

Advocacy and Advocates: Definitions and Ethical Dimensions

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To be an advocate and to engage in advocacy is to adopt a stance, advance a cause, and attempt to produce a result in behalf of an interest of a person, group, or cause.

The wellspring of advocacy in the human services is the age-old biblical admonition of our collective responsibility for those who are elderly, disabled, widowed, orphaned, poor, and those who cannot care for themselves and have no one to care for them.

Advocates achieve legitimacy for their position from a variety of sources. Some advocates are invested with legal status from conferred rights, powers, and duties, while others are constrained or empowered by moral rights, duties, and obligations. Some advocates are legitimized by their “clients” (those for whom they advocate), while others simply declare their own legitimacy.

Advocacy in behalf of older people, the field of aging, and those matters that concern today’s and tomorrow’s elders comports with the following general observations. Some special considerations concerning old age are noted in the discussion as they are relevant.

The techniques of advocacy cut a wide swath. Modes include jawboning, demagoguery, rhetoric, mass communication, and traditional

*From jawboning to
community organizing to
lobbying to legal proceedings.*

public relations; political organizing, community organizing, Internet and mass-mail broadsides; legislative lobbying; publication in mass media, trade, and scholarly materials; formal legal proceedings, formal representation of

individuals and groups, and formal surrogate decision-making.

There are virtually no limits to the breadth or narrowness of the cause in time, space, or intended effect. Some advocates represent causes that would reform basic institutions and programs of government, family or economic relationships, and fundamental rights of individuals and legal entities. Others seek to protect or secure a single narrow benefit or right for just one individual in truly unique circumstances.

Thus, advocacy presents a complexity of issues in terms of the substance of the cause, the party or parties represented, the techniques engaged in, the legitimacy of the representation, and the legal and moral constraints of the particular advocacy processes.

WHO ARE THE ADVOCATES?

Advocates may be friends or family members of the beneficiary, attorneys for the individual,

public interest lawyers, government attorneys, representatives of organized groups, for-profit and nonprofit organizations, trade associations, professional associations, labor unions, social workers in public and nonpublic agencies, legislators at all levels of government, other public employees, as well as journalists and educators.

Some of the better-recognized efforts pursuing public policy and legislation in behalf of the elderly have been mass organizations. Some have disappeared from the scene, others have grown; some have diminished in their public presence, others have become entrepreneurial and seem to have changed their focus. The Townsend Movement for old-age pensions of the 1930s, the McClain Citizens Committee for Old Age Pensions, National Retired Teachers Association, and AARP of the 1950s, and the Gray Panthers of the 1970s indicate the variety of organizations and fates. Of course, presentation of the history of advocacy in behalf of older people is beyond the scope of this essay, but understanding the history is indeed important to our understanding of the role and effectiveness of such mass movements (Pratt, 1995).

What is critical to our understanding of advocacy, *self*-advocacy aside, is an appreciation that advocacy involves one party seeking to represent the interests of another. This basic fact suggests that one must be alert to the possibility that the interests of the advocate and the beneficiary may not always be congruent.

Second, while the idea of one party expending energy, time, and money on behalf of another suggests beneficent motives, the outcomes of advocacy may not always be beneficent. Indeed, many causes, conditions, and types of individuals engage the interests of advocates with diametrically opposing interventions designed to alleviate or remedy wrongful care, treatment, conditions, or other matters. In too many instances, there are unanticipated outcomes, some of which were the result of poor or short-sighted planning. Advocacy in and of itself does not confer effectiveness or universally accepted beneficence on the part of the advocate.

Third, the advocate's legitimacy may be drawn from a grant of power or request for assistance from the beneficiary to the advocate, from a grant of power by a court or administrative

agency, or simply by the assumption of legitimacy by an individual or group to advance an interest by virtue of our rights set out in the First Amendment to the Constitution of the United States and state constitutions. Furthermore, such advocacy may proceed under the statutes of the federal government and the several states governing for-profit and not-for-profit enterprises and legislative lobbying, as well as those regulating such activities as public rallies, parades, picketing, advertising, and like matters.

All advocates for people or causes not personal to them, that is, advocates in behalf of others, confront ethical dilemmas arising from the substance of their advocacy. All owe moral obligations to their beneficiaries whether or not those obligations have been articulated or made known explicitly. Some, but not all, owe legal obligations arising out of special relationships between the advocate and the beneficiary. Common legal obligations arise out of the attorney-client, patient-physician, clergy-communicant, and contracting parties' relationships.

This essay will undertake to offer some brief and familiar definitions and examples of various forms of advocacy, techniques applied, ethical dilemmas and problems encountered, and a method for resolving them. Others (Berger, 1976; Fritz, 1979; Brown, 1990) have developed perspectives on advocacy in behalf of the elderly. This essay seeks to explore the ethical dimensions and concerns that have received less attention in earlier efforts.

Obviously, advocacy in aging consists of many complex dimensions, some of them arising from characteristics of the person or group who is the intended beneficiary.

ADVOCACY FOR THE INDIVIDUAL

Advocacy advancing, protecting, and vindicating the rights, interests, and preferences of the elderly individual could be called personal, or individual, advocacy. The personal advocate, perhaps more than any other, confronts the most difficult tasks. The personal advocate is often faced with the task of assisting the beneficiary to secure his or her desires, preferences, and customary choices or advancing or representing what might be regarded as the benefi-

ciary's best interests. However, "best interests" do not always comport with individual preferences or desires. Distinguishing between what are simply a beneficiary's foolish decisions or poor judgment and legal incompetence is not as straightforward as it might seem. An older person's capacity for financial management may not be different in old age from what it was in middle age. Poor personal health practices that may be consistent across the lifespan are no more deserving of imposed surrogate decision-making at 80 than they were at 45. Questioning a person's ability to drive may be no more imperative in late life than it was when the individual was age 55. Living independently as opposed to some group residential arrangement may reflect strong personal preferences that may take into account assumed substantial risks.

The everyday, real-life situations do not typically reach forums of legal decision-making. Advocates engaged in advancing the interests of elderly individuals include people who are neither family nor friend, but are lawyers, social workers, counselors, therapists, and patient advocates in both long- and short-term-care situations. Most commonly, however, advocates are spouses, adult children, or friends.

Marshall Kapp details the roles of lawyers in individual advocacy in another article in this issue. However, while many cases boil down to a relatively simple matter of resolving "particular disputes speedily and conclusively in the client's favor," many issues involve the lawyer as counselor. In theory, the attorney is retained to advance the client's expressed interest. But attorneys and other personal advocates may be confronted with a client's "expressed interests" that are patently foolish or certainly against the best interests of the client. Some common examples include instructions to disperse funds to charities or other purposes in amounts that would impair the individual's financial capacity to maintain house and home, instructions that powers-of-attorney be given to clearly designing or otherwise untrustworthy individuals, requests for assistance in arranging purchases of unsafe and inappropriate equipment (e.g., a motorcycle for a frail 83-year-old, welding equipment for a visually impaired and physically shaky 90-year-old), assistance in making

inappropriate speculative investments that would put an already marginal financial condition at great risk. And what is the personal advocate to do in vindicating the disabled person's (elderly or not) privilege to drive when the safety issues involved are "iffy"?

These issues and others raise difficult questions regarding the personal advocate's ethical obligations of beneficence and non-maleficence, respect, distributive justice (i.e., a just distribution of benefits and burdens), fidelity (the keeping of promises), and honesty (Beauchamp and Childress, 1983). Techniques for ethical analysis and problem resolution are discussed later in this article.

ADVOCACY FOR ELDERS IN A LOCAL GROUP

Advocacy for elders who share a "local" relationship (e.g., as patients or residents in a long-term-care or other residential facility or members of a senior center) is a common form of advocacy.

Advocates in these situations are often elected or selected representatives from within the group. Their role may be defined as representing majority interests or may simply be a matter of them having appointed themselves. How such advocates select or present issues to the management may be as much a matter of personal prejudice as it is principle. For example, to the extent that some residents of a long-term-care facility place high value on self-determining, articulate, and active behavioral characteristics, residents with serious disabilities may be disadvantaged by policies favored by the more independent and vocal residents, who are most likely to become resident "advocates." These advocates may lobby to, say, restrict dining halls to those not reliant upon wheelchairs or walkers or to those capable of "acceptable" table manners. Such advocacy may be limited to representation of group complaints or proposals, with little support for residents seeking change on personal issues or those not popularly espoused.

To be sure, those sufficiently capable, energetic, courageous, and independent to undertake advocacy in their own behalf may well find avenues through which to do so. Or social ser-

vice personnel within and outside the facility, community-based ombudsmen, or even attorneys or family members may take on such advocacy efforts for a group.

The ethical dilemmas that frequently arise here are those having to do with serious and complex competing demands: the needs and requirements of residents or members versus the capacity of staff, inadequate in supply and in capability; the needs and requirements of some residents or members, for example, people with serious cognitive impairment or incontinent individuals versus those who are not comparably disabled and who want roommates or table companions more similar to themselves; the needs and requirements of residents or members versus the resource capability of management (Powers, 2003).

In fact, such situations are pervasive among groups of older people, and attempts to apply principles of beneficence and just distribution that may be in conflict can indeed be vexing. Advocates, whether drawn from the group or the outside, cannot avoid such situations. Nor can they resolve them satisfactorily without both knowledge of and orientation to processes of resolution, which are discussed below.

The following three classes of advocacy typically involve advocacy by an organization or attorney, or both, seeking redress of wrongs or vindication of rights through class-action litigation. Kapp's article (see page 31) in this issue deals with public interest lawyers and the techniques they use.

ADVOCACY FOR GROUPS WITH SPECIFIC CHARACTERISTICS

Advocacy is often for the benefit of groups with specific characteristics such as disability, residence in long-term-care institutions, particular Medicaid or economic status, residence in a rural area, racial/ethnic status, residence in a "broad geographic area" (a particular nation, state, county, city).

Advocacy for groups of individuals occurs on two levels, which must be distinguished: litigating, on the one hand, and, on the other, political-community organizing, which often includes a strong educational component directed at

developing articulate and effective lay advocates from the group of intended beneficiaries.

As Kapp has indicated, a litigation strategy requires identification of a plaintiff or group of named plaintiffs seeking redress of wrongs or vindication of asserted rights who represent all of those similarly situated throughout the jurisdiction claimed—a class action seeking a remedy that may be enforced against defendant(s) on behalf of all members of the class who have not opted out of the litigation.

Advocacy for groups with special characteristics has two equally important dimensions: The first is adoption of some specific changes that the advocate contends must be made in order to improve the life situations of group members, to extend protections to them, or to correct injustices visited upon them. The second dimension is achievement of change in understanding among important "publics" who have the power and influence to make the adoption of change possible.

Just how critical the "specific changes" component is may be seen in two very different results in the advocacy efforts of those concerned with mental illness and mental retardation, respectively. In the 1970s, advocates engaged in efforts regarding these two seemingly related concerns undertook different approaches with strikingly different outcomes.

Both sets of advocates sought to overturn the common single-sided intervention of placement in institutional care, which had spawned monstrous segregated institutions, some with more than 5,000 beds, warehousing their residents. Both sets enlisted the support of advocates within and outside of governments at all levels, as well as clinicians and other professionals. The popular and scholarly press joined in the efforts. The two sets of advocates pressed their respective cases in the courts and in the general population. Both sought rejection of the institutional-placement "solution."

Despite a nationally funded effort to develop community-based mental health services, the mental health movement failed to develop the resources and programs to provide care for the hundreds of thousands of mentally ill and recovering people discharged from the mental hospitals of this country, despite their need for

ongoing treatment. In considerable contrast, however, the advocates for people with mental retardation achieved substantial success in eliminating the institutional solution and providing the resources, programs, and ongoing structures for support necessary for those with developmental disabilities.

In my opinion, the difference lay in the failure of the mental health movement to fully appreciate the full array of systems that had to change if the hospitals were to be closed and unavailable to provide treatment. These advocates appear to have believed that pharmaceutical interventions and a few scattered outpatient programs would suffice. There seemed to be little understanding of the need for major changes in the medical care system to vastly expand daycare programs, clinic availability, and the role of acute hospital mental-health care, and for improvements in long-term care generally for those with psychological disabilities. And there was little effort to bring such changes about. Furthermore, little effort was invested in labor-market issues, social service support in the community for the mentally ill and their families, or changes in the educational systems of the United States to assist in early identification and intervention.

The advocates for people with developmental disability, on the other hand, better understood the various systems and proceeded to seek change on a much broader basis. Their analysis of the barriers and problems mental retardation presented led them to a wider array of “solutions” and interventions that have radically changed for the better the lives of the people whom they sought to help.

These advocates readily understood the importance of shifting the mindset of families and developmentally disabled people themselves to a new view of their own potential and of the interventions that could make the realization of this potential a reality. The advocates also understood the importance of working with the various players in and out of government at all levels that needed to participate, and the importance of taking into account structure and law at various levels to achieve the results. All of this proved to be important: changes in personal perceptions; litigation; popular political support resulting in program changes at federal,

state, and local levels; professional and clinical understanding of developmental disabilities and interventions; and massive education of the public. And advocacy occurred in all these areas.

This example teaches important lessons for our advocacy for groups of elders with special characteristics. First and foremost is the recognition that some groups of older people do require and deserve special attention because of poverty, disability, minority status, and the like. This recognition runs counter to more general advocacy efforts that attempt to portray the older population as vibrant, healthy, active, and worthy—certainly an understandable counter to generally held ageist visions of old age. This “positive” view of aging was virtually official policy of the U.S. Administration on Aging during the Reagan years and was reflected in advertising campaigns of the National Council on the Aging and the National Advertising Council in the “Get off your Rocker” ads, and in the materials distributed by the Gray Panthers. The commonly adopted position diluted significantly any efforts by older people and within the independent living movement to direct attention to elders with disabilities.

Second, the advocates in aging devoted more attention to the Older Americans Act—Title 3 and its relatively low-impact programs than to the special concerns that required efforts directed at other important programs and societal systems. To this day, it is striking that the foremost governmental advocate, the Administration on Aging, headed by an assistant secretary of the U.S. Department of Health and Human Services, has failed to seize upon the eloquence and sweep of Title 1 of the Older Americans Act as its watchword and guide to its advocacy efforts within and outside of the federal establishment.

Finally, community organizing as a method of advocacy fell into substantial decline. These failures of strategic planning can be viewed as ethical, as well as intellectual, lapses.

ADVOCACY FOR THE INTERESTS OF ELDERS IN GENERAL

Advocacy for the interests of older people in general may be directed at such broad issues as images of aging, stereotypes, anti-ageism, or

broad across-the-board programs such as Medical Assistance for the Aged, Medicare, drug benefits, guardianship and protective services reform, access to services, organization, or issue advocacy. Within governmental structures, it is common for legislative bodies to create units intended to serve as the voice of special groups. Some prominent examples include the original Children's Bureau at the federal level, the Administration on Aging, the National Institutes of Aging, Cancer, and the Small Business Administration, as well as state and local level special commissions and agencies. Some sort of institution or organization usually undertakes such advocacy.

This category of advocacy differs from the foregoing categories on two counts: First, its focus is more on affecting political decision-making through the exercise of political influence on those who control resources; and second, considerable effort, energy, and resources are continuously devoted to maintenance of the advocate organization itself. Such maintenance efforts piggyback on issue advocacy without fully disclosing what positions will be taken (see, for example, AARP solicitation, n.d.). These advocates include so-called trade associations as well as umbrella organizations for a network of organizations.

Such advocates often play important roles in the political processes involved in program development. Some examples of the most important advocates in the aging game are the following: American Association of Homes and Services for the Aging (AAHSA), American Health Care Association (AHCA), AARP (formerly the American Association of Retired Persons), Alzheimer's Association, National Association of Area Agencies on Aging (N4A), National Association of State Units on Aging (NASUA), National Council on the Aging (NCOA), and the National Senior Citizens Council (NCSC).

Perhaps surprisingly, these organizational advocates often have intrinsic conflicts of interest with many in the general population of present or prospective elders—a fact that should serve as cautionary for those planning or observing the way such organizations proceed with their advocacy efforts. Some advocacy organizations develop over time to become operating

entities that have economic self-interest or organizational alliances or relationships that may predetermine positions on political and economic issues concerning the elderly. AARP and NCOA are significant examples of evolution. Achenbaum's (2000) excellent celebratory review of NCOA's fifty-year history is instructive. His list of the early advocates who were there at the organization's creation is inspiring—leaders from various professions, the university, government, and agencies and institutions joined to make NCOA an important gerontological voice to all sectors of America. But Achenbaum then goes on to describe the economic pressures on survival that lead to partnerships with governmental granting entities and the formation of and affiliation with special-interest groups with their own axes to grind. These included, for example, the National Institute of Senior Centers, the National Institute of Senior Housing, the National Adult Day Services Association, and the National Association on Financial Issues and Services for Elders. The result for NCOA has been to render the organization "fiscally secure" (Achenbaum, p. 9).

Other advocacy organizations, like AAHSA and AHCA, are trade associations that serve the interests of their members, which serve the elderly. Not only are the trade associations obligated to give their members priority, but they must also assure their own survival as organizations. Some goals that an organization advocating for the well-being of elders might be expected to support, like massive reduction in the number of long-term-care beds and support instead for in-home care, are diametrically opposed to positions of the trade associations, which seek more funding for the facilities now in place.

Somewhat similar are NASUA and N4A, which are essentially membership organizations that rely in large part upon federal largesse and related state funding for their continued existence. The priorities set by those public agencies significantly influence the organizations' own priorities and efforts, drawing energy away from what priorities the ultimate beneficiaries of their efforts—the elderly and various subgroups—might select or prefer.

NCOA and NCSC have both membership interests (which may or may not be congruent with

interests of the broader group of elderly they purport to represent), and interests in particular programs, federally funded (U.S. Department of Labor, 2003; National Council on the Aging, 2003). These programs are important to their respective institutional maintenance by virtue of the overhead costs which are included in such grants. As such, they occupy a high priority in the competition for staff attention in those organizations.

Some organizations like AARP have significant proprietary enterprises with associated entrepreneurial goals that may be incongruent with the goals, desires, and objectives of AARP members. In terms of conflict of interest, it is not only the interests of AARP members that must be considered, but also the interests of those they purport to represent. In taking what may be an important position offered as a principled one, it is also necessary to avoid even the appearance of impropriety. How badly AARP stumbled on that account may be seen from the 15,000 withdrawals from AARP membership reported by the AARP CEO, William Novelli, shortly after that organization's endorsement of the Bush Medicare reform proposal (New York Times, 2003).

Finally, the Alzheimer's Association has significant institutional maintenance concerns reflected in its massive fundraising and public relations efforts. These concerns may obstruct cooperative efforts with other organizations and agencies that are seeking support from a more limited constituency base, notwithstanding the substantial benefits arising from the Alzheimer's Association's activities supporting local chapters, research, conferences, and information generally. For example, its website (Alzheimer's Association, 2003) makes no mention of the NCOA Alzheimer's Disease Education and Referral Center.

None of the above is meant to suggest that the organizations are engaged in unethical behavior. Nonetheless, all advocates confront ethical questions, particularly those advocates whose efforts are not necessarily related to any reliable assessment of the wishes, preferences, or views of their alleged constituency, much less conflicting constituencies.

The issue really comes down to whether advocates consider as carefully and deliberately

their ethical dilemmas as they do strategic and resource allocation decisions that have engendered them.

AN ETHICAL IMPERATIVE FOR ADVOCATES

Indeed, ethical dilemmas abound for all advocates in aging but are seldom addressed systematically, largely because these dilemmas are not recognized. Personal advocates seldom have access to those who might help them in addressing such dilemmas. Most organizational advocates have neither the procedures nor the skilled personnel to address such issues, much less an awareness of moral obligations. More often than not, so-called ethical issues devolve into whether legal liability may or may not ensue from this or that choice (Kapp, 1998).

Ethical dilemmas arise out of conflicts between and among ethical principles. These conflicts deserve no less attention than do so-called legal questions (Walton, 1983).

Elsewhere, largely in the context of resolving ethical dilemmas arising in the care and treatment of individuals, I have suggested a protocol outline for resolution of ethical dilemmas (Cohen, 1996).

In many ways such a protocol calls for a discipline analogous to that encountered in assessing legal obligations. It is necessary to sort out the relevant facts and confront the various interests that may be at stake (including those of the advocate or advocacy organization). We must determine just what the stakes are, and how outcomes will be affected by alternative courses of action. Underlying all of these steps, of course, is assessing the situation in terms of ethical principles—how beneficent or non-maleficent is this or that course of action? How well or poorly does any course of action respect the persons involved including, of course, the beneficiary(ies)? Who will bear the burdens and who will reap the benefits of this or that action, and are they proportional? To what extent have we kept our explicit or implied promises to the beneficiary? And are we entirely truthful in any and all propositions put forth?

In short, resolution of ethical dilemmas includes the following elements:

- Alternative characterizations of the problem giving rise to the dilemma.
- Powerful gathering of facts.
- Clear expression of preference, values, and perceptions of all parties expressing an interest in the situation, including that of the advocate.
- Articulation of all competing interests.
- Projection of outcomes from alternative courses of action.
- Analysis to assess how the facts, values, and interests and various courses of action reflect ethical principles in play.

Advocacy for individuals and causes may be more highly developed in the United States than anywhere else in the world. It is a precious commodity in a diverse society. Technology of the past century, and both communication science and the social science of law and social service, have made it increasingly powerful. To preserve and develop the advocacy, we must understand it as never before. ♡

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