

MARCH-APRIL 1972

Bi-monthly Journal of the Department of National Health and Welfare, Ottawa

NO. 2



MENTAL RETARDATION

VOL. XX

MARCH - APRIL 1972

No. 2

MENTAL HEALTH DIVISION

Published by Authority of The Honourable John Munro Minister of National Health and Welfare

Maurice LeClair, M.D.

Deputy Minister of National Health

Joseph W. Willard Deputy Minister of National Welfare



interviewing and understanding the importance of the family environment in the growth and development of personality. Various aspects of clinical knowledge are also offered to the students proportional to their background and according to their expected future roles within a chosen profession.

Many of the learning experiences are now being offered to mixed groups of students of the various professions in the framework of seminars, clinical ward rounds, conducted bus tours of the community, family visiting projects, various types of field work exercises, and summer projects. Extensive use is made of such techniques as role-playing, and self-confrontation on videotape replays. Most courses and programs of an interprofessional nature are designed to operate initially on the periphery of the main health professional curricula.

There are still a great many problems to be resolved in the content of methods of these programs, and with their evaluation. Difficulties which are encountered with the introduction of new ideas are those which come from any major innovation. It appears now, that the majority of a faculty must eventually be in favor of teaching students of various health professions together - at certain stages of their curriculum. To achieve this, experiments will be continued with various types of shared programs, and with an increased involvement of faculty members and students from the various health and health-related professional schools.

### A Major Helping Form?

### VOLUNTARY CITIZEN ADVOCACY IN THE HUMAN SERVICES

- Wolf Wolfensberger, Ph.D.

"Defend the lowly and fatherless
Rescue the weak and the needy
Render justice to the afflicted and poor
From the hand of the wicked deliver them".

- Psalms 82: 3-4

FOR MANY YEARS, SO-CALLED "PROTECTIVE SERVICES" have endeavored to protect the welfare of individuals who are of limited competence. Similar motives have given rise to more recent efforts to establish "advocacy" in human services. Either type of action characteristically refers to client-oriented endeavors undertaken

Dr. Wolfensberger is a Visiting Scholar, National Institute on Mental Retardation, York University Campus, Toronto. An extensive treatment of the theme discussed here is provided in a monograph on "Citizen Advocacy and Protective Services", prepared by W. Wolfensberger and H. Zauha for the President's Committee on Mental Retardation. For further plans and developments in Canada, inquiries can be addressed to the author.

by agencies and their staff, and perhaps even by specific agencies created in order to play an advocacy or protective role.

As desirable as such protection and advocacy are, they are seriously limited in their scope and effectiveness by a number of phenomena. These include agency impersonality, discontinuity in personal relationships with clients, rigidity, limitations in mandate and available options, impracticality of arrangement, but above all, built-in conflicts of interest on the part of agency employees and professionals.

Typically, these workers have strong loyalties to both their professions and their agencies, and it is unrealistic to assert that the interests of a profession or agency are always consistent with those of a client. The very fact that the livelihood of an agency's staff member depends upon the agency and upon his conformity to his superior's demands constitutes a conflict of interests. Particularly in government service, the spectacle of an agency employee following the instructions of his superiors in publicly defending practices which are not in the interests of the agency's actual or potential clientele is only too familiar. Rare is the public agency worker who - at the risk of his job - consistently advocates <u>publicly</u> what he believes <u>privately</u>. Also, because of the mobility of agency personnel, they cannot provide the highly individualized as well as sustained (perhaps even lifelong) representation of interests which is essential to the welfare of many severely impaired individuals.

#### The Citizen Advocate

In order to attain the ideals of advocacy and protective services while simultaneously avoiding the drawbacks inherent in the protective services of the past, or of agency advocacy today, a quite different schema of "citizen advocacy" was formulated in 1966, systematized in 1968-69, and first implemented in early 1970. Even in the short time span since, the schema has drawn a great deal of attention across North America, and is now being adopted in various localities.

A citizen advocate is a competent citizen volunteer who, with the support of an independent back-up system, represents, as if they were his own, the interests of another person who is in some way impaired or handicapped. Many individuals are impaired or disadvantaged in such a way and/or to such a degree that they cannot adequately satisfy their major needs or represent their own interests in society. Such individuals need other citizens who, in important functions, act for them or with them; who vigorously support, represent, and safeguard their interests; and who assure that their "protégés" achieve the fullest possible benefits of citizenship.

Depending on the needs of the impaired person, advocacy roles can range from formal to informal, and from short-term to long-term, or even life-long. Formal advocacy roles include adoptive parenthood, guardianship, and the conservatorship of property. Informal roles include friendship, guidance, and what has been called "guide-advocacy". "Expressive advocacy" roles emphasize the personal relationship, and the exchange of affection and concern. "Instrumental advocacy" is more concerned with practical problem-solving. Many roles are "instrumental-expressive" in meeting both types of needs.

#### Handicapped Children and Adults

Perhaps the most perfect type of advocacy occurs when a citizen chooses to rear as his own, and perhaps adopt, a handicapped and neglected child. While few citizens can play such an ideal role, there are many other roles - in relation to adults as well as children - that are less demanding and yet much needed. Among these are the provision of transportation, counsel, or other services for the handicapped child of a family who love and accept the child, but lack the means to solve the child's problems. An advocate can make certain that the child gets the education and training which the community has a responsibility to provide. Advocates can sponsor institutionalized children without (adequate) family ties by visiting them, giving them gifts, or taking them on trips or to entertainments. Handicapped adults can be assisted in such practical matters as managing money, finding and maintaining living quarters, securing jobs, learning how to use transportation services, and how to vote. Citizen advocates can give friendship and emotional support by offering companionship, and by sharing worship or the observance of holidays and special occasions.

A person who is returning from the institution to live in a community hostel or apartment needs a wide range of social experiences in the community. A special relationship is desirable for each such person, since hostel or other agency personnel must spread their relationships across so many individuals. An advocate for a young handicapped adult can contribute much to the successful adjustment or readjustment of his protégé, keeping him out of trouble, teaching him how to use his free time well, and offering advice and support in time of stress and crisis. Young handicapped adults and advocates of the same age can share apartments, with the advocate providing the skills and fellowship that make more independent apartment living possible for the handicapped roommate.

Many parents of impaired children are quite willing and capable of looking after the interests of their child, but have great fears and misgivings about their child's future once their health declines or they pass away. Citizen advocacy can be the means of providing parental successors who would continue to give compassionate, individualized attention to the impaired person, and who would try to preserve the general type and quality of life that he enjoyed when his parents looked after his interests.

## Agency "Watchdogs" and Citizen Advocacy Office

Advocates are especially needed as "watchdogs" of agencies, preventing them from "passing the buck", and keeping them relevant, change-oriented, and honest. Particularly in large cities or in large agencies, an individual client may soon lose his identity, or may actually be forgotten.

While citizen advocacy may be of benefit to a wide variety of impaired, handicapped and disadvantaged persons, it is needed the most by those least able to speak for themselves. Generally, this includes children, and many of the aged, retarded, mentally disordered seriously speech-impaired (e.g., some of the cerebral palsied), and those who do not speak the prevailing language (some recent immigrants, Indians and Eskimos).

While the efforts of citizen volunteers are noble and desirable, they are not sufficient to sustain a successful major and systematic service form unless co-ordinated and backed-up by local or regional advocacy offices. Ordinarily, a local advocacy office would not carry out advocacy functions directly, but instead would attract, select, orient, guide and reinforce citizen advocates, and match them with protégés. It would assess the needs of a person for advocacy, as well as the ability of a citizen volunteer to contribute through advocacy. It would train advocates, emphasizing commitment to the advocacy concept, understanding of the impaired person and the services of potential use to him, and many other areas of action. Finally, advocacy offices would provide emotional and practical assistance, support, and back-up to advocates, and mediate legal and professional services that may be needed by the advocate and his protégé. While all the advocates must be unpaid volunteers, it is of critical importance to the success of the schema that the advocacy office have at least one paid staff member who would be available at any time.

### The Free Agent

In contrast to professionals working as employees of agencies, the volunteer is free of loyalties to any profession or agency, and he is a free agent even in regard to the advocacy office. No one can "fire" him if he becomes obnoxious. He is a volunteer to a specific person, not to an agency. And even if the actions of some advocates should be occasionally irrational, it is still better to have such irrational involvement on behalf of the voiceless than to have none at all. After all, parenthood is frequently irrational in its representation of child interests, but we accept this as being culturally normative.

Since an advocate must sometimes represent the interests of his protégé vis-à-vis a service-rendering agency, an advocacy office ideally should be independently financed and affiliated. Except for initial funding purposes, an advocacy office should never be under the aegis of an agency whose clients might become protégés. Among the desirable alternatives is for voluntary citizen action groups (associations in the field of mental retardation, aging, cerebral palsy, mental health, etc.) to hand over their direct services (if any) to public agencies, and to operate advocacy offices instead. Many avenues for funding of such offices suggest themselves. Also desirable would be the attachment of advocacy offices to the legislative branch of government, much like ombudsman offices usually are.

Obviously, none of the aspects of citizen advocacy are new or unique. What is new and unique is the unification and systematization of all the advocacy components into one comprehensive, practical, and appealing schema. By systematizing the schema, it can now be perceived to subsume many activities that already have a tradition of success (e.g., Big Brothers, Man-to-Man), but of going far beyond these. Also, it is made more appealing and practically implementable at a time of great receptivity for such concepts.

# Major Helping Form?

At this time, the major operational model of citizen advocacy exists in Nebraska, where four such services - all on behalf of the mentally retarded - are in operation. Three of these are local (Lincoln, Omaha and Columbus). The fourth is state-wide,

and is operated by the Nebraska Youth Association for Retarded Children. Many other offices are being planned across the United States, especially in Ohio and Texas, and a number of projects have been initiated. In Canada, keen interest has been shown within the Canadian Association for the Mentally Retarded, and the National Institute on Mental Retardation held a national citizen advocacy leadership training workshop in March of 1971. A fledgling pilot advocacy project has been launched in Kingston, Ontario, on behalf of the mentally retarded.

In the limited space here, it is difficult to convey the extent of enthusiasm with which the citizen advocacy schema has been received despite its recent formulation, and despite the fact that it is only now that descriptions of it are beginning to appear in the professional literature. Because of certain current trends such as disenchantment with technology, fear of anonymity, idealism among youth, and the revival of volunteerism and consumerism, citizen advocacy may well become a major helping form, paralleling the more traditional agency service structures. Such a helping form may make many professionals and agency workers uncomfortable - but it may also make them better helpers.

#### CITIZEN ADVOCACY IN A MENTAL RETARDATION UNIT

- Charles W. Smiley, M.S.W.
- Mildred C. Craik, M.S.W.

IN MAY OF 1971 THE SOCIAL WORK STAFF of the mental retardation unit of our Hospital decided to initiate a Citizen Advocacy Program. By November of the same year the program was fully operational. This was after a great deal of work which involved the location and screening of 106 citizen advocates and the matching of 61 advocate-retardate teams. The city of Kingston showed remarkable acceptance and enthusiasm for the project - the first of its kind in Canada. The purpose of this article is to describe how the program was initiated, and how it has effected the life of at least one patient.

## Advocacy in Practice

The Advocacy Program is designed to provide the mentally retarded individual in the community or hospital with a non-professional, community person who is a combination of <u>friend</u>, <u>big-brother</u>, <u>social worker</u>, and <u>legal counsellor</u>. The advocate may be involved in solving practical and material problems; representing the retardate's interests with the law and other agencies; provide advice and assistance with the practical problems of transportation, clothing, voting, shopping, housing, church attendance, personal growth and development; insuring the retardate's access to appropriate education, training and job opportunities; helping the retardate

Mr. Smiley is Chief Social Worker, Rockwood Mental Retardation Unit, Kingston Psychiatric Hospital, Kingston, Ontario. Miss Craik is Director of Social Work at the hospital.

with the problems of recreation, social experiences and group membership; providing emotional support during crisis; and bringing fellowship and friendship to the retardate.

An example of Citizen Advocacy in practice is illustrated by the case of a 31-year-old Rockwood resident who has spent most of his life in government institutions. Tom Brown\* was never taught the alphabet, how to count or make change. He was the first retardate we matched with a citizen advocate. Tom became a member of Dr. H. Weston's household in Kingston though he spends most of his nights at the Rockwood Retardation Unit. He is not leading a protective, institutionalized life. He spends most of his weekdays working in various homes and at a car wash.

The doors of Rockwood first opened to an independence Tom values almost fiercely when he was introduced to his citizen advocate, Mrs. Weston. Mrs. Weston arranged for Tom to come to her home to help her with the gardening. This was the first time he had been outside the institution without an attendant. He had spent his earlier years at Orillia Hospital before coming to Kingston Psychiatric in 1960. If you ask too many questions about his past, he replies: "I don't keep my memory going back. There's lots in the future."

But he does recall his first job at the Westons - raking leaves for a compost pile. When he had mastered the world of leaves, seedlings and lawns, Tom was given other responsibilities. They included setting a table for formal dinners, serving food correctly, helping in its preparation and washing the dishes.

Since his involvement with the Weston family, Tom's life has changed completely. His skills are in demand and are earning him money. He has his own transportation to and from jobs and a girl friend. He is also preparing for the day when Rockwood is no longer his home, and he is in the world full-time, whether it is a halfway house or some other residence.

## Developing the Program

The social work staff at Rockwood was able to develop the program and locate the advocates through hard work, long hours and in effect relentless publicity. We saturated Kingston with information about the program and its value to the community. Members of the staff were on the local television channel, they had spot announcements on the local radio stations and a series of articles in the Kingston newspaper and in the weeklies of the surrounding towns.

We also developed presentations for different social clubs, churches and business groups in the Kingston area. In a typical presentation we had a social worker talk for 15 minutes on the general topic of mental retardation. Then another worker spoke for 15 minutes on the principles of "normalization" and on the value and reasons for moving large numbers of the retarded out of the government institutions and back into the community.

<sup>\*</sup> The names used here are pseudonyms.