

On the Horizon: Policy Developments Concerning People with Intellectual Disability

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Introduction

In addition to our general systemic advocacy role, the Office of the Public Advocate (OPA) has involvement in the lives of people with intellectual disability via a number of our program areas.

OPA's Community Visitors regularly visit the supported residences and group homes where many people with intellectual disability reside. Over 5,000 visits were conducted by over 300 Community Visitors in 2010/11. Of these visits, there were 2,782 visits in the 'disability services' stream to residences where a significant number of people with intellectual disability live (OPA 2011a, p. 10).

In the same period OPA's Independent Third Persons, of whom there are now more than 220, attended almost 2000 police interviews of people with apparent cognitive impairments or mental ill health (OPA 2011b, p. 30).

OPA runs a small program where staff attend internal prison disciplinary hearings involving prisoners with intellectual disability. In the last reporting period 136 hearings were attended (OPA 2011b, p. 30).

OPA also acts as guardian as last resort for some people with intellectual disability. In the last financial year OPA was appointed guardian on 1730 occasions, with around 16 per cent of OPA's new guardianship clients having an intellectual disability (OPA 2011b, pp. 6-7). Nineteen per cent of OPA's 563 investigations for the Victorian Civil and Administrative Tribunal (VCAT) in the last financial year concerned people with intellectual disability (OPA 2011b, p. 11). And during the same period 29 per cent of OPA's 476 individual advocacy clients were people with intellectual disability (OPA 2011b, p. 13).

The theme of this Roundtable is 'services and families working together', and we all know that in many ways the glue that holds the disability services sector together is the willingness of families and services to work together to improve the wellbeing of people with a disability. We also know that stresses exist that make the relationship at times a fraught and highly pressured one. Service providers operate with less than ideal resources at their disposal and with a workforce that is not as highly trained or professionalised as it might be. Families, meanwhile, have an emotional investment in the wellbeing of individuals that can never be replicated by a service provider, no matter how empathetic or engaged the service provider might be. Families are the carers of the very great majority of people with a disability, and in those situations

where they are no longer providing the primary care, they usually have the knowledge and experience that comes with having provided that care for their family member for longer than anybody else.

At times these tensions reach breaking point. OPA's Advocate Guardian program becomes involved when there is a failure in what are unsatisfactorily known as 'informal' care arrangements. This can occur when there is no family involvement with the person, when family members can't work together in the interests of the person, or where families and service providers are unable to work together.

There are a number of systemic reform initiatives that are underway in Victoria that engage the interconnecting roles of families and service providers. I want to look at three of these in this paper, which cover the following interrelated areas: the justice system, guardianship laws and supported decision making.

There are a number of other policy developments relevant to people with intellectual disability and their families that I won't discuss here. These include, for instance, the impact of the continued roll out of Individual Support Packages. On this point, I just note here that a recent report by the Victorian Auditor-General (2011, p. x), while broadly supportive, contained a number of recommendations concerning, for instance, the need for greater equity in Individual Support Package allocation and better crisis support.

1. The justice system

There is currently an inquiry being conducted by the Victorian Parliament's Law Reform Committee on 'Access to and Interaction with the Justice System by People with an Intellectual Disability and their Families and Carers'. A similar inquiry is going on in New South Wales, with that state's Law Reform Commission conducting an inquiry into 'People with cognitive and mental health impairments in the criminal justice system'.

The establishment of the Victorian parliamentary inquiry was, to some extent, a response of the new Baillieu government to the public release by OPA of a report on disability and violence at the start of 2011. That report (Dillon 2010) documented 86 cases of violence suffered by OPA clients in the Advocate Guardian program, and its public release made front page news (McKenzie 2011). Among the many alarming points made in the report was the observation that only one of the 32 disclosures of sexual assault had resulted in a perpetrator being imprisoned (Dillon 2010, p. 15). The government responded by announcing that it would seek 'the support of the parliament for a reference to the Law Reform Committee to undertake an inquiry into how people with a disability can get better access to justice' (Wooldridge 2011).

The original terms of reference for the Law Reform Committee (2011) required the Committee to conduct an 'Inquiry into access to and interaction with the justice system by people with an intellectual disability and their families and carers'. At the end of June a new paragraph was added to the terms of reference which asked the Committee to apply its findings 'to people with a disability other than an intellectual disability, for example those with an acquired brain injury or neurological condition leading to cognitive disability'.

There are a couple of important points to note about the terms of reference. First, the Committee is investigating not just situations of ‘violence’ but the broader topic of the ‘justice system’. Note also that this reference is not to the ‘criminal justice system’, which suggests that the Committee is interested in access to justice matters in the civil realm. It is also worth mentioning that the Committee is looking not only at perpetrators and victims, but also at families and carers.

OPA (2011c) has now made a substantial submission to this inquiry and given oral evidence. Key among our 22 recommendations we are seeking the following:

- Better support for people with disabilities to bring claims through the criminal justice system (we have called for a witness support program to be established for people with disabilities)
- Better emergency responses to disclosures or suspicions of violence (including provision of alternative accommodation)
- Better preventive measures (including more risk conscious accommodation decisions and better education strategies).

Other improvements OPA would like to see include the following:

- Better disability assessments of prison populations, and provision of appropriate services. Currently the number of prisoners with intellectual disability (see Holland et al 2007, pp. 17, 26) is significantly underestimated because of the lack of active screening. A trial screening process is reportedly being developed in Victoria.
- Consideration of the impact of any abolition of suspended sentences on people with disabilities and their families.
- Consideration of the efficacy of intervention orders, especially when used in relation to co-habitants.

We would also like to pose the question: should the government be looking to introduce a ‘failure to protect’ crime, where a person with profound disabilities is harmed and where obvious warning signals or dangers were ignored by someone in a position of responsibility? I will be interested to hear people’s thoughts about this. The final report of the Committee is due in March 2012.

2. The review of guardianship

Victoria’s guardianship legislation was enacted in 1986 and its enactment was groundbreaking for a number of reasons, most particularly for its use of an informal tribunal to make decisions concerning the appointment of administrators and guardians. Victoria’s guardianship laws are currently being reviewed by the Victorian Law Reform Commission (VLRC).

There have been a number of significant changes since 1986 that have made the review of Victoria’s guardianship legislation imperative.

The paradigmatic disability which the legislation sought to address was lifelong intellectual disability, yet only 16 per cent of OPA’s new guardianship clients in 2010/11 had an intellectual disability. Most of OPA’s new guardianship clients

(2011b, p. 7) have acquired disabilities during their lives, such as dementia (33 per cent), acquired brain injuries (18 per cent) or mental illnesses (17 per cent).

This gives rise to policy questions such as whether substitute decision makers should exercise the so-called 'substituted judgement' approach to their decisions, and be constrained to act wherever possible in accordance with a person's pre-incapacity wishes and behaviour. This can be quite contested terrain, especially when the implementation of such pre-incapacity wishes may lead to harm of some kind (the substituted judgement approach also raises philosophical questions about the extent to which people should be bound by their previous choices). The Victorian Law Reform Commission (2011, pp. 327-330) is considering this matter.

Another trend in the guardianship jurisdiction, which can be depicted as part of the modern risk management approach, concerns the increasing expectation among some in the disability field that formal decision-making authority should exist as a matter of course in relation to people with cognitive impairments. This can be seen as a form of risk transfer (see further the work of David Green, Anne-Maree Sawyer and colleagues (Green 2007, Green and Sawyer 2008, Sawyer 2008, Brett et al 2010)). One quite trivial anecdote here from OPA serves to illustrate the modern interplay between guardianship and risk management. One of OPA's guardianship clients wished to go horse riding, and it was only when the guardian gave her approval that the service provider arranged for this to happen. The risk was with the guardian, not the service provider. (I note here that the decision itself was an 'everyday care' one rather than technically the sort of decision a guardian has authority to make.)

At the same time that this is happening, a trend at the policy and legislative level runs in the opposite direction, which is informed as much as anything by international human rights developments. This trend may be described as the push to limit the state's appointment of substitute decision makers to situations of absolute necessity. The key development here is the adoption in 2006 of the United Nations *Convention on the Rights of Persons with Disabilities* (signed by Australia in 2007 and ratified by Australia in 2008).

Article 12(2) of the Disabilities Convention holds that '... persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life', while Article 12 (4) states that: '... all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse ... Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, ... apply for the shortest time possible and are subject to regular review ...'

Nor should this be seen as mere aspiration. While the enforceability of United Nations treaties in Australia is far from automatic (see, for instance, Chappell, Chesterman and Hill 2009, p. 214), the ratification of a treaty amounts to a legal statement by the country in question that the country considers itself bound by the treaty's terms, and the consequences of breaching a treaty can be unpredictable. When it comes to state-level policy, the enforceability of ratified international treaties is clearer, with the federal government having in its armoury the constitutional ability to broaden its policy reach through use of the external affairs power.

In essence the point here is that state governments increasingly consider themselves bound to implement the spirit and letter of international treaties such as the Disabilities Convention.

There is an argument, which I won't engage further here, that guardianship itself is inconsistent with the Convention. I will just make the point here that Australia ratified the Convention on the understanding that the Convention does allow for guardianship orders to be made, and indeed Australia made a declaratory statement to this effect.

Suffice it to say that this trend away from state-appointed substitute decision making is influencing the reform of guardianship laws throughout the world. Here in Victoria there is a considerable amount of energy being put in the guardianship review process into looking at alternatives to substitute decision making, which I'll examine in the next section on supported decision making.

The Victorian Law Reform Commission is examining a number of important reform proposals that I won't discuss in detail here. One of the more significant reform proposals is that OPA acquire broader investigation powers in relation to people with disabilities who are subject to abuse, exploitation or neglect (see VLRC 2011, pp. 375-6). Other important areas for reform include processes at VCAT, medical treatment arrangements where a person cannot consent to treatment, and the interrelationship between guardianship and other laws, including mental health and disability legislation (see VLRC 2011).

One important proposal in relation to this Roundtable brings two of the conflicting trends I have discussed to a head, namely:

- the increasing desire, particularly among service providers, for formal decision-making authority to exist in relation to people with cognitive impairments, and
- the move away from state-appointed substitute decision making (which is informed by international human rights developments).

The proposal that pits these two trends against each other concerns so-called 'anticipatory' orders and is of particular relevance to people with intellectual disability and their families and carers. I'll discuss this proposal in some detail here.

The vast majority of people with intellectual disability, and indeed most people with any form of cognitive impairment, do not have formal decision makers appointed by, or for, them. They do not have guardians or administrators, and have not appointed representatives under enduring powers of attorney. 'Informal' arrangements (and again I point out the unsatisfactory nature of this term) are the norm.

Long-term carers of adults with lifelong disabilities are often surprised to learn that they have limited legal status with regard to the person in their care. This is particularly the case for parents who are carers of their adult children. The reason why such carers do not have formal decision-making authority is somewhat circuitous, but can be explained like this. One of the central criteria for the appointment of a guardian or administrator is that the proposed represented person is in need of such an arrangement (*Guardianship and Administration Act 1986*, sections 22(1)(c), 46(1)(a)(iii)). When a satisfactory informal arrangement is in place, VCAT will not

disrupt it and make a guardianship or administration order. So, somewhat circuitously, the reason the parent won't be appointed guardian is because the parent is already there providing support. There is no need for an order.

Unsurprisingly, many lifelong carers are unhappy about this, and the Victorian Law Reform Commission (2011, pp. 202-4) is considering whether a new form of order, a so-called 'anticipatory' order, might be put in place here. The idea is that a person could be appointed as the guardian or administrator when someone they care for is likely at some future point to be in need of such an order.

OPA has several concerns about this possible development.

OPA is concerned about guardians and administrators being appointed on the basis of possible or likely future need, simply because of the unintended consequences that might result. The considerable emphasis now being placed on ensuring that the least restrictive guardianship arrangements are in place will likely be jeopardized if VCAT is empowered to make anticipatory orders. The impulse in the making of such orders will be to be overly protective. Indeed OPA has pointed out that this reform would run counter to the trend, driven by international human rights developments, to reduce state-appointed substitute decision-making arrangements to situations of absolute necessity.

In addition, the creation of such orders will also inevitably accelerate and normalise the growing trend among service providers to expect that substitute decision-making arrangements are, or will be put, in place for people with cognitive impairments. This will lead to more and more guardianship applications, which will not necessarily be of benefit to people with cognitive impairments.

Finally, OPA is of the view that the making of an anticipatory order will not actually give life-long carers quite the power that many suspect it might. It would give the guardian an elevated ability to make key life decisions in relation to the person in their care, but I point out that people, including carers, can now make guardianship applications if key life decisions are being made to the detriment of the person in their care.

Having said all that, OPA is very sympathetic to the claims of life-long carers, who are almost uniformly known to be undervalued and underappreciated by the disability services system, and indeed by society more generally. OPA has suggested some other changes to the law that might be made. OPA, for instance, has proposed that life-long carers be afforded an elevated ability to receive information about the person in their care (overcoming privacy restrictions). We have also argued that life-long carers should be able to assume a legally recognised advocacy role in relation to people in their care.

Again, I'll be interested in people's thoughts about this issue.

3. Supported decision-making

The final area I wish to address is developments in the supported decision-making field. In some ways, as Barbara Carter has pointed out (2009, p. 3), supported

decision making is something everyone does to some extent. Almost no-one makes all their decisions in isolation from the advice and support of anybody else.

But over the last two decades the term ‘supported decision making’ has come to refer to the group of practices whereby people with cognitive impairments are assisted to make or implement decisions about their own lives (Carter 2009, p. 4). The unarguable underwriting principle here is that people with cognitive disabilities generally have the capacity to play greater decision-making roles in their lives than they currently exercise.

The most significant source of authority for the increasing utilisation of supported decision making is the *Convention on the Rights of Persons with Disabilities*. While the term ‘supported decision making’ does not appear in the Convention, there is agreement that the Convention requires substitute decision making to be minimised wherever possible.

As the United Nations ‘Enable’ (2011) website points out:

‘The Convention recognizes that some persons with disabilities require assistance to exercise [legal] capacity, so States must do what they can to support those individuals and introduce safeguards against abuse of that support. Support could take the form of one trusted person or a network of people; it might be necessary occasionally or all the time ... Supported decision-making can take many forms.’

In other words, whenever a person can be assisted either to make, or have a central role in, decisions that affect them, then that should be preferred to substitute decision-making.

Supported decision-making initiatives all seek to improve the extent to which people with disabilities take part in the making of decisions that affect them. One of the questions that faces supported decision-making advocates concerns the extent to which initiatives in this field require legislative and policy changes in order to be implemented.

There are a range of initiatives able to be undertaken within existing legal and policy settings. For instance, Jo Watson and Rhonda Joseph at Scope have done considerable work at the service delivery level to show how supported decision-making principles can be used to improve the involvement of people with even the most profound disabilities in decisions that affect them. At the same time the Department of Human Services has constructed a guide to help services implement the principles of supported decision making, which I am advised should be available very shortly.

Work is also being conducted at the policy and legislative level to create supported decision-making alternatives to existing substitute decision-making options.

Substitute decision-making arrangements confer on somebody the authority to make decisions about another person. Guardians and administrators are examples of substitute decision makers. They are appointed by VCAT to act in a substitute role. Another example of substitute decision making occurs when an enduring power of attorney enables a personally-appointed representative to stand in the shoes of a

person who is deemed no longer to have the capacity to make his or her own decisions.

The line separating substitute decision making from supported decision making is not as clear as the theory might have it. For instance, guardians and administrators are required, in exercising their substitute decision-making power, to take ‘into account, as far as possible, the wishes of the represented person’ (*Guardianship and Administration Act 1986*, ss. 28(2)(e), 49(2)(b)). And OPA’s Advocate Guardians certainly work within a culture that is very receptive to the underwriting principles and impulses that are driving supported decision-making developments. But the point also needs to be made that substitute decision makers do have ultimate authority to override the wishes of the people for whom they have been appointed.

A number of developments are going on that seek to utilise supported decision making as an alternative to guardianship.

For instance, the South Australian Office of the Public Advocate is involved in a pilot project that is testing the extent to which supported decision-making arrangements can obviate the need for guardianship orders.

Meanwhile Michelle Browning (2010), who works at the New South Wales Office of the Public Guardian, undertook a Churchill Fellowship in 2010 and wrote a report on the transferability of certain overseas supported decision-making developments into Australian (particularly New South Wales) law and practice.

I want here to focus, though, on recent developments in the review of Victoria’s guardianship laws, with the Victorian Law Reform Commission signalling that legislative change in this area is, or should be, on the horizon.

Victorian Law Reform Commission

In its 2011 *Consultation Paper* the Commission (VLRC 2011, pp. 129-32) suggested giving legislative recognition to two possible supported decision-making innovations.

The first proposal is that ‘supported decision-making agreements’ could be entered into by people who might not be deemed to have sufficient capacity to enter other legal arrangements (such as enduring powers of attorney). These agreements would enable one or more supporters to access private information about the person being supported and to advise others of decisions that have been made. But these supporters would not be decision makers. The Commission (p. 130) compares such a proposed supporter to the Centrelink ‘correspondence nominee’ a person might have.

The Commission (p. 130) has also proposed creating ‘co-decision-making agreements’, in which people could nominate another person as someone with whom they will make joint decisions (see also Chesterman 2010, pp. 11-12). These agreements would be particularly useful, the Commission envisages, for people with fluctuating or declining capacity, who would not be ceding all power to a substitute decision maker. Decision-making responsibility would be shared.

In addition to these two new forms of personal appointment, the Commission (p. 131) has proposed that VCAT be able to make orders to the same effect; namely ‘supported decision-making orders’ and ‘co-decision-making orders’.

While the Commission (p. 132, 379), rightly in OPA’s view, does not believe OPA should have a role as a supported decision-maker or co-decision maker, OPA might have responsibility for establishing a new volunteer program that would encourage members of the public to take on these new supported decision-making roles.

It remains to be seen whether the Commission will include these proposals in its final recommendations, which are due at the end of December 2011. There are two main arguments against their inclusion. One is the simple fact that they would add complexity to an already inadequately understood jurisdiction. The other is that supported decision-making arrangements, particularly in the financial realm, might too easily enable the abuse of people with disabilities (see Chesterman 2010, pp. 8, 10). OPA, for the record, hopes that the proposals are included in the Commission’s final recommendations, and indeed that they are introduced into new guardianship legislation in due course.

Conclusion

This paper has considered possible policy changes in three areas that would, in OPA’s view, lead to improvements in the lives of people with intellectual disability. I look forward to discussing these and other developments with participants at this Roundtable.

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