

# SUSIE'S STORY SUPPORTED DECISION MAKING

FACILITATOR: Debbie Knowles



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# Susie's SDM Journey

## Within the SDM model:

The decision makers' network acts as a Team for the expressed wishes of the decision maker.

Susie, as the decision maker, was able to put forward any decision(s) she wished.



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## How the SDM Journey began for Susie

- My colleague and I developed a flyer for clients of Cara to explain what the Supported Decision Making Process might be able to do for them on a personal basis.
- Cher attended a Leadership Forum at Cara and spoke to all Team Leaders, Managers and Executive Managers about the Supported Decision Making Process.
- I attended team meetings with Managers, Team Leaders and support staff to speak about the SDM process so that staff who thought a client might benefit could ensure the clients received information about the SDM information sessions.
- Clients who were unsure if they wanted to be involved, but wanted to hear more information about the SDM process, were invited to attend a series of information sessions.



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➤ SDM Information Sessions were held for interested clients

**A series of information sessions were held over the next couple of weeks. At these sessions Cher asked a number of questions of each individual and then spoke about the Supported Decision Making Process.**



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# Are you interested in SDM

At the end of the series of sessions clients were asked if they would be interested in being a part of the SDM process.



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# RECRUITMENT

Over a series of sessions, **a number of clients self nominated.**

Cher assisted us with the selection process and

**Susie was offered the opportunity to become a decision maker.**

# MEETING WITH THE SELF NOMINATED DECISION MAKER

I contacted Susie's accommodation manager to explain I would be working with Susie to assist her to become a decision maker under SDM. Susie's manager was very supportive of the process and explained a little about Susie's background and also advised that he knew Susie would prefer if we could have a meeting when her housemate was at her day option.

I phoned and arranged to visit Susie at her home and discussed with her the best time to have our first meeting with Cher.

Cher and I met with Susie at her home on the 20<sup>th</sup> January, 2014. Susie shares her home with another woman and there are also two other women who live in the adjoining house. The service provides twenty four hour active supported accommodation.



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# PROFILE OF THE DECISION MAKER

Susie is a nineteen year old woman who attends school at Unley High. She is in her final year. Prior to living at her present address she was supported in another Cara service for a short period of time after being discharged from the Women's and Children's hospital where she lived on a permanent basis for fourteen months. Susie has muscular atrophy and requires twenty four hour active support.

Susie previously lived at home with her grandfather and father. Susie's mother moved interstate many years ago and has remarried. Susie was left in the care of her Maternal Grandparents and Susie's father. Susie rarely sees her mother and siblings and mainly keeps in touch by Facebook.

Following the death of her paternal grandfather, who was her primary carer following the death of her Grandmother, Susie was sent to Melbourne to live with her Mother. This was not successful and Susie was sent back to Adelaide after only two weeks with her Mother. Susie was in crisis and was therefore placed in a hospital setting until appropriate accommodation could be found to better meet her needs.



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Until the death of her grandfather, Susie had never received a mainstream education and had very few opportunities to mix with young people of her own age within a community setting.

This was a very traumatic time for Susie, as not only did she lose her much loved grandfather but she lost her home and she lost contact with her paternal cousins. Susie's father rarely visits her, no one knows when he is going to turn up to visit, and Susie can not contact him. Susie explained "my dad is not good with technology, he does not have a computer or a phone".

Susie was moved from her original accommodation through Cara to her present accommodation three years ago, as it was recognized that she would ideally suit the model of service; there were two other young women who lived at the service who were young and who also had physical disabilities and were at different levels of independence; the service was able to offer Susie her much needed 24 hour active support to meet her medical support needs.



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At the time Susie was offered this accommodation, there was another young woman accommodated temporarily at the service and Susie was told this young woman would only be accommodated there for about three weeks as she did not meet the current model of service being offered. Susie agreed to move to the service as she felt it would better meet her needs.

Susie has built up a really good relationship with the two women who live on the other side of the house, and in many ways they have become mentors for her encouraging her to become more independent, teaching her about technology and encouraging her to talk to them as part of her support network when needed.



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The other young woman who shares Susie's side of the house was unable to be re-accommodated and this has caused concerns for Susie. Susie is afraid of this young woman as she is very active and Susie feels vulnerable in her company. Staff has put strategies in place to keep Susie safe, like locks on the bathroom door. Susie shares a bathroom with this young woman and she is anxious being in this young woman's company and in the shared kitchen, even though there is a gate installed to assist her to feel less anxious. Susie spends most of her time in her bedroom or front lounge room and also has taken to using her electric wheelchair to go out whenever she can.

Susie chooses her own meals and gives instructions to staff on how she likes her meals prepared. Susie is able to manage a key card for her spending money and has received some training from one of the support staff on how to better manage her money. Unfortunately this support staff is about to resign from Cara.



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Susie has attended a mainstream school for the past three years at Unley High. However, she has found it very difficult to integrate with the other students, having started at the school in her final three years of high school. Susie tends to spend her lunch time and recess on her own on her phone and spends most of her time with her teachers during class time.

Susie is very shy when she is unsure of someone and her teachers have stated they do not see the same Susie at school as she is at home. Susie's link teacher said that Susie would not attempt to undertake any of her school assignments without her teacher's support.

Her Case Manager also stated she has experienced the same reception from Susie, where Susie rarely talks or opens up to her.

# HOW WERE SUSIE'S SUPPORTERS FOUND?

Susie was also able to inform us of a number of people that she speaks to by phone or on face book. We asked her if she knew of anyone who might like to be her supporters. Susie mentioned some staff members of Cara who had previously supported her that she keeps in contact with through Facebook and phone calls. Susie gave me permission to contact these women to see if they would be interested in attending a meeting with Susie, Cher and myself to discuss the SDM Process. From further discussion we found out the name of Susie's Case Manager from Disability SA, who she had not seen for a while. Susie also spoke of her school link teacher and how she was assisting her with her assessments for her final year at school. Susie explained to Cher and I at that she has an advocate through citizen advocacy and also a mentor through the Julia Farr program that she speaks to from time to time. She was able to give us their phone numbers so that we could contact them. Susie was extremely chatty with us, in contrast to her extreme shyness during the information sessions.



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## **SUSIE'S FIRST SDM MEETING**

Following this first discussion with Susie, I then set about contacting as many people as I could to see if they would be interested in attending an information session with Susie about SDM and how they might be able to support Susie in the process. I had to undertake some detective work to track down some of the people.

The first meeting went extremely well with Cher explaining the SDM process and the role of the supporter, facilitator and the decision maker.

Two of the women who attended the meeting agreed to be Susie's supporters, so we were able to make a further meeting to set up the agreement. Susie's teacher Lyn and her advocate from citizen advocacy agreed to attend the next meeting also and we were able to use the facilities of the school for our meetings.

At this next meeting the contents of Susie's agreement were discussed and chosen by Susie; these were then written up and signed at this second formal meeting with her Supporters, Teacher, Cher and myself in attendance.



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# SUSIE'S AGREEMENT:

**To be my supporter(s) and support me to make decisions about:**

**Where I live** – progress my wishes of who I share my home with.

**Who I spend time with** – integrate more at school and explore a buddy system for myself and others, and opportunities for me to have a voice.

**What I do** (work/study/activities)- explore opportunities that might lead to work in the future.

**My Health** – Assistance to have a healthy lifestyle. **Assistance to move from Children's to Adult Health Service**. I would like to take my supporter(s) to all of my appointments. (Talk to my G.P.)

**Managing my money-** explore mainstream financial counselling

**Reconnect with my two cousins**



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## I want my supporter(s) to support me by: (for example)

- Providing information in a way that I can understand
- Discussing the good things and the bad things that could happen
- I would prefer to meet outside of my home.
- I would like support to put important things on my iPad that need to be discussed with pros and cons.

From that point onwards “Team Susie” continued to grow; through ongoing discussions with Susie, her Supporters and Teacher, we were able to contact more and more people who were willing to become part of Susie’s Team.



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Susie agreed to give a copy of her agreement to her two supporters, her Disability SA Case Manager and her Citizen Advocate.

As the meetings took on a life of their own, so did Susie's support team and Susie was obviously enjoying the fact the meetings were all focussed on her and her wishes. It was and still is Susie's decision on who attends the meetings and also on what topics we talk about. Although the agreement is a guide to begin a discussion on the topic in question, Susie is in control of the meetings and has on occasions asked me to skip one of the topics on the agreement as she was not comfortable discussing it at that particular meeting.

**Note: the focus at Susie's meetings was always to concentrate on finding a community solution if possible, rather than a paid supporter solution to meet Susie's wishes and /or issues.**



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# THE FACILITATOR:

As the facilitator I made the decision to forge ahead with meetings even if only one or two people could attend. Some meetings were small and others were extremely well attended, depending on people's availability and all were very productive.

I would phone people in between meetings to get their update and input and even made a phone call in one of the meetings to get an update from one of Susie's supporters as she was unable to attend the meeting.

After each meeting I prepared a summary of the meeting using the agreement headings as the guide, explaining to everyone what had occurred at the meeting and who had agreed to do what for Susie. This was then emailed to everyone on "Team Susie".

There were many discussions during these meetings, and outside of these meetings, that went much further than the original agreement and they were all very exciting and Susie enjoyed having the opportunity to discuss things that were very important to her and also to hear of different ideas that people were coming up with that might support her in her aim to achieve her wishes.



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# CONCERNS RAISED ABOUT THE PROCESS AND IT'S EFFECT ON SUSIE:

There were concerns raised by Susie's support staff who were unsure of some of the information that Susie was coming home with and they felt that Susie may be vulnerable to some of the suggestions.

Cher and I set up a meeting to discuss these concerns and they were very quickly resolved. It was noted that Susie was becoming "a little cheeky" with her comments but when discussed further this was seen "as a protected eighteen year old" who was learning to become more assertive and enjoy the feeling of having so much say in her life. Yes she was needing some assistance to understand the effect her comments were having on the support staff, but they soon realized that would come in time as Susie adapted to her new found "empowerment" and "voice".

For many of the people who attended the meetings, they commented they had never seen Susie so vocal and were delighted to see a much more confident Susie than they had ever previously experienced.



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- **PRESENT SITUATION – WHERE ARE WE UP TO TODAY WITH SUSIE’S HOPES AND DREAMS.**

**Where I live** – progress my wishes of who I share my home with.

**Who I spend time with** – integrate more at school and explore a buddy system for myself and others, and opportunities for me to have a voice.

**What I do** (work/study/activities)- explore opportunities that might lead to work in the future.

**My Health** –Assistance to have a healthy lifestyle. **Assistance to move from Children’s to Adult Health Service**. I would like to take my supporter(s) to all of my appointments. (Talk to my G.P.)

**Managing my money-** explore mainstream financial counselling

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## **UNEXPECTED ADDITIONAL POSSIBILITIES THAT HAVE COME FROM “TEAM SUSIE” DISCUSSIONS BOTH INSIDE AND OUTSIDE OF THE TEAM MEETINGS:**

- During discussions Susie informed us that she has never been on a holiday.
- During discussions at her SDM team meetings it was revealed that Susie has never been in the water at the beach.
- Numerous possible future work option choices were discussed and follow up is now underway.
- Future Conference opportunities for Susie to attend and (or) present her research project with funding available through the Julia Farr Group.
- An opportunity for Susie to publish and launch her Cook Book.
- Assistance with independent living aids (for when Susie is out in the community)
- A Huge Confidence Boost for Susie.



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# MEET TEAM SUSIE



Lions Club Members  
FOR FUNDING  
SUSIE'S COOKBOOK



Ginetta

FROM MULTIPLE  
SOLUTIONS



Lorraine & Kirstie  
SUSIE'S SUPPORTERS



Joan

SUSIE'S TEAM  
LEADER AT CARA



John  
FROM TECHNICAL  
AID FOR THE  
DISABLED



Debbie  
FACILITATOR



Ali

SUSIE'S MENTOR  
THROUGH JULIA  
FARR GROUP



Lynn

SUSIE'S LINK  
TEACHER



Kaye

FROM BETTER  
PATHWAYS



Cher

SDM PROJECT  
OFFICER



Cynthia

VOLUNTEER CO-  
ORDINATOR WOMENS &  
CHILDRENS HOSPITAL



**Susie**

**The Decision Maker**



Lucy

FROM DISABILITY  
SA



Volunteers from star  
TO ASSIST WITH  
PUBLISHING SUSIE'S  
COOKBOOK



Nicky

PRESIDENT OF UNLEY  
HIGH'S STUDENT  
COUNCIL



Lisa

SUSIE'S SSO



Josie

SUSIE'S DISABILITY SA  
CASE MANAGER



Beck

SUSIE'S ADVOCATE FROM  
CITIZEN ADVOCACY

# AT THE EXIT MEETING FOR “TEAM SUSIE” DISCUSSION TOOK PLACE ON HOW WE WOULD MOVE FORWARD IN THE FUTURE.

We reminded ourselves of the purpose of the supported decision making (SDM) process; it is not just about Susie's agreement, as this is just a guide, but it is about putting a process in place where SUSIE can tell us what she wants in her life and has the support she needs to make things happen. **It is all about the SDM journey**

The supported decision making model connects with services and local community and measures success in a different way:

**Success is not the enacting of the decision, but whether there is an environment where decisions can be made and rights upheld.**

“TEAM SUSIE” has that perfect environment and acts as a network for the expressed wishes of SUSIE and where SUSIE, as the decision maker, is able to put forward any decision she wishes.



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In order to ensure that Susie's wishes continue to be monitored "TEAM SUSIE" committed and agreed to the following:

**"TEAM SUSIE" will continue meeting approximately every six weeks** to keep the momentum going and to check in on how Susie's wishes are advancing. This will be a shared approach with different people offering to host the meeting, depending on the issues at hand and the availability of office space etc. Josie agreed to host the first meeting of TEAM SUSIE at one of disability S.A.'S offices and she has already sent out an invitation to everyone.

- When looking at avenues of support for Susie all agreed that **mainstream services will always be investigated first** so that Susie is not reliant on paid workers or CARA for all of her support.
- Susie agreed that she felt more confident these days and she feels she can do things and change things with support from her team. Therefore "Team Susie" agreed that it is important to be aware that **it is not about helping or rescuing Susie, it is about supporting Susie to achieve outcomes for herself.**
- It is important to check that Susie has not changed her mind about some of the things she has put in her agreement. Her will is current, but she may see things differently in the future, **so we need to check in with Susie on a regular basis.**
- **Note: I sent out an email list of everyone's contacts in "Team Susie".**



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# WHERE MY JOURNEY WITH SDM HAS TAKEN ME – WHAT I HAVE LEARNT AND HOW MY THINKING HAS CHANGED

When I first began learning about the process of supported decision making I was wondering how this fitted with person centred planning, active support and the different types of goal setting processes used by the numerous agencies.

It was not long after beginning the initial training that everything started to fall in to place for me as I found SDM to be truly inspirational (particularly after listening, communicating and learning from the decision makers themselves). My thought processes were further cemented as I facilitated and experienced the process first hand with Susie.



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I believe SDM ensures all areas of a person's life receive input at the same time, and the process is ongoing, whereas with a typical goal setting type of model, one area is usually dealt with at a time, and then ticked off and dated as being achieved.

I see that it is absolutely crucial to focus on community options and supports that enable the person to become a much deserved valued member of their community: each of us has the right to be provided with opportunities to contribute to and grow within our communities and not be solely reliant on service provision for most or every aspect of our life.

Goal setting can sometimes shrink the horizons for people with disabilities. Supported Decision Making is about growing a persons social capital, by connecting them with lots of people, and people who are not just paid service providers;



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The emphasis is on utilizing everyone possible to help the decision maker **to do the things they want to do, with the people they want to be with;**

This provides the decision maker with hope for the future by building on their strengths and most importantly giving the person control over their own life.

A number of people live their lives in fear, instead of taking a chance at something they really want to try. This stops them from moving forward and growing as a person. They stay where they are because it is comfortable, sometimes encouraged by their families, friends and support workers, out of fear of change or that something might go wrong.



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Supported Decision Making encourages the decision maker to move forward towards their hopes and dreams for the future, by acting on their **expressed wish**, rather than in their best interest.

Some people have lots of life chances but they can manage to mess them up whilst others only get a few, but they make the most of what they get. Resources are so limited in the field of disability. As service providers we need to keep this in mind when we encourage someone to use the limited resources they do have.

**We need to make sure they are using these resources for things that are really important to them;** not things that others may think are important for them; or their parents or housemates think are important; or those things that are convenient for staff.



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**A lot of people living with disabilities get very few life chances**, so we have a responsibility to ensure these experiences are the most fantastic they can be, and things they will cherish for the rest of their lives. I know from my own experiences over many years that when a person finally manages to achieve something they always wanted to achieve, like playing a game of billiards as part of a club for the first time; or going to the footy interstate with a group of “real” friends to see their much loved team at a grand final, **how their happiness grew:**

- Because they chose to be part of a group of people that share the same interest and passion:
- Because they are able to make a contribution whilst sharing ordinary places with their friends,
- Because their friendships and acquaintances grew,
- Because their social conversations grew,
- Because their confidence grew,
- Because they felt a sense of belonging,
- Because they are truly respected and valued members of their community.



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**I believe that Supported Decision Making is one of the best ways to provide “life chances” for the decision maker.**

I also believe that supported decision making is the essence that is needed to bind all the other ingredients around Person Centred Planning Processes together. **SDM is how you do it.** Without it, it is like trying to cook an omelette without an egg or expecting a teenager to survive without a mobile phone.

And most importantly Supported Decision Making has the ability to heal the decision makers negative feelings from the past, helping the decision maker to find their place in society.

I believe for Susie this is happening and will continue to happen – as our CEO at Cara said to Cher and I recently – **“because of her involvement with SDM Susie’s life will look very different in a few years to what it is now”**.



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