

SUPPORTED DECISION MAKING AS AN ALTERNATIVE TO GUARDIANSHIP ORDERS: THE SOUTH AUSTRALIAN TRIAL

MARY-ANN DE MESTRE*

[Supported decision making is]...designed to restore more choice and control to people with disabilities over the types of support they may need or require...[It] involve[s] embedding important facilitation mechanisms such as independent planning and supported decision making to enable people to take advantage of the opportunities of personalization.¹

Supported decision making has been promoted as a primary means of respecting the right to legal capacity without discrimination on the basis of disability.² This is recognised in article 12 of the United Nations (UN) Convention on the Rights of Persons with Disabilities by facilitating the participation of people with disabilities in society on an equal basis.³ Supported decision making has been held to be inherently different from guardianship as the focus of decision making is different from that of a guardian: the participant is the decision maker in the supported decision making model.⁴ Legislative models of supported decision making for people with disabilities have been implemented in some countries, predominately in Canada, and information approaches are said to be on the increase around the world.⁵ Developments have included proposals by the Victorian Law Reform Commission, the development of personal budget models of service delivery, notions of ‘family’ decision making and various pilot programs including South Australia’s non-statutory model trialled by the Office of the Public Advocate.⁶

I THE SOUTH AUSTRALIAN PILOT

The Supported Decision Making Project was conducted by the Office of the Public Advocate from December 2010 until 2012. The MS McLeod Benevolent Fund funded the project aimed at enabling people with a cognitive disability to make individual decisions about a variety of life choices by providing an alternative to substitute decision making. In Australia, supported decision making is based on the principles associated with disability reform. Legislation has recognised supportive relationships and that people with a disability should, where possible, make decisions for themselves.⁷

* Mary-Ann De Mestre is a Bachelor of Arts/Science graduate from the University of Sydney and is currently in her final year of a Bachelor of Laws degree at the University of Western Sydney.

¹ Andrew Power et al, *Active Citizenship and Disability: Implementing the Personalisation of Support* (Cambridge University Press, 2013) 441-2.

² Terry Carney and Fleur Beaupert, ‘Public and Private Bricolage: Challenges Balancing Law, Services and Civil Society in Advancing “CRPD” Supported Decision-Making’ (2013) 36 (1) *UNSW Law Journal* 175, 199.

³ *United Nations Convention on the Rights of Persons with Disabilities* (2007) art 12; *ibid*.

⁴ Margaret Wallace, ‘Evaluation of the Supported Decision Making Project’ (Report, South Australian Office of the Public Advocate, November 2012) 44.

⁵ Carney and Beaupert, above n 2, 199.

⁶ *Ibid* 179.

⁷ John Brayley, ‘Supported Decision Making: A Case for Change’ (Paper presented at the Supported Decision Making Forum, Queensland University of Technology, Brisbane, June 2013) 6.

The South Australian trial was a non-statutory model, which involved setting up an agreement between a person with a disability and a supporter.⁸ The decision supporter was either a family member or close friend who would help make decisions about an individual's healthcare, accommodation and lifestyle.⁹ Twenty-six people, 14 women and 10 men¹⁰ with a variety of disabilities that affected their decision making abilities signed agreements with chosen decision supporters.¹¹ The target groups for recruitment were people with an intellectual disability or acquired brain injury, and people who might otherwise have been subject to a guardianship order.¹² An agreement was also made with an independent party to be a monitor who would keep track of how the arrangement was going.¹³ The agreement allowed the person with a disability who was receiving support to express a wish to receive support, form a trusting relationship with another, indicate which decisions they may need support for, and indicate from whom they wished to receive support.¹⁴

II EVALUATION OF THE MODEL

The trial was subject to independent evaluation by Margaret Wallace who interviewed 53 per cent of the participants and 27 per cent of the supporters to collect qualitative data and use quantitative data to make conclusive findings.¹⁵ On the evidence collated the evaluation concluded that participants felt an increased level of confidence in making decisions and a level of growth in support networks. By having support, the individual felt a greater sense of control in their lives. One participant concluded:

I thought decision making would help me. I needed something to help me instead of other people making decisions for me. I like to make my own decisions on my future.¹⁶

The evaluation noted that a 'particular strength of the process was that the supported decision making agreement gave the participant formal approval...that said somebody is going to listen to me...it restores power.' There was evidence to suggest that participants improved their own decision making skills and considered expanding the areas about which they wanted to make decisions.¹⁷

Despite the positive findings for the project the evaluation concluded that the project infrastructure did not appear to be sufficiently developed to support the possible alternatives to the current guardianship stream. It was noted that a considered process was needed to identify the potential uses of the model and to clarify the boundaries and intersections the

⁸ The project Committee decided to exclude people with dementia, or mental illness as a primary diagnosis, from the trial.

⁹ Many of the decisions included choices about medical treatment, independent accommodation, lifestyle choices, aged care, work and choosing support: Wallace, above n 4, 29-30.

¹⁰ Two of the referrals ultimately did not proceed with the trial.

¹¹ South Australian Office of the Public Advocate, 'Annual Report 2012' (Report, South Australian Office of the Public Advocate, 2012) 59.

¹² All of the participants fit the selection criteria for the project. The criteria called for adults with a disability, who did not have a mental illness as a primary diagnosis or degenerative dementia, had not been assessed as experiencing abuse or neglect, or were not at the centre of significant conflict among family and friends: Wallace, above n 4, 15.

¹³ Wallace, above n 4, 15.

¹⁴ *Ibid* 61.

¹⁵ *Ibid* 13.

¹⁶ *Ibid* 31.

¹⁷ *Ibid* 33-38.

model would have with guardianship.¹⁸ Three of the participants reported that they felt frustrated about the extent to which their wishes could be achieved. It was recorded that two of the participants wanted to make decisions about their financial affairs but faced problems due to the conflict between the supported decision making principles and administration orders.

The supported decision making agreements were seen as having real advantages. They gave legitimacy to the participants to express their views and have conversations. They opened up useful dialogue between a number of sources to allow further support for the participants. The evaluation nonetheless concluded that the project ‘gives evidence that supported decision making [can be] both a companion process and viable alternative to substitute decision making for participants’.¹⁹

III FUTURE IMPLICATIONS OF SUPPORTED DECISION MAKING AS AN ALTERNATIVE METHOD

John Brayley, the South Australian Public Advocate, has stated:

The minimisation of guardianship not only depends on supported decision making reform, but reform to our service systems, so that they are based on true personalisation and choice, reform to our adult protection systems so that they provide a right to safety rather than a welfare response, and a commitment to overcome inequity and discrimination.²⁰

Supported decision making is now strongly favoured over substitute decision making models that have been traditionally adopted by adult guardianship laws. This is because they give effect to the equality principle in article 12 of the UN Convention on the Rights of People with Disabilities.²¹ The model promotes the primary right to legal capacity without discrimination on the basis of disability as it facilitates the participation of people with disabilities in society on an equal basis with others.²²

In the absence of a legally recognised formal guardianship order, limited legal protections are afforded to supporters of informal frameworks. This creates barriers for a person with a disability to access natural decision-making supports. It has implications that one may still need to have plenary guardianship orders to make day-to-day required decisions.²³ It is important to note the future implications of implementing a supported decision making model as an alternative to guardianship orders. There can be unintended consequences associated with implementing informal arrangements. Terry Carney and Fleur Beaupert have highlighted the potential risk of substantial informal coercion. Informal arrangements allow the individual freedom to make lifestyle decisions, but that can come at the potential cost of enhanced

¹⁸ Ibid 46.

¹⁹ Ibid 5.

²⁰ John Brayley, ‘The Future of Supported and Substitute Decision Making’ (Paper presented at a workshop of the World Congress of Adult Guardianship, Melbourne, Victoria, October 2012) 2.

²¹ Carney and Beaupert, above n 2, 177.

²² Ibid 199.

²³ Advocacy for Inclusion, ‘Supported Decision Making, Legal Capacity and Guardianship: Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory’ (Report, Advocacy for Inclusion, August 2012) 17.

opportunity for misreading wishes and potential abuse. The model may be beneficial for those who have a support network, but the question can be raised as to what happens to those individuals who are isolated? Perhaps if the model makes provision for those who are isolated to join a viable network or be introduced to an appropriate supporter this may help to consolidate supported decision making as a more viable option.²⁴

Supported decision making can be said to be an effective, less restrictive alternative to guardianship. It allows for the participation of trusted friends, family members and advocates giving people with disabilities the help they need to understand and make choices so that they may make their own decisions on all areas of their lives.²⁵ Supported decision making shows great promise for increasing self-determination and improving quality of life outcomes in accordance with the UN Convention on the Rights of Persons with Disabilities.²⁶

New South Wales is currently conducting its own Supported Decision Making pilot. It is a joint project of the NSW Government's Ageing, Disability and Home Care, the NSW Trustee & Guardian and the Public Guardian. It is due to conclude this year.²⁷ As described by the Australian Law Reform Commission, 'the pilot will develop, trial and independently evaluate a supported decision making framework for people with a disability, their families, carers, advocates and service providers in NSW.'²⁸ The aim of the pilot is to form an evidence base on the effectiveness of a framework for supported decision making by identifying key policy, legal and ethical considerations. The process will help to evaluate the use of the tools, resources and educational material needed. Recommendations can then be made for the broader application of a supported decision making framework.²⁹

²⁴ Carney and Beaupert, above n 2, 195.

²⁵ Burton Blatt Institute, *The Jenny Hatch Justice Project* (2013) <<http://supporteddecisionmaking.org/>>.

²⁶ *United Nations Convention on the Rights of Persons with Disabilities* (2007) art 12.

²⁷ Family & Community Services Ageing, Disability & Home Care, 'Supported Decision Making Pilot' (Factsheet, NSW Government, October 2013) 1 <http://www.adhc.nsw.gov.au/__data/assets/file/0003/279039/S_DMP_fact_sheet_Oct2013.pdf>.

²⁸ Australian Law Reform Commission, 'Equality, Capacity and Disability in Commonwealth Laws' (Issues Paper 44, Commonwealth of Australia, November 2013) 25.

²⁹ South Australian Office of the Public Advocate, 'NSW Supported Decision Making Pilot' (Paper presented at the Supported Decision Making Conference, Melbourne, Victoria, 18 October 2013) 17.