Redefining capacity

SDM does not involve any testing of functional capacity; instead it is built around the presumption that everyone who can express a preference and communicate their preferences can and should be able to direct their life path. This is also known as the right to self-determination. In this model competency is attached to the process not the person. SDM relies on the facilitator’s ability to respond to the wishes of the Decision Maker rather than the Decision Maker’s ability.

Key ingredients

Participants must self-select; no-one should be coerced into an SDM agreement.
Decision Makers choose their supporters from their natural, unpaid network, to avoid conflicts of interest.
All roles are clearly defined, including the facilitator and trainer.

Agreements last for a fixed time period and are highly individualised to each person.

Rights and responsibilities are those of the Decision Makers.

Esentially the Decision Maker’s expressed wish, will and preference are respected. Best interest decisions by others are not acceptable.

The Decision Maker needs to be able to agree to not act on their decisions before they use their chosen support.
Supporters and their team have to agree that the Decision Maker has the final say.

Expressed Wish not Best Interest

Sometimes it can be hard when the people we care about most want to do something that we feel isn’t necessarily in their best interest. However some of the most valuable lessons in life are those that we make by discovering what we don’t actually want, even if we originally thought we did. Supporters are there to listen, reflect, respect and empower. If we always try and rescue or take over, then people will never be able to learn how to decide what is best for them and identify their unique life path.

Previous SDM projects in South Australia have found that participants have experienced increased confidence in making decisions and that the capacity of both the person and their support network has been enhanced.

Safeguards within the SDM model:
Regular mentoring & supervision.
Clarity of roles.
Involving whole support network.
Maintaining relationships.
Connecting to local community.
Adhering to services policies and procedures.
Police checks as warranted.
Decision Maker more invested in decisions being made.

More involvement in decision making has shown better satisfaction in outcomes and less concerning behaviours. This training is also being independently evaluated and has health ethics approval.

The supported decision making project is running from September 2014 to June 2015. During the project, each trainee facilitator can only work with one person at a time so it may be that if there are several people who want to take part that they will need to wait a little while before they can begin. At this stage it will also only be with Decision Makers who are current clients of the trainee facilitator in the project. The emphasis is on the ability and capacity of the trainee facilitator rather than the ability of the Decision Maker.

The trainee facilitators are being trained by Cher Nicholson from the Health and Community Services Complaints Commission. Cher will attend the meetings to help everyone learn how it works. Once the project has ended Cher will stop attending, but the team will keep meeting to continue to support the decision making process and uphold and progress the Decision Maker’s expressed wishes into the future.

If you require further information it is best to get this information from Cher Nicholson as the service providers at this stage are trainees in the model.

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Supported Decision Making Information Booklet
A Guide for Paid Staff and Professionals

A Supported Decision Making model has been developed in South Australia to meet the future legal requirements under the UN Convention on the Rights of Persons with Disabilities. Article 12 of the CRPD says that all people should be able to make their own decisions and that if they need help to make decisions, they should get the support they need, instead of someone else making the decisions for them.
People seek support from people they know when they have decisions that are important to them to make. Thinking things though with people we trust can help us decide what the best option for us is.

The challenge and main principle of Supported Decision Making is to change our ideas from Best Interest with good intent to working with and for the Expressed Wishes and preference of the Decision Maker (person with disability).

This project invites people who would like to make some decisions about what their life might look like and to choose one or more trusted supporters to help them make these decisions in a way that suits them. In this model the trusted supporter cannot be a paid worker in direct service delivery of the decision maker. Once all agree, the decisions and support strategies are written down as an Agreement and commitment. A team is then formed around each person consisting of family, friends, service providers and community who are in a position to uphold and progress the wishes of the decision maker. The Agreement is not intended to last indefinitely but instead is to help establish a long term supportive environment in which the Decision Maker can continue to direct their own life. It is also a commitment by all parties to uphold the Decision Maker’s wishes.

It is up to the Decision Maker if they want to exclude anyone from their team. They are counselled about the possible effects of exclusion but the final decision is theirs.

There are four phases in the SA Supported Decision Making model:-
1. Recruitment of the Decision Maker and then their chosen supporter/s
2. Agreement/Commitment
3. Establishment and team building
4. Exit and sustainability

Examples of types of support:

Helping find out what the options are, going to visit places to get information and maybe just checking them out to see if that is somewhere you might go.

Putting the information into a format that can best be understood.

Repeating information more than once to help remember it.

Going through the good and bad points of each option and thinking about what the consequences might be.

Offering the time necessary to give a good view of the decision being made.

Thinking about how the different options match up with what else is important to the person.

Giving time to think about the options and/or setting a deadline.

Knowing when it is a bad time and coming back later.

Regularly checking back in to make sure they are still happy with the decision they made.

Helping them look at the decision and where it fits in the context of their life.

Support with seeing how the decision may affect others in their life or might change relationships.

Looking carefully at the responsibilities that might come with their rights and the consequences.

Offering a range of thoughts for them to consider maybe with many people before they make their decision.

Supported decision making can be any decision and below are some examples that previous Decision Makers chose.

Supported Decision Making may enhance other person centred models (PCP)

In other PCP the locus of control tends towards the Service and choices are largely based on what can be provided. SDM uses natural relationships and promotes non-service options available to all citizens of the community.

In SDM the Decision Maker has the last say about what direction they want their life to take and supporters and service providers support that vision. SDM works to promote decisions that are not dependent upon finance or service delivery.

Examples of types of decisions:-

How you spend your time – doing things you enjoy with people you like. Disconnecting from things that you do not want to do anymore.

Where you spend your days – doing things that you are good at or want to get good at.

Choosing when, where, how and who you spend time with.

Where you live and who you live with, now or in the future.

Your health – how you want to stay as fit and healthy as possible as well as decisions that you need to make if you get sick.

Relationships – who you want to spend special time with or finding someone new.

Ending relationships that you do not want to be in anymore.

Working out if you want to do things in a group or alone or with other people with disability or in the community in mainstream services.

Taking part in events or experiences that you have not done before such as holidays, rock concerts, sport or theatre and arts.

Having the right to make decisions you want and not necessarily those that others make for you as everyone else in the community does.

Having the right to not have decisions dependent on service delivery or funding but to explore all options with support.

Having the same rights and responsibilities as all others in our community.

For those Decision Makers who go ahead and join the project they have to agree to use the model and the team before making the decision.

For the supporter and the rest of the team they have to agree that the Decision Maker makes the final decision even if they do not agree with the decision.