

Evaluation Report of the Link and Learn Supported Decision Making Project



A Report made to the
Community Services
Directorate, Office for
Disability, ACT.

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Executive Summary

The Supported Decision Making (SDM) project Link and Learn represents an attempt by the Community Services Directorate, Office for Disability ACT to implement a training model that builds a culture of SDM across the State, whilst offering specialist support and volunteer recruitment to decision makers through volunteers and project support where necessary.

All Link and Learn awareness raising, training and skills development sessions were evaluated positively across the project period and engaged a wide range of stakeholders.

Evidence suggests:

- skills development built decision making skills in participants with disability and identified people requiring additional project and volunteer decision support .
- training led to implementation of SDM by many participants across the sector, but that more needs to be known about the resultant outcomes.
- that similarly to other projects across Australia, Link and learn found volunteer recruitment very difficult, time-consuming and, therefore, not easily scaled up.

To address the lack of volunteers Link and Learn developed its own model, *The Strengths Based Activation Model* of SDM. Evidence suggests this model

- makes the most of *existing* (as opposed to volunteer) networks and activates decision support where necessary, a much more efficient approach for project staff,
- shows real promise but, given it was implemented later in the project, requires further evaluation to test its outcomes.

The evidence suggests Link and Learn project outcomes:

- were specific to time with outcomes specific to the issue at that time, but that the issues changed for people often. This indicated an ongoing need for SDM,
- were harder to achieve because of systemic, organisational and structural barriers,
- related, like other projects in Australia, to a host of human rights areas – discrimination and awareness raising, living independently, health, family life, privacy and participation in cultural life, recreation and leisure amongst others,
- related largely to decisions that took place in everyday situations and, only to a lesser degree, to legal decisions.

Link and Learn was successful in the outcomes it produced and adapted thoughtfully as project staff struggled to find solutions to key issues as the project developed over time. It is recommended that:

- The outcomes of training that develop *a culture of SDM* are independently evaluated,
- *The Strengths Based Activation Model* is itself extended and independently evaluated,
- Where legal decision-making takes place, a *Statement of Will and Preference* as a *Guidance Document*, would ensure ‘best interests’ decisions are tempered with accountability to the decision maker,
- A review be undertaken to support longer term and more sustainable funding for SDM that supports NDIS notions of choice and control but which, when extended for SDM.

Extended Summary

Key findings:

- Link and Learn was innovative in its conceptualisation, aspirational in its objectives and both successful and innovative in its execution.
- The Link and Learn model assumed building a culture of SDM in ACT through targeted training to those who could support a broader range of decision-makers requiring such support and, in addition, project recruitment of additional decision support and program input for a smaller more vulnerable group requiring support at a higher level.
- Mid-point project formative evaluation of training and skills development showed very positive outcomes and this continued to the end of the project. Much potential is indicated for widening the culture of SDM especially given ACT mental health legislation and the focus of the NDIS on choice and control. However it is not known how Link and Learn training was implemented by participants and so the knock-on effects of the training in producing SDM and better lives remains unknown.
- Mid-point volunteer recruitment to decision support networks, like other SDM projects, proved difficult and time consuming leaving project staff to fill the gaps. This volunteer recruitment plan is not practical and cannot easily be scaled-up.
- End project findings indicate real potential for the resultant *Strengths Based Activation SDM Model*. This model: assumes different roles for already existent members of a person's network; provides training to this group and the person; and activates the relevant network role where necessary.
- All SDM work by Link and Learn produced important outcomes in terms of protecting, defending and fulfilling human rights for the decision-maker. It was found these rights were about immediate issues, but that SDM was required temporally to ensure issues were addressed as they emerged. This finding further highlights SDM models that are sustainable over time. However more outcomes testing of *the Strengths Based Activation SDM Model* is required.
- Testing the outcomes of building a culture of SDM and the new model is a priority. Both models ensure SDM is relational and everyday in form. However the findings indicate decision-makers often need to take legal decisions. A new mechanism is required to bridge the gap between relational decision making and formal legal decision making which does not involve Guardianship.
- The models that had emerged by the end of the Link and Learn project funding period indicates that to new funding approaches are required for SDM that are sustainable over time, but which maintain the independence of the SDM project concerned.

Recommendations and Risks:

Recommendations	Risks
<p>1. ACT Community Service Directorate should adopt ‘Building an SDM Culture’ across services, carers groups, advocacy and other groups that reflect ACT mental health legislation, human rights and the NDIS. This differs from most other SDM projects designed for the few..</p>	<ul style="list-style-type: none"> i. ‘Cultures’ are hard to change. It takes time. ii. The outcomes of Link and Learn training and skills development remain unknown in terms of outcomes for decision-makers receiving SDM support from those who have been trained by Link and Learn. iii. Additional cost is required to confirm benefit and value added. iv. Building a culture may require more funding in order to achieve comprehensive coverage. This may be saved in the long run by better services producing better outcomes. But this is open to further exploration longitudinally.
<p>2. It is recommended that if Building a Culture of SDM is adopted that the success of the Link and Learn and any subsequent training is researched or evaluated in terms of the outcomes for decision-makers.</p>	<ul style="list-style-type: none"> i. Whilst the model as presently evaluated has potential, it may be found that more work is required to ensure consistency of SDM application over time. ii. The training, awareness-raising and skills development delivered by Link and Learn only moved to their new <i>Strengths Based Activation SDM Model</i> late in the day. Retraining will be required. iii. Given providers are struggling in the NDIS market, training costs may need to stretch to staff back-fill to ensure the widest training attendance and to ensure the culture is as widespread as intended. iv. IF SDM is taken to be a core element of choice and control it may be an important element to be built in to Cert III and IV delivery. This may take some time. v. Additional costs are implied to confirm benefit of the ‘building a culture model’ and to further quantify the value added.
<p>3. The <i>Strengths Based Activation SDM Model</i> should undergo more testing.</p>	<ul style="list-style-type: none"> i. Present indications of outcome in terms of human rights are good but the model cannot be confirmed to have worked in all circumstances and situations without more testing. ii. The model indicates more sustainable outcomes over time with least effort. However this efficiency should also be tested over time. iii. The model is significantly different from those in other areas of operation in Australia and abroad so needs advertising and discussion around its pros and cons.
<p>4. ACT Community Service Directorate should undertake a review of how to provide more sustainable SDM funding to support ‘a culture of SDM’ and the added value it accomplishes.</p>	<ul style="list-style-type: none"> i. Building a model based on equal access and social justice will have cost implications as it would imply greater demand for SDM and SDM training. This is not likely to be met consistently through project funding. But there are few other funding options that would leave SDM projects sufficiently independent to operate free of conflicts of interest. ii. NDIS funding and training around the time of pre-planning and review of plans could bed SDM in as a regular feature of decision-making in people’s lives under the ‘Strengths Based Activation SDM Model’. However, the importance of independence from services needs to be preserved, whatever funding source is used.

Further Dimensions:

Recommendations	Risks
<p>5. ACT Community Service Directorate should consider the adopting of the Statement of Will and Preference. This guidance document will act as an important link between the relational and everyday model of decision-making and the necessity, at times, for a decision-maker to be an ‘entity’ for the purposes of legal decisions. The Statement will establish some ‘equality of arms’ since decisions made in contradiction to the Statement, will have to explain why they have not taken the Statement into account in favour of best interests decision-making.</p>	<ul style="list-style-type: none"> i. Where courts, Tribunals, Guardians, medical practitioners, Trustees, families, and others require a Statement of Will and preference this may take time to achieve. This project and the ADACAS project <i>Spectrums of Support</i> show that unless SDM is built in to everyday life, developing such a statement can take time. Getting a person to be decision ready is a long process. This emphasises the importance of bedding this into a culture over time, so more decision-makers are decision ready. ii. There may be resistance from some quarters and in relation to the legal positioning of such a Statement. iii. There may be some time delay before such a device as the Statement can be implemented. There may be a significant period of deliberation alongside placing the model into law, policy and practice.
<p>6. It is recommended that debates about the boundary between Guardianship and supported decision making take account of modern contexts. The NDIS has increased Guardianship applications (not all appropriate) as well as the interest in SDM.</p>	<ul style="list-style-type: none"> i. Clarity over the boundaries between Guardianship and SDM need to take account of the model of SDM that is ultimately adopted in the ACT. However, whatever, if cost is a sole arbiter in this deliberation it is likely to fail. The value added in achieving choice and control is vital. Guardianship and SDM reflect the dominant narrative of choice and control and are both therefore likely to be more in demand in present contexts, but to produce value as a result. ii. Independent of the cost criterion, deliberations around where will and preference end, and Guardianship begins, need further discussion. Included in this deliberation in ACT is the extent to which, <i>inter alia</i>: a decision-maker can meet the five stage SDM process outlined in <i>Spectrums of Support</i>; the extent to which a <i>Statement of Will and Preference</i> can be applied; and the success of a <i>Strengths Based Activation SDM Model</i>.
<p>7. If the above recommendations are adopted the role of SDM projects will begin to change. As well as training and specialist decision support they will, given the wider application of SDM, need to act in a role that monitors the quality of SDM and to receive complaints around SDM.</p>	<ul style="list-style-type: none"> i. The formalisation of the role of an SDM project can place SDM projects in a powerful position. They may be seen as part of a formal system rather than sitting in an advocacy framework. Detailed consideration needs to be given to how to <i>ensure SDM remains within an advocacy frame</i>. SDM should not be part of the wider service system.
<p>8. It is recommended that new models of outcome be adopted to measure the impact of SDM. Human rights outcomes</p>	<ul style="list-style-type: none"> i. SDM needs to be responsive to life changes and to ongoing decisions. However, records of the benefit

Recommendations	Risks
exploring rights that are being protected, defended and fulfilled over time align with the UN CRPD and create better ways of ensuring negative rights are addressed and positive rights are progressively realised.	<p>of SDM may have cost implications and collection of data can impose on their everyday lives.</p> <p>ii. There are other outcomes that may also be important so discussion is required around all relevant outcomes within a wider NDIS context.</p>

1. Section 1: Background to the Evaluation

1.1. The Link and Learn project

In June 2014 and then February 2015 the Executive Director (DACT) of the Community Service Directorate agreed to funding for the development, delivery and evaluation of a Supported Decision-Making (SDM) Community Education Program Link and Learn Pilot. In the evaluation Request for Quote it is stated that:

'SDM provides people with a cognitive and/or psychosocial disability with a mechanism to enable them to have ownership of making their own decisions. SDM will be embedded in the ACT through development, delivery and evaluation of an education and network building pilot known as Link and Learn. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) clearly establishes SDM as the first resort, the preferred alternative and, where necessary, a precursor to guardianship. Under the National Disability Strategy (outcome 2.12) the ACT Government is committed to ensuring SDM safeguards for those people who need them are in place, including accountability of guardianship and substitute decision-makers.'

A media Release about the project was issued in August 2015 (Appendix 1).

The Link and Learn project was designed to implement and deliver five key activities and the evaluation to explore the processes, outputs and outcomes. The evaluation was subject to Human Research Ethics Committee review at RMIT:

- A. **Awareness raising activities** about supported decision making among people with disability, their current and potential supporters.

The evaluation involved distributing a questionnaire which was completed by participants at the sessions (n=118, approximately a 40% response rate). This was supplemented by two phone interviews, 3 face to face interviews with participants and observation in one session delivered by Link and Learn.

- B. **Skill development activities** to develop people with disability and supporters' skills in supported decision making.
- C. **Professional training** to various professional groups.

The evaluation involved distribution of a questionnaire (n=73), observations in three skills development sessions and in two training sessions, and interviews with 8 people who had attended these sessions.

- D. **Decision support relationship building** activities to create supported decision making relationships between people with disability and supporter/s.

The evaluation involved narratives collected over time from five decision makers (two on three occasions and three on two occasions). Interviews were also held with a decision maker and family member and with four decision supporters providing decision support to their children. To explore outcomes further, a review of the human rights implications was undertaken for Link and Learn cases, 21 being chosen where input by Link and Learn was held to be significant and not passing.

- E. An **online community of practice on supported decision making** is established to link interested people with disability, decision supporters and professionals

This was not implemented as discussed later

The evaluation further involved seven formal interviews with Link and Learn staff and countless discussions over the evaluation period.

Project Staffing. Link and Learn employed one full time project coordinator and a 0.7FTE administrative and management support worker whose role also covered delivery of awareness-raising, training and mentoring at times.

Most previous SDM projects had a complement of two staff, the second operating at varying time fractions¹. The majority focus of activities in most other projects was also likely to be limited to identifying decision-makers, matching where necessary and then providing support and mentoring to the resultant decision-making dyads/groups. The WA project was an exception, in that it sought to bed SDM into services as a means of widening the SDM approach beyond the SDM relationships alone.

It can be said that the funding requirement for Link and Learn was innovative and forward-looking. The approach was intended to build wide knowledge and awareness of

¹ This was true of the first ACT project, the projects in NSW, the second South Australia project and the WA project. The first SA project had three staff and the Victorian project just one (with support from staff at the Office of the Public Advocate).

SDM (A and B and D above) and, through the community of practice (E above), to maintain the engagement and capacity of SDM stakeholders in a sustainable way. The ACT model therefore implies '**building a culture of SDM** into the community and into services'.

The remit for Link and Learn was therefore much broader than for most other funded SDM projects but the staffing complement was not significantly greater than other projects. Towards the end of 2016 the second staff member left post at a key time for the project leaving a gap for several months whilst new recruitment and training and induction took place.

At this point the Link and Learn coordinator was contemplating the project implementation experience and adapting and refining a new model of SDM practice which reflected project learning up to that point. More is said of this later. However, for the moment it is worth noting that the recruitment and following training reflected the adapted approach. The result was that there is a significant period in which the project did not operate at full capacity.

Key Point 1: The Link and Learn project was innovative in its planning and at inception. As well as organising to support decision makers, it was tasked with building a culture of SDM into stakeholder communities and services through awareness raising, training and building a community of practice.

Key Point 2: Despite having a wider remit, the staffing complement for Link and Learn was no greater than for most other SDM projects. Staffing issues at a key moment just over a year into the project therefore amplified the struggle to meet all the project aims. As a result the community of practice has yet to be actioned.

1.2 Status and purpose of this report

This report is the final evaluation report made to the Community Services Directorate, Office for Disability ACT.

The evaluation set out initially in relation to the RFQ has undergone significant change. This was highlighted in the second milestone report to the Community Service Directorate and reflected the changes to the Link and Learn project that had been taking place and some real issues with applying some of the tools originally developed.

To understand this evaluation report it is essential to have an understanding of the key historical themes around supported decision making, the models adopted in Australia and elsewhere and to do so in terms of the contemporary NDIS context and that in ACT in particular. With that in mind the second section of this report lays out this context and associated assumptions and contentions around supported decision making (SDM for brevity).

The arguments posited in Section 2 are later used to explain how the Link and Learn project sought to reconceptualise its operation based on experiences. The arguments will help the reader to understand how the evaluation changed in terms of its program logic, over the project period and how these changes in the evaluation reflected changes in Link and Learn practices. They also reflected a changed methodology more capable of capturing SDM processes and outcomes as will be explained later.

Section 3 of this report discusses the online community of practice, presents data from the awareness-raising sessions and from the training and professional and skills development activities delivered by Link and Learn staff over the project period. This is supplemented by data from interviews undertaken with participants at a number of these events.

It is concluded that:

1. The choice and targeting of training across service areas initially favoured mental health services given the recent implementation of mental health legislation in ACT and only later started to broaden out
2. The training covered areas independent of support services, for example community legal practices and Guardians. In doing so the training began to link up different parties who might both have roles in supporting a person's will and preference
3. There was an overwhelming positive response to the training with just a few minor issues. Amongst the most important were those relating to where the boundaries of SDM were perceived to lie.
4. Interview data indicated a very positive response to the training in which managers were actively seeking to build SDM into their everyday practice. It was not possible to explore the impact of these changes and further research is warranted if the model is maintained.
5. That the adaptation to training warranted by later changes in Link and Learn model were not fully evaluated as the project period was coming to an end.

6. That, overall, the Link and Learn has made a significant contribution to building a 'culture of SDM' across disability and associated services.

Further implications of these findings are discussed in Section 3 and 5.

Section 4 uses narratives to explore the processes and outcomes of Link and Learn's *support relationship building* more deeply and to unravel some of the mechanisms that led to these outcomes.

Because of the Link and Learn project development over time these case studies are shown to represent a thoughtful adaptation by Link and Learn project staff to their experiences over the project period. In responding to experiences over time the project had to refine its model of SDM and associated processes.

A further analysis of 21 supported decision making relationships in terms of the human rights that then reported and some of these findings are considered in more depth in relation to the breadth of human rights areas covered by Link and Learn.

This section concludes that:

1. Unlike most other SDM projects Link and Learn focused not just on the person, but more importantly on the activation of the networks capable of decision-support. This might be summarised as 'making the most of natural networks', 'consolidation of networks to allow activation of decision support where necessary' working on the assumption of a 'distributed competence' model and not simply an 'individual competence' model.
2. By the end of the project, the model refinement over time ended in a unique approach to SDM which had potential to: build a culture of SDM across services and other agencies; that activated people and groups across each person's network with Link and Learn training and support where necessary, to maximise the chance of the network achieving the person's will and preference; that offered support tied to utilitarian outcomes direct from the project for those who were isolated or had complex and ongoing problems; that accomplished both social outcomes, human rights outcomes laid out in the CRPD and legal outcomes in collaboration with other agencies.
3. The outcomes of the project have the potential to address both 'formal' (legal, see below) and 'informal' (relational, see below) outcomes and to accomplish human rights across a number of CRPD domains.
4. The data indicates there remain a number of problematic areas in which SDM could reasonably work with advocacy organisations to change culture and practice to support will and preference.

5. The model offers potential for dove-tailing with Guardianship.
6. Unlike other models, there is potential for a 'scaling up' of the Link and Learn model though the mechanism for funding remains unclear.
7. It is important to build a culture of SDM within services to support the new model and this needs to be built into teaching and learning as well as in service training
8. Ultimately, by the end of the project period, insufficient time was available to test the new model more systematically but that is worth doing.
9. Further research will be required to explore any other expansions of the project model over the course of time.
10. The areas of health and community inclusion (Articles 19 and 25 of the CRPD) were the more likely areas of input but many of the other substantive Articles were also part of the SDM input.
11. The areas of civil and political rights (largely negative rights in which infringements are recognizable) featured alongside economic, cultural and social rights subject under the CRPD to 'progressive realisation' where change is about the improvement in outcome and not about infringement. The protecting, defending and ensuring human rights as suggested in the CRPD therefore requires SDM which recognizes the legal aspects of SDM (for negative rights) and which also supports relational rights (positive rights). This distinction between legal and ethical rights is considered in the section to follow.

Further implications of these findings are discussed in Section 3 and 5.

Section 5 of this report reflects on the project findings. The discussion revisits the differing approaches to SDM across Australia and internationally to explore the niche Link and Learn created over the project period. Key successes, issues and barriers are considered in light of the evaluation findings and then further opportunities are discussed not least in light of the NDIS context in the ACT.

Throughout this document Key Points and recommendations are set out in offset text to the right (like this statement).

Section 2: Situating Link and Learn in the Broader SDM Context

2.1 Fundamentals

Several factors have come together to prompt the adoption of supported decision-making. As will be argued, Australia, amongst many other countries, is really only at the start of what is likely to be a long history of refinement in the concepts and operationalisation of SDM. Indeed, much is yet to be done to establish the efficacy of different models and to measure their outcomes. The move towards SDM has been prompted by a number of context relevant factors.

Reading and re-reading the literature on supported decision-making points to the fact that this is an area which is: emergent and in which clarity over best practice is yet to be established; is one in which several perspectives have, and can be applied; and in which the outcomes and intentions can vary significantly. Interpreting the literature is troublesome given the variation. However underlying each conceptualisation lie a number of stakeholders, the actions of whom within any project context, define 'who' is involved, 'how' they act and, concomitantly, what the limits of the project and its potential outcomes might be.

The key areas of activity lie with the following stakeholder groups: The decision-maker; the decision supporter or group; the SDM project staff. The literature has predominantly and implicitly focused on competing theories about the identity of the decision-maker as outlined below.

2.1.1 *The 'decision-maker' identity*

a) as legal entity

One key approach to the concept of supported decision-making in Australia has come from a 'legal' conceptualisation of the person – where 'person' is meant 'legal entity' recognised as having rights and obligations, for example to enter into contracts or to be sued. 'Personhood' which confers this status at birth for each individual is a prerequisite to legal capacity.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), to which Australia is signatory, establishes in Article 12 Equal Recognition before the law, requiring States Parties to exercise the support required to meet their legal responsibilities. The place of the 'person' as a legal entity is more likely to apply to negative rights, largely the civil and political rights in which recognizable infringements to rights are clearly observable and actionable.

In terms of SDM the Australian Law Reform Commission (ALRC, 2014)² states the need for traditional 'best interests' decisions made on behalf of the person to be replaced,

'Given that the focus on will and preferences is such a key idea in all discussion, the ALRC considers that it needs to be identified as a general principle. It reflects the framing principles of dignity, equality, autonomy and inclusion and participation', (ibid, para 3.5).

ALRC also set out in the document the standards to be applied where such will and preference cannot fully be determined.

In recommendation 3-3 (para 3.57) ALRC distinguishes between supported decision-making and representative decision-making. In the SDM model the supporter must support the person to express their will and preferences, assist them to develop their own decision-making capacity, communicate by any means through which they can be understood and, in doing so, have their cultural and linguistic circumstances respected. In the 'representative' model the representative must give effect to what the will and preference of the person through all means available and, in the absence of such information, choose the least restrictive practice and avoid all unnecessary harm.

The key issues are well documented as follows,

'Supported decision-making recognises that many people with intellectual disability or cognitive impairment can make their own decisions with support and assistance. This may involve support and assistance to find and process the information needed to make a decision, express their will and preferences, and/or communicate their decision. Without such assistance, the same people may be deemed to have impaired decision-making capacity, particularly when applying traditional tests of capacity' (Queensland Government, 2014: p. 2)³

In short, one interpretation of the CRPD rests in a 'legal' conceptualisation of the 'person' and a number of things follow on from this premise.

Chesterman and Carter (2009)⁴, for example, argue that 'Decisional capacity may be divided into four sub-capacities. These are (1) Understanding [the facts of the decision] (2) Appreciation [of the nature and significance of the decision] (3) Reasoning [to be able to

²ALRC (2014) *Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124)*. Commonwealth of Australia, Canberra.

³ Queensland Government (2014) *Office of the Public Advocate Systems Advocacy: A journey towards autonomy? Supported decision-making in theory and practice: A review of the literature*. Brisbane: The State of Queensland (Department of Justice and Attorney General).

⁴Chesterman, J. and Carter, B. (2009) *Supported decision-making: Background and discussion paper*. Melbourne, Office of the public advocate. November.

derive conclusions from premises] (4) Choice [to communicate a preferred decisions from amongst options]⁵.

Importantly, they define SDM as follows,

'Supported decision-making refers to formal arrangements that go beyond the informal assistance of family and friends but stop short of substitute decision-making through Guardianship, administration and Enduring Powers of Attorney⁶.

It is important to look at some of the assumptions in this conceptualisation: First that the focus is on establishing a particular type of identity for *an individual* - for the person, a *legal identity* – that, such legal identity applies to decisions requiring the person to be a legal entity, i.e. *legal decisions* – and, finally SDM is considered a *'formal arrangement'*, i.e. *beyond natural networks including the family*. It may also be added that formal arrangements must relate to formal (legal) decisions and so there is a linear path and outcome assumed.

Key Point 3 - Legal conceptualisations assume a legal identity of an individual, in relation to legal decisions, and to do so redefine the individual within a framework in which a supporter establishes the person's will and preference. Since the person is a legal entity the decisions they make are subject to the law and, as such, there is a need for the support to be established under a formal legislative framework.

Chesterman and Carter (2009) therefore explore the construction of different formal arrangements in other jurisdictions and in a later paper Chesterman (2010)⁷ sets out options for legislative recognition.

As will be shown from much of the data in this study, such assumptions can ignore the everyday machinations in the day to day decision-making in the lives of many of the participants. Criticisms of the model largely rest in arguments which relate to what has been termed the 'recognition of interdependency' (Queensland Government, 2014, *op cit*. p. 6).

⁵ Explanations in square brackets added.

⁶ Chesterman and Carter *op cit*, p.7

⁷ Chesterman, J. (2010) *Supported Decision-Making: Options for legislative recognition*. Melbourne: Office of the Public Advocate. January.

Ramcharan et al., (2013)⁸ for example, argue that no-one has 'freedom of choice'. Rather, all of our choices and decisions are made within a context of relationships and constrained by environmental and resource availability. We may decide, for example, not to spend the family wealth on a personal trip around the world since, to do so would impact others and have its own knock-on effects on our capacity to make future choices. We make decisions about where and with whom we live based on the resources we can muster individually or collectively, in discussion with those making the decision – and we may never reach our ideal living situation. We may choose what clubs to attend and what friends to hang out with. Both choice and decision are always undertaken in an interactional context and within a framework of resource constraint. Such decisions may be about issues tied to legal issues but, equally, they may also be about everyday decisions and about building community inclusion.

This tier of decisions lie largely in the realms of positive human rights which are most closely associated with economic, social and cultural rights. These rights are subject to 'progressive realisation' by States signatories to the CRPD. The movement over time to improvements in such rights in any State signatory to the Convention is all that is needed to be demonstrated and it is much less likely to be able to claim a right to improvement on behalf of individuals in this respect.

In their paper Supported Decision Making, Psychosocial Disability and the NDIS, ADACAS states that, 'The dominant support paradigm for SDM is that of freely given or community based support. This is consistent with Article 19 of the UNCRPD which protects the right to full inclusion in community life. To fulfil this principle the CRPD states that decision support should be established from networks and community support'⁹. It should be noted how this definition differs from that provided earlier relating to SDM being formal and to do with the person as a legal entity.

All humans rely upon family, friends, colleagues, and (support) services too as we negotiate how our decisions accomplish our identity and our self-determination within this framework of interdependence. Some have termed this 'relational autonomy' (Kennedy, 2001)¹⁰. We also do so culturally and as such our decision-making does not always reflect the underpinning philosophical assumptions of western jurisprudence, nor

⁸Ramcharan P, Leighton D, Laragy C, Despott, N. and Guven, N. (2013) *It's My Choice Toolkit*. A Practical Design Fund project funded by the Australian Government Department of Families H, Community Services and Indigenous Affairs (ed). RMIT University & Inclusion Melbourne.

⁹ADACAS (2016) *Supported decision making, psychosocial disability and the national Disability insurance Scheme*. Watson, ACT: ADACAS.

¹⁰ Kennedy, C.H. (2001) Social Interaction Interventions for youth with severe disabilities should emphasise interdependence, *Mental Retardation and Developmental Disability Research Review*, 7, 2: pp122-127.

indeed, the centrality of the individual within neo-liberal philosophies. We work and decide in groups, those groups upon whom our decisions are likely to have an impact.

In *Spectrums of Support* (ADACAS, 2013)¹¹ many of the above propositions were highlighted. It was argued that, capacity for self-determination and autonomy was not limited by the individual decision-making ability of the participants, but by their circumstances and the level of support they received. ADACAS argue that

'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'¹².

Some have argued on this basis that the informality of everyday relationships should not be formalised to primarily define the person as a legal entity but, rather, should focus upon everyday environments, lives and decisions, decisions which may never reach the legal system. Without addressing this level of decision-making the gap between formal Guardianship and the important decisions that can enrich lives on a day-to-day basis would be lost and SDM severely limited¹³.

Key Point 4 - In the relational model each person is seen as part of an organic set of interdependencies within which decisions are made. Faulted and fragile though such mechanisms may be, it is the person's everyday relationships and environments which dictate the conditions within which they make decisions and they cannot therefore be avoided or ignored. Imposing formal mechanisms further empowers the state to intervene in these natural decision-making relationships and undermines 'family'¹⁴ life.

The competing legal and relational models above have the potential to promote competing policy and practice at either of ends of the dichotomy. Queensland Government (2009) sets out the case against legislation as: over-reach in which more of the private and everyday lives of people are subjected to formal mechanisms; that

¹¹ADACAS (2013) *Spectrums of Support: A report on a project Exploring Supported Decision Making for People with a Disability in the ACT*. Watson, ACT: ADACAS.

¹²Ibid. P. 55.

¹³ Later in this document the ALRC notion of representation discussed earlier will be brought into play, i.e. the representative must *give effect to what the will and preference of the person is likely to be through all means available* and, in the absence of such information, choose the least restrictive practice and avoid all unnecessary harm. The notion of 'by all means available' is important in respect to the arguments in 'the later discussion.

¹⁴ By 'family' is meant here the everyday relationships which both structure the person's life, which support the person to live their life as they see fit and which are the constant and not intermittent in structuring their lives.

insufficient evidence is available to make recommendations around legal or other forms of practice.

In contrast their case for legislation is that: it provides authority for decision-supporters; there is third party recognition for the support; it enforces protections for supporters from civil or criminal liability; it provides safeguards, positive duties and a monitoring role; and also that it may help in access to service systems whilst keeping people out of Guardianship arrangements.

Key Point 5 - Present arguments about whether to legislate the role of supporters is theoretical and not sufficiently tested empirically. The argument has been constructed at diametrically opposed extremes and no consideration has as yet been sufficiently given to whether a dual model supporting each is possible. (More is said of this in the discussion to this report).

Since there is limited legislation across most jurisdictions in Australia¹⁵ it is not possible to characterise Australian projects as being formal (legal) or informal (relational) for the purposes of this report. However, it is possible to say that the formal and relational approaches are likely to differ along the following lines: the type of training provided to supporters; the nature of the issues addressed by decision supporters; the matching (if this takes place) and everyday engagement with the person requiring support; the type of person who can access SDM; and the formality and nature of the SDM arrangement.

2.1.2 *The 'decision support or group' and the SDM project staff*

In the absence of legislation, most SDM projects in Australia have worked on the assumption that one supporter carries lead if not primary responsibility for decision support. What Bigby et al. (2017)¹⁶ call 'dyads' in which there was primary responsibility for one such decision supporter was true of a number of SDM pilot projects: two SDM projects in South Australia, one in New South Wales (Westwood Spice, 2015) and Victoria (Calnin, 2016). These very much fit with the 'formal' approach to SDM and with the

¹⁵Chesterman considers a number of forms of support; support group; representation Agreement (drawing on Canadian models); Public advocate; Tribunal appointed assistant decision maker. See Chesterman, J. and Careter, B. (2009) Supported decision-making: Background: Discussion Paper (2009). Melbourne: Office of the Public Advocate.

¹⁶Bigby, C., Douglas, J., Carney, T., Then, S., Wiesel, I & Smith, E. (2017) Delivering decision making support to people with cognitive disability – what has been learned from the pilot programs in Australia from 2010 to 2015? *The Australian Journal of Social Issues*, DOI: 10.1002/ajs4.19

importance of legal responsibility. Given these limits of the decision supporter's role these projects will have needed to deliver training about the limits of their role. They are also more likely to have a monitoring arm to ensure probity and legality.

The first project in South Australia (Wallace, 2012)¹⁷ sought to ensure most supporters had some prior long terms relationship with the person. However one person was identified in the informal role. This model in some ways straddles the formal and informal approaches. Similarly in the second South Australian project (de Mestre, 2014)¹⁸ services also supported the family and volunteers. Both of these projects began to recognise the importance of the interactional environments for decision-making in which each person operated. They therefore offer a model that spans the both formal and relational models outlined above.

Western Australia¹⁹ alongside its earlier LAC work driven by locality, community and (decision-making) networks (Bartnik, 2003)²⁰ adopted a model which privileged the already existent networks as collective decision support, an informal or relational model arrangement. This model draws significantly on the 'circles of support' model in which a group of people usually involving family and friends is built around a 'focus person'(person with disability) to assist with the thinking about, the focus person's stated or known goals and aspirations and achieving these through the circle's actions.

Key Point 6: The formal model locates decisions in the dyad with others in the person's network *consulted*; models which balance informal and formal elements *involve* others in the person's network. Informal models locate *control* within the network itself with the person at the centre. At the extremes the impetus of the formal model is to have an identifiable legal person and competence is assumed to belong to the individual even where supported; In the relational model the competence is seen to be distributed, i.e. to come from the group's interaction around the focus person.

¹⁷Wallace, M. (2012) *Evaluation of the Supported Decision Making Project*. Adelaide: Office of the Public Advocate/Muirgen Consulting.

¹⁸De Mestre, M. (2014) Supported decision making as an alternative to Guardianship orders: The South Australian Trial, *Elder Review*, 8 pp 1-4.

¹⁹ See Western Australia's Individualised Services (2013) Supported decision making project resources: videos, <http://waindividualisedservices.org.au/wais-publications-and-resources> (accessed 18 January 2017).

Western Australia's Individualised Services (2014) Supported decision making project resources, <http://waindividualisedservices.org.au/supported-decision-making-project-resources/> (accessed 9th February 2017).

²⁰ Bartnik, E (2003) Review of the Local Area Coordination Program Western Australia. http://www.dsc.wa.gov.au/cproot/847/2/final_report_LAC_review1.pdf.

In the relational model the partnership with family has often been criticized given the potential conflicts of interest (see for example, Mill, Mays and McConnell, 2009; Dowson and Duffy, 2011; Murphy, Clegg and Almack, 2011; Saltink et al., 2012)²¹. However given the centrality of family to a person's decisions the relational model will seek to build capacity for families to enter decision-support roles. Indeed many microboards and Velboards have registered with the NDIA as providers.

Advising on support categories for the NDIS *Microboards Australia*²² prompts participants to set up such boards under a number of support categories: self-management capacity building, improved living arrangement, increased social and community participation and improved life choices. A recent evaluation of five circles of support in the UK 'provided accounts of success in enabling the core member to live more independent lives with improved social care outcomes within cost envelopes that appeared to be less than more traditional types of support' (Wistow et al., (2016, p.1)²³.

However Circles of Support are likely to suit families who already have strong networks and the capacity to engage and mobilise additional networks. For those who are isolated, the recruitment of people to support such networks has been problematic.

For both formal and informal models of SDM, in the absence of wider networks it has been found that it takes time to recruit decision supporters, that it is often very difficult to recruit to these roles and that there is a high drop-out rate later on. This was mentioned by both the Victorian evaluation (2016)²⁴ and by ADACAS (2013)²⁵ in reporting their first SDM project.

Key Point 7: The formal model establishes a dyad which changes authority relations and which may affect the operation of the natural networks. It is more likely to involve matching the person with a volunteer. It *builds strength in*

²¹Dowson, S & Duffy, S (2011). Head to head: Do we need independent brokers?

<http://www.communitycare.co.uk/2011/10/13/head-to-head-do-we-need-independent-brokers/#.UtX8KTAyZ8F>: Mill, A., Mays, R. and McConnell, D. (2009) Negotiating autonomy within the family: the experiences of young adults with intellectual disabilities, *British Journal of Learning Disabilities*, 38, 194-200; Murphy, G., Clegg, J. and Almack, K. (2011) Constructing adulthood decisions about the futures of young people with moderate-profound intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities*, 24, 61-73; Saaltink, R., MacKinnon, G., Owen, F. and Tardif-Williams, C. (2012) Protection, participation and protection through participation: Young people with intellectual disabilities and decision making in the family context, *Journal of Intellectual Disability Research*, 56, 11, 1076-1086.

²²<http://microboard.org.au/ndis/>

²³Wistow, Gerald, Perkins, Margaret, Knapp, Martin, Bauer, Annette and Bonin, Eva-Maria (2016) Circles of support and personalisation: exploring the economic case. *Journal of Intellectual Disabilities*. ISSN 1744-6295 DOI: 10.1177/1744629516637997

²⁴Burgen, B. (2016) 'Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project', *Research and Practice in Intellectual and Developmental Disabilities*, 3 (2), 165-181.

²⁵ADACAS (2013) op cit.

specified decision making areas. Theoretically, the dyad consults but may not involve services or wider network in supporting decision-making. The informal model seeks to *build strength into existing networks of support.* This requires additional work to make sure the network is operational and in order to address potential conflicts of interest.

In both models, recruitment of volunteers has been difficult begging questions about scaling-up models that use volunteer recruitment.

2.2 What is the Decision-support for?

One of the issues with much of the literature on SDM, and particularly the evaluation reports thus far, is that very few examples of the decisions and details of their nature have been reported. In their useful article on approaches to supported decision-making for people with mental health problems Davidson et al. (2015)²⁶ review literature on a number of attempts to specify the areas in which SDM might apply. Bach and Kerzner (2010)²⁷ for example, argue that it may apply to ‘..formulating ones purposes, to explore the range of choices and make a decision; with other parties to make agreements that give effect to ones decisions...to act on decisions that one has made and to meet one’s obligations under any agreements made for that purpose’ (p.73). This may apply to person centred planning, advocacy, communication and interpretive supports, representational supports, relationship-building and administrative support. Davidson et al (2015)²⁸ point to the work of Chartres and Brayley (2010, p.28)²⁹ who add informal assistance from family and friends, SDM networks; information, education and awareness, advocacy, community support systems and practical assistance.

There are then a wide range of contentions about what the focus might be for the decision maker and, as a result, for the decision supporter in their role. Once again, it is possible to conceptualise these around the formal and informal dimensions.

Following careful thinking about a ‘stepped model’ to decision-making the first South Australian project focused on an early intervention group and an ‘alternative to

²⁶ Davidson, G., Kelly, B., MacDonald, G., Rizzo, M., Lombard, L., Aborgunroin, O., Clift-Matthews, V. & Martin, A. (2015) Supported decision-making: A review of the international literature, *International Journal of Law and Psychiatry*, 38: pp61-67.

²⁷ Bach, M. and Kerzner, L. (2010) *A new paradigm for protecting autonomy and the right to legal capacity.* Toronto: Law Commission of Ontario.

²⁸ Davidson, G., et al, (2015, op cit.

²⁹ Chartres, D. & Brayley, J (2010) *Office of the Public Advocate South Australia: Submission to the Productivity Commission Inquiry into Disability Care and Support.* Collinswood: Office of the Public Advocate.

Guardianship' group. This model included Agreements (including the areas for decision-making) and monitors (to ensure probity).

'The areas of life in which Supported Decision Making could be used focussed on accommodation, lifestyle and health decisions, consistent with the areas that may be included in a Guardianship Order, while acknowledging that decisions in these areas could have financial implications. However, the project Committee decided that the scope should be limited to areas not covered by financial Administration Orders'³⁰.

In the Victorian project (Burgen, 2016)³¹ volunteers were asked to provide support to people who were isolated and an SDM Agreement which specified the areas for decision-making focus was signed by the parties. The support was to be solution-focused '...a major decision of the type that might have fallen to a substitute decision-maker if one had been appointed, such as major health decisions'³². This approach tries to place a clear boundary between SDM and Guardianship.

In a separate presentation Burgen (2015)³³ lists a series of decisions taken which includes health decisions (medical procedures and contraception), access to services (holidays with unfamiliar people, one-to-one support, attending a garden club, accepting ISP funding, support for chosen activities, becoming a volunteer and joining a support group), accommodation (where to live and better participation in home decision-making) and reductions in employment. It is not clear to what extent these were those signed in the Agreements, but they seem quite broad.

In the New South Wales Project (Westwood Spice, 2015)³⁴, in

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

In short, there is a recognition that Agreements can be limiting. However, the project ended with 20 participants (6 dropped out) 9 of whom were under financial management. Of the supporters 10 were paid service providers, seven family members and one a paid advocate. A wide range of life areas in which decision makers wanted support are listed. The most significant area of change related to budgeting (not surprising perhaps given

³⁰Wallace, M. (2012) Evaluation of the Supported Decision-Making Project, Adelaide, Office of the Public Advocate: p.9.

³¹Burgen, B. (2016) 'Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project', Research and Practice in Intellectual and Developmental Disabilities, 3 (2), 165–181., p.169.

³²Ibid, p. 166

³³Burgen, B. (2015) OPA Supported decision making project, ASIDSDM Symposium

³⁴Westwood Spice (2015) My Life, My Decision: An Independent Evaluation of the Supported Decision Making Pilot for the Department of Family and Community Services (New South Wales), Sydney: p.24.

the number under financial management), but also in other new areas of decision-making too – living arrangements, holidays, recreation, fitness and what to wear.

The resources for SDM used in Western Australia draw on O'Brien and O'Brien's five accomplishments as the framework for areas that improve a person's quality of life³⁵ and focus on the circles of support that are available to the person with a disability and how these might build capacity for decision support³⁶. Potentially limitless decisions can be made under this model making it more comprehensive but less focused in its approach. This lack of targeting around key decisions may be a product of the informal approach to SDM as represented by the WA model.

Key Point 8 - There remains much debate about what areas are covered by decision-support. Agreements are more likely in formal models where there is more likelihood the support will be limited to identified areas. This provides focus and enables a quasi-legal apparatus around the 'person'. It is easier to identify from this specified outcomes. The informal model potentially encompasses everyday decisions, lifestyle decisions and more formal areas of decision-making. The operation may be more diffuse as a result and, unless there is a focus on key life areas, a chance to miss important areas for engagement in the support. Importantly covering both civil and political as well as economic, social and cultural rights may accord better with Australia's requirements as signatory to the CRPD.

2.2.3 *The SDM staff*

All SDM projects have had a coordinator but staffing for projects across Australia have been relatively small the largest being three people in South Australia between 2010-2012. The smallest staff complement was in the Victorian project though the coordinator had themselves support from the Office of the Public Advocate staff. Projects with monitoring arrangements have had to fund this role (ADACAS, 2013; Wallace, 2012; Bigby et al, 2017). Three have employed facilitators who had varied roles including delivery of training and providing support in New South Wales and WA and providing support within services where the person was a client (Community Matter, 2015)³⁷.

³⁵ Fulton, K. & Pearman, L (n.d.) Supported Decision-Making, WAIS. Available at <http://waindividualisedservices.org.au/wp-content/uploads/2014/11/Supported-Decision-Making-all-4-Booklets-in-One.pdf>, last accessed 6th Jan 2018: P.34.

³⁶ Ibid, p.7

³⁷Community Matters (2015) *HCSCC Supported Decision Making Program 2014–15: Evaluation Report*, Adelaide, South Australia, Health and Community Services Commissioner's Office.

Almost inevitably the training and practice manuals largely produced by project coordinators also reflected the orientation of each of the projects.

Coordinators roles differed by project given differences in: methods of recruiting persons who required SDM, the focus of support from Agreements or not, and for identifying the sources of decision support. This impacts on the tone, content and volume of training required and the amount of time supporting and mentoring decision makers and those who support them. Link and Learn adopted the *Spectrums of Support*³⁸ five stage approach which applies more readily to naturally existing support networks and this approach is discussed a little later.

2.3 Models and assumptions.

In the introduction above a number of characterising features of two theoretical models of SDM – the formal (legal) and informal (relational) have been characterised and compared with relevant reference to different SDM projects across Australia. Many of these comparisons between Australian projects have been made in the excellent review of SDM evaluations recently published by Bigby et al. (2017)³⁹. Table 1 below seeks to make a comparison at the extremes between the ‘legal’ and ‘relational’ models.

In the following section evaluation findings are presented. The arguments set out above are re-visited more substantively later in Section 4 but in presenting the evaluation results in Sections 3 and 4 to follow, allusions are made to aspects of the foregoing discussion in this section.

³⁸ADACAS (2013) *Spectrums of Support: A report on a project Exploring Supported Decision Making for People with a Disability in the ACT*. Watson, ACT: ADACAS.

³⁹Bigby, C., Douglas, J., Carney, T., Then, S., Wiesel, I & Smith, E. (2017) Delivering decision making support to people with cognitive disability – what has been learned from the pilot programs in Australia from 2010 to 2015? *The Australian Journal of Social Issues*, DOI: 10.1002/ajs4.19

Table 1: Comparing legal and relational models of SDM against a number of criteria

Criterion	Legal	Relational	Comments
Who has access?	Criteria employed with a 'most in need' of SDM approach.	Criteria less rigid – assumes all need SDM in different ways at different times.	The legal approach is more targeted but likely to ignore the needs of a broader population and vice versa
Who is chosen to be a supporter?	One person who is a volunteer or friend/family member. May also include a paid role. Matching required for those not known to each other.	Most likely to be situated in a family/friendship group where possible and extended where necessary. Matching less likely to take place.	Legal model introduces one-to-one relations, may require matching, recognises new authority in relationships and alters balance of power. The relational model does not confer power. Decision supporter may not be as motivated and may not gain recognition of their role from others.
What training?	SDM training and also training on 'limitations to the decision support role' and 'authority'.	SDM training emphasising how to establish voice, power for the person and avoiding conflicts of interest	Legal approach: additional training only some may understand. Relational: Focus on relationship and SDM may eschew formal legal processes and possibilities.
Targeted upon what?	Utility in key decisions with legal implications. Instrumental in orientation.	Targets decisions in the person's everyday life and not just specified legal decisions.	Legal: resolves key rights through legal process (Article 12 CRPD) but may miss decisions that are otherwise important to the person (Article 19 of CRPD) – and vice versa.
Nature of relationship	One-to-one	Potentially encompasses a circle of support	Legal: One-to-one approach introduces another tier of paternalism and authority. May miss important relationships to decisions. Transactional – could maintain conflicts of interest, may not be the best group to support the person to make decisions.
Formality	More likely to involve Agreements and monitoring arrangements.	Less likely to involve Agreements and monitoring.	Legal: offers protection over decisions by the person but means more intervention in their lives. Relational: maintains everyday relations, offers no protection for wrongful advice and may maintain conflicts of interest.

Section 3: Evaluation of the Training and Awareness-raising sessions and professional development

3.1 Background:

It was argued earlier that the aims set out in the Link and Learn funding agreement were aspirational expecting more than other SDM projects with the same staff complement.

However, it was also argued that the model design represented a significant departure from previous models. It was suggested that the Link and Learn model sought to bed in a '*culture of SDM*' amongst stakeholders. To do so the project was required to⁴⁰:

- Undertake 25 activities to raise awareness of SDM in ACT
- Undertake a minimum of 20 activities that developed supported decision-making skills in people with disability and their communities.
- Build supported decision-making skills and deliver 25 training sessions for professionals who interact with people with disability
- Establish a community of practice – an on-line community of practice.

It will be shown below that there have been major transformations as a result of the Link and Learn project work. It will be suggested that:

- the outcomes were positive;
- there were good reasons why the community of practice was difficult to operationalise and that an emergent model over the project period has led to an alternative approach for future operationalisation.
- the networking across awareness-raising, training and skills development were positive, but had other impacts by:
 - potentially addressing the interface between legal and relational models;
 - starting a clarification of how to create space for best practices around both SDM and Guardianship;
 - finding a mechanism for more systematic identification of those needing SDM;
 - linking the NDIS and health and other service systems to SDM, at least theoretically.
- There is merit in considering the efficacy of the emergent Link and Learn model but research is necessary to explore its ongoing success.

⁴⁰ The area relating to establishing and mentoring supported decision-making relationships is considered in the section to follow.

Finally the evaluation identified two periods in the operation of Link and Learn. In the early days significant efforts were made to meet the agreed project objectives. Towards the end of 2016, although significant progress had been made there were some key problems emerging with the assumed model. As reported earlier in relation to other projects, Link and Learn had major issues, despite huge effort, in recruiting volunteer decision supporters in the early period. For the Link and Learn or any subsequent project to be a success some alternative approach was required. In the later project period from the start of 2017 a new model began to emerge around SDM as reported shortly.

Further, Link and Learn was also becoming aware of the very positive ways in which their networking through awareness raising, skills development and training were beginning to create a new niche and operating system in the ACT. This positioning began to clarify their niche and where they sat in relation to Guardianship and to services seeking to implement SDM.

The new model subsequently developed in the main between December 2016 and around May 2017 continued to be refined up to the end of the project operating period. There was therefore an interregnum of some months which impacted recruitment and support relationship building, as well as producing ethical issues about how to transfer support for decision-makers after the project's funding period ended. The project coordinator also moved on to a new role in October 2017 with just months to run until the project end.

In short the new model seemed to have efficacy but could not be fully tested within the project period. More is said of this later. However in what is reported below reference will be made to the *early project period* and *later project period* as necessary.

3.2 Link and Learn Outputs.

Link and Learn met its targets in 3 of the 4 areas relating to training, awareness raising, professional development.

Key Point 9: Link and Learn states that it delivered: awareness-raising to 300 people (a target of 25 activities was met); it delivered more than 20 workshops to develop SDM skills (a target of 20 activities was met); delivered over 30 professional development sessions (target 25 training session met).

However, as will be argued shortly, it is not so much the activities and sessions that are important but, rather, their knock-on effects and the extent to which they began to establish a 'culture of SDM' amongst stakeholders in the ACT.

3.3 The Community of Practice.

During the project period a community of practice was not set up as envisaged. In the early project period there was a high demand for Link and Learn as it met its various aims. The project was finding significant time taken up with awareness-raising and training out of which there were significant enquiries about providing 'support relationship building' and for further information and resources. At that point the coordinator felt that demand for the project was already very high and that it would be counterproductive to advertise more broadly and have a web presence if they were unable to meet the resultant demands on the project staff.

In the later period of the project there was a view that a web based presence may not be sufficient to bed in and support SDM:

'People are very generous and very impassioned after the training but envisioning and doing it is something else...The Facebook group was supposed to do it. At this point no-one's really keen. They're not putting their hands up at training to say this is what they use. The other problem is that it requires time and digital connectedness and many of the people we're working with don't have access. What we need to use is much more direct' (Link and Learn Coordinator Interview).

Amongst many suggestions raised about being more direct if the project continues after its pilot period are SDM Shopfronts which would be strategically placed in hospitals, ACAT and other community services to deliver information, resources and support⁴¹. The Link and Learn staff in conversation during a visit made by the evaluator in June 2017 also noted:

'We've always struggled with that workshop model. How do you get SDM relationships out of that? If we're talking about embedding SDM what we've decided is that...we're going to run, for want of a better word, some helpdesk - clinics to support with a decision, or a question, and get advice about a specific topic. If they've done the training they know something about it and where to come and get more information...we have made an effort to contact all those people who did come and left details...we are embedding at a couple of different levels if we have

⁴¹ It should be noted that this idea came from a collaboration with someone who knew the work of ADACAS, had seen the possibilities in relation to Advanced Care Planning and had teamed up on some joint work.

contact with decision-makers – we are making ourselves more available to support people who need support with decision-making and letting people know of the opportunity' (Link and Learn staff interview).

Other suggestions during the project period were to recruit Ambassadors who would link people up with the project and for both decision-makers and supporters to have 'walking groups' (or other informal support groups) where decision makers or decision supporters could exchange ideas and take back questions to Link and Learn if necessary (for a formal response).

Key point 10 – There were good reasons for not implementing the web-based Community of Practice as originally conceived. By the end of the project period Link and Learn were talking primarily about an active space they termed SDM Shopfronts able to provide information, access resources, how to fill gaps in their SDM networks; get one-off support for a decision or access further support if necessary. By being strategically placed and regularly attended such Shopfronts were seen as more active and responsive.

3.4 Awareness-raising.

The awareness raising sessions were delivered to a wide range of groups and varied in length from 30 minutes to 2 hours. The sessions covered key areas relating to identifying what SDM is and how SDM relates to human rights and choice and control. The principles of SDM as they relate to decision makers and supporters were then covered. Link and Learn were very careful to design further elements into the sessions that reflected the interest and focus of each group. For example the Mental Health Act and recovery featured more prominently in relation to mental health whereas the NDIS and choice for people with disability (and those with psycho-social issues not least given their concerns about access around the 'significant and enduring' criterion).

As part of the evaluation those attending awareness raising sessions were asked to complete a questionnaire in relation to the session. Data were collected from 118 participants⁴² across fourteen organisations covering mental health providers, consumer

⁴² A further 12 questionnaires were rejected because of missing data and being filled out improperly across rather than within categories. I received some collated feedback sheets from some organisations but these were not included in the present data analysis.

networks, corrections programs, disability service providers, financial planners, community services, youth services and aged care services. The results are laid out in Appendix 2.

Some of the key findings from this data in relation to supported decision making are:

- 83% (n=112) felt that 'all the main questions...about supported decision-making have been answered' (q.1)
- 97.3% (n=116) think that 'supported decision-making is necessary' (q.16)
- 79.3% (n=109) 'understand better what a support group is and how it works' (q.3)
- 87.3% (n=102) saying they would 'seek to make a better and stronger support group for the person' (q.4) as a result of the session and 93.8% (n=113) who agreed they 'understand their role in supporting a person to make decisions better than before' (q.8).

In relation to the potential outcome for the person:

- 84% (n=112) agreed the person's life for whom decision support is provided would improve as a result of the new information (q.11) and 78.5% (n=107) agreed the person will grow as a result of what has been learned (q.14)

In relation to the boundary between SDM and other decision, choice and advocacy services:

- 60% (n=105) agreed that advocacy support is still required despite the implementation of SDM (q.17);
- 68.4% (n=114) think differently about Guardianship decision-making after the information from the session (q.13)
- 78.4% (n=111) felt better informed about the formal service roles in choice making (q.12)

Importantly 87.6% (n=113) felt more confident in supporting a person to make their own decisions. Whilst this represents an immediate reaction to the session it nevertheless highlights the extent to which the sessions had delivered something new, a model perhaps, about how to provide support at varying levels of decision-making based on a set series of stated principles.

Fewer participants (57.5%, n=113) knew of resources other than those covered in the session that were 'available to support a person in their decision making indicating the importance of the role of Link and Learn. It is likely they would soon become seen as the 'go to' place for SDM given this finding.

Key Point 21: The results of the questionnaires to awareness raising participants indicated strong support for SDM and for the Link and Learn 5 stage model. The outcomes likely to follow on from the training for decision makers was considered positive and the majority also felt more confident in their SDM roles. Less clarity, though still a majority, expressed concerns about how SDM linked with other services, with advocacy organisations and with Guardianship.

Whilst these results are very positive it remains unclear the extent to which that knowledge knocks on to practice and what outcomes it will have delivered independent of Link and Learn. More research would have been required to explore these dimensions of the Link and Learn's impact and if the project is extended it is a vital area to research and evaluate. It would measure the extent to which an awareness raising model produces long term and sustainable change in the everyday delivery of supported decision-making and the extent to which the approach is capable of contributing to achieving 'a culture of SDM in ACT'.

However, as noted by the coordinator the project staff also recognised that 'envisioning and doing' are different things and the doing SDM often requires additional support. The model developed later in the project began, therefore, to think about active ways of providing such support on a longer term basis.

Key Point 22: The awareness-raising will have had a knock-on effect in terms of the delivery of SDM by those attending. This is important to understanding how well Link and Learn was establishing a culture of SDM more widely. The sustainability of change through awareness raising is also an important issue. More research would be required to explore the extent to which SDM was implemented based on awareness raising.

3.5 Training and skills development

Training took two forms. There were over twenty skills development sessions and, additionally, more than 30 professional development sessions. In the former the focus was on decision making and its principles. In the latter professional development focused upon setting out legislative changes such as the ACT Mental Health Act 2016, Guardianship and Management of Property as well as professional roles and responsibilities as they related to SDM. It was envisaged that each group would take away sufficient information to be able to advocate for the SDM model amongst colleagues and clients.

In terms of the skills development there was a slow take up of sessions early on. Both family carer organisations and organisations of people with disability were reticent to participate. Indeed there was some gate-keeping by organisations where Link and Learn sought to engage with residents' councils and other groups of people with disabilities.

Key Point 23: There was reticence by some carers groups and some gate-keeping around people with disabilities which served to slow the delivery of skills development sessions.

Once take up started it was soon found that in most cases one training session was simply not sufficient to meet the needs of the groups to whom they presented. Moreover to create bespoke sessions that met the specific needs of each group meant additional adaptation of the resources. This was the case for professional groups in particular. In many cases after session 1 some of the key issues for the groups became clear and this led to further adaptation of training resources for a second session.

Key point 24: Link and Learn resources needed to be adapted for each group who received professional development. This took time although once the range of resources has been fully developed it may only take time in updating the relevant material where necessary.

The professional development sessions developed somewhat differently given recent implementation of the ACT Mental Health Act in March 2016 which raised a flurry of enquiries given the focus of the Act on decision-making and choice. Professional development sessions were therefore run in both disability and mental health arenas. Indeed some community legal centres were also eager to access the Link and Learn training. Later on sessions were run for Guardians and Trustees, ACAT, the Law Society, disability support organisations, clinicians, and other community support and educational providers.

Some Link and Learn enquiries for professional development came from organisations in the sector whose clients had a particular issue that needed to be addressed. For example, one organisation made an enquiry because of the closure of a rehabilitation facility and another came from an organisation whose block funding was likely to be withdrawn. Another person wanted a review of their medication. Each situation was likely to raise key and critical issues for the persons involved but were more advocacy than SDM focused. Some people seem to view SDM as a solution rather than a 'way of life' or a 'way of doing things' with a focus on supporting the person to make a decision, rather than advocating for them once a decision has been made.

Key Point 25: Referrals were often focused on advocacy and not SDM. Attention needs to be given to the difference between the need for advocacy and the need for supported decision-making. The close link between the two indicates a need for SDM to be able to pass on advocacy requests. That Link and Learn was based within ADACAS would make such an approach efficient.

There were additional problems with organising training. Some organisations simply could not fund the backfill for staff attending training and this led to late withdrawals and smaller groups than anticipated. Link and Learn considered running training sessions across organisations because they found that any fewer than 8 participants led to less interactive sessions. Moreover, given the adaptation of sessions to reflect each organisation specifically this could be lost in mixed groups. They also found making links with the NDIA for LAC training was very difficult given NDIA staff turnover and staff workload.

Key Point 26: There were a number of reasons for lack of attendance or cancellation of Training. It is significant that many organisations in the sector are finding it increasingly difficult to back-fill for staff attending training.

3.5.1 Observations from the skills development and professional development sessions.

As part of the evaluation observations of two professional development workshops and one skills development workshop were undertaken. More detailed interviews were also undertaken with 8 participants to these sessions exploring in more detail not just the training but its relevance and knock-on effects.

In all of these Link and Learn staff had produced resources specific for the day. For the professional development sessions powerpoint presentations were used and venues offering suitable technology were sourced and handouts provided to participants. These sessions were in conference style delivery with Link and Learn presenters up front. For the work with people with disabilities in the skills development session handouts were used and a circle of chairs and table were used as a means of supporting discussion.

The following are key observations from the skills development session with people with disabilities. This was the second session being run for this group.

The handouts used had a strong emphasis on the use of easy words and images and the Link and Learn facilitator worked through the handout page by page. In the session it was

observed that participants were helping each other to use the resource as each point was being made. Cleverly, each part of the session gave participants a choice between two images and participants used a tick to choose between options once a discussion of the issues had taken place.

Key Point 26: In working with people with disability to develop skills the easy English handouts, questions requiring a choice between two options, an interactive rather than didactic approach and peer support amongst the group worked well to include all and maximise the message being delivered.

In opening the session the Link and Learn facilitator asked whether anyone had made a decision since the last training session. One person related the following story:

'I got another job and I checked it out. My heart says it's not really for me. I talked to my family and friends and then made my decision. I went out and celebrated my decision.'

The story demonstrated how people can come to decisions and how they often rely on others to help them to decide. In the following discussion everyone at the session agreed it was easier to make a decision when somebody else helps. But many also felt they could make some decisions on their own.

Some participants in the session were more engaged than others and more able to follow the discussion. However, the group felt dynamic, alive and participatory. At the end most participants said when invited, that they would attend another session. One person ventured at this point that,

'All this stuff with advocates is helping me. It's making me feel mature and that'.

Key Point 27: The Link and Learn engagement with people with disabilities was lively and positive and had prompted some people to actually explore their own decisions and seek advice around what was important to them. This means there were, like the awareness raising sessions, knock-on outcomes from the Link and Learn input. The session seemed to be well received by all who attended.

An interview was undertaken with a member of staff at this organisation to explore more about her own views relating to SDM and the Link and Learn pilot in particular. The interviewee felt that the SDM input had

'...opened up my mind on what it was like not to be able to do your own thing and what will happen if you don't have a voice to say you don't like it. I also realised that

whatever a person does, it has a relationship to their past. You do things in a certain way because of experience, so you need to know why the person is doing it that way'.

The interviewee felt that in their organisation it was often very busy and it was easy to get carried away and forget to pay attention to supporting people's decision-making. The number of new people using the service and new staff also meant that there was a need to continually update the training.

'I think it would be good to have it [training] every six months or so because there are new people coming in all the time. That would be good'.

When asked about Guardianship the interviewee said most Guardians listened to the person. However, in some cases Guardians had made decisions that were not ones the person would choose but the person went along with them anyway. The interviewee thought SDM overlapped with Guardianship.

Key point 27: Even after SDM training some workers found it difficult to distinguish between SDM and Guardianship and felt the roles overlapped. More clarity is needed on how these differ. Moreover the discussion highlighted that there remain Guardians (and others too) who themselves need SDM training and more knowledge around will and preference over best interest.

The interviewee also felt that SDM had to some extent confirmed the organisation's approach to decision-making but that they needed to be vigilant at all times around the way they worked with clients:

'I found Link and Learn very good. I really like it and it was refreshing to know about the things we do every day and we tend to take it for granted how to make decisions for others. It also changed how I ask questions and how I do my work at [organisation name]' (Disability Support Worker, Interview)

Key Point 28: SDM training helped participants to see the phases of decision making. The intention must be that SDM becomes a social and embodied practice, a way of life, a dominant cultural theme across services, people with disabilities, family carers and others. This bedding in of an SDM culture may be vital in maximising the success of the NDIS and ensuring choice and control. This may mean regular training or some mechanism that requires compliance around SDM.

Observations were also carried out at two professional development sessions.

In both sessions discussion about the boundaries between Guardianship, EPAs and SDM roles took place. In particular identifying the rights of each party involved in decision making (including family carers) was central to much of this discussion. The power of particular decision-makers was also raised.

In the sessions for mental health workers, the medical profession were identified to be 'presumptuous' in some cases and to make decisions without consultation, participation, information or discussion in others. It was felt that the new Mental Health Act meant medical practitioners decisions would be more open to challenge. The question remained how to establish an 'equality of arms'⁴³ (between medics who assumed decision-making power on best interests and the rights to maximise will and preference through supporting decisions).

Key Point 29: The ACT Mental Health Act is an important resource and allows the person's independent and supported decisions to be seen to confer 'procedural fairness' to decision-making processes. It is an important mechanism for achieving change in decision-making practice. However, there remains deep seated presumptions amongst some medical practitioners about their right to decide and impose their decision. Training may make a difference but it may not be sufficient. However, as reported in the introduction, one of the limitations is that without legislation decision-makers have little chance of establishing equality of arms in such circumstances, even with decision support. This is a key problematic for the future.

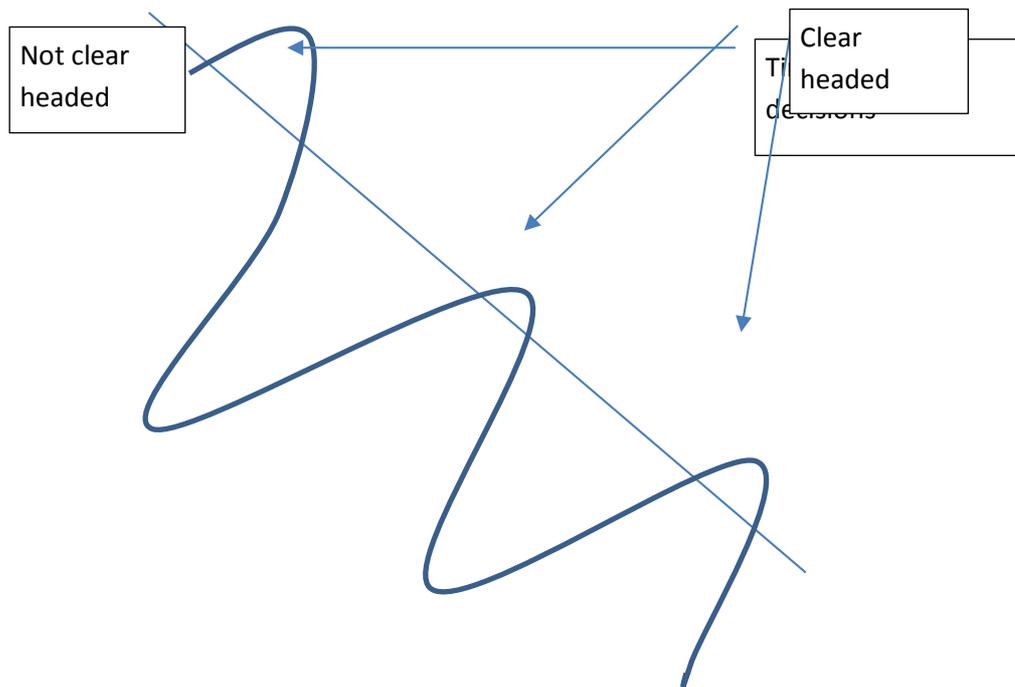
Once again the worth of the Link and Learn training in changing practice was visible in observations of the professional development session for mental health workers. The following story was related by a participant:

I had a client not happy with the anti-psychotics...this person has anxiety and severe depression. As someone trying to support him I don't have all the information and I don't even know him well enough and I certainly don't know why he's on anti-psychotics. That very day after the [last SDM] workshop I began spending more time listening... because we may not have had a space to hear in the right way. Six of the seven elements of the [Mental Health] Act had a cross next to them'.

⁴³ Clarke, S. and Finnegan, P. (2005) *One Law for All? The impact of the Human Rights Act of people with learning difficulties*. London: Values into Action.

An important model for mental health decision-making was then presented by the Link and Learn facilitators. This recognised that many people were most clear-headed only at certain times. A person is also likely to be stressed in any formal setting. There are key times when people's clarity allows for discussion about decisions as shown in Diagram 1 below:

Diagram 1 Showing how decision-making takes place best when a person is clear-headed



The example highlighted that SDM takes time and this was a major theme in all discussions. On the other hand the question was where this time could be most efficiently expended in pursuit of the person's aims. More is said about this in the discussion later.

Key Point 30: SDM takes time. It takes time to work with a person and it may take significant time to build decision support into people's lives. Questions arise as to where and by whom that time is expended. An 'SDM culture' operating across services and amongst family carers would mean that it becomes a necessary part of everyday culture surrounding decision-making. This would imply that alongside 'most difficult cases' supported by an SDM project, that much SDM will take place as a result of ongoing training in SDM to various stakeholders who go on to operating as decision supporters. A culture of SDM requires people who are trained and mobilised to implement SDM.

In the discussions about the roles taken in SDM, participants in the training also related that Guardians were often not responsive to requests and to discussion. For some there was over reach in terms of decisions not covered by the Order or not much evidence of consulting with the person subject to the Order or with others. As one participant said,

'We can always support people to improve their decision-making and not subject them to the decision of others. Guardianship does not allow this. It all unravels when a person [Guardian] says, "That's not your decision. Your decision is ...' (Training Day participant, Interview).

As will be discussed later the concept of 'equality of arms' is important to finding a resolution between Guardianship and SDM.

In an interview with a person who had taken part in a previous professional development session, the following story was told:

'The client who has the decision supporter is a lot happier with having a decision supporter. They have always come to appointments with me together. I have always been able to speak to the client directly and the decision-supporter has only interacted with me when they think something is not clear or when the client has turned to the decision supporter and said, should I do this or that and the decision supporter has said it's up to you mate... The person with a Guardian... is very unhappy with the Guardian ...I have written to the Guardian and not had a response...It just strikes me that if a person can have a decision supporter it appears to be a much easier relationship and...much easier to work with... There is a space emerging in which supported decision making is taking place...The way the legal system operates, they have always gone to Guardianship and financial management up to now'.

In the quote above it can be seen that some lines are being redrawn about whose responsibility this person sees as being relevant and appropriate in certain situations. SDM is opening up an important space which if seen as everyday practice will become an accepted culture. Once again the systems of accountability for Guardians and the boundaries with other forms of decision-making are raised as important issues as mentioned before.

Key Point 31: A key problematic for SDM is that if informality is a necessary part of SDM then how and when can the decision-making process be heard and recognised as anything more than hearsay? The discussion about Guardianship, about medics and family carers as well as those seeking to implement SDM pointed to the struggle with roles and clarity. More importantly it spoke about the relative power of different stakeholders in the relationship with the

person requiring decision support. More role clarity and more on flattening hierarchies of power would be useful.

An interview with one person who had previously attended a Link and Learn professional development session helped to further disentangle some of these issues. They describe learning that everybody, all of us, need support with our decisions. Some require more support. So for example if a legal team is to receive instructions to act for a person it may take some time exploring what the person wants to achieve, exploring the options and potential outcomes with them. This means they would achieve procedural and substantive fairness in pursuing their case. More will be said of formalising such a process later.

Key Point 32: Most work in decision support does not require the decision maker to be a 'legal entity'. Most takes place in the cut and thrust of everyday lives where everyday decisions can produce positive impacts without resort to the law. This represents an approach which protects and promotes their human rights. However, where a person is taking a decision in which they have to defend their human rights and to do so requires legal status then some formal acknowledgement of the decision-making process would ensure that their will and preference is taken into account.

Case examples were provided in the training sessions which showed how much time the SDM process might take, the time taken for discussion, the plain language material developed to help in the process, the time in reassurance and continued contact. In one case about eligibility for the NDIS the interviewee relates:

'Link and Learn helped me to interact with him in the right way...He said he really appreciated me taking the trouble to go through it'

Although the person did not access NDIS as a result of the work undertaken by this person, the SDM work had done a number of things: It had prevented a waste of NDIA time in pursuing a complaint or an appeal; it had prevented decisions being made which would later cost to be undone; it had prevented more anxiety over a longer period which may have cost in terms of the person's health and for health and/or medical interventions. This was one from a series of case studies heard over the course of data collection which made an essential point about the benefits of SDM.

Key Point 33: SDM may itself cost, but may also save costs downstream because: it means that inappropriate services and decisions do not need to be rescinded; it means there is no need to duplicate decisions; it means the person is more

likely to be satisfied and to experience better life outcomes as a result.

Similarly for service workers to give more time now using an SDM approach with clients, more time needs to be costed and funded if it is to take place. Further, as one interviewee from a legal centre argued in pursuing legal rights, legal services (private firms in particular) would have to reduce the number of cases seen if SDM is used and given their *pro bono* funding envelope. And where more specialist input is required from Link and Learn, funds would need to be set aside for this work also.

SDM does not just protect and defend rights. It also has the potential to save funds. Key decisions need to be made about the funding contribution to SDM on the dual basis of protecting, defending and ensuring rights on the one hand and producing downstream cost-savings on the other. In the later discussion this is examined in relation to whether NDIS funding could be targeted at SDM as a cost saving approach.

In one of the sessions in which observations took place the manager present felt it was vital to extend SDM training and to build it into everything staff did. This manager was going to trial placing Link and Learn's five key stages of decision support next to the phone of each member of staff. The importance of SDM proponents implementing the model within practice is important. Were there to be a more systematic way to do this it could pay significant dividends. As argued earlier, the outcomes of the Link and Learn project are unique insofar as they achieved some cultural change which supported the wider adoption and use of the SDM model. Bedding it in even further may be helpful.

Key Point 34: It may be useful to consider whether SDM should at some point in the future be a part of VE Cert III Community Services and Cert IV Disability alongside advocacy to reflect the choice and control dimensions of the NDIS and to ensure all staff are versed in SDM as required practice.

3.5.2 *Results of the Training questionnaire.*

As part of the evaluation a questionnaire (Appendix 3) was also distributed to participants. In all 73 questionnaires were returned from 12 organisations.

The following are the key findings from training participants.

The training was considered to be high quality⁴⁴ (q.4 high quality - 95.4%, n=65) with content that was 'fit for purpose' (q.2 content acceptable and understandable - 87.5%, n=64; q.3. And appropriate for needs – 89%, n=73) and would recommend it to others (q.31 – 92.8%, n=69). However a smaller percentage 67.5%, n=68 (q.15) rated the course as not being too idealistic, indicating perhaps some reservations about SDM in practice. Over ninety five per cent (n=67) felt SDM to be an essential service (q.29) and felt positive about the idea of supported decision making (n=66) (q.28).

Key Point 35: Participants in training considered it to be highquality, fit for purpose leading people to see the importance of SDM and garnering their support for it. A significant group of participants found the course content idealistic.

Results on the knowledge gain around roles were high though in relation to application and resultant relationships the results were slightly less positive. For example 86.5%, n=67 (q.9) felt they knew more about 'getting people together to support decision-making' and 89.3%, (n=64) (q.16) felt they understood their 'role in supporting the person to make their own decisions' and understanding the role of decision-makers 92.3%, n=65 (q.13). It was also considered that the outcomes for the decision maker would improve with 76.2%, n=63 (q.27) feeling the decision maker would grow as a result of the training and 'would maximise the extent to which the person makes decisions and choices for themselves (79.6%, n=64 q. 26).

In relation to application and the resultant relationships around SDM a consistently mid-sized group of about a quarter of respondents remained neutral. So, whilst 71.2% (q.11) said they would 'make changes to make a better and stronger support group for the person', 23.7% remained neutral. 'Relationships with other support group members' were felt likely to improve as a result of the training, but with 22.4% of respondents remaining neutral in this regard.

The result seem to affirm a reticence about how the implementation of the training would work in practice and reaffirms the earlier finding that some felt the course to be too 'idealistic'.

Key Point 36: Large proportions of participants in training felt they had gained knowledge about their role in SDM. However, when asked about the application and resultant

⁴⁴ Unless otherwise stated all percentages reported are a combination of those who 'strongly agree' and 'agree' with the statements in a five point likert scale running from 'strongly agree' to 'strongly disagree'.

relationships when implemented there was a mid-sized group who were unsure how it would work in practice.

The role of other groups in relation to SDM also seems to have been clarified for the majority. Many felt they understood the role of formal services in SDM (q.20, 77.6%) and the role of Guardians (q.22, 77.6%, n=64) and the continuing need for advocacy (q.30, 69.3%, n=62). However, there were divergent views about whether the training would stop 'the person from looking for more formal solutions such as Guardianship in relation to major decisions and choices for this person'. Only 6.5% strongly agreed with this statement, 32.3% agreed, 35.5% were neutral, 17.7% disagreed and 8.1% disagreed strongly.

Key Point 37: There remain questions about the role of Guardians in decision making. These questions are both theoretical and practical. This interface between the two remains a significant issue.

3.6 Some Further Key Points

A further theme to arise from the interviews was around Guardianship and a further interview with person who collaborated with Link and Learn on Advanced Health Care Planning. The data collected in these areas proved most enlightening and central to some of the arguments made later in the discussion section of this report.

3.6.1 *The relations between SDM and Guardianship*

Link and Learn has done some sessions with Guardians at EPA sessions and there is a feeling that both are necessary in different circumstances. As one interview put it

'It doesn't matter if we change legislation or not, if we don't change the people accepting their consent. The legislation if not going to change the culture...So we do have discussion around joint training in hospitals, social workers in the hospital, doctors in the hospitals, other agencies where consent is actually being received' (Training participant interviewee).

Several examples in this report point to the difficulties with those who assume power to make best interest decision without taking into account the person's will and preference. Building a culture of SDM is therefore very important.

In relation to Guardianship it was reported that since the introduction of the NDIS more people are being referred for Guardianship when they might be able to make their own decisions. Such issues related to areas such as behavior or house rules for example.

Indeed some of the NDIA service or support Agreements are complex enough to prompt some to refer these decisions to Guardians. This is ironic in that the NDIS is expressly concerned with choice and control. However, there would seem to be a space emerging in which SDM may play a role in some cases in some cases.

Key Point 38: The NDIS is producing more enquiries from people who want to be able to make decision for themselves. These decisions may not meet the criteria for Guardianship, but may do for SDM in some circumstances.

There is a question then about whether the extent to which SDM prevents Guardianship is the right question. The increase in requests to both SDMs and Guardians may be more to do with the policy and service context rather than anything else. This raises the issue about the boundary between the two and how this is managed. One interviewee who had been in SDM training and knew something about Guardianship suggested that:

'Having people around them they trust to do that rather than having a government organisation doing on their behalf when it's quite sterile. Guardians are not family, not friends – Guardians may meet with them once every six months so they may not even feel comfortable even discussing exactly what they do want and may in certain circumstances feel quite intimidated by them' (Training participant interviewee).

Some people have suggested that Tribunals could also consider whether they offer up the possibility of SDM, adjourning a case so that this work around will and preference can be done. As discussed in the next sub-section there may be a way to do this more systematically which would align SDM, Guardianship, the NDIS with its focus on choice and Control, whilst maximizing the chances people will have their human rights met.

There are several ways in which space is being created for SDM to operate to maximize choice and control. Some of the mechanisms, particularly in relation to the NDIS are set out in Section 5 of this report. As one interviewee put it:

'I think it [Link and Learn] is a vital project. We're not there yet in relation to SDM, and with the NDIS Guardians are not there yet either. The NDIS is changing face daily...there's a lot of people who don't feel equipped to go and liaise with the planners and people who are nervous about that anyway; there's a lot of people who aren't turning up to their planning meetings which affects NDIA's ability to communicate with them and make the plans appropriate so the more we can empower people to feel they can have a say in their own lives, the more we can achieve that choice and control'; (Training participant interview).

In the following sub-section consideration is given to how to potentially bridge the gap between SDM and more formal legal forms of decision making.

3.7 A Statement of Will and Preference.

One interviewee had collaborated with Link and Learn on the development of a small workbook call an Advanced Health Care Plan. This was not a legal document but a guiding document. This was plain language and designed for use by people with intellectual disabilities in hospital, though useable by others too. The interviewee explained that many people with intellectual disability were assumed not to have capacity when it came to health care decisions and an assumption was sometimes made that an Enduring Power of Attorney (EPA) would be used in such circumstances.

However, in the ACT there are three important documents in a health care choice: The EPA (alegal document); a Statement of Will and Preference (a Guiding document); and a Health Direction under the Medical treatment Act (another legal document). As the interviewee goes on to explain:

'It was most important to us that if someone is choosing to ignore someone's wishes they would have to explain why if someone has done the workbook which follows a supported decision making model: of being able to take time over the decision, document how the decisions were made, It's a bit like the maths teacher who says, I don't care if you get the wrong answer, I just want to see the working' – so any medicos who ignore it must answer why they chose to ignore it when they've seen the workings and can see that the decision was made with or without support and it is the decision of that person. So its actually the principle of 'showing the workings'. Also we have written in a couple of place what a good life looks like – it is about value statements and what's important in your life. So in amongst this stuff which is 'Please don't judge my good life by your good life' (Interview, Link and Learn collaborator).

In relation to the discussion around Guardianship a similar document as a Statement of Will and Preference might be a way of bridging the gap between SDM and Guardianship or between the relational and legal models of SDM outlined in the introduction to this report. Such a document would:

- Allow relational advocacy to take the primary role until such time as any legal decision has to be made
- It would ensure that when legal decisions by Guardians, Trustees or medical staff are made that the person's voice is heard

- The document would contribute an 'equality of arms' by empowering the person's voice. It would ensure there was a good reason to ask why a decision on best interest had been made despite the person's will and preference.

In short a Statement of Will and Preference could be a tool which manages the boundaries between the legal and relational forms of decision making. This is discussed more later in the discussion section of this report.

Section 4. Decision Support Relationship Building

4.1 Background

Link and Learn had the benefit of the *Spectrums of Support* (2013)⁴⁵ work previously undertaken by ADACAS in relation to the five stages of supported decision-making. In that report they identified a five stage process in decision support:

- Raising awareness – developing understanding of the right to self-determination and roles of wider networks of support through use of a series of principles⁴⁶ for decision support created in plain English
- Becoming Decision ready – involving, where necessary, coaching from a monitor to the decision-maker and supporters to: articulate a decision; improve key ideas about what is involved and what supports might be needed and consideration of the role of the decision supporter
- Decision Support – making sure the support frameworks were in place and appropriate to the decision and that trust was built and conflicts of interest identified.
- Being a decision maker and learning to support decisions – the person may act towards a decision, with only as much support from the decision supporter as necessary. This stage might involve a supported decision making agreement about these rights, roles, values and behaviours of each of the parties.
- Fulfilling a decision – Decision maker and supporter fulfill the decision working to an agreement where necessary with ongoing support from the monitor.

Using this model, grounded in the everyday relationships and contexts of the decision-maker ADACAS was able to offer proof of concept for the model in their *Spectrums of Support* work.

The same five stage model featured across the project work of Link and Learn acting as an established framework for the project.

The original intention of this evaluation was to have explored these ideas through interview but, also to explore in more detail what formal outcomes were produced. This reflected the program logic originally agreed for the evaluation work (Appendix 5). From the perspectives of decision makers and decision supporters the outcomes were proposed to relate to: everyday, lifestyle and pervasive (major) decisions; resources, social

⁴⁵ ADACAS (2013) *Spectrums of Support: A report on a project Exploring Supported Decision Making for People with a Disability in the ACT*. Watson, ACT: ADACAS.

⁴⁶Principles, in summary, included: Understanding that decision making is a learned skill, recognition of each person's right to decide, respect for values, goals and experiences of the decision maker and that the decision belongs to them, understanding that the decision supporters relationship with the decision maker, matters and that vested interests should not feature; the relationship between decision maker and supported must be built on trust.

capital, psycho-social well-being and personal growth. A tranche of questionnaires outlining these outcomes were produced. However there were a number of problems with these resources:

First the speed and numbers recruited by Link and Learn were initially very small meaning that any comparison across the group would not have statistical merit. Second it would have been very difficult to explore changes over time for each of the groups because causation between SDM and the outcomes could not easily be proven even where change was found. Indeed because the range of questions covered so many life areas there was a danger that the focus on each of the decisions and their impact would be lost. Gauged against the multitude of outcomes in the tools this may have placed the changes produced by SDM in a more negative light than concentrating on the specific narratives which described the decision support itself.

Third the experience of trying to use these tools in early interviews proved difficult. Decision supporters struggled to see the relevance of all the questions and decision-makers in particular showed signs that the number and range of questions were more than just an inconvenience. Both groups were better at exploring their experiences through their stories. Because of this a more narrative interview style was adopted in which the elements of the relevant outcome produced were tied back to the measures in the outcome tools during the interviews as necessary. Further, a human rights approach to interpretation of the data allowed a consideration of transcripts in terms of what human rights were protected, defended and ensured by the SDM input, as reported shortly.

4.2 Building support relationship building over the project period.

In all the Link and Learn project reports mentoring 50 individuals in a range of decision-making domains with varying intensity (from 2 hours to 80 hours). The Link and Learn support relationship building can be thought of as taking place in two main periods of activity and a middle period of reconceptualisation. As previously noted, much of the early period of the project focused upon the awareness raising, training and skills development, as reported earlier. In this early period support relationship building found the recruitment decision supporters slower than anticipated. Like other SDM projects this represents a major weakness in models which rely on volunteer decision supporter recruitment. This takes significant time, resources and ongoing support.

Key Point 39: The assumption that volunteers can be easily recruited and that this can be scaled up the larger SDM projects may be problematic. Many projects have struggled with this. The question is whether there is a solution that can work and provide social justice across the disability sector, as opposed to the few for whom volunteers can be recruited.

So whilst the awareness raising and training had led to significant 'referrals' it was difficult to attend to all of these through support relationship building. It should be noted, however, that significant number of people had attended the awareness raising and training sessions and an unknown number were perhaps employing its principles in practice. There were a considerable number of enquiries from attendees across the project period in which advice around decision support did not require active engagement from Link and Learn. This indicates that the impact of the project was potentially greater than its own direct support relationship building work.

Key Point 40: It should be noted that those who had already undertaken awareness-raising and training and skills development prior to the introduction of the new model had not been trained using the new model.

Towards the back end of 2016 as reported below the project had to address this issue in order to build the number of those receiving support relationship building. Some of their engagements were taking place with established circles of support where, perhaps, the need for SDM was not as pressing as it was for other decision-makers. There was a need to develop a new model and this took place over a period of months. One member of the Link and Learn team left at this point and there was a period of reflection that went on over the holiday period and until a new member of staff was recruited. This period of reflection gave birth to a new model which emerged around May 2017, giving Link and Learn just 7 months to implement and test this model. The Link and Learn staff were very much aware of the need not to do so without having replacement support available for ethical reasons.

4.3 The new model – The Strengths Based Network Activation SDM Model.

It had become apparent to Link and Learn staff that no decision maker was completely isolated and that reflection on the way that most people make decisions made it possible to "map" the supports in the life of an individual.

This meant that it was possible to engage in a conversation about how decisions were made in the past and how an identified current decision under consideration might be supported. Recognising this context of decision making, as had *Spectrums of Support*,

allowed better targeted capacity building and identification of the gaps in support to enable the rights of that individual decision maker.

Moreover, each context pre-exists the SDM input and each is unique. As such the ways in which extant supports are used is very individual and so is the subsequent individual engagement in the process of SDM. By rethinking the role of Link and Learn in this way it was possible to identify 'blocks to participation' can reveal patterns of decision making support that are lacking now or even across a lifetime. These patterns and blocks are the key identifiable focus of the project.

Key point 41: The first part of the new model sought to identify networks and gaps in decision making. In exploring these it is possible to identify patterns and blocks of input for the SDM project.

A participant with psychosocial disability and "socially isolated" may have skills to make decisions but without support at key points is unable to initiate or sustain a broadening network of support. To ensure the decision maker has maximum control over this process a strengths-based approach can be adopted to measure the quantum of 'the support this person requires for this decision,' rather than the person's 'capacity to make decisions'. This can be applied to all areas of life - everyday decisions (day to day decisions about whether to have tea or coffee, what program to watch on TV, whether to go out or stay in etc) , lifestyle decisions (around chosen rituals and how the person represents themselves through dress, decorations and so forth), pervasive decisions (i.e. those which affect their whole life such as housing, who to live with, employment or day services, family life and privacy) and legal decisions.

Approaching the person's strengths in each of these areas permits each decision maker to participate to the extent of their ability in decisions about how to achieve their own good life and allows space for the spectrum of support which goes some way to moving from "idealistic" to practical application.

Key Point 42: The second key element of the model is to build upon the decision maker's strengths and then seek to explore the extent to which their distributed support network can fit in to protect, defend and ensure their everyday, lifestyle, pervasive choices and legal decisions.

Using a network model, where an individual accesses support in the first instance to examine decision making and to identify extant supports, offers opportunity to embed

SDM as a tool so that support needed for future decisions is identified by the individual and those in the network are “activated” as relevant to the decision.

Members of the network need not be named as a “decision supporter” in any formal sense but only by the individual decision maker. It also opens up the decision making process and SDM to those whose lived experience is group decision making or whose socio cultural background is dominated by collective decision making. This also allows for the possibility of a more tailored funding of decision support expertise rather than a blanket application.

Key Point 43: Key individuals who provide support in identified areas by the decision maker can be ‘activated’ in ways that are relevant to the decision being made. So long as these parties are aware of the decision making principles and the person’s right to decide, the role of SDM project staff becomes to activate the right decision support.

The model assumes no decision supporter to be there unless the person’s strengths do not cover a decision area on which they are focused. It does not formalize support unless it is felt additional agreements are necessary or where there is a need for legal or other formal supports. As the Link and Learn project coordinator says in describing the approach:

‘...they are getting support but just not from the very formalized source assumed in the [original] model – they may be isolated in terms of a social contact but that doesn’t mean they don’t have a decision network. It just looks different to how the project was conceived. So what we’ve done is taken the process of the first year and taken into account all the different contexts’.

Key Point 44: It can also be seen in this quote how the new model allows for a wider trained public (support staff, services, families, friends) to be playing a role once trained. It therefore fits hand –in-hand with the ‘building a culture of SDM ’ assumed in the project. Further it allows a conceptions of SDM which needs to get embedded in the modern apparatus of the NDIS, Guardianship, (mental) health services and so forth.

The model further assumes decision support to be distributed in existing networks – that no single decision-supporter necessarily needs separate recruitment and training as a

volunteer as in other models. It assumes that where there is a network support gap, for example in relation to legal issues, that the right person in the network can draw such additional support into the group or gain advice from the SDM team on what to do. It also leaves open the recruitment of volunteers who might fill gaps rather than partner with one person over time.

'So we've come up with two principles...people with impaired decision-making capability have support where they need it..it has to be adaptive and fluid so... For any specific decision we can look at the network and then we can look at the decision and then pull out the bits they want to activate' (Interview Coordinators Link and Learn).

It potentially transforms the work of the SDM project particularly where such groups can be drawn into larger training groups working through real life scenarios rather than requiring significant one-to-one support over a longer period of time. It is, therefore a potentially efficient approach.

Key point 45: The approach to SDM support must be fluid and adaptable. It must rely on activating support where it is not forthcoming. This approach is efficient for SDM project workers as it relies on the trained informal network to support and activate decisions until they cannot do so. Only then would the SDM project staff become involved in (finding) additional support.

Moreover the relevance of bedding the model into a wider number of potential support groups over time heightens the chance that decision support becomes a known and established culture that widens the network of supporters over time:

'One of the things we are thinking about is a model that is fundable that can be picked up by different organisations. So an advocacy organisation or a disability support organization but the trick is knowing where you fit into it...and somebody could ask for it [SDM] in their NDIS package' (Interview Link and Learn Coordinators).

The model was adopted from around May to the project end seven months later. More will be said of this model in the discussion section of this report.

4.4 Characterising Link and Learn support relationship building

The project evaluation collected narratives from over time from five decision makers. Interviews were held with two on three occasions and with another three on two occasions. Further interviews were held with one decision maker with their family support and with four families providing SDM for children. One further interview of a parent who headed a Microboard and observation at another Microboard meeting have not been used in the following discussion of evaluation findings⁴⁷.

In the presentation of narratives below, all names have been changed and details of situations designed to maintain confidentiality. The narratives are meant to explore the context within which each lives, to explore the Link and Learn engagement with them and to set out some of the human rights issues at stake. The sub-section to follow takes a more systematic look at the human rights that featured for 21 people for whom Link and Learn provided decision support of one kind or another.

4.4.1 *Narrative vignettes*

Narrative 1 – Stacey

Stacey lives in a small granny flat with support. On the two occasions I visited Stacey was in the same place of the couch watching TV, which remained on during the interviews. The entertainment system – TV, DVDs, CDs took up a significant wall in the home. Stacey was very welcoming and the support worker left on each occasion I visited since there would be no privacy were she to be there during the interviews. Stacey was more likely to respond in monosyllabic answers, rather than in expansive ways. For example,

Interviewer:-Have they [Link and Learn] talked about making decision?

Stacey: Yes. A bit scary

Interviewer: Did they leave information?

Stacey: Yes

And you have found them useful?

Stacey: Yes. And [name support worker] did it with me.

The main issue in Stacey's life and over which she wants a decision made is the daily visits of the nurses which she simply does not like.

⁴⁷It was felt that these Microboards were already SDM savvy and strong enough to survive on their own without additional support. As discussed earlier this mechanism may be possible for some but is very difficult for many to organise and manage over time.

Stacey: At the moment the nurses come every day and I don't want them coming. [support worker] put me in contact with them [Link and Learn].

The main issue for Stacey is in one sense 'health', though in another it relates to the dignity and respect with which she is treated by the nursing staff and the regularity of their visits and issues of privacy given the regularity of those visits.

On a second visit Stacey explained she was very eager to help other people. She had made a friend who had said he would help her to get into a self advocacy group. But she said that some people did not like her and were trying to convince her out of seeing this person. Link and Learn had convened a meeting with nurses and although some things had changed Stacey still did not like them coming. Stacey wanted to talk with Link and Learn again indicating a level of trust and some satisfaction with how things had changed even if not complete happiness.

The Link and Learn input for Stacey was straight forward compared to some of the decision support offered by Link and Learn. Latterly Link and Learn report that Stacey has, through them, been providing support to a friend with disability on safety, drawing on the SDM model. In one way then Stacey is beginning to both become confident about using SDM, helping others to do so and in beginning through her connection with Link and Learn to 'help others', one of her wishes in life.

In terms of the five stage model Stacey has become aware of SDM, has had SDM training, become decision ready, has had decision support and sought to change her situation in one area relating to her privacy. Indeed, it would seem she is now actively supporting another person by applying the SDM approach, indicating a significant rise in confidence with SDM conferring meaning to her wish to help others.

Narrative 2 - Bevan

For example Bevan lives with anxiety and lack of confidence. During his relationship with Link and Learn Bevan has sometimes been very engaged and at other times not. His life seems to consist of a series of personal crises of 'faith' in himself and others. Other SDM evaluations have reported on the gains in confidence in decision-making of the decision makers. Bevan's issues are intermittent and so his confidence swings over time.

Conversations with Bevan point to a person who is deeply upset by the tragedies of the world and its unfairness to some people. None of this is self-engrossed. It is a reflection of

his sense that the world is unfair to some. One can see his consideration for others in the following extract:

'I am living in a really noisy place. I can hear everyone in the flats below and beside me and so. It's a complex situation – music, dogs barking - I guess people get lonely and they want their pets around them. And then the social worker through Link and Learn would be really good to help me with the NDIS and she came into the picture and that's been for the last month or so and that's been really helpful' (Interview Bevan)

Bevan is really affected when others are not fair to him.

ADACAS had previously helped Bevan to transfer from a housing flat to somewhere closer to his mum. He re-counts:

'It was my fault. I chose it [the flat] and didn't realise how much I needed my family.

Link and Learn support through the NDIA meant Bevan has funding for a support coordinator who keeps a very close communication with Link and Learn. The support coordinator sees his role as follows:

'So its about building the capacity to support him to understand he is making the right decision or let's talk about why you're having these second thoughts...It actually takes a lot of time' (Interview with Bevan's support coordinator).

The support coordinator met with Bevan for a couple hours each week and arranged with Bevan to interview people as support workers,

'...and the ones we contacted were happy to come on a support and decision making course to learn how to support Bevan. Because the support worker becomes part of the support circle that helps Bevan make his decisions...' (Interview with Bevan's support coordinator).

Key Point 46: This example shows how it may be possible to do two things. First it offers a way in which the NDIS can provide funding for decision support. Second it shows how it may be possible to bed in SDM more widely amongst support workers, expanding the use and capacity of its ideas and practices.

The interview with Bevan's support coordinator took place later on in the project and he spoke about how much time he had spent with Bevan talking about what part his family, services and others played in his decision making. Bevan is attentive to this because he is adamant he does not want a Guardian or EPA. Bevan loves art and theatre. He has been in many groups in the past, one recently which he left because he had a falling out with someone at the centre.

'When someone does something wrong I can't seem to stop thinking about it or get over it' (Interview Bevan).

Bevan says of making his own decisions that,

'First of all we went to the NDIS, I got sort of tongue tied and it gets very personal and its hard to keep track of the right questions to ask. I find it hard, especially with bureaucracy they go really slow. It takes much longer than you thought. Recently I stopped going to an art centre and I regret that decision now' (Bevan, Interview).

Bevan's story exemplifies well how Link and Learn have operated to support Bevan to make decisions with support using the ADACAS five categories of decision making. It also shows how the new model of decision-making can help to reframe where support comes from and where training is required to ensure decisions can be both made and activated given the ways he was encouraged to use his natural network for that support.

For Bevan key human rights issues related to a raft of issues. They related to equality and discrimination, awareness of stereotyping, living independently, family life and participation in cultural life, particularly in art and theatre. By working to ensure these rights were met as best as possible Bevan's life would be enriched and the outcomes would be better. All did seem to be going well, though on a third occasion when I chatted with Bevan he was once again having major issues with his confidence and still unsure whether he had made the right decisions.

This points to the fact that not all people can gain confidence without additional help and that some problems are so deep-rooted and intermittent that it may feel at times that there is little progress. The important point though is that Bevan has SDM tools he can use and he still has the support required to make his decisions when he needs to do so. In terms of the five stage decision-making model Bevan is aware, has had significant SDM training, has received additional decision support as required. However, his situation means he is not always ready or able to make decisions and needs help fulfilling the

decision in some circumstances. Not all people will grow in confidence as a result of SDM as noted in Diagram 1 shown earlier. Many project evaluations take this as a necessary result of the SDM input, but in this evaluation it has been found that this is necessarily possible for all people.

Narrative 3 - John

John, a decision maker, lives in supported living with seven others. There are strong house rules and many of the activities of the home are organized around the friends of the home and around others who live in homes run by the same organization. John lives with an intellectual disability, speaks very slowly and not expansively. John had attended two skills development sessions run by Link and Learn and made it known to them that there were issues in his life. When I first met John he said

'It's a bit hard here. Lot's of ladies. Hard to be myself. With food its hard...I can't have something as tea. It's tiny. Sometimes I want to cook. [You go to bed hungry?] yeah' (Interview John, decision maker).

When asked about the training and the one to one support John enthused about the Link and Learn staff member. Further questioning elicited the following:

[she's given you more confidence] yeah [ask more more food] sometimes, yeah [more confident to ask for more] yeah [caused problems with other residents] only a bit. X is very noisy [can't do things when its noisy] No' (Interview John, decision maker).

Although the issues around food and the noise were key issues upon which John needed to make a decision about how to proceed, he became more animated and expansive when asked about his aims and goals in a second visit.

[what can improve your life?] I want to go away on holiday [On holiday?] Yes. I want to go with someone – to the coast – [name of coastal resort] I have a friend there. I love walking...One day I want to move to another house [Need to make a decision about that?] I want to talk about that to [name Link and Learn staff member] – I have a friend and I want to live in [name of seaside resort] I love warmth, (Interview John, decision maker).

John gave me to believe a meeting would be convened around the housing matter and that Link and Learn would be there (which Link and Learn staff report is now in train). However, the relevant manager was on extended leave and it could not take place until

he arrived back. When asked whether he was happier given the work with Link and Learn John said, 'I still find it a bit hard'. . Link and Learn had also provided some training around Trustees. John's living circumstances remained a worry and how he could be supported with decisions that were difficult. For example the house was not his own, nor was most of the space in the home, the rules and activities were rather tightly planned and it was certainly not possible to move somewhere better quickly. Latterly Link and Learn report that John has a new co-ordinator and discussions about a home move have started.

In terms of his human rights John was affected by issues relating to his privacy, his independence and living in the community, and felt his physical and mental integrity were under threat since he simply could not be himself in the present environment. There was a felt sense in John that he had been treated differently because of his disability and that he was therefore being discriminated against.

In terms of the five stages of decision-making John has moved through awareness, training and decision-support, and has tried to activate some of the issues for himself. However, fulfilling the decisions about noise in the home and hunger has not yet been fully resolved. John has, however, become more confident as a result of his connections with Link and Learn.

Narrative 4 - Jake

Link and Learn provided decision support strengthening across the project period to Jake. When I first met Jake he had a serious life threatening illness and had somehow to tell his son Andrew who lived in supported accommodation and has a significant disability himself. There was a real issue with this because Andrew visited home three days a week and got very upset every time he had to go back to his own accommodation. Andrew would be devastated at the loss of his father. When Jake's son became involved with the NDIA he needed some help to develop his plan and to understand what NDIA papers were saying and why things were changing and why he might move to new accommodation. There was a need to break all of this down into smaller units which Jake's son could understand. Neither Jake nor his son trust the service to be doing what is right for him. Jake said that

'Link and Learn do get to the bottom of things and they do change things. Sometimes it's a tiny tiny thing, but always very important' (Interview Jake, decision maker).

After recovery from illness Jake was very excited to tell me more about his growing involvement with Link and Learn and a trip he had made to a conference where he had talked about SDM for his son. Jake was particularly proud to report on work on decisions with Andrew who could now choose between honey and Vegemite. He also reported on how he was training the support workers in Andrew's house about SDM. Jake even pointed out where Andrew's will and preferences were shown through his behaviour and how not meeting these often acted as a trigger to self harm.

This story once again shows how the work of Link and Learn has unseen outcomes and that staff are themselves being trained in SDM by Jake who has a disability himself, but who can impart knowledge in applying a decision making approach given his own training and experiences. The range of issues around human rights here might be construed as belonging to both Jake and Andrew. So issues around health, children with disabilities, family life and protecting the integrity of the person in relation to Andrew.

Jake has exceeded the five SDM stages. He has become a trainer himself for another person with disability in his own family. He has imparted SDM principles to staff and is an ambassador for SDM and for Link and Learn.

Narrative 5 - Doug

Doug has a complex history and family life. Brought up on farm in which his mother died Doug found himself living with a step mother and then, when that did not work out, with an Aunt who died soon after. After his mother's death Doug had worked the farm on his own so having to move out was hard. The family came to a decision when the aunt with whom he lived died for Doug to move into a small home where he lives a quiet but independent life. He likes nothing more than to be with his nieces and to pick them up from school. However, things have moved on in terms of the complex family relations and Doug has found himself having to move again, this time to his sister's home, whilst another small house is built at the back of her garden. Luckily this house is on the same road on which he presently lives.

Doug has had many changes in his life. He would love to do some farm work and often goes walking in the country near to hand. He feels unable to take on full time work now given his health. He has been challenged immensely by the simple practicalities of moving home where he would have appreciated more help. He had to clean the home, arrange for workmen to do so some work, sell things he does not need and has been

taking his possessions to his sister's house one wheelbarrow at a time. Doug is a very patient and understanding man, saying '*They're too busy. They work all the time*'. Doug is a bit sad that some of possessions cannot go with him.

However Doug's major worries are around the speed at which all these changes are moving, and in particular the communication and speed of the Trustees. Over three visits to Doug I was aware of how all his time predictions had been blowing out. Things did move along but much more slowly than he wished. The Trustees had talked with Doug's brother and sister but not with him and so he raised this with Link and Learn. As he says, *'I would love to have a year when I don't have problems at all'*.

On my last visit he showed me the plot on which his house would stand and we talked through different houses and quotes associated with them. Doug was very enthusiastic about the prospect of his new dwelling and I think very relieved he had the support he needed from Link and Learn throughout the process. On his instructions this had been accomplished without Link and Learn discussing their work with Doug's family. For Doug this was vital because under all the complexity and strife, his family meant more to him than anything and so the situation had been managed without family discord. He understood where he had made compromises but was very much willing to live with these.

Doug says:

'I really don't need to be in the trustees long term. I can't let my family members get involved. I'll get the new house built but the Trustees have been so slow and I haven't got the planning permission yet. I've got to get it done...' (Interview Doug, Decision Maker).

Link and Learn were very aware of the family dynamics in working with Doug and on his request have not got around the table to talk things through. Although Link and Learn felt uncomfortable about this and in the absence of this support network they have taken responsibility to support his decisions and to communicate with the Trustees to try and get things activated on Doug's behalf. They also accompany him to meetings with the Trustees. This support from Link and Learn was in the realm of a Doug having to act as a 'legal entity' around financial and contractual issues relating to housing.

The Link and Learn coordinator said in relation to Doug that

'From time to time there are decisions that are so big that it doesn't matter how capable you are, if you're vulnerable you might need someone else to contribute to the process, to the capacity and to the safeguarding' (Interview Link and Learn Coordinator).

The Link and Learn project has provided training for Doug and has supported him with an ongoing issue and sought to establish an 'equality of arms' for Doug in his communication with Trustees so that his decisions are represented fully. In ensuring his voice they have ensured equal recognition before the law, protected his right to live independently in the community, respected his family life at a time that might potentially have been divisive, and ensured that his privacy in all the formal procedures he has faced has been respected. Link and Learn are also aware that subsequent to this major issue Doug is likely to need support in his application to the NDIS and in relation to other life areas in which he is not fulfilled.

Doug has addressed the five stages of decision making through the support of Link and learn and is close to seeing his will and preference accomplished.

There are a number of further narratives from which data can be extracted but the attempt has been to show using these vignettes how Link and Learn has taken people's circumstances into account in their support relationship building and to express how their input has had a major impact in the lives of the people for whom they have provided that support.

Some of the issues covered point to differences in complexion from previous evaluations. For example, a gain in confidence is not necessarily guaranteed for decision makers. Some lack confidence (as many of us do) in formal situations, some have recurrent problems which at times make it difficult to act as confidently as one might choose, and services and systems are often resistant to change. Secondly it is important to note that even where decisions are taken it does not always lead to change that transforms lives. There may be incremental steps towards a good life and systemic and structural barriers can pose a real barrier to change.

4.5 Human Rights Outcomes

For twenty one decision-makers receiving support the primary human rights addressed in the work of Link and Learn were identified (Appendix 4). It must be remembered that human rights universal, interdependent and indivisible. The relevance of certain rights will therefore depend upon each person's context and situation at any one point in time and

connected to other rights too. It is therefore possible to see a number of related rights at play in person's situations as exemplified in the vignettes previously presented and to see these changing over time.

The identified human rights in Appendix 4 therefore relate to the primary area of concern for the person in terms of their current context and in terms of the issues around decision making as the related to Link and Learn. For the sample it is not surprising to see that broad level issues around equality and non-discrimination, Article 5 (A5) and awareness raising, in this case about the person's right to decide, are the most prominent of categories identified in the data, being relevant to 14 of the 21 people concerned. These rest in the principles and preamble of the CRPD prior to substantive rights set out in Articles 10-30.

Of the more specific rights outlined in the CRPD, ten participants received decision support relating to Article 19 'Living independently and being included in the community' and Article 25, the right to health. Health is more likely to be a negative right and independence and community living a positive right, highlighting a point made earlier about the need to span both legal and relational approaches to SDM.

Eight decision makers received support related to respect for family life, (Article A 23). Seven received support around decision-making participation in cultural life, recreation, leisure and sport (A30) and respect for privacy (A22), equal recognition before the law (A12), whilst 6 decision-makers had decision making issues relating to protecting the integrity of the person (A17). Issues around the rights of women (A6) and children (A7) featured less as did situations of risk and humanitarian emergencies (A11).

A complex of issues around living situation and circumstances was often found. Wanting to move home, troubles in relation to other residents, their right to privacy and safety, as well as contact with family, often featured together. Like other SDM studies there were a number in this evaluation who had decisions to make about health, whether that was about treatment options and consent particularly in relation to drugs. The relationships many had with medical and nursing staff as well as support workers featured strongly and were linked to issues of power around the right to make a decision. Some were about legal issues but there were other more relational issues around health care delivery such as privacy but also being treated with dignity and respect. In short human rights are seldom singular but are experienced as a complex of interrelated issues.

Earlier it was shown that Link and Learn staff argued that people often had decision making networks even if they were socially isolated. The right to be included in the community and participation in the cultural, life, recreation, leisure and sport were key issues for many people. This often highlights that without support people cannot accomplish their decisions whether through lack of support, or control of their lives by others. More broadly the examples point to the resources people with disability do not have to purchase the support required to activate those who can achieve their will and preference. At some point and for very many people with a disability it is the access to resources that they can activate that diminishes their capacity to control their decisions and to activate them and accomplish their rights..

Family life is extraordinarily complex. In this study issues arising related to decisions about telling a relative with disability about a life threatening illness, complexity in relation to property ownership, simply seeing family and wider family and their children, to getting family members to offer practical and other support where needed. Many had challenging relationships with family members and yet often saw them as playing a major role in their lives. In describing the work using the new model with Bevan (see narrative 2 earlier) the Link and Learn coordinator, for example, outlined that they had:

'...talked about all the people in his network which included his dad and his brother and his mum and his sister...so [name] what do these people actually do for you? What's their role in supported decision-making?' 'Dad will tell me all the negatives. Dad will tell me all the things that could go wrong', Great. So how do we use that? That's an important part of making a decision. ...We're not going to change that. It's there! So then he says, 'There's my brother. I don't really agree with him but I like to talk to him and he gives me all the other options and he's really useful. He helps me make decisions. But you don't want to say to his brother – you're the supported decision-maker. Mum takes all the emotions out of the decisions. So when he came in the other day crumbling with self doubt I asked, 'Who would actually make the decision with you? I won't always be here, so who can you turn to?' (Coordinator interview Link and Learn).

The lives of people who have issues with their own decision making are no less complex than anyone else. Indeed, in some ways they are more complex. The data showed that despite best efforts from Link and Learn that certain issues remained almost immovable and that change was only likely in the long term, if at all. For example John's (see narrative 3) wish to move home and to live with friends at the beach seemed a long way away; even the wish to move out of his present accommodation was not something that had been addressed substantively. Link and Learn were supporting John to convey his will

and preference to move and this seemed a long process, but one Link and Learn remained engaged over subsequent to John's initial issues.

Moreover, for John the 'rules of the house' and the systems of using fixed networks of contacts, made it very difficult for him to express the wish for independent relationships or for more privacy in the home. The everyday struggle for independence and to self-author his own life remained a very real and ongoing issue. Added to this the intransigence of some in their decision-making, for example doctors and some Guardians and Trustees (see narrative 5) remained a major issue in which SDM is left to chip away.

In short there are a significant number of issues to do with lack of resources to be able to activate choice, there remain systemic issues that are hard to challenge and change and there are issues about authority which remain despite new legislation and policy and the CRPD. All of these relate to issues of power and authority versus the resources to buy a way to independence. So, although SDM has supported decision and change which improve people's lives it is often within a pre-existing framework of control.

This means that the lives of many people with disability are likely to continue to lack the texture and richness of others. Martha Nussbaum⁴⁸ in her work on capabilities talks of people whose everyday life shows 'adaptive preferences' that is, they begin to realize their decisions and choice are limited whatever they do and so they become used to a life they don't choose. They do not have high expectations and they do not, after a time, even complain. Unless these systems of power and the availability of personal resources increases substantially it remains hard to see how this will change. SDM, though, does make sure that people requiring decision support get the best they can in the context and circumstances; it ensures there is a check and balance in place against the system of other forms of power; and it moves people long towards their will and preferences as far as is possible.

Key Point 47: Service systems and structures along with the assumption of the right to apply 'best interest' tests are often deep seated in services. Within the context of 'possibility' SDM has been found to give effect to people's human rights. However much more needs to be done to continue to address values that implicitly challenge human rights within services. This means the work of Link and Learn in seeking to bed in a culture of SDM is all the more important.

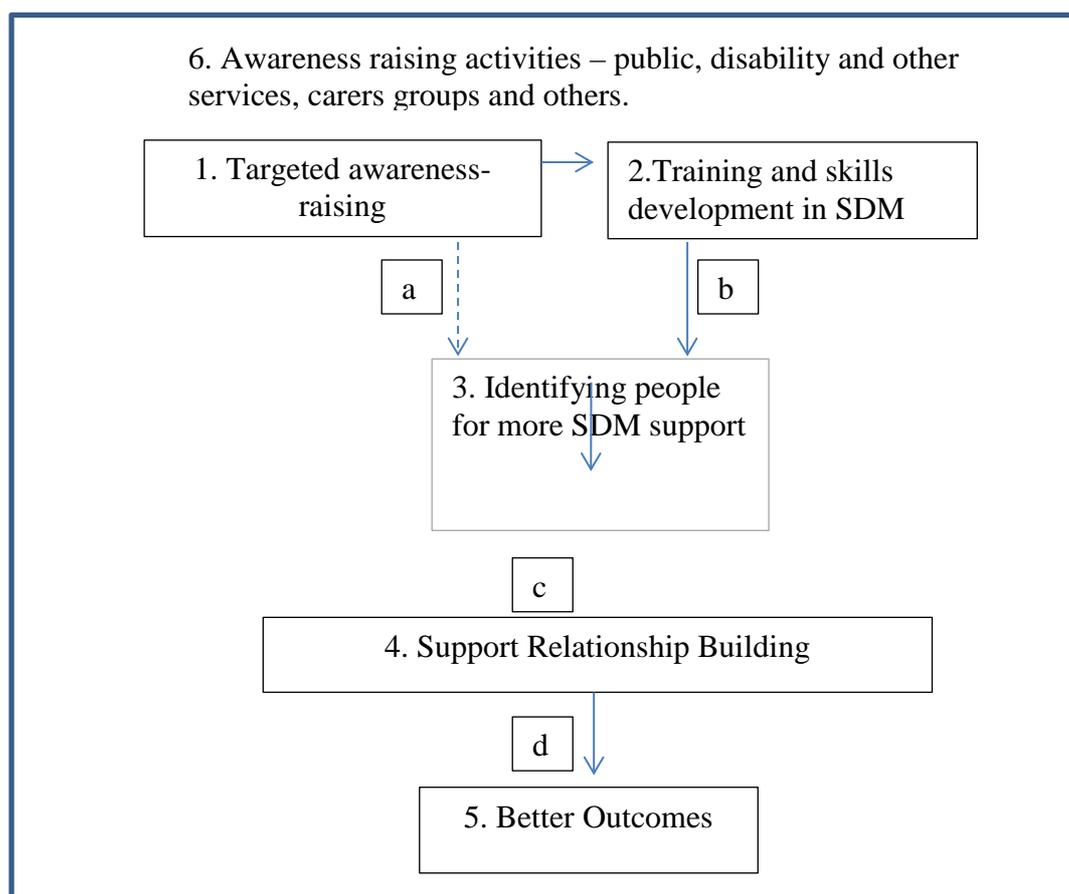
⁴⁸ Nussbaum, M. C. (2000). *Women and Human Development: The Capabilities Approach*, Cambridge, U.K., Cambridge University Press.

Section5: Discussion and Conclusion.

5.1 Meeting objectives - The Link and Learn experience

To discuss the success of Link and Learn in terms of its objectives a basic diagram has been developed to support discussion. This is presented in Diagram 2 below which presents a model of how the flow through from activities led to outcomes. Consideration of the experience of Link and Learn is considered for each box and in relation to the links between boxes.

Diagram 2: Diagrammatic representation of the flow through designed to produce better outcomes for people using SDM.



Box 1. Targeted Awareness-raising (see Box 1, Diagram 2):

- Awareness raising was delivered to 300 people and more than 25 activities were delivered so meeting the stated project objective.

- Awareness-raising was delivered to a wide range of groups not just disability and mental health related.
- Data from the questionnaire shows that awareness-raising was very well received. Participants were very positive and about SDM. They felt the knowledge they had gained could be confidently applied by them to improve the lives of people with whom they worked or lived

Key point 47: Some people at awareness raising went away and applied SDM. This was an unmeasured outcome of the Link and Learn project⁴⁹.

- Most continuing uncertainty after training was registered in relation to how SDM linked to other service such as advocacy, Guardianship and the role of formal services.

Key point 48: There is more work to do in refining the identity of SDM and its links to other services.

The Link and Learn project was innovative. Unlike previous projects in Australia which focused largely on support for a stated number of SDM relationships, this project further sought to develop a 'culture of SDM' by raising awareness of the project but also what SDM is and how it can be applied. There is reason to believe this was in good measure, successful. More needs to be known about the impact of use by others but also any issues that arise where those implementing SDM do not use the support of an SDM project.

The target awareness-raising could be said to have achieved part of the job of wider awareness-raising activities (Item 6. Diagram 2) but it did so in a more targeted manner, meaning it may have had more impact than a non-targeted public awareness approach.

Link and Learn received a significant number of inquiries from people who had attended the awareness-raising sessions (Diagram 2, a.). The majority of these queries could be handled through advice but a few led to support relationship building. This raises an issue about how any SDM project prioritises those to whom they extend more support as opposed to those they do not. This also links to the level of funding received by the project.

Recommendation: A thorough review of new ways to provide more sustainable SDM funding taking account of the evaluation findings, is required if it is to meet demand, and

⁴⁹It should be noted that for this project evaluation funds were not available to pursue this systematically. Future evaluations will need to incorporate these into the program logic and explore the underlying theory of change,

provide social justice for all those who require decision support.

Box 2 – Training and Skills development in SDM

- Link and Learn delivered over 30 formal training sessions adapted to the specific needs of their audience and 20 bespoke skills development sessions and therefore met the program target. Target groups spanned not simply services by formal decision making bodies, legal centres, health staff but included families and associated services all of whom might have an interest in applying SDM or how their work might link in with SDM.
- The adaptations to resources for training and skills development were time consuming but essential in responding to the particular interests and learning approaches of each of the groups. ADACAS resources were highly rated by all groups concerned.
- Issues in the process of organizing training reflected: a market based system of care - organisations do not want to have to back-fill for staff attending training;lack of trust – families who have a major role in decision making and their organisations can be skeptical and concerned about how SDM affects their family role in decision-making whilst some disability service providers feel that demanding clients can be problematic for them: workload – NDIA Local Area Coordinators (LACs) were extraordinarily hard to sign up for training

Recommendation. It is suggested that a future strategy for funding training in SDM be considered to cover replacement care costs and staff back-fill. Some agreement with the NDIA locally or with the NDIS is essential given the centrality of SDM to choice and control throughout the My NDIS process.

- There is evidence that people attending the training and skill development sessions, particularly managers and support staff were taking back messages to their teams to implement SDM and were themselves using the principles and methods in everyday practice. It is not known how effective this was nor the outcomes produced as a result. More research is required in this respect if the model adopted is about building a culture of SDM and has any element of a train the trainer model implicit.

Recommendation: Where an SDM model seeks to build a culture of SDM wider than the project (for example through awareness raising, training or skills development) , it is necessary in the future to look not just at the outcomes of the SDM project itself, but also its wider use and impact by those who carry the message and practice of SDM to their own networks and services. There will need to be both refresher training and monitoring by the SDM project in respect of the wider use of SDM.

- Data shows that the training helped much deeper understanding of SDM and its processes. Although still positive, a mid-sized group of those completing the questionnaire after training, were not sure the training would improve the relationships with other decision support group members and how it would work in practice. Many still felt the training would not stop them from looking to Guardianship .
- As planned the training led to a number of referrals to Link and Learn (Diagram 2, b.). As with awareness raising, this raises issues about how projects like Link and Learn prioritise those cases they adopt for more support. As mentioned previously this means a selection model but, additionally, in pursuit of social justice a way in which all people requiring SDM are given an even chance of access to the service, i.e. social justice. More sustainable funding sources would be required to do this

Box 3, Diagram 2 - identifying people for more SDM support:

- Link and Learn mentored 50 individuals over the project period committing time ranging from 2 to 80 hours. The project met its program objectives⁵⁰.
- Recruitment of volunteers as decision supporters proved very difficult. Neither attempts to find volunteers nor Link and Learn staff filling that gap are sustainable. Finding sufficient volunteers to scale up is unlikely to work.
- The roles and program outcomes for Link and Learn were much greater than in other SDM projects with a similar complement of staff. This reduced the time spent on identifying those to whom support relationship building should be provided.

⁵⁰ There are always issues with what constitutes a case. Some of the support relationship building carried out by Link and Learn involved two hours input at its lowest level. This approach used once their new model had been implemented recognised the five stages of decision making but also the built in strengths of the decision maker and their networks. This made possible shorter inputs rather than a blanket approach which would have soaked up more time.

- The rate of referral to Link and Learn from awareness-raising, training and skills development, as well as other enquiries, was too great for Link and Learn to be able to respond to all.
- It was not clear how decisions were made about who was chosen by Link and Learn for additional support relationship building.
- If the provision of SDM is to reflect equal access and delivery to all who require support, the demand could be great. Although some projects single out specific 'vulnerable' groups (*see* Section 1) this leaves a huge gap of SDM needs that will go unfulfilled.

Box 4, Diagram 2 - Support relationship building processes

- The support relationship building process worked on the well confirmed assumptions as outlined previously. However the lack of success with volunteer recruitment meant that another model needed to be developed.
- Link and Learn developed a new model as a result [which I term the *Strengths Based Network Activation SDM Model* from this point on]. The Strengths Based Network Activation SDM Model seeks to make use of existing informal networks and strengths. Key blocks and patterns in the person's life become a key focus; the person's decision making strengths are considered and what is missing for the purposes of the decision being made; the roles of the decision-maker's network are identified and for each decision the right person is activated where there is a decision making gap. Where the network cannot cover the gap the SDM project may do so or seek to expand the network for that purpose.
- *Positives of the Strengths Based Network Activation SDM Model* are: it implicitly recognises the decision maker's strengths; it only attracts additional support where necessary hence maximizing the person's own will and preference; it supports the building a culture of SDM by targeting training to a large number of people over time; it is efficient for SDM projects as most support exists within natural networks. Their role is to activate the correct network member where necessary, find network members for a specific task or in complex cases perhaps, to provide more support or support relationship building. In finding further network members it is possible to see a space for linking to the NDIS or other arenas such as health, and to funding for specified SDM support.

- The early training, awareness-raising and skills development sessions did not deliver information on the *Strengths Based Network Activation SDM* Model as it was not at that time developed. Since the model changed the relationship of outside organisations to Link and Learn it needs, if adopted, to be tied into future information and training about SDM in the ACT. The Spectrums of support five activities of SDM would remain. However a trial needs to be accompanied by close research and evaluation.

Recommendation. It is recommended that the Link and Learn model, Strengths Based Network Activation SDM Model is adopted and further tested for its efficacy, its efficiency and its potential to meet the demand from greater numbers of people who would benefit from SDM.

Boxes 5 and 6, Diagram 2 – Better Outcomes

- The outcomes of SDM were found to be wide and varied (Diagram 2, Box d). They linked to one off issues and so assumptions in the original evaluation program logic that decisions would transform lives in a wide range of ways were found to be faulted. The outcomes of decisions related to one person at one point in time and many people had other issues pending over which they wanted to make decisions in the future. Looking at the decisions and the *outcomes specific to those decisions* would have established a more realistic program logic for the evaluation.

Recommendation. SDM addresses decision making issues at one point in time. Yet the evaluation data shows that even where people become more confident in decision making for themselves that there is often a more consistent need over time for wider decision support. Adopting a 'culture of SDM' is one important way to expand the reach of SDM.

- Applying a human rights-based approach to exploring the intensive work supporting SDM relationships and their outcomes was found to be more appropriate. It was shown for a sample of 21 people that under the substantive rights laid out in the CRPD (Articles 10-30) that the most common areas of decision making related to: Living independently and being included in the community (Article 19) and Health (Article 25). Other common areas related to family life, cultural, recreational and leisure inclusion, privacy and equal recognition before the law. It was also found that not all decisions were likely to require the person to be a legal entity for the purposes of making and carrying out that

decision. These results seem broadly to accord with findings from other SDM projects.

Recommendation: Any SDM model adopted should start on the assumption that it is working with the informal or relational approach. But the model must have a mechanism to formalize this where the person becomes decision maker for legal purposes.

- It was found that although Link and Learn achieved positive outcomes in relation to a number of decisions systemic and structural barriers remained obdurate, as did many people (medics, some Guardians and family) and organisations who continued to exercise their assumed right to impose best interest over will and preference. Cultural issues within disability services implemented for 'the best interests of the group of clients' as a whole also had impact on a decision makers' capacity to execute change in this context.
- Unlike other SDM evaluations which report confidence as an outcome this project found that, dependent upon circumstance and the person concerned, such confidence is not necessarily guaranteed, important though it is. Despite this some people showed an increase in confidence in exerting their right to have their will and preference recognized.
- Power, authority and control are at the heart of issues around the success of will and preferences in many contexts. A key concept that might help in finding a solution is 'equality of arms' which attempts to balance the power and authority of different parties. The question is whether a mechanism can be found which allows informal networks to operate without the formalities of legislation. This is considered shortly.
- Finally there is a need to consider where the role of SDM ends and where the role of individual advocacy begins. In some cases Link and learn were speaking up as if the person's voice was their own to ensure their will and preference was heard, i.e. advocacy. More attention is required in relation to this boundary and how it is managed and funded.

Recommendation: There is a need to develop and adopt a mechanism that produces 'equality of arms' for decision makers. The Statement of Will and Preference is one important approach that can be supported more widely by

Courts, Trustees, Guardians and Tribunals as a guidance document. In achieving an equality of arms it is also important to distinguish the role of advocacy from SDM and so thought needs to be given to how this is organized.

Box 6, Diagram 2 – Wider awareness raising activities

- Link and Learn was not able to operationalize the community of practice or website as originally envisaged as a program outcome.
- Despite this it is important to note that a lot of knock on information about the project was rippling out from the awareness raising, training and other networking undertaken by the project staff. This in part met the intentions of the community of practice.
- Through the project period the staff felt increasing expectations that could not be delivered made increasing the wider profile a problem. They also felt that web-based information and networking would not be as powerful as face to face contacts. Such contacts might be operationalised and targeted through strategically placed 'shop fronts', by recruitment of SDM Ambassadors or by other informal peer support mechanisms such as walking groups.

5.2 The Link and Learn contribution to SDM innovation

It was suggested in the introduction to this report that the arguments around supported decision-making are as yet young and that there is not much empirical evidence that is needed to support the development of new SDM approaches.

Key questions remain for the implementation of supported decision making in Australia and the ACT if they are to meet the requirements and vision of the CRPD. These issues are not inconsequential because if not successfully people will not achieve their choices, exert control and express their will and preference. This will affect the potential of the NDIS to deliver on its promise of choice and control.

In the introduction to this report distinctions were drawn between the formal or legal model of SDM and the informal relational model. This evaluation has proven that it cannot be one or the other. Both are necessary and both are vital to maintain and protect. If this is the case how might the two co-exist? Is it necessary to build two approaches?

One suggestion drawing on the work of Advanced Health Care Plans is to bridge the gap where this is needed. Earlier the idea of a 'Statement of Will and Preference' was mentioned. This Statement of Will and Preference would be a Guiding document and would have sections which demonstrated what measures had been taken to ensure the will and preference of the decision maker had been explored.

The Statement of Will and Preference would not feature in the day to day decision-making of informal decision making networks. However, where called upon to make a case in which the person as a legal entity such a document can be developed by the decision making group, by an SDM initiative or ordered by Tribunal, court and so forth. The document would not be legal but those who did not reflect the will and preference as stated would have to make the case as to why it was ignored. The mechanism therefore confers 'equality of arms' at least to a greater degree than previously.

Recommendation: It is recommended that a Statement of Will and Preference is developed in consultation with stakeholders. This statement will be a guidance document and only be developed in circumstances in which a decision maker enters a situation that requires his or her will and preference to be known for formal or legal purposes or to address known conflicts of interest over a decision within the decision making group. In accordance with the CRPD and the recommendations of the ALRC the Statement of Will and Preference would ensure that even where there were 'best interest' tests they would be subject to will and preference and accountabilities thereof.

The Statement of Will and Preference might also be helpful in distinguishing the role of SDM and that of Guardianship by distinguishing the extent to which the document reflects the person's will and preference and what risks remain. It is envisaged that something like the five stage *Spectrums of Support* SDM model would make up at least part of the document. Criteria which would tip decision making into Guardianship would need to be discussed and criteria would need to be developed to identify the point at which the need for Guardianship was proven.

A second issue related in some ways to the above is the extent to which it is possible to support a culture of SDM more broadly than the SDM project itself. There is much evidence from this evaluation that those in the sector made aware of SDM saw it as positive, were willing to try and implement it in their practice, and saw it as an essential element of the NDIS in its emphasis on choice and control.

If that is the case there are perhaps some issues around conflict of interest where families and or services or others seek to employ SDM. A Statement of Will and Preference can help to ensure that these conflicts are recognized and that the will and preference truly comes primarily from the person to the degree they are able. It also offers some mechanism to support the quality of a decision making network operating independent of a supported decision making program. It perhaps adds a role to any SDM program, that of monitoring the quality of Statements of Choice as well as providing support to decision networks where necessary.

Moreover a Statement of Will and Preference may also distinguish the SDM element from the advocacy element insofar as once a decision has been made it is possible individual advocacy will be necessary so that the person's voice is heard and the outcome actioned.

In short a Statement of Will and Preference can act as a means through which a much wider group than the SDM project becomes involved in delivering SDM across services and in families as matter of course. This proposition represents a paradigm shift in thinking about SDM which has, up to now, focused primarily on small projects providing support for smaller number of decision networks.

Supported decision making has been thought of as a being provided to *identified decision-making groups*. The alternative is to make decision support a key feature of all services – to build *a culture of decision-support* more broadly. What potential is there to bed in a culture of decision-making more broadly, to develop a network of trainers and therefore to reduce the burden of specialist supported decision-making project staff?

There seems to have been an assumption in much writing that the small supported decision-making projects can be scaled up. Does this assumption not suggest that significant funds will be provided at some point? Australian models, because of their approach and the funding, have covered relatively few people. In the grand scheme of things can that degree of coverage really achieve social justice for all those people who require decision support? If not, then what other mechanisms might help address this underfunding? Is there a more efficient way to manage support for decision making?

In the example of Bevan (*see narrative 2 above*) a support coordinator funded via the NDIA had spent time using the Link and Learn model to support Bevan towards decisions. There are potentially other ways in which SDM can play a role in the lives of people with disabilities under NDIS funding. It is likely that people making decisions and choices which reflect their real interests will save money in the long run as services will not be replaced or duplicated over time and there will be no downstream damage to repair where the services purchased do not fit the person's aspirations.

There is also no doubt that SDM training would be essential to LACs, planner, those involved in the pre-planning phases as well as to those acting in a Plan or Correspondence Nominee roles.

Recommendation: That a review of new forms of funding for SDM be undertaken with particular focus in the NDIS and that SDM training in the NDIA is widespread and supports the NDIS to achieve the vision of choice and control along with better outcomes.

By adopting a model which beds in SDM more widely as a culture across services, the role of the SDM programs would change significantly. While still providing specialist support and advice in complex situations, their training and monitoring role would become more formal. They might bed in a series of accredited trainers and it is also worth to think about the extent to which SDM comes to be featured across Cert III Community Services and Cert IV Disability courses also.

However, building a culture of SDM more broadly requires a new model of SDM because unlike other SDM projects the strength of SDM will be in the distributed support for people and not on volunteers recruited by an SDM project. As has been argued the recruitment of volunteers has been shown on too many occasions to be resource intensive and the likelihood of scaling up seems minimal.

Recommendation: If the 'culture of SDM' is to be adopted decisions need to be made about monitoring by SDM projects to ensure quality SDM is being practices. Training will also be a key element of the approach. Will the SDM project be solely responsible for this? Is a train the trainer model appropriate? Can SDM be added into qualifications such as Cert III community services or Cert Iv id Disability? These are all key issues in which decisions will need to be made.

Link and Learn have been innovative in their work and the staff have recognized the issues through their experiences and developed what was described earlier as the *Strengths Based Network Activation SDMM* Model. This model makes use of currently existing decision making networks where necessary and offers a model for activating the network where the decision maker requires support to establish their will and preference. It probably extends the model in the second South Australian project (de Mestre, 2014)⁵¹ where the volunteers worked with the disability service staff around the interest of persons requiring additional support. However unlike the South Australian model the Link and

⁵¹ De Mestre, M. (2014) Supported decision making as an alternative to Guardianship orders: The South Australian Trial, *Elder Review*, 8 pp 1-4.

Learn model does not immediately require a volunteer to be recruited. Rather, additional support may only take place where the network has not the skills or capacity for a particular issue. This is very little different to the ways in which all people search out additional support when necessary. The approach also clears a way for the provision of SDM amongst services and families.

This does raise the issue of maintaining quality, an issue that is yet to be addressed were the *Strengths Based Network Activation SDM* Model to be adopted.

*Recommendation: It is recommended that the *Strengths Based Network Activation SDM* Model⁵² alongside the *Spectrums of Support* five stages of decision making be adopted and trialled and evaluated.*

5.3 Conclusion

The Link and Learn SDM project represents one of several attempts across Australia to be in supported decision-making in practice. Like other countries Australia is still seeking evidence from such projects to build a more robust SDM system capable of addressing the ideas set out in the CRPD.

This evaluation has found that the Link and Learn was innovative in its conceptualisation, aspirational in its objectives and both successful and innovative in its execution.

In conceptualization the Link and Learn model, unlike other projects, sought to 'build a culture' of SDM more broadly across services and the interested public, as well providing support to decision makers where required.

The program was aspirational because, with a similar staff complement, it additionally required targets to be met around training and skills development, awareness raising and building a community of practice. Link and learn has similar staff complement to other SDM projects with a more singular focus on supporting individual decision makers as the main program objective.

Despite being aspirational Link and Learn met all but one program objective.

The awareness, training and skills development were well received and many participants seemed motivated to be SDM into their practice. It is not possible to say to what extent

⁵² The name *Strengths Based Network Activation SDM* Model is that of the author of this evaluation. THE MODEL WAS DEVELOPED BY THE COORDINATORS OF LINK AND LEARN AND REMAINS IN THEIR OWNERSHIP. The moral right to use the model, and to give it a name for the purposes of the report only, is acknowledged.

this happened and what quality of SDM was being achieved by those who had attended sessions run by Link and Learn. However the evaluation found evidence which gives confidence that SDM fits with the contemporary context of choice and control, making it a high demand skill. Through the train the trainer approach there is evidence that supports the development of a successful SDM culture more broadly across services, but the requirement for more testing of this model.

Support relationship building met the program target and there is evidence from the evaluation of strong outcomes in a number of human rights areas for those who received support relationship building. The most frequent areas in which support for a decision was required related to health issues, and to living independently and being included in the community.

The evaluation also found outcomes to be related to key issues in the person's life at that time but that often systems and people could be resistant to their will and preference.

The one program target not met during the project period was the development of a community of practice. However, through their project experience the Link and Learn staff have developed an alternative approach to this for the future which will involve setting up Shop fronts in key places in which SDM is likely to be required or used and to build more interactive forms of support over time.

The project was innovative in its execution, but faced issues.

Link and Learn staff recognized that difficulties in volunteer recruitment to decision support networks meant a project or scale up relying on this would not work. They built a new model, the *Strengths Based Network Activation SDM* Model which uses already existent networks for a decision and only looks for additional support where the decision maker requires it. This support can be drawn from specialist experts for that issue or can be a supported decision making program. The model aligns with building an SDM culture more broadly in that, with training, it potentially expands the network of SDM operatives. .

The project is also innovative in that it offers a solution to issue about whether a legal or relational model of SDM is adopted. It has been recommended on the basis of the evaluation findings in this report that a *Statement of Will and Preference* be produced in situations where the decision maker is involved as a legal entity but that independent of this the majority of decisions should be supported within the naturally occurring *Strengths Based Network Activation SDM* network without formality.

Whilst the Statement of Choice would be a guidance document it would offer some measure contributing to 'equality of arms' to the decision maker. In situations where a

Statement of Will and Preference was ignored the party rejecting will and preference in favour of best interests would be accountable for that decision and open to challenge about why will and preference had been rejected.

The Statement of Will and Preference may also mediate the work of SDM and that of Guardianship though more work would be required to establish the criteria involved. It should also be noted that the evaluation found that applications for both Guardianship and SDM to be increasing quickly within the context of the NDIS. This emphasises the importance of having a model that can establish where each is most appropriate and in what circumstances.

Finally it was found that SDM is aligned with the NDIS context and offers a major opportunity which if built into the NDIA funding framework more systematically could produce far better choice and control outcomes. A much more systematic consideration is required in relation to funding SDM if the Link and learn model is to be scaled up. Building a culture of SDM does not come cheap but doing so may be the next phase in the development of SDM practice in Australia.

Link and Learn staff struggled with significant challenges during the project period and yet achieved project outcomes which move the debate on supported decision making in Australia along significantly. This gives hope that with further thought and testing their model will be tested more systematically over time and that ACT will become a leader in SDM practice.



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Appendix 1

Media release announcing Link and learn:

Link and Learn for greater support to make individual choices

Released 13/08/2015

Minister for Disability Joy Burch today announced the start of a new supported decision-making pilot for people with disability.

The '*Link and Learn*' pilot will enable people with disability to create supported decision-making relationships and equip people with disability and their supporters with decision-making skills. It will also provide professional development for health professionals, support workers, legal professionals, teachers and businesses.

The pilot will support people with intellectual, cognitive or psychosocial disabilities to make decisions about their lives including employment, housing and their own care.

"The pilot supports INVOLVE – Canberra Disability Commitment by empowering people with disability to have greater control and choice with decision-making and the ACT Government's commitment to making Canberra an inclusive community where everyone can participate and reach their full potential," Ms Burch said.

"I would like to congratulate the partnership of ADACAS, Imagine More and JFA Purple Orange on winning the tender for this innovative pilot program.

"The combined strength of this partnership, their experience in the sector, commitment to building better communities and the dedication of the agencies give me confidence that this pilot will be a great success.

"Supported decision-making is a central principle of the United Nations Convention on the Rights of Persons with Disabilities. This pilot represents a significant contribution to the international human rights movement that is embedding supported decision-making in policy and practice," Ms Burch concluded.

The \$270,000 pilot has been jointly funded by Disability ACT and the ACT NDIS Taskforce and will run over the next two years. ADACAS and its partners will begin recruiting for the program shortly.

Assoc. Professor Paul Ramcharan from Royal Melbourne Institute of Technology (RMIT) has been engaged as evaluator for the project.

Appendix 2– Results of the Awareness Raising survey

	Agree strongly % (n=)	Agree % (n=)	Neutral % (n=)	Disagree % (n=)	Disagree strongly % (n=)	N=
1. All the main questions I had about decision-making have been answered	20.5 (23)	62.5 (70)	14.3			112
2. I do NOT know more about getting people together to support decision-making		5.5 (6)	7.3 (6.8)	46.8 (51)	40.4 (44)	109
3. I understand what a 'support group' does and how it works	19.3 (21)	60.0 (66)	17.4 (19)	2.8 (3)		109
4. I will make changes to make a better and stronger support group for the person	25.5 (26)	61.8 (63)	12.7 (13)			102
5. I understand choice-making skills better as a result of the information	30.1 (34)	62.8 (7)	4.4 (5)	0.9 (1)		113
6. I do NOT understand the role of decision-makers better as a result of the information	1.7 (2)	2.6 (3)	6.1 (7)	47.8 (55)	41.7 (48)	115
7. My relationship with other members of the person's support group has/will improve as a result of this training	13.1 (14)	60.7 (65)	26.2 (28)			107
8. I understand better my role in supporting the person to make their own decisions	26.5 (30)	67.3 (76)	6.2 (7)			113
9. I feel more confident in supporting the person to make their own decisions	24.8 (28)	62.8 (71)	12.4 (14)			113
10. I know what other resources are available to support the person in their decision-making	10.6 (12)	46.9 (53)	35.4 (40)	6.2 (7)	0.8 (1)	113
11. I do NOT think the person's life will improve as a result of this new information	0.9 (1)	8 (9)	7.1 (8)	42 (47)	42 (47)	112

12. I feel better informed about what formal service roles are in supporting choice-making	13.5 (15)	64.9 (72)	18 (20)	3.6 (4)		111
13. I think differently about Guardianship decision-making after this information.	20.2 (23)	48.2 (55)	27.2 (31)	3.5 (4)	0.9 (1)	114
14. The person will grow as a result of what I have learned	19.6 (21)	57.9 (62)	20.6 (22)	0.9 (1)	0.9 (1)	107
15. I feel very negative towards the idea of supported decision-making		0.9 (1)	4.5 (5)	27.7 (31)	67 (75)	112
16. Supported decision-making is necessary	64.6 (73)	32.7 (37)	2.7 (3)			113
17. If I use supported decision-making I will still need advocacy support	13.3 (14)	46.7 (49)	34.3 (36)	5.7 (6)		105

Appendix 3– Professional Development Training

Results of questionnaire completed by those attending professional development sessions run by Link and Learn.

Please say to what extent you agree with the following statements in relation to the training provided by the L&L project.							
	Agree strongly % (n)	agree	neutral	disagree	Disagree strongly	Please state what would help	N=
1. It was easy to book for this training	67.7 (44)	18.5 (12)	13.8 (9)				65
2. The training content was acceptable and understandable	54.7 (35)	32.8 (21)	4.7 (3)				64
3. The training content was appropriate for my needs	58.9 (43)	30.1 (22)	6.8 (4)				73
4. The training was NOT of a high quality	4.6 (3)			29.2 (19)	66.2 (43)		65
5. The venue for this training was good	47 (31)	42.4 (28)	7.6 (5)	1.5 (1)	1.5 (1)		66
6. The trainers were approachable	73.1 (49)	22.4 (15)	1.5 (1)	1.5 (1)	1.5 (1)		67
7. I did NOT learn a lot from this training	1.6 (1)	3.1 (2)	6.3 (4)	28.1 (18)	60.9 (39)		64
8. All the main questions I had about decision-making have been answered	23.9 (16)	46.3 (31)	25.4 (17)	4.5 (3)			67
9. I now know more about getting people together to support decision-making	35.8 (24)	50.7 (34)	11.9 (8)	1.5 (1)			67

10. I understand what a support group does and how it works*	23.7 (14)	47.5 (28)	25.4 (15)	3.4 (2)			59
11. I will make changes to make a better and stronger support group for the person	35.6 (21)	35.6 (21)	23.7 (14)	3.4 (2)	1.7 (1)		59
12. I do NOT understand choice-making skills better as a result of this course	1.5 (1)	1.5 (1)	4.5 (3)	38.8 (26)	53.7 (36)		67
13. I understand the role of decision-makers better as a result of this training	44.6 (29)	47.7 (31)	4.6 (3)	1.5 (1)	1.5 (1)		65
14. My relationship with other members of the person's support group will NOT improve as a result of this training	1.7 (1)	1.7 (1)	22.4 (13)	43.1 (25)	31 (18)		58
15. The ideas in this course were too idealistic	5.9 (4)	11.8 (8)	14.7 (10)	44.1 (30)	23.5 (16)		68
16. I understand better my role in supporting the person to make their own decisions	35.9 (23)	53.4 (39)	3.1 (2)				64
17. The way I make decisions with the person has changed since the training	13.8 (8)	53.4 (31)	27.6 (16)	5.2 (3)			58
18. I know what other resources are available to support the person in their decision-making	11.8 (8)	64.7 (44)	16.2 (11)	5.9 (4)	1.5 (1)		68
19. I think the person's life will improve as a result of this training	15.6 (10)	56.3 (36)	28.1 (18)				64
20. I feel better informed about what formal service roles are in supporting decision-making	19.4 (13)	58.2 (39)	10.4 (7)	9 (6)	3 (2)		67
21. I do NOT think the support will work for a longer period as a result of this training		7.4 (5)	23.5 (16)	47.1 (32)	22.1 (15)		68

22. I understand better how Guardians can improve the decision making of people for whom they are Guardian.	20.3 (13)	56.3 (36)	20.3 (13)	3.1 (2)			64
23. I understand better when to look for a Guardian and when to look for an SDM	17.2 (11)	48.4 (31)	25 (16)	7.8 (5)	1.6 (1)		64
24. I think this training has stopped me from looking for more formal solutions such as Guardianship in relation to the major decisions and choices for this person.	6.5 (4)	32.3 (20)	35.5 (22)	17.7 (11)	8.1 (5)		62
25. This training has helped me in my decision-making as a Guardian	4.2 (2)	35.4 (17)	54.2 (26)	6.3 (3)			48
26. I think this training will maximise the extent to which the person makes decisions and choices for themselves	28.1 (18)	51.6 (33)	15.6 (10)	3.1 (2)	1.6 (1)		64
27. The person will NOT grow as a result of what I have learned in this course		6.3 (4)	17.5 (11)	38.1 (24)	38.1 (24)		63
28. I feel very positive towards the idea of supported decision-making	53 (35)	42.4 (28)	4.5 (3)				66
29. Supported decision-making is an essential service	64.2 (43)	29.9 (20)	4.5 (3)	1.5 (1)			67
30. Even with supported decision-making I would still need the support of advocacy groups.	25.8 (16)	43.5 (27)	25.8 (16)	4.8 (3)			62
31. I would NOT recommend this training to others.	1.4 (1)	1.4 (1)	4.3 (3)	23.2 (16_)	69.6 (48)		69
Thank you for completing this evaluation form							

Appendix 4

Table showing primary human rights around key issues of decision making for 21 decision makers receiving support from Link and Learn

Relevant CRPD human right article and name	Decision maker number																					Total	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21		
5 Equality and non-discrimination		x	x			x	x	x		x	x	x	x	x	x	x					x	14	
6 Women with disabilities				x			x															2	
7 Children with disabilities				x								x										2	
8 <u>Awareness-raising</u>		x	x			x			x		x	x	x		x	x	x	x	x	x	x	14	
9 Accessibility		x									x												
10 Right to life																							
11 Situations of risk and humanitarian emergencies																		x	x			2	
12 Equal recognition before the law	x							x	x			x		x						x		x	7
13 Access to justice																							
14 Liberty and security of the person												x											1
15 Freedom from torture or cruel, inhuman or degrading treatment or punishment																							
16 Freedom from exploitation, violence and abuse																							
17 Protecting the integrity of the person	x		x			x	x		x					x									6
18 Liberty of movement and nationality																							
19 Living independently and being included in the community	x	x	x			x	x		x		x	x	x								x		10
20 Personal mobility																							
21 <u>Freedom of expression and opinion, and access to information</u>	x																						
22 Respect for privacy	x		x			x								x	x	x			x				7
23 Respect for and the family	x	x							x	x	x	x		x							x		8
24 Education																							
25 Health			x	x				x	x	x			x	x			x			x	x		10
26 Habilitation and rehabilitation												x											

Relevant CRPD human right article and name	Decision maker number																					Total
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	
27 Work and employment																						
28 Adequate standard of living and social protection							x															1
29 Participation in political and public life																						
30 Participation in cultural life, recreation, leisure and sport		x	x						x		x	x	x							x		7

Appendix 5

Link and Learn Program Logic showing original assumptions about the link to outcomes which were not found to hold leading to a different methodological approach for data collections which explored narratives and outcomes rated against addressing human rights.

Link and Learn – Program Logic Draft 21st July 2015

<p>Inputs:</p> <ol style="list-style-type: none"> 1. <i>SDM awareness-raising</i> – people with disabilities and current/future supporters 2. <i>SDM skills development</i> – People with disabilities and supporters 3. <i>Decision support relationship building</i> – sample of 25 people with disabilities and supporters 4. <i>Training</i> to professionals and train the trainer for SDM champions 5. <i>On-line community of practice</i> 	<p>ADECAS Processes (subject to refinement):</p> <ol style="list-style-type: none"> 1. <i>SDM awareness-raising -25 Activities:</i> incorporating diverse engagement (mainstream, specialist media, information sessions) and diverse engagement (people with disabilities, family and supporters). 2. <i>Decision support relationship building - 20 Activities:</i> Group – SDM skills development supported decision-making workshops and individualised: tailored skills development 3. <i>Decision support relationship building – 25 relationships</i> – develop circle of support amongst known and trusted people and supporters (preferably unpaid) - Freely given support to establish an independent and sustainable person centred approach – ongoing mentoring 4. <i>Training</i> – 25 sessions delivered to professionals – smaller number of train the trainer sessions for SDM champions 5. <i>On-line community of practice</i> – Set up a social media community – monitor use and engagement 	<p>Outputs:</p> <ol style="list-style-type: none"> 1. <i>SDM awareness-raising</i> Disability service providers, people with disabilities, family carers, supporters aware of SDM, know the provider, know how to access the service if needed and aware of the on-line community of practice positive attitudes to people with disabilities and to SDM (Method T1 and T3 survey). 2. <i>Decision support relationship building</i> Formative – accessible, acceptable appropriate and quality training, wish to recommend or use again (Method Evaluation of training survey) Summative – Felt choice-making skills and knowledge increase, better engaged with circle, confidence in making decisions together, improved well-being, understanding role of decision-makers, accessing additional resources to support the person and develop their network, perception of sustainability and capacity to resist formal (Guardianship) options (Method Interviews n=7 at T1 – T2 – T3: Survey all 20 at T1 and T2) 3. <i>Decision support relationship building</i> Person with a disability has better confidence and skills in making decisions and is better engaged with circle, felt sense of self-determination Family and supporters better engaged, confident and perceive alternative to Guardianship. Better understanding of role of professionals, better conversion of resources into networks and relationships, increased sense of well-being, person-centred. Method (Method Interviews n= 7 at T1 – T2 – T3: Survey all 25 at T1 and T2). 4. <i>Training</i> Formative - accessible, acceptable appropriate and quality training, wish to recommend or use again – Observation (Method Evaluation of training survey) Summative – Confidence, knowledge and skills in SDM, better relations with Circle; better understanding of their role in securing and creating an opportunity structure through which resources are converted into outcomes; felt sense of support from ADECAS; perceptions of sustainability and outcomes; compatibility with present PCP, case management arrangement and with NDIS. Barrier and supporting factors (Method – interviews with random sample of ten participants including at least two Champions at T1 and T2). 5. <i>On-line community of practice</i> – Coverage of on-line community, knowledge of SDM amongst key stakeholders, potential to use SDM; quality of information provided, response of community to SDM and greater self determination for people with disabilities. (Method – survey distributed through professional organisations, carers organisations and advocacy groups). 	<p>Outcomes:</p> <ol style="list-style-type: none"> 1. Better lives of choice 2. Improved Psychosocial well-being 3. Capability (cf Nussbaum) and personal growth 4. Cost – benefit versus risk 5. Capacity for sustainable circles and SDM skills 6. Positive attitudes to SDM and to decision-making of people with disabilities 7. Perceived growth in positive human rights (economic, social and cultural) 8. Perceived improvement in defending, protecting and fulfilling negative rights (civil and political) 9. Improved social capital – linking, bridging and binding as well as access to resources that lead to flourishing, resilient and
<p>Method relating to Input and Processes:</p> <ul style="list-style-type: none"> • Interview ADECAS staff T1, T2, T3 (<i>inter alia</i> - Planning and strategizing each process; lessons learned and response; producing accessibility, availability, comprehensiveness; perceived outcomes of each process; issues and problems; supporting factors; exploration of one to one work mentoring; issues with recruitment of networks (for circle, amongst professional and organisations, amongst families); perceived sustainability of model; cost and efficiency of model; perceived responses from stakeholders of the initiative). • Collect and analyse all planning and training materials 		<p>T1 – Pre-implementation T2 – Mid way through T3 – End of Evaluation period</p>	