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HCSCC Supported Decision Making Project

The HCSCC Supported Decision Making (SDM) Project is part of HCSCC's ongoing commitment to improving the safety and quality of services provided to vulnerable people with disability, as outlined in the "*Report on HCSCC's role in contributing to improving the safety and quality of disability services provided to vulnerable people*" in March 2103. Please see links below to HCSCC reports. This report overviews HCSCC's concerns about the ability of service providers to enable service users to enjoy their full rights as provided in the HCSCC Charter of Rights and the United Nations Convention on the Rights of Persons with Disabilities. Article 12 of the Convention, *Equal Recognition before the Law*, describes the right of a person with disabilities to make their own decisions with support of their choosing. The fundamental intent of Article 12 is that the practice of workers and others, should reflect that people with disabilities can make their own decisions, that they can choose their supports and that all parties should work according to the person's expressed wish, will or preference, rather than decision making on their behalf in their best interests.

The SDM project originally began as a pilot project in the Office of the Public Advocate (OPA) during 2010-2012. The OPA SDM project was coordinated by Cher Nicholson who is now leading the HCSCC SDM project. The OPA project was initially funded by the Julia Farr MS McLeod Benevolent Fund and its purpose was to develop a model of practise that would enable the intent of Article 12 of the UN Convention to be into practice. Evaluation of the OPA project was well received and there is national and international interest in the SA SDM model. In May of 2013, Cher Nicholson was invited to Ireland where she presented the SA SDM model for Amnesty International . The SA SDM model has now been replicated with very similar positive results, in small numbers, in Canberra, Australia. The University of Galway, Ireland, uses the SA SDM model to teach and debate SDM and the practise of Article 12. Please see link for information about the OPA SDM project.

In August 2013 HCSCC employed Cher Nicholson to extend the work started with the OPA SDM project. There will be two rounds of activity in the HCSCC SDM project. The first round commenced in October 2013 and will close in May 2014. The second round will commence in August 2014 and will close in April 2015. HCSCC has commissioned an independent evaluation of the project. Cher's role in the HCSCC SDM Project is to train, mentor and coach disability service workers to run the SDM processes. Eight key disability service providers have taken part in the training and coaching/mentoring program. They are from government and non government services, with one local council taking part.

The HCSCC SDM Practise 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 people non verbal. Some live in institutional settings and/or are

dependent on disability services for most of their needs. The Supporters are preferably drawn from the Decision Makers natural networks and are of their choosing (not paid workers) who commit to support the Decision Maker to make their own decisions, in areas of their own choosing. They do this by offering support with decisions when asked and provide support by offering information in a way that the Decision Maker can understand; explaining the information in a format that is appropriate and within the context of that person's life; helping them to realise their decisions by going to other resources or persons who may be able to help progress their decision making. Support is specifically tailored to each individual Decision Maker's needs. If there are no natural Supporters identified by the Decision Maker, Supporters are found through a selection process that means it is still the Decision Maker's choice.

The HCSCC SDM Practise model works from a strengths base approach and aids in maintaining and renewing the social relationships of the Decision Makers. The model focuses on current and future opportunities for the Decision Maker – their wishes and dreams rather than their past experiences, or the limitations of organisations that work with them. The model operates by focussing on the Decision Maker as a member of their wider community. With the support of the SDM structure, the Decision Maker is put in the driving seat of their own life. Although a Decision Maker agrees to not act until the support has been offered, they know that the final decision rests with them. The facilitator sets up a SDM structure during a short term intervention that will eventually promote, encourage and make community connections that are long term relationships and resources..

HCSCC SDM Trainee Facilitator training began in October 2013 with intensive skills development workshops. Ongoing coaching and mentoring in the workplace will happen for six months. Paid peer consultants with lived experience of disability who took part in the previous OPA SDM project, assisted with the training. SDM Trainee Facilitators reported that meeting the peer consultants was a powerful way for modelling the practise of SDM. The paid peer consultants reported that they felt affirmed and valued by the process. Recently the City of Playford awarded each of the HCSCC SDM Project Peer Consultants with an "Outstanding Achievement Award" in the category of "Personal Development". There are two people from key agencies in Ireland and England who also attended the initial skills based training and are being coached/mentored by skype.

The HCSCC SDM practise model uses trainee facilitators (disability service workers) to set up a structure of support to support Decision Makers (people with disabilities) to make their own decisions. HCSCC SDM Trainee Facilitators set up the arrangements between the Decision Makers and their supporters – the trainee facilitators do not participate in the actual decision making processes. The support network works as a team to bring to life the expressed wishes of the Decision Maker., they do this through a series of meetings to expand the connections and relationships of the Decision Makers (people with disabilities The role of facilitator is pivotal to the SDM structures success.)

The role of the Trainer - Cher Nicholson

- Maintain the Integrity of the SA SDM Model
- Be the expert consultant on the SA SDM Model
- Be the go to person re any questions regarding the model
- Deliver all coaching and mentoring of the model
- Be responsible for all the paperwork generated regarding the SA SDM model- the uniformity and integrity of the paperwork. (particularly in each of the trainee facilitators workplaces)
- Responsible for all training in the SA SDM model
- Responsible for all the use of paid peer consultants in the SDM model
- Responsible for all education to service providers management in the SA SDM model
- Responsible for building a community of practise that may operate during and after the trainee facilitators complete their experience of the SDM model.
- Plan and communicate with trainee facilitators all phases of the model in their workplaces and maintain the integrity of the SDM structure.
- Aids the trainee facilitator , initially by demonstration to set up the SA SDM structure with their own Decision Maker
- Aids the trainee facilitator to build on existing skills to build all relationships when setting up a strength based structure of SDM.
- The trainer acts as a resource for all parties when challenges and difficulties occur.
- Trainer will take necessary action with consultation when the training to be implemented in the SA SDM model.. This will be aided by regular feedback sessions.
- The trainer will in the first instance try and resolve all complaints and advise the trainee facilitator of the steps in a complaints procedure when necessary.
- Responsible for and with trainee facilitator's timelines being met within the projects boundaries
- Trainr will be responsible in collaboration with HCSCC for budget limits for the SDM project
- Overseas all meetings to set up the SDM structure

The role of the Trainee Facilitator

- Sets up the framework and process of Supported Decision Making
- Builds on and maintains the relationships in the SDM structure
- Arranges all meetings whilst setting up and maintaining the Supported Decision Making structure
- The trainee facilitator will be aware of all decisions that are being made and how support is provided
- The trainee facilitator will provide assistance to the decision maker and supporter in undertaking the SDM process Offer guidance and motivation as needed.
- Will provide information and feedback to trainer as required.

- Demonstrate the skills needed for support within their own interactions.
- The trainee facilitator will inform the trainer when there are challenges and difficulties as well as when things are going well.
- The trainee facilitator will act as a resource for all parties within the structure and when outside the scope of their knowledge know where to access assistance
- The trainee facilitator will take the necessary action with consultation if the facilitator believes that the supported decision making agreement has broken down or the commitment has been breached.
- The trainee facilitator will give feedback to their own organisation re progress and challenges to see in what ways they may be supported. The trainer will offer assistance with this when asked.
- The trainee facilitator will use the agreement to underpin the decision makers wishes with decisions and support
- The trainee facilitator will offer assistance and training to the Decision maker and Supporters or aid them to seek education or assistance where relevant elsewhere as situations or events arise.
- The trainee facilitator will undertake the recruitment of Decision makers as described in their training.
- The trainee facilitator will endeavour to attend the community of practise meeting
- Facilitates all meetings to set up the SDM structure with the trainer

The role of the Decision Maker

- **Will need to express wish to receive support**
- **To be able to form a trusting relationship with another person/s (supporters)**
- **To indicate what decisions they may need support for**
- **To indicate who they wish to receive support from for which decisions**
- **To express a wish to end support if that time comes**
- **To be aware that they are responsible for the final decision and not the supporter.**
- **Agree not to act until they have used the process**
- **To stay connected to the facilitator and discuss with them if they no longer want to take part in the SDM process**
- **Understand they they do not have to be in the SDM process .**
- **Spend time at meetings and individually with people within the structure to communicate their expressed wish and will and preference**
- **To understand that they make the final decision and therefore take responsibility for what happens with that decision.**
- **To understand that just because you decide something that it does not always mean it will happen (none of us can do that.**

- **Understand that they will have a team (SDM structure) that is working for and with them to help with decisions and creating an environment and community that is equal to those people without a disability.**

The role of the Supporter/s

- **To understand that the Decision Maker has chosen them to support them and values their trusted relationship**
- **Cannot be a paid person invested in their service delivery but may be a worker who no longer offers direct support.**
- **Respect and value the Decision makers autonomy and dignity**
- **Understand that the SDM process is a new start and not bring past unpopular decisions into conversations**
- **Know the Decision makers goals, values and preferences to aid them with knowing the context of their decisions.**
- **Respect the individual decision making style of the Decision Maker and recognise when and how support may be offered**
- **To maintain a trusting relationship with the Decision Maker and not talk to others in the structure without their consent.**
- **Be willing in the role of supporter to fulfil their duty to the Decision Maker and not use this role as a way of advancing their own interest or any other person's interests.**
- **To be able to spend as much time as is required to so support the Decision Maker to make each decision.**
- **To stay connected to the facilitator and let them know if they no longer want to be part of the SDM process.**
- **To explain to the Decision Maker the pros and cons of decisions**
- **To aid in access of information to make decisions in a format that the Decision Maker can understand**
- **To help the Decision Maker express their wishes to others if required or asked.**
- **To support by explaining the context of decisions in the Decision Makers environment and personal relationships**
- **To assist the Decision Maker to access resources within the community.**
- **To have self awareness re their bias**
- **To excuse themselves from the process when and if appropriate – when circumstances change.**
- **To try and work from the strength prospective and work with what what can be done rather than what cannot be done.**
- **Try and remain in the present and look to the future rather than reminding the Decision Maker of past issues or problems.**

- **Work with other in the SDM structure to make community connections and relationships.**

Once all parties are clear about their roles they progress to an agreement to commit to progressing decisions. The agreement or contract is not a legally binding but like mediation or counselling agreements it has the intent of committing each participant to certain behaviours that gives optimum possibility to progressing the desired outcomes of the Decision Maker which are not reliant on finances or disability specific services. The SDM process is a short term intervention by a trained facilitator to optimize possibilities with community connections through decision making.

The AGREEMENT

Occurs once all roles and responsibilities are defined

- **The document itself is deliberately worded**
- **Although it has a set format is individually tailored to each Decision Makers decisions and ways that the supporter will deliver their support.**
- **The agreement constitutes a consent and agreement to commit to what is written on the agreement (facilitated by the trainee facilitator)**
- **Is a non statutory agreement a informal contract – more a written commitment of all parties of the who, how when and what**
- **decisions that the Decision Maker is working on and agreeing on a way forward.**
- **Decision Maker adds what they specifically want to make decisions about and then add whatever kind of support they want and need and how that may happen.**
- **Each organisation can choose to add their own logo and endorsement**
- **As many of our Decision Makers have made few decisions it can be helpful to prompt the decision maker by letting them know how others have used the agreement and their circumstances and context of the decision.**
- **The agreement will be reviewed regularly and will have a review date and a end date.**
- **The agreement clearly sets out the roles and responsibilities of the Decision maker and the supporter/s**
- **All parties get a copy of the agreement and the Decision Maker can decide who they want to have copies.**
- **The agreement is used as a reference point at all meetings that follow.**
- **Types of decisions and areas nominated on the agreements for decisions are: Accommodation, Lifestyle, Health, Financial. - The Decision maker is able to put forth any specific decision they wish. Large decisions would be broken down to small steps.**

MEETINGS

The HCSCC SDM practise 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 where rights have been upheld.

For more information about the HCSCCC SDM Project please contact Cher Nicholson on 82268652 or email info@hcscclsa.gov.au

Links

Link to HCSCC report: http://www.hcscclsa.gov.au/wp-content/uploads/2013/10/h_disability_public_report_march_2013.pdf

Link to HCSCC context paper: "*Towards safety and quality in disability services: Confronting the corruption of care*":

http://www.hcscclsa.gov.au/wp-content/uploads/2013/10/h_towards_safety_and_quality_in_disability_service_s.pdf

Link to UN Convention:

<http://www.un.org/disabilities/convention/conventionfull.shtml>

Link to OPA SDM Project:

http://www.opa.sa.gov.au/resources/supported_decision_making