South Australian Supported Decision-Making Training: Adelaide

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Overview

This research brief discusses training conducted by Asset South Australia on its unique program for providing 'supported decision-making'. Asset's model has developed from an initial trial program developed by Cher Nicholson in partnership with the South Australian Office of the Public Advocate. The model was further developed in partnership with the South Australian Health Services Complaints Commission ('**HSCC**'). Asset South Australia has further developed the practice model since the conclusion of the program under the HSCC Supported Decision-Making Project. The HSCC described the program in March 2013 in the following terms:

> The model is centred on a person with a disability, the 'decision maker', and one or more supporters. The decision makers are people with complex needs including physical and intellectual disabilities, with some being non-verbal. Some live in institutional settings and/or are dependent on disability services for most of their needs.
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> The supporters are preferably drawn from the decision makers natural networks, are of their choosing and are not paid workers. The decision maker supported by their supporter makes an agreement/commitment about what decisions they want to make and how support will be delivered. Informal and formal networks are co-opted to form a team around the decision maker to aid with the decisions and to help enact [his/her] wishes. The aim of the team is to connect and mainstream the decision maker outside of disability services. Their progression is then not dependent on finances or service provision.
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> The model works with what is possible rather than what is available in disability services. It aids in maintaining and renewing the social relationships of the decision maker. The model focuses on current and future opportunities for the decision maker, [his/her] wishes and dreams rather than [his/her] experiences, or the limitations of organisations that work with them. Cher's role in the project is to train, mentor and coach disability service workers to run the SDM processes.

Initially, there were eight key disability service providers taking part in the training and coaching/mentoring program. They included a mix of government and non-government services, a local council and two overseas participants. Under the training for the purposes of this audit, two main bodies were involved – one non-government organisation (Cara) and one government agency (Strathmont). The overview continues:

> Paid peer consultants with lived experience of disability who took part in the previous Office of the Public Advocate SDM project, assisted with the training. The trainees reported that meeting the peer consultants was a powerful way for modelling the practise of SDM.

> Similarly, the paid peer consultants reported that they felt affirmed and valued by the process. A 'Community of Practise' led by Cher was held monthly with guest speakers and discussions to advance the skills, experience and knowledge of the trainee facilitators. The model allows all parties to measure success in a different way. Success may not be the enacting of a decision, but creating an environment where decisions can be made and rights have been upheld.

The 2015 evaluation of the project provides greater detail about the model.

Each decision-maker receives the support for a **six-month** period**. Meetings occur once a week.** Within the six month period, a facilitator is meant to assist a decision-maker to identify supporters, establish a decision-making agreement, and begin enacting decisions. At the end of the six months, a person may wish to create another agreement and continue the process. Some members of the first trial are today on their fourth or fifth agreement.

The support centres on four areas of life:

- Finance
- Healthcare
- Accommodation
- Lifestyle

The aim is to explore these four areas and discuss where the person is feeling dissatisfied and may wish for some support.

The Participants

The training occurred at a major non-government disability service provider in South Australia, Cara. Five disability support workers attended from Strathmont, which is a government run service, and one support worker from Cara. Five Japanese participants were also attending the training. They were part of a university research group and consisted of a 'care program coordinator', a lawyer who also worked as a guardian, an disability welfare academic, a mother of a daughter with a disability, and a businessperson who was seeking a life change and was researching disability rights.

All members were interviewed prior to joining the training program. They were asked about 'best interests', 'expressed wish' and other ideas relevant to the course, including being provided with scenarios. Some applicants were turned away.

The Trainers

Cher Nicholson led the training. Her professional background is in nursing, psychology, counselling, disability advocacy, and so on. She was assisted by two co-trainers, Debbie Knowles and Liz Garret. Both have over three decades professional experience in disability services, including as direct support workers. Both began working in large scale, standalone institutions, and discussed the transition to an approach based on the expressed wishes, will and preference, from decades of working in a 'best interests' model. (They shared a number of insights on how workers who have a longstanding 'best interests' might transition to a 'will and preferences' approach).

18 'peer-consultants' were paid to present at the training. All had received supported decision-making arrangements under the program. Some openly discussed their decision-making agreement while others provided assistance to trainee facilitators to improve their communication skills.

Other guest speakers included representatives of the Office of the Public Advocate, the South Australian Civil Admin Tribunal, CEO of the Julia Farr organisation, the Cara media officer, family members who were in a support role and current facilitators.

Terminology

'Decision-maker' refers to the person receiving support to make decisions.

'Supporter' refers to a *non-paid* informal supporter who enters into a support contract with the decision-maker. The supporter is elected by the decision-maker, and is meant to assist in gathering information, communicating and enacting decisions.

'Facilitator' refers to the paid professional who assists the decision-maker to enter into a support agreement. The facilitator may provide assistance to the person by: explaining the process, inviting the decision-maker to elect a supporter or list of potential supporters, reaching out to potential supporters, facilitating discussions between the decision-maker and the supporter, referring decision-makers and supporters to appropriate services (e.g. housing services, domestic violence services, sports facilities). As the 2015 evaluation of the project notes, '(f)acilitators act as coaches for supporters, ensuring that they develop the knowledge, skills and attitudes necessary to support the individual in making their [sic] own decisions.'

'Coach/Mentor' is the person who conducted the training to the facilitator and provides a 'coaching/mentoring' role. The trainer may attend the first couple of meetings, or may assist in preparing the supported decision-making agreement. The trainer's role is to uphold the integrity of the supported decision-making approach. The 2015 evaluation noted that, for facilitators, 'mentoring was a crucial element in the development of skills and in developing the confidence to put them to use.'

'Expressed wish, will and preferences.' The program draws on the term, 'expressed wish, and will and preferences.' This is positioned in contrast to a 'best interests' approach. Expressed wish is distinguished from will and preferences. Expressed wish would typically take the form of explicit communication about a preferred action. Will and preferences is something less clear, though remains an expression of a person's agency. From this view, some people may not be able to express their wishes. However, all people can express their will and preferences. The focus of any support, therefore, must be to discover the will and preference of the person.

Content

Week 1 provided an overview of the South Australian supported decision-making model, including in relation to international human rights law, and domestic law, policy and practice. They offered an introduction to Article 12 of the CRPD, and a number of guest speakers outlined current substituted decision-making law and policy in South Australia. Much time was spent unpacking the difference between 'best interests' and 'expressed wish, will and preference.' Activities helped explore these differences.

Facilitation is Key

An important point is that Asset was training people to *facilitate* support for decision-making, rather than giving direct support to people to make decisions. It was not simply a matter of offering different options for a person to choose from. The facilitator essentially created space for conversations about the person's expressed wishes, and for exploring his or her will and preference, including his or her hopes and dreams. Actions were then *delegated* by the facilitator to informal supporters, professionals and others, to enact these wishes.

One exemplary comment by Cher was:

> If you're thinking "how", how can I support this person to solve a problem – like addressing an unhappy relationship between housemates – then you're probably in a 'best interests mode'. The focus should come back to assisting the person or his or her supporters to come up with those actions.

Purposeful Conversation

The trainers stressed the importance of interviews and conversations being purposeful – 'not just chatting'. There were less 'how' or 'why' questions and more questions focused on hearing from the person, having his or her voice at the centre of the conversation, with an aim to uncover his or her wishes, preferences and dreams for the future. Questions often started with the words 'Tell me more about…' or 'What is it about X that you enjoy/don't like…'

Mentoring and Avoiding Problem-Solving/Rescuing

The role of the mentor (which at this point is Cher) is to provide guidance to facilitators, including providing technical assistance, lending credibility and emotional support to the facilitator, and upholding the integrity of the supported decision-making approach. An example of the key role of the mentor is captured in the following comments of a trainee facilitator:

> …when this new model was put forward, I remember Cher having to educate me about three or four times on what 'expressed wish' meant…and she would say, "No, actually, that's the 'best interests' model. You need to work towards the decision maker's express wish." So that was a change. I had an attitudinal change there.

Trainee facilitators were encouraged to resist the urge to problem-solve. Instead, the aim is to clearly identify the expressed wish, will and preference of the person, and to capture that in the decision-making agreement.

As well as receiving ongoing coaching from the mentor, there was a monthly meeting between the facilitators at the service. This would help them to share information and sometimes invite speakers to present to the various facilitators. This was useful for ongoing training, reflection and sharing knowledge.

Stories of Barriers and 'Best Interests'

One young woman – who received intensive support – wanted to eat a particular food, as she had done her whole life. She did not have a swallow reflex. On the advice of a doctor and speech pathologist, workers were informed that she should not be given this preferred food because it would put her at risk of choking. This was based on the risk factor associated with this food and people who do not have a swallow reflex. The workers felt torn between the expert opinion and her expressed wish. The woman held a meeting with the doctor, speech pathologist and the workers and agreed to sign a form waiving the workers right to sue, and clearly establishing her wish to eat the preferred food, knowing full well the associated risks. This was not enough according to the service and the professionals. In the end, she asked for an individual assessment of the choking hazard. The independent assessor noted that although there was a risk associated with the eating of this particular food for people who did not have a swallow reflex, this risk was a generalisation. Some people – including this particular woman – was not at risk to the same extent and her workers were then able to assist her to eat this desired food.

One supporter told the group how she had gotten pregnant at 30 and was told she was going to have twins. She was a soon-to-be single mother, a wheelchair user, and a woman with cerebral palsy in 1989 in South Australia. Her parents and the disability support agency did not wish to support her and encouraged her to terminate the pregnancy. Instead she 'fled to Melbourne' and received support from her sister during the pregnancy. She continued on to raise the two children and is now a grandmother, and had taken part in the supported decision-making process as a supporter of a young woman with extremely complex communication support needs.

The Importance of Referral and Recognising Limits of Support

Cher also emphasised the need to identify when a facilitator should refer to other services, and to recognise his or her own limits. If an urgent issue came up, such as domestic violence, then the role of the facilitator is to refer to domestic violence services. If a person is in the midst of a crisis then it may be necessary for the facilitator to suspend the meetings for a time, and to reconvene when the crisis is over. The facilitator must make the call whether or not to suspend the support relationship or to amend the decision-making agreement. Suspension didn't occur in all crises that have emerged so far. For example, one decision-maker continued to have her meeting with her supporter even as she was hospitalised and eventually went on to palliative care, before eventually dying. The support meeting was used as a means to uncover her end-of-life wishes.

Differences between 'Expressed Wish' and 'Will and Preferences' – Uncovering Meaning

Trainee facilitators were invited to consider the differences between 'expressed wish' and 'will and preferences'. Although expressed wish was paramount, it was not always taken as an absolute, as the person's will and preferences might differ from his or her expressed wish. For example, a participant may say he or she wants to leave the supported decision-making arrangement. This

happened on one occasion when the person thought the process was causing distress to her parent. People have an absolute right to exit the program. However, facilitators were encouraged to follow up with someone who has said they want to leave the program. Often, a wish to leave the process is made in the 'heat' of a difficult meeting, and after some time passes, the person is often keen to keep going with the process – this is what occurred with the woman who was concerned about her parent's distress.

Sometimes it appeared that a decision-maker was expressing a wish because he or she thought this was what a supporter wanted to hear – seemingly in conflict with his or her 'deeper' will and preference. Many people with disabilities have not really been asked what they want, so expressing wishes may not come easily. The facilitators are asked to look for when a person is saying something to please others. A number of communication techniques are then drawn upon; for example, asking person to elaborate on their expressed wish, gently confronting some contradiction in their wishes ("on the one hand you are saying X, but on the other you are saying Y. What do you think about that?"), and so on.

As such, expressed wishes are not adhered to 'blindly, but are considered in the context of a decision or issue. Consider the following example:

> A man expressed the wish to own a dog. After further discussion he indicated that he didn't wish to clean up dog excrement in his backyard. When gently confronted with the contradiction between these two things, the conversation turned to why he wanted a dog. He said he wanted a dog to 'bark at people who knock on my door at night', and who 'come into my garden'. It became apparent that the man did not feel safe in his home. The conversation turned from having a dog to improving home security.

An important means of discerning between expressed wish and will and preference, was getting to know the person well, including others that the decision-maker knows well. Trust is crucial, and it is important to keep relationships with supporters and family intact.

Communication

Excellent communication skills were perhaps the most essential requirement for good facilitation. A decision-maker may be non-verbal, while another may be 'over'-verbal; that is, talking a lot, jumping from topic to topic. In either case, drawing the focus to a person's will and preferences can be a challenge. Where a person is speaking a lot, the advice was to not 'get caught in the story'. Instead of focusing on content, the most effective communication approach would be to reframe so as to draw attention back to wishes and preferences, and focus the meeting. One method would be to empathise by trying to summarise how the person was feeling – e.g. "you feel frustrated?" – instead of focusing on the details of the story. Often, this would affirm the person's experience and could offer a 'launching pad' to consider wishes for future action to remedy or prevent the frustration. This technique was referred to as simply, 'reflection of feelings', and was credited as being one of the most important communication skills to use.

'Active listening' was a key part of the facilitators role. A few techniques were practiced (and in week 2, peer consultants assisted with this). These included summarising, paraphrasing, echoing, etc.

Another communication technique was to ask whether a difficult matter could be set aside until after the meeting. For example, a parent attends a meeting as a supporter for the first time and is infuriated because they feel the facilitator is intruding on his or her daughter's life and giving her false hope. The facilitator might politely offer to discuss those issues after the meeting but ask that for the short time they have for the meeting – which usually lasts an hour – the focus might stay on identifying the person's wishes. Another example would be a decision-maker stating in a meeting that she had a big argument with her parent and that this was on her mind. Again, the facilitator is discouraged from seeking to mediate the conflict and instead, encouraged to ask whether the conflict could be set aside. After all, the purpose of the meeting is to address the decision-making agreement and to bring the focus back to the wishes and preferences of the person. The facilitator might even refer the parent and son/daughter to some kind of mediation service or some kind of family counselling service.

What challenges arise when family members – or any two people – are 'enmeshed' with one another?

Decision-makers may have extremely close relationships with family members. Facilitators must be skilled in discovering the differences between the decision-makers wishes, will and preferences, and that of family members. This can be especially difficult when the decision-maker says one thing in front of a parent, for example, and another thing when the parent leaves the room. Facilitators must be skilled in negotiating these differences and in promoting communication. For example, one peer consultant, a 22 year old woman, had complex communication support needs and her father was a key supporter in her life, assisting her in almost everything she did. The peer consultant said she wanted to eventually move out of home, but could not face saying this to her father, with whom she was in a very close (and supportive) relationship. In discussions with the facilitator, the young woman wanted to hold off on telling her father until a later date. The wish to move out of home was not high on her priority list so she could afford to let the issue rest for the time being.

What happened when parents were reluctant for a potential decision-maker to be involved?

This situation was not uncommon, especially at the beginning of the support process. There are no formulas for building relationships with parents or other family members. A one-to-one approach has been most effective. It was not unusual for a decision-maker *not* to nominate a family member. However, even if a parent is not elected by the person the facilitators can continue to involve parents, with the decision-maker's consent. This would include providing options for sharing information on how the support is going (e.g. weekly emails, phone calls, monthly updates, plain language info about the support). One family didn't want to be involved at all. They had seen numerous new approaches to service delivery come and go over the many years in which their relative was receiving support. But after a few weeks they noticed a positive difference in their son's life and became involved. They are now, according to Asset trainers, 'passionate advocates' who volunteer time to help train new facilitators.

Community Development

Another key role of the facilitator was to perform a type of 'community development'. The facilitator was often in the role of following up on a person's expressed wish by communicating that expressed wish to relevant people in his or her life – often outside of disability services. This might be inviting a

supporter to enquire with a local sports club or faith-based group about a particular wish, or it might be about calling a local organisation and inviting (or, ideally, asking a supporter if they would invite) someone to come and speak to the person about the organisation.

For example, one decision-maker wanted dog. He had a supporter – *not* the facilitator – invite someone from a dogs home to meet the decision-maker at his supported decision-making meeting. The dogs home worker brought two different dogs to the meeting to discuss what would be involved in looking after a big, active dog, compared with a less active, smaller dog. Another facilitator, connected a decision-making, who was making electronic music, to a musician who she knew in her personal life. They are now collaborating. Once again, one of the aims of the facilitator is to "connect and mainstream the decision maker outside of disability services."[1]

'The facilitator communicates wishes and preferences to those that matter.'

The facilitator was also often a resource for third parties who had concerns. So, for example, facilitators might assist disability support workers who felt uneasy about supporting a decision-maker with a particular decision, by offering to enquire about their duty of care in relation to a person's expressed wish. The facilitator can get in touch with the disability service management, or understand legal obligations so as to come up with solutions that meet both needs. Another example was where a decision-maker had decided on an option which meant she left her day service while she explored an alternative thing to do in her day. The day service told the parents that she would lose her funding if she left the day service. This turned out to be incorrect, but the parents were justifiably worried. The facilitator enquired about this with the relevant government department, and informed the service that its message to the decision-makers parents was incorrect, and conveyed that to the decision-maker and her family. Day services can be very resistant to change. The facilitator could act as advocate, or as an 'interpreter' who can clarify as to what is and isn't possible in services.

Inviting others to be involved: Keeping it Simple

When inviting supporters or others (such as some outside community member or professional with knowledge) it is not necessary to explain the full supported decision-making model, including its underlying philosophy, basis in international human rights law, and so on. Facilitators simply need to say, 'I'm doing some work with this person, and we were wondering if you would like to come and speak to us because X has indicated that you are someone who might help'. Keeping it simple is important. At first facilitators sought to explain the whole model to everyone but it quickly got out of hand, with parents and others ringing the services and wanting to ask management what is going on, seeking lots of written material in a panic. If supporters ask for material, it should be available, but insisting on it in the first place can cause over-complication.

Recording Benefits to Third Parties

Cher also encouraged everyone to make a note of the third parties that engage with the supported decision-making program. This is important for the purposes of funding (by highlighting how many people can benefit from the process) and accurate reporting (by identifying the full extent of the

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[1] Health Services Complaints Commission, 'Overview of the HCSCC Supported Decision Making Project', South Australian Government, 2015, 1.

impact of the program). The initial Office of Public Advocate trial evaluation for the only referred to the 26 'decision-makers', but the reality was that numerous third parties benefited too, including family service providers and others. Further, in seeking to identify the 26 decision-makers who were appropriate for receiving support, over 80 people with disabilities were consulted in initial stages of the project. Many could be seen to have benefited by taking part in the initial consultations and by observing some of their peers complete the process.

Non-judgment

Trainees were encouraged to stay neutral, not in the sense of being passive or unfriendly, but in suspending judgment. Facilitators could encourage the person by asking more questions with an air curiosity and respect. At the same time, they were even encouraged to celebrate milestones in the person's decision-making to boost confidence, and so on. However, they were discouraged from statements such as 'well done' or 'that's good'. These statements reflect the opinion of the facilitator, which should not really come into the support.

The Importance of the Facilitator

Interestingly, according to Cher, Asset's supported decision-making model has been criticised for investing too much money into the facilitator. From this view, the investment is going to the facilitator rather than to the person's will and preferences. Cher's response is that without skilled facilitation people's will and preference will remain hidden.

Peer Consultants

Week 2 was far more 'hands on'. Over 18 peer consultants provided assistance with the training. Peer consultants had their cab charges paid for, and were given honorariums in the form of gift vouchers at preferred stores. They had explored paying people but the administration costs were high, taxation caused problems and the payments could compromise the person's disability support pension. They settled on gift-voucher honorariums.

Peer consultants were assisted by the trainers with preparation and debriefing. The extent of this preparation and debriefing was not explained in detail to trainees. However, Cher made it clear that the peer consultants were well supported before and after presenting to trainees – and that anyone considering using peer consultants in their training should ensure that they receive sufficient preparation and debriefing.

Practice considerations

Communication techniques were discussed in greater depth:

- Focusing
- Silence
- Gentle confrontation of contradictions
- Summarising
- Pictograms
- Reframing negative comments to positives about future action or strengths

Keeping communication brief and simple was emphasised again and again. As a general rule, for every sentence of the facilitator, the decision-maker ought to have made five.

Presenters

Peer Consultants

As noted, over 18 peer-consultants attended. These people had had diverse experiences with disability services, in life, and with their particular supported decision-making agreement. According to the trainers, it was not necessary for facilitators to know what the person's disability was, simply to work to discover their wishes and preferences. If anything needs to be known, the most beneficial thing to know is what kind of support is useful to the person. Typically, the person or their supporters know this.

Some members of the group were older, others were in their late teens when they started their support. Some peer consultants were verbal, others were not. Some had physical disabilities, some had cognitive disabilities. Some lived independently and were employed, others had profound disabilities and lived, long term in 60-person disability institutions. One peer consultant was legally required to have 24 hour supervision because he was 'licensed' by an South Australian court (i.e. placed on a supervision order). The diversity of experiences and communication styles among the group reinforced the message that no one method of support will work for all people. Every person will have different wishes and preferences, hopes and dreams, support networks, challenges.

Office of the Public Advocate (2 representatives) and Lin Gilfillan, South Australian Civil and Administrative Tribunal (SACAT)

Two representatives of the Office of the Public Advocate presented on the role of the Office – public guardians, arbitration of family disputes, registration of family guardians. Their hotline is typically used by services and third parties concerned about a person's mental capacity, or about a family dispute. Lin Gilfillan discussed her role as a member of the SACAT.

All three presenters stressed that guardianship arrangements typically addressed third party concerns – concerns about protection from financial, physical, sexual abuse; concerns about family disputes.

Interestingly, they argued that the new advanced healthcare decision-making act appears to have reduced the number of guardianship orders because it has expanded the number of people who can 'consent' to healthcare decisions on behalf of a person with a disability, or with support needs. Under the Act, persons responsible for 'day-to-day health support' can assist a person to give consent to (some) medical decisions. This is not to say that people are having medical work done against their will. Instead, it appears that consent is being drawn from the person's relations and trusted professional supporters so as to avoid the requirement to have a guardianship order clarify who can consent on behalf of the person.

The presenters suggested that the SACAT had recently shifted from a more protectionist/welfarist reading of the Guardianship and Administration Act (SA) to a greater focus on equality and rights.

The majority of substituted decisions that occurred against a person's will and preferences are related to accommodation (particularly older people), healthcare (around psychosis) or liberty and

movement in order to 'prevent' a person from spending time with someone who is exploiting and abusing them.

[Lorna Hallahan](#)

Ms. Hallahan gave a general sense of the social model of disability and discussed historical devaluing of people with disabilities.

Margaret Brown, University of South Australia

Adjunct Research Fellow who has worked on adv. directives and was instrumental in developing the South Australian advanced directives policy. Brown was Cher's mentor.

Dianne Chartres, Consultant, formerly Office of the Public Advocate, South Australia

Di Chartres, a co-designer of the original trial, has a background in policy, criminal law, disability and community development. Chartres established the mental impairment diversion program in South Australia.

In Chartres view, guardianship is about protection and is always about third party concerns, e.g. services concerned about liability, family concerned about property, community members concerned about abuse. In her [Churchill report](#), Chartres final recommendations characterise supported decision-making as a matter of 'human development'.[2] Chartres originally noted that supported decision-making should not become 'professionalized' but that nevertheless 'clear guidance is required on the issues, approach, support and context for both people with disabilities and their supporters.'[3]

During the training, she expressed concern that 'supported decision-making' is becoming a noun, used to refer to an *intervention*. Instead, it ought to be used as a verb, to describe a *process*. She asked whether supported decision-making is even the right word, given that much of the process is about providing the person with support more generally – support in line with the CRPD, of which only a portion is about decision-making.

Robbie Williams, former CEO of Julia Farr

Julia Farr is a large disability service in South Australia. Williams was discussing what a good life looks like. He drew from a number of popular theories of disability, such as social role valorisation, normalisation, the social model, etc. He broke down what it means to belong to community and highlighted four types of 'capital' typically denied to people with disabilities:

- 'Personal capital'
    - Courage, self-worth, strengths and gifts, potential to grow, hope for the future, to own decisions
- 'Knowledge capital'

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[2] D Chartres, 'To investigate supported decision making practices, capacity building strategies and other alternatives to guardianship' The Winston Churchill Memorial Trust of Australia, 2011, p.3
[3] Ibid.

- o Access to information, opportunities to learn new things, making the best of the resources available
- 'Material capital'
  - o Personal material capital (belongings, assets, financial wealth), public material capital (swimming pools, museums, parks, etc.),
- 'Social capital'
  - o Connections to people important to person, opportunity to meet new people.

Such things are often – or even mostly – unavailable to people with disabilities on an equal basis with others. The supported decision-making program seeks to keep an eye to these things: fostering informal connections, encouraging and facilitating engagement between person and community organisations and resources, boosting courage and confidence to make decisions, meet new people, identify strengths, and so on.

Jayne Barrett, CEO of disability organisation

Jayne Barrett is a CEO of 'Circles of Support' and discussed 'circles of support', 'micro-boards' and 'micro-businesses'. There is a lot of information on these approaches online. The important thing to note was that Barrett was working avowedly in the 'best interests' approach. Cher included her because they have been long time colleagues and because she wanted to show alternative approaches so that participants could make up their own minds.

(I can elaborate if needed, and have made a table in my notes of the differences between these practices and supported decision-making. However, I should note that not all Circles of Support operate in a 'best interests' approach. This was the particular approach taken by Barrett's group but cannot be generalised to all circles of support or micro-boards.)

Current Facilitators

We were joined by about ten current facilitators who have assisted a decision-maker to enter into a supported decision-making agreement. Some of the reflections of facilitators included the following:

- Management didn't know about supported decision-making and were indifferent or even resistant to the program so there weren't many people at their first session for potential participants.
- Some resistance from parents as they had been through so many 'new' approaches and disability service fads. Programs to 'improve lives' are often rolled out or trialled; workers are often as sceptical as families and individuals.
- A number of positive flow-on effects came about because of the agreements. One participant had a sibling with a disability who she was supporting, and employed some of the same support measures.
- Confidence rose in one participant, who said at the beginning, 'I can't do anything without my sister or parents.'
- One young man who was a decision-maker lived beside his grandmother, who was his supporter, and she had dementia and needed her own support; the facilitator assisted them to discuss important things in the young man's life, but it also appeared to help

her be clearer about her wishes (lesson: some supporters will not have 'ideal mental capacity' and that's OK).

- 'As a facilitator, my job was to create a network around the decision-maker.'
- Getting everyone together was very difficult.
- 'Management can get protective of an individual'.
- 'There is a need to 'think big' – dreams have not happened, never been considered, or have been spoilt.'
- One decision-maker was a 39 y.o. man on full guardianship on a lifetime 'license' (which is a supervision order) for murder. There was a lot of stigma, and a lot of doubt from staff and family. Since starting the supported DM agreement there have been no cases of violence, 1 year on, which is significant given past experiences. The agreement has seen him reconnecting to family, and the man has his first friendship outside of paid support workers, fellow disability support clients and family, in his life. He says 'no' when he never used to—frustration appears to have decreased. (This man later joined as a peer consultant to assist with communication training). He now has a library membership and is enrolled in a TAFE course.
- Another decision-maker, a 21 y.o. man, listed a number of supporters. Facilitators reflected that sometimes it's not good to have too many supporters in the meeting. Originally, the man's father thought he needed to be there for all communication but the young man is communicating verbally.
- One decision-maker ended up in hospital and was really unwell. We suggested suspending meetings, but the person insisted, and in fact, afterward, having had a distressing experience of having their speaking board taken from him, he used the supported decision-making meeting to create an advanced healthcare directive to ensure this did not happen following hospitalisations in the future.
- 'It is challenging to encourage a person to 'think big' when their world has been shrunk. You have to be entrepreneurial and do some detective work in this role'.
- Sometimes they choose 'supporters' who you think, that's not a good idea, and it ends up working out. Even one case in which it appeared that the person was having all of their money – bar a small amount – being withheld by a relative whom this decision-maker chose as a 'supporter', they wanted to explore the person's wishes and preferences and to discuss what was happening with finances rather than calling the police or the Office of the Public Advocate. They informed the service provider and asked the case manager to explore, so that it was a separate matter to the meeting, which stayed focused on discovering and promoting the will and preference of the person.
- Independent evaluations have consistently found that decision-makers have improved 'courage, confidence and happiness' following supported decision-making agreements.
- The more contained someone's life is within institutionalised services, the smaller the decisions the person often starts with. One decision-maker sought to buy a tube of preferred toothpaste as one of her first and most personally significant decisions. From here, her decision-making expanded to 'bigger' life decisions.
- Some meetings occur in community spaces, libraries, gyms, high schools. The aim here is to open opportunities for community connection. (e.g. "While we're here did you know you could borrow movies, magazines and books from the library for free?").

- Monthly meetings would be held between any facilitators who could attend, in order to build 'a community of practice' and provide opportunities for further learning, information and knowledge sharing, and so on.

ACTIVITIES

The training included activities designed to draw out the distinctions between supporting and rescuing, between best interests and will and preference, between charity and rights. Other activities sought to promote 'narrative' and 'strengths-based' approaches to support. Some were role-play, while others were simply group discussions with people who had received decision-making support. Family members and other supporters attended, and answered a number of questions by the group.