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Excerpts from Brian Martin's article: Muzzling disability advocacy

The views expressed in this article are the author's own and do not necessarily represent the views of Queensland Parents for People with a Disability.

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.

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

Some people with disabilities are highly capable and able to speak up for

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 ordinate 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?

FACSIA'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.

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" (Hammond, 1998; 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.

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.

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14 February 2007 For the full version of Brian Martins article go to <http://www.uow.edu.au/arts/sts/bmartin/ar/mda.html> or call the QPPD office for more information.

Changing the ethos of a workplace does not occur through the writing of policies or the provision of a few hours of training on abuse issues. It involves a change in the way that management operates the services. While individual services can address these issues through positive commitment by residential service management, there is still a clear need for competent, independent monitoring by service operations, not only for abuse but all service activities.

Abuse is not a separate issue that can be isolated. It is a fundamental part of all activities that occur in residential services. Policies and practices that seek to address only the results of visible abuse ignore this reality. A change in ethos would see management practices that require all staff to be trained in skills that enable them to instigate positive practices, that value people with intellectual disability and which ensure that those accessing residential services would have the same treatment that staff would expect for themselves.

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