

Advocacy Systems

The decade that began in 1967 saw exceptional growth in local services for people then identified as “mentally retarded”. Wolf Wolfensberger influenced this critical period by producing and promulgating a comprehensive set of guiding patterns: a definition of the principle of normalization fit for the time¹ and operationalized in PASS, an evaluation method²; ComServ, the design for a locally governed system of community services sufficient to make institutions unnecessary; a systematic approach to planning for social change; The Third Stage in the Evolution of Voluntary Associations, a call to move from service provision to a mission of monitoring, safeguarding, advocacy and innovation; and a study of guardianship and protection that resulted in Citizen Advocacy programs³ and in the design for the focus of this entry, *A Multi-Component Advocacy/Protection Schema* (hereafter *The Multi-component Schema*).⁴

Wolfensberger's influence in this period was substantial. A courageous and charismatic practitioner of what he called Change Agency, he disturbed many meetings, conferences and journal readers with meticulously articulated ideas delivered with a prophetic edge. Many opponents joined (often heated) debate within the terms that he set, thus engaging in the slow and deliberate process of prophetic persuasion he believed was the way to treat change in the lives of socially devalued people. Substantial numbers of local association leaders joined state and provincial officials and agency managers in the many workshops sponsored by the Canadian National Institute on Mental Retardation where he was Visiting Scholar and the Training Institute for Human Service Planning, Leadership, and Change Agency that he founded at Syracuse University. These efforts produced a growing cadre of associates, committed to the long term struggle to put his concepts to work.

A few of this number, in Georgia, Wisconsin and Nebraska, found an opportunity when the US Congress established Protection and Advocacy Systems in the 1975 Developmental Disabilities Amendments. Congress' purpose was to protect the legal and human rights of people with developmental disabilities through legal action and advocacy by creating state agencies free of conflict of interest. Modest funding for a year of planning (1976) was allocated.

¹ <https://wolfwolfensberger.com/life-s-work/normalization>

² <https://wolfwolfensberger.com/life-s-work/pass-passing>

³ <https://wolfwolfensberger.com/life-s-work/citizen-advocacy>

⁴http://digitalcommons.unmc.edu/wolf_books all quotations are from this version. Available thanks to the Wolfensberger Collection maintained by the University of Nebraska Medical Center. I strongly recommend study of this monograph to anyone interested in protection and advocacy. It is as timely and provocative today as it was 40 years ago.

In these three states, small groups immersed in Wolfensberger's ideas won the competition to plan their state's system. Particularly in Georgia, where circumstances provided most opportunities to implement his ideas, his consultation gave the *Multi-component Schema* a pre-publication test bed as a guide to planning and implementation.

In the other 47 states it was taken for granted that the Protection and Advocacy System would be a kind of legal practice, staffed with attorneys and para-legal advocates who would wield the growing number of laws, regulations and court cases that acknowledged the rights of people with developmental disabilities to assert those rights in individual situations and class action law suits.

Wolfensberger's thinking challenged this obvious-to-others design at its foundations and created deeply interesting problems for planners to struggle with. *The Multi-component Schema has three roots*: a world view, identification with an overriding concern of many families, and a rigorous analysis of conflict of interest. These quotations partially express the sober world view that underlies the design.

[Even with an comprehensive, fully safeguarded service system and active citizen involvement] ...there would still be a great deal of human suffering, there would still be abuses, there would still be people falling between the cracks, and there would still be loneliness, alienation, and misery. (P. 76)

I am now convinced that a human service system--even an entire society--that lacks a significant number of voluntary one-to-one relationships between citizens and people in need absolutely will not work, and will collapse. When people are no longer willing to involve themselves personally and individually, it is all over. (P. 65)

The Multi-component Schema rests on Citizen Advocacy --a one-to-one relationship by which a competent citizen volunteer, free from built-in conflicts of interest, advances the welfare and interests of an impaired or limited person, as if that person's interests were the advocate's own (p. 30). Empathic listening to many families' deep concern, summed up in the phrase "Who will be there for my son or daughter when I am gone?", and extensive study of various guardianship and protective service schemes, primed Wolfensberger for a breakthrough of intuition that revealed the essence of Citizen Advocacy to him in the midst of a conference on guardianship.

Wolfensberger turned his very considerable powers of analysis on conflict of interest. The results shape every element of *The Multi-Component Schema*. Conflict of interest might be nefarious, but it much more often expresses structural conflicts between values. Structures that generate conflicts between responsibility to individual interest and the rules that necessarily come with public funding, for example, encumber case managers and service

workers, no matter how able or committed they may be. Responsibility for a group can conflict with promoting individual interests, this encumbers protective services or public guardian schemes.

The Multi-component Schema reflects Wolfensberger's scholastic way of thinking. Seek universally valid principles, test current thinking and practice against them, build a design logically consistent with these principles regardless of short term feasibility and weigh their pros and cons. He thought systemically: each individual design he created connected to and depended on all the others. So *The Multi-component Schema* implied a comprehensive community service system and third stage voluntary associations as they implied and depended on a complete array of protection and advocacy components. Once this principled design is stated rigorously consider the actual circumstances of implementation, the trade-offs and compromises involved and discern what might be possible and consequent priorities. Concerning the inevitable shortfall between his comprehensive design and its implementation he said, *a reasonable ideal is to pursue the implementation of a system that incorporates ideologies that are as positive as very weak human beings are able to adopt, and to operationalize strategies which are at least sound in principle even though not perfect in practice (P. 77).*

Georgia's planners, who won a bitter competition for the designation to operate the Georgia Advocacy Office (GAO) as the state's protection and advocacy system, saw the possibility of realizing some of the key aspects of *The Multi-component Schema*.⁵

- The resulting effort put first priority on support for the development and operation of local Citizen Advocacy Offices and early attention on diversifying funding through donations and a legislative appropriation dedicated to Citizen Advocacy. (An important constraint: in the early years the whole allocation of federal funds to GAO was less than the operating budget of a single state institution unit.)
- GAO attorneys' role was to build citizen capacity in two ways. First, by developing family leadership around inclusive education and adult service issues. Second, by systematically building a network of practicing lawyers willing and able to represent people with developmental disabilities. This included educational efforts with attorneys and judges,

⁵ That this approach worked out at a modest scale for a time owes most to the strong, skilled and persistent (some would say intransigent) leadership of Patricia Powell, my friend and colleague in planning and founding GAO and its director in the early years. Her deep personal commitment to Wolf and his teaching combined with her managerial skills, her connections and her political nous to build public and legislative support sufficient to keep GAO on course and successfully navigate many efforts to sink GAO or at least pull it back to conformity with the law office model of protection and advocacy. Trica's leadership exemplifies Wolf's preternatural capacity to recruit and challenge very capable people to accomplish far more than they imagined themselves able to do.

joining in organizing a disability law section of the Georgia Bar, referring cases, and consultation with lawyers who took cases. Attention to issues that might be resolved through class actions was left to very capable and already active lawyers with affiliations outside GAO.

- A very modest investment in immediate response to abuse by a highly skilled staff advocate whose mission included directly engaging citizens with the abused person.
- Investment of non-government funds in educational efforts, provided by Wolfensberger and his associates. This effort supported the development of citizen leadership and GAO staff and contributed to normalization informed efforts to reform services. (*The Multi-component Schema* held that competent services are a necessary element in protecting people with developmental disabilities.)
- Investment in a variety of renewal activities for GAO allies and staff. These included systematic use of *CAPE - Citizen Advocacy Program Evaluation* (O'Brien & Wolfensberger, 1977) to support fidelity to principles and adaptive practices, sponsoring participation in available Training Institute events, and close supervision to assure the greatest possible consistency between decisions and the principle of normalization as defined in *PASS 3*. These investments recognized that effective support to advocacy and protection depends far less on following policy and procedure than it depends on internalizing an ethic.

Each of these aspects of GAO reflect a rigorous common definition of advocacy (pp. 18-21) and its implications for GAO's purview. Advocacy has four qualities. It is speaking for another with vigor and vehemence. It is doing more than is routinely acceptable on behalf of the other person's cause. The advocate incurs a personal cost. The advocate is as free of conflict of interest as is possible. It follows that citizens, rather than GAO employees, are the source of advocacy. Therefore, GAO's proper role is to use a variety of socially valued means to create the conditions that increase the number of voluntary one-to-one relationships between ordinary citizens and people in need of advocacy and protection.

Nothing differentiated GAO from other state's protection and advocacy systems, and nothing generated more conflicts with other advocacy groups, than its adoption of Wolfensberger's position on the place of laws and legal proceedings in advocacy and protection and GAO's consequent focus on mobilizing individual relationships with citizens –including practicing attorneys. Then, as now, class action lawsuits were seen by most as a higher form of advocacy, offering leverage to make large scale, systems change. Wolfensberger's position is fundamentally different⁶. It expresses the world view that shaped all of his work and convinced GAO's planners that it was at least one legitimate approach to filling the protection and advocacy mandate. In summary, he says

⁶ Outlined in *The Multi-component Schema* and developed at much greater length in *The Limitations of the Law in Human Services*. CAMR/GAO 1979; 2nd expanded edition Valor Press, 2015

The power of the law or the courts to solve patterns of social problems or abuse is extremely limited. A misconception seems to be currently sweeping the U.S. at least that solutions to human service problems lie in the law. More and more laws are being passed, they are becoming longer and more complex, and in many instances, less enforceable and less respected. In a society where almost all social "glues" (i.e., stabilizing social institutions) are coming apart, people are turning to litigation to resolve problems which are not resolvable because the social preconditions do not exist. The underlying problem with seeking legislative, litigative, or related judicial solutions is that what the culture does not have, or is unwilling to give, cannot be won by law or in a court of law. By and large, the law does what the culture wants it to do, and a lot of things we are asking from the law in the courts are things society cannot, and does not want to give. In consequence, a legal advocacy/protection approach is insufficient, and should be viewed more as an adjunct to a social solution rather than the other way around.

In my view, following *The Multi-component Schema* design proved a fruitful approach to developing protection and advocacy. The effects were usually modest and development was slow but the numbers of citizens engaged in advocacy of various form steadily grew.

Changing circumstances steadily moved GAO farther from the principles and priorities set out in *The Multi-component Schema*. Externally, the parallel developments that initially supported GAO's efforts eroded: associations that pioneered a move toward the Third Stage declined to the vanishing point; the development of community services striving to implement normalization stalled; the state government reacted to well argued and successful lawsuits against institutionalization brought by others with hostility and a terrible mix of intransigence and incompetence. Internally, more funding attached to mandates to serve more groups of devalued people in federally prescribed ways broadened GAO's purview past the point of incoherence; distance grew between what federal administrators assessed and what GAO did; chronic conflict with other groups that more board members and managers believed should be close partners compromised clarity; links to the Training Institute grew weaker; changes of management brought new understandings of the work. GAO continues to do good and important work to the benefit of people with disabilities, though at some distance from its initial design

Those few Citizen Advocacy Offices able to follow *The Multi-component Schema* and put down strong local roots have shown resilience and continue to justify Wolfensberger's confidence if not his belief that advocates would be recruited in their thousands. The service system's implacable and enduring capacity to resist the fulness of on-the-ground results promised by the victories of highly skilled and committed litigators keeps Wolfensberger's perspective on the limits of the law a viable, if mostly forgotten, position.