

The 'consumer choice' challenges for people with cognitive impairments

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In this talk I want to discuss some of the most significant challenges that the advent and emphasis on consumer-directed care presents for people with cognitive impairments in the disability and aged care sectors. In doing that I want to talk briefly about the experience of the Victorian Office of the Public Advocate (OPA) in working with some of Victoria's most marginalised people, with a particular emphasis on our experience both as a substitute decision maker and as a facilitator of supported decision making. I then want to discuss how these experiences relate to the implementation of the idea that people in receipt of disability and aged care services should play more central roles in determining which services are delivered to them, and how they are delivered.

Substitute decision making

I shall shortly discuss the moves towards, and challenges presented by, the advent of consumer-directed care in both the aged care and disability sectors. But I do want to begin by noting that despite these developments, formal substitute decision making laws continue to apply in these areas.

Substitute decision making occurs when a person, whether formally appointed or not, makes a decision for another person. The formal mechanisms by which decision-making authority can be transferred include the activation of enduring powers of attorney and the appointment of guardians.

The Office of the Public Advocate (OPA) has a central role in relation to substitute decision making, as Victoria's adult guardian of last resort. We exercised this role in 1,645 situations last financial year (OPA 2016, p. 14). We regularly interact with the aged care and disability sectors. Over 41 per cent of our guardianship clients are people with dementia, in relation to whom we are required to make significant decisions, most typically concerning where the person is to live. People with intellectual disability constitute just under 30 per cent of our guardianship clients (OPA 2016, p. 14).

One of a number of complexities that OPA experiences in engaging with both the aged care and increasingly the disability sector, as the National Disability Insurance Scheme (NDIS) is being rolled out, is that both of these policy areas are governed by federal laws, while substitute decision making laws largely exist at the state and territory level.

This does mean that local jurisdictional laws and, perhaps more importantly, local practices exist that are not uniform across the country. This does make it hard for federal policy makers and bureaucrats to understand and engage appropriately with key state and territory agencies such as OPA in the provision of aged care and NDIS-funded services.

An added layer of complexity exists here in relation to the NDIS, as its governing federal legislation itself enables the appointment of substitute decision makers. The *NDIS Act* enables the appointment by the National Disability Insurance Agency (NDIA) of 'nominees', who (section 78) can have quite broad powers, indeed the same powers as participants, in relation to plan preparation and management. The role of nominees is also somewhat akin to that of guardians, although the appointment of a nominee does not involve a tribunal hearing.

How state and territory guardianship and enduring powers of attorney laws are working and will work in the NDIS context is a matter that OPA has wrestled with extensively (see, for instance, Australian Guardianship and Administration Council 2015, pp. 11-12) and this remains the subject of some debate.

As a general comment it is fair to say that the number of guardians and nominees being appointed for NDIS participants is lower than we anticipated. In large part I think that this is because NDIS participation is not contractual in nature. Rather, participation determinations are ultimately made by the NDIA, hopefully, but not essentially, with significant input from participants.

In addition to system-wide reform recommendations on this topic, OPA has proposed that the NDIA employ 'guardianship liaison officers' in each state and territory to enable particular difficulties to be resolved on a case-by-case basis, and this idea has been supported by the NDIA, though it is yet to be put into practice.

A final remark to make in this introductory section on substitute decision making is that the appointment of someone, or an agency like OPA, as a substitute decision maker does not mean that the decision maker can ignore the wishes of the person. For instance, in making guardianship decisions a guardian is required to act in the person's 'best interests', which includes 'taking into account, as far as possible, the wishes of the represented person' (*Guardianship and Administration Act 1986*, section 28; see also *Powers of Attorney Act 2014*, section 21). I should also note that we consider the 'best interests' paradigm to be an outdated one, and we support, and indeed we encouraged, the reform calls made on this matter by the Victorian Law Reform Commission (2012; see also Australian Law Reform Commission 2014).

Consumer-directed care

Recent reforms in both the aged care and disability sectors are underscored by a commitment to 'consumer-directed care'. This carries with it enormous potential benefits to individuals and to the systems as a whole, with the promise of more targeted and appropriate service delivery. It also carries obvious challenges when the consumers are people with significant cognitive disability (see further Chesterman 2014).

The commitment to consumer-directed care is clearly articulated in foundation documents in both policy areas.

For instance, one of the Commonwealth Home Support Programme objectives, according to the Programme Manual (Department of Social Services 2015, 13), is to 'Facilitate client choice', and included in the intended outcomes are that 'Frail, older people ... are supported to live in their own homes' and 'are supported to be more independent at home and in the community'.

The guiding principles articulated in the legislation that underpins the NDIS, meanwhile, include the following statements (*NDIS Act 2013*, sections 4 and 5): 'People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability'; 'People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals ...'; and 'people with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves'.

Human rights synergies

The consumer-directed care reform imperative dovetails with, and arguably draws from, human rights developments that seek to reduce and even eliminate substitute decision making in favour of supporting people with disabilities to make their own decisions. This is a shift that has most clearly been marked, of course, by the adoption and implementation of the Convention on the Rights of Persons with Disabilities (CRPD), which calls (article 12) for the recognition that 'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'.

One paradigm-changing, if not uniformly accepted, statement about the changing human rights landscape has come from the treaty-monitoring committee responsible for overseeing the CRPD. The Committee on the Rights of Persons with Disabilities is on record (2014, par. 28) as calling for 'the abolition of substitute decision-making regimes and the development of supported decision-making alternatives'.

The push to limit substitute decision making in favour of supporting people to make their own decisions is having an impact not only internationally but nationally and here in Victoria.

The Australian Law Reform Commission (ALRC) has led the way federally, calling (2014, p. 11) for 'Reform of Commonwealth, state and territory laws and legal frameworks concerning individual decision-making'. The ALRC proposed new 'National Decision-Making Principles and Guidelines' which would require that 'supported decision-making is encouraged', that 'representative decision-makers are appointed only as a last resort', and that 'the will, preferences and rights of persons direct decisions that affect their lives'. The ALRC recommended reform to a number of pieces of legislation, including the *NDIS Act* (p. 136) and the *Aged Care Act* (p. 170).

Four pieces of Victorian legislation in 2014 evidenced, at least to some extent, this paradigm change.

The *Mental Health Act 2014* (Vic) contains a statement (section 11(1)(c)) that 'persons receiving mental health services should be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions'.

The *Powers of Attorney Act 2014* (Vic) enables (Part 7) 'supportive attorneys' to be appointed who do not have power to make decisions but who have power to collect information and to implement decisions. Meanwhile the Guardianship and Administration Bill 2014 (Vic), which lapsed just prior to the 2014 state election, contained a new entity of 'supportive guardians', who would have been appointed by VCAT and would have had similar powers to 'supportive attorneys'.

More recently the Medical Treatment Planning and Decisions Bill will, if enacted, give far greater power to patients in Victoria to determine the medical treatments they will have in the future, in situations when they are no longer able to make medical decisions. This will occur by enabling people to complete either binding or suggestive advance directives (cl. 12), and the requirement that a patient's 'medical treatment decision maker', where one is needed, prioritises the patients 'values' and 'preferences' and doesn't simply act in their 'best interests' (cl. 61). The new legislation also enables (cl. 31) a 'support person' to be appointed, whose role (cl. 32) would include 'to support the person to make, communicate and give effect to the person's medical treatment decisions'.

The positive aspect of these reforms, many of which OPA has actively promoted, is clear. For far too long people with disability have had too little a role in making and putting into effect the decisions that affect them.

Supporting decision making: who, what, when, where and how?

The point I am wanting to make in identifying these reforms is a simple one: the consumer-directed care reforms in the aged care and disability sectors are consistent with human rights developments that are clearly informing domestic reforms.

A brief qualifying point is warranted here: namely that care should be taken in treating the term 'consumer-directed care' as necessarily synonymous with the concept that consumers should make, or be supported to make, their own decisions. The principle of 'consumer-directed care' can quite easily be interpreted to mean that the consumer *or their representative* should make decisions about service provision. Here the term is being used to distinguish, for instance, support provided to meet an individual's circumstances from a block-funded approach to service delivery. So while the term 'consumer-directed care' suggests direct consumer involvement, many of the aims behind the consumer-directed care reforms – such as more targeted expenditure and more

in-home tailored support – could actually be met when representatives rather than the consumers themselves are making service provision decisions. Of course this could be profoundly disempowering for consumers.

Having made that point, the consistency between consumer-directed care reforms and human rights developments are obvious. I wanted to make this point in order to say, in essence, that there is no turning back. Consumer-directed care, or some variation on it, is here to stay.

The broad effect of this change, of course, should be that people are encouraged to make their own decisions, rather than have others make decisions for them. The central challenge, though, is what this actually means for people whose disabilities affect their ability to make decisions.

Broken down a little more, the challenges here can be encapsulated in a number of questions. How are people with cognitive impairments to be supported to make their own decisions? Who is going to support them? What practices and techniques might supporters utilise? How will the provision of support be funded?

In the disability sector these questions are at least being raised and engaged, even if they are not yet being definitively answered. It is fair to say that in the aged care sector, the debate is far less progressed. Perhaps this is not surprising, as the aged care field remains a considerable way behind the disability sector when it comes to rights advocacy and recognition.

Evidence for this proposition comes from the fact that while we have the CRPD, there is yet to be an international convention on the rights of older people. Another indicator of the different level of the rights debates in both sectors is the still-heavy reliance in the aged care sector, despite an increasing emphasis on the provision of in-home care, on the supply of services in institutional settings. Although not without periodic calls and indeed evidence to the contrary, this is a model that the disability sector has generally moved on from (and one hopes in the fully-implemented NDIS world that it is not revisited).

When it comes to supported decision making with older people who have cognitive impairments, the discussion is not all that advanced. Uncertainty exists, for instance, about the extent to which supported decision-making practices can be utilised in relation to people with dementia (see for example Fetherstonhaugh et al 2014). As with many ideas under the ‘supported decision making’ banner, we need here evidence about what works.

The Australian Law Reform Commission is currently undertaking an inquiry on ‘protecting the rights of older Australians from abuse’. A significant group of people who are at risk of abuse are older people with cognitive impairments. In thinking about legal protective reforms that might be made, it is likely, given the ALRC’s 2014 report on *Equality, capacity and disability in Commonwealth laws*, that the ALRC will recommend mechanisms by which older people with cognitive impairments might be supported to make their own decisions. That report is due in May 2017 and will hopefully encourage supported decision-making developments in relation to older people.

In the disability arena, the questions I raised are being actively engaged, even if, as I say, they have not definitively been answered.

We already know that there is very little in-depth analysis of which practices labelled as examples of supported decision-making actually work. A vital contribution here will be the large multi-jurisdictional Australian Research Council-funded project ‘Effective decision making support for people with cognitive disability’. That project, involving four universities and 12 partner agencies (in which OPA is a project partner and in which I am one of a number of Partner Investigators), will provide the most rigorous analysis yet of supported decision-making activities.

We await the outcomes of that research with great interest. In the meantime, what do we know?

A series of pilot supported decision-making projects have been run in various jurisdictions in Australia in the disability area (see Carney 2014). Two of these pilot projects have involved OPA

(Vic). One, which was part-funded by the Victoria Law Foundation, used volunteers to support the decision making by 18 isolated people with cognitive impairments (see Burgen 2016). I note here that we use the term 'volunteer' to indicate an unpaid person who is typically a stranger to the person being supported. In using this term we are of course mindful that for as long as records have existed, carers have provided unpaid support to people with disabilities.

The other supported decision-making project involving OPA, the Oval project, is being run by the advocacy organisation Valid with OPA's support. This program, which will run until the middle of 2017, has been funded by the National Disability Insurance Agency. The Oval project is again utilising volunteer supporters who are this time assisting isolated people with cognitive impairments in the Barwon region of Victoria to make NDIS-related decisions. Michelle Browning, who is also presenting at this roundtable, has been employed by OPA to work on this project and, among other things, she is nearing completion of a final report on the program's national implications.

While we do await and look forward to the generation of reliable evidence about what 'supported decision-making' activities actually work, we have been able to glean from these pilot activities a number of important lessons.

We now know considerably more than we did about the challenges in identifying, selecting and training volunteer supporters (see Burgen 2016). We have also learnt quite a bit about the challenge of identifying appropriate pathways by which we can identify and gain access to people who may wish for, and benefit from, support in their decision making, but who do not have supporters currently in their lives.

We also know, through often vigorous debate, that questions continue to exist about how supported decision-making relates to guardianship and advocacy. In discussions I have had about these developments, one legitimate fear voiced by carers and advocates is that the rhetorical focus on supporting the decisions of consumers should not come at the expense of adequately funding advocacy services, where this is needed. This is a real danger, especially in the new NDIS context, as any rush to seek and obtain NDIS-related choices of participants with significant cognitive impairments, without the time and skills being utilised meaningfully to inform people about possibilities, will result in poor 'bounded choice' outcomes. A person in a group home who is asked where they want to live may well simply say 'here', if they are not properly brought on a journey and supported to understand what other options there might be and how they might choose between them.

In addition, we have learnt two key lessons from the pilots, neither of which will surprise people involved in this roundtable.

The first is that effective supported decision-making relationships take time to develop. It takes time to establish the trust and awareness of preferences and capabilities that are integral to such relationships (see Burgen 2016).

The second is that supported decision-making programs, even those that involve unpaid volunteers as supporters, are costly to run. They require the provision of training and professional oversight to ensure that already at-risk individuals are not harmed, taken advantage of, or even corralled into making particular choices.

This leads us to the question of how supported decision-making initiatives ought to be funded. I won't look at this in any depth, but I just want to flag the arguments here as they are being carried out in relation to the NDIS.

One argument is that funding ought to be provided by the NDIA under its 'Information, linkages and capacity building' framework, positioning supported decision making as an activity that focusses on improving the ability of people with disabilities generally, among other things, to engage with mainstream services.

Another argument is that the provision of support should simply be a funded NDIS service, where it is needed by an NDIS participant. This is arguably possible under the heading of 'support coordination', although that term does look more synonymous with case management than supported decision making.

A third argument is that support ought to be funded outside the NDIS, to enable the role to be more exploratory and not at risk of becoming purely instrumental, and to ensure that any NDIS-related decisions can be supported independently.

I don't plan to contribute here further to that debate, suffice it to say of course that all three arguments have merit.

Conclusion

Let me conclude. I hope this presentation has given you a sense of OPA's take on the challenges posed by the move to consumer-directed care in the disability and aged care sectors. This move, as I have said, has clear synergies with human rights developments, and we are seeing ever more evidence of reforms that seek to enable and support people to make their own decisions, rather than have others make decisions for them. While there are, and will be, obvious benefits to this move, which will far outweigh the disadvantages, we need to ensure that this shift does in fact lead to improvements in the ability of people meaningfully to direct their own lives. Supported decision-making initiatives are one important way in which people in receipt of disability and aged care services might meaningfully be engaged in decision making about what services are provided to them, how they are provided, and by whom they are provided. We can learn much from these initiatives in ensuring that consumer-directed care can be meaningfully implemented for people with significant cognitive impairments.

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