

# Some Thoughts on Citizen Advocacy Offices Recruiting Advocates for the Mentally Disordered or for Multiple Needy Classes<sup>1</sup>

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NOTE: As the founder of Citizen Advocacy (CA), Wolf Wolfensberger had always made it clear that CA could conceivably be a response to people with a wide range of identities & needs. For readers unfamiliar with Citizen Advocacy, it is a personal advocacy scheme in which the CA office establishes & supports typically one-to-one, unpaid, independent relationship commitments between people whose well-being is at risk (referred to as “protégés”) & suitable other members of the community (referred to as “citizen advocates”). In the following article, hitherto unpublished but submitted some years ago to the now-defunct journal the Citizen Advocacy Forum, Wolfensberger nonetheless points out some pitfalls to the CA scheme in responding to various classes of protégés in need of advocacy, & not just to those with an intellectual disability.

In underscoring the challenges inherent in recruiting advocates for protégés from different classes, including those who have a mental disorder, Wolfensberger touches on certain aspects of Social Role Valorization (SRV) teaching. In the context of advocating for someone who is wounded, perhaps deeply so, he refers to the importance of being (or becoming) familiar with a person’s wounds, & concomitantly knowing the particular risk factors associated with the person or the class to which the person is assumed to belong. As well, Wolfensberger emphasizes the need for advocate fidelity and continuity—despite possible difficulties—in advocating for those whose disposition is apt to elicit rejection, & who may be rejecting of others,

including the advocate. Indeed, the article serves as a reminder of the potential of personal advocacy commitments in addressing many of the wounds inflicted on devalued people. – Mitchel Peters

HISTORICALLY, THE VAST MAJORITY of Citizen Advocacy offices have recruited citizen advocates for mentally retarded persons. But there has always been debate in the Citizen Advocacy culture about the pros and cons of a single office recruiting advocates either for any needy person regardless of the source of the need, or for at least persons of more than a single needy class, such as the mentally retarded.

Of course, there is no obstacle within Citizen Advocacy theory itself to operating Citizen Advocacy offices either for only a specific needy class or even subclass, or for any kind of needy person. But there are many challenges and pitfalls in a single Citizen Advocacy office trying to accommodate more than one distinct class of protégés. Proponents of this kind of office are typically not aware of what these problems are, usually because they have not had any close-up experience with any such office, or even not with any kind of operating Citizen Advocacy office.

First of all, any needy class comes with certain identities and characteristic vulnerabilities with which one needs to be familiar. This brings with it the practical problem that Citizen Advocacy staff will have to be or become twice (or even more times) as knowledgeable and sophisticated if they

were to serve two or more classes than if only one class were at issue. In turn, this would mean that it would be extremely desirable for such a Citizen Advocacy office to be a larger one, so as to be able to employ several staff members who could each specialize on a particular class that such an office would serve, rather than to gamble on the likelihood that a single staff member would be equally knowledgeable and capable vis-à-vis each of the classes at issue. Of course, one big problem with this is that a larger office would need to be much better funded, but funding is always very difficult for any kind of Citizen Advocacy enterprise to come by.

One related rationale for not lightly taking on more than one class of protégés if one can afford only one Citizen Advocacy staff member is that when there is staff discontinuity, it would be easier to recruit a replacement for a staff member who had been working with only one class of advocates than a member who had developed expertise in working with two or more.

Furthermore, there are a great many more specific difficulties and pitfalls in working with needy populations who, despite their neediness, are likely to be mentally competent at least part of the time. Classes of needy people that might fit this scenario are the imprisoned, the poor, immigrants, certain subclasses of elderly persons, and certain subclasses of the mentally disordered. This presents several challenges.

One is that persons who are not impaired in intelligence are likely to be able to acquire a better and faster understanding of what Citizen Advocacy is all about. They may request more such information, and become suspicious if they feel that any information is being withheld, especially if they are already of a suspicious mindset. In turn, Citizen Advocacy offices are more likely to be forthcoming with such protégés than with those of impaired intelligence. Staff of those Citizen Advocacy offices that only recruit advocates for people of limited mentality may not even be aware of the difference in information transmittal

to the protégés that would typically take place if the protégés were of average or higher intelligence.

Further, some Citizen Advocacy offices have tried to conceal their identity and function from protégés and many other parties. They tried to do matching and supporting without giving the appearance of having done so. This has sometimes led to bizarre practices. Two motives have been behind this strategy. (a) The Citizen Advocacy office tried to avoid the image of being a service agency. (b) The office wanted to avoid stigmatizing the protégé, as might happen if other people came to know that the person really needed a protector, or that third parties were playing match-maker because no natural protector had come forward. By concealing itself and its activities, a Citizen Advocacy program might get away with such pretenses when protégés are mentally limited, but not with more intelligent protégés, and particularly not with any prone to believe in conspiracies, that people behind the scenes are pulling the strings that affect their lives, etc.

Also, the more a protégé possesses mental competency despite his or her other neediness, and the more wounded such a protégé is, the more one will run into situations where that which is truly in the best interest of such a person is not what the person will want or accept. In turn, this implies that such a person is apt to vigorously object to a particular advocacy action on his or her behalf that, despite its benefits for him or her, is not in accord with his or her wishes. Yet further in turn, this implies that the role of the citizen advocate is going to be a very difficult one. In fact, many citizen advocates will simply not be able to carry on with conviction over extended periods of time when they realize that what the protégé desires is bad for him or her (perhaps even very self-destructive), and that the protégé constantly countermands or sabotages that which is good for him or her. Not merely the normative person, but even an otherwise potentially very good advocate, is eventually apt to throw up his or her hands and withdraw from an advocacy role and relationship, perhaps even with some bad

feelings, in essence saying, "Who am I to stand in the way of a person who is not stupid but who irrationally desires all sorts of things for him/herself that are bad, and who wants me to get these bad things for him/her."

In the case of the mentally disordered specifically, a number of additional phenomena or special challenges need to be kept in mind.

One phenomenon that makes Citizen Advocacy for mentally disordered people difficult is that mentally disordered people hold a great variety of beliefs as to what their condition is, and what accounts for it (e.g., Baur, 1991); and sometimes, some of these ideas are systematically generated and inculcated into such persons by organized groups of people who have, or have had, mental problems themselves. Thus, opinions among the mentally afflicted may vary as to whether any mental disorder is a narrowly-circumscribed medical or "chemical" problem, whether there is a moral element to their situation, whether they are victims of conspiracies or circumstances, whether they are victims of parental errors or even mistreatment during their upbringing, etc. These ideas are apt to shape what a mentally disordered person wants, or is willing to have done for him or herself.

As part of their beliefs about mental conditions, a usually militant minority of people who have been clients of the mental services system have developed their own alternative—and often idiosyncratic—idiom, often riddled with code words, such as "survivors" for people like themselves. Both Citizen Advocacy office people and (potential) advocates may have to wrestle with this problem.

Another reality about mentally disordered protégés is that they may live with delusions—possibly of long standing. This presents problems both to the Citizen Advocacy office and to an advocate. Should a person's apparent delusions be interpreted as such to the advocate? Is the apparent delusion a real delusion, or does the person actually have a rich relative, or has the FBI really tracked the person at some time, or are the voices heard

in the person's head the voices of a radio station picked up by the person's dental work acting as an antenna and amplifier? Stranger things than these have actually happened.

One possibility (suggested by Len Surdyka) is for the Citizen Advocacy office to describe the apparent vulnerabilities of a protégé to a new advocate, present the situation as the office sees it, but also as the protégé seems to see it, and let the citizen advocate make up his/her own mind.

At any rate, advocates may find it very problematic how to respond to an apparent delusion. Agreeing with the protégé's delusions would reinforce them. Disagreeing with them might alienate the protégé from the advocate. One possibility that might work with some protégés is to agree to work only on certain specific instrumental problems that are mutually agreed upon (e.g., finding better housing, or getting or holding a job), and not deal with the protégé's beliefs. However, this could result in situations where the protégé desperately needs an advocacy to which the protégé has not agreed.

Some citizen advocates may come to believe that they would be disloyal to their protégé if they rejected the protégé's delusions. They may then begin to treat delusions as real, and act upon these false beliefs. This may not only be disastrous for everyone, but also project to the public the idea that crazy people are advocating for other crazy people—a compounding rather than an alleviation of their craziness—and which the public would think is the last thing that crazy people need.

Among other things, such advocates may demand that the Citizen Advocacy office also treat the delusions as real, and support the advocates in this. When the office does not play along, and does not provide support for an action that is based on the assumption that a delusion is real, a crisis may occur in the relationship between the office and the advocate, and the advocate may even dissociate him/herself from the office.

Another problem is that many mentally disordered people have a tendency to vacillate in ratio-

nality, and in their ability or willingness to relate to any kind of surrogate or spokesperson. In fact, those with paranoid tendencies may develop suspicions about an advocate and reject his or her ministrations, or even very presence. Those with episodes of severe disturbance may even sometimes fail to recognize a previously familiar citizen advocate or Citizen Advocacy staff member, or may assume the advocate is someone other than he or she seems to be or claims to be. A good example is the founder of the American Association on Mental Health, Clifford Beers (1876-1943). When he had a psychotic episode, he was repeatedly visited by his brother, but he variously did not recognize him as his brother or suspected that he was an impostor.

These realities make extreme demands on potential advocates, as those few Citizen Advocacy offices have discovered that have tried to serve mentally disordered people. Their successes have been relatively modest, compared especially to offices serving mentally retarded people, and their staff have commonly been stressed almost beyond human endurance.

At the same time, there is no doubt that mentally disordered people who take a rejecting or even adversarial stance toward their advocates nonetheless very badly need advocates outside the service system who, despite all the problems, endure faithfully in their presence and roles. For instance, one of the things that probably helped the aforementioned Clifford Beers to recover was that his brother kept faithfully visiting him through it all, and bit by bit, Beers gained confidence in his brother and his true identity. Without this crucial link to the outside world of reality, Beers might have continued to withdraw and cut himself off, and might have entered a life-long state of insanity and residency in an asylum, as so many people in fact have done and still do under similar circumstances.

Of course, one way to avoid some of the problems of matching citizen advocates to mentally disordered people is to concentrate on a subclass of such persons that is more likely to be recep-

tive to the ministrations of a citizen advocate. For instance, I suspect that those mentally disordered persons who are incarcerated in institutions where they are badly treated, are very reduced in circumstances, and relatively helpless, will be vastly more receptive to the efforts of a citizen advocate than mentally disordered people who live with considerable discretions in the community. An example of one class of mentally disordered people that readily comes to mind are those incarcerated long-term in so-called forensic psychiatric units, as studied by the Georgia Advocacy Office in 1998. In fact, there is one advocacy goal that such persons are very likely to agree upon with an advocate, namely, getting the person out of the detentive setting into a less-institutional or even non-institutional residential one, possibly even as a transitional step to an even less structured setting. Of course, once released from such settings (if indeed they ever are), they may become less receptive to advocacy on their behalf.

Citizen advocates have proven to be crucially important when a protégé is of fragile health, or is dealt with by the health care system. It is then very important for the Citizen Advocacy office to emphasize to advocates the inherent value of every human life. With a mentally disturbed protégé, this same message to advocates is very important even when no life-and-death issues are on the table, but when the protégé is at risk of being severely devalued or even dehumanized because of his/her bizarre beliefs, behaviors and appearances. ☺

#### ENDNOTE

1. I thank Len Surdyka and Elizabeth O'Berry for very helpful comments on an earlier draft.

#### REFERENCES

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