

Muzzling disability advocacy

Brian Martin

Adelle had been abandoned by services and her family because of her difficult behaviour. The closest thing to a home was the psychiatric ward of the local hospital. Acquaintances, pretending to be friends, took her in, took her money and flushed her medication down the toilet in order to manipulate her more easily. This cycle continued until Martha, in the formal role of advocate, entered Adelle's life and said "no more." With Martha's protection, Adelle learned how to stay out of hospital. She later married, fulfilling a long-time dream.

James was kept at home most of the time by his loving and protective mother who worried about his intellectual disability. He had very little experience in the wider world. Adam became an advocate and father figure for James, encouraging his mother to allow him some freedom. James now walks to the shop to buy groceries and has joined Adam for trips to the nearby city, something he would never have imagined before.

Sally attends the local primary school with all the neighbourhood girls, several of whom have become her friends, and is learning a lot. If Sally had lived 20 years ago, her only option would have been a "special school," because she has cerebral palsy. In such a place she would have stagnated and remained isolated. Sally can thank the efforts of tenacious advocates, mainly parents, who helped bring about a change in school policy that allowed students like Sally to be part of the school community.

Some people with disabilities are highly capable and able to speak up for themselves. But others need assistance, for example those with severe intellectual disabilities or who are homeless, abused or in prison. Those who struggle against the greatest disadvantage are at greatest risk of further degradation.

If service systems — for education, welfare, accommodation and employment — worked perfectly, there would be no problem. But all services have flaws, so there needs to

be someone to speak up and make sure they work better.

The very idea of advocacy is a recognition that some people need assistance because they can't manage certain tasks on their own. A few people can represent themselves in court, but most need a lawyer to deal with the complexities. Some worthy litigants can't afford a lawyer, so the government offers legal aid and some lawyers offer pro bono services.

Governments in Australia fund numerous services for people with disabilities, including accommodation facilities, carers, medical assistance, income support, financial management, workplaces, training and education. But these services are not perfect, and sometimes fail badly. They need to be kept on their toes by articulate spokespeople. To help in this, the government funds disability advocacy. Most of the funding comes from the Australian government, through the federal Department of Families, Community Services and Indigenous Affairs (FACSIA), with additional funding by state governments and a small amount of private support.

In 2006, FACSIA conducted a review of its \$12m funding for the disability advocacy sector. The stated aim of the review was to improve the amount and delivery of advocacy, naturally enough. But many in the sector, for reasons described later, believe the resulting reform will be devastating to advocacy and hence damaging to people with disabilities who need advocacy.

The nature of advocacy

Systems to address human needs and wants — everything from food to entertainment — seldom run perfectly, so they need some method to keep them on their toes. Albert Hirschman (1970) distinguished between two basic methods, which he called exit and voice. Exit is leaving and finding another provider. Customers who don't like a breakfast cereal usually exit by choosing another brand.

Voice means speaking out, making a complaint. If there are no

alternatives, or loyalty is great, then people are more likely to choose voice. Religious people who are upset about what is happening within their church — anything from cover-up of paedophilia to refusal to ordain women — could change religions, but many decide to work within to change things.

Some people have little choice and little capacity to change things on their own. Children with disabilities may have no real choice of schooling, if no schools are willing to provide the sort of support they need. There is nowhere to exit, so they need voice. Sometimes parents are the voice, but taking on an entire school system is not easy. Advocacy is designed to fill the gap when voice is needed but people with disabilities can't do it for themselves.

Some groups have many members with the capacity to advocate on the group's behalf. The labour movement arose to advocate on behalf of workers against exploitative employers; it was especially important to protect workers with the least skills and bargaining power. The feminist movement arose to challenge the subordination of women, offering support to individuals dealing with rape, abuse and discrimination.

Some people with disabilities are extremely talented and articulate and are quite capable of speaking out on their own behalf. But others — for example people with severe intellectual disabilities — need assistance: they need social advocacy.

What is needed for effective advocacy? Advocates need commitment and relevant skills. They also need to be independent.

When independence is compromised, so is advocacy. Companies sometimes set up associations for their own employees, so there is little capacity for a powerful union challenge to company actions. When pharmaceutical companies, for example, fund community groups, these groups are less likely to be critical of drugs produced by the companies.

Types of disability advocacy

In self-advocacy, people with disabilities are assisted to be able to speak out on their own behalf. This is highly desirable for those who can develop this capacity, but is not feasible in many cases.

Social advocacy on behalf of an individual is called individual advocacy. The advocate can be paid or unpaid.

In paid advocacy, a worker typically advocates on behalf of several different individuals with disabilities. A paid advocate might spend the day assisting Mary find more suitable accommodation, attending a service meeting for Charles, and making sure the hospital knows about Claire's circumstances. Some advocacy actions are short and final. Sometimes lots of effort is required for a particular individual over weeks, months or years.

Social advocacy on behalf of an individual can also be carried out on an unpaid, voluntary basis. One model for developing unpaid advocacy is called Citizen Advocacy. Staff, usually paid, search out and select people with disabilities who have significant and valid needs, called protégés. For each protégé, the staff then seek a carefully selected member of the community to become the protégé's citizen advocate, on an unpaid basis, usually for the indefinite future. The advocacy is done by the unpaid citizen advocates, who are given support by the staff. Martha — introduced earlier — was a citizen advocate for Adelle and Adam a citizen advocate for James.

In family advocacy, families are assisted to recognise the legitimacy and value of their voice when encountering systems that affect their children with disabilities, often impacting on the entire family. Families are helped to understand the issues arising as their children grow older, increase their knowledge about the service system they may come up against, and develop a deep understanding of the need for advocacy in the life of their family member.

In systems advocacy, paid staff tackle obstacles to people with disabilities that are built into education, health, welfare, employment and other systems. When systems advocacy is effective, it can change conditions affecting thousands of

people, reducing the amount of individual advocacy required. Sally, enabled to attend her local school, is one of many who have benefited from systems advocacy.

Equity?

FACISIA's 2006 "Consultation paper" on the future of disability advocacy was unclear about the fate of different types of advocacy, but it seemed the initial idea was to gradually move from specialised types of advocacy to a one-stop-shop model providing crisis individual advocacy to all comers.

This change was backed by the rhetoric of equity: it was said to be unfair for some people to receive quality advocacy if others didn't have the same access. This argument sounds superficially plausible but doesn't stand up to scrutiny.

Only some heart patients have access to the top heart surgeon. Does that mean that no one should have access to the top heart surgeon? It might be more equitable, in some sense, to get rid of medical specialties and replace them with general practitioners who will handle all tasks, but no one thinks this is sensible.

Some towns do not have a train service. That may be unfair, but does it mean that no towns should have train services? The solution is not to get rid of quality for those who have it but to improve access to services for those who don't.

Turning advocacy into a one-stop shop would undermine citizen advocacy and systems advocacy, which require more specialised skills and are more like long-term investments. It takes skill, time and effort to recruit a single citizen advocate, but if the match is a good one, the benefits to the protégé will continue for many years. It takes skill, time and effort to change a single damaging policy or practice, but successes in improving systems bring benefits for large numbers of people for a long time and shape how future policies are formulated.

In principle, individual advocates could do a bit of citizen advocacy and a bit of systems advocacy, but this is a prescription for neglect of these types of advocacy, because they are harder to do and their results are long term rather than immediate. It's like asking a doctor in the emergency ward to do a bit of preventive medicine — it's a

nice thought, but emergencies usually take up all the time.

Many submissions to the advocacy review fiercely defended special types of advocacy. It remains to be seen what will happen.

The review recommended introduction of a national toll-free telephone hotline, to help increase access to advocacy, for example to those in rural and remote areas. But this won't be much use to a homeless person or one being abused in prison. Nor will be help people whose disabilities make it impossible to speak. A hotline is actually most useful to those who are relatively knowledgeable and articulate, and less useful to many of those in greatest need. Furthermore, given that resources for advocacy are far less than required to cope with the demand for it, a hotline may only give false hope to many of those able to access it and increase frustration when only a token response is possible.

Carers and families

A little-noticed feature of the review is the recommendation that advocacy be available not just to people with disabilities but also to their families and carers.

This widening of the target group for advocacy is highly problematic on a number of levels. Already there is a huge unmet demand for advocacy. Adding families and carers to the target group for this struggling system will overload it.

Social advocacy is meant for our society's most disadvantaged and marginalised people, in order to give voice to the voiceless. Advocacy is not intended *for* families — instead, families can learn how to be effective advocates for their members who need it: this is advocacy *by* families. When families think they need advocacy for themselves, what they really need is a disability service system that provides suitable services for their family member with a disability, thereby easing the strain on the family. Families that want support and their own voice can seek other avenues, such as Carers Australia.

Tensions could arise between the goals of advocates and the desires of families, for example when agencies are working systemically towards the devolution of large residential care

facilities and families ask advocates to help obtain residential care for their children with disabilities.

Many carers and families make extraordinary efforts and sacrifices, but this is not always the case. Consider Fred, whose was convinced by his brothers and sisters to sign away the home left to him by his caring parents after their death: as a result, he was left destitute. Or Sonia, whose carer used the government benefit payment for private vices while treating her shamefully.

Advocates appreciate and seek to work with responsible carers and families, but their first priority must be the person in greatest need. This is one of the core principles of advocacy: the advocate needs to speak and act on behalf of the person with a disability, without conflicting loyalties. Advocacy for families is a misinterpretation of the purpose of disability advocacy.

Competitive tendering

FACSIA proposes that disability advocacy be put out to tender. This is the most serious threat of all, because it compromises independence and quality.

Governments in English-speaking countries have adopted competitive contracting with enthusiasm in recent decades (Domberger, 1998). In the right circumstances, contracting can be quite effective in lowering costs. For example, a city government might invite tenders for bus services, as done in London.

In deciding whether to move to competitive contracting, there are several key issues for governments: (1) the existence of a market in providing the service; (2) the capacity to specify measurable and comparable outputs; (3) the relevance of government-owned assets; (4) and public value for money.

In the case of bus services in London, there is a market: there are several large bus companies in the country, so they can bid for routes and, if unsuccessful, sell their surplus buses. The main measure of output is the cost of the service; however, quality of service is also important, and harder to measure. The main assets are the buses, owned by companies; another option is for the government to own the buses and lease them to

operators, as done elsewhere in Europe. Finally, the question of value for money is assessed by costs and the provision of a reliable service.

Looking at the same four key issues shows that competitive contracting for advocacy is not sensible.

(1) *A market in advocacy?* Skilled staff in disability advocacy organisations have no significant alternative market besides the government. Unlike a bus company and its employees, tendering to do advocacy is a boom or bust proposition, with devastating impacts on those who lose out. The result is likely to be irrevocable loss of expertise.

Many advocacy agencies were set up after community members, concerned that the needs of local people with disabilities were not being met, joined together and called for government funding for advocacy. Advocacy agencies continue to rely on contributions from volunteer boards. This community ownership and in-kind contribution cannot be bought and sold on the market. It will be lost with competitive tendering.

(2) *Measurable outputs?* The outputs of advocacy agencies are not easily measured, and there is no agreed way of comparing the outputs from different types of advocacy. Both the quality and amount of advocacy are important, as well as a time dimension, namely whether the effects are long-lasting. Hence, comparing bids to run advocacy programmes would be a complex, value-laden process.

(3) *Assets.* Physical assets are not a major factor in advocacy. But intangible assets — especially reputation, a track record of independence from services, and positive imagery for people with disabilities — are vital. The relationship of agencies and advocates to people with disabilities cannot be bought and sold on the market.

(4) *Public value: advocacy or sycophancy?* Advocates are expected to speak out in many ways, including challenging the quality of support services. Tendering for advocacy might reduce financial costs to the government, but it would muzzle advocacy.

Watchdog bodies like ombudsmen are similar to advocacy in providing a voice to challenge problems in the system. Imagine

calling for tenders to run ombudsman services: this would be a recipe for turning a watchdog into a lapdog.

There are plenty of examples of regulatory bodies that have been “captured” by the industry they are supposed to regulate, through funding, promises of employment, and attacks on critics. For example, many organisations set up internal processes to handle grievances, including hotlines for whistleblowers. These are well known, by experienced whistleblower advisers, to be useless or worse (Devine, 1997). Toothless regulators allow abuse to continue unchecked, giving only the appearance of dealing with the problem.

Tendering is a mortal threat to the independence of advocacy. It would provide the opportunity for the Department to defund any critics that get out of line and fund those seen as compliant and unthreatening. But the problem is deeper than this. Even if the Department funded advocacy without any bias, many advocates would fear loss of funding, and curtail their advocacy accordingly. Self-censorship is a greater danger than the overt variety.

In summary, disability advocacy is not suitable for competitive contracting: there is not suitable market for provision of advocacy, the outputs (results) are not easily measurable or comparable, the intangible assets of advocacy programmes are not readily transferable, and the public value of advocacy — through being an independent voice for the voiceless, often to challenge government services and policies — would be undermined.

The only rationale FACSIA gives for introducing competitive funding is “to ensure that the \$12 million invested in the National Disability Advocacy Programme is directed more fairly across different regions in Australia” (FACSIA, 2006). But distributing funding more fairly can be done *without* tendering: this apparent justification is spurious. Therefore, given the points made above, it is reasonable to infer that the underlying driving force is political or ideological, not efficiency or equity.

A final point: in a tendering process, the competition should be fair and seen to be fair. This means no conflicts of interest: “it is essential that a selection procedure is implemented

— usually by committee — that is seen to avoid conflicts of interest and contains some measure of external independence” (Domberger and Hall, 1995, p. 7). FACSIA has not mentioned plans for any such independence. An in-house tendering process is ideal for making decisions without accountability.

What should be done?

The National Disability Advocacy Program definitely needs improvement. That is vital, for the benefit of people with disabilities. The first and most essential step is to find out what is happening currently, namely what advocacy is being done and how effective it is. Remarkably, there seem to be no studies of the outcomes of advocacy. At best, there are figures on the number of advocacy actions, for example the number of times individual advocates have assisted clients. But such figures — held by the department, but not available in the advocacy sector — do not say whether the assistance was excellent, fair or useless.

The department is preoccupied with the way agencies are organised, whereas the essential foundation for making sensible decisions is knowing which agencies are effective.

Another useful step would be to establish appropriate targets. Citizen advocacy programmes, for example, are being given the wrong signals: their agreements specify the number of new matches to be made in a year. But advocacy is done by current citizen advocates, so a better indicator is the number of relationships supported by the programme. A new match that lasts just a month is quite different from one that lasts five years. Also important is the level of advocacy within relationships, not captured by the department’s targets (Martin, 2003).

One worthwhile approach to improvement is a method called “appreciative inquiry” (Whitney and Trosten-Bloom, 2003). The basic idea is for organisation members to look at what is being done well, work out what makes that good work possible and then strengthen those things. This is the direct opposite to the usual approach of looking for problems and trying to fix them. According to its proponents, appreciative inquiry has

the powerful effect of bringing out the best in everyone.

Conclusion

Advocacy is vital for people with disabilities. Advocacy agencies need more money and support for the huge level of unmet need. Instead, FACSIA is expecting more advocacy without any more money. Rather than find out what works, the Department is changing the way advocacy is organised, without any evidence that it will lead to improvement. Indeed, many advocates think the results will be disastrous.

The review’s processes of consultation seem to many to be a facade for a predetermined agenda. This is leading to two divergent responses: exit and voice.

Advocacy is hard work, and can be demoralising. Frustration and burn-out are serious risks, leading to high turnover, with loss of valuable expertise. The Department, if it calls for tenders, will make the job even more precarious. Some advocacy agencies will toe the line in a self-interested manner, or even try to build little empires. This is leading to an exodus of talented and experienced workers from the sector, leaving it weaker than before.

On the other hand, some brave figures in the sector are exercising their capacity to speak out about the threat to their good work. They are organising supporters to apply pressure on sympathetic politicians.

The review is damaging advocacy in Australia, both through its process and its likely outcomes. How much better it would be for people in the advocacy sector to work with a supportive Department to better exercise voice — on behalf of those who really need it.

Acknowledgements

I thank many individuals in the advocacy movement for helpful discussions and inspiration. Chris Aulich gave valuable advice about contracting. Sharon Callaghan, Mitchel Peters and Yasmin Rittau offered incisive comments on drafts. Catherine Hogan made a major contribution with critical comment and suggested input. None of them should be assumed to agree with the views expressed here.

References

- Devine, Tom (1997) *The Whistle-blower’s Survival Guide: Courage without Martyrdom* (Washington, DC: Fund for Constitutional Government).
- Domberger, Simon (1998) *The Contracting Organization: A Strategic Guide to Outsourcing* (Oxford: Oxford University Press).
- Domberger, Simon and Christine Hall, eds. (1995) *The Contracting Casebook: Competitive Tendering in Action* (Canberra: Australian Government Publishing Service).
- FACSIA (2006) *Enhancing the National Disability Advocacy Program: Consultation Paper* (Sydney: Department of Families, Community Services and Indigenous Affairs), September.
- Hirschman, Albert O. (1970) *Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations, and States* (Cambridge, MA: Harvard University Press).
- Martin, Brian (2003) “Citizen advocacy and paid advocacy: a comparison,” *Interaction*, Vol. 17, Issue 1, pp. 15-20.
- Whitney, Diana and Amanda Trosten-Bloom (2003) *The Power of Appreciative Inquiry: A Practical Guide to Positive Change* (San Francisco: Barrett-Koehler).

Dr Brian Martin is a social scientist at the University of Wollongong and the chair of the board of Illawarra Citizen Advocacy. These are his own views.

*Phone: 02-4221 3763 work,
02-4221 7860 home
Email: bmartin@uow.edu.au*

14 February 2007