Development Of Citizen Advocacy As A Volunteer Role In A Residential Facility For Mentally Retarded

by Thomas A. Bishop

The first public residential facility for the mentally retarded was founded in 1848 with a goal of "teaching and training" mentally retarded people (Howe, 1848) for useful work and contributions to society. Quoting from Dr. Howe's report "...it would be demonstrated that no idiot need be confined or restrained by force; that the young can be trained for industry order and self-respect;..." (Kanner, 1964, pp. 41-42). This right to training was assumed to be a duty and responsibility of society (c.f., Wolfensberger, 1975). One hundred twenty-five years later, recent court decisions[1] and accreditations organizations[2] are agreed that residential facilities built and maintained after 1925 function to segregate the retarded rather than train them (Wolfensberger, 1975). This isolation and segregation has resulted in a form of cruel and unusual punishment; in fact, in the state of Pennsylvania a Federal District court ruled that the very existence of the institution violates Federal and State law.[3] Therefore, a system to insure that clients' needs and rights are met should become a part of each residential facility.

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RIGHTS OF INSTITUTIONALIZED CITIZENS

It is clear that within institutions many rights are habitually violated (Robinson and Robinson, 1976). A number of human and legal rights that are being systematically denied or abridged have been identified (Wald, 1976; President's Committee on Mental Retardation, 1976). In the following contrasts between current conditions and those ethically and/or legally required, we will illustrate actions performed by an individual we shall call the citizen advocate.

Privacy and Dignity

In institutions, in order to produce the least amount of work for the staff and to maintain the most conventional codes of behavior, rules and routines dominate the day. Residents are "herded" in groups. Sleeping, waking, toileting, bathing, and eating are strictly regimented. In many institutions conformity is the chief lesson taught (Braginsky and Braginsky, 1971). In the United States, 40 percent of residents are housed in rooms containing more than 30 persons

(Baumeister, 1970). A survey of England's institutions found 60% of the residents were housed in dormitories where no personal possessions at all were displayed (Morris, 1969). That figure is probably indicative of U.S. institutions as well. Conditions such as this render an individual completely devoid of privacy or a sense of personal identity.

Consider, in contrast, an environment catering to the individual. Residents have private or semi-private rooms. These rooms are equipped with dressers where each resident has his own comb, toothbrush, clothes, and other personal possessions. Bathing is done in individual showers; there are partitions between toilets. Citizen advocates have effected this type of change in conditions by enlightening their public officials about conditions they encounter in large public facilities. Their testimony has been most valuable in public hearings and in class action litigation filed on behalf of institutionalized citizenry.

Personal Rights

The most basic rights of men and women are the freedom to love, marry, and procreate. The institutionalized resident is segregated from the opposite sex. Consequences of enforced segregation include open masturbation, homosexuality, and often, aggression.

Some residents may neither be capable or desirous of loving, sexual relationships. But, consider this alternative for those appropriate. Residents are provided with honest and explicit sexual education and the citizen advocate provides assistance by being a role model as well as providing informal guidance about dating, marriage and children.

Civil and Commercial Rights

Civil and commercial rights are the right to vote, to contract, to work, to sue, to serve on a jury, etc. These rights are consistently denied mentally retarded citizens, especially those who are institutionalized. A citizen commands respect when he wields political power through his vote; economic power by his ability to hold a job, spend the money he earns, and contract to buy or sell goods and services; and the power to demand these rights in court. When a person cannot do (or is not permitted to do) any of these things, chances are they will be seen as a liability, someone to whom little attention need be paid.

The citizen advocate can intervene in these situations by seeing to it that systems within the institution allow for the exercising of these rights by the clients they serve. They may serve clients incapable of personally exercising these rights by assuring that someone with the person's best interest in mind assumes these legal rights for them, such as a parent or guardian.

Habilitation

To this point we have talked about poor environmental conditions within institutions as well as the denial of personal and civil rights of persons cared for within this setting. Emerging from these basic personal and civil rights is the right to active treatment training, or habilitation programs. According to Kenneth D. Gaver, "active habilitation requires a written individualized plan:

1. based on a comprehensive assessment of the individual's social, psychological, health and vocational capacities and libilities;

2. based on the goals of individual's adaptive capability and the ability to live independently;

3. based upon objectives related to these goals;

4. comprised of defined services and activities or programs related to the objectives;

5. specific as to the responsibilities for the conduct of such services or activities;

6. specific as to the means to measure the progress or outcome;

7. clear as to periodic review and revision of the plan."[4]

However, Gaver admits that most institutions cannot meet the requirements for an individualized plan for habilitation. Instead of serving, as Howe invisioned, as a "training center" most institutions provide what is known as custodial care. These custodial programs provide the bare necessities to sustain life, i.e. meals, a reasonably safe place to stay, and very minimal supervision. It was this situation Hungerford had in mind when he states "...in an institution there is always tomorrow so that he who starts out a student ends up, by default, an inmate."[5] Custodial programs are characterized by unrelieved deprivation; there are no programs; nothing to feel, to see, to touch, or to do.

The more appropriate, as well as legally required, situation is that in which the institution functions congruent to its originator's intentions and Gaver's outline; a short-term training center where an individual is given the assistance he needs to function in the community.

The citizen advocate can individually provide much needed stimulation for his resident in a custodial institution, while advocating collectively with other advocates for a return to the "training center" and community services model.

ADVOCACY IN MENTAL RETARDATION FACILITIES

As cited in the above situations, there is a clear need for a way to ensure services are delivered to mentally retarded people in a consistant, humane, and high quality manner. Advocacy has been a recent way to meet this goal and is defined as a person or group acting on behalf of another person or group in order to protect the rights of the latter. Historically, three approaches have emerged: In-house advocates, regulatory agencies or certifying groups, and courts. Each of these approaches had advantages, but ultimately has failed because if its disadvantages.

In-House Advocates

Administrators of residential facilities have appointed or hired staff as advocates for the population they serve. Such agency personnel can easily identify problems specific to their institution. These individuals can only address very minor issues, however. An in-house advocate can only operate within the parameters of his institution's administrative structure. As such, he deals with only those problems he's "allowed" to address by his superiors. In order to be effective he must exceed delegated authority and seek assistance from outside the facility. Persons in this situation are often alienated from the facility's staff, dismissed, or forced to resign.

Regulatory Agencies and Certifying Groups

An advantage of regulatory agencies is they are examining the institution with positions outside of the institution's administrative structure. Another advantage are the

detailed standards which relate directly to clients' rights.

The disadvantages are that surveys by these agencies rarely occur (visits are announced in advance) more frequently than every 6 months. They are unable to address problems or issues on a daily basis. Also, the standards are stated so broadly as to be subject to interpretation (Department of Health, Education and Welfare, 1978) and make compliance difficult to enforce.

Courts

The legal system has effected significant changes in the quality and quantity of care within some residential facilities. Three landmark decisions (Wyatt vs. Hardin, New York State Association for Retarded Citizens vs. Carey, Halderman and the United States vs. Pennhurst State School and Hospital) have established or reaffirmed the rights of mentally retarded people to treatment, protection from cruel and unusual punishment in the form of institutionalization without treatment, and to community services. The legal system has the advantage of being able to establish policy and overrule a facility or state.

There are several disadvantages of relying upon the legal system as an advocate. First, the time between the identification of the problem and its resolution is often long. The cases cited above have been in the courts 5 to 7 years and are still under jurisdiction of the courts. It does not seem desirable that the problems in-house advocates encounter daily should be handled by courts over years of time.

A second disadvantage is the expenses incurred in the litigation process. Such legal proceedings are quite expensive.

Thirdly, each decision made by the courts affects only those facilities for which it was filed. Facilities not the target of such a suit have not followed court decisions enacted at other institutions.

CITIZEN ADVOCACY

If the in-house advocates, certifying agencies and group, and the courts are ultimately ineffective at protecting the rights of our institutionalized citizens, what options have we available?

What I propose is Citizen Advocacy, defined by Dr. Wolf Wolfensberger as "a mature, competent citizen volunteer representing, as if they were his own, the interest of another citizen who is impaired in his instrumental competency, or has major expressive needs that are unmet and that are likely to remain unmet without special intervention." Citizen advocates work one-to-one with the mentally retarded person and function in three roles, 1) friend, 2) informal counselor or teacher, 3) spokesperson for their individual's rights.

Friend

The metally retarded living in our institutions are isolated by the geographic location and size of the facility. Eastern Oregon Hospital and Training Center in Pendleton, Oregon, for example, indicates 81% of its mentally retarded population is from counties on the opposite side of the state. Data generated by this facility indicates at least one-third of the residents have not had contact with anyone outside the facility (i.e., friend, family member, clergyman, etc.) in the past 12 months. Of the 356 residents they serve, there are 70 for whom they have no knowledge of the existence of relatives or guardians.

In addition to geographic isolation, residents are isolated by the stigmas that often accompany such individuals

and the agencies providing services for them.

The citizen advocate fills this void by being a caring, personal friend to the resident. The citizen advocate provides the much needed social intervention for his "friend" and involves him in normal community experiences such as shopping, going out to dinner or a movie, seeing a play, etc.; whatever they, as friends, enjoy doing together. This provides for the resident an increased sense of "self worth" and a knowledge that someone really cares.

Informal Counselor or Teacher

As we have stated earlier, most institutions provide only custodial programs. Even in those where educational programs are provided, these programs do not span the length of a day. The number of interactions in training situations or otherwise is sharply below what is needed. A 1971 study revealed that children are called into dialogue with adults only three minutes per week on the average ward (Giles, 1971).

Whether the institution is custodial or educational in philosophy and operation the citizen advocate can be most valuable by providing informal training and guidance; something the limited staff of the institution simply cannot provide.

The citizen advocate provides his friend with assistance and guidance in important areas of his life, irregardless of his functioning level. For a resident about to leave the institution for an independent living situation in the community, this might include money management, finding an apartment, or looking for a job. For the more severely retarded resident this might be assistance with learning to tie a shoe, distinguish colors, or learning basic self-help skills. In any case, the citizen advocate addresses the personal education needs of his friend on an informal basis.

An example of this type of intervention is that of a 31 year old resident who has spent most of his life in government institutions. He was never taught the alphabet, how to count, or handle money. Since his relationship with his citizen advocate, his life has changed completely. He has learned skills which are in demand; earns and spends his own money, has a girlfriend, and is looking forward to returning to the community (Smiley and Craik, 1972). Such success stories are not uncommon. The informal help of a citizen advocate can facilitate many a resident's return to a productive role in the community.

Spokesperson For Their Friends Rights

The institutions are, at times, in violation of residents rights in many fashions. The citizen advocate's third role, therefore, is speaking for the rights of his "friend". The need may be as subtle as a lack of appropriate clothing for his friend or as complex as the agency not providing a much needed service such as a speech therapy program.

In this role the advocate can work with institution staff to effect these changes but has the freedom and responsibility to pursue matters outside the service delivery system. As stated by the Office of Volunteer Development, Department of Health, Education and Welfare "This may mean expressing needs of persons in such a way as to persuade service professionals to make themselves available and tailor their service to those needs. This may mean persuading budget makers and decision makers at local, state, and even national legislative levels that services are needed and deserve budgetary support."[6]

The staff of residential facilities has a tendency to present or accentuate the positive when interpreting their services to the public. However, to enlist volunteers as advocates, the volunteers must understand the problems, needs, and frustrations of the staff and residents. By risking such trust in volunteers, they take on staff goals and can work towards changes outside of the administrative bureaucracy of the facility.

IMPLEMENTATION

Administrative Structure

The coordinator(s) of the Citizen Advocacy Program, whether paid or volunteer, should be responsible to an agency or organization outside of the facility. An advocacy oriented, non-profit, organization such as a local association for Retarded Citizens would be most ideal. Citizen Advocacy Programs are operating in some locations in cooperation with Big Brother-Big Sister, Community Action Programs, Mental Health Associations, etc. The coordinator(s) should work with the facility's administrative staff to develop procedures for referrals, confidentiality matching residents with advocates, off-campus activities, etc. The facility's social services staff most often make referrals, assist with the matching process, and provide the coordinator and advocate with information about the resident's background and current program.

Training and Support

The coordinator(s) must provide the citizen advocate volunteer with orientation and training. The training program should include, 1) introductory information on mental retardation/developmental disabilities, 2) orientation to the facility and the state's service delivery system, 3) information on the history of services provided the mentally retarded and current trends, 4) the resident's rights policy or statement of the facility, 5) policies and procedures, i.e., how to "sign out" a resident for the day, auto insurance requirements, confidentiality, etc., and 6) guidelines for suggested activities.

A useful tool in institutions with a Quality Assurance System (Calvert, Favell, Risley, Dalke, Grove, and Crowley, Note #7) is the checklist. This is a monitoring device which is used to evaluate the environment and programs of the institution. If the facility does not have a Q.A.S., checklists are sometimes available from the local Association for Retarded Citizens.

The coordinator(s) provide on-going support to the trained citizen advocate by assisting him and his friend with any problems they may encounter. The advocates should meet together regularly as a support group to share successes and frustrations as well as to receive (in-service) information provided by the coordinator.

Finally, the citizen advocate needs to be made aware of who to contact at the local, state, and even national level should the institutional bureaucracy remain unresponsive to identified needs of residents.

Available Resources

The National Association for Retarded Citizens[8] is a valuable resource for those interested in the development of a Citizen Advocacy Program. Two films are available on Citizen Advocacy from National Association for Retarded Citizens (N.A.R.C.); Justice and the Art of Gentle Outrage and Something Shared. These films are loaned at no charge or may be purchased from Southwest Film Labs, P.O. Box 21328, Dallas, Texas 75211.

V.I.S.T.A. (Volunteers in Service to America), an ACTION

program, has provided positions to assist with Citizen Advocacy Programs in several states. Application should be made through each state's ACTION office.

The National Institute on Mental Retardation[9] publishes "Your Citizen Advocacy Program." This manual for staff and volunteers provides information on recruitment, pairing, training, board-staff training, etc. Available from the same source is "Orientation Manual of Mental Retardation, Part 1". This book has proven most valuable in the training of volunteers to work with the mentally retarded.

CONCLUSION

Mental Retardation facilities have long used the volunteer to provide support services. Citizen advocates, however, are at all times a volunteer to the specific person rather than the agency. It establishes a relationship between two people that dignifies both. This relationship interferes with the function of the institution only when the institution fails to do its duty.

In a larger sense, Citizen Advocacy provides an avenue for an increased awareness of the deficits of current service systems. Institutions for the mentally retarded are only what the public have allowed them to become or demanded them to be.

FOOTNOTES

[1]E.g., Wyatt vs. Hardin, New York Association for Retarded Citizens vs. Carey.

[2]ICF/MR (Department of Health, Education and Welfare Standards and Quality Bureau, 1978), AC/MR-DD standards (Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons, 1978).

[3]Halderman vs. Pennhurst State School and Hospital.

[4]Gaver, K.D., Reaction comment to Halpern, C.R., principal paper on the right to habilitation. In the Presidents Committee on Mental Retardation (Ed.). The Mentally Retarded Citizen and the Law, New York: Free Press, 1976.

[5]Hungerford, R.H. Comment on institutionalization in Christmas in Purgatory: a Photographic Essay on Mental Retardation. (Blatt and Kaplan, Ed.) Syracuse, New York: Human Policy Press, 1974.

[6]Office of Volunteer Development; Policy background description; the Volunteer as Advocate.

[7]Calvert, T.L., Favel, J.E., Risley, T.R., Dalke, B., Grove, D., and Crowley, R. Blue Mountain Training Model; A System for Delivering Services to Clients in Mental Retardation Facilities. Paper presented to Region I American Association on Mental Deficiency Conference, October 1978. (For information contact: Terry L. Calbert, P.O. Box A, Pendleton, Oregon 97801).

[8]National Association for Retarded Citizens, 2709 Ave. E. East, P.O. Box 6109, Arlington, Texas 76001.

[9]National Institute on Mental Retardation, Kinsmen NIMR Building, York University Campus, 4700 Keele Street, Downsview, (Toronto), Ontario, Canada M3J 1P3.

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