



Office of the Public Advocate

OPA Supported Decision Making Pilot Project

ASID SDM Symposium 2015



Session overview

- **What was the project**
- **Broad context for the development of the project**
- **How Supported Decision Making was interpreted and provided**
- **Who were the participants**
- **Who were the volunteers**
- **Learnings from the project**



The pilot project

In October 2013, the Office of the Public Advocate (OPA) commenced development of an 18 month pilot supported decision-making project.

The OPA recruited, trained and matched volunteers with 18 participants with intellectual disabilities and few informal supports and who wanted support with their decision making.

The project ended in June 2015.



Why an SDM project?

UN Convention on the Rights of People with Disabilities:

- Article 12 – Equal recognition before the law

‘State Parties shall take appropriate measures to provide access by persons with disabilities to *the support they may require in exercising their legal capacity.*

UN Committee on the rights of Persons with Disabilities, Concluding observations on the initial report of Australia, 4 October 2013:

24. *The Committee is concerned* about the possibility of maintaining the regime of substitute decision-making, and that there is *still no detailed and viable framework for supported decision-making in the exercise of legal capacity.*

26. The Committee further recommends that (Australia) provides training... *on the primacy of supported decision-making mechanisms in the exercise of legal capacity.*

(my italics)



Why an SDM project

Legally appointed substitute decision making in Victoria

In 2013 – 2014 VCAT heard 2077 new applications for guardianship and 783 reassessments of guardianship

VCAT Annual Report 2013 – 2014

- In 2014 – 2015 VCAT referred 789 new guardianship matters to the OPA
- 722 guardianship cases carried over

OPA Annual Report 2015



Why OPA's SDM project? Victorian Law Reform Commission – Guardianship and Administration legislation

Recommendation that OPA conduct a trial of supported decision-making, matching isolated people in need of decision-making support with volunteer supporters, using a service mechanism similar to the Community Guardianship program.

In June 2013, Victorian Law Foundation awarded a grant providing partial funding towards OPA's trial of Supported Decision-Making.



What did we mean by supported decision making?

‘Supported decision-making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.’

Robert Dinerstein, Implementing Legal Capacity Under Article 12 of the UN Convention, Human Rights Brief, Vol 19, Issue 12, 2012



What did we mean by supported decision making?

‘Once you understand the choices and the good and bad things that could happen for each choice, you can make your own decision and be your own boss’

from Yukon (Health and Social Services) brochure on Supported Decision-Making Agreements



What was the project

Project aims

The Office of the Public Advocate's (OPA) Supported Decision-Making Pilot Project aimed to:

- explore and develop a service model connecting trained volunteers with socially isolated people wanting support to make decisions
- promote participants' dignity and autonomy by facilitating their decision making
- create a formal and structured arrangement to assist and build the participants decision-making capacity
- build a skilled volunteer team to provide support and build participants' capacity to make their own decisions
- explore whether substitute decision making can be replaced by support for decision making



The Project - Participants

A project for people with an intellectual disability who would like some help with making big decisions.

Some big decisions may be about:

- **Taking care of yourself and your health** – going to the doctor or the dentist, deciding about medications, arranging tests, consenting to surgery
- **Where you want to live**
- **Social and leisure activities** – what you want to do, when and with whom
- **Work, training and day options** – what would you like to do during the day
- **Relationships** – who you want to spend time with



Volunteers:

Who would help you with big decisions?

- A volunteer who has been trained to help will be matched with you
- The volunteer will get to know you and help you for 12 months
- The volunteer will do their best to help you reach the goals you decide
- The volunteer will **not** make decisions for you
- The volunteer will **not** tell you what you should do.

What does a Supported Decision-Making Volunteer do?

- respects and values the participant's rights and wishes
- assists the participant to make and, if necessary, express a decision
- assists the participant to obtain relevant information
- explains relevant information and considerations
- assists the participant to carry out their expressed wish, if needed



The Project: What Volunteers / Decision Maker Supporters can do:

Help with decision-making may mean helping you with:

- Finding out what your choices are
- Finding all the information you need to decide the best choice for you
- Thinking through what those choices mean for you
- Setting your goals
- Planning the steps needed to reach your goal
- Support with making appointments or telling people what you want
- Learning about speaking out and your rights



Who were the participants

Demographics:

- **18 participants**
- **Range of ages**
- **Accommodation varied**
- **Mild to borderline intellectual disability**
- **Six participants were under OPA guardianship (four active and two monitoring)**
- **Two participants from individual advocacy**
- **10 in total from OPA programs – TAS, A-G program**
- **Metro and Geelong areas, later decided to pick up from Ballarat**

Other referrals from:

- **SRS accommodation managers and house supervisors**
- **DHS and NGO case managers**
- **Disability advocacy services**



Who were the participants

•**Social isolation:**

- Either no family contact at all or strained and undermining family relationships
- Two participants had IVOs on family members

•**State intervention**

- Four participants had lived in foster care group homes
- Three recent DHS intervention / removal of their children

•**Fallen 'between the cracks'**

- Not registered for disability services
- Five had lived with parents / child and become carers. Services not attached to participant.



Types of decisions:

Health:

- Medical procedure (cataract operation)
- Contraception, attending appointments

Services:

- To go on holiday with unfamiliar people
- To accept 1:1 support services and attend garden club
- To accept ISP funding for 1:1 support to go to chosen activities
- To become a volunteer at an Animal refuge
- To join support group

Accommodation:

- Where to live (within limited options)
- To meet with management and speak out about (staff) issues

Work:

- To reduce days of work

Two participants decided to withdraw from the project



Who were the volunteers

Recruited through OPA volunteer networks

Rigorous interview, police check

Induction session and then quarterly updates

3 opted out after induction

2 opted out due to health reasons



What some participants said about the project:

'It has been very good and excellent. So helpful.

It made my dreams come true; I'm now a volunteer at (animal shelter) and walking the dogs. I'm going for my Learner's Permit.

Having a computer and phone (for the first time) has been really great – I can listen to music and study for my Learner's Permit.'

'(the volunteer) helped me think through the decision of whether to drop down a day of work. I'm really pleased I made the decision. It is good not getting up so early in winter when it is so cold. I do other things instead, like go to the coffee shop and play scrabble with (a local community) group.

(The project) helped me to grow as an independent person. I feel more confident and am growing in confidence in making decisions and sticking to them. It helps to have someone not family to talk to about decisions. I don't get so upset by family now.'



What some participants said about the project:

‘It was a good experience. It was a long time (9 months) from when I started to get the ISP to do what I want. Volunteers and participants need patience. One day at a time. Now someone else in the house wants to do the same thing (have a volunteer to help with supported decision making).’

‘I’m happy that I have learnt to make my own decisions now with help. I like the way it is now. I don’t want anything to change.’



What the volunteers found rewarding – capacity building

- Seeing that expectations from past experiences and about the future are changing - the participant learning they can change what their future looks like,
- participants learn there are choices and trying things out
- the difference support is making to the participant's outlook and life: e.g. most participants were brighter and happier in appearance
- After lots of support and encouragement watching the participant try services and being very pleased with themselves
- After years of not being allowed to try things, to do them and change from fearful to happy after a very positive experience
- Being able to resolve issues and barriers to the participant reaching their goals
- Creating other smaller ways for inclusion, local and sustainable activities



What were some things volunteers learnt

- There are so many limitations on reaching goals / decisions and everything takes so much longer, has extra expenses and unexpected hurdles
- Respect where the participant is at
- Empower and explore what the decision is for – the real wish / decision is (often) not apparent
- If the participant does not want you there (for all sorts of reasons) it is best to accept
- Think of your safety
- Trust that it is the participant's wishes
- The importance of trust



Learnings

- Some of the responses and skills required of a volunteer who is supporting a person to make decisions included, commitment to their participant's right to make decisions, commitment to developing a respectful and trusting relationship, patience to develop the relationship and to learn about the participant's life and goals before decision making and problem-solving, patience and perseverance with the slow systems and responses around their participant
- Support for decision making is a very time and resource intensive process
- A barrier to decision making or implementation of decisions often appeared to be the lack of interest by staff in the participant as a person and, or, in exploring their wishes and potential goals and decisions
- Lack of resources e.g. time, staff, training, were further barriers
- For some participants, the relationship with the volunteer appeared to have contributed to their sense of self and identity and autonomy



Learnings

- Decisions would not have caused VCAT application (in effect, informal substitute decision making)
- Area of unrecognised and, or, unmet need
- Worked well with substitute decision maker because they were better informed about the participant's wishes and could advocate



Summary

- **Much can be achieved through provision of decision making support to socially isolated people with intellectual disability but it is a time consuming process.**
- **Development of a trusting and respectful relationship and gathering a complete understanding of the participant's situation, wishes and views was often a very slow process.**
- **Comprehensive engagement and flexible responses were needed for the many, often systemic, barriers that can arise when supporting people to exercise their choices.**