



**Self –Determination and Cultural Change: A Report on
Supported Decision Making for People Experiencing
Psychosocial and Intellectual disability.**

ADACAS

ACT Disability Advocacy Network

Table of contents

Introduction	P.3
Decision Support and the NDIS	P.3
Background to Supported Decision Making	p.4
The Project	
Project Vision	P.4
Project Resources	P.4
Participants	P.4.
Project Coordinator Role	P.5
Actions	P.5
Establishing Decision Support	P.5
Giving 1:1 Professional Support	P.5
Developing Community Capacity to Support Decisions	P.5
Outcomes	
Individual Outcomes	P.6
Community Outcomes	P. 8
Project Outcomes	P.9
Recommendations	P.10
Developing Community Capacity through training and systemic policy development	P.10
Developing Individual Capacity Through 1:1 Support	P.12
Funding Project Manager	P.12
Key Findings	p.14
Appendix 1 Key themes and Individual Outcomes	
Gatekeeping and Overreach	P.17
Guardianship	P.19
Cultural Change, Capacity Building and Deinstitutionalization	P.20
Community Wide Capacity Building	P.23
Professional Support: "I want to make decisions, not a friend."	P.25
Appendix 2 Principles for Decision Support	P.28
Appendix 3 Universal Model for Decision Support	P.30

Self –Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual disability.

In August 2013 ADACAS was granted \$20 000 through the NDIS Sector Development Fund to explore supported decision making (SDM) for people experiencing psychosocial and intellectual disability.

Decision Support and the NDIS

A central impetus of the NDIS is to enable people to live the life that they choose by exercising choice and control over their supports and services, fulfilling, in part, Australia’s human rights responsibilities under the United Nations Convention on Rights of Persons’ with Disability (UNCRPD), particularly Article 12 Equality Before the Law and Article 5 Non Discrimination.

While the NDIS creates significant change for the service landscape, for those whose decision making capacity is impaired, or simply not recognised, there is a need to create mechanisms for decision support, if they are to gain meaningful access to the scheme. Supported decision making, where a person is given as much support as is needed to be engaged in decision making, is recognised within the UNCRPD as a necessary support that ensures peoples right and capacity to engage decision making¹. ADACAS own work in SDM positions it as an access tool, as vital to ensuring participation and equality as Braille on an ATM or a wheel chair ramp.²

¹ From Provision to Practice, United Nations Convention on the Rights of Persons with Disability., <http://www.un.org/disabilities/default.asp?id=242>

² May, F., and Rea, K., *Spectrums of Support: Report Exploring Decision Support for People with Disability in the ACT*, http://www.adacas.org.au/decision-support/copy_of_SupportedDecisionMakingProjectFinalReport.pdf

Background to Supported Decision Making

Supported decision making is based on the premise that all people have capacity to hold rights. Some people need support to exercise their rights. Supported decision making assumes that all people, regardless of their ability or disability, have some capacity to be engaged in decision making³. Rather than measuring capacity the focus for SDM is on measuring the support as person needs to be engaged as far as possible in each decision being made⁴.

Project Vision

To build the capacity of people experiencing psychosocial and intellectual impairment to live the life that they choose by making more decisions for themselves, with decision support.

To build the capacity of their communities to recognise and support their decisions.

To explore how decision support might be made both accessible and sustainable.

Project resources

- Principles for decision support (appendix 1)
- Adacas experience facilitating decision support projects in a range of contexts.⁵
- ADACAS experience in working in a person centred, human rights framework.

Participants

Engaged 5 people who experience psychosocial and intellectual disability who were recognised as people who could be more engaged in decision making. These people are referred to as the Decision Makers.

Additionally the project engaged the respective communities of the decision makers. This included family, guardians, support and key workers, allied health professionals and shop workers. This

³ From Provision to Practice, op.cit.

⁴ Bach, M., and Kerzner, L., *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity*, <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>

⁵ see, <http://www.support-my-decisions.org.au>, May, F., and Rea, K., op.cit.

recognises a relational understanding of and response to, disability and recognises that barriers to decision making are cultural and environmental.⁶

Project Coordinator Role

Work was undertaken by a project co-ordinator whose approach was to

Identifying and engaging decision makers

Working with those in the lives of decision maker to ensure they recognise their right to decide.

Build capacity of community as a whole to engage in supported decision making.

Identify freely given decision supporters

Give 1:1 Professional decision support where no freely given supporter is available, or where this is the preference of the decision maker.

Actions

Establishing decision support

Identifying individual/s in the person's life and establish freely given support relationship.

Explore options and resources for introducing a supporter for socially isolated decision makers.

Giving professional support where no freely given relationship, pre-existing or introduced, could be established.

Giving 1:1 Professional Decision Support

Working with decision makers giving 1:1 professional decision support across 5 key areas;

⁶ Preamble through to Article 25, United Nations Convention on the Rights of Persons with Disabilities, <http://www.un.org/disabilities/default.asp?id=199>

- Build expectation to be engaged in decision making
- Teach decision making skills
- Make a decision
- Fulfil a decision
- Ensure decision is respected and recognised by others.

Developing community capacity to support decisions

Working with the people who share the life of decision makers to build their capacity to;

- Understand every person has right to decide
- Recognise and respect the decisions of people with impaired capacity
- Give decision support using rights based principles
- Advocate for the decisions of those with impaired capacity
- Model decision support to others to affect broader cultural change and increase community capacity.

This work took place through modelling effective support, 1:1 mentoring and group training.

Outcomes

Individual Outcomes

Overwhelmingly the outcomes indicate that people whose capacity is impaired can be more engaged in decision making with support and recognition.

Key individual outcomes :

Self –Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual disability.

Page 6

Decision makers, some of whom had very limited experience, began to recognise that they have a right to decide, can be supported to decide, and that asserting this right can empower them to have more control over their lives.

Decision makers gained experience in being supported to decide across a range of decisions including

- Planning for, choosing and purchasing a pet
- Having more control in day to day life, including decisions about clothing and food
- Ending restrictive practises
- Social contacts
- Health care
- Paid supports
- Being more informed about medication
- Parenting
- Work

Decision makers;

- Grew through new experiences, emerging from exploration of real options driven by them. Decision makers were enabled to explore dignity of risk and the responsibilities that go with rights. They began to experience how safety could be replaced with safeguards.
- Are less vulnerable to the influences of others as they recognise, explore and assert their own decisions.
- Developed confidence in sharing a decision to create improved access and equity in mainstream working environment and less need to use supported employment in the future.
- Demonstrated to others their capacity to make a wide range of decisions when supported to do so.

- Improved their ability to negotiate with service providers to ensure that supports provided truly reflect their values and ambitions, rather than the impetus of service provision.
- Increased confidence as family members, including family guardians, service providers and health workers, recognised both their right and capacity to actively live the life that they choose
- Have increased expectation to be engaged in decision making, and experienced decision making skills including how to explore options, manage risks, consider responsibilities and consequences.

Community outcomes

Key support workers were able to recognise their own potential roles in supporting the decisions of those they work with on a day to day basis. Conversely they are also more aware of the ways in their practises and vested interests can adversely impact self-determination.

People in the lives of the decision makers more readily recognise that people whose capacity is impaired have the right to decide and that substitute decisions should only be made when all other supports have been exhausted.

Family members and care workers developed their skills in supporting day to day decisions, and the value of this process in supporting people to become ready for more pervasive decisions, including the NDIS.

Allied health workers recognised the right of a person with impaired capacity to be engaged in health care decisions, and the role that decision support can play in ensuring health care decision could be made and fulfilled. They explored the benefit of adopting a more inclusive approach to people with intellectual and psychosocial disability, and that there are skills they can learn to underpin this approach.

Values and practises that operate to limit participation, access and equality, were challenged. People who share the lives of those with impaired capacity have explored or observed an alternative, person centred approach that encourages equality and participation.

Self –Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual disability.

Page 8

Project outcomes

Recognition that, in this cohort, each person's access to and experience of decision making had less to do with their functional capacity and more to do with the values and attitudes of those with whom they interact. There is a positive correlation between recognition of a person's right to decide and their engagement in decision making. Decision support is able to model effective support to others while building and demonstrating a person's capacity to decide.

With support people were able to demonstrate their capacity to decide, challenging stereotypes about people experiencing mental health issues.

Greater recognition of the importance of taking of a whole of community approach in building decision support. This approach, where everyone has a potential role in supporting decisions means supported decision making is both more accessible and more sustainable than support models where the focus is largely on the 1:1 support relationship.

Principles for decision support expanded to accommodate the whole of community approach, particularly in relation to informal support and the management of vested interests.

Recognition that a range of decision support options and expertise needs to be available. This includes primary decision support, either freely given or professional. It also includes secondary support given by care workers, family members and professionals familiar with the rights based principles. This ensures that people are able to get support when and where it is needed.

Introduced support relationships are not necessarily an effective or efficient use of project resources⁷. Project time spent exploring introduced support relationships through a range of organisations who do good works in the community, as well as those established as volunteer networks, did not produce positive outcomes. Stigma around mental illness, lack of confidence in engaging with people with psychosocial disability and the complex nature of some decisions, created difficulty in gaining commitment from volunteers. Some decision makers themselves indicated their preference for a

⁷ Australian Bureau of Statistics, Voluntary Work. Australia 2011., <http://volunteeringaustralia.org/wp-content/uploads/VA-4441.0-Voluntary-Work-Australia-2010.pdf>, This shows that while rates of volunteering per capita have remained consistent, volunteering across community and welfare sectors has declined.

professional supporter. This preference reflected a lack of willingness to invest in personal relationship, the need for skill, knowledge and experienced supporters when making and fulfilling complex and significant decisions, (for example decisions about supports and services, housing, care and protection matters.).

Developed greater understanding of the possibilities for professional decision support as an accessible and sustainable model. Professional support carried weight with clinicians and professionals and may, in some cases, be more readily available when needed. The professional support model may also have potential for consumer peers, who were reluctant to engage the volunteer model, indicating an increasing trend toward paid peer workers.

Recommendations

Two tiered response to develop capacity of individuals and community at large to engage with supporting decisions.

1. Developing community capacity through training and systemic policy development

Focus of training

1. Family
2. Service providers
3. Mental health clinicians
4. Allied health workers
5. Guardians
6. Peers - how to give support
7. PWD – what to look for in a supporter

Benefits –

- Whole of community approach is more sustainable (broadly sharing resources and more readily available)

Self –Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual disability.

Page 10

- Adopts a relational model consistent with values of the UNCRPD
- Normalises SDM for all
- In relation to psychosocial disability – opportunity to change values and beliefs in the sector and beyond
- Challenges stigmas and stereotypes about people who experience psycho-social disability
- Tailored training developed around a group of key sections in the community who have opportunity to influence outcomes for people with disability and the broader community
- Opportunity to influence broader policy agenda including review of Guardianship legislation in the ACT, input to other systemic policy action locally and nationally
- Potential role for paid peer workers
- Opportunity to develop role and relationship specific principles for SDM which could acknowledge and respond to specific areas of vested interest

Limitations

- Support is focused and driven by the motivation of people who do not live with disability
- Support is limited to those who come into contact with and are open to the ideas and practices of supported decision making
- Without further individual work providing demonstration of the effects of SDM achievement of cultural change may be limited
- Needs to be intensive training over time to embed new ways of working for existing workers and teams
- Additional work needs to be undertaken to ensure that all people understand the limits of their role as supporters, according to the principles for decision support.
- Without ongoing mentoring implementation of new skills learnt during training is likely to be unsustainable

Self –Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual disability.

Page 11

2. Developing individual capacity through 1:1 support

Support given by professional or known, freely given supporter to people experiencing psychosocial and intellectual disability.

Emphasis on building decision making expectation, experience and capacity, this support would:

- Ideally run parallel to the community capacity development work as an opportunity to model different ways to support
- Ensure support for socially isolated individuals
- Ensure that there are resources for support that can be accessed and driven by people with disability.
- Be an opportunity to develop processes for people with psychosocial and intellectual disability to participate in developing advance agreements
- Be an opportunity to develop processes for people with psychosocial and intellectual disability to exercise choice and control in NDIS
- Recognises that different people want different kinds of support and support relationships
- Provide genuine changed outcomes for individuals
- Deliver new ways of interacting
- Be an empowerment and capacity building approach consistent with goals of NDIS

Limitations

·Individual support is time intensive but achieves very tangible benefits for individuals as demonstrated in this project.

- Risk that principles for decision support may be misused when SDM is practised in formally.
- Need to be in the life of the individual until they have developed confidence as a decision maker, have the recognition of others and have fulfilled their decision.

3. Funding for project manager

That a project manager role be funded to continue to build the capacity of individuals and the community at large to engage in supported decision. Responsibilities are training, professional decision support, oversight for freely given support relationships, policy development, input to social policy agenda.

Benefits

Deliberate strategy to carry and forward the growing momentum around supported decision making.

Ensure that individuals with impaired capacity are able to meaningfully access the NDIS by adopting supported decision making as an access tool.

Operate with a proactive element that could ensure those who are socially isolated, whose lives are closely controlled by others or whose capacity to decide is not currently recognised or supported might come to better understand their right to decide and experience decision support.

Opportunity to engage peer workers in SDM so that they might model and lead changes in values and approaches to decision making in the mental health sector and beyond.

Gain further understanding of how people with impaired capacity can be engaged in decision making across all areas of their lives.

Fulfils responsibilities under the CRPD.

Develops capacity of a community as a whole to support decisions in a range of contexts, including the NDIS, healthcare, services and supports, education, guardianship and family life.

Would develop and promote broader cultural change needed to ensure all people are able to approach decision making with the same rights and responsibilities, regardless of their ability or disability.

Ability to work concurrently and proactively with decision makers and those who share their lives and develop the capacity of the community as a whole to engage in supported decision making.

Develop greater understanding about the relationships between supported decision making and guardianship, creating clarity for decision makers, supporters, guardians, families, support workers and others.

Has potential for oversight to ensure that supported decision making is not misused and the rights of vulnerable people are protected.

Limitations

Alone, a project manager will achieve limited change.

Requires a long term commitment to achieve sustained change.

Key findings

Capacity of this group is poorly recognised and not well supported (decisions made don't reflect capacity but values and attitudes of others) as a result there needs to be investment in the sector plus wider community to create change.

Decision making skills can be learnt

The decisions of people in this group are highly limited by institutional values, support imperatives, clinicians and other professionals. There is a real need to ensure broader cultural change to ensure people are meaningfully engaged in creating the life of their choosing.

There is a widely held value that decision making is too risky for this cohort underpinning the need to promote understanding of values, and responsibilities, particularly of care workers and guardians.

Our community in general are yet to fully appreciate shifts in the ways in which functional decision making capacity is understood. To ensure that all people are able exercise their right to decide the premise that all people have some capacity to engage decision making, even with support, needs to be better understood and more broadly respected by the community at large.

Need for more work to explore how people who are actively experiencing mental illness might be supported to make decisions, including decisions about how they are to be treated when they are unwell. More recognition that capacity is decision specific and, even when unwell people retain capacity to make some specific decisions.

Need for more work with families, particularly to ensure that people with disability are able to access and drive planning opportunities under the NDIS.

Need for more work in relation to supported decision making and guardianship. While supported decision making can be used consistently with the Guardian and Management of Property Act to ensure least restrictive practise and the will and preference of the protected person, subjectivity around what might constitute a 'significant decision' proved an ongoing impediment to decision makers engaging as many decisions as they could, and as far as they could.

Need to undertake more work around how people who experience intellectual as well as psychosocial disability, can be supported to engage in advance planning.

Freely given support continue to presents problems for sustainability and accessibility where there is social isolation, a lack of willing volunteers, or willingness of decision makers to engage it. Professional support was able to fill these gaps. Additionally the complexity and sensitivity of some decisions being made makes freely given support less tenable. Professional support was able to bring additional expertise in the context of very complex decision making. The project reinforced need for a spectrum of support options to be available which cater to the needs of different individuals.

Clear demonstration of SDM improving outcomes for individuals in medical settings, including mental health treatment.

Professional decision support is effective. Builds capacity of individuals disenfranchised from decision making, to build expectation and skill to be engaged in the decisions that are important to them.

Professional decision support is able to respond to critical decisions as they arise, with supporter able to advocate for recognition of the decision makers capacity and right to exercise this capacity

Professional decision support is an effective way to build appreciation that all people have the right to decide and that this right can be exercised with support, regardless of a person's functional capacity. The authority of a professional supporter adds weight to challenging long held, institutionalised, at time paternalistic values and practices around safety and risk, rights and responsibilities, functional capacity, equality and participation.

Professional support can create as well as respond to need –creating potential for people who are socially isolated or whose lives are closely governed by others, to experience decision making with support.

Through professional support individuals were able to demonstrate their capacity to make and fulfil decisions. This was is a powerful current for cultural change.

Secondary supported decision making, given in day to day life by those who share the lives of people with disability is an effective way to develop experience, expectation and skill of decision makers. With training and mentoring, those who share the lives of people with impaired capacity can play an effective decision support role using the rights based principles of decision support.

Professional decision support is the preferred model for some consumers.

Training works – because it builds the capacity of the community at large to support decisions, contributes to cultural change. Training which is delivered through an intensive action learning model is more likely to result in changed practices within workplaces.

Appendix 1

Key Themes and Individual Outcomes

Gatekeeping and Overreach

Hans was referred project by a health professional who believed support for decision making would be ideal as plans were being developed for Hans' future. Service providers were working with Hans, who is in his 30s and living with his ageing parents, to be more involved in the community with an eventual plan toward independent living. It was reported that, to date, Hans had not responded well to initiatives, and his mother, often the focus of his complex and highly challenging behaviors, was under considerable strain as a result.

It would have been opportune to explore with Hans how he had been engaged in most recent decisions about his future, and if supported decision making might be a way to garner a more positive outcome. The principles of supported decision making dictate that the decision maker is always in control – and this includes having the control to decide if they would like to explore decision support in the first place. Hans, however, did not have opportunity to explore this for himself.

Attempting to engaged Hans in supported decision making meant negotiating a complex series of a competing rights and values that shape who accesses and what happens in his world. Service providers were there on the one hand, to support Hans to explore a new, more engaged life, but were limited, on the other hand, by their prioritization of his family life and mother's needs. They understood supported decision making as a possible unknown, and, like other unknowns it was an experience to be avoided least it trigger challenging behaviors. As a result, Hans support service did not believe that it was in his best interest to participate in supported decision making, and while it was not their role to stop him from joining the project, they would not support him to do so. They raised concern too, that Hans may not make decisions that were reasonable or good for him, that may not be consistent with what his family would choose for him, or choose options that they could not support. They requested that, should he engage, they be given the opportunity to pre-approve options to ensure that they fit in with service provision.

Hans allied health workers had different agenda. They wanted to be sure that decisions made by Hans would not 'undo' the good work they had done to manage his health and behaviors. One professionals' in-principle support for Hans' participation was awarded on the basis that SDM might

Self –Determination and Cultural Change: A Report on Supported Decision Making for People Experiencing Psychosocial and Intellectual disability.

Page 17

prove to be another behavior management tool. Certainly there was appeal for her in the potential for Hans to learn skills that include considering others in his decisions. Another health professional was unconvinced that Hans had capacity to make decisions, even with support. He expressed concern about what more control might mean for Han's family guardian, who, he felt, was very good for the family. The guardian herself had concerns about the potential impact of supported decision making on Han's mother.

Each of these perceived barriers to decision making – Han's health, his family, his social connectedness, his mother's well-being and safety, emerged from care for the family as a whole and the professional interests of each of the service providers within specific areas of his life. Each was motivated by a traditional care perspective for Hans and his family. Hans himself, however, as an individual with his own rights, hopes and dreams, was not visible. Their competing values, personal and professional interests 'trumped' Hans right to have a say in living the life of his choosing, along with his right to have a say in access to learning about or experiencing decision support.

These conversations, with the people around Hans, took significant project time over a period of 4 months. Given the limited project resources a decision was made not to pursue Hans' participation in the project further. There are, however, important learnings. Supported decision making represents a significant shift in the values with which people with disability are engaged. Its emphasis is on safeguarding rather than safety, on being an active citizen not a passive subject, on participation and inclusion, on development and experience rather than routine. These concepts reflect the values of the UNCRPD, but challenge the dominant paradigms that have shaped the ways in which our community has engaged with people with disability in the past. It will take time and exposure to these new ideas for those in Hans' life to consider that he may react more positively if he was engaged in decisions being made about his activities, even when things go wrong, or that he has the right to decide something that others do not agree with, to the extent that those decisions do not harm another. The idea that Hans has a right to approach decision making with the same rights and responsibilities as those who do not have a disability, and can do so with support, will need to be coached and modelled. This equality of opportunity includes the degree to which the needs of others are part of Hans' own decision making style. It will take time and training for service providers to recognise that service provision should be built around Hans's decisions, not the other way round. It will also take time for those in Hans' life to recognise that potentially they have a role in supporting Hans' decisions. This investment, however, is necessary, if those, like Hans, whose lives are shaped by

the values and attitudes of others, are to experience choice and control in the NDIS, and beyond. SDM requires building the capacity of the community as a whole, as both decision makers and supporters.

Recommendation: Investment in SDM training to ensure that

1. Training for those who share the lives of people with disability, including families, clinicians, service providers and allied health workers, to recognise the right of people with impaired capacity to learn about and access decision support, and be active decision makers be recognised. This should be funded as an essential component of sustainable and accessible supported decision making.
2. People with psychosocial and intellectual disability
 - Access decision support and
 - are active decision makers

Guardianship

Hans' experience, as with others in the project, highlights the need to clarify the relationships between guardianship and supported decision making in the ACT. This process is occurring in other jurisdictions, including South Australia, Victoria and NSW⁸. There is an inherent conflict in a guardian 'approving' a person's access to learn about and experience decision making or to seek a supporter. The question whether this constitutes a significant decision under the Guardian and Management of Property Act, 1991, (GMP) has not been tested.

Other aspects of the relationship and the potential of supported decision making to work within existing guardianship legislation in the ACT need further exploration. Decision making capacity is

⁸ Office of the Public Advocate South Australia, Supported Decision Making Project., http://www.opa.sa.gov.au/resources/supported_decision_making, Office of the Public Advocate Victoria, <http://www.publicadvocate.vic.gov.au/research/>,

increasingly understood on a fluctuating spectrum that is time and decision specific.⁹ In the Victorian legislation, for example, supports needed for each decision, at the specific time it is being made, need to be explored and exhausted, before substitute decision making should take place. This approach could be supported by the Principles of the GMP, Part 1A, which states (2d) that substitute decisions should have the least interference in the life of the protected person and that the (2e) the protected person must be encouraged to look after themselves. and (2a) that the wishes of the protected person must be followed as far as possible¹⁰. If capacity is assumed and a supported decision is attempted for each and every decision, the decision maker's will and preference may at least have been established through the support process and subsequently used to inform any substitute decisions that may need to be made. Guardians in the project had concerns, and at times wanted to dictate, the areas of decision making in which participants could be active before any attempts to make a supported decision had been tried. The practise of guardianship in this way may not only be at odds with the principles in the Act, but unnecessarily restrict a person's rights.

Recommendations:

Additional work needs to be undertaken to clarify the relationship between supported decision making and guardianship. This work needs to give decision makers, guardians and decision supporters clarity in their roles.

The ACT Government undertakes a review of the existing Guardian and Management of Property ACT to ensure that the rights of all citizens, including those with a decision making impairment, are upheld, according to our Human Rights Framework.

Cultural Change, Capacity Building and Deinstitutionalization

Elsa's story is one of unrecognized capacity, of self-determination over safety and the need to take a whole of community approach to capacity building to fulfil the goals of the CRPD. Elsa's is a woman in

⁹ For example, Victorian Law Reform Commission, Guardianship: Final Report, <http://www.lawreform.vic.gov.au/projects/guardianship-final-report>, International Psychogenetics (2013), 25:10, 157, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3750821/>

¹⁰ *Guardian and Management of Property ACT 1991*. P.3., <http://www.legislation.act.gov.au/a/1991-current/pdf/1991-62.pdf>

her early 60s whose life is lived almost exclusively in the company of those paid to be there. She has lived her life largely in institutions. Her current home is shared with just one other woman whose company for the most part she enjoys, and a cat that she adores. Culturally and socially, however, Elsa's life remains institutionalized. Elsa does not have a sense of her own autonomy, asking for permission of support workers before undertaking most tasks. She has very limited control over where she goes what she eats and wears. Restrictive practices in Elsa's life are not stamped with an end date or redundancy through capacity building. Visually Elsa's home is marked by signs that indicate spaces she is not allowed to enter, reminders to staff pinned up to ensure Elsa and her housemate are safe, clean and in routine.

Many of Elsa's support staff, have spent some part of their working life in large conglomerate institutional settings. The support they give Elsa's is marked by care, but also by paternalism. This is seen in the ongoing prioritization of safety over self-determination in Elsa's life and an unquestioned belief that they know what is best for her. The habits and practices of large institutions had been carried by both Elsa and her support staff into her current home.

A key worker, new in Elsa's life and household, had been appointed to support Elsa to plan a richer, more self-determined future. Despite being on a pension Elsa, with limited opportunity to spend, had saved a very significant amount of money. However plans had stalled. Elsa, unused to the experience of choice and control, was unable to articulate what she would like to choose for her future. Her service provider hoped that SDM might provide additional support to Elsa and so she became a decision maker in the project.

Initial conversations with Elsa and her staff confirmed the need for a two tiered approach to decision support. Some of Elsa's support staff were highly resistant to supported decision making. Her 'failure' to engage in recent planning process with her new key worker confirmed their belief that she lacked capacity to make decisions, when what she really lacked was experience and support. The restrictive practices, ever present visually, in the delivery of support and in Elsa's quiet acceptance, further confirmed this view. They were concerned about what self-determination would mean for Elsa's

safety, their ability to manage a more self-determined Elsa, and the impact decision making might have on support routines.

Elsa's staff needed training to consider Elsa's right to decide. They needed time to consider how long held values and practices would be challenged by recognition of that right. They needed training to learn and observe new strategies to support her toward a more self-determined life. Most powerfully they also needed opportunity to observe Elsa as a decision maker.

We approached this by working 1:1 with Elsa across the five key areas of decision support (appendix 2) to build her expectation, understanding and skill so that she could identify, articulate and fulfill decisions that would create a life of her choosing. This work started with smaller day to day decisions, asking Elsa what she wanted more or less of, what made her happy, sad, angry. This process saw Elsa move in a relatively short period of time from considering decisions about her shoes (a pair of high heels previously denied by support staff least they hurt her feet or back), and underwear (silky and lacy, not practical and cotton) to quite significant decisions. Ultimately Elsa wanted to show that she could make decisions relating to some of the restrictive practices in her life.

At projects end, Elsa has demonstrated significant capacity to make decisions which enable her to express herself more freely (in her choice of clothing for instance) and ability to make considered choices which demonstrated that some of the long term restrictive practices in her life could be lifted. She also demonstrated her interest in and ability, when supported, to understand the treatments which she receives. It is hoped that some of these changes can be sustained through new approaches by the people around her, particularly service providers, who have had opportunity to recognize Elsa's right and capacity to decide and to develop their own potential in supporting her day to day decisions and enabling her to have greater self-determination.

Community Wide Capacity Building

In his first three months as a decision maker in the project David made some significant gains building his skill and identity as a decision maker. David has spent many of his nearly 6 decades living in institutions- and did not have a strong sense of his own autonomy – asking for permission before undertaking most tasks. Through 1:1 decision support, David was beginning to recognize both his own right and capacity to decide, and, this recognition was mirrored by care workers, who through training seeing rights based decision support being modeled, were beginning to understand the potential of their support in creating opportunity for David to live a more self-determined life.

These gains had grown from a decision David had made when he first entered the project. This particular decision had felt very urgent to David, so, as soon as he signed on, a search was undertaken for a freely given decision supporter. Sadly, but not uncommonly, no one in his circles of friends, family or work colleagues was willing to take on the role. David's usual process for decision making was to engage key staff members. Respecting David's need for immediacy and his current decision making process, the search for a freely given supporter was postponed. David agreed that he would like to make his decision with the project coordinator giving professional support, but that his key workers would be engaged so that they could learn to better support him to make decisions using the rights based decision support principles.

Most significantly, to support David to approach decision making in the same way as others, David's support staff needed to learn about dignity of risk so that they could support him to manage risk, rather than try to shut it down. They needed to better understand their boundaries, that David had a right to explore options and decide outcomes that they did not necessarily agree with or want to support. They also needed to recognize that they had a role in supporting David to build skills that would make a broader range of options, along with the new experiences they might bring into David's life, possible.

Three months into the project David has a serious fall, requiring surgery. When the time came, post-surgery for David to consider his rehab options, a case meeting, attended by his brother, nursing staff, allied health workers, his key worker, house manager and a risk management expert. David was not present, his options been briefly explored with him prior to the case meeting by a health worker. At

that meeting it was announced that David was to have ‘functional rehabilitation’, described as the rehab he will get from going about his daily activities. He did not qualify for formal rehabilitation, it was explained because, it was assumed, he did not have the capacity to set goals.

Functional rehabilitation, with a likely outcome being a limited return of movement would have had a devastating impact on David’s life. David’s wellbeing, work, social, family and home life were all tied to his ability to be active. His service provider later explained, for example, that his current home could not have been appropriately modified. The most likely result would have seen David moving to a nursing home, where once again he would have been living in conglomerate care setting.

The issue of David’s capacity to set goals went unchallenged at the meeting. David’s key worker thought it “unfair” but did not believe it was his place to challenge the decision of the health workers. The house manager had encountered these same assumptions in the past, and having had no success creating a different outcome, believe there was little to do but accept it. Even David’ brother, usually a vigorous advocate did not speak up. David himself accepted the authority of those around him. He did not question this process, or ask for support to explore a different outcome or decision. Becoming a decision maker takes time and David had had many decides living in a world where important decisions are made by others.

Yet David has the right to the same health care as others, and be engaged in decision about that care- so there was a real need to be proactive in supporting David to be engaged in his healthcare decision. This situation illustrates the importance of having decision support responses that can be proactive – filling real need where the decision maker is unable to recognise the need for support themselves.

Framing the question or decision that David might consider was important here. David, often impulsive, missing his home and bored after weeks in hospital, when asked by health workers if he wanted to go home or stay in hospital for more treatment, answered that he wanted to go home, immediately. However, his decision supporter, in thinking about David’s life and the value he placed on being active and contributing, recognised that the question about what should come next could be asked in a more meaningful way. When asked to make a decision about what he wanted in the future , David was very clear about wanting to be able to go back to work, look after his pet, travel to visit family, and do all the things he used to do before his fall. The decision was not so much rehab or home, but in being able to do all he used to do, or not. Given that he wanted to become mobile again – rehab become one of the options and consequences David was supported to explore in a

decision about his future. It did not take David long to decide that rehab was the right option for him. Even more empowering, as David has been supported to explore his decision he was also able to share it, with some support, with the health workers who were making recommendations. David made his own case for accessing rehab, thereby challenging assumptions about in (in)ability to participate in the first place.

David's decision also offered opportunity for secondary supported decision making with allied health workers. There is little point in David making a decision to attend rehab, if others do not recognise and pursue this decision for him, in the same way they would for others. These same health workers were open to the rights based principles, and indicated an interest in learning more. Two weeks after the case meeting David was approved for rehab, which he completed.

David's decisions illustrate the difference professional decision support, skilled in using the principles, can make, not only to the life of the decision maker, but in building the capacity of the community as a whole to engage in supported decision making. Supported decision making is not disability specific. It illustrates the value of professional support in developing the skill of care workers to support day to day decisions, and the real necessity of doing so. With training and experience they are more likely to recognise and be confident advocates and supporters of David's right to decide in more crucial decisions, such as healthcare. It illustrates the value of professional decision support in ensuring those who are socially isolated or supporters do not have the skill or authority to advocate in certain, more complex situations, can fill. It illustrates the need to have decision support responses that are proactive, filling real unrecognised need.

Professional Support: " I want to make decisions, not a friend."

Caroline is a 22 year old woman who has just finished studying to be a learning support aid. She wants to work with children in primary schools so that she can bring her experience of psychosocial and intellectual disability into the classroom. When she joined the program Caroline was considering her future. Where she will work, where she will live and with whom. While she has a strong and inspiring vision – Caroline recognises that she needs decision support to break down this down into a series of smaller, achievable decisions.

Working with the project coordinator, Caroline's goal has been to find a decision supporter who is not connected to her family. She fears that, sometime in the future, her brother may end up being a substitute decision maker for her – and anticipates he would make too many decisions on her behalf and that these would not be the decisions Caroline herself would make. Caroline's mother had encouraged her to join the program. She wanted to avoid guardianship for Caroline but wanted to find alternatives to ensure that Caroline is not vulnerable, for example, in a health care decision or financial decision where she needs additional support to understand information.

Of all the decision makers, Caroline lives her life largely in mainstream, yet, finding a freely given supporter for Caroline was a challenge. Caroline's strongest connections are with family. Her experience of friendship has been tarnished by bullying and stigma. She is uncertain of when to trust someone, and if fearful her response is to withdraw – leaving her socially isolated.

Despite her sense that connecting with others can be 'risky' Catherine agreed that finding and establishing a freely given decision support would be a main focus of her participation in the project. Eventually we linked with Compeer, run through St Vincent de Paul. This matches volunteer 'friends' to people recovering from mental illness – and shared rights based values compatible with supported decision making. Caroline agreed that she would like to use the program to find a friend, who, all going well, might eventually become her decision supporter. Together we wrote her application, fielded inquiries about what her intellectual disability might present for a supporter (as this was new to Compeer), and developed a process for the two programs to work in tangent. Eventually a potential match was identified.

In the interim Caroline and the coordinator explored what supports and safeguards she might need to enter into the friendship. She "could not remember ever having a real friend", so could not draw on a positive experience of friendship on which she could base this new relationship, so part of supported decision making for Caroline was exploring friendship, identifying what would make her feel comfortable, what she termed 'escape hatches' and what she needed from the volunteer.

While the compeer program has potential for establishing a relationship that could lead to freely given decision support, Caroline has made the decision, at this stage, not to proceed with the compeer match. She says she would feel safer if she and I could continue to work within the coordinator, preferring the boundaries of professional decision support. At this Caroline is unable to make the

emotional and personal investment required to maintain a friendship. “I want to make decisions, not a friend.”

Appendix 2

Principles for decision supporters

Every person and every decision will need their own specific supports. These principles provide a framework for giving decision support. They protect you and as well at the decision maker. If you are unable to agree to all these principles then the decision support role is not the right one for you. In this case the best thing you can do to help the decision maker find a decision supporter who can follow these principles.

#1. Everyone has a Right to Decide

Every person has the right to make decisions about the things that are important to them. Disability is not a reason to exclude someone from making decisions.

#2. The Right to Decide can be exercised with support

Regardless of their decision making capacity, people can be supported to be involved in the decisions that affect them. The focus is on support not capacity.

#3. Give only as much support as is needed

You must only give as much support as is needed so that the decision maker remains active and in control. The levels and kinds of support given will depend on the decision being made.

#4. Everyone has something to learn

Supported decision making is not disability specific. Everyone has a role. Everyone has something to learn. Decision making is a skill that you can learn. So is supporting a decision.

#5. Respect the decision maker

Decision support is about respecting the values, experiences and goals of the decision maker. You must be able to do this even when you do not share them, so that the decision maker can decide for themselves.

#6. The decision maker is always in control

The decision maker is always in control. This means they are actively and engaged as far as possible in their decision. They choose the decision that they want to make and who will support them. They can change their mind, make mistakes, learn from experiences and make decisions that others don't agree with.

#7. Your Relationship to the Decision Maker and their decision matters

You must have a relationship with the decision maker built on trust. Everyone has vested interests. You must be able to recognise your own vested interest in the decision being made, and in the life of the decision maker, and then consider if you can truly support the decision according to these principles. If you are unable to do this the biggest difference you can make to the decision maker is find a person who can support the person and the decision, according to these principles.

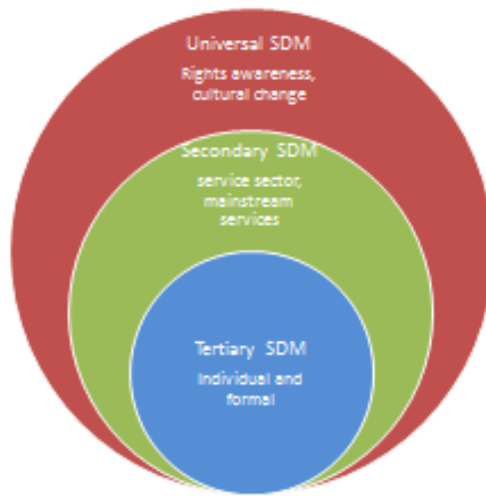
#8. Equality

Decision support is about enabling a person with a disability to approach decision making with the same expectations, freedoms and responsibilities as those who do not have a disability.

Appendix 3

Universal Model for Decision Support

Supported Decision Making – a change agenda



© ADACAS July 2013

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

Secondary – those who directly interact with pwd 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.

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. This publication is copyright, apart from use by those agencies for which it has been produced. Non-profit associations and groups have permission to reproduce parts of this publication as long as the original meaning is retained and proper credit is given to the ACT Disability, Aged and Carer Advocacy Service. (ADACAS). All other individuals and agencies seeking to reproduce material from this publication should obtain the permission of the CEO of ADACAS.

Contact: Fiona May Chief Executive Officer PO Box 144 Dickson ACT 2602. Ph 62425060.

Acknowledgments:

ADACAS also acknowledges the contributions of the many people who gave their knowledge, time and experience to this project.

© Copyright ACT Disability, Aged and Carer Advocacy Service 2014