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# SERVING OUR ELDERS – ADVOCATES AND ADVERSARIES

In every state, federal funds are allocated through the Older Americans Act for advocacy for elder citizens. This article is based on a program implemented by the outstanding Milwaukee County Department on Aging, and provides an example of the work of elder advocates nationwide.

## Stephanie Sue Stein\*

Most practitioners in the field of aging services take as their definitive blueprint for advocacy the language and admonitions of the Older Americans Act (O.A.A.) of 1965.<sup>1</sup> The O.A.A. and all of its amendments, including those of 2000, establishes structures, services, and regulations for the operation of community based services throughout the United States. The regulations are minimal; the services are basic and under funded. It is the structure and underlying philosophy of that structure that is remarkable.

Title II of the O.A.A. creates the position of Assistant Secretary of Aging, one of whose duties is to "serve as the effective and visible advocate for older individuals within the Department of Health and Human Services (DHHS) and with other departments, agencies, and instrumentalities of the Federal Government by maintaining active review and commenting responsibilities over all Federal policies affecting older

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<sup>1. 42</sup> U.S.C. §§ 3001-3030.

individuals."2

Title II also requires states to create state units on aging which are to

(D) serve as effective and visible advocate for older individuals by reviewing and commenting upon all State plans, budgets, and policies which affect older individuals and providing technical assistance to any agency, organization, association, or individual representing the needs of older individuals.<sup>3</sup>

Title II then authorizes states to create and designate planning and service areas called Area Agencies on Aging whose function is to

(B) serve as the advocate and focal point for older individuals within the community by (in cooperation with agencies, organizations, and individuals participating in activities under the plan) monitoring, evaluating, and commenting upon all policies, programs, hearings, levies, and community actions which will affect older individuals;<sup>4</sup>

Hence, a federal law passed in 1965, and continuously authorized up to and including O.A.A. Amendments in 2000, requires those agencies and persons who will administer funds appropriated under this Act to advocate visibly and effectively for the lives of older people whom they represent.

This advocacy is not limited to the programs funded under the O.A.A., but extends to the conditions and lives of people age sixty and over, and to all of the public and private systems that affect those lives.

The O.A.A. also makes provision, through its Title VII, for vulnerable elder rights and protection activities. These activities include ombudsman services for long term care recipients, elder abuse investigation and reporting, and legal services. The legal services provisions of the Act are broad and minimally funded. In Wisconsin, however, a state funded and highly regarded

<sup>2. 42</sup> U.S.C. § 3012(a)(1).

<sup>3.</sup> Id.

<sup>4.</sup> Id.

program has been established to carry out those provisions—the Benefit Specialist Program (B.S.P.).

Wisconsin's B.S.P. provides help and assistance for "persons who are having a problem with their private or government benefits." Legal backup in Wisconsin to these non-attorneys is provided by two agencies: the Elder Law Center of the Coalition of Wisconsin Aging Groups for most of the state, and Legal Action of Wisconsin for Southeastern Wisconsin. In most cases area agencies on aging, benefit specialists, and senior legal organizations advocate together on behalf of senior rights benefits and programs. In some cases, however, advocates become adversaries. I will discuss from an agency oversight perspective those legal functions that benefit older persons, instances in which adversarial legal action has confounded our understanding, and suggestions for continued relationships built on joint advocacy.

### WORKING TOGETHER - PUBLIC BENEFITS AND REPRESENTATION

The B.S.P. is contracted to counties and other providers by Area Agencies on Aging, of which the Milwaukee County Area Agency is one of six. In Milwaukee County, the contract for benefit specialist services and legal backup is held by Legal Action of Wisconsin, a legal services corporation. Benefit specialists in Milwaukee County are partners in assisting elders to obtain public and private benefits through a myriad of programs, most especially Medicare, Medicaid, Social Security, and Veterans' Affairs. Without this highly trained human resource, elders would have very little assistance in the confusing regulations and bureaucratic appeals procedures governing public benefits. In some states volunteers or aging professionals outside their areas of expertise and time constraints, may be the only available assistance.

Benefit specialists and their legal backup organizations also provide timely and expert training to seniors and aging professionals about changes in laws and benefits. Benefit specialists in Milwaukee County are part of the professional organizations whose networking is meant to help all seniors.

<sup>5.</sup> Wisconsin Department of Health and Family Services, http://www.dhfs.state.wi.us/aging/Genage/BENSPECS.HTM (last visited Mar. 1, 2004).

Legal Action of Wisconsin, through its Senior Law Division, participates in the citizen oversight of advocacy issues by attending meetings of the Milwaukee County Commission on Aging's Advocacy Committee and comments on the interpretation of public benefit law and change when appropriate.

#### BENEFITS AND PRIVATE LEGAL PRACTICE

This nation, states, and counties have a growing cadre of elder law attorneys. Private elder law attorneys also take part in senior professional organizations and lend their expertise to the aging advocacy community to further public policy that will assist all elders. While helping persons with public benefits, the broader value of elder law specialists is to enable elders and their families to take appropriate action to plan for and meet their long term care needs, to execute end of life and substitute decision-making documents, and to help elders use their assets to support their lives and provide for their survivors.

Whereas senior serving organizations are an essential part of information and assistance about all public programs—Medicare, Medicaid, Social Security, etc.—there is no possibility or perceived responsibility for those entities to know about or give advice on personal financial planning for elders and their families. It is of great benefit to public senior serving organizations to have trained specialists in elder law to whom to refer questions about estate, long term care, and survivorship planning.

#### RIGHTS AND PROTECTION

Attorneys employed in public law firms and in private practice serve an invaluable role in safeguarding the personal rights and guaranteed protections of elders. We who are engaged in program administration cannot and could not be the final safeguard and arbiter of the personal, financial, and property rights of seniors. The protection of rights, both guaranteed by public law and overseen by the courts, must be handled by those trained and sworn to do so. Often, those of us administering public programs are the defendants in public rights and protection actions. That is appropriate. Although we self-monitor as advocates, we may and do act in ways that may need

mitigation. We welcome and learn from those interventions. It is in these situations, however, when roles become blurred.

#### ADVOCATES AS ADVERSARIES: WHEN ROLES COLLIDE

We have created a public legal benefit system in Wisconsin that suggests that we, as program administrators and the legal service community are in the business of advocacy together. Yet we are the government. We craft the operation of public benefits. We petition for guardianship and we investigate elder abuse. Thus, at times, our fellow advocates, public and private attorneys, become our adversaries. Sometimes this role is puzzling, and following are three instances of our adversarial relationships.

#### THE COP6-WAIVER LAWSUIT

On March I, 1993, I began my new job as the Director of the Milwaukee County Department on Aging. When I arrived, my assistant director informed me I would be involved the very next week in arbitration, budget reconciliation, and lawsuit negotiation. The lawsuit in question, Doe and Moe v. Patricia Goodrich, later amended to Doe v. Whitburn, was filed in the U. S. District Court for the Eastern District on November 20, 1990, on behalf of the plaintiffs and all of their class by Legal Action of Wisconsin. This action led to a Consent Judgment and stipulated reporting procedures. These reporting requirements were finally vacated in spring of 2003, thirteen years later. What brought on this action? What did the remedy provide? Who benefited? Did we act as advocates or adversaries?

In 1990, when the suit was brought, control of all Medicaid benefits, including COP-Waiver benefits, rested in the County DHHS, then named Wisconsin DHHS, Milwaukee Branch. Persons over the age of eighteen applying for this program made application to DHHS and waited for eligibility and

<sup>6. &</sup>quot;Community Options Program." Wis. Stat. § 46.27 (2003). (The Community Options Program is a Wisconsin funded program which funds services for people who are nursing home eligible and allows them to live in the community. COP WAIVER is the name Wisconsin uses for its federal waiver of Medicaid, which allows those people who meet both a nursing home level of care and Medicaid eligibility to be served in home and community based care.)

Case No. 900-C-1120.

service. Advocates for older adults within and outside of county government had long contended that persons over sixty were not getting access to, or benefit from, the COP-Waiver program in relation to their prevalence in the community. Advocates contended that the DHHS structure was too big and too complicated for older people to navigate. Further, they contended that the county needed a new structure to serve elders in order to encourage them to apply for benefits in a more elder-friendly environment.

Two distinct activities happened to address this issue: Legal Action filed suit demanding access, and the State and the county entered into a stipulated consent agreement. The aging advocates of the county successfully lobbied the County Executive and the Board of Supervisors. In budget action, an independent department of county government was created and began operation as the County Department on Aging on January 1, 1991. The COP-Waiver program began to be administered by the Milwaukee County Department on Aging (MCDA), designated an Area Agency on Aging, for persons sixty and over, and the MCDA now became the named defendant in the lawsuit.

To carry out the terms of the stipulation, the MCDA codified procedures—valuable to them as a new department. The MCDA standardized Medicaid referral procedures. The MCDA maintained dates of referral, assessment, eligibility and service. The MCDA continued to report on this activity to Legal Action on a monthly basis for thirteen years. These reports were detailed, lengthy, repetitive, and costly to produce. These reports were not responsible for one single older person gaining access to a COP-Waiver benefit.

In fact, COP-Waiver funding from 1990 through 2003 was capped and was not a Medicaid entitlement. As aging advocates rallied for larger legislative appropriations, older people qualified for the program, were reported on waiting lists.

In 2001 MCDA was selected through competitive proposal to operate a new Medicaid waiver called Family Care. This waiver, unlike the COP-Waiver, is capitated and in twenty-four months (July 1, 2000 to July 1, 2002) had to reach entitlement, i.e., all eligible persons had to be identified. On July 1, 2000 there were some 2,800 persons on the waiting list for COP-Waiver, all being diligently tracked and reported. On July 1, 2002, there were *zero* people on waiting lists and all eligible persons were

enrolled in and being served by Family Care. In February of 2003 the County Corporation Counsel successfully moved to vacate the Consent Decree.

In retrospect, advocacy led to an independent Department on Aging that encouraged, rather than discouraged, older people to apply for the COP-Waiver and all other programs. Often people were served through O.A.A. or County funded programs while waiting for service.

Advocacy led to the Family Care program, which provides an entitlement to home and community services to financially and functionally eligible seniors.

Adversity, even after the situation changed drastically, led to a series of reports—not more money, not more service—but *reports*. With the passage of time, the reports and inaction were incoherent. We, the advocates, administrators, and program operators, had a difficult time understanding the thirteen year continuance of an adversarial relationship.

#### PROTECTION OF RIGHTS

The Department on Aging is the adult protective service and the elder abuse lead agency for Milwaukee County. When investigations lead to either professional belief that an elder is not safe and not able to craft sound decisions about living in the community, or that an elder is the victim of elder abuse and is not capable of discerning it, then it is our obligation to invoke protective service measures to try to protect that individual.

We employ elder advocates who do not take lightly the movements to guardianship, involuntary commitment for observation, or protective placement. We understand the necessary burdens of proof placed upon us to move the legal system to remove rights from citizens. Many elders known to us in this community live in deplorable situations and act in inappropriate ways so as to offend the sensibilities of the broader community. This behavior does not, in and of itself, give us license to act in a protective manner. Often, though, when in our judgment—that of trained nurses and social workers, psychologists and counsel—there is no longer decisional ability, we are required to act in the best interest of the elder.

In one such case, an elder abuse referral was made about Mrs. X, who was living in a known crack house. Her caregiver

was an adult male son who refused our professionals entrance to the home. Returning in the company of the police, Department on Aging staff found Mrs. X unclean, malnourished, disoriented, and unable to answer simple questions. Mrs. X was removed from the home and an emergency detention was obtained. Next, a relative of Mrs. X's, who worked at the emergency placement facility, broke all rules of professional consent and called Mrs. X's son to tell him where she was placed. Then the son, armed with a Power of Attorney, arrived and removed Mrs. X from the facility. When the social worker, police, and psychologist next visited Mrs. X's home, they were greeted by a public law attorney who stated that Mrs. X could not be re-examined by a psychologist to see if she had decisional capacity because their client did not give her consent for examination.

Several weeks later, the son was arrested and Mrs. X was afforded a guardian by the courts. This process took three months. Mrs. X's nieces, who had filed the original elder abuse complaint, to this day do not understand how Mrs. X's rights were being violated by keeping her in that situation. Advocates did not understand why a psychological examination, necessary to determine the elder's competence, would have violated her rights. Adversaries faced off in a serious situation, armed with the same laws and different perspectives.

#### RIGHTS/BENEFITS/PRIVATE

Family Care, the new Medicaid waiver benefit in Wisconsin, has spawned new and never before tested relationships. Whereas Family Care is a Medicaid entitlement and all Medicaid asset rules apply, members may pay all or part of their care privately to bring them to Medicaid income eligibility.

Recently, a private attorney grieved a Medicaid denial based on that stipulation. The client has monthly income from many sources greatly exceeds the Family Care limitations. Through her attorney, however, she submitted a care plan calling for the necessity of round-the-clock private- care nursing staff and two daily personal attendants, thus driving the care plan cost above her income level. Her Family Care team of professional advocates argued at fair hearing that a reasonable care plan could be executed and delivered at one-third of the cost, thus making her able to afford it herself and ineligible for the Family Care benefit. Her attorney did not prevail at the fair

hearing but is planning further action.

Advocates counseled the woman and her family to spend her own money wisely to obtain services. Adversaries counseled her to sue the public system.

#### RECOMMENDATION

Recognizing and agreeing with my friends in the legal community that it is healthy and good for there to be tension between government systems and legal professionals whose duty is to obtain benefits and protect rights, I nevertheless contend that there is a place for discussion.

In each of the three examples previously cited, aging professionals attempted to discuss, outside of the legal system, solutions to these actions. In none of these cases did we prevail.

Sitting at tables with each other and following the precepts of the O.A.A., federal, state, and local aging officials have convinced elected policy makers to change systems, to craft new programs, and to appropriate money.

Sitting down at a table with the understanding that discussion may lead to solutions or compromise or opinion-changing just might work for aging professionals and elder law attorneys.

It has worked in community education.

It has worked in the development of Interdisciplinary teams studying elder abuse in each county in Wisconsin.

It can and should work in crafting, executing and changing programs and procedures. Aging professionals, benefit specialists, and elder law attorneys are, in the end, advocates all—not adversaries. A call can be made to initiate discussion and clarify position. Options can be discussed and debated. Solutions can be forged. Aging professionals can argue that their interpretations of benefit and protection law have validity when meeting across a table rather than across a courtroom. Meetings and discussions should be regular actions when advocates from elder serving government organizations and advocates who practice elder law work to solve problems together. The O.A.A. provides a network and a philosophy for us—advocates all—to embrace. Let us do it together.