

REFLECTIONS ON THE STATUS OF
CITIZEN ADVOCACY

By

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The opinions expressed herein are those of the author and do not necessarily reflect policy of the NIMR/CAMR or GAO.

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* This paper is based on a series of presentations given at events where the development of citizen advocacy was critically examined. The first time this occurred was at a national workshop to review citizen advocacy developments across Canada, convened by the National Institute on Mental Retardation, Toronto, June 2-3, 1974. The material presented here presupposes that the reader has studied citizen advocacy and is familiar with its terminology and key concepts.

INTRODUCTION

It is very gratifying to see that since 1970 so many citizen advocacy (CA) offices have been operationalized. At the same time, it is rather alarming for me to note that virtually from the very beginning, CA offices-and I would be inclined to say CA staff-have often ignored the very reasons for which this service was conceptualized. As a result, they have been introducing a very systematic inadequacy into the entire CA movement. The fact that we have had such a large number of CA offices, and that a large number of implementive efforts are always underway somewhere, is not only gratifying but also disquieting because the pattern that gets set has a profound impact on what CA is, how it is perceived, what it will be some years from now, what it will or will not be able to accomplish, and whether it will survive in the long run. Before I speculate as to why this trend has occurred, I want to specify first what it is that I believe has happened.

AN HISTORICAL REFLECTION

Initially, CA had its birth when the United Cerebral Palsy Association, after years of concern, held a nation-wide conference in the United States in which several groups and about 25 persons were involved (United Cerebral Palsy Associations, 1966). The key question at this conference was, "What will happen to my child when I'm gone?" It is in response to that concern at that conference that CA was first formulated in a somewhat primitive version. Many people, even those in human services, have great difficulty achieving a full understanding of the deep anxieties which beset many family members of handicapped persons, and particularly parents of such persons. These anxieties are apt to be heightened under a number of conditions, such as the following:

1. The handicapped person is so impaired that there is little or no likelihood of ever achieving full, or perhaps even partial, independence.
2. There is a fairly high likelihood that the handicapped person will outlive both parents.
3. The parents are of advanced years or in ill health.
4. There do not appear to be any other family members who will assume a major responsible and competent responsibility vis-à-vis the handicapped Person for the duration of that person's lifetime.
5. The family has limited material means, and there is a high likelihood that the handicapped person will be dependent on public funds.
6. Parental fear is particularly likely to be high when suitable services for the handicapped person is absent or few, and/or where there has been a history of abuse and scandal in potentially relevant services.

Even when favorable conditions, perhaps opposite to the ones above, prevail, they may bring their own concerns or even worries, as for instance the following:

1. Where the impaired person does have siblings, the parents may want to assure that the siblings will not be expected to assume a parental role vis-à-vis their handicapped brother or sister.

2. A family may have considerable material assets, but the impaired person will never be able to attain the competence to deal wisely with an inheritance of any extent. A further common concern in such a situation is that the agencies that serve the impaired person, or the government, may lay claim to any inheritance in order to cover the costs of service. In the past, there have been numerous instances where under such circumstances, even considerable assets were, in essence, confiscated and/or dissipated in a short time, sometimes for very inferior services, soon leaving the impaired person as penurious as if s/he had inherited nothing.

Sometimes a movement or service has a beginning because of one reason but ends up accomplishing something quite different. That is not necessarily a bad thing. But a parent with a severely impaired child is still confronted with the legitimate question: what will happen to my child when I'm gone? I tell parents that to this question there is no really adequate answer-and never will be. Because human affairs are too transient, and because of the human condition and bondage, you cannot guarantee that something bad might not happen to a person after his/ her parents have died.

You cannot guarantee that when you are dead and gone everything you want will come true, that there will not be some kind of tragedy that the world will not blow up. You cannot even guarantee the well being of a competent, well-adjusted, healthy child because even for the most fortunate person in life this world may fall apart. All you can do-and that you can do – is to apply a "decision theory" framework whereby you maximize probabilities for desired outcomes to occur, and minimize occur. That is all anybody can ask for, that is all anybody can do, that is what we should be doing, and that is what CA was intended to do for parents who were faced with the question, "What happens to my child after I'm gone?" In other words, CA was intended to be such a strategy of optimizing the likelihood that an impaired person would be protected if and when there was no family that could or would do it.

MAJOR THEORETICAL DETERMINANTS OF ADVOCATE-PROTEGE PAIRING

Below we will sketch the areas of human need which CA offices have tended to address poorly, including the need to recruit successors to the parent role. However, in order to understand the shortcomings, it is most helpful to review the most basic dimensions of CA need and of advocate-protege pairing. What are the dimensions, which should determine, or at least affect, our advocate protege recruitment, matching, roles, and functioning? What is it that we should look at and think about as to whom we recruit how we match them, and what we tell them they are supposed to do? There appear to be at least four critical dimensions: the protege's needs along the instrumental-expressive need continuum; the protege's needs along the formal-informal advocacy form continuum; the intensity of a protege's needs; and the amount of relationship reciprocity that the protege can offer the advocate. Relative to all the above four

is the (potential) advocate's ability to respond appropriately to the respective protege need or limitation. Readers will follow the discussion below by frequent reference to Table 1. One of the most basic dimensions of protege needs is the instrumental-expressive continuum, ie. the extent to which a (potential) protege needs practical problem solving or emotional/affective support. This continuum is one of a number of dimensions on a very high level of conceptualization that CA staff must internalize. How CA staff look upon the instrumental- expressive continuum of protege need, how they perceive and / or understand it, will determine what that staff will do: how they recruit, whom they recruit-and not just advocates, but proteges as well. It will determine what they tell advocates, and how they guide and follow them up.

While CA relationships can fall along a continuum of instrumental to expressive relationships, the formal-informal relationships are more dichotomous. The formal ones (guardianship, conservatorships, etc.) require court or similarly highly structured decisions, whereas the informal ones require only the mediation of the CA office. (CA-like relationships outside the context of a CA office might be called "personal advocacy.")

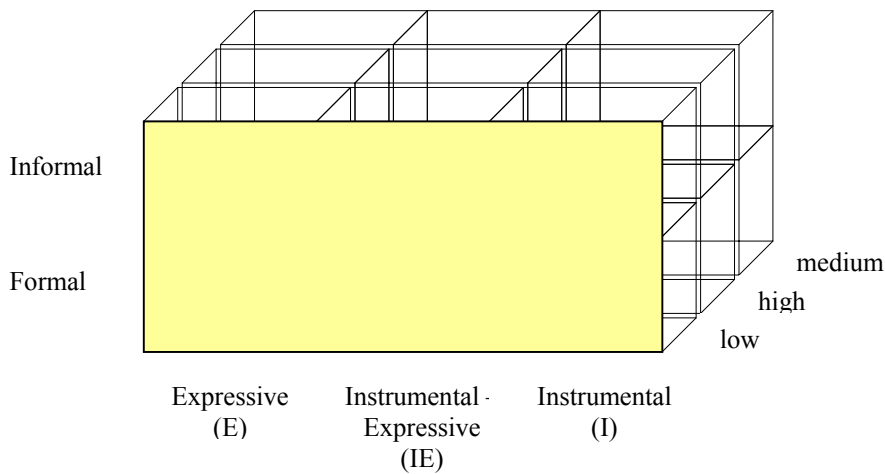
The intensity or demand dimension, which is a true continuum, refers to the intensity of the protege's need for CA, and thus the demands that are apt to be made upon the advocate. Of course, it is conceivable that more than one advocate might be appointed for one protege so that the protege's need intensity is spread out over several advocates and the demand made upon any one of these is not proportionate to the protege's full need.

Another factor (not shown on Table 1) is very subtle indeed, but has all incredible impact in terms of what CA staff will do. It has to do with the amount or degree of "relationship reciprocity" which the protege is capable or willing to offer. By this we mean that some people will not or cannot reciprocate socially or affectively. Take, for example, a man who had an accident and who had lain unconscious in a hospital for several years. His wife came so many times a week to hold his hand, but there had not been any relationship reciprocity in many years. Another example would be an old person in a nursing home who cannot respond appropriately to individuals who know and love him/her because s/he has lost awareness, though not consciousness. There are newborn infants that at best will emit a little gurgle sound when they are happy but do not recognize a person as an individual and may not even be able to emit what one can call love responses. There may be a profoundly retarded person who habitually looks and acts passively. In contrast, an autistic child may actively try to shut out people. All these are people whom, to some degree or totally, cannot offer reciprocity in a relationship. How CA staff conceptualize, or feel about, this very critical dimension will determine whether they will recruit such persons as proteges, or advocates for them.

A lot of CA staff have, in effect, ruled out non-reciprocating relationships, as discussed further below. If one feels that reciprocity must exist in a CA relationship, then one obviously is not apt to recruit advocates for proteges that do not reciprocate, one will recoil from recruiting purely instrumental advocates

for proteges that have only instrumental needs, and one will probably not even seek out proteges with purely instrumental needs. Yet if CA does not address the needs of non-reciprocating proteges, no one is apt to do so. Also, if one recruits instrumental-expressive advocates for proteges who have only instrumental needs, one is likely to denormalize the proteges (as via overprotection), or lose the advocates who expect expressive reciprocity that the protege cannot or will not extend.

Certainly, lots of potential advocates do not get satisfaction from a non-reciprocating person, and particularly not unless they are specially selected for this kind of service and receive a clear and strong orientation to it. In such relationships, they will need other reinforcements, and a different initial mind set and orientation towards their mission, and therefore also different recruitment and training.



SHORTCOMINGS IN THE EMPHASIS OF CITIZEN ADVOCACY OFFICES TO DATE

Tables 1 and 2 show the informal / formal dimension; the expressive, instrumental-expressive and instrumental continuum; and the need dimension divided into low, moderate and high-demand categories. Table 2 divides up the layers of the CA cake into three slices which yield eighteen boxes, of which fifteen correspond to some CA form, while three boxes do not because there is practically no such thing as a formal expressive relationship. The law does not provide for love, only for problem solving. The closest thing to this relationship form, perhaps the only exception, is a formal expressive relationship where an adult adopts another adult as a symbol of affection, which happens very rarely.

For instance, once in a while a young adult and a mature family establish a special relationship where the family adopts that adult as a symbol of affection. But even then, more often than not it is done more for tax and inheritance reasons rather than as a symbol of affection; so essentially, the option is not applicable.

Table 3 illustrates one of several useful systems of classifying CA relationships. Obviously, it is reasonable to assume that in each of the fifteen applicable boxes, we might have different types of needs and therefore also of advocacies. For instance, one of the boxes implies a need for an instrumental-expressive relationship at a moderate level of demand by means of a formal CA relationship. Table 4, in connection with Table 2, underlines the kinds of CA relationships which CA offices have actually pursued to date, and where CA offices have put their emphases. The numbers in the boxes of Table 2 rank-order these emphases into four levels: the number one stands for highest emphasis, four stands for practically zero emphasis, two for moderate, and three for low. If one looks at the publicity materials of CA offices, their slide shows films and fliers, recruitment procedures, training content and methods, statistics, etc., one finds that what they have overwhelmingly tended to do is to emphasize informal rather than formal relationships. High emphasis has so been on the instrumental-expressive and expressive relationships; there have been very few purely instrumental relationships. In the need dimension, emphasis has been placed on relationships that have been moderately demanding. Second-highest or moderate emphasis has been put by CA offices on informal relationships of the expressive-instrumental and expressive forms, and more in the high-demand than low-demand relationships-to a good extent, still within the instrumental role category.

The third highest emphasis has been on low-demand and on informal moderate

demand instrumental forms. Everything else has been a level four. In about half of the potential categories of relationship, there has been almost zero emphasis. Thus, there has been avoidance of both the very lightly and the very highly demanding relationships. Relationships toward which there has been virtually no orientation or recruitment include the following: minimally demanding ones, the highly demanding ones, the almost purely instrumental ones, and the formal ones. By the same token, that means that low emphasis has been placed on recruitment of formal advocates, such as adoptive parents, legal guardians, trustees, conservators of property, etc. In the informal category, relationships are practically unheard of, which are primarily instrumental in nature, or which make demands for only very infrequent involvements. We can thus say that it is in only two out of the fifteen baskets that CA offices have put most of their eggs. The personal observation that CA offices appeared to have addressed themselves primarily to less impaired individuals was dramatically validated by the 1976 NARC survey of CA offices in the United States (NARC, 1977) which found that 44% of proteges were mildly retarded, 39% were moderately retarded, and only 11% were severely or profoundly retarded. Also, the same hypothesis was supported by the finding that people living with their families were much more likely to be assigned an advocate (in 40% of relationships) than people in nursing homes and institutions (18%). Furthermore, only 3% of relationships were purely instrumental, and the number of legal guardianships was minuscule. We can see from the foregoing that consciously or unconsciously, CA must have excluded either proteges with certain needs from advocates, or advocates from serving proteges with certain needs, or both. I therefore had to conclude that CA has failed to carry out at least one of its major intended missions. And what is also painful is that in this respect, it has failed in pretty much the way that the critics said it would in not yet offering much of an answer to "What happens to my child when I'm gone?"

PRIORITY OF EMPHASIS IN CITIZEN ADVOCACY OFFICES TO DATE

3	3	4
N/A	4	4

Low Demand

- 1: HIGH EMPHASIS
- 2: MODERATE
- 3: LOW
- 4: ALMOST ZERO

1	1	3
N/A	4	4

Moderate Demand



2	2	2
N/A	4	4

High Demand

TABLE 3

PRIORITIES OF CITIZEN ADVOCACY OFFICES TO DATE
IN RELATIONSHIP ESTABLISHMENT

HIGH EMPHASIS

INFORMAL INSTRUMENTAL-EXPRESSIVE, MODERATELY DEMANDING
INFORMAL EXPRESSIVE, MODERATELY DEMANDING

MODERATE EMPHASIS

INFORMAL EXPRESSIVE, HIGHLY DEMANDING
INFORMAL INSTRUMENTAL-EXPRESSIVE, HIGHLY DEMANDING
INFORMAL INSTRUMENTAL, HIGHLY DEMANDING

LOW EMPHASIS

INFORMAL EXPRESSIVE, LOW DEMANDING
INFORMAL INSTRUMENTAL-EXPRESSIVE, LOW DEMANDING
INFORMAL INSTRUMENTAL, MODERATELY DEMANDING

NEAR-ZERO EMPHASIS

FORMAL INSTRUMENTAL-EXPRESSIVE, HIGHLY DEMANDING
FORMAL INSTRUMENTAL-EXPRESSIVE, MODERATELY DEMANDING
FORMAL INSTRUMENTAL-EXPRESSIVE, LOW DEMANDING
FORMAL INSTRUMENTAL, HIGHLY DEMANDING
FORMAL INSTRUMENTAL, MODERATELY DEMANDING
FORMAL INSTRUMENTAL, LOW DEMANDING
INFORMAL INSTRUMENTAL, LOW DEMANDING
ANY RELATIONSHIPS WITH LOW RECIPROCITY

ROLES	ADVOCATE ROLES AND CHARACTERISTICS						EMOTIONAL HELP	PRACTICAL HELP
	LONG-TERM	SHORT-TERM	INFORMAL	FORMAL				
ADVOCATE-FRIEND	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
ADVOCATE-GUIDE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
GUARDIAN	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
TRUSTEE	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PARENTAL SUCCESSOR	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ADOPTIVE PARENT	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ADVOCATE-SPOUSE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EMERGENCY ADVOCATE		<input type="checkbox"/>	<input type="checkbox"/>					<input checked="" type="checkbox"/>

This CA shortcoming raises very painful and existential questions. If CA fails on that issue, then what is left? What are the alternatives? Where do we go? Citizen advocacy was to be a last-ditch stand, a last effort, because all the other many protective service forms which were designed to address this issue have failed-at least in my judgement. All over the world there has been a constant stream of

conferences where people recapitulate the same protective service and guardianship approaches over and over, assuming that their schemes can be implemented, and if implemented, would solve the problems. Such types of solutions have been proposed endlessly now for about a hundred years at hundreds of conferences and in hundreds of publications-and we will continue to see an endless stream of such conferences and publications that will analyze wills, guardianships, trusts, casework approaches, and so on; but in essence, no meaningful functional systematic solution for more than an occasional individual has come of it yet, and I do not think much more will ever come of it other than either formal legal provisions, or protective services on the social casework-type model - perhaps with a bit of legalism thrown in. None of these are much of an answer to a parent's question, so if CA fails to answer that question also, does that mean there is no solution? This is a distinct possibility, but it is too soon to say because there is still time to redirect the CA movement so that it will make a commitment to answering that parental question. Each CA staff member should make that internal commitment: not to let all sorts of options go fallow and unutilized, or issues unrecognized; and not to be controlled by biases so as to foreclose options and not recruit people that are available, and not to pair people as one might.

WHY AVAILABLE VOLUNTEERS AND RELATIONSHIPS HAVE BEEN EXCLUDED

In order to help CA offices to reorient themselves properly to the needed kinds of CA relationships, we will need to understand whence has come the systematic bias toward some, and away from other, relationships and priorities, most or all of which had been analyzed in the CA text (Wolfensberger & Zauha, 1972), and have been emphasized in any training session I have ever had anything to do with. Since the exposure to the issue has been there, and yet has gone in one ear and out the other, there must be a very strong set of dynamics at work to override so much teaching, so much reading, and so many opportunities. So why do a lot of our CA staff have that problem?

I think we need to take another step back and search out another reason why they have that difficulty.

I believe that the answer has something to do with the fact that CA attracts more highly ideologized staff than probably any other human helping form I know. Generally, staff that is recruited, attracted, and trained to CA tend to be almost quivering with ideology and commitment. This creates a problem in that this beautiful phenomenon sets up certain expectations for advocates and advocacy that becomes pitfalls, as explained below.

Overidealized Mistaken Views of Normalized Relationships First and foremost, people involved in CA are oriented toward relationship. To them, relationship implies not just reciprocity, but in addition, intensity one might say an intensive reciprocity. Staff are recruited by emphasizing this, or they (and others) get ideologized that way. In their training, staff are even oriented toward looking at, and transacting, one particular type of relationship: somewhere along the line,

most CA staff get a noseful of normalization theory that will orient them to looking for culturally normative relationships. In turn, they will look at one certain type of normativeness, namely, oddly enough, an idealized normativeness that strives to establish relationships at the more intense end of the intensity continuum. In this respect, CA staff people resemble somewhat the members of T-group cults. Often CA staff consists of people (frequently young) who have very beautiful ideas and ideals, and these ideals have tremendous impact on (a) what they perceive is needed and not needed, desirable and not desirable, moral and immoral, (b) whom they recruit as advocates, and (c) whom they recruit as proteges. An excessive orientation to idealized normative relationships depreciates formal relationships. Another problem is that even though formal relationships (other than marriage and natural parenthood) are culturally normative in the sense that everybody knows that they exist and would not be surprised if they encountered one, they are not commonly implemented. Because formal relationships (other than marriage) are not commonly set up in our culture, the CA staff view them as non-normative, and therefore do not pursue them. As a result, even people who desperately need formal legal guardians may be matched with informal friends instead. Reluctance to Establish Non-Reciprocating Relationships One peculiar result to which the combinations of ideologization and commitment to normativeness in relationships contributes is that CA staff rule out one-sided relationships-because almost unconsciously, one-sided relationships are viewed as "immoral," or at least "impure." Also ruled out are relationships that the CA staff themselves would not enjoy, or enjoy as being noble, and so on.

Further ruled out might be the matches to proteges who engage in socially unacceptable offensive behavior. Matches in which a person is so disordered as to be unresponsive are certainly not pursued as a result of the above-discussed CA staff ideology. And who is it that cannot respond reciprocatingly? Obviously, the people who have either gross emotional impairments, or gross awareness impairments; to some degree, even infants – which explains why CA staff has had such low orientation to the advancement of adoption. I view the typical child placement agencies in our culture as agents of legitimized, legalized crime against children. The callousness, the wrongness that they engage in - it is so legitimized and also so routinized, and directed at such a helpless group, as to be one of the biggest crimes in helping forms in existence. In some respects, it is a worse crime than the institutions for the handicapped. At least we can somewhat understand why people have difficulty relating to handicapped persons, but what damage is being done systematically even to ordinary, normative infants and young children is just incredible. A resident of a nursing home may only need instrumental advocacy. But how many CA offices made even one single match for purely instrumental purposes to a person in a nursing home who was aged and lacking I in awareness? In this situation, an instrumental relationship may mean seeing to it that the resident gets proper medical services, that s/he is warm and gets good food, that his/her property does not get stolen by the nursing home operator or staff, etc. Other types of

instrumental missions are certainly conceivable (such as getting such a person out of a nursing home altogether), but are not mandatory in each instance. Not only have CA staff avoided these kinds of relationships, but they have hardly even conceptualized them. One reason may be that a CA coordinator had not internalized them, and the issue thus does not burn up his/her gut. Another, and even stronger possibility is that the initial coordinator of a CA office had aimed its publicity at bringing in the volunteers who will want to do the "friendship thing." By the time one has brought that volunteer in, it is absurd or even dangerous to ask him/her to do the more instrumental, "less rewarding," thing.

People who are the most severely devalued are among those who need advocacy the most. Table 5 lists who the most devalued people are apt to be, at least in our society. We can see that non-reciprocating people are among those whom few people want to be with, or work for or with. This tells us that we need to make special efforts to recruit advocates for them. Also, we need to be aware of our own devaluations that might lead us to express the larger societal devaluation patterns by steering potential advocates away from such potential proteges. Hyperidealized Moralism of Citizen Advocacy Staff

I now come to another major reason closely tied to the above and yet distinct as to why some kinds of relationships have not been established, and why some kinds of advocates have not been recruited. Mainly, it is a deeply unconscious but very real moralism on the part of the CA staff which is offended by the idea that a person could or should be involved in the affairs of another person unless his/her involvement included an intense, warm personal relationship, and humanistic concern. Citizen advocacy staff feel that unless someone has that warm, humanistic concern, s/he should not be involved in the affairs of another person. That is a form of moralism-for better or for worse-and I think it is as a result of this moralism that there has been very little effort to recruit candidates for low-demand relationships where minimal interaction may actually be needed. I am talking especially of low-demand, long-term relationships, where maybe one or two or three interactions a year are needed to address entirely instrumental decisions, perhaps on a matter-of-fact basis - whether to make a major purchase, whether a medication change or operation should be pursued, whether a transfer to another service should be blocked, and things of this nature.*

* proper plan, I think you will succeed. You may have to establish for the court that there is someone to assume individual guardianship. The court will have to be convinced that this person is properly qualified and will carry out the role; you may have to show that you can provide back-up and review; and so on. If you have all these resources at your disposal, and you plan it right and win your first such case, I think it's downhill from then on.
Workshop Participant: I don't know if I could look somebody in the eye and say,

TABLE 5

THE PERSONS (CLIENTS) THAT ARE MOST APT TO CHALLENGE THE VALUES AND ACCEPTANCE OF HUMAN SERVICE WORKERS ARE THE ONES PEOPLE HAVE THE GREATEST DIFFICULTY IDENTIFYING WITH

1. PEOPLE WHO DO NOT LOOK LIKE ONE'S IMAGE OF HUMANS
2. PERSONS WHO DO NOT RECIPROCATE RELATIONSHIPS, E.G.: WHO HAVE LOST AWARENESS, ARE TOTALLY WITHDRAWN, REJECT POSITIVE SOCIAL CONTACTS, ARE AND ALWAYS HAVE BEEN MOST PROFOUNDLY RETARDED
3. PERSONS WHO ARE SEEN AS DELIBERATELY AND HABITUALLY VIOLATING MAJOR SOCIETAL VALUE STRUCTURES, E.G.:
 - WHO ARE PRISONERS OR ARE BELIEVED TO BREAK THE LAW AS A CAREER
 - WHO ABUSE THEMSELVES VIA ALCOHOL HARD DRUGS
 - WHO REFUSE TO WORK
4. CLIENTS WHO MAKE SEVERE SUSTAINED EMOTIONAL DEMANDS UPON WORKERS
5. MILDLY HANDICAPPED PERSONS WHO ARE NOT DIFFERENT ENOUGH TO EVOKE WORKERS' SPECIAL CONCERN ORIENTATION

I am talking particularly about long-term, low-demand, situations (though not ruling out short-term, low-demand ones), and the reason I am focusing attention on the long-term is

"You should take on this person, but there's going to be no reciprocity in the relationship, you're not going to get anything back directly from that person, you're not going to see any response." I don't know if I can look people in the eye and say, "You should do this"-because I don't do it.

Wolfensberger: Aha! That's one of the reasons, exactly. Let's be sharp and clear about it. You, as a CA officer, have severe problems relating to non-reciprocal relationships, and you are projecting your problem on your advocates. Therefore, you are not recruiting people who don't have that problem because you say to yourself, "I would have difficulty relating to a person who is unconscious and who can't smile back to me, who can't press my hand, and by golly, I won't ask anybody else to do it." Exactly! That, in my opinion, is one of the major reasons for the problems we are reviewing.

because it is a fact that there are vast armies of people who could greatly benefit from such advocacies but are not getting them because of CA staff moralism.

We cannot always clearly categorize an advocacy relationship, but let us be careful that we do not go the other way and reject intellectual rigour with soft language such as "people cannot be put into boxes, there are no categories, we never know, everything is individual." In reality, we can define principles, establish categories, and so on. What we may have special difficulties with is the borderline case; while we do not know in every such instance what to do, that is often a relatively minor, technical, and soluble issue; but we have got to clearly define the controlling principles, major relevant classes of behaviors and key issues.

Thus, we know that needs for low-demand (i.e., low intensity) but long-term, and primarily instrumental, advocacy do exist. For instance, one advocate I have known was a long-term legal guardian for a retarded man who lived in the same community. They interacted maybe two or three times a year, and usually only in regard to a major issue. He would call her and tell her his problem; or once in a while she called him or dropped by his residence, and it worked quite adequately. Such an advocate has to have an understanding of the person and his/her need, but it does not involve anything like the intensity and the expressiveness that is so often projected onto guardianship or other advocacy relationships. Long-term instrumental advocacies are also urgently needed where people have sufficient expressive relationships, but not sufficient protection and advocacy. For instance, this situation often occurs where proteges come from supportive but incompetent families, or reside in institutions that maintain a warm, friendly atmosphere with low staff turnover but without outside advocacy for the residents. Relatedly, we have seen an increasing number of handicapped people live in relatively adequate community group homes-not to mention the inadequate ones for the moment. In these community group homes and/or communal settings, residents' expressive needs may be quite adequately (even if not ideally) met, but there will be instrumental needs that will go unmet unless we isolate the need and recruit advocates to pursue or meet it. Citizen advocacy must respond to both aspects of a person's life. When we try to address some of the omissions of CA efforts in the past, we must avoid the introduction of yet new errors, especially considering that CA is constantly under attack, and there are endless perverse efforts to do something that is not CA but to call it CA. For instance, between approximately 1975-1980, I frequently admonished CA programs not to depreciate the desirability, utility, and feasibility of purely instrumental relationships. But no sooner was this point emphasized than it became pervertedly implemented as some people concluded that instrumental and expressive CA should be strictly separated from each other within a CA office. As a result, a number of programs have drastically reduced their recruitment of instrumental-expressive relationships, because one part of the program recruited only instrumental ones, and the other one only

expressive ones. One program that did this cited a perverse benefit and rationalization: the CA program was now easier to describe.

THE NEED FOR A BROADER VOLUNTEER RECRUITMENT OUTLOOK

We see from the foregoing that it is utterly important that whoever does the recruitment of advocates perceives the total range of needs, and recruits for the total range of needs. Such a recruiter will attract people who are capable and willing to serve in different ways, and then s/he can match them on this basis. There are entire categories of potential advocates we have rarely recruited. For instance, there is one kind of protege (and thereby advocate) whom staff typically rule out because of the reciprocity demand issue: the protege who rejects his/her advocate conceptually and emotionally. Staff have not been able to handle situations in which a person needs an advocate, should have an advocate, even must have an advocate-but rejects one. Again, such a staff response is a bit of a distortion of normativeness and normalization. It is a normative fact in our culture that some persons are not competent to make some decisions, and it is also normative (both statistically and phenomenologically) to protect some persons, through due process, against destroying themselves. There are instances where an advocate must be imposed upon a person without or even against, his/her expressed will. We have to internalize the reality that such occasions do exist. And yet, if you listen to the CA staff, almost all say, "We'd never impose an advocate on anybody." Suppose you have a fourteen year old boy, mentally handicapped or not, who has \$100, 000 in the bank and who says to his trust officer, "Okay, come on Daddy-o, let me have those hundred Gs, I'm ready to spend!" Should you say, "All right, here's your hundred Gs," and tomorrow it's gone. Or should you say, "You need a guardian of your property. Hopefully, it will not be the official trustee of the province or state who administers the property of 300 other people, but a competent and suited individual volunteer citizen advocate; and at least until you are of age (or whatever) somebody is going to keep you from blowing your \$100, 000. Some day, if and when you become competent, then you can blow your Gs any way you want to." In the meantime, there will be need for setting up a trust, or limited guardianship, but some such trusts are even set up for highly competent people. A lot of rich people set up trusts for their children whom they do not want to be able to spend all of it even though the children are presumed to be totally competent. But aside from that kind of contingency, at least until adult majority has been achieved, there is nothing wrong with imposing an advocate upon a minor. There are many other examples. For instance, society grabs people who are emotionally disordered and takes their rights and liberty away "for their own good." There is some controversy whether this is right and good, but I would think that no matter how

you cut the cake, there comes a time and a place where most people would agree that it is appropriate to protect some persons against themselves, at least some of the time, even contrary to their will, or in the absence of their capacity to state their will. Of course, we would need due legal process all the way, and not some of the perverse processes we have had; and such a person may need someone who offers to relate to him/her not just instrumentally, but also, and perhaps exclusively, expressively-even if initially rejected. I also think that it is highly desirable that even the supposedly hardboiled criminal offender in prison has someone who comes in and offers him/herself, even though she is verbally abused, told to go away and not come back, and all sorts of things. I consider it highly appropriate for somebody to keep coming back and say, "I'm available, you may not like me but I'm here, I offer my help." Such an advocate may take care of some instrumental things, make sure the offender can get a suitable lawyer, that appeals are handled, etc. But just because the prisoner says, "I don't want you," I do not think it is appropriate to say, "Oh, if he says he doesn't want us, we dance out of the picture." Obviously, there will always be people of impaired competence or reduced freedom. In regard to them, the issue boils down to (a) who may legitimately declare a person incompetent or reduce his/her freedom, and (b) who is to protect the limited person, and how. Unfortunately, CA staff have tended to take the hard line of "We would never impose protection," rather than the pragmatic one of "Let's find avenues of protecting people at risk properly." An interesting fact here is that there are two types of reciprocity. One consists of a relationship that is interactive, but in which the protege holds no affection for the advocate. Thus, a legal offender may relate to an advocate, but not offer any affection. This is clearly distinct from the second kind of reciprocity, which involves mutual affection. When I talk about lack of reciprocity, I may refer to either of the two types of situations. Some people can relate as advocates to someone who relates back but does not love back, but other people cannot even relate adaptively to someone who relates but does not love back. That, to some degree, I think, has been a CA staff problem. They have difficulty not only conceptualizing nonreciprocity of relationship, they have difficulty conceptualizing non-reciprocity of affection. Thus, the nobility of their dynamics is flawed if they cannot conceptualize one person relating or loving when the other person does not relate or love back. The language that is used about CA enters very prominently in determining what actually gets done. The language one uses can determine one's behavior, as well as the other way around, and language can reflect one's real, though not always fully conscious, beliefs. Many of the CA programs do not want to use the terms "advocate" and "protege" but, if anything, "friend," "special friend", etc. Yet that is exactly part of the problem: they can only conceptualize friendships and not any other relationships! Their very language, then, reveals their expectations and limitations. And, of course, when you go out and say, "Ours is a special friend program," you are not going to recruit the purely instrumental advocate, and therefore are not going to pair for non-reciprocating relationships. The language tells the world that the relationships must involve mutual friends.

That is why I do not like that word. It is okay to say that some of our CA relationships are friendship relationships, but to state that CA is friendship is a gross distortion. From the beginning, it was meant to be many things, not only one thing-but that is what so many CA services have failed to grasp. Another important observation on recruitment is that CA staff tend to recruit people much like themselves, thus unconsciously enacting in their recruitment appeals and practices some of the dynamics of identification and distantiation. Often CA staff consists of young adult Caucasian females in their mid-twenties to early thirties who have college degrees and perhaps some human service training-and look whom they are apt to recruit according to the 1974 NARC survey: 75% of advocates were female, 40% were college students, most of them were 20-30 years old, Caucasians, many were secretaries, social workers and teachers! Another study of five CA programs in Florida in ca. 1976 found that 71% of advocates were female, 54% between ages 20~29, 75% single, 56% college students, and only 6% were home makers. Thus, CA offices have also recruited disproportionately from among people who were already in human services, instead of activating previously uninvolved persons. One proposed remedy to the problem of imbalance in recruitment which just about every CA program seems to encounter is to adopt, as policy, a strategy of priorities and time lines for recruiting each type of CA relationship. Unless the CA office itself makes a policy decision as to what kinds of proteges and advocates it wants to recruit, and then goes out and finds these people, the office will depend mostly on referrals (e.g., from providing agencies), and it will thus be the referring bodies which facto set relationship priorities for the CA office, rather than the CA office deciding where it should put its energies at a given point in time. More adaptive would be for a CA office to decide that over the course of a year it will try to establish so many relationships of this type, so many of another, so many for children, so many for adults, so many for severely impaired people, so many for more mildly handicapped people, and so on. Then it could set more specific target dates, such as two expressive relationships with mildly impaired persons by the end of the first month; by the end of the second month, one instrumental relationship (preferably adoption) for a severely handicapped child, etc. In this way the CA office is (a) less likely to be at the mercy of chance, and of referrals from service providers or other agencies in regard to the kinds of relationships it helps to establish, and (b) more apt to hold the reins in controlling where to put its energies, what kinds of potential proteges and advocates to seek out, etc. The importance of having a wide variety of CA relationships has been recognized in the CAPE tool that was designed to assess the quality of CA services (O'Brien & Wolfensberger, 1979). In addition, we have designed a convenient inventory (Appendix A) which CA staff can use to ask themselves whether their program is adhering to the essentials of CA, and whether their recruitment of advocates and proteges is balanced.

MISCELLANEOUS OTHER RECURRING ISSUES

A few other issues are worthy of some review in this context, some of these having a further bearing on the really overriding theoretical and ideological issues

already covered above.

Why We Need Advocates Who Are Volunteers

It is sometimes very lonely when you take a stand that is strongly based on ideology, and there may not be any "research evidence" to support it. It feels good to discover that there is research which supports your prior ideological view, even though you would not have given it up just because there was no research to support it. Fortunately, there is a body of research which supports the observation that handicapped, rejected or downtrodden people develop a sense of worthlessness, and that "world building" and "world testing" takes place for such a person when there is another person who gladly and voluntarily relates to him/her without being paid or told to do it. When someone comes in and relates to you when you are feeling worthless, but s/he is being paid to do so, then that does not heal your wounded image of yourself because you are still the worthless person that someone will relate to only if paid to do so. If someone comes and elects to relate to you because s/he wants to, hopefully because s/he finds it rewarding, then that recapitulates the real world of most people in that this is what happens in the real world where people normatively elect other people to relate to. Such voluntary relating "builds one's world," and world building is part of the developmental model. This is a very powerful argument to keep in mind as to why the advocate must be unpaid. While world building involves mostly reciprocating relationships, the principle may apply also to "invisibly reciprocating" ones as, for instance, in the case of a person who appears to reject the advocate. The fact that an advocate does not reject a protege just because s/he rejects the advocate may help to build the protege's world. In addition, of course, unpaid volunteers have vastly fewer conflicts of interest than paid workers who surrender a good part of their will to the structures that pay them. The Issue of the Personality of the Citizen Advocacy Staff There is a tenuous balance between the essential principles of CA that must be adhered to if a program is to call itself "citizen advocacy," and the need to permit the CA staff expressivity and individuality. This is a burning issue in some other services as well, particularly in residential services where people who are at the head of a small residence find that unless they can project their personality into the residential community, they cannot or will not stay with it. The task is so demanding that there must be some very highly personalized reward system*. It is also important for CA people to evolve a suitable style of

* At one conference where this material was presented, the following exchange took place.

* Workshop Participant: I think that there is a real need to make sure CA staff do not run amok; there have to be some checks and balances on that personality variable in the program, and that has to come from a variety of sources, hopefully including the CA board of directors. They have to have a sufficient understanding of general goals and concepts and objectives to make sure that things stay in

teaching and communicating about CA. If our method of using three overhead projectors simultaneously is not your style, then it would certainly come across as false if you adopted it. On the other hand, this method also helps to achieve competence in one form of interpretation so that you can choose alternative forms more competently thereafter. This is the rationale behind our offering people a script and transparencies in preparing CA presentations. This is one way you can do it, and if you can do it some other way, that is fine too. But problems do enter in when it is done in other ways. Is it then still done in ways which preserve the essentials? In many cases, a person may say, "Okay, I'm going to do it differently, I'm going to do it my way"-and then all too often advocacy comes out as "being friends." All the other things, which were there in the structured approach, are gone, and only one CA emphasis is retained: the informal, moderate-need, instrumental-expressive form. That, of course, is much more than projecting one's individual style; it means changing the essence of the CA helping form. It then gets to the point where Big Brothers, the John Howard Society, the Elizabeth Fry Society, Job Therapy. etc., each with a significant difference from all the others, still end up all being called citizen advocacy. This is why we have to walk a narrow path. If we know what the essentials are, and thoroughly understand these, then within these essentials, it is a matter of doing what permits a specific individual to be effective. But let us not call the perverting of CA into some other (though perhaps beneficial) helping form "staff creativeness" and "individuality."

CONCLUSION

In this paper, emphasis has been on elements that are often omitted from CA implementation. Not addressed have been any number of other ways in which CA can, and often is, perverted or degraded, especially by adding or substituting elements. However, the aforementioned CAPE tool can be used to great effect in identifying most of these problems.

REFERENCES

National Association for Retarded Citizens. 1976 citizen advocacy program

balance. The co-ordinator needs to be able to reflect personally on that variable and be able to adjust.

Wolfensberger: You can see that it's a real dilemma. The CA board must do that, and yet quite often, the board may have had a very fractionated initial understanding of the CA concept itself. Unless you can get members of the board into some kind of formal training course at the beginning, before they hire somebody, then it is often the staff person educating the board and, therefore, whatever the staff person has already projected into the CA schema is what the board will pick up as being the schema.

survey results. Arlington, TX: Author, 1977.

O'Brien, J., and Wolfensberger, W. Standards for citizen advocacy program evaluation (CAPE).

Toronto: Canadian Association for the Mentally Retarded, 1979.

United Cerebral Palsy Association. Proceedings of the conference on protective supervision and services for the handicapped, New Kensington, Pennsylvania, November 15-17, 1966. New York: UWA 1966.

Wolfensberger, W., and Zaub, H. Citizen advocacy and protective services for the handicapped.

Toronto: National Institute on Mental Retardation, 1973.

APPENDIX A

Wolf Wolfensberger
April 1981

CITIZEN ADVOCACY (CA) PROGRAM QUALITY INVENTORY

IN CAPE			MY CA OFFICE		
YES	IMPLIED ONLY	NO	DOES IT WELL OR A LOT	DOESN'T DO IT A BIT	
		X			A. ALLEGIANCE/COMMITMENT TO CA CONCEPT PRINCIPLES
		X			1. Do we teach all of CA?
		X			2. Do we promote the "six core principles" of CA?
					3. Is the concept of "representation clearly imbedded in our program and its dissemination?"
X					4. Is the CA office free from conflict of interest in its
X					a. governance?
X					b. funding?
					c. location?
X					5. Are the advocates free from conflict of interest? I.e., are they unpaid volunteers who volunteer to their protege and not to the CA office?
					B. ADHERENCE TO PRINCIPLES OF SOUND IMPLEMENTATION
		X			1. Was the board/committee formed and/or was the service funded, prior to operation?
		X			2. Is the board committed to the CA concept and active?
		X			3. Is the CA office/operation stable
	X				C. BALANCE IN PROTEGE RECRUITMENT
	X				1. Do we aggressively recruit proteges who have high/demanding needs?
	X				2. Do we recruit severely impaired proteges?
		X			3. Do we aggressively recruit proteges who live in very unsatisfactory conditions (e.g., in institutions)?
	X				4. Do we recruit proteges who have low needs?
		X			5. Do we recruit proteges who are unlike "ourselves?"
		X			6. Do we recruit severely and profoundly impaired proteges with low needs?
X					7. Do we recruit proteges who are unable to reciprocate in a relationship?

IN CAPE		
YES	IMPLIED ONLY	NO
		X
	X	
		X
		X
	X	
	X	
	X	
X		
X		
X		
		X
		X
		X
X		
		X

MY CA OFFICE		
DOES IT		DOESN'T DO,IT
WELL OR A LOT	A BIT	
		8. Do we recruit proteges who need advocates but who do not want them?
		9. Do we recruit proteges who need only instrumental advocacy?
		D. BALANCE IN ADVOCATE RECRUITMENT
		1. Do we have "most favorite devalued unrecruited" advocates?
		2. Do we recruit advocates who are unlike "ourselves"?
		3. Do we recruit more than one advocate for people with high/demanding needs?
		4. Do we aggressively recruit;
		a. guardians?
		b. trustees?
		c. adoptive families/parents?
		d. long-term advocates?
		5. Do we recruit advocates for low-demand relationships?
		6. Do we recruit purely instrumental advocates?
		7. Do we recruit advocates for people who reject them?
		E. MISCELLANEOUS
		1. Do we have and recruit heterogenous staff?
		2. Do we count all advocacy relationships, including:
		a. Pilot Parent relationships?
		b. relationships which we did not match, but which take advantage of the support our office offers?
		3. Do we track and support relationships once we have matched them?
		4. Do we interpret to advocates, expect, and support them to do what they can to accept difficulties as part of life?