustrates a spectrum of possible responses locating the place of decision support within community, policy and legal frameworks. The idea of a spectrum of responses, cast in recognition for the spectrum of capacity, forms the basis for the Victorian Law Reform Commission Guardianship Act Review.[9]   This project has

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[5][5]"/>[5] Bach, Michael and Kerzner,Lana, (2010) A new paradigm for protecting autonomy and the right to legal capacity at, http://www.lco-cdo.org/disabilities/bach-kerzner.pdf
[6] http://humanservices.alberta.ca/guardianship-trusteeship/opg-guardianship-supported-decision-making.html
[7] Collaborative Authors, *Essential Principles: Irish Legal Capacity Law*. http://www.nuigalway.ie/cdlp/documents/principles_web.pdf
[8] Office of the Public Advocate, Op.Cit.
[9] Victorian Law Reform Commission, *Guardianship: Final Report*, http://www.lawreform.vic.gov.au/projects/guardianship-final-report

sought to understand the ways in which the current spectrum of responses might be implemented to meet the unique needs of each person, enabling them to build capacity to decide, create decision making experience and expectation and how these might be made available to ensure all people are able to access the level and types of decision support they require.

The Decision Making Model

The SDM model, initially developed by the Office of the Public Advocate, South Australia with support from the Julia Farr Foundation, was chosen because it provided the most detailed experience of formal, relationship based, supported decision making. Grounded in human rights, it was a good match with ADACAS's own organisational values. In this model, SDM takes place in a freely given relationship, with a decision supporter providing as much support as necessary for a decision to be explored, weighed, made and recognised. The decision maker is always in control and is encouraged to approach decision making with the same expectations as a person that does not have a disability. This means, for example, that they are free to change their mind, take a risk or make a decision that their decision supporter does not agree with. It also means they have the power to end the relationship with their supporter at any time.

The decision maker and the decision supporter work together, with the responsibilities of each person in either making or supporting the decision, along with the decision itself articulated in an SDM agreement. The agreement can be used to gain recognition for the decision and confirm decision making capacity for others to respect. This relationship is overseen by a monitor who acts as safeguard and coach.

Project Description and Framework

Roles and Responsibilities

The project was carried out in two overlapping phases. Identifying the socio-cultural framework in which decisions are made and then engaging decision makers to make a decision using support.

A project coordinator worked an average of 15 hours per week, between October and December and then eight hours per week from January to June. This represents 230 hours of decision support time and excludes reporting time. The coordinator oversaw the project in its entirety. This role included establishing and overseeing the research design, undertaking the community engagement phase, providing support to the monitor, creating coaching resources and developing processes and approaches to meet the diverse support needs of decision makers and supporters. A part time monitor worked an average of 18 hours per week, from February to May 2013. Her role was to facilitate the creation of the SDM agreements, oversee the relationship and provide coaching support where necessary. This totalled of 332 project hours. Combined hours were spent providing decision support interventions for decision makers.

The Socio-Cultural Framework for Decision Making

The research framework was developed through conversations with stakeholders, where attitudes, values and approaches to decision making by people with disability, as well as those who share their life were explored and identified. These conversations created a snapshot of the socio-cultural context that shapes access to decision making, and uncovered questions as to how people with a diverse range of experience and expectations might be supported to make decisions within a formal, relationship based, supported decision making model.

Four organisations providing residential and other services to people with disability were approached in July 2012, inviting those they support to become involved in the project. [10] The invitation explained that information gathered would be used to make recommendations about the kinds of resources that may support people to make more decisions for themselves under Disability Care, and included the offer of an information session about supported decision-making. Three service providers became involved in the project, although each with their unique response.

At the centre of the project were people with a decision making impairment, or those whose decision making capacity was either unrecognised or undervalued. This definition,

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[10] To ensure privacy and allow for free reporting names of service providers will be kept confidential.

encompassing those whose decision making capacity is impaired and those for whom there is an assumed impairment, is drawn on a social model of disability, and recognises that a person's ability to be an active decision maker, to access decision making opportunity and to enjoy respect and support for their decisions, is shaped by the attitudinal environment in which they live.[11]

Service Provider 1 identified six people who they believed would like to learn more about decision making, were able to have greater participation in decision making, or wanted to be more engaged in the decisions that were important to them. These six people lived in supported accommodation. All, coincidently, lived under a guardianship order.

Each person participated in a series of one to one conversations to ascertain their expectation to be engaged in decision making, their experience as decision makers and their approaches to decisions. At the request of guardians either a staff member or advocate from ADACAS was present at three of the interviews. These conversations explored key concepts in decision making, including:

- · choice;
- · trust;
- · the right to decide;
- · risk;
- · support for decision making; and
- · recognition as a decision maker.

The conversations were iterative in nature, asking questions about each concept or experience giving, when need information about the concept then returning to the question being asked. Information was given using examples relevant to each person.

Service Provider 2 responded to the invitation to be involved in the research by taking up the offer of an information session. From the outset this provider was enthusiastic about adding to the strategies already employed to engage those they support in decision making. They were, however, reluctant to identify people with disability to participate in the research due to anticipated negative responses from family guardians, instead making a request for an information session for their staff. This created an opportunity to explore some of the values and approaches of care staff to decision making by people with disability.

In October ADACAS hosted a forum attended by 17 care workers and managers. At the start of the forum participants were surveyed to identify their understanding of key concepts in decision making and how their role as carers interacts with these concepts. The survey included questions around:

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[11] United Nations, Enable: Annex 1 – Convention on the Rights of Persons with Disabilities, (e), http://www.qai.org.au/index.php?option=com_content&view=article&id=257:sdm-forum-unedited-transcript-28-june-2013&catid=33:forum-materials&Itemid=59.

- rights of people with disability to decide for themselves;
- their role as carers in relation to those rights and duty of care;
- respect for the decisions of those that they care for; and
- offering choices.

This was followed by a presentation covering concepts such as the right to decide, capacity, choice, best interest, expressed wish and duty of care, risk enablement and supported decision making. Following discussion the group was resurveyed.

Service Provider 3 responded to the invitation to become involved by identifying the project as a potential resource for older parents planning to transition their adult children with disability into more independent living situations. Fourteen family carers attended a forum and provided valuable insight into attitudes to decision making held by this group of carers. Participants completed a survey at the start and again following the forum. The forum included a short presentation on the principles and practise of SDM, based on the South Australian model, followed by discussion. Taking the lead of the participants, focused the discussion on duty of care, decision making capacity and the right to decide.

Setting the framework also saw engagement with stakeholders in contact with people whose capacity is impaired, or perceived to be impaired. Discussions were held with the Office of the Public Advocate and the President of the ACT Civil and Administrative Tribunal (ACAT). This raised awareness of the research and explored opportunities for SDM within the current practice of guardianship in the ACT. The project was presented to the ACT NDIS Expert Panel. The coordinator attended the 2nd World Congress on Adult Guardianship. Papers were given at the Supported Decision Making Network Forum in Melbourne, (March 2012), and the Supported Decision Making Conference in Brisbane (June 2012), where a decision maker from this project also presented his experiences[12].

In December 2012 ADACAS was successful in obtaining an NDIS Practical Design Fund Grant, to develop a supported decision making web based tool. Development of this site ran concurrently with the research project. These two projects were mutually beneficial, with the experience from the research shaping the content of the web site. Written material from the web site was reproduced to coach decision makers, family members, guardians and decision supporters. As part of the site's development the coordinator attended a workshop with Scope Inc on writing in easy English. This underpinned the development of easy English resources created for decision makers and supporters in the project. This web site is now operational at www.support-my-decision.org.au.

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[12] Queensland Advocacy Incorporated, June 2013, *SDM Forum*,
http://www.qai.org.au/index.php?option=com_content&view=article&id=257:sdm-forum-unedited-transcript-28-june-2013&catid=33:forum-materials&Itemid=59

Engaging Decision Makers

Between November 2012 and January 2013, six decision makers were engaged to test the model and they remained in contact in the program until its conclusion in June 2013.

The group was identified in a number of ways. Two decision makers expressed enthusiasm to be decision makers through initial community engagement, a further two contacted ADACAS on the recommendation of ACAT, and the final two were existing ADACAS clients. This group was selected to represent a very broad range of decision making experiences and decision support needs. This provided the opportunity to apply the model in a range of untried contexts and respond to some of the issues encountered in the South Australian trial.

Engaging the decision makers in the model included five stages. Certain aspects of each stage, for example promoting a decision makers right to decide, ran concurrently with other stages. Time spent in each stage depended on the experience and expectation of each decision maker as well as the decision being made. Also recognised was that not every decision maker, or every decision accessed each stage to fulfil a decision. Establishing decision support, recognising the right to decide, or understanding more about how a decision is made, may be all the support needed for a decision maker to fulfil a particular decision. However this same decision maker may need to access all stages at another time, with a different decision.

Developing rapport between the monitor, decision maker, and once identified, supporters was the essential element for each and every stage. In getting to know decision makers and developing an understanding of their socio-cultural circumstances the monitor was able to target specific areas that may need support. Exploring the values and approaches of decision supporters highlighted areas for potential coaching. Time spent with decision makers and supporters was used to identify potential vulnerabilities in the support relationship for monitoring and coaching.

Stage 1 Raising Awareness

Awareness raising activities focused on developing greater understanding of each person's right to self determination and the availability and potential of formal decision support. This was undertaken initially by the project co-coordinator and then the monitor.

Key materials developed to support this activity included Principles for Decision Support and easy English material on the right to decide, initially developed for the ADACAS website. This information was used by the Monitor as a guide for conversations about abstract concepts, such as decision making and rights, in easy English.

Where possible, awareness raising had an additional focus on those who shared the lives of the decision makers. The right of the decision maker to decide was promoted by the coordinator among guardians, family members and key support workers. Key people,

influential in the lives of the decision maker, were surveyed to ascertain attitudes and values toward decision making and the right to decide. Special attention was paid to attitudes and values that may prevent the decision maker from approaching a decision with the same expectations and responsibilities as those that do not have a disability. This included the ability to make mistakes, change your mind and take a risk.

Possible relationships and influences where additional support might be needed to ensure access and participation were identified here. At the request of those decision makers concerned about the possible negative impact their participation in the project might generate, the project co-ordinator had additional discussions with two family guardians.

Stage 2 Becoming Decision Ready

In Stage 2 the monitor worked with decision makers to build decision readiness. Where already identified (1 case), decision supporters, with coaching from the monitor, had a role here.

Building decision readiness involved activity in three key areas;

- giving support to articulate a decision;

- improving understanding of key concepts in decision making and what might be involved in a decision, including how support might be given;

- building expectation of decision makers to be active in fulfilling a decision; and

- making a commitment to actively fulfil that decision.

Key materials created for Stage 2 included information sheets initially developed as part of the support-my-decision web site. Easy English descriptions of important concepts in decision making, including options, risk, and the roles and limits of guardians, along with information about how a decision could be approached, underpinned capacity building and were commonly used here.

In this stage decision makers also had opportunity to explore the potential of decision support and consider the kinds of support they might like to decide.

Stage 3 Decision Support

Stage 3 focused on identifying and securing decision support and developing individual support frameworks. The shape of each framework was specific to the decision being made, the support needs of the decision maker, and the experience and values of decision supporters to support that decision.

Monitor and decision maker work together to identify and initiate decision support, with the monitor giving only as much support as is needed. This support may include

approaching the supporter, describing principles for decision support, identifying the kinds of support that the decision maker may require.

Important concepts in this stage were trust, principles for decision support, vested interest, guardianship and the right to decide.

The monitor has an important role, ensuring that the identified decision supporter will be able to meet the support requirements of the decision maker. In addition to any support needs anticipated by the decision maker, factors here include ensuring the proposed supporter is able to work to principles of decision support, is open to coaching by the Monitor and logistical issues.

Once identified the decision supporter must agree to give only as much support as is needed while working within the rights based principles of decision support. These principles include:

- Appreciation that decision making is a learnt skill developed with experience, As is supporting a person to decide;

- Recognition for every person's right to decide, regardless of their ability;.

- A belief that every person can decide when given as much, and only as much, support as is needed;

- Respect for the values, goals and experiences of each decision maker to enable them to approach decision making in their own way;

- Recognition that the decision belongs to the decision maker. This means enabling them to approach decision making with the same expectations, freedoms and responsibilities as those who do not have a disability. This includes the freedom to take risks, change their mind, learn from mistakes and make a decision that others do not agree with; and

- Understanding that a decision supporter's relationship with the decision maker matters. The decision support relationship is built on trust. Decision support cannot be given by a person who has a vested interest in the decision maker's life.

Monitor works with decision supporter, building understanding of their role, promoting awareness of the availability of coaching and exploring areas where this might be of benefit.

Key materials developed here included the Principles for Decision Supporters and easy English information sheets on the right to decide, roles and responsibilities of decision makers and supporters, and guardianship.

Stage 4 Being a Decision Maker and Learning to Support Decisions

Decision maker articulates decision and begins to act toward the fulfilment of their decision. This stage may include the development of a supported decision making agreement. Monitor and supporter recognise and respect the support requirements of the decision maker and give only as much support as is needed.

Monitor relinquishes responsibilities and actions of decision support, as soon as possible, to the decision supporter, who with support from the monitor, is building their capacity in this role.

Where a Supported Decision Making Agreement is required monitor facilitates conversation between decision maker and supporter to

- articulate the decision for the agreement;

- anticipate, where possible, desired support responses;

- explore and document values and behaviours that might challenge supporter in their role; and

- explore values and behaviours that may challenge the decision maker in fulfilling their decision, and identify and document support responses.

Develop resources and implement coaching strategies that build capacity of decision maker and supporter.

Monitor continues to advocate for decision maker's right to decide with those who share their life.

Stage 5 Fulfilling a Decision

Decision maker and supporter work together toward the fulfilment of the agreement or the decision.

Monitor provides ongoing support to ensure decision maker remains connected to the decision and that appropriate support is being given. This includes ensuring that people do not fall back into old habits.

Complete and review decision.

Consider next decision and possible support needs.

Timeframes

Decision makers were engaged over a period of 24 weeks from January to June 2013. Time spent in each stage depended on the experience and expectations of the decision maker, as well as of those around them, their social connectedness and readiness to decide. Decision makers moved through each stage with varying degrees of independence. Each stage was not exclusive. For example, a decision maker could be developing their decision readiness while identifying a decision supporter. This will be explored in detail under themes.

It is important to recognise that each of these five stages represents the possible components of a formal supported decision program. Not all decision makers will need to access all elements of the program. By ensuring that the decision maker is always in control, monitor and supporter can give only as much support as is needed, to access only those parts of decision support that are required to make and articulate the decision.

Table 1 shows time spent in each stage in weeks. Each week counted was a week where the decision maker had formal contact with the program, by phone call, meeting or both.

Table 1 Time spent in each stage[13]

Decision Maker	Stage 1 Awareness Building	Stage 2 Decision Readiness	Stage 3 Decision Support	Stage 4 Become a Decision Maker	Stage 5 Fulfil Decision
Toby	18 weeks -	-	-	-	-
Claire	1 week	10 weeks	11 weeks	1 week	-
Natalie	2 weeks	4 weeks	10 weeks	2 weeks	2 weeks
Rob	1 week	2 weeks	2 weeks	10 weeks	4 weeks
Scott	1 week	1 week	6 weeks	6 weeks	10 weeks
Jasmine	16 weeks	-	4 weeks	2 weeks	3 weeks

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[13] Names and personal details of individuals have been changed to protect their privacy.

Findings

The Socio-Cultural Framework for Decision Making

The initial community engagement with individuals, service providers, families and carers highlighted some of the ways in which the attitudinal environment in which people live shapes their access to, and attitudes about decision making and created a picture of the socio-cultural framework in which the SDM model would be tested.

The initial six interviews, held with people whose decision making potential was not well recognised, revealed a diverse range of expectations and experiences of decision making. Each of these people enjoyed limited autonomy with lives largely lived in the service system and closely monitored by family.

At the start of the session three of the six interviewees said that they did not have any decision that they would like to make. By session's end five of the six were able to express a decision. One person wished to make a decision about working less which, following exploration of possible consequences, was expressed at session's end as more possibly a decision about changing working hours.   A second person expressed her wish to be heard on decisions relating to work, which she was clearly able to article but had not shared with anyone. Additionally, generally expressed dissatisfaction around shopping, when explored, became a decision about being able to choose her own clothes. A third person wished to make a decision around accommodation. By the end of the interviews five of the participants expressed their wish to make more decisions or make a specific decision. This included a decision about visits with family and another about carers.

Exploring this shift from 'no-decision' to articulating a decision provided important questions for the research in relation to decision readiness and accessing support. When first asked, two of the three interviewees answered that they did not know what a decision was. When given time to consider the possibility of decisions they could make framed, for example, in the potential of things they might like to change, getting more of what made them happy, or even who chose their clothes this morning, two of the three interviewees was able to express a decision.   The shift from 'no-decision' to decision highlights that not being able to express a decision is not the same as having no decisions at all, and raised the question as to how people with little experience in decision making might be supported to develop the skill to articulate their decisions.

The interviews also revealed the impact of others on their involvement in decision making. Fear of not being "allowed" to make a decision, of being seen as a "trouble maker" by care workers, or of upsetting family members were reasons given for not actively pursuing decisions made or claiming 'no decisions'. All six interviewees expressed little or no expectation that decisions once made would be respected, or that they would be given the support needed to fulfil their decision.   Past experience of not being "allowed" to make

decisions appears to underpin an unofficial surrender of their role as decision makers to others. Figure 1 illustrates a cycle where decisions made do not necessarily reflect capacity to decide, but rather a lack of expectation to be respected and supported to fulfil a decision due to the socio-cultural context of their circumstances.

Figure 1 Lowered expectation to decide when individuals are embedded in service systems.

The interviews raised questions in relation to access to DisabilityCare Australia that would shape the remainder of the research. How might people who believe they have no decisions to make or have so little expectation of being involved in decision making become active participants in DisabilityCare Australia?   How, or indeed would, a person who had surrendered their role as a decision maker ask for support to articulate, let alone make, a decision?   It was recognised that promoting expectation to decide would need to be considered and pursued as one component of decision readiness. Where expectation to decide is very low, it is likely that considerable activity would need to take place before a decision maker might access decision support.

The interviews also revealed the potential for personalised expertise to support people with disability claim their identity and expectation as decision makers. There is a need to develop expertise to support people to learn and talk about the decisions that are important

to them and build confidence in their right to decide. This recognises that people will not ask for support for decision making unless they recognise their right and potential as active decision makers.

With this understanding, it is apparent that supported decision making needs to be available to DisabilityCare participants, not as something they might choose to include in a support plan, but as a freely accessible and available resource before, during and after engagement with DisabilityCare Australia planners. Participants cannot choose to include something that they do not know exists to support them to do an activity (make decisions) that they have no expectation of doing. Synonymous with the physically and sensorally accessible DisabilityCare Australia premises currently being established around the country, decision support initiatives must be available as a right to those who need them.

Expertise is needed to support the development of decision readiness, in people whose decision making potential has not been recognised, so that they might build confidence and expectation to be engaged in decisions under DisabilityCare Australia and beyond. Given the impact on decision making by those who share the life of our interviewees, resources need to target not only decision makers, but care workers, families and others.

> Recommendation: That support to develop decision readiness be provided for individuals, families and care workers.

Questions relating to the impact of others on access to decision making were developed further in the forum undertaken with staff from Service Provider 2. Surveys completed at the beginning and repeated at the end of the forum, along with discussion held, show this particular group of paid carers to be highly aware of the right of people with disability to make decisions for themselves and believed that this right to decide could be exercised with support. However, it was revealed that this value set did not always shape work practises.

In learning more about what constituted decision making, a number of carers realised that what they offered as daily choice (in for example what to wear,) does not constitute decision making, particularly in relation to enabling people to learn from bad decisions. This group of workers, while universally in favour of the right to decide, for the most part, unable to reconcile this with their perceived duty of care. They recognised the great potential of their role in providing opportunity for people to practise decision making in their daily lives, gaining experience with small decisions to become ready for the more important ones. Many recognised that supporting people to decide takes time, time which they believed they usually did not have within the available support hours and that this was a significant barrier to creating decision making opportunity. Another significant barrier to carers enabling active decision making was the wish of a guardian. Despite this tension carers believed in their role in supporting people to make decisions for themselves.

While the principles of SDM exclude paid carers from acting as decision supporters on the basis of vested interested, this information session highlighted their potential as a decision

making resource. People with little expectation or experience of decision making need opportunity to practise with the small decisions, so as to become ready for the more significant ones. Care workers, through their values and practises, potentially have many opportunities to develop decision making experience. This may improve the quality and quantity of decisions people with disability make, including decisions made under DisabilityCare Australia.

Surveys undertaken with care workers provided a starting point for possible responses aimed at developing the capacity of care workers to promote decision making. Conflicts and shifts in answers between the first and second surveys show the need for resources to clarify roles and understanding of rights and responsibilities. Many of the care workers were unfamiliar with key concepts in decision making, including where a best interest decision might come into play or what a person's expressed wish is.

> Recommendation: That a training program be created that recognises the role of care workers as a decision making resource for people with disability and promotes their capacity to fulfil this role.

This would explore values that impact on decision making, the rights of people with disability, their responsibilities as care workers, especially as they relate to dignity of risk and duty of care, and provide practical responses for creating decision making experience in day to day life. This could be delivered, on a user pays basis, through service provides, as part of their preparation DisabilityCare Australia.

This consultation showed that care workers, in particular this group, were keen to learn more, but even with more expertise, believed that family guardians may limit their ability to create decision making experience among those they support. A number reported that family guardians often stifle their ability to offer real choice, overreaching their boundaries and extending their influence into the minutia of peoples lives. Some care workers did not believe it was their responsibility to interfere in family relationships, others revealed their sense of intimidation at the authority of some family guardians. Also potentially significant here is the diversity of values in relation to the authority of family and elders held by an increasing culturally and linguistically diverse care workforce.

> Recommendation: Training programs with care workers highlight the limitation of guardianship to important and increasingly specific decisions, and provide information to empower care workers to advocate on behalf of those they support.

Overwhelmingly engagement with family carers, including through the family carers forum with Service Provider 3, revealed the need to raise awareness of decision making as a skill learnt with coaching and experience, and exercised with support. It was revealed that most members of this particular group, while open in principle to universality of the right to decide, strongly favoured proxy decision making over the perceived "risk" of enabling choice by people with disability. They doubted the "capacity" of the people they cared for to make

any decisions, even with support, and worried that access to decision making may impact on the safety of their loved ones.

Concurrently there was some agreement that empowering their children to make more of their own decisions may be a means to ensure their needs are meet when they themselves are no longer able to advocate for them, and indeed this is the basis for their interest in the SDM project. At the initial presentation one parent of an adult child described her daughter as:

"Wonderful! She never gives me any problems. She is so compliant."

As this mother's understanding of SDM and decision making concepts grew, she realised that compliance, potentially, could make her daughter highly vulnerable. Further, this parent could see the potential for SDM to empower her daughter to speak up about what she wants, learn about trust and the benefit of an ongoing decision supporter being able to advocate when she herself was no longer able to.

This aspect of the research reveals the need for resources that raise awareness among family carers about the rights of, and possibilities for people with disability to decide for themselves. It raises questions as to how people whose lives are very closely governed by the values of others might access and benefit from self-directed funding. Again the question of how this particular group might access resources to become decision ready or ask for decision support, was raised. While families and care workers were generally open to the right to decide, risk adverse value sets embedded in old "protectionist" logic provide justification for ongoing, substitute decision making practises. In this context, where people with disability have limited independence and express the idea that they have "no decisions" it is likely that they will face barriers to self-determination under the scheme.

Investigation into the socio-cultural context of decision making by people with disability reveals tension between old and new frameworks. While family members respected the right of their loved ones to be involved in decision making, many were unable to reconcile this with a perceived duty of care and their "responsibility" to render risk from their loved ones experience. This conflict reflects older, protectionist responses to disability running concurrently with rights based values of self-determination. Revealed through the surveys, workshops and incidental conversations, this conflicting value set was widely held, encountered across the program and expressed by decision supporters, family members and also paid carers. Many who held these values expressed the likelihood of defaulting to the familiar "duty of care" responses should they disagree with a decision of the decision maker. At its most extreme, duty of care was identified as a potential reason for withdrawing support for decision making or not engaging support at all. Effectively, a perceived duty of care could justify continued substitute decision making even while holding a belief in the right to decide. Addressing this conflict is recognised as an aspect of the broader cultural change needed to promote access to decision making.

When explored against a socio-cultural framework it becomes apparent that fostering more active decision making by people whose lives are heavily influenced by the values and decisions of others, will require more than the establishment of commonly recognised aspects of decision support, such as a supported decision making agreements or the provision of easy English information.   The project revealed a new layer of support responses, not yet well recognised, whose delivery needs to precede these more commonly understood support responses.   For this group of people, increased self-determination will require cultural change. Cultural change to raise the expectation of those previously marginalised in decision making to become active decision makers. Cultural change to normalise active decision making by people with disability by those who share their lives, particularly those who have become, either formally or informally, substitute decision makers.

This layer needs to be delivered within a community wide focus. For people with disability, the project showed the effectiveness of expertise, supporting people to develop both confidence and capacity to recognise and articulate decisions.   This important step must take place before people will feel that they have a need to access support to make a decision.   Care workers and family carers have an invaluable role in providing everyday opportunity for people to develop decision making experience. This potentially builds the identity of people with intellectual disability as decision makers, for recognition by others.

A supported decision making program would have both the authority and expertise to deliver community based education programs facilitating cultural change. Supported decision making programs have the potential to be a bridge between old and new frameworks, through both monitors and decision supporters modelling behaviour and promoting different values. In addition, broadly based community education initiatives are required that promote individuals right to decide. These would target decision makers, carers and family members.

> Recommendation: That community based education programs which facilitate cultural change are implemented as part of a broader supported decision making agenda.

Trialing New Dimensions for the SDM model

In addition to illustrating the need for a cultural change agenda, exploring the socio-cultural framework revealed two key areas for the ADACAS project to build on the South Australian SDM model. The interviews with individuals, family carers and service providers highlighted the impact of others on expectation for people with disability to be active decision makers. Those participating in the initial interviews enjoyed nominal independence, with lives highly embedded in the service system or within family life. The question as to how this group might access decision support extended beyond the efficacy of the model into the kinds of cultural change that would need to occur for them to be included and respected as decision makers. How could, for example, a carer recognise their family member required decision support to access DisabilityCare Australia if their potential to be involved in decision making was yet to be perceived? Identifying resources that break down access barriers by promoting the right to decide and the identity of people with disability as active decision makers was one area identified for further research.

The interviews illustrated the need to test the model with decision makers whose support needs were more significant. In the South Australian trial decision makers had to be decision ready; that is they had to be able to articulate their decision with a minimum of support. Many of the ADACAS interviewees may not have qualified to participate in that trial, either because they were not decision ready or they were reluctant to express a potential decision. Yet the interviews showed that with skilled support, inexperienced and reluctant decision makers could become decision ready. In response the ADACAS project included decision makers who were not yet decision ready, to explore what responses might be needed to secure formal decision support.

The ADACAS project also included innovative responses to decision makers who did not have a decision supporter. In the South Australian trial the most common reason given for not making a supported decision making agreement was an inability to identify appropriate decision support. Social isolation was common to those interviewed and this was shared by four of the six decision makers identified for the ADACAS trial. Rather than exclude participants, the project set about exploring ways in which socially isolated people might access decision support.

Participants themselves also shaped the way the model was employed. The South Australian Trial specifically excluded financial decisions. Three of the six decision makers identified for the ADACAS trial wanted to make decisions relating to money and finances.

Including decision makers with a very diverse range of decision making experience illustrated in the project the importance of creating responses to decision support that could be individualised to meet the experience and expectation of a wide range of decision makers and underpin the widest possible access to decision support. At the start of the project three decision makers were able to express their desire for change but lacked the

experience, expectation or commitment to drive that change. One decision maker could not conceive that he had a decision to make but was, as a soon-to be-school leaver, about to have important life decisions imposed on him. Two decision makers were decision ready. This meant being able to share decisions with others, with support if required, within a short period of time. These same two decision makers were also able to identify people in their lives willing and able to support their decisions. They were in a freely given relationship with these supporters, who themselves were willing to work to the principles for decision supporters. In terms of person resources, these two people would have qualified to participate in the South Australian trial, with the exception that both wanted support to make financial decisions. This would have excluded them.

> Recommendation: That supported decision making programs provide responsive flexible models of decision support tailored to individual need.

Raising Awareness

The initial interviews illustrated the need to raise awareness of the right to decide and the potential of decision support. This need was reflected in the cohort of decision makers. Just one of the six decision makers was able to convey a sense of his right to make his own decisions. None of the decision makers was aware of the possibility that they could be supported to make more decisions.

Web searches revealed limited relevant resources for describing the right to decide to adults with intellectual disability.[14] As the concept of rights is abstract - they cannot be seen or touched – the most successful strategies developed for use in the project described the right to decide in terms that were accessible to each decision maker. For Claire, the right to decide means being "the boss", for Scott it is about having control "so people listen when I say no", while Natalie was empowered by the idea that her right meant that others could not "tell her what to do". Decision makers were encouraged to think about the things they would like to have more control over and, should there be a person in their life that they trusted, share this. They were encouraged to remind those around them that they have a right to decide.

All six decision makers used the opportunity to learn about the availability of decision support and its rights based principles. Two decision makers expressed concern about their guardian's willingness to respect their right to decide and the possible tensions a decision supporter may bring to their life. These same decision makers had sought permission from their guardians to be involved in the project. This provided the opportunity for the

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[14] Resources here are largely focused on children, are not written in accessible Easy and Plain English formats, and do specifically encompass the right to decide.

coordinator to discuss decision support with family guardians. Some guardians raised their concern about the vulnerabilities of loved ones, particularly in relation to financial decisions and lifestyle decisions. Reassuring guardians that supported decision making could reduce vulnerability by building new skills while working in tangent with existing guardianship orders, helped create acceptance for the possibilities of supported decision making. One guardian, acutely distressed by the tension that being a family guardian placed on the relationship with his daughter, was inspired by the possibility that supported decision making could reduce the number of decisions he may have to make for his daughter.

Decision makers responded strongly to the truth that all people have the right to decide "regardless of their ability, or disability" by recognising their potential as decision makers. This in turn underpinned a commitment to making a decision within the program. There was one exception here.

Toby is a man in his 20s with a dual diagnosis. A client of ADACAS, Toby was at risk of homelessness. Acutely unhappy with the decisions that his family guardians were making on his behalf, Toby expressed his desire to make more decisions for himself. Time was spent describing supported decision making and promoting the right to decide and in February Toby expressed a willingness to make a decision, either about his home or to begin a review of his guardianship, within the program.

These two decisions were inter related, and a point of considerable conflict, as Toby's guardians had the right to make accommodation decisions. Their style as guardians was not consultative and it had been observed by Toby's advocate that in the past they made decisions on Toby's behalf that did not take his will and preference into account. They also choose not to share the reasoning behind substitute decisions with Toby or his advocate.

As his housing situation became more uncertain, Toby became less able to make a commitment to his decision. Appointments to meet were made and cancelled, then made again at Toby's request. The project coordinator would occasionally check in with Toby to let him know that the support was available when he was ready to use it. This pattern continued until the end of the project. Toby's willingness to decide was keen, however he was unable to sustain the focus on a decision needed to drive change at this particular time. Toby's engagement with the research project has given him a sense of his right to make the decisions that are important to him and he remains open and hopeful about his potential to become a more independent decision maker. Toby also believes that, as his housing situation settles, he will feel more able to make a commitment to drive his decision forward. He is very confident that he would access formal supported decision making in the future, if it were available to him.

Toby's experience in the program illustrates the importance of time and timeliness in supported decision making. For Toby, decision support means giving him time to build expectation that he is able to drive change in his life through the decisions he makes.

While Toby used minimal project resources, semi regular contact to remind him of his potential as a decision maker were invaluable in developing his expectation to become more active in important decisions in the future.

In relation to timeliness, supported decision making must support people to approach decision making in the same way as those who do not have a disability. This includes the ability to make a decision when the time is right for the individual and for each decision. For Toby to make one of the significant decisions he has identified, decision support will need to be available to at time that suits him and his decision. Should Toby's decision develop a deadline, for example for a scheduled review of his guardianship orders, then support in this stage may include raising awareness of time sensitivies. Supported decision making programs need to be structured to accommodate timeliness. Once individuals are engaged as decision makers, support time can neither be imposed nor meter out.

> Recommendation: That supported decision making programs recognise and accommodate individual needs around timeliness.

Developing Decision Readiness

Two decision makers, Rob and Scott, were decision ready. The remaining four decision makers, Natalie, Claire, Jasmine and Toby, needed support to become decision ready. Initially this was understood as an inability to articulate a decision. However, the project provided opportunity to learn more about what readiness to decide might mean for people whose decision making capacity is unrecognised. One aspect of decision readiness is the ability to recognise a decision and the potential for change. This recognition might be very general and could require support to explore in more depth.

Natalie expressed dissatisfaction about her work and, with support, was able to express this as a decision about changes to her support and medication routine as they related to her working hours. A decision supporter could have a role here, however as Natalie had not yet identified a supporter, this role fell to the coordinator. During two hour-long conversations one week apart, Natalie was supported to unpack her dissatisfaction and to explore the possibilities for change and her own agency in creating this change.

Once decision ready, Natalie did not need to make a supported decision making agreement to fulfil this particular decision. Instead she was supported by the coordinator to discuss her decision with a care worker and work manager. Here Natalie was able to informally access elements of decision support to build her experience, identity and expectation as decision a maker. This in turn built her readiness to make and fulfil what was for Natalie, a more challenging decision using an SDM agreement. Practise with this smaller decision gave Natalie the experience to consider what she may need from a decision supporter in the

formal SDM context. Natalie also gained recognition from others, including support workers, colleagues and her family, for her capacity for self-determination.

In this process Natalie highlights another aspect of decision readiness - willingness to share her decision rather than claim "no decision", with the expectation that this will be met with both respect and change.   Respect from the coordinator, at this point her stand - in decision supporter, gave Natalie both confidence and purpose to sharing her decision. Natalie reported that knowing she had a person who had taken time to really understand what she wanted and could, if needed, advocate on her behalf, gave her the confidence to speak up about her decision.

An additional foundation for decision readiness recognised in the project, is perception of what a decision may entail, including an understanding of a range of decision making concepts such as change, the future, the role of other people within a decision, risk and identifying achievable options. Claire, a participant in the initial interviews who continued in the project, gave the impression of being decision ready. She wanted to make a decision about her home. She knew that it needed to accommodate her wheel chair and be accessible to her work. However, when time was spent supporting Claire to articulate her decision her lack of experience and its impact on her ability to effectively conceive it became apparent. Claire needed support to understand that, while the one house she had her heart set on would fulfil many of her needs, it was already home to someone else. She also needed time and support to consider the financial and service implications of such a significant decision. Claire was another decision maker who lacked a supporter and the monitor worked with her to build her capacity to cast forward and begin to recognise what her decision may entail and understand key concepts. In developing a sense of what it means to compromise, for example, Claire became more willing to consider a range of different options. With support to think about consequences she could begin to think about the skills, including cooking and improved financial literacy, she might need in a different, more independent future.

From Claire we also came to understand the centrality of expectation to decision readiness. When talking about the possibility of a new home Claire brimmed with enthusiasm. She keenly expressed her desire to move out of an institution and into a home where she lives with a person she likes and she has a key to the front door: "support workers will have to knock and I will let them in." However Claire's considerable excitement about the potential for change would be quickly extinguished each time she considered her family, in particular her mother, who is also her guardian.

> "She will not let me (move out). I am 46 years old but my mum will never let me make my own decisions. Everyone listens to her. No one listens to me. Everyone else thinks that they know best about me."

For Claire, becoming decision ready meant building her expectation that she could be active in creating change in her life. Claire needed to build her expectation to a point where it would not be extinguished against the enormous authority of her guardian. This was the case even when smaller less complex "practise" decisions were raised. "She will never let me" became the response even when simple decisions about her supports and social life were considered. Claire regularly reflected that support staff would consult her guardian and only support her to act on her decisions if permission had first been obtained.

For Claire, as with other decision makers in the program, it was recognised that building decision readiness would mean building the capacity of those around her to understand, respect and support her right to decide. This is particularly important because Claire's significant physical support needs and the institutional context in which they are met, leave her with little independence to fulfil even her most basic decisions. The habit of support workers to take direction from her guardian leaves Claire completely disempowered as a decision maker. Here, the socio-cultural context in which Claire's decisions are made has far more impact on her decision readiness and self-determination than that of her intellectual impairment.

For Claire, respect and recognition for smaller day-to-day decisions by the support workers who share her daily life would increase her expectation to be involved in important decisions. They would build Claire's experience to decide on the things that are important to her and to understand what may be involved in fulfilling a decision. Supporting Claire to fulfil simple decisions would develop, rather than stifle, her expectation be an active decision maker. Being involved in small decisions would help make Claire become ready for the large ones that are most important to her.

While giving in principle support for Claire's right to decide, conversations between the monitor, the coordinator and those who support Claire revealed that they saw advocating for her decisions as beyond the scope of their role: "It's a mother-daughter thing. I don't get involved in family stuff." Enabling Claire to take a risk, learn from a mistake or do something that her guardian did not agree with would, as they understood it, be a breach of their duty of care. For Claire, becoming decision ready will require significant change in approaches and values of those who share her life.

The project illustrated that, with support, people who are not recognised as being decision ready can build their capacity and expectation to be active decision makers. Including activities that build decision readiness within a formal SDM program is an effective way to ensure that people with a very broad range of decision making experience and expectation are enabled to access decision support.   Support activities in this area need to be personalised to meet the individual response of the decision maker and include activities that:

- · Develop expectation to be active decision makers:

- Build capacity to understand concepts in decision making and what might be involved in making a decision; and
- Support expression of a decision.

For some decision makers, however, this activity needs to be supplemented by resources that promote and advocate for the rights of people with disability to decide, targeted at care workers, families and family guardians.

> Recommendation: That support for decision making encompasses capacity building resources for care workers, families and family guardians, in addition to capacity building for individuals.

Establishing Decision Support and Developing a Support Framework

Securing decision support was the most time consuming activity within the project. While four of the six decision makers were able to identify potential supporters at the start of the project, just two were able to establish a freely given support relationship. The main barriers to securing decision support included social isolation and tensions within relationships involving family guardians. The difficulty in establishing freely given support relationships led ADACAS to explore the potential of introduced peer relationships and professional decision support.

Two of the decision makers, Rob and Scott, secured decision support within a period of weeks. Rob is an experienced decision maker who, in the past, had enlisted the support of his father and sister along with a leader from his church, to make decisions. He is highly engaged in the community through work, sport and church and has only minimal contact with the service sector.

Rob's father made contact with ADACAS following the community engagement phase of the project. In Rob's own words, he "got scammed" and this prompted questions from some family members as to whether guardianship might now be the best way to protect him against financial vulnerability. Wanting to avoid this, Rob's father sought out the project as a means to build Rob's capacity to make financial decisions.

However it was Rob's goal to continue to live his life with the same confidence he had before he got scammed that set the framework in which Rob accessed and experienced decision support. Rob recognised that to regain the confidence to keep doing what loves, he would need to develop skills to know when he could trust others. Part of the power of the person that defrauded Rob had been in convincing him not to talk to his usual support network about what was happening. He also sought the ability to be more assertive: "I want people to listen when I say no". He also recognised that he needed support in relation to financial decisions.

Rob chose his father Don and sister, Karen as his decision supporters. Rob enlisted Don to support him with decisions about money and signing contracts because he had a past role in supporting Rob with budgeting. Rob recognised and respected Don's expertise.   He chose Karen as support for aspects of any decision that involved trust. He did this, he explained, because he would rather talk to her about relationships.

Like Rob, Scott chose two members of his family to act as supporters in his decision to investigate purchasing of a new home. He chose two because he recognised their different strength: "Deb is good at listening to me… Adam is good with money." Scott chose family members because they "understand my situation without me having to tell them all the time".

The way in which Rob and Scott adapted the model by using two supporters, illustrates the importance of flexibility in support responses. In addition to using two supporters, both decision makers reflected that in the future they may use just one of these supporters or, in Rob's case, a completely different supporter for other decisions. There has been an emphasis on the benefit of freely given support because it has the potential to be ongoing and potentially life long. What also needs to be recognised is the possibility that some people may also seek more fluid or multiple decision support relationships. Indeed such fluidity may more consistently mirror the support for decision making that most people use throughout their life; seeking out a range of friends and experts specific to the decision being made. If supported decision making is to enable people with disability to approach decision making in the same way as those who do not have a disability, then accommodations must also be made for fluidity in approaches to support.

Finding Decision Support

For Claire and Natalie, securing decision support needed a significant investment of time. Both identified potential decision supporters at the start of the project. Claire and Natalie looked to trusted friends for decision support, both of whom had mild intellectual disability and lived in institutional settings. Here there was potential to explore the peer support within the SDM model.   The friends strongly identified with the disempowerment borne of not being heard, were excited when the principles of decision support were discussed and the possibility of a role in empowering another to have control. They were, for example, quick to agree to being able to support a decision they did not agree with because they knew what it felt like when others "take your choices from you". However, even with the offer of coaching and support from the monitor neither felt able to commit to the role. Natalie's friend believed she lacked the experience as a consumer to support her decision to buy a new computer: "I don't shop much. People in shops don't listen to me." Fear of damaging her friendship with Natalie was also at play in her decision not to become a supporter. She explained she did not have many friends and that she did not want to do anything that may jeopardise their friendship. While Claire's friend declined because he himself had been trying to move out of an institutional setting for many years, his own lack

of success left him believing he was unable to support Claire to fulfil her decision to find a new home.

Undeterred Claire, with support from the coordinator, approached her cousin and then her nephew. Both declined, citing not wanting to "come between mother and daughter" as the reason.   As months passed, Claire continued to develop her decision readiness while trying to secure decision support. At one point, she became so desperate to be supported in her decisions that she called the coordinator to report that she had approached her uncle and he had agreed to support her. Here, time spent getting to know Claire was invaluable. Early in the project Claire identified this uncle as a person that she most definitely did not trust. As project time ticked down, Claire suggested we approach the owners of a local business. This couple were always friendly and helpful to Claire and the possibilities for using introduced supporters were discussed.   Establishing an introduced support relationship went beyond the resources of this project due to time constraints but is deserving of further exploration.

There are a range of existing frameworks that offer potential for introducing freely given support relationships, including "micro boards and circles of support".[15] A research project running concurrently with this project specifically explored opportunities for establishing citizens advocacy in the ACT and may offer insight. [16] However, this model would need to be adapted to work within the SDM principles and specifically excludes the possibility of substitute decision making that exists in the Citizens Advocacy Model, to deliver human rights objectives. Resources to research and adapt these, however, were outside the scope of this project. A new research project initiated by the Victorian Office of the Public Advocate is exploring the use of volunteers to support people with disability and may also offer insight.

Claire, however, was unable to secure decision support within the timeframes and resources of this project. For the duration of the project the coordinator continued to work with Claire to build her understanding of her decision and her role as an active decision maker. This includes knowing that she needs to explore additional options, learn new skills and consider supports and services that could be transferred with her into a new home. Claire was supported to use the support-my-decision website. Here she made a map of her decision. This records what Claire feels is most important about her decision, the range of options and consequences considered along with skills she may need to develop. She could use this map to stay connected to her decision and to show others so as to gain respect for her capacity to decide. However, while Claire is very proud of the decision made and

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[15] Watson, J., Scope Victoria, 2011, *Listening to those rarely Heard,*
http://www.scopevic.org.au/index.php/site/resources/listeningtothoserarelyheard
[16] Forthcoming research project ATCCOSS, funded by Disability ACT. This report was not available at the time of publication.

recorded in the map, she has said that she is unlikely to show it to her guardian or key support workers for fear that it will not be respected.

There are a number of significant points in relation to the importance of formal decision support be learnt from Claire's story. Claire's capacity to make a decision does not match the opportunities she has for self-determination. Claire has shown that, with support, she is able to make a significant and complex decision about her home. Without ongoing support, her ability to fulfil this decision and to have that decision making capacity confirmed is shaped by the values and behaviours of those who share her life - family members, support workers and her guardian. Her support needs make her dependent on them. Their behaviour leaves her powerless to determine her own future. Here again, the importance of cultural change emerges.

Claire also illustrates that while skilled use of informal resources such as the support-my-decision website are valuable in building understanding of decision making, they cannot replace a decision supporter to advocate for her right to decide among service providers and family members. Claire's newly developed expectation to be an active decision maker is tenuous. There is a real risk that Claire, even with a well formed decision, will again become inert against the will of her guardians whose strongly stated preference is for Claire to stay exactly where she lives. How might Claire exercise choice and control under DisabilityCare Australia without skilled, formalised decision support given by a trusted person?

Like Claire, Natalie exhausted her list of potential decision supporters without success. After her friend Amanda declined to be her supporter, Natalie approached her sister, Francesca, who was also her joint guardian. The conflict between the best interest and express wish modus operandi was recognised. However this was balanced against the potential to explore how formal supported decision making might work in tangent with guardianship. Could the rights based principles of SDM challenge the best interest approach and reduce the extent to which a guardian used, or misused their powers? Francesca was open to the benefits of Natalie learning to be a decision maker. She worried that support staff did not listen to Natalie and wanted her to be less vulnerable to the will of others. Extremely caring of her sister, Francesca's hopes were for Natalie to be more assertive and to learn if she herself could be a better guardian. In the end, however, Francesca did not become Natalie's supporter. She believed that, no matter how much Natalie developed her capacity to decide, there would always be some decisions, particularly financial decisions, that Francesca would be called on to make on Natalie's behalf. She worried that supporting an expressed wish approach would make it more difficult to be a substitute decision maker at these times.

Exploring the Possibility of Peer Support

At this point in the project both Natalie and Claire were decision ready, but without support. The possibility of an introduced peer supporter was further pursued. The project coordinator made contact with Linda, an ADACAS client who in the past had identified her willingness to do volunteer work helping others. A woman whose physical support needs meant that at 47 she was an unwilling resident of an aged care facility, Linda felt unable to support Claire in her accommodation decision. She felt confident however, that she may be able to support Natalie's decision to buy a new computer.

The role and principles of decision supporter were described to Linda who shared Amanda's concern about her ability to be effective when she herself was not always respected by others. Linda, however, felt that with support from the monitor along with the backing of an advocate, if needed, this could be overcome. Linda was enthusiastic about the possibility of the role and the principles of decision support because: "I know what it feels like when no one listens". She had thought about scenarios involving risk or a decision that she did not agree with and was, of all the decision supporters, fastest to note that the decision, including the risks and mistakes, would belong to Claire: "I can point them out. Tell her what I think. What she decides is her choice. It's not mine."

Linda pointed out some of the limitations she anticipated in her ability to support Claire, who wanted her decision supporter to go shopping with her and give her support to weigh up different features, sizes and prices when she purchased her computer. Linda, however, needed physical support to get to the shops. She was concerned that having a support worker present might undermine their authority. She feared that the salespersons would speak only to her support person. Linda highlighted logistical considerations including the cost of taxis and coordinating her own support worker routines to fit in with Natalie's. Linda, it must be noted, was willing to give over her own limited support hours to support Natalie.

These issues, she believed, could all be overcome and she was confident in what she could contribute to the support relationship. Unfortunately the relationship did not develop further. When they met, Natalie did not believe that Linda would be the right supporter for her and, as the decision maker is always in control, the relationship did not progress. Linda remains keen to become a decision supporter and remains hopeful of future opportunities.

The experience, while invaluable in exploring the great potential for introduced supporters with lived experience, left Natalie with a clear decision but lacking the support she needed to make it. Increasingly evident was the difficulty in progressing Natalie's decision without a supporter. This galvanised our decision to explore professionally given decision support.

The argument for Professional Decision Support

Freely given support is a corner stone of the South Australian SDM model. When making a decision most people seek input and advice from a person they respect and trust. Rather than being seen as disability specific, supported decision making is the normative method in which most people make a decision in that we generally seek input from significant others in decisions that we make. Within the context of a supported decision making program, it formalises this natural, normal support to protect vulnerabilities and develop skills.

Having a person who is paid to fulfil this role, the argument goes, subverts this natural relationship and further cements a person's life in service world. Decision support is beyond the realm of support workers and service providers because the fact that they are paid to be in the person's life means they have a vested interest. There are inequities in the power relationship between worker and client which inevitably influence the outcome of decisions. Relationships formed around service do not mirror the patterns of friendships built on affinity and trust. Decision support emerging from natural relationships is sustainable and, theoretically, available. It could be available, for example, when Toby was ready to decide or for the time it would take for Claire to make a complex decision like finding a new home. The time of paid care workers is meted out, they work to shifts and move on to new jobs.

Yet four of the six decision makers lacked the support they needed to make the decisions that are important to them. The significant extent to which social isolation impacts the lives of people with disability was reflected in the Shut Out report.[17] If a person's right to decide is universally supported, then decision support responses need to meet the socio-cultural context of all people, including those who are socially isolated. This means acknowledging the extent to which social isolation impacts on people with disability and developing support responses able to accommodate this.

There are two competing principles within the debate. One is delivering a model for decision support that upholds person centred practises to promote and support natural, freely given relationships in the lives of people with disability. This sits against creating readily available decision support that could be accessed by any person that needed it, including those who are socially isolated. Given the centrality of decision making in delivering self-determination under DisabiltyCare Australia, there is an argument for exploring decision support frameworks widely accessible to a cohort so broadly affected by social isolation. Given the issues with using known paid workers as decision supporters, the concept of professional decision supporters, specifically trained and skilled in providing rights based decision support, needed exploration.

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[17] National People with Disabilities and Carer Council, 2010, SHUTOUT; The Experience of People with Disability in Australia,http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia

One Experience of Professional Support

For Natalie, time to make her agreement and be supported within the project was running out.   ADACAS took the decision to act as a decision support. Delivering support using the same no fee for service model that advocacy is delivered, and by a person who had no other role in Natalie's life, eliminated issues around vested interest.

The project monitor, Rozi, stepped in as decision support with the project coordinator fulfilling the monitor role. Natalie was able to create and fulfil her agreement within 16 hours over a period of four weeks. One of the most powerful lessons learned using a professional supporter was the degree to which Natalie was empowered in a short period of time. Comfortable and familiar with the person centred approach of the decision support guidelines Rozi was a skilled and effective supporter.   As such Natalie retained control of her decision at all times, was supported to approach it in her own way and to do as much as she could for herself. Rozi worked with Natalie to give detail to her decision, including where her new computer might be set up, how this limited its size and who would install it. Natalie used brochures and the internet to identify models that were within budget, to look at in store.

When Natalie visited the store armed with questions, Rozi, reported that without support, Natalie would have had scant opportunity to ask them: "She might as well have been invisible." When they eventually found a sales assistant to answer questions he looked over the top of Natalie's wheelchair to speak directly to Rozi. He did this even when it was Natalie who asked a question. Rozi directed the conversation to exclude herself and include Natalie, eventually declaring that this would be Natalie's purchase.   Rozi was able to model communication behaviours to the sales person, including slowing down the conversation to give Natalie processing time and positioning Natalie's wheelchair to ensure that he could see her when she was speaking.

On the second visit to the store Rozi noted that the assistant was more confident and comfortable speaking directly to Natalie. He noticed her come into the store and sought her out, offering service and information.   He took time to answer her questions, looked her in the eye and spoke at a pace to mirror hers. This time, appropriately, it was Rozi who was persona-non-grata.

When they next met, Natalie reported to Rozi that she had been to the shops with one of her support workers, where a conversation about a different purchase had taken place over the top of her, excluding her. Rather than silently accept this as she had done in the past, Natalie put an end to it asking the sales person to speak to her - "I am the one that might buy something today" - and telling her worker that she wanted to be supported in a different way.

Rather than social isolation being cause for "no decision", with a professional supporter Natalie was able to make and fulfil a decision. This has built her expectation to make other

decisions that are important to her. She has been forthcoming in sharing this with family, her guardian and key support workers, all of whom have been impressed by the display of a skill that they were unaware Natalie had. Professional support provided Natalie with an opportunity to confirm her capacity as a decision maker to herself and those around her.

Through professional decision support Natalie also experienced a better way to be supported. She has found new voice to tell others how she would like to be supported. Her father has noticed that she is more assertive in telling people what she wants and less likely to quietly accept what she doesn't like. As such Natalie is less vulnerable to the interests of others and more able to achieve the things that she wants. Her parents, concerned about what Natalie's future will look like as they age, are celebrating this.

Delivering professional decision support was not, however, without its problems. The project has ended and Rozi has moved on. Natalie has stated that she would like to continue to use a decision supporter, particularly for decisions that involve money. Having support made her feel "safer". While Natalie's expectation has been ignited, she is potentially limited by the lack of ongoing support.

Rozi reported that the intimacy of being in Natalie's room, talking about options and then shopping together felt intimate: "It's what you do with a girlfriend, not a support worker." Rozi, while careful to remind Natalie of the boundaries of their relationship, remained concerned that Natalie may not recognise these and feel hurt when Rozi was no longer paid to be in her life.

While the preference for freely given support remains, the project makes a case for the possibilities of making professional decision support available for those who are socially isolated or when avenues for freely given support have been exhausted. This might enable people to make important decisions until a freely given supporter could be identified or introduced.

What is striking about Rozi's experience as a professional supporter was the opportunity to model, and then observe the effectiveness of her approach to decision support. Rozi noted that care workers recognised and mirrored support approaches asking Natalie, for example, what she would like to pack for a weekend away and supporting her to consider options. In the past Natalie had complained that care workers packed for her without asking her what she would like. Professional decision support has currency to create cultural change by modelling support behaviour to families, care workers and others in the broader community.

> Recommendation: That supported decision making programs further develop a range of decision supporter models including freely given known supporters, volunteer introduced supporters and professional support.

Developing SDM Agreements

Developing SDM agreements provided opportunity to further explore values and support needs of both decision maker and supporter, giving a depth of understanding to the individual framework in which support could be given and received. This provided opportunity to develop an individualised support and coaching framework relevant to the values and needs of each relationship. The support framework recognises that giving decision support is as much a learnt skill as decision making, and the monitor has a role in identifying areas of need so that more appropriate supports can be modelled, discussed and taught. Discussions with both decision makers and supporters flag potential areas of risk within the relationship for ongoing monitoring. One decision supporter, for example, commented that they may be tempted to unduly influence a decision they did not agree with. Another felt the need to shield the decision maker from certain options, while one decision maker recognised that if inactive long enough, his supporter would undertake a task that he himself was capable of completing but did not like to do.

As practitioners of person centred approaches, Rob's supporters Don and Karen were able to agree to the principles of decision support almost immediately, although both recognised that they may need coaching when it came to supporting Rob to learn from his mistakes. Addressing this conflict formed part of Rob's support framework.

Of all the decision makers, Rob spent the most time developing both the structure and wording of his agreement to ensure that it met his needs.   Rob met with the project monitor, usually fortnightly but weekly when required, over a period of 12 weeks before he was satisfied that his agreement captured his decision and met his support needs. Rob was precise in specifying how he would use his agreement, how and when he wanted to be supported. He wanted an agreement that would tell people he could make his own decisions, but that in relation to decisions involved the signing of contracts or amounts greater than $100.00 he would need to discuss his decision with his decision supporter first. He also wanted his supporter to recognise the boundaries around support: "I don't want to have to talk to you about every cent I spend."

The structure of the agreement was integral to the way in which Rob planned to use it. He wanted to be able to show his agreement if he was feeling pressured to sign a contract or give money to a person he did not know if he could trust. He wanted it to provide an exit strategy in situations where he recognised potential financial risk. This was important because when he had been defrauded he had recognised the risk but felt unable to walk away.

This meant developing Rob's agreement in two parts. The first part featured minimal detail so that Rob could show it to strangers without revealing information about himself that he wanted to keep private. Especially important was not revealing that his father was his decision supporter.

I chose my Dad to be my supporter for financial contracts. If I have to show it (my agreement) to someone I don't want everyone to know that it's my Dad. I want the protection without people thinking that I can't make my own decisions or that I have to ask Dad.

This first page simply stated that he could make his own decisions, but would not make any financial decisions without first speaking with his decision supporter. The second part identified his supporter and how he wanted to be supported. Being clear about how to name people in a way that protected Rob's dignity and how he wanted to be supported took time. Thinking about probable scenarios and feeding these back to both Rob and his supporter was an important step in enabling Rob to develop a precise agreement that gave him the level of "comfort" he was seeking.

The final part of the agreement, included to promote decision making beyond the short term scope of the project, was to add to the agreement future decisions that Rob would like to make. These were decisions expressed in the early days of engaging with Rob, that he would like to have made had the issue of fraud not been pressing.

Once the agreement was created Rob and his supporter needed minimal time. This was partly due to the nature of Rob's agreement, which was to be used in times of crisis, and partly due to the nature of the relationship between Rob and his supporters.

Conversely, Natalie's agreement was brief. She did not place importance on the document itself, but valued the time taken while developing the agreement to talk about and clarify the kinds of support she would like to make her decision. This again highlighted the importance of having flexible approaches to SDM that recognise and accommodate the values and approaches of each decision maker.

> Recommendation: That decision support programs recognise that supported decision making agreements may have multiple purposes for the decision maker and that the documents therefore need to be flexible to meet individual need.

Coaching and Monitoring

For Scott, having family members as decision support showed the potency of formal SDM to improve the quality of relationships for people with disability. Scott is a member of a large, blended family where conflict about what might constitute his best interest left him feeling disempowered and deeply distressed. He did not want to have to spend time sharing this situation with others.

While developing his SDM agreement, it became apparent that Scott would need his decision supporters to help him stay connected to this decision. Scott would often share worries about what will be said about him at a forthcoming ACAT review. This review is relevant to Scott's decision because he would like to use his SDM agreement, along with his experience in the project, to show that he is able to manage his money independent of the Public Trustee. The project monitor noted that, when distressed, Scott becomes disconnected from his decision and is unable to act. Conversely, Scott's family and by extension his decision supporters, had become "used" to Scott's distress and had a tendency to act "on his behalf" when he became inactive.

The monitor recognised that Scott's supporters needed to develop their own capacity to support Scott to act. Particularly important was the need to nurture new patterns of communication and behaviour to supplant those grown from shared family history.

The project monitor facilitated a series of conversations between Scott and his supporters to create a "to do" of things Scott needs to do for himself to fulfil his decision. To ensure that his supporters don't act on his behalf, the list clearly identifies Scott's responsibilities and those of his supporters. This list has been attached to his SDM agreement. This has included working with Scott to break down his research into clear tasks, including learning how to use the internet to research a property, developing a timetable for doing this and checking on his progress. Independent of support, Scott identified a list of his needs and wants in relation to a potential purchase. These included public transport, ability to keep animals, proximity to family, and suburbs with good capital growth. Developing a way for Scott to record and weigh these is also under discussion.

When his decision supporters were together the monitor recognised that Scott often withdrew from conversations. She was able to coach them to slow down their conversation to give Scott time to process and be engaged. Supporting them to recognise that Scott's decision making style was distinct from their own was important. Scott, for example, did not participate when they ran through possible options quickly to consider if they merited further consideration. Rather his style was deliberate and methodical. Prioritising options and giving information in small chunks was a support strategy that enabled Scott's engagement. The monitor's role was invaluable in the success of the SDM relationship in demonstrating the principles of SDM – talking to him not at him, asking not assuming, and taking time to understand his motivations.

While Scott and his supporters were quick to notice the benefit of this new communication regimen, ongoing contact with the monitor has been essential to ensure that relationship does not slip back into past habits. Following a longer than usual break in contact, the monitor found that Scott's supporters had assumed that he was working through his list and that a number of important decisions in relation to the review of Scott's Trusteeship had been made on his behalf, by another party.

Scott and his decision supporters have illustrated the importance of expert, personalised coaching and oversight given, much like advocacy, for as long as is needed to fulfil a decision.

> Recommendation: That any supported decision making initiative include a paid monitor role to oversight and coach decision makers and decisions supporters.

Boundaries of SDM

In the ways that they used their SDM agreement, accessed decision support or engaged with advocacy, new information about SDM was learnt from each of the decision makers. It was providing Jasmine with as much support as is needed to decide what pushed the boundaries of the model the furthest.

Jasmine became a decision maker in this research program in February 2013. A family member sought the appointment of a guardian on her 18th birthday and ACAT suggested that SDM might provide an alternative to guardianship, or reduce the extent to which the order impacted on her autonomy. When her guardianship hearing went ahead, Jasmine ended up with two guardians, her long separated parents, who have polarised views on what might constitute her best interest.

Jasmine and her guardians faced important decisions about her future. The hearing itself revealed considerations about with which parent, and in which State, Jasmine might reside and what she might do when she completed school. Jasmine has complex communication needs and, in relation to decision readiness, her capacity to understand and use the abstract concepts relevant to decision making, including thinking into the future, anticipating consequences and imagining options, was quite low. However, as a school leaver, significant decisions would be imposed on her, decision ready or not. In this context could Jasmine be supported to make a decision about her future using a relationship based SDM model?

Rozi, the monitor, met Jasmine on a weekly basis at her school. School was chosen because it was a place where Jasmine was comfortable and was not associated with the views of a particular parent. Jasmine's peers, all keen on the idea of making decisions for themselves, were helpful in establishing communication with Jasmine. One friend noted that she would

not talk when she was tired. Another led Rozi to a place at school where Jasmine went to rest or feel safe.

 Rozi spoke with teachers and learning support staff who, while supportive of the project, almost universally shared low expectations of Jasmine's role as a decision maker: "She will always just choose the last thing you offer." It did not appear to be understood as something she could be active in now, nor imagined as a skill she might develop for her future. Nor was there awareness that this group could have a key role in supporting and developing Jasmine as a decision maker.

Rozi spent time with Jasmine talking about choices she makes at home and practising making small decisions at school. These include choices at the canteen and how Jasmine spends her time. In these small choices Rozi recognised approaches that worked with Jasmine. Starting with limited, always visual options was the key. Strategies included revisiting a possible choice to confirm that what was indicated was what she really wanted, asking her to describe why she had made her choice and, once a decision had been fulfilled, talking about it to see if she was happy with her choice. While Jasmine exhibited more capacity and expectation to choose, when supported, her ability to understand the complex decisions that faced her remained a barrier to decision making.

Identifying decision support for Jasmine ran concurrently with development of her decision readiness. Finding decision support for Jasmine proved challenging. When invited to nominate a person to support her Jasmine was unable to identify anyone. This may have been, in part, because she had not grasped the role of the supporter. It may also have been circumstance. Jasmine's life is lived largely between family and school. As with the 18 - 24 year old cohort in South Australia, Jasmine had not yet had time to establish a network that may include people able to support her.   Given Jasmine's family situation, engaging one of Jasmine's siblings was fraught with potential for vested interest. A teacher came forward but was excluded on the basis that she was paid to be in Jasmine's life.   Jasmine's school friends shared similar support needs, so peer support was ruled out. By the end of April, after 11 weeks of being supported in the program, Jasmine had not articulated a decision that she herself would like to make. As well as decision readiness she lacked a supporter. Yet Jasmine herself faced major life decisions.

Jasmine's circumstance placed her well beyond the boundaries of the tested SDM model and raised questions as to how she might continue to participate. We recognised that, while Jasmine could be more active in important decisions, her ability to conceive a decision, understand consequences and imagine the future meant that, within the project, Jasmine was being supported to express her will and preference rather than make an independent decision.

Following discussion with both guardians, Rozi stepped in as decision supporter and a strategy was devised to support Jasmine to make a decision about what she would do upon

leaving school. Given the conflict between her guardians, who would ultimately make this decision on her behalf, a plan was devised to support Jasmine to explore one option she herself chose, and two more options, one proposed by each of her guardians.

Jasmine's mother believed she was happiest when outdoors and proposed a supported employee gardening option. Jasmine's father, enthused by recent gains she had made at school wanted her to continue to attend formal education. An option was identified where Jasmine could study both literature and develop practical horticulture skills. The third option, Jasmine's option, proved more challenging.   Jasmine had told Rozi that she liked to make things. Within time and other project limitations a possible option that met Jasmine's wish to build could not be identified. The decision was taken to spend project time exploring the two identified options.

On the first week Jasmine visited the employment program. She spent time meeting people and observing what they were doing. Photographs were taken to create a picture board. This would be used to remind her of what she had seen. These paid particular attention to the things Jasmine had liked (the people) or disliked (the noise of the lawn mower). This process was repeated the following week, with the second option. On the third week, to ensure both options were fresh in her mind, Rozi took Jasmine for a brief visit to see both options. Back at school the two options were then considered. Jasmines choose option 2. She was able to describe why she chose it. When revisited, the option she most preferred remained the same.

Jasmine's experience illustrates the potential of SDM to enable active participation in complex decisions for a person with moderately high support needs.   Before her involvement in the program, decisions about Jasmine's future had been cast between the competing values of her guardians. Decision support provided a framework to bring Jasmine's will and preference to the very centre of substitute decision making, including complex decisions to be made by her guardians. This fulfils the intent of the *ACT Guardianship and Management of Property Act,* 1991 in minimising the impact of guardianship by keeping the will and preference of the protected person at the centre of decisions. The project has provided an effective, formal mechanism in which this can occur.

Jasmine's involvement in the program encouraged others to consider her potential as a person who could be active in making decisions and demonstrated strategies for her to do this. Teachers and learning support workers began to recognise her capacity for further engagement in decision making. Rozi not only built expectations that Jasmine could decide more, but modelled support behaviour to enable her be engaged in decision making.

In Jasmine's case, a decision supporter would have a key role in advocating to ensure her will and preference were recognised and respected by her guardians.   Without ongoing decision support it is not possible to ensure that weight is given to Jasmine's will and preference. The experiences of others in the program, however, highlight both the need

and role for decision support in minimising the impact of family guardianship on people's lives, thus creating avenues for self-determination.

Recommendation: That decision support be provided to people to enable their will and preference to be heard in substitute decisions that are being made by others.

Supported Decision Making and Guardianship

Toby, Claire and Natalie all shared important decisions, often long held, that appear to remain unfilled because they challenged the values of their guardians, rather than because they meet any best interest justification. These related to work, accommodation and guardianship. Claire has wanted to move for more than a decade. Her guardian refuses to consider her decision to move because she was "safe" where she lived and all her support needs were met. She fears that, should Claire move out of the institution she would never be able to "get back in when it all went wrong". Her value on safety and protection has greater weight than her belief in Claire's right to self-determination. The authority of Claire's guardian stretches across her life. Care workers do not implement change or support Claire to do things that her guardian does not agree with. This leaves Claire without the opportunity to experience risk taking, an essential component in learning to make decisions.   Decision support would enable Claire not only to make her decision, but to negotiate tensions with her guardian to move a long held but inert decision forward.

Natalie's guardian did not want her to "make waves at work" because: "She has a good job... it's better not to complain."   Toby was at imminent risk of homelessness for the duration of the project. Toby's advocate worked with him to identify alternative accommodation. Toby met and liked both the flat and his potential new flatmate, a man his own age who shared similar interests. However his family guardian responsible for decisions about Toby's accommodation, vetoed the move. She would not provide a reason to either Toby or his advocate. Nor would she describe how this decision was in Toby's best interest.   Here decision support would have a role in establishing and maintaining boundaries around existing guardianship arrangements, ensuring that will and preference were recognised and respected, and that substitute decisions were reserved for times and decisions where Toby was unable to decide.

Overreach by guardians was also evident in small, day to day decisions of decision makers. Family guardians placing limitations on daily routines, food choices, how people spent their time and even what they wore, was reported by both decision makers and interviewees. Care workers also revealed the ways in which the perceived authority of family guardians shaped their practises and limited their ability to support choice. For Claire and Natalie, this overreach left them little opportunity to develop decision making experience practising on small decisions, to become ready for the more significant ones. The project highlighted the

importance of decision supporters developing awareness among decision makers and care workers of the right to decide, to build capacity to protect from the overreach of guardians.

The principle giving primacy to the decision maker's control provided a place to work from when dealing with overreaching guardians. The guardian of one decision maker insisted on giving her approval before her daughter could become a decision maker in the project. With considerable effort approval was eventually gained and as the decision maker developed her decision readiness she began to become more assertive with both family members and care workers. Many were respectful of her newly found sense of self determination. Her guardian however, stepped into gatekeeper role, trying to deny her daughter access to the project, telling the coordinator that "she could not continue with all this decision making business" on the basis of an implied serious and ongoing health issue: "I cannot tell you more than that. It's between her and her doctor." She would not allow her daughter to speak to the coordinator by phone, nor would she pass on messages "in case it upsets her". Recognising that any decision to discontinue belonged to the decision maker the coordinator continued to try to make contact. Eventually successful, the decision maker reported that she had had a slight cold, was now better and was keen to continue. She could not recall a recent trip to the doctor.

At a broader community level, the project highlighted the need to improve understanding about the role of family guardians. Significant project time and resources were given to guardians to highlight the right to decide and describe the boundaries of guardianship. Often in focus was the need to limit guardianship and substitute decision making to important decisions. A number of guardians in contact with the project, either through the initial community engagement or as family guardians of decision makers, sought out resources to clarify their role. Jasmine's guardians, for example, had many questions around what might constitute an important decision and what was meant by will and preference. While they respected her right to decide, they too looked to the coordinator for information about how this might fit with best interest decision making.

Overwhelmingly, particularly for older family guardians, there is a need to describe and promote the UNCRPD and what the shift promoting active engagement by people with disability may mean to their established, existing roles as "protectors". The possibility for more active decision making, even if only to consider will and preference in substitute decisions, was regularly countered by family guardians with the belief that "he can't have the right to decide, he doesn't have the capacity". Useful responses here centred on the idea that every person is born with the right to decide, with decision making capacity as something that can be learnt and developed. Promoting a spectrum of possible supports, including collective support models,[18] relationship based formal support models, and day to

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[18] Watson, J, Op. Cit.

day activities to promote expectation and experience was also helpful in encouraging established substitute decision makers to consider alternative approaches to substitute decision making.

Consistent with the work of the Victorian Law Reform Commission, this project demonstrates the power of decision support models to challenge our reliance on substitute decision making as a valid and common alternative for people whose decision making capacity is perceived to be limited. As discussed, many participants in our project had a relationship with guardians. They were either subject to long term guardianship (Toby, Claire and Natalie), newly appointed with a guardian (Jasmine), seeking to avoid guardianship (Rob) or in Scott's case seeking to use supported decision making to prove that he did not need to remain under the Public Trustee and was capable of making and fulfilling financial decisions himself. In the context of a review of guardianship laws, substitute decision making needs to become an option of last resort, only implemented after the full spectrum of supported decision making options have been implemented and demonstrated to have been insufficient to enable a person to exercise their right to decide. Guardianship orders need to be decision and time limited, recognising both the potential for fluctuating capacity and the potential for people to develop decision making skill over time.

The project demonstrated both the need and potential of a formal SDM program to create change around the impact of guardianship on the lives of people with disability, within the current legislative environment. The project became a useful resource, coaching guardians to approach their role in new ways and providing rights based information to limit the potential impact of substitute decision making on peoples lives. It provided the opportunity to empower people with disability to understand the extent to which guardianship could impact their lives.

What is also apparent is the need for practical resources that describes the roles and responsibilities of guardianship to guardians. Equally recommended is the production of easy English resources, empowering those subject to guardianship by highlighting their right to decide, the right to decision support, respect for will and preference, and the limitations of guardianship.

The project generated recognition of the effectiveness of supported decision making in reducing the impact of guardianship and in maintaining self-determination. ADACAS continues to field requests for decision support, including referrals from ACAT. These often relate to people who are seeking to either avoid or exit guardianship or to minimise the range of substitute decision orders. As the project is now finished we are currently unable to provide assistance for these referrals.

> Recommendations: That an approach be made to the ACAT to fund the development of easy English materials that describe the responsibilities and limitations of guardianship under the current legislations.

That a review of guardianship legislation in the ACT be progressed as a matter of priority.

That the ACT Government continues to fund decision support programs which enable people to avoid or minimise guardianship and administrative orders.

Relationship Between Decision Support and Advocacy

During the course of the project a number of the decision makers had, for part or all of the duration of their participation, an individual advocate at ADACAS. Two participants were already ADACAS clients before they joined the project, others needed advocacy around specific issues that were otherwise barriers to their successful participation in the project.

The relationship between advocacy and supported decision making proved to be extremely beneficial. Many of the advocacy principles that guide the work of ADACAS are fully consistent with the principles of decision support. Advocacy strategies proved useful from time to time for both the coordinator and monitor in progressing issues for decision makers.

Individual advocacy is grounded in an expressed wish model. That is, the wish of the advocacy client guides the advocacy action in almost all circumstances. This approach is fully consistent with decision support, which is underpinned by the decision makers right to decide, and vests responsibility for and ownership of each decision in the decision maker. There are no conflicts of interest between the role of advocates and the role of decision support staff or supporters.

Recommendation: That close relationships between individual advocacy and supported decision making initiatives be integral to the development of decision support.

Spectrums of Support

While this project set out to explore the use of one particular supported decision making model, each decision maker responded to the availability of decision support in different ways.

For Toby, support for decision making is currently about building his identity as an active decision maker to the point where he is able to make a commitment to fulfilling a decision. Toby's current identity as a decision maker is intricately tied to the values and habits of his guardian, so in addition to building Toby's expectation, support for decision making needs to include a focus on advocating for this right to decide among significant others in his life. In the future, Toby may well need additional supports, including to explore a decision, secure a support relationship or make a formal agreement.

Supporting learning about what it really means to make a decision is one key focus within Claire's decision support. As a person who had been "kept safe" all of her life, protected from change and risk, support for Claire's decision making involved enabling her to understand risk and responsibility so that she can truly begin to consider options, consequences and compromise. While use of informal tools such as the support-my-decision website was a successful strategy for Claire, she needs support to negotiate with key workers and her guardian to create the opportunity to practice on the small decisions, to gain experience and expertise to be ready to make more significant decisions. Building an understanding of these things has the potential to empower Claire against the authority that her guardian has in her life, so that she might build an increasingly self-determined future. It can also enable her to become more aware of the kinds of support she may need from her decision supporter.

For Rob, support for decision making was intricately bound to the authority of his supported decision making agreement. It was in developing this that Rob and his supporters spent the most time, ensuring that its wording could be readily used by Rob as evidence of his own authority to decide. The final agreement of itself was a significant outcome for Rob. It provided an opportunity, time and expertise for Rob and his supporters to explore their values and skills, and to learn from the circumstances that led to Rob's decision. For Scott, support to decide meant keeping him connected to his decision, modeling and developing support strategies so those family members whom he had chosen to support him did not slip back into old patterns of substitute decision making, which had the effect of disconnecting him from his decision. Where support for Scott's decision was long term but finite, Rob believes that he may carry his SDM agreement for "protection" for quite some time.

Conversely once decision support had been engaged, Natalie's support needs were short term. While it took her just four weeks of formal support to fulfill her decision the benefits, in terms of her ability to articulate how she wishes to be supported and wider recognition for her capacity to decide, are long term. While Natalie's decision to buy a new computer was the decision she wanted to making using the formal elements of the program, what was also apparent was there were many other decisions Natalie wanted to make, once she had developed the confidence to articulate her decisions. Other significant decisions made while in the program, including one about her work, did not need decision support or a formal agreement. Support for decision making was in recognition, by Natalie and those around her, of her right and potential as a decision maker.

And finally for Jasmine support for decision making was cast within the context of substitute decision making and proved to be a powerful mechanism for ensuring that the will and preference of the protected person remained central to the decision being made by others. It tested the boundaries of supported decision making and identified the potential for decision support to be used in situations where the individual is not the ultimate decision maker, and by individuals who are unable to fully grasp the concepts of decision making.

Consistent with the spectrum of support needs identified for each of our participants, we also explored the spectrum of decision supporter options that most effectively respond to those needs; as well as the spectrum of additional resources, including formal agreements and the web based tool, that support the decision support relationship. For Rob and Scott the supporter and resources more closely followed the South Australian model. For Claire, Natalie and Jasmine, support for decision making is about finding and establishing relationships of trust, free of vested interest, in which support can be given. While for Toby support for decision making focused on igniting his expectation to decide and recognising the need to respond within his timeframes. Despite their diverse engagement with the project, each of the decision makers achieved outcomes through their participation (See Table 2).

Table 2 Decision Makers Achievements

	Toby	Claire	Natalie	Rob	Scott	Jasmine
Developed awareness of the right to decide and availability of decision support	√	√	√	√	√	√
Developed skills to articulate decision	√	√	√	√	√	
Identified support activities needed to make and fulfil decision		√	√	√	√	
Experienced freely given support relationship	√			√		
Experience paid decision support relationship			√			√
Made a decision		√	√	√	√	√
Created SMD agreement			√	√	√	√
Fulfilled decision		√	√	√		
Reported increased capacity and expectation to be involved in future decisions	√	√	√	√	√	
Capacity of decision maker to be more involved in decisions recognised by others		√	√	√	√	√

Conclusion

While each of the decision makers shared many elements of support, overwhelming what featured most strongly was the need to establish decision support tailored to individual need and the role of the formal project in generating cultural change among family members, support workers, guardians and the wider community.

This illustrates that supported decision making must be more than just support to consider options or find information. It is more than an agreement or support relationship. Support needs are fluid.   Support for decision making is about making readily accessible, resources and expertise adaptable to the needs of the individual and their socio-cultural circumstance. Supports for decision making are both time and decision specific.

Overall, the diverse support needs of the decision makers created understanding of a possible spectrum for decision support, located formally, within programs and informally within families, communities and support services.   While the model itself was structured as a series of stages, each with particular learnings, activities and achievements, participants, both decision makers and supporters, did not experience the model sequentially or universally. Resources accessed were decision, experience and support specific.   The complexity of Scott's decision, for example, his support needs and family situation which underpinned the coaching requirements of his supporters, means that he drew on supports and resources from each of the stages to fulfil his decision. Natalie, however, made a number of decisions while in contact with the project although these did not need a formal SDM agreement and some required more support than others. Natalie needed support to believe that change could happen, consider her options and share her decision with care workers for it to be recognised and fulfilled.

While on a small scale, this project has demonstrated that both formal and informal supported decision making actions do create change for individuals, for families, for the service system and more broadly in the community. There is now clear evidence that supported decision making initiatives are valuable and enable people with disability to be active decision makers who can exercise choice and control of the decisions that affect their lives.

Overall the diversity of decision makers support needs, aims and expectations added to what is understood about supported decision making by highlighting the potential for formal decision support programs to support a very broad range of people and decisions. The project articulated a formal, structured decision support model within which decision makers are able to take from each stage of the program only as much support as they need to make a decision.

The Way Forward

The questions remains then, how can supported decision making models enable individuals to exercise more choice and control as they enter the DisabilityCare Australia system? What needs to be in place, before, during and after participants enter the scheme? How can people with little or no experience of decision making learn about their right to decide and their right to access support as they develop their identity as decision makers?

The response is multifaceted. Decision support initiatives need to take place across a wide spectrum of the community, for individuals, for those closely associated with individuals and for the community more broadly so that the rights enshrined in the UNCRPD are enabled and activated for Australians living with disability. It is clear that the more embedded an individual is in the service system, the less likely they are to be active decision makers and the more support they will need to change this (Figure 1). Raising the expectation to decide is a crucial precursor to decision making and is a distinct initiative that will require resourcing.

In designing a decision making response it is useful to consider a tiered approach such as that which exists within the health sector.[19] Conceptualising this model within the framework of the universality of the UNCRPD casts the range of decision support needs and initiatives onto a spectrum (Figure 2). Universally cultural change initiatives are the responsibility of Australia as a party to the convention and encompass the understanding that all Australians have of their responsibility to recognise people with disability as decision makers, active agents in their own life.[20] This means that as a society we have a responsibility to assist people with whom we come in contact to be decision makers through the ways in which we interact with them. This is a cultural change agenda that will not happen on its own, it requires investment. Service systems require additional initiatives, which focus on ensuring that paid carers understand and have the skills and resources to enable the development of decision making skills by people with little or no experience of decision making. Families and guardians require initiatives that support them to shift from protectionist models of care to enabling their loved ones to experience the right, responsibility and risk of being decision makers and thus develop skills that are themselves protective, particularly as ageing parents seek to create long term arrangements that meet the ongoing needs of their adult children. Finally, individuals themselves need to be enabled to access as much support as they need, tailored to the specific circumstances, timeframes and decisions that face them at any point in their lives. The wider impact, or ripple effect, of this individual work on the approaches and understanding of others who are in the lives of individuals with disability must be recognised and celebrated (Figure 3).

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[19] Brayley, John, Queensland Advocacy Incorporated, Op. Cit.

[20] Danda, A, Ibid.

Decision support models need to be diverse, flexible and responsive to individual needs. Decision support needs to be implemented carefully to ensure that it is delivered with a focus on capacity building and does not become yet another service system on which people are encouraged to become dependent.

For Australia to fulfil its responsibilities under the UNCRPD, a spectrum of decision support responses need to become as mainstream as ramps, automatic doors and braille on ATM machines and be viewed as fundamental accessibility issues that are rights rather than additional extras in the life of a person with disability. Decision support responses must therefore be freely available to all people on the basis of need, rather than meted, rationed or only available to those lucky enough to have them included in DisabilityCare Australia support packages. Unlike physical and sensory accessibility responses, accessibility to the right to make decisions emphasises the interdependence, rather than independence of decision making. Interdependent decision making is a normative response and recognises the social context in which everyone makes decisions.

This project focused on working with people with cognitive disability to enable their decision making through support and has made significant advances on the model developed and trialled by South Australia. We now have a clearer picture of the spectrum of support that needs to be available to ensure that people with cognitive impairment can be active decision makers in their own lives. The project also provides a basis for further work. In addition to the recommendations already presented, a key area of work remains in exploring how supported decision making models should to respond to the needs of people living with mental illness or psychosocial disability (this group is the focus of ADACAS's next SDM project) and the needs of frail older people, particularly those experiencing dementia. Supported decision making has the potential to increase the opportunities and rights of people in both of these groups to be active decision makers.
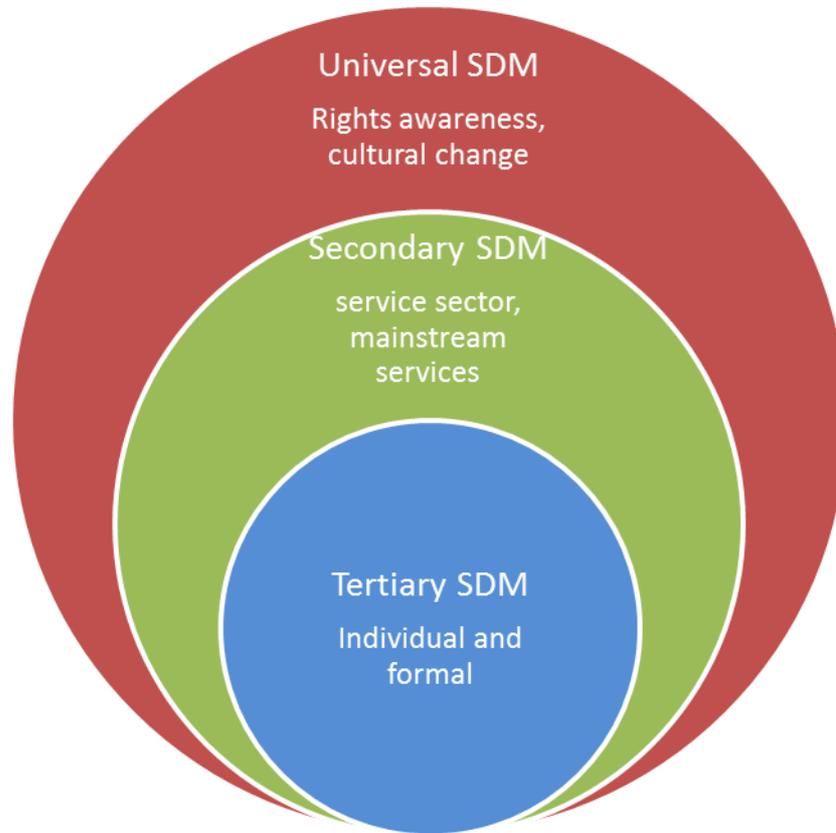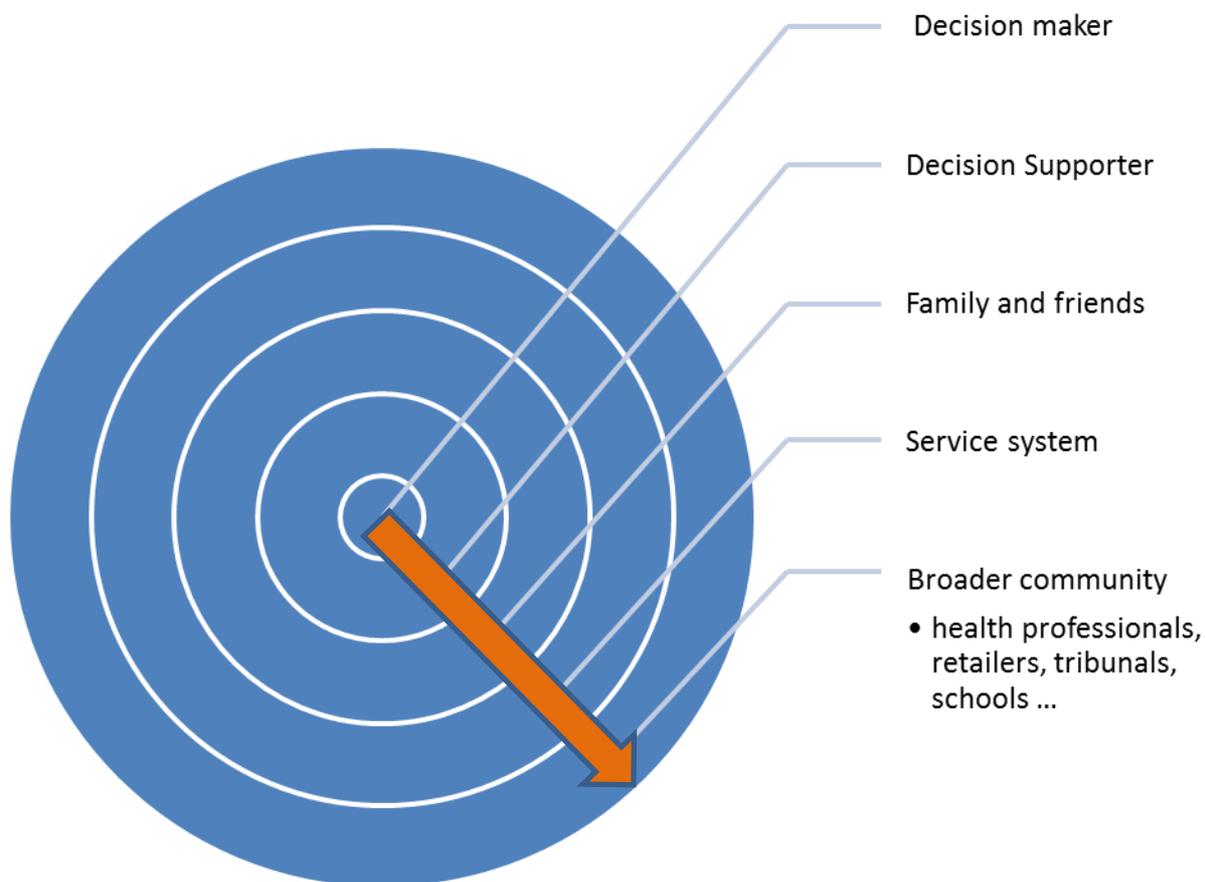
Figure 2 Tiered model of supported decision making interventions

Universal – recognition of universal legal capacity, education and awareness raising. Cultural change using a health prevention model. Invest in human interdependence.

Secondary – those who directly interact with people with disability, including disability sector, DCA and mainstream services/sectors. Education, modelling, coaching in assisting capacity building. Raising expectations of decision makers

Tertiary – formal SDM, one on one work with individuals to build capacity, coaching supporters, modelling new flexible ways of support.

Figure 3 The impact of tertiary supported decision making initiatives spreads widely through the community as others learn from changed behaviour and modelling by individuals, decision supporters and monitors.