

## COMMENTARY

### Clarifying, Operationalising, and Evaluating Supported Decision Making Models

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The appointment of a person to act as a *substitute* decision maker, as under traditional adult guardianship legislation, is rightly criticised for its paternalism and denial of rights of people with impaired capacity. Its replacement by the notion of “supported decision making” has the wind in its sails on several counts: as being the strong preference (or even as “required”) under international law (the United Nations Convention on the Rights of Persons with Disabilities [UNCRPD] 2006); as realising the autonomy, values, and citizenship rights of people with impairments; and as better dovetailing with the extension of “choice” within government and non-government services. However, supported or assisted decision making comes in a bewildering variety of forms (Australian Capital Territory [ACT] Disability, Aged and Carer Advocacy Service, 2013; Boundy & Fleischer, 2013; Browning, 2010; Then, 2013).

Two particular questions about supported decision making remain unanswered: *First*, its meaning is often very uncertain, not least because it covers a very wide spectrum of possible models. These models range from the purely informal supports we all enjoy as citizens when making decisions in our daily lives, through organisational assistance associated with service provision (or other civil society schemes), up to the variety of different forms of legally structured schemes of supported decision making. Such important *conceptual* subtleties – including the distinctions between “support with” decision making and “supported decision making”, the relationship with legal capacity, or differences between civil society schemes (which do not engage the law) and those grounded in the exercise of legal powers – are among the “enigmatic” features of various supported decision-making schemes touched on by Browning, Bigby, and Douglas (2014) in their paper titled “Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice”. These are important distinctions for emerging practice, because overseas research has shown that many ingredients go into determining how successful or otherwise such programs may be, as illustrated by a recent international study of schemes in the United States, Canada, England, Northern Ireland, Sweden, France, and the Irish Republic (Power, Lord, & deFranco, 2013).

The *second* outstanding question is whether any of these models, on either side of the assisted or supported decision-making divide, actually *achieve* enough of what they set out to deliver, and at what cost in terms of risks to the person or misunderstandings on the part of the community. Not only is there little evidence internationally about which, if

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any, of the overseas models “works” (Kohn, Blumenthal, & Campbell, 2013), but it cannot be assumed that what is beneficial to, for example, people with early progressive dementia will be helpful for a different group, such as people with intellectual disability (Kohn & Blumenthal, 2014). Nor can it lightly be assumed that members of the community (including those working in banks or shops) will understand that a legally appointed supporter does not act as a substitute decision maker, or that de facto paternalism (or even abuse) will not emerge (Carney & Beaupert, 2013). Yet despite such reservations, the trend towards recognition of greater choice within and consumer control of services for people with disabilities (including personal budgets and other measures fostered by the National Disability Insurance Scheme) means that there is no time to lose in devising workable ways of realising the full autonomy of people with decisional impairments, while also protecting against the risk of de facto paternalism or other risks. People with an intellectual disability, for instance, are said to have suffered in the United Kingdom due to the lack of adequate capacity building and other measures to equip people to properly engage with the new environment of personal choice (Fyson & Cromby, 2013), even if the measures are not easy to construct (Carney, 2012).

The merit of the paper by Browning, Bigby, and Douglas (2014) is that it both highlights such practical challenges and contributes to a more rigorous refinement of conceptual distinctions. It provides consumers, carers, practitioners, policymakers, and service providers with “sharper tools” (much more precise language) to bring to bear on the task of putting together schemes of supported decision making that achieve the lofty aims of the UNCRPD. Of course, conceptual clarity is only the first of the two questions. Achieving greater command over what is meant by supported decision making still leaves the second question of whether there is enough reliable evidence to found an evidence-based approach to the design of policies and programs. In recognition that so little research exists internationally, several small-scale pilot evaluations have begun in Australia.

### **Australian Piloting of Supported Decision Making Models**

Limited trials of supported decision making have already been completed in South Australia and the ACT, while one is in train for New South Wales, and Western Australia and Queensland also have work in the pipeline. Other developments include Victoria (for people with acquired brain injury) and work planned by the South Australian Health and Community Services Complaints Commissioner.

The South Australian trial of supported decision agreements between the consumer and a supporter, under the auspices of the South Australian Office of Public Advocate between November 2010 and 2012, involved 26 “decision ready” people for whom supporters were contracted to assist in making health, accommodation, and lifestyle decisions. The project developed and refined an operational model of supported decision making, adapted from the “stepped model” of decision making (Brayley, 2012). Three of the features of this model are: that it entails freely given or “relationship driven” support, where the decision maker always remains in control; that it distinguishes between “assistance” and “support”; and that it makes provision for an external monitor of the relationship of support. An independent evaluation found that participants experienced a boost in confidence about making their own decisions and reported generally positive reactions from consumers, supporters, and service providers, but the scheme proved to be a mixed bag operationally (Wallace, 2012). It also found that case management support was often necessary to “support” the

implementation of decisions. Thus, the project did not cover people with mental illness and was unable to recruit people already under guardianship, and the evaluation did not have the resources to drill deeply into underlying processes.

The ACT trial (ACT Disability, Aged and Carer Advocacy Service, 2013) tested an elaborated version of the South Australian supported decision-making model through close analysis of the experience of six people (all under guardianship), who participated in a pilot program offering various types of *capacity-building* support for participants across some or all of the different “life course stages” of making a decision (from the initial raising of awareness about potential decisions, to becoming “decision ready”, through to implementing a decision). In addition to exploring issues around the interface with guardianship, the ACT trial extended the model in three other ways: by not excluding more socially isolated participants unable to identify a supporter; by including people wanting to make a financial decision; and by not confining supporters to being volunteers (professional workers without a conflict of interest acted in some circumstances). This pilot confirmed the inappropriateness of any inflexible “one-size-fits-all” approach to supported decision making, concluding, among other things, that

while each of the decision makers shared many elements of support, overwhelming what featured most strongly was the need to establish decision support tailored to individual need and the role of the formal project in generating cultural change among family members, support workers, guardians and the wider community. (ACT Disability, Aged and Carer Advocacy Service, 2013, p. 54)

In New South Wales, the Departments of Family and Community Services, Ageing Disability and Home Care, the Public Guardian, and the New South Wales Trustee and Guardian have joined forces to develop, trial, and evaluate a scaled-back and mainly *facilitated* model of supported decision making. The pilot covers ageing, disability, and home care clients, of varying ages, service types, and life stages (including some under guardianship or financial management orders), offering a suite of various fact sheets, aids, and other accessible tools to engage and provide information resources for families, carers, advocates, and service providers. The pilot, running from the beginning of 2013 to mid-2014, has recruited 24 participants from its catchment base in Western Sydney (the Metro North region around Parramatta and Hornsby). Supporters have been recruited both from the pool of lay volunteers (family or friendship networks) and also from what the ACT would term professionals (key workers). The pilot is being independently evaluated (by WestWood Spice) at three main points during the life of the project. This will assess whether participants and stakeholders feel that new decision-making pathways have been opened, and will tap their views about the adequacy of decision-making resources or tools and general information sessions developed as part of the project.

Developments in other parts of the federation remain at the very early stages of consideration. Victoria is putting the final touches on the design of a Victorian Office of Public Advocate trial (funded by the Victoria Law Foundation). This pilot will recruit 20 *isolated* people with cognitive disability and match them with skilled *volunteers* (strangers), to, among other things, test the viability of some of the reforms suggested in the report of the Victorian Law Reform Commission (2012), namely supported decision making and co-decision making (paras 8.13–8.31; 8.78–8.87). Queensland is exploring the features of the guardianship system (as widely conceived) which promote or restrict the realisation of individual choice. This work may help to determine what the ongoing role of guardianship should be, and shed light on the viability of the United States’ suggestion that reformed guardianship taking on board the “person-centred decision making” models

developed for developmental disabilities by transforming itself into a “person-centred” model of guardianship, may be little different from supported decision making (Boundy & Fleischner, 2013, p. 13; Johns, 2012, p. 1543–1544 [the model], p. 1558 [person-centred guardianship]). For its part, in Western Australia, Individualised Services Inc. (an unincorporated group of support organisations committed to individualised supports and services) has obtained some funding to explore the role of supported decision making within an individualised service model.

### Conclusion

So, where do we currently stand in our thinking about supported decision making? A great deal of progress has been made at a conceptual level in clarifying the many points on the spectrum of supported decision making and in identifying the multiplicity of variables in play in rendering decision-making support, such a fluid and indeed “complex” field of planning. This work is far from done, of course. Thus, speaking at a recent seminar in Queensland in June, 2013, Professor Amita Dhanda threw out a challenge of whether supported decision making would be better conceived as a *universal* component of community life for *all* citizens, rather than something targeting only those with a disability.

However, it is ventured here that by far the largest part of the agenda of unfinished business is in developing the research base that is so necessary to sound policymaking or law reform. The Australian pilot programs have made an important first contribution. However, they are very small-scale (from 6 to 26 participants) and short-term in character (revealing little about their viability once the “honeymoon” effect wears off for all concerned). They are also quite *selective*, in that they have largely drawn in people whose cognitive incapacity is associated with intellectual disability (thus offering virtually no guidance about people with an acquired brain injury [ABI], dementia, or mental illness, other than the hint that the existing models may be ill-suited to meeting their needs in practice). Despite their best endeavours, none of the pilots has had the funding to engage in rigorous independent evaluation, instead being forced to gather satisfaction measures (and without any control group as a benchmark).

Even with these limitations, the preliminary findings from the pilots serve to reinforce the urgent need for an independent, medium-term, comparative study, which would evaluate different models in different jurisdictions. Such a study should be designed to uncover relevant differences in or between the needs of particular disability groups; and it should examine individual differences, such as those due to age or geographic location, to being or not being under guardianship, or variance in the strength or otherwise of any existing networks of informal support. That people under guardianship proved so difficult to recruit in the South Australian trial, or that evidence emerged of conflicts between supporters and guardians in the ACT study, are two examples of why such variables may prove significant to the practical design and delivery of supported decision-making programs. That volunteers from within or even outside family and friendship networks have proven near impossible to recruit for up to half of all trial participants is another warning bell. That the cheaper “facilitation models”, such as that in New South Wales and elsewhere (provision of “resources” and “decisional tools”), have had limited resonance or effectiveness (by contrast with the more resource-intensive work of tailor-made coordination and capacity building) is yet another.

These are more than straws in the wind. They appear to bear out the truth of the remark by the former Chief Justice of the High Court of Australia, Sir Anthony Mason, in

warning of the perils of embarking on policymaking or legislative reform without ensuring that there is a sound evidence-based approach, observing that “[a]s things currently stand, [current] proposals seem to reflect little more than ideals that have not been carefully thought through, with the risk that they will result in experimental law-making” (Mason, 2013, p. 173). There is no shortage of pressing issues to research before rushing to adopt particular programs or legislative models. As the article by Browning, Bigby, and Douglas (2014) highlights, the list of possible research questions for future trials and research into supported decision making to address includes “how supported and substituted decision making could coexist and how mental capacity could be assessed in this new supported decision making paradigm” and the way “interdependence” of decision making is accommodated in practice. It is only through rigorous, independent, and adequately funded research into such questions that the risks of another “experiment” in bad policymaking might be mitigated and the “enigmatic” mystery of supported decision making rendered more comprehensible and meaningful in practice.

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