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4 Citizen advocacy

Overview

- Citizen advocacy is a system for protecting and promoting the interests of people with disabilities.
- Citizen advocacy can be supported using the methods of awareness, valuing, understanding, endorsement and action.
- Because of institutional obstacles to the expansion of citizen advocacy, it may be worth rethinking the way citizen advocacy is organised.¹

In 2005, Steve Lopez, a journalist with the *Los Angeles Times*, came across a homeless man playing a violin that had only two of its four strings. Intrigued, Lopez sought more information. He discovered that decades ago the violinist, Nathaniel Ayers, a middle-aged black man, had attended Julliard, an elite music school in New York. But Ayers never graduated. Lopez used his journalistic skills to track down Ayers’ sister, who said Ayers had played the double bass when he was younger.

Lopez decided to write a story about Ayers, reaching a large audience through the *Los Angeles Times*. Many readers were touched and several donated string instruments to Ayers. Lopez became more involved with Ayers, finding a place for him to live and creating opportunities for him to hear the Los Angeles Philharmonic and be tutored by its lead cellist. But it

¹ I thank John Armstrong, Lyn Carson and Mitchel Peters for valuable feedback on drafts of this chapter.

was not an easy process. Ayers had dropped out of Julliard after he started hearing voices. His mental problems made it impossible for him to continue a musical career, though his mind was filled with music. Lopez was able to do a lot for Ayers despite Ayers' shyness, resistance to change and occasional tirades.

The story of Ayers and Lopez was later made into a movie titled *The Soloist*, with Ayers played by Jamie Foxx and Lopez played by Robert Downey, Jr.² Unusually for Hollywood films, *The Soloist* does not have a fairy-tale ending, because it is based on a true story: at the film's conclusion, Ayers is doing better but the future is uncertain and he is not likely to ever become an actual soloist on the classical stage.

The uplifting message is that one person can make a difference in the life of another person — someone who needed help. As the film says at the end, there are 90,000 homeless people in Los Angeles. Ayers was lucky enough to have a friend in Lopez. But what about all the others?³

In the late 1960s, a group of parents in Omaha, Nebraska had a problem. Their adult children had intellectual disabilities. That was not the problem. The parents loved their children, and had cared for them at home for their children's entire lives. But

2 Lopez wrote a book to accompany the film: Steve Lopez, *The Soloist: A Lost Dream, an Unlikely Friendship, and the Redemptive Power of Music* (New York: G. P. Putnam's Sons, 2008). Where details differ, I have followed the book.

3 Another Hollywood portrayal in this vein is *The Blind Side* (2010), also based on a true story. These cases are atypical in that they involve white people assisting disadvantaged African-Americans, though in reality those who provide assistance are more likely to be other African-Americans. In these Hollywood shows, the protégés demonstrate or develop considerable talents, although in many actual cases this does not occur.

as the parents aged and faced the prospect of death or incapacity themselves, they feared for their children. Would they be put in an institution, with little support and open to abuse?

A young social scientist named Wolf Wolfensberger came up with a possible solution. Ask someone else — a member of the community, not connected to the family — to agree to be an ally for a person with a disability. The community member was called a citizen advocate, or advocate for short, and the person with a disability was called a protégé. The advocate would fill a needed role in the protégé's life, for example as a protector, friend or surrogate parent. The advocate would make sure the protégé had suitable accommodation, was being treated all right, gained skills necessary for everyday life — whatever was needed. An advocate wasn't expected to do everything personally, just to make sure things happened for their protégé. "Advocate" is the term used most commonly — other potential labels are mentor, guide and friend.

How were these relationships to be created? Would it be possible to find anyone to take on a long-term commitment for a person with an intellectual disability? This wasn't going to be easy.

People with disabilities are often stigmatised, and people with intellectual disabilities are even more stigmatised than those who are blind or unable to walk. Some people with severe intellectual disabilities are unable to communicate. Becoming an advocate in such cases is not so much being a friend as being an ally or protector.

Wolfensberger proposed setting up an office with paid staff whose job would be to find people with disabilities, evaluate their needs, find community members who would agree to become advocates, establish protégé-advocate relationships and

continue to support them. Thus was born the concept of citizen advocacy.

The first citizen advocacy programme was set up in Omaha. Since then, dozens of programmes have been established in the United States, Australia, Britain and New Zealand.⁴ The orientation broadened out from finding advocates for adults with intellectual disabilities whose parents were ageing to finding advocates for anybody with a disability who had serious unmet needs, including babies, young children and young adults. Needs might be unmet because of poverty, abuse, homelessness, or overprotective carers.

When his mother passed away, a 26 year-old man had no one and nowhere to live. His citizen advocate found him a place to live and located his father who was thrilled to be a part of his life again. When we see this man now — he is about to turn 30 — he tells us with pride that he has 18 people in his family.⁵

Many people with intellectual disabilities face enormous difficulties in their lives. Some are abused by family members or staff in human services. They are easy targets when they do not have communication skills to clearly explain what happened in a way that is credible to others. Even more common is neglect. Their lives may consist mainly of waiting — waiting for an

⁴ Most of the knowledge about the history of citizen advocacy resides in the memories of coordinators and others who have been involved a long time. There seems to be no substantive written history of citizen advocacy, nor a manual for coordinators to do their work. One useful source is the journal *Citizen Advocacy Forum*.

⁵ The stories throughout this chapter were contributed by various Australian citizen advocacy programmes to the website of the Citizen Advocacy Network, <http://www.bmartin.cc/CAN/>. The network is no longer active.

occasional excursion or visit, with no regular activity to engage their energies and develop their skills.

Most staff in human services do as well as they can. However, the risk in relying on services is that people with disabilities can become passive recipients of assistance, in other words dependent clients.

Those who live with relatives are usually the lucky ones, but not always. Some families protect their members with intellectual disabilities too well, preventing them from going out, meeting others and experiencing ordinary activities like shopping, taking the train or meeting friends.

The beneficial impact of a citizen advocate can be hard to appreciate. Many people with intellectual disabilities have been cared for by human services their entire lives. For some, whose relatives are unable or unwilling to look after them, everyone they meet is paid to be there. Furthermore, often there is little continuity in the paid staff, who frequently move to other jobs or postings.

Then an advocate comes on the scene — someone who wants to be there, someone who is not paid. This alone can make an enormous difference. For protégés who live with overprotective carers, an advocate can ease a transition to a wider set of experiences and challenges. Protégés who are able to communicate can experience, with an advocate, a relationship in which they are expected to give as well as receive. The experience of reciprocity can be liberating.

In a sense, citizen advocacy tries to create the linkages that should exist in a caring community. A valued member of the community typically has strong relationships with family members, neighbours, friends, work colleagues and others through associations such as churches and sporting clubs. Why should someone with a disability have any less? An advocate can

help integrate a protégé into a variety of relationships that others take for granted.

Everyone in Allan's life settled for far less than what was best for him. As well as having an intellectual and physical disability, he is blind. The only people around were staff who did not imagine life ever looking different for Allan. No one expected anything of him and his life was spent sitting ... and waiting. Peter has become involved in Allan's life and is providing many and varied experiences for him. They share time together and Peter is assisting Allan to build and fulfil dreams. He is getting to know Allan as a man with potential and hope for the future.

The idea behind citizen advocacy is to find and help those in need, ideally those with the greatest unmet needs. Some people with intellectual disabilities do not require additional assistance. They might live with caring families or live on their own with a network of support. However, others are neglected, exploited or abused. Sometimes their own behaviours alienate those closest to them. They are the ones who can benefit most from citizen advocates.

Wolfensberger and his early collaborators established a set of principles for citizen advocacy.⁶ Wolfensberger was acutely

⁶ John O'Brien and Wolf Wolfensberger, *CAPE: Standard for Citizen Advocacy Program Evaluation*, Test Edition (Canadian Association for the Mentally Retarded, c. 1980). This manual is used when external teams evaluate citizen advocacy programmes. More generally, citizen advocacy is built on an approach to people with disabilities called normalisation or social role valorisation. See Robert J. Flynn and Raymond A. Lemay (eds.), *A Quarter-Century of Normalization and Social Role Valorization: Evolution and Impact* (Ottawa: University of Ottawa Press, 1999); David G. Race, *Social Role Valorization and the English Experience* (London: Whiting & Birch, 1999); Wolf Wolfensberger, *A Brief Introduction to Social Role Valorization: A High-Level*

aware of the problems with institutions such as asylums, aged care homes and sheltered workshops. These sorts of institutions were originally established in the 1800s as an humanitarian solution to a perceived social problem, but they soon became part of the problem: the institutions, however well intended, began serving the needs of the staff and managers more than their clientele. Wolfensberger wanted citizen advocacy to be different from institutionalised care, just as a parent, friend, neighbour or colleague is different from a paid service worker.

One principle is advocate independence. The advocate's decision to begin and continue the relationship with their protégé should be freely made, with no external incentives. That means no payment, no covering of expenses, no course credit, no rewards. No one would expect any of these for being a friend or colleague. As soon as advocates begin expecting something in return, they start entering the mentality of the service worker and this, all too often, undermines the relationship.

The citizen advocate of a 12 year-old boy is supporting his parents to make decisions and choices about his future education and employment needs. The advocate attends meetings at the education department and helps his parents to clarify and understand what is being suggested. The advocate also asks the questions that the parents are reluctant to address.

My involvement

In 1996, I was contacted by Julie Clarke, coordinator of Illawarra Citizen Advocacy. She told me about citizen advocacy

Concept for Addressing the Plight of Societally Devalued People, and for Structuring Human Services, 3d ed. (Syracuse, NY: Training Institute for Human Service Planning, Leadership & Change Agency, Syracuse University, 1998).

and about a couple of current protégés, and invited me to be an advocate. I declined to be an advocate — but I did agree to join the board of management. Soon I was learning about citizen advocacy by meeting advocates and protégés and discussing plans of action in one of the most successful programmes of its kind in the world. A year later I became chair of the board, a position I held for the next decade.

Through my involvement with Illawarra Citizen Advocacy, I learned about the terrible things happening to some people with intellectual disabilities and about the capacity of ordinary people to make a tremendous difference in others' lives. I also learned about citizen advocacy as a system.

A coordinator's viewpoint

Here's a typical scenario.⁷ A few individuals learn about citizen advocacy and form a group to auspice a new programme. After months or years of learning, lobbying and campaigning, the group may be successful in attracting enough money from businesses or governments to set up a programme. Offices are rented and one, two or possibly more staff are hired. The key person hired is the coordinator, who is in charge of recruiting protégés and advocates.

A coordinator has many things to do any given day. Instead of examining a single day, let's look instead at a typical sequence of actions involved in making and maintaining one relationship between a protégé and an advocate, efforts that

⁷ I've drawn here on my experience with Illawarra Citizen Advocacy. Mitchel Peters provided several insightful comments to correct and broaden my perspective. See his valuable "Articles by Mitchel Peters about Citizen Advocacy," <http://www.bmartin.cc/CAN/policies/Peters/>.

typically take place over weeks, months and years, in among other activities.

The process starts with a search for a protégé. This means someone with a disability, typically an intellectual disability. But not just anyone with a disability — someone who has unmet needs, for example someone who has no family or friends, someone without suitable accommodation, someone in regular trouble with the police, or someone being abused.

Labelled as having a dual disability, Loretta's future was grim. She had no place to call home except the psychiatric ward of the local hospital. Her so-called friends would take her in, take her money and flush her medication down the toilet. She was abandoned by service agencies. This cycle continued until a citizen advocate stepped in and said "no more." After two years without having to spend time in the hospital, Loretta fulfilled a long-time dream — she married.

So what sort of protégé should be sought? In a well-organised programme, there's a plan for the year. It might involve finding ten new protégés in a year, with targets for specified variables.

One variable is age: the plan for ten protégés might include two children, one teenager, one young adult, two over age 65 and four aged 25–64, with the age categories specified in the manual for evaluating citizen advocacy programmes.⁸ Because it is usually easier to find protégés in the age group 25–64 and easier to find advocates for protégés of about their own age, younger and older people with disabilities may be neglected. Therefore, a good plan will give special emphasis to these groups.

Another variable is reciprocity, the capacity of a protégé to interact with an advocate. Individuals who can't communicate

⁸ O'Brien and Wolfensberger, *CAPE*.

are at special risk, so the plan might specify finding at least one protégé who cannot reciprocate. Other important variables include a protégé's need for vigorous spokespersonship, the need for a long-term relationship, the prospect of establishing a formal relationship such as adoption, and whether the advocate's role is expressive (such as friendship) or instrumental (accomplishing tasks such as finding accommodation) or both. Given the number of variables to consider, a plan gives guidance but cannot be too prescriptive, because real-life protégés don't necessarily satisfy all the theoretical requirements.

Let's say the target is a young adult needing a long-term relationship. Where to look? A lot of protégé recruitment comes via word of mouth. The coordinator hears of someone and goes to check. But even to hear, it helps to be out in the community. It might mean visiting street shelters, special schools or parents' groups. It might mean asking contacts in the police, welfare or employment sectors.

Chris, the coordinator, has discovered Emma, a potential protégé. What next? Chris needs to spend time with Emma, finding out about her life and, in particular, assessing her needs. Emma is twenty years old. She has a moderate intellectual disability and lives in a group home supported by a welfare organisation. Emma's family members hardly ever visit: they live in a nearby city and have a hard time dealing with their own difficulties. Emma is well looked after but is stagnating. She spends most of her time in the group home watching television, except for regular group excursions to parks or shopping centres. She has no friends unless you count the other three in the home and the stream of service workers who manage it.

Chris, after several meetings with Emma and discussions with service workers and Emma's family, decides Emma needs an advocate who will encourage her to acquire skills, possibly

get a job, meet more people and spend time in the community. Chris is aiming to find a woman aged 30 to 50, living not too far from Emma, who is sociable, well-networked and desirably with experience in helping young people develop their capacities. Chris next aims to find an advocate fitting this profile.

Finding advocates is the most challenging part of the coordinator's job. It's a big thing to ask. "I've just told you about Emma. Would you be willing to be her advocate? That means protecting and defending her, as if her needs were your own. It's for the indefinite future — as long as she needs an advocate."

Advocates undertake a huge commitment. Who would do it? Amazingly, some people are willing — but only a few. The challenge for the coordinator is to find someone who is ideally matched to the protégé. For Emma, that means someone who has the skills, commitment and willingness to help her grow — someone who fits Chris's profile for being Emma's advocate.

How to find this person? To find possible advocates, it's a matter of networking and continually asking. Visit a mother's group, a neighbourhood centre, a local church, a sporting club, and ask people who they know who fits the profile, who has a passion for social justice, who is just the right person for Emma.

Members of the programme's board of management sometimes can suggest potential advocates. Board members, who are volunteers, can and often do assist in a number of aspects of the coordinator's work. Often, some board members have disabilities themselves, some are advocates and some support family members with disabilities. Such board members have a deep insight into the tasks undertaken and the challenges faced by the coordinator.

Advocates do wonderful things, but they don't need to be wonderful in every way. They are ordinary people, with the usual range of shortcomings. They might have personal diffi-

culties or be struggling financially. All that matters, from the coordinator's point of view, is that they will do a good job as an advocate. This is certainly possible. Everyone knows people whose lives are a mess but who are dedicated parents or loyal friends.

However, being an advocate is not a one-way street. Advocates benefit too. They build new relationships and often gain immense satisfaction from seeing their protégés blossom or avoid disaster. Helping others often brings joy to the giver. Being an advocate is a highly personal way of helping. Many advocates say they get more out of their relationships than their protégés.⁹

Still, Chris as the coordinator doesn't find it easy to find an advocate for Emma. Rejection after rejection is hard to take. But finally a woman named Claire says yes. She seems to be a perfect fit.

The next part of Chris' job is more straightforward: explaining to Claire exactly what is involved in being a citizen advocate and making absolutely sure she is ready to take on this role. Emma has to be prepared as well. Then comes the big moment when Emma and Claire first meet. Some relationships spark immediately; others require time to develop; yet others require ongoing assistance by the coordinator.

After the relationship is established, Chris plays a new role, as advisor and encourager and critic, in a process called follow-along and support, interacting mainly with the advocate, Claire. If Claire has any difficulties, she can contact Chris for advice. In

⁹ Wolf Wolfensberger, "What advocates have said," *Citizen Advocacy Forum*, 11(2), November 2001, 4–27. In *The Soloist*, Steve Lopez writes, concerning his relationship with Nathaniel Ayers, "it's not a stretch to say that this man I hoped to save has done as much for me as I have for him" (p. 268).

any case, Chris will check in with Claire every month or so, to ask how things are going, to offer comment or advice and sometimes to encourage Claire to be more forceful in pushing for Emma's interests.

Claire can also contact others, called advocate associates, for assistance. These are doctors, pharmacists, lawyers, physiotherapists and a host of others who have volunteered to help advocates in specialist areas. Part of Chris' job is to find volunteers to be advocate associates.

From the coordinator's point of view, there is a logical sequence to each relationship: finding a potential protégé, determining the protégé's needs, finding a potential advocate, initiating the relationship and providing ongoing support to the advocate to maintain the relationship. Daily work is far less ordered, because it involves a mixture of all these tasks, and others. A day might involve meeting several potential protégés, searching for advocates for protégés on the waiting list and doing urgent follow-along for several advocates whose protégés are in some sort of crisis. Then there are routine activities like handling correspondence, maintaining files and preparing newsletters.

Advocate and protégé viewpoints

From an advocate's point of view, things are rather different. Claire was simply going about her life when approached by Chris, who told her about Emma and how Emma would benefit from having an advocate. Claire was cautious initially but, after hearing more, decided this was something she could and would do. After being briefed about the role she would be expected to play, Claire met Emma. From then on, Emma and her needs provided the stimulus for Claire's involvement, along with helpful support from Chris. Claire met Emma every week and

introduced her to her friends. Claire encouraged Emma to undertake studies and helped get her enrolled in a suitable course. As Emma developed her capacities, Claire encouraged her to continue to try new things — and provided support when Emma had difficulties.

A protégé's perspective is different again. Emma was going along with her life, not taking much initiative, letting time pass by. Then Chris came along and asked a lot of questions and did a lot of listening, and offered to try to find someone to be an advocate. Emma thought this sounded good, so she said yes. A couple of months later she was introduced to Claire and from then on Claire was an important part of her life, especially in opening doors to new experiences and achievements. Emma occasionally met Chris and others in the citizen advocacy programme, but her main connection was Claire, who cared about her personally.

Relationships

At the interpersonal level, of Emma and Claire, citizen advocacy seems like a good thing. Most relationships are beneficial to protégés, sometimes helping to provide meaning to an empty life, sometimes helping prevent abuse and degradation, and sometimes even making the difference between life and death. The stories of successful relationships are heart-warming.

Some relationships are set up to be brief. These so-called crisis matches are designed to help a protégé survive a difficult period, such as illness, loss of accommodation, a family dispute, financial problems, pregnancy or imprisonment.

Red tape and a series of unfortunate circumstances landed Tom in a locked psychiatric unit. Although the professionals agreed that it was an inappropriate place for this gentle

young man to live, he remained there for three months. He had nowhere else to go.

Tom needed someone on his side immediately so Peter was asked to be his crisis advocate. Through Peter's vigorous advocacy and representation, using the media and the Anti-Discrimination Board, Tom was released and now lives in his own unit, with support provided. The programme is now seeking an ongoing advocate to watch out for Tom's long-term, stable future. In the meantime, Peter will continue to protect Tom.

Crisis matches are valuable. Even so, most citizen advocacy programmes prefer to concentrate on establishing long-term relationships, because these provide ongoing benefits, often preventing crises from developing. Some relationships are life-long, until either the protégé or advocate dies.

Some relationships don't work out so well. Maybe the advocate is too busy to devote sufficient time to their protégé; maybe the match isn't ideal, so there aren't enough common interests; maybe the protégé displays such difficult behaviours that the advocate can't cope. That some relationships fail is not surprising. After all, some friends fall out or drift apart.

The most common reasons why relationships end are that the protégé or advocate moves away — though some long-distance connections can be maintained — or the advocate becomes too busy or loses interest. In some cases, on the other hand, the protégé develops skills and support so that advocacy is no longer required, which is the best sort of completion to the relationship.

Promoting citizen advocacy

If citizen advocacy is such a good thing, why isn't there more of it? One possible explanation is that relatively few people are

willing to be advocates. After all, Chris had to tell 20 potential advocates about Emma before finding Claire. But citizen advocacy coordinators agree that advocates can be found — it's a matter of persistence and skill. Furthermore, when advocates tell friends how rewarding they have found the experience, this makes others more receptive to becoming advocates. A coordinator is like a matchmaker. Making a good match can be difficult, but with perseverance it usually can be done.

Another problem is that the job of a coordinator is so hard. There's no formal training for it. New coordinators are often tossed in the deep end, expected to make matches, yet daunted by the difficulty of finding suitable protégés and discouraged by repeated knock-backs from potential advocates. They sometimes leave the job after a year or two and the cycle begins again. But there are some talented and experienced coordinators. They are willing to assist new coordinators. The job is challenging, but it can be incredibly rewarding, especially when seeing people with disabilities like Emma have their lives changed by dedicated advocates.

The bigger problem is obtaining funding for citizen advocacy programmes, to pay staff and for an office, transport, phone and other costs. Obtaining funding is both difficult and contains traps.

In the United States, the usual pattern is to seek funding from a variety of sources, including governments, companies and individuals. The advantage of having funding from multiple sources is that the programme is not beholden to any of them. Some advocates speak out about the failure of agencies that are supposed to be providing services to their protégés. What if the agency is providing funding to the programme? That's risky, as funding might be cut off in reprisal. Another possibility is that someone in the funding body is friendly with someone in the

agency being criticised. The programme needs to be as independent as possible of any particular funding source so advocates can speak without fear or favour.

Obtaining funding from several different sources is certainly a good idea, but it's hard to bring off in practice. There are only a few dozen citizen advocacy programmes in the US, with a few staff each. Their efforts are highly valuable, but address only a tiny fraction of the millions of people with disabilities who might benefit from advocates.

In Australia, most citizen advocacy programmes are funded by governments, most of them by the federal government through the Department of Families, Community Services and Indigenous Affairs (FACSIA). The advantage of this arrangement is reasonably stable funding at decent levels, without the need for endless efforts at fundraising that can divert energy away from the work of citizen advocacy itself. Some Australian programmes have tried to gain corporate sponsorship, but with little success. There is not a tradition of business support for these sorts of efforts as in the US. FACSIA funds but does not directly run the frontline services for people with disabilities, whereas state governments both fund and provide services. When advocates speak out, it is usually to challenge failures in state, local and private agencies, not FACSIA.¹⁰

If citizen advocacy is so good, why isn't there more funding for it? One explanation is that it isn't widely known. Another is that supporters of citizen advocacy simply haven't tried hard

¹⁰ The name and scope of the federal government department that funds citizen advocacy keep changing. Its most recent name is the Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA). Because it funds employment services, there is a greater potential for an advocate to come into conflict with a department-funded agency.

enough. Yet another is that citizen advocacy is an expensive form of advocacy.

Types of advocacy

Advocacy occurs in many areas. Lawyers are advocates within the legal system. Workers form and join trade unions that act as advocates for workers, individually and collectively. Women get together to campaign for women's rights. Greenpeace, Friends of the Earth and many other groups campaign on environmental issues, essentially being advocates for the environment.

Disability advocacy fits into this wider picture of advocacy. There are several ways to do it. One is for people with disabilities to advocate on their own behalf, an approach called self-advocacy. There are many talented campaigners among people with physical disabilities, and their courageous efforts have brought massive changes in many arenas for those with impairments in vision, hearing and mobility. The word disability usually brings to mind images of a person in a wheelchair or a person with visual impairment with a guide dog.

People with intellectual disabilities — the largest category of disability — are invisible by comparison. Their very disabilities mean that many of them do not have the skills in reading, writing and speaking to be highly effective campaigners. Some can advocate on their own behalf, but many cannot, at least not without considerable support and coaching.

Self-advocacy can be powerful when it works. But meetings of self-advocacy groups for people with intellectual disabilities, assisted by a paid worker, sometimes are little more than social occasions.

Another approach is systems advocacy. Rather than focus on individuals, as in citizen advocacy, the systems approach targets the social, political and economic obstacles to people

with disabilities. Systems advocates may lobby or campaign to bring about change or sometimes support others to do so.

Education is one key system. Many people with disabilities are put in special schools, where they receive specialised attention but do not learn skills for coping outside. Furthermore, children and teachers in conventional schools do not learn how to include people with disabilities.

Systems advocates may put pressure on principals or education departments to change their policies and practices. Alternatively, or as well, systems advocates may assist parents to take action to get their children into conventional schools, helping parents develop skills in mobilising support, negotiating with principals and teachers, and dealing with educational bureaucracies.

In between self-advocacy and systems advocacy is individual advocacy: advocating on behalf of an individual. Citizen advocacy is one type. The other main approach is for the advocate to be a paid worker. Typically, a paid advocate will assist several different people with disabilities.

The Australian federal government began funding disability advocacy programmes in the 1980s, including self-advocacy, systems advocacy, citizen advocacy and individual paid advocacy. Some funding has come from state governments too. In 2006, FACSIA announced a review of what they called advocacy services. The agenda quickly became clear: to cut back on systems advocacy and citizen advocacy and to concentrate on paid individual advocacy. Why would this be?

One line of argument is that citizen advocacy is more expensive — a sort of boutique type of advocacy. This theme had been repeated in the department for years. To test this assumption, I carried out an assessment using data from Illawarra Citizen Advocacy. The Illawarra programme had long

been highly successful. It had met its target of establishing 12 or 15 new matches per year and in 2002 was supporting some 70 existing relationships.

The reason why citizen advocacy can seem to be expensive is due to the method of counting advocacy actions. A paid advocate might see dozens of people with disabilities in a year and undertake hundreds of actions, for example contacting service providers and accompanying clients to meetings. This seems like a lot compared to finding just a dozen new citizen advocates. What this comparison misses is the advocacy by citizen advocates. Recruiting an advocate for a protégé doesn't, on its own, do anything for the protégé. It's what the advocate does in the following weeks and months that counts.

Over a couple of months, Julie Clarke, long-time coordinator of Illawarra Citizen Advocacy, asked advocates how much time they had spent with their protégés in the previous month. Some had spent little or no time whereas others had spent many hours. Adding up the figures, the total amount of time devoted to advocacy was far greater than any paid advocate could possibly have spent.¹¹ This stands to reason: dozens of citizen advocates were out doing things with and for their protégés without any cost to the taxpayer. By this comparison, citizen advocacy seems like a bargain compared to paid individual advocacy.

Institutionalised for most of her life, a 30 year-old woman moved into the community and was living alone in a unit, totally isolated and vulnerable, as she was unable to walk following a motor vehicle accident in which both her legs were broken. She was tormented, teased and the target of thieves which made her fearful for her life. When her citizen advocate met her he likened her deprivation to that of a

¹¹ Brian Martin, "Citizen advocacy and paid advocacy: a comparison," *Interaction*, 17(1), 2003, 15–20.

prisoner of war. With his support she has moved to safe housing and her stolen possessions have been replaced. The citizen advocate is now challenging the Motor Accident Insurance Board for compensation and is committed to ensuring that she will never be victimised again.

Systems advocacy can be even more effective in strictly financial terms. When parents organise to put pressure on the school system to open access to their children, most of the effort is by the parents: the systems advocates provide a supporting and facilitating role. The changes in the school system benefit the children involved immediately, but also go on benefiting many other children in the future. Advocacy of this sort is tremendously effective.

There's another comparison possible. What about the quality of the advocacy? A paid individual advocate will develop a lot of experience, with knowledge of disability issues and ways of tackling problems. Paid advocates usually have relevant training, for example in social work. Citizen advocates, in comparison, are untrained and have limited experience, typically working with just a single protégé. But this also has an advantage. By focusing on the needs of a single person over a long period, often many years, a citizen advocate learns an enormous amount about their protégé and how to address their needs.

A key difference between citizen advocacy and paid individual advocacy is the payment itself. A citizen advocate is a free agent, able to take action without worrying about wages or a job. Funding bodies seem not to be attracted to this sort of independence, preferring instead to maintain levers of control. In a bureaucracy, accountability — namely ensuring that subordinates toe the line — can be more important than effectiveness.

The same dynamics apply to agencies funded by bureaucracies. The agency managers like things to be under their control.

Paid individual advocacy fits this model. Citizen advocacy does not, because the advocates are free agents, and systems advocacy does not because system changes are less predictable and controllable. This, I believe, is the underlying reason for FACSIA's push towards paid individual advocacy.

Obstacles

Citizen advocacy may be a good thing, but it has been taken up to only a limited degree. The obstacles are many.

As already discussed, funding for programmes is a key obstacle. Private funding sources are limited and subject to many other demands. Government funding for disability advocacy can bring with it pressure to move to paid advocacy.

Another obstacle is the difficulty of being a programme coordinator. Finding protégés and advocates is hard work and can become demoralising. Coordinators who are not successful at finding citizen advocates may be tempted to take the easier option of doing advocacy themselves and steering the programme towards paid individual advocacy.

At the level of advocates, the main difficulties are time and commitment. If one's protégé is a top priority, there's no problem. But if family, friends, jobs and recreation come first, protégés may be neglected and eventually abandoned.

Tactics

The tactics to support citizen advocacy can be examined at two levels: the point of view of advocates and the point of view of citizen advocacy as a social movement. Let's start with advocates and look at five methods for promoting a good thing: awareness, valuing, understanding, endorsement and action.

These are the same methods important in promoting other good things, such as writing and happiness, as discussed in chapter 1.

Advocates obviously know about what they are doing and believe it is a good thing: *awareness* and *valuing* are solidly covered. They also know the reasons why it is worthwhile, with the rationale for getting to know their protégé and their protégé's needs explained and its value apparent in their ongoing relationship: *understanding* is covered.

When it comes to *endorsement*, advocacy relationships are on weaker ground. The most authoritative backing of the relationship comes from the citizen advocacy office, but this has little recognition in the wider society. Nevertheless, if the office establishes good practices and has a good image — professional, well positioned, a good reputation — then its endorsement of a relationship will be influential with advocates. Just as important is endorsement by key people in an advocate's life: family members, friends, neighbours, co-workers. If these people are supportive, the advocate will be encouraged to continue; if they are indifferent or sceptical, then it is easier to let the relationship drift.

The key method for an advocate to continue is to be active in the relationship: this is the method of *action*. This is obvious enough, but it is more than a truism. The key is to put the protégé in a central part of one's life, like a family member or close friend, rather than as an afterthought to be squeezed in when there's time.

In summary, at the level of the advocate-protégé relationship, citizen advocacy does all the things necessary to turn a good thing into a habit. It's no surprise, then, that many advocates remain committed to their protégés for years, probably as long as many good friendships.

But relationships have to get started somehow, so we need to look at the methods used to promote citizen advocacy generally. If the context is right, then a lot of people will want to become citizen advocates and those who do will receive encouragement to continue: their habits will be reinforced by the people and circumstances around them.

If citizen advocacy is a good thing, then the ultimate goal is to make it a routine occurrence, something that occurs as a matter of course. That is very far from the case now: it's quite unusual for someone to initiate a strong voluntary relationship with a person with an intellectual disability or mental illness, especially someone who cannot easily reciprocate. These sorts of relationships do occur, such as the one between Nathaniel Ayers and Steve Lopez. In citizen advocacy circles, some of these become "blessed relationships," a rather strange expression. It means that when citizen advocacy coordinators come across such spontaneous relationships, they endorse and support them, in other words give them their blessing.

Spontaneous advocacy relationships are rare. A citizen advocacy programme might make dozens of matches for every blessed relationship discovered and supported. This shows that matchmaking efforts are needed to create relationships. And matchmaking is certainly not a routine occurrence. What methods can help make it so?

The first method is promoting *awareness*. When people know about and understand citizen advocacy, nearly always they are more supportive. Obviously, potential funders need to know about citizen advocacy before they'll offer financial support. Potential advocates need to know about citizen advocacy, and about protégés, before they'll volunteer to become an advocate.

Programmes make some efforts to raise awareness, but usually in a targeted manner. Coordinators might give talks at

clubs and societies and organise some media coverage of effective relationships. But these sorts of efforts are secondary to finding protégés and advocates, and for this a much more targeted approach is used. To find Emma, a potential protégé, Chris asked around at boarding houses and at schools. To find an advocate for Emma, Chris used networks in the neighbourhood. Chris would talk to one contact, asking who they might know fitting the profile for Emma's advocate, get some names and get in touch with them, and so on — until finding Claire. Along the way, Chris told a number of people about citizen advocacy. However, this is a very laborious way of spreading the word.

In some ways, publicity can actually be detrimental to citizen advocacy programmes. If the programme is regularly in the media, others may think that it is a service for people with disabilities, able to handle problems on the spot. Some people with disabilities may show up and ask for support. Other services — schools, hospitals, housing bodies — may refer their own clients to citizen advocacy programmes. This might be okay for a programme offering paid advocacy, because each new person can be added to the client list. But citizen advocacy programmes are not set up to handle large numbers of new cases; the major effort is in finding citizen advocates who will provide ongoing advocacy, rather than dealing with an immediate problem.

Furthermore, there is a risk in relying on referrals. Some of those who are *not* referred may be the ones in greatest need of advocacy, because they are unknown to agencies or because agencies are not doing a good job and don't want others to know about it. The ones in greatest need are far less likely to contact a programme on their own. That's certainly the case for potential protégés who cannot communicate.

The upshot is that citizen advocacy programmes seldom have a high public profile. The average member of the public knows something about disabilities, but has little awareness of disability advocacy. The usual idea is that governments and charities deal with disability issues. That there would be people freely choosing to be advocates for individuals with disabilities is an alien concept.

The second method is *valuing* citizen advocacy. This is not such a problem as awareness: once understood, most people see it as highly laudable — at least in the abstract. Welcoming a person with an intellectual disability into your life is another matter. An advocate may well introduce their protégé to family members, friends and others. If they are hostile or undermining, then the advocate may lose incentive. This doesn't seem to be a problem for most of the relationships I've heard about, but no doubt is a factor in some situations.

The more relationships are established in a community, the more protégés will be integrated into people's lives and the more routine this will seem. So as more relationships are created, they should have more support from people in a community.

The third method is for people to *understand* citizen advocacy. This is a big challenge. Society is increasingly based on relying on experts and specialists to fix problems. If you want food, you buy it at a shop. If you have a problem with your body, you see a doctor. There is a general expectation that someone else will deal with social problems. People with intellectual disabilities are commonly seen as someone else's problems: parents, welfare agencies, governments. Why should an ordinary citizen step up and take a major role? Furthermore, specialists are thought to know better: they are experts. So what would an ordinary citizen, an amateur with no formal training, know about it?

Although professionalisation and specialisation are powerful forces, there are counter-movements. Some people grow their own food. Others seek self-help solutions for their health problems or set up groups and networks for sharing information and advice. Citizen advocacy can be seen as part of this flowering of mutual help. However, as it operates in practice, it is closer to a halfway house between mutual help and dependence on experts: the advocates fit into the mutual-help model but the citizen advocacy office is run on an expert model: coordinators are supposed to become experts in establishing and supporting relationships, and some of them become very good at it indeed.

The reliance on paid staff to create and support relationships, however valuable in its own right, is a barrier to wider understanding of citizen advocacy and helps explain why relationship-building has never become a habit in the wider community. Aside from the rare spontaneous relationships, like Nathaniel Ayers and Steve Lopez, citizen advocacy in practice occurs only in areas with offices.

The fourth method, *endorsement*, is for citizen advocacy to be supported by authoritative figures or groups. This is very much part of the citizen advocacy model: reputation is seen as extremely important so that the image of programmes rubs off on protégés, who otherwise are susceptible to image degradation. Programmes seek board members who play significant roles in the community, for example in business or the professions. Funding from governments and reputable companies provides credibility.

Programmes are more credible when they are seen as being independent rather than tools of a funding body: the most powerful endorsements come from those who have nothing to gain from providing endorsement. In this sense, advocates are

powerful personal endorsers of citizen advocacy, because they seek no personal gain and often make great personal sacrifices on behalf of their protégés.

Finally, there is the fifth method, *action*. Because citizen advocacy has obtained only limited backing from authoritative figures and only limited funding, only a few individuals — programme coordinators — actually go about the key functions of recruiting protégés and advocates. At the level of creating and supporting relationships, only a few people ever get to develop the habit. Developing a community-wide, collective habit of doing citizen advocacy is a vision that, unfortunately, is far from current reality.

My view is that to expand citizen advocacy, the most promising path is to promote it as a fully voluntary system.¹² The advocates would undertake their roles without any form of compensation, as at present, but so would the matchmakers. Anyone who wanted to would be encouraged to find a potential protégé, assess this person's needs and then find someone to be an advocate for the protégé. A current advocate would have a head start in doing this.

The main advantage of this sort of system is that the necessity to obtain funding would be removed. Support for relationships could become more a mutual process, with telecommunications enabling connections at a distance. If funding was available, it could be used to promote and support the whole approach or to train people as matchmakers.

The big advantage of a fully voluntary system is that citizen advocacy could expand more easily. Publicity could be used to encourage more people to become matchmakers or advocates.

¹² Brian Martin, "Citizen advocacy futures," *Citizen Advocacy Forum*, 14(I & II), January-December 2004, 44–49.

No doubt there are risks in this approach: some advocates might not be as prepared or supported as much as they should be. Citizen advocacy, as presently organised, has a very strict set of protocols. However, in practice what happens is not nearly as regulated as the protocols might suggest. A fully voluntary system would risk a further loosening of advocate practice, but with the advantage of greater presence in the community and greater overall experience in advocacy. Given the strict protocols involved with citizen advocacy as it exists today, it would probably be better for a voluntary system to have a different name.

These ideas are speculative, because hardly anyone in the citizen advocacy movement is thinking about changing the model. When funding disappears, programmes fold up and that's the end of the story. My purpose here is to point out an alternative way of promoting a good thing.

Conclusion

Most people who learn about citizen advocacy think it is worthwhile. So what can be done to promote it? To answer this, it helps to look at the five tactics of awareness, valuing, understanding, endorsement and action.

Awareness is fundamental — and lack of awareness is a big obstacle to citizen advocacy. Hardly anyone knows it exists. To be taken up more widely, awareness campaigns are needed.

Valuing is far less of an obstacle, because nearly everyone involved with citizen advocacy appreciates it.

Understanding is important — and there are some challenges in understanding citizen advocacy. The basic idea is simple enough: there's someone with a disability who has unmet needs. This person is called a protégé. There's someone else, called a citizen advocate, who stands by this protégé, providing

protection, support and opportunities. Some additional features of citizen advocacy are harder to grasp. The advocate is unpaid and may be committed to their protégé for the indefinite future. This can take a while to understand because commitments to strangers, and to people with disabilities, are not that common. The idea of advocacy is not always easily understood. It can be interpreted as friendship. Some advocates are friends with their protégés, but others are not — their primary role might be to stop abuse or ensure accommodation. There is plenty that can be learned about citizen advocacy. Even so, the basic ideas are the most important and are not too hard.

Endorsement by respected figures is a good way to promote citizen advocacy — but there has not been much high-level endorsement. For citizen advocates, the primary endorsement comes from the programme; family and friends may add their support. In wider society, outside disability circles, citizen advocacy is little known and seldom mentioned by prominent figures. Few leading politicians, doctors, editors, sporting heroes or rock stars make ringing testimonies to the power of citizen advocacy.

Action, the final tactic, simply means doing citizen advocacy. That means the daily or weekly efforts of citizen advocates themselves. This is the core of what keeps it alive.

To sum up, citizen advocacy thrives at the level of protégés and advocates through regular actions by advocates. Citizen advocacy is highly valued by most of those who know about it. The greatest obstacles to the spread of citizen advocacy are lack of awareness and endorsement.

Citizen advocates are not supposed to accept any payment or other compensation. Their efforts are voluntary or, in the language of citizen advocacy, “freely given.” In principle, citizen advocacy could readily proliferate, because all an advocate needs

is awareness, understanding and the support necessary to develop a habit — the habit of taking action on behalf of their protégé. In practice, a key obstacle is funding, not for advocates but for citizen advocacy programmes to pay salaries, rent and expenses. Because citizen advocacy is such a challenge to the usual approach — which is for service agencies with paid staff to address the needs of people with disabilities — funding for citizen advocacy has never been enough to cater for more than a small proportion of potential protégés.

Citizen advocacy often works quite well at the level of individuals, but at the level of systems — funding of programmes — it has struggled to maintain a toehold for minimal recurrent support. To me, this suggests it is worth considering a different model for promoting citizen advocacy, based on encouraging lots of people to become matchmakers, most of them unpaid. To do this would require a number of innovations, including how-to manuals for recruiting protégés and advocates and making matches, and a network of match-maker supporters.

Current participants in citizen advocacy programmes are very unlikely to move to such an alternative because of their commitment to the citizen advocacy model as it exists. It is more likely to occur through the introduction of an entirely new approach.