

The Future of Supported and Substitute Decision Making

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*Presented at a workshop of the
World Congress of Adult Guardianship, October 2012, Melbourne, Victoria*

The Public Advocate, John Brayley participated in a panel of international and Australian speakers at a workshop entitled “Frameworks for the future of supported and substituted decision making”.

Speakers were asked to deliver a 10 minute presentation addressing two key questions.

- (a) Can supported decision making completely replace substituted decision making?*
- (b) How do you imagine supported decision making schemes would work in practice?*

Below is the presentation delivered to the workshop:

Supported decision making is a key intervention to uphold the autonomy and personal authority of people. In South Australia we have had a positive experience with our supported decision making trial. People have signed agreements with supporters and the parties received education and assistance from a facilitator. This has been valued. I see a place for having both legislative provisions that recognise supported decision making, and small services to facilitate it independent of other providers. I also would recommend that wherever possible such supported decision making services have at least some staff who have a personal lived experience of disability – I will justify this later.

Yet as much as we need to expand and sustain supported decision making, this intervention alone cannot minimise guardianship. I wish to raise three areas that I consider are relevant – first the nature of incapacity from a systems perspective, second the different functions that supported decision making might serve for the individual, and third the impact of discrimination and the need for “reasonable accommodation” to prevent it.

Traditionally we look at incapacity from an individual linear perspective rather than a systems perspective. If there is a problem, the problem rests with the individual who has a disability. The problem is then solved with a finding of mental incapacity and an order directed at that individual.

Yet when we were doing the early intervention part of our supported decision making trial, I would hear from our facilitator about people’s stories who were not under

orders, yet their disability, their cognitive impairment, seemed very similar to the disability of many other people who were under orders. If the people who were either on or off guardianship seemed similar, then what was different were the environments that surrounded them.

The recognition of environmental barriers to participation is part of the UNCRPD preamble. It is also inherent in general systems theory. So if we are looking at the problem guardianship is seeking to solve, is it decision making or is there some other systemic problem? In guardianship terms where is the real incapacity? Is it a decision making incapacity of the individual or is it a family incapacity to resolve conflict, a service incapacity to provide necessary options, a community incapacity to give 'at risk' people a right to personal safety, or economic incapacity through poverty and social exclusion of people with disability?

The difficulty with a singular focus on supported decision making, is that it is based on the traditional assumption that the problem rests with the person's decision making which therefore needs support, whereas in many cases the problem rests with the environment in which the person lives.

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.

So back to supported decision making – what does it offer the individual? First it can offer exactly what its name describes – support for decision making. People may need help with each of the steps needed to make a decision, at least for a period of time. People who are impulsive may also appreciate the slowing down of the decision making process. But these are not the only benefits, and some of the other benefits of supported decision making to the individual are not really due to support.

The Supported Decision Making agreement can be a significant symbol of autonomy. One participant in our project remarked that this had been the first time in a long time that anyone had expressed confidence in her as a person to make decisions. The value is in this recognition. To some extent at times I think a Supported Decision Making service might be better labelled as an “autonomy and personal authority service”, promoting the concept of autonomy rather than one of support.

On the negative side supported decision making might also be embarked on to benefit and reassure others, rather than to benefit the person with a disability. For example early in our project, a couple of participants said they wanted supported decision making so that their existing decisions will be acted on. They thought this more likely if they were seen to discuss decisions with a supporter. This is not desirable.

For other people, the Supported Decision Making agreement is a way of stopping those in their lives who have been substitute decision makers from continuing to make decisions for them in this way. Family or friends can still be involved, important relationships are preserved, but the significant others cease to exercise informal substitute decision making, because they are now educated and signed up as decision supporters.

The third issue in this presentation I wish to highlight is the one of discrimination. Artificial and unrealistic expectations can be set for people who are seen to have a disability, which ignores what we know about the real nature and variability of human decision making, and illustrates the unreasonableness of applying one person's way of making a decision on another person. This is relevant to both substitute and supported decision making.

There has now been significant research on decision making theory based in both the sciences and humanities. In short as humans we are not rational in our decision making, and as people we can vary greatly in our decision making styles – our speed of decision making, reliance on analysis as opposed to intuition or the extent we have faith in or question the views of others whether they be family members or professionals. These are aspects of decision making the theorists describe as metapreferences. Furthermore a percentage of our general community – up to 50% - have impairments in areas such as health literacy. Yet we focus our decision making interventions on people who have identifiable illnesses or conditions, and we can be prone to attribute variation and differences to disability rather than the variation and differences that exist between individuals. At times we can expect people with disability to make their life decisions using the rational and somewhat dry decision making style used in administrative law.

With respect to non-discrimination, hospitals, disability services, banks amongst others need to demonstrate 'reasonable accommodation' in their communication and provision of decision assistance with clear information, decision making aides, and a preparedness to take time to explain options. This is a right, and the engagement of a substitute cannot be a quick convenience for a provider. This general responsibility is part of what our project defines as assisted rather than supported decision making. Interestingly literacy research suggests that there are many people in our community who are not labelled as disabled who might also benefit from such assistance.

Finally I wish to comment on peer workers. Supported decision making involves education of all parties – the supported person, the supporter and the monitor. A person with a lived experience of disability is very well placed to do this education, and according to feedback about the use of a peer worker in our project, education from a peer can have a great influence. People with disability should also be well represented on management committees of supported decision making services.

While a lack of personal authority on one's life may be put down to people's cognitive disabilities, people with physical and sensory disabilities, also experience identical

marginalisation and disempowerment. Staff who have any personal experience of disability, as well as designated peer workers, can be in a unique position to truly appreciate the client's predicament, as well as deliver convincing education about what can be possible with respect to personal decision making and authority.

I trust that this gives a picture of a future of expanded supported decision making, a reduced reliance on guardianship, but a future which can only be achieved through changing the environment surrounding people with a disability – in other words by truly enacting the UN Convention in full, rather than just article 12.

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