

Supported Decision-making in Australia: Meeting the challenge of moving from capacity to capacity-building?

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Supported decision-making models are widely commended, but legislation is scant; and, while other forms of decision-making support are more plentiful, evaluations are few and methodological rigor is largely absent. This paper reviews Australian law and practice, law reform proposals, and trials of decision support programs, to assess what has been achieved so far in realising the aspirations of the *Convention on the Rights of Persons with Disabilities* of providing 'support' with 'safeguards'. Taking the example of a current control group evaluation of impacts of experientially-derived training materials for supporters, the paper discusses the role of evidence-based approaches to transitioning from substitute to supported decision-making through capacity-building programs for supporters of people with cognitive impairments.

Keywords: supported decision-making; law reform; programs of support; evaluation; evidence-based policy; capacity-building.

[A] Introduction.

- Adult guardianship removes a person's ability to decide for themselves.
- The *Convention on the Rights of Persons with Disabilities* ('CRPD') instead promotes supported decision-making (S-D) for people with a disability, so they keep rather than loses their formal individual autonomy; are treated as capable rather than incapable of making decisions; and retain a social and legal equality with other citizens lost when a substitute decision-maker steps into their shoes.
- CRPD monitoring committee argues S-D should entirely replace substitute decision-making (Arstein-Kerslake & Flynn, 2015; UN Committee on the Rights of Persons with Disabilities, 2014).
- There is a suite of possible measures to choose from: covering '*supported decision-making*, support *with* decision-making and broader *support to exercise legal capacity*, across a range of law, policy and practice.' (Gooding, 2015) at 52 [emphasis in original].
- Nothing 'not to like' about pushing in this direction, but conceals the 'wicked' character of the problem, being 'complex, unpredictable, open ended, or intractable' (Head & Alford, 2015) at 712, and conceptually tricky its conceptual

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mapping – with S-D largely predicated on the social model of disability (focussing on things external to the person or their impairment) while in reality a more nuanced ‘interactionist’ model has purchase (Riddle, 2012);

- Wide gulf between formal and substantive realisation of the lofty goals – self-actualisation rarely is found in pure form, unadulterated by some normal or potentially ‘questionable’ forms of external influence.
- Ethically surely not enough to create the *conditions* for an autonomous decision without asking if the decision is *in fact* autonomous, meaning cannot ignore the subtle shadings of external social influence running from casual conversational discussion of options, through ‘mere’ moral blackmail and ending in outright coercion or undue influence which negates autonomy (Carney, Tait, & Touyz, 2007).
- Adequacy of ‘safeguards’ or other accountability processes around autonomy especially wickedly problematic (Carney, 2016/17 in press; Kong, 2015)? As the Ontario Law Commission recently observed, ‘[i]t is not difficult to imagine a regime in which all individuals retained legal capacity but in which the interactions of “supporters” with the supported individuals were paternalistic and controlling’ (LCO, 2015: 146) also (Parker, 2016).
- In all S-D settings commonly claimed that supporters ‘can read’ the will of the person being supported – at least more truly than someone less familiar with their life. But ‘better’ is not necessarily ‘correct’.
- So finding ways of bringing home to supporters how fraught is their capacity genuinely to help people to realise their will and preferences, and finding ways of identifying and, where appropriate of redressing, mistaken readings of will and preferences – are just two of the ‘wicked’ problems faced in this area of law and policy, as the Ontario Law Commission has recognised, writing that:

Where a decision is being made through this kind of empathetic inference, the individual carrying out this exercise should be aware that they are undertaking a significantly morally freighted activity and that the obligations on them are high. Further, the individual at the centre should not be left to solely suffer the legal consequences. That is, legal accountability structures should mirror, as closely as possible, the actual decision-making process (LCO, 2015: 147).

- These are some of the wicked conundrums I consider in arguing that provision of adequate safeguards should be a major priority for policy development and evaluation.

[B] Background.

- Capacity inevitably lies at heart of substitute decision-making by way of adult guardianship appointments, despite 1980s shift from abstract cognitive tests to more functional issue of what a person can or cannot do (Flynn & Arstein-Kerslake, 2014: 86-87).

- Big issues at stake in guardianship and S-D, for '[i]t is a terrible thing to be assessed as lacking capacity when you do not...[and] [i]t is a terrible thing to be said to have capacity when you do not.' (Herring & Wall, 2015: 698).
- S-D rightly has no 'capacity' basis for policing its equivalent boundary lines (for let there be no mistake, boundary lines still exist: (Richardson, 2012: 95-96; 2013).
- S-D essentially shifts the focus from the capacity of the person being *assisted* to the adequacy of the capacity of those *providing* assistance. Such assistance may be from family, civil society or special government or non-government programs (especially for more isolated individuals), or from people appointed under any supported decision-making laws: see (Carney & Beaupert, 2013: 183-188). Different considerations arise for each setting; they are not all of a piece. Informal civil society arrangements account for the great bulk of support, because law struggles for purchase over the affairs and lives of ordinary citizens (Gooding, 2015: 48)
- Little is known about how well informal support arrangements work, but undue or 'hidden' paternalism is a major concern (Nunnelley, 2015: 67, 75).
- not that supporters cannot make a good fist of dealing with reading will and preferences of people with even the most profound difficulties, as Jo Watson's study of five cases demonstrates (Watson, 2016: 4-6); though, as Hillman et al demonstrate, 'incidental or subtle' rights violations do occur (Hillman et al., 2012: 1068).
- Rather, I suggest, it is that we know too little about what programs may contribute to *capacity-building for supporters*, thus expanding the social capital of the person being supported (Hillman et al., 2013: 923).
- And that too little work has gone into devising effective safeguards against deviation from the ideal (Kong, 2015; though see, Ottmann, McVilly, & Maragoudaki, 2016).
- Cannot simply *presume* that unaided informal or other support is adequate. Some supporters have a need for capacity-building or other assistance to better perform their role. Arguably provision of that capacity-building is a corollary of CRPD socio-economic 'right' to support.
- Research cupboard on S-D capacity-building is bare (Bigby, Whiteside, & Douglas, 2015: 11); take-up of *legislative* avenues of S-D difficult to ascertain (since exercise of the options is more akin to making a contract) but tends to be low (LCO, 2014: 128-130) and likewise there is little information about utilisation or effectiveness (Kohn & Blumenthal, 2014; for detailed discussion see: Kohn, Blumenthal, & Campbell, 2013 especially at 1129-1143).

[C] What can capacity-building programs offer?

- Capacity-building covers everything from mobilising financial support to fund (and, as in Sweden, ‘advocate’ for) realisation of the socio-economic right to S-D in Art 12 of the CRPD, through to mobilisation of human capital resources within civil society or the family (Gooding, 2015: 63-64).
- Although social capital is an amorphous notion (covering things like informal networks, network bonding and bridging, and trust), any enhancements of it benefit people with a disability (Koutsogeorgou et al., 2014). Likewise any ‘capacity-building’ of the relevant knowledge and abilities of individual supporters.
- If at least some informal decision-making supporters require advice and training in how to actualise the autonomy of those being assisted and avoid paternalism or abuse, an operational way of identifying the supporters to be targeted by the program is called for. And likewise in deploying safeguards to detect and remedy any abuse.
- Plethora of ‘off the shelf’ selections of S-D measures *presumed* to be beneficial, and none have been rigorously evaluated for the effectiveness or durability of their impact (even for the yet to be developed ‘guidebook’ from the US S-D Resource Centre Blanck & Martinis, 2015: 29).
- Bigby et al ARC Linkage is an international first in seeking to remedy this lack of an evidence base or rigorous evaluation of what works, for whom, and for how long.²
- In recognition of the high level of trust and responsibility reposed in supporters in furthering the rights of the person being supported to participate in decision making and to being directed by their will and preferences, the capacity-building program includes five safeguards:
 - (i) *continual review and reflection* about whether support is consistent with a paradigm based on commitment, knowledge of the person and respect for will, preference and rights, or whether it is sliding into the old paradigm, driven by ‘best interest’ perspectives;
 - (ii) *accountability* through requiring supporters to be able to explain how they come to know the person’s preferences, the rationale for their support, and evidence how they provide any support that lies behind shared or substitute decisions made with a person;
 - (iii) *orchestration* through requiring supporters to act in concert with others and not alone;

² ARC Linkage grant, ‘Effective Decision Making Support for People with Cognitive Disability’ (2015-2019) [CI’s Chris Bigby, Jacinta Douglas, Terry Carney, Ilan Vizel, & Shih-Ning Then; PI’s John Chesterman, Jodie Cook & Imelda Dodds].

(iv) *person-centred strategies* requiring supporters to tailor support strategies to the person and the decision; and finally

(v) by promoting respect for *rights and least restrictive alternatives* consistent with the values of the CRPD. #

- Elephant in the room question is whether S-D can avoid risks of de facto paternalism, confirmation of learned helplessness and deference, or perpetuation of the ‘inequality’ associated with living in or being supported within an asymmetrical relationship?
- Serious doubt held about whether this can easily be achieved, given the example of ALRC’s safeguards around reformed Centrelink ‘payment nominee’ provisions serving to *increase* rather than reduce risk because its safeguards are inferior to existing –and quite unacceptably weak – protections (Carney, 2016/17 in press).
- Some commentators see a complete answer to this dilemma in what I may term a ‘weight of numbers’ solution in the form of ‘circles of support’; here it is said that someone in the network will appreciate what is happening and ensure that a more acceptable outcome is realised (Flynn & Arstein-Kerslake, 2014), however this may not counter the subtle forms of domination and compromising of agency through learned helplessness.
- The British Columbia appointment of a person to be an independent ‘monitor’ of the actions of one or two supporters (such as where the supporter is the partner of the person, or say involves both parents) is another approach to devising safeguards (LCO, 2015: 188-190) Yet in practice this too is dubious, since, to use Kong’s characterisation, many of the people being supported will present to outsiders as being ‘happy’ or complicit in any paternalistic compromising of their autonomy (Kong, 2015: 710).
- Common law remedies of undue influence offer some possible safeguards but are generally seen to be of limited help : (LCO, 2015: 139), while Margaret Hall explores relying on concepts of vulnerability to draw the line. Adopting feminist conceptions of autonomy as ‘fundamentally *relational*, contextual, and *developed*,...exercised through (and not in resistance to) relationships with other human beings’, she stresses that the object is to locate ‘the *right kind of relationship*’ (Hall, 2012: 86, 87)
- However as Craigie points out, at a *practical level*, what may appear to others as totally harmless levels of coercion or incentives for someone to continue reflecting on and developing their initial expression of will – such as common social dialogue involving putting forward an alternative position or seeking to prolong the conversation – may be deeply problematic for a person whose previous history of dependency or paternalism (Craigie, 2015: 404).
- The operational challenge this poses for capacity-building is that of constructing educative programs encouraging supporters to learn how to foster the self-worth and confidence in agency of the person being supported, and developing supporters’ self-reflective sensitivity to the prospect that their well-

meaning conversations about a decision may unintentionally negate the very autonomy, will and preferences of the person being supported. Grounding such program strands in experiential findings of what helps to sensitise supporters to such risks and then measuring the degree of realisation (and durability) of any such capacity-building is a research challenge which it can be anticipated will more than fully test the current ARC project and future researchers.

[D] Conclusion

- Wicked problems associated with the design and delivery of supported decision-making are challenging ones as much for the law as they are for social policy and social research.
- There needs to be a clear-eyed acknowledgement of the S-D relationship ‘as one of *influence* and *interaction* in order to put in place the essential safeguards to ensure genuine choice for the individual and realization of her will and preferences’ (Arstein-Kerslake, 2016: 90).
- In a liberal pluralist democracy which values individual choice rights (including the dignity of risk and of idiosyncrasy) and recognises the contextuality of lived lives (relational autonomy), there is little ‘not to like’ about a preference or requirement for supported rather than substitute decision-making.
- However as this paper has shown, there are a lot of important questions to be answered as the social (and to a lesser extent ‘legal’) experiment with different forms of support are trialled or implemented across the world.
- Hope is that our ARC project will at least shed light on whether a capacity-building program constructed from prior fieldwork experience actually makes a difference, and if so, for how long its benefits subsist.
- Other issues around safeguards are largely ones for the future?

- Arstein-Kerslake, A. (2016). An Empowering Dependency: Exploring support for the exercise of legal capacity. *Scandinavian Journal of Disability Research*, 18(1), 77-92.
- Arstein-Kerslake, A., & Flynn, E. (2015). The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A roadmap for equality before the law. *The International Journal of Human Rights*, 1-20.
- Bigby, C., Whiteside, M., & Douglas, J. (2015). *Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas*. Retrieved from Melbourne:
http://apo.org.au/files/Resource/final_full_report_for_support_for_decision_making_dilemmas_and_challenges_6_june_2015_0.pdf
- Blanck, P., & Martinis, J. (2015). “The Right to Make Choices”: The National Resource Center for Supported Decision-Making. *Inclusion*, 3(1), 24-33.
- Carney, T. (2016/17 in press). Australian Guardianship Tribunals: An adequate response to CRPD disability rights recognition and protection of the vulnerable over the lifecourse? *Journal of Ethics in Mental Health*, forthcoming.
- Carney, T., & Beaupert, F. (2013). Public and Private Bricolage-Challenges balancing law, services & civil society in advancing CRPD supported decision making. *University of New South Wales Law Journal*, 36(1), 175-201.
- Carney, T., Tait, D., & Touyz, S. (2007). Coercion is Coercion?: Reflections on clinical trends in use of compulsion in treatment of anorexia nervosa patients *Australasian Psychiatry*, 15(5), 390-395.
- Craigie, J. (2015). A Fine Balance: Reconsidering Patient Autonomy in Light of the UN Convention on the Rights of Persons with Disabilities. *Bioethics*, 29(6), 398-405.
- Flynn, E., & Arstein-Kerslake, A. (2014). Legislating Personhood: Realising the right to support in exercising legal capacity. *International Journal of Law in Context*, 10(1), 81-104.
- Gooding, P. (2015). Navigating the ‘Flashing Amber Lights’ of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns. *Human Rights Law Review*, 15(1), 45-71.
- Hall, M. (2012). Mental Capacity in the (Civil) Law: Capacity, autonomy and vulnerability. *McGill Law Journal*, 58(1), 61-94.
- Head, B. W., & Alford, J. (2015). Wicked Problems: Implications for public policy and management. *Administration & Society*, 47(6), 711-739.
- Herring, J., & Wall, J. (2015). Autonomy, Capacity and Vulnerable Adults: Filling the gaps in the Mental Capacity Act. *Legal Studies*, 35(4), 698-719.
- Hillman, A., Donnelly, M., Dew, A., Stancliffe, R. J., Whitaker, L., Knox, M., . . . Parmenter, T. R. (2013). The dynamics of support over time in the intentional support networks of nine people with intellectual disability. *Disability & Society*, 28(7), 922-936.
- Hillman, A., Donnelly, M., Whitaker, L., Dew, A., Stancliffe, R., Knox, M., . . . Parmenter, T. (2012). Experiencing rights within positive, person-centred support

- networks of people with intellectual disability in Australia. *Journal of Intellectual Disability Research*, 56(11), 1065-1075.
- Kohn, N. A., & Blumenthal, J. A. (2014). A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities. *Disability and Health Journal*, 7(1), S40-S43.
- Kohn, N. A., Blumenthal, J. A., & Campbell, A. T. (2013). Supported Decision-Making: A Viable Alternative to Guardianship? *Penn State Law Review*, 117(4), 1111-1157.
- Kong, C. (2015). The Convention for the Rights of Persons with Disabilities and Article 12: Prospective Feminist Lessons against the "Will and Preferences" Paradigm. *Laws*, 4(4), 709-728.
- Koutsogeorgou, E., Leonardi, M., Bickenbach, J. E., Cerniauskaite, M., Quintas, R., & Raggi, A. (2014). Social Capital, Disability, and Usefulness of the International Classification of Functioning, Disability and Health for the development and monitoring of policy interventions. *Disability & Society*, 29(7), 1104-1116.
- LCO. (2014). *Legal Capacity, Decision-making and Guardianship. Discussion Paper May 2014*. Retrieved from Toronto:
- LCO. (2015). *Legal Capacity, Decision-Making and Guardianship; Interim Report*. Retrieved from Toronto:
- Nunnelley, S. (2015). *Personal Support Networks in Practice and Theory: Assessing the implications for supported decision-making law*. Retrieved from Toronto:
- Ottmann, G., McVilly, K., & Maragoudaki, M. (2016). 'I Walk from Trouble': Exploring safeguards with adults with intellectual disabilities—an Australian qualitative study. *Disability & Society*, 31(1), 47-63.
- Parker, M. (2016). Getting the Balance Right: Conceptual considerations concerning legal capacity and supported decision-making. *Journal of Bioethical Inquiry*, 13(3), 381-393.
- Richardson, G. (2012). Mental Disabilities and the law: From substitute to supported decision-making? *Current Legal Problems*, 65(1), 333-354.
- Richardson, G. (2013). Mental Capacity in the Shadow of Suicide: What can the law do? *International Journal of Law in Context*, 9(01), 87-105.
- Riddle, C. A. (2012). Defining Disability: Metaphysical not political. *Medicine, Health Care and Philosophy*, 16(3), 377-384.
- UN Committee on the Rights of Persons with Disabilities. (2014). *General Comment No. 1* (2014). Retrieved from Geneva: <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>
- Watson, J. (2016). Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability. *Laws*, 5(1), 6 [1-9pp].