

Ten things I learned working at the Office of the Public Advocate

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The Office of the Public Advocate (OPA) is a statutory office set up under the *Victorian Guardianship and Administration Act 1986*. It provides individual and systemic advocacy for people with disabilities and the Public Advocate may be appointed by the Victorian Civil and Administrative Tribunal (VCAT) as guardian of last resort for adults with a cognitive disability. OPA also investigates and reports on applications to VCAT for the appointment of a guardian or administrator (financial manager).

OPA employs around 28 advocate/guardians whose main responsibilities are to provide advocacy, act as a guardian and investigate applications to VCAT. There is no established profession of guardian, nor is there any specific university or professional qualification for the position. Current advocate/guardians are drawn from a range of professional backgrounds and experience including social work, nursing, law, psychology, disability studies and education. They share a commitment to promoting the dignity, rights and interests of people with disabilities.

I have worked at OPA since 1992 and some time ago, as Acting Public Advocate, I was asked to provide a welcoming talk to a group of new advocate/guardians as part of their orientation program. It was later suggested to me that some of what I said may be worth repeating to a wider audience and be relevant to people working in other areas of disability. I spoke about ten things I have learned or observed during my time at OPA.

1. Nobody is immune from disability

Maybe this is just stating the obvious. Any one of us, within the next hour, year or decade could find herself with a disability of one kind or another. Equally, this could happen to someone we love, perhaps someone we love even more than we love ourselves. Alternatively, you could say that everyone has some type of disability; it is simply a matter of type and degree or that disability is instead a social construct where the response of society creates disability from a particular personal characteristic or impairment.

Whichever way you look at it, the message for me is that we are all in this together and we grow or are diminished by the way we handle this reality. In my experience, people working in the disability field will always say that they agree with this. However, deep down, some people fundamentally know it in their bones and believe it and some do not. I don't think there is a great deal that can be done about this, except to try to guard against an "us and them" approach developing either in your practice or in the organisation where you work.

2. All disabilities are not equal

If you are going to have a disability, I would advise you to try to have one that is medically clear and attracts funding and good service provision. Arguments about the diagnosis of disability and associated arguments about eligibility for services can be used to exclude people from treatment and services or keep them in a state of uncertainty for years.

Assessments, second opinions and reviews of eligibility can cost as much as providing the service the person is seeking in the first place.

Some disability services are specifically funded and some are not. If you have an acquired brain injury through a workplace accident or traffic accident, your treatment and services (in Victoria at least) will be funded through Workcover or TAC. If you acquire it through alcohol and drug abuse or an hypoxic brain injury such as a seizure or swimming pool accident, it will not. Psychiatric disabilities are problematic for a number of reasons, particularly if you do not have private health insurance. In any case, even if you receive psychiatric treatment, whether in a private or public hospital, community services and accommodation following your discharge will be very hard to obtain. Above all, try not to have two or more disabilities at once. The danger here is that all the effort will go into working out why you are not eligible for services associated with one disability because of the existence of your second disability. If you are also abusing drugs and alcohol, you might as well abandon all hope.

P.S. Beware of the justification that can be offered by service providers, or OPA, for not providing adequate assistance or for ceasing involvement, based on the argument that the person is thereby being empowered to take responsibility for him or herself. They may well be ready for that degree of autonomy, but it may also be an excuse, lacking empathy, that assumes far greater agency and independence of the person than the professional expects of themselves.

3. If something is “fragmented”, does that mean that it is broken?

Everyone working in the disability and health fields knows that the social and community service system has become very complicated. Arrangements vary across state boundaries and across regional boundaries within each State. Services are more often contracted out than provided directly by government, a legacy of the “steering, not rowing” debate. Aged care is the responsibility of the Commonwealth government and Disability services are the responsibility of the State governments, and the Commonwealth State Disability Agreement is a less than perfect co-ordinating arrangement between them. In the interests of flexibility, competition, efficiency and transparency, a person may need to deal with multiple agencies, government, non-government and private, in order to have their particular needs met. Even when arrangements are finally in place, a change in policy, an increase in age or a change in needs may necessitate new arrangements with different service providers and the whole process begins again.

This fragmentation of services has generated increased job opportunities for case managers who are needed to manage people’s care packages and navigate a way through systems. But case managers are usually attached to a particular disability-specific service and may not have the knowledge or authority to negotiate outside their own system. Sometimes guardianship is seen as an answer to this problem with a guardian being seen as some sort of super case-manager. Perhaps, however, we should admit that when we use weasel words such as “fragmented”, “devolved” or “diversified”, we may actually mean that the system is broken or

in chaos. Perhaps the answer lies in more integration and less competition as is the case in Scandinavian countries.

4. Personality survives/transcends disability

Personality characteristics are more likely to be intensified by disability than suppressed by it. People with acquired disabilities are usually recognisably the same people as before, gregarious or private, optimistic or pessimistic, selfish or altruistic, emotional or stoic, intense or relaxed in their approach to life. People who have disabilities from birth have the same range of personality characteristics as anyone else. The difference seems to be that personal characteristics are often intensified by disability, perhaps because some of the self-limiting mechanisms by which we control our personal behaviour have been affected.

Being mindful of this is an important part of person-centred practice. While it may seem obvious when you think about it, I fear that we often act as if it were not the case.

5. Get to know your client and allow them to get to know you

It may seem trite to suggest that it is important to get to know the person for whom you are guardian or advocate. Unless you can understand who a person is, how they live their life and what makes them tick, you are not in a very good position to be making decisions for them or advocating on their behalf. The quality of your guardianship or advocacy for a person is closely linked to the quality of the relationship you have with them, and this relationship should be characterised by understanding and respect.

Another part of a good guardianship or advocacy relationship is allowing your client to get to know you, not only as a professional but also as a person. I understand that this is more controversial but most people are reluctant to allow you access to important personal, intimate areas of their life unless they know and understand something about you in return, beyond the fact that you work for the Office of the Public Advocate. It is part of negotiating trust and building a working relationship based on respect. At the same time, the maintenance of appropriate professional boundaries and not becoming too personally involved remain important considerations that need to be regularly discussed with your colleagues and supervisor.

6. There is no value in reminding people about hurts they have forgotten

Frequently a guardian is appointed in circumstances of conflict that has its origins deep in family history. The conflict may be about who was overseas for twenty years and was not there to look after a parent who was sick. It may be about who regularly started the family fights at Christmas dinners or who has always been seen as the favoured family member. These historic grievances may have been forgotten by the person who is under guardianship but are rarely forgotten by other family members.

Part of the role of a guardian is to find out what the person's wishes are now and take these into account as far as possible when making decisions. If, for example, they have forgotten

the past and now want to see a particular person, it does not seem sensible to remind them about why they previously did not wish to see them, unless there is some real concern about their safety. (If you can persuade various family members not to remind them of past hurts, you are doing really well!). Be prepared, however, for this to be seen as very unfair by other family members. Because of this, I think it is important to give all involved time to tell their stories, and not rush to tell them that you are interested in the present and the future rather than the past. Moreover, while you may need to say at some stage that, as the guardian or advocate, you cannot heal all the family hurts, do be gentle about it, remember that disability places enormous pressures on everyone involved and don't just say "That is not my role".

7. One of the best things we can do is hold open the door for reconciliation

This follows from my previous comment. As a person nears the end of their life, different things become significant, and "unfinished business" is probably the most important of all. This is equally true for both persons in a relationship and the opportunity for apology, forgiveness and making peace is crucial. OPA has had experience with a client, unconscious in hospital as a result of an ultimately fatal assault by a family member, where it was believed that allowing a visit may provide an opportunity for some form of reconciliation. The Public Advocate perceived that it was consistent with the person that she would choose to see the family member if able to make that choice. Nobody will ever know if some form of reconciliation took place during that visit.

8. Take responsibility

If you are not prepared to make difficult decisions and take responsibility for what you do as an advocate or guardian, you are in the wrong job. The decisions you make are of enormous importance for the person you are guardian for and there is rarely certainty about what is the right decision. There is a high degree of judgment involved. We have guidelines, policies and processes to follow but in the end, you need to have faith in your judgment and be prepared to explain and justify why you made the decisions you did. In this, you will have the full support of the organisation.

There seems to be an increasing reluctance by professionals and by the organizations that employ them, to accept responsibility. Attempting to transfer risk and responsibility to the individual and avoiding organisational risk by strategies such as the appointment of a guardian appear to be emerging features of service provision. Encouraging other professionals to accept their own responsibilities may also be a part of your role from time to time.

9. People are complicated

People are complicated. Nobody is defined by one particular aspect or feature of his or her life and we change our minds. I was once guardian for a man with mild dementia who was facing an operation that may have required him to have a blood transfusion. This was contrary to his faith, or perhaps more to the faith of his wife and one of his children, but he told me that if a blood transfusion was needed to save his life he wanted to have it as "he had a lot of

living left to do". I believe he understood that this was contrary to his faith. I gave consent for the blood transfusion to be given, if needed, as a last resort and did not tell his family what he had told me. This was partly about respecting his current wishes even though he had been found by the Tribunal not to have the legal capacity to make this decision for himself. It was also about understanding that there were many things that were important to him in life, of which his faith was one and his wish to be part of the lives of his grandchildren was another. Finally, it was about being prepared to take responsibility for the decision, as I mentioned above.

10. Be careful about earlier views

A person should not be locked into a view s/he may have expressed at a different time and in different circumstances. For this reason, I am always wary about taking at face value a view that a person may have expressed in anticipation of certain occurrences. When he was a teenager, my very tall, fit, basketball-playing son told me that if he became a paraplegic, he would not want to live. He is now a very tall, fit, bicycle-riding, married father of two little girls and has probably changed his mind. What if he had been able to sign an "advance directive" then and was in hospital now, unable to express an opinion?. A person may dread dementia and ask that no medical treatment be given to her if she develops Alzheimer's Disease and is unable to look after herself. However, if she does develop Alzheimer's Disease, she may be quite happy living at home, or later in a dementia specific hostel, enjoying activities and visits from her family. How can you know in advance when life will be so bad that it will not be worth living?.

Autonomy is highly valued in our society and making advance directives or Enduring Powers of Attorney with clear instructions to the attorney or agent has a great deal of support in our community as a means of promoting autonomy. There is no clear mechanism at present for making advance directives in Australia, except arguably in common law, but the issue is very much on the agenda.

Conclusion

I would like to think that there are other things that I have learnt in my years at the Office of the Public Advocate. These are just a few that I hope you may find helpful or may strike a chord. I hope also that they generate your own thinking about what you have learnt from your work in the disability area.

Barbara Carter has held a variety of positions at the Office of the Public Advocate since 1992, her last full-time position being manager of guardianship and advocacy. The opinions expressed in this article are her own and do not necessarily reflect the views of the Office of the Public Advocate.