

CITIZEN ADVOCACY FOR THE HANDICAPPED,  
IMPAIRED, AND DISADVANTAGED:

AN OVERVIEW

by

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## The Background of "Protective Services"

In their relationship with each other or their children, spouses can be said to exercise both "instrumental" and "expressive" functions (Parsons & Bales, 1955). Instrumental functions are those which solve the practical problems of everyday life, such as earning a living, mowing the lawn, washing the dishes, and bathing the children. Expressive functions involve the exchange of affection that meet deep-seated needs and that often make instrumental demands meaningful or bearable.

Generally, in our society a child has one or two parents<sup>1</sup> who provide for his physical and emotional needs, who socialize him into the larger culture, and who vigorously represent his interests. As time passes and as the child grows up, the parental role becomes less instrumental, but it retains its expressive nature for life. In other words, as long as parents live, they remain a source of emotional ties and support to their children, even though the parental functions become less and less problem-solving and task-oriented.

The expressive function of parenthood implies a deep emotional commitment. Ordinarily, this commitment to the person of the child lasts through life and persists even when the parent disapproves of the young (or grown) child's behavior. Indeed, this commitment is usually firmer and more stable than that of marriage; it can scarcely be called a rational one--but then, society does not expect it to be. To the contrary, most people would agree that it is desirable that

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<sup>1</sup> The term "parent" as used throughout this narrative may refer to social as well as biological parents.

every person have at least one relationship that endures beyond rationality, and that is not terminated by erratic or unsanctioned behavior or by misfortunes that may befall a human life.

Our society highly endorses, but does not legally demand, expressive parental role performance. In contrast, instrumental parental role performance is, to a significant degree, mandated by law. Thus, while parental failure to demonstrate or extend love to a child is not punishable by law, parents are made legally responsible for their children's support, and child neglect or abuse is punishable.

Inevitably, there will be children who do not have a living or functioning parent. In such cases, our society provides certain substitutes. Most commonly these consist of adoptive or foster parenthood, or of various child rearing institutions. But while society provides a substitute for instrumental parental roles, and while considerable lip service and some attention is placed on expressive functions, these latter functions are not safeguarded to the same degree as instrumental ones.

When a child who does not have a living or functioning parent also happens to be handicapped or impaired<sup>2</sup>, his situation and needs are generally the same as those of nonhandicapped children in similar circumstances. In other words, much like any child, a homeless handicapped child should have a family willing to provide him a home and to raise him, either on an adoptive or foster basis.

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<sup>2</sup> The terms "handicapped" and "impaired" are here used in their widest sense. Such handicaps or impairment could be due to a wide range of conditions including physical and sensory disabilities, mental retardation, character and personality disorders, poverty, and discrimination.

However, the needs of handicapped and nonhandicapped children often become less comparable as handicapped persons approach adulthood, even though the circumstances of a severely impaired adult often resemble those of a child without a living or functioning parent. Thus, a severely impaired adult may be in need of instrumental and expressive support of such a degree as is ordinarily only extended to children. Yet, unlike a child, he is usually not expected to be taken into a family home; if he cannot live by himself, he is expected to live in an institution, a nursing home, or one of the growing number of home-like hostels in the

Even if a family could be found to take him in, we might prefer some type of group placement. As Nirje (1969b) has pointed out, just as the normalization principle dictates that a handicapped child, like other children, should generally live at home, so should many handicapped adults live away from home because this is what is expected from nonhandicapped adults.

In the past, when a seriously impaired child, or an impaired adult who was not fully independent, came into a situation in which he did not have at least one parent playing an adequate instrumental and hopefully also an expressive role in his life, certain human management agencies would enter the case. These agencies generally carried out societally-sanctioned functions, and their actions strongly determined case outcome. In some handicap areas, such as mental retardation, the outcome until recently has almost invariably been institutionalization. Once institutionalized, a retarded person was virtually certain to be

dehumanized (White & Wolfensberger, 1969; Wolfensberger, 1969b). He also became a ward of the state which, in many states, meant that the institution superintendent became the legal guardian, even if the retarded resident still had functioning and involved parents.

Today, we can legitimately wonder what might have happened if the involved agencies and professionals had had a commitment to a vigorous search for foster parents, adoptive parents, citizen-guardians, and citizen-friends for the dependent handicapped. Such a commitment might have been successful in keeping a significant proportion of persons out of institutions, in preventing their being dehumanized in the institutions, or in habilitating them back into the community. The fact is that such vigorous efforts were rarely made<sup>3</sup>, in part because prevailing clinical lore and agency myths held them to be futile, and in part because maintenance of many types of impaired individuals in the community was not believed to be in the best interests of society.

During the so-called "alarmist period" when many of the handicapped were believed to be a major threat to society (ca. 1890-1925; see review by Wolfensberger, 1969b), the perceived interests of society were given the most lopsided precedence over the interests of the impaired person of his family. As this period passed, feeble efforts stirred here and there to re-establish an equilibrium between these interests,

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<sup>3</sup> An exception has been documented by Franklin (1969a, 1969b, 1969c), demonstrating successful adoptive placement of children with severe medical problems.

and a number of plans were devised to aid in safeguarding impaired persons against neglect, abandonment, abuse, exploitation, etc. Many of the services that have sprung from these efforts have been subsumed under the concept of "protective services," and interest in such services has undergone an upsurge in the recent past. A number of major conferences on this topic have been held, and a surprising amount of good literature has accumulated (see the annotated bibliography by Helsel, 1967; also Boggs, 1966; Helsel, 1965; Lehmann & Mathiasen, 1963; United Cerebral Palsy Association 1966, 1968).

#### Major Types of Prevailing Protective Services

Guardianship. A guardian has legally-vested duties and prerogatives comparable to those of a parent of a minor, except that guardians are not usually expected to take their wards into their homes and families. Guardianship can be private or public. Most existing and proposed protective service schemas imply some kind of public guardianship, usually to be exercised by a court, the administrator of a residential service such as an institution, or by a human service agency. For example, Minnesota has had a long tradition of public guardianship for the retarded (Thomson, 1963). This measure was enacted in 1917, but primarily in order to protect society from the retarded rather than vice versa. The Commissioner of Public Welfare was designated as the guardian, functioning through the county welfare agencies. In practice, this particular type of guardianship, if enacted while the parents were still alive and functioning, did not imply that they had to surrender parental rights (Levy, 1965; Minnesota Department of Public Welfare, 1956).

Louisiana legislation provides, for a court-appointed "tutor," generally a lawyer, who plays a guardian-type role. For individuals who are mentally disordered, the court may also appoint a "curator" who generally is expected to report to the court if the services to and condition of his ward are unsatisfactory.

Adoptive Parenthood. Adoption is comparable to guardianship, except that it implies a more intimate personal as well as legal tie. Thus, the adopted person usually becomes a real part of the adopting family, and may even assume its name. One distinction between guardianship and adoption is that the former is somewhat more appropriate for adults, and the latter for children.

Conservatorship. This service is concerned with the administration of a (dependent) person's estate. Conservatorship can be carried out by banks; trust companies; private individuals, singly or as a group; and special committees or other groups which are part of a self-help organization such as an association for the retarded. This type of service is concerned primarily with the property of a person, rather than the person himself.

Trusts. The term "trust" can refer to a range of provisions. Generally, a trust involves the administration of some property, usually money. If it does no more, the trust resembles a conservatorship. However, a trust may also concern itself with the welfare of the person. In this case, though, such a concern is not likely to equal that which one might expect under a guardianship. The Retardate Trust set up by the Massachusetts Association for Retarded Children in 1961 (MARC, undated) is an example of a combination of personal and financial provisions.

## A Critique of Prevailing Protective Services

Current protective service laws and practices, though well-intentioned, suffer from a number of major shortcomings. Indeed, the law itself has been much more effective in protecting property rights than in protecting human rights. Among the shortcomings of the protective services are:

Impersonality of service. Impaired persons may need various degrees of instrumental and expressive support. Instrumental support can consist of almost anything, and may be needed in a rapid, flexible manner. It can range from day-to-day child rearing to helping a retarded adult whose car has broken down to get to work, to obtain a loan, and to buy another car. Expressive support involves indications of personal interest, signs of individual thoughtfulness, shows of affection, etc. Social service-type agencies are suited to set up arrangements under which instrumental functions are accomplished on a routine basis (e.g., delivery of Social Security benefits; setting up a foster home placement), but rarely on a direct or emergency basis (e.g., to take a child to the hospital in an emergency; to provide transportation to, or obtain an emergency loan for, the retarded adult whose car broke down, or to help him buy a new one). Agencies are even less suited to meet a person's expressive needs. Although agency personnel, on an individual basis, may occasionally play expressive functions, the point is that they often will not, cannot, and cannot be expected to.

A good example is a proposal which has recently been implemented in California. This measure calls for a guardian-like "personal surrogate" for retarded persons--but it specifies that surrogates should be officials of state government, working out of regional centers, with guardianship functions vested in the directors of the regional centers.<sup>4</sup> Can an employee of the state be expected to invite 75 or more of his wards to his home for Thanksgiving or Christmas? While one can have an expressive relationship with a retarded person without doing so, it is something one can expect in such a relationship. Also, a relationship based on a specific person's continuity in his employment position obviously cannot be expected to be a long-range one.

On similar grounds, I find objectionable the proposal of the International League of Societies for the Mentally Handicapped (1970) for paid professional public guardians. This proposal, like many other measures, also suffers from excessive formalism and "protective overkill" by calling for declarations of incompetence by multidisciplinary professional teams, and by a judicial tribunal.

By the very nature of things, it would appear that agencies and their staff can play only limited instrumental and even more limited expressive roles as far as impaired persons are concerned. In other words, agency services, by their nature, have a built-in element of the impersonal.

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<sup>4</sup> Initially, the proposal had been defeated in the legislature, but later, a very similar one was adopted vesting guardianship in the State Department of Health and delegating it to directors of regional centers, and thereby to their staff.

Uninspired and uninspiring administration. Agency administration of a protective service provision is not likely to rise above the caliber of other agency operations. Public human service agencies--perhaps by the very nature of our system--are notoriously uninspired, bureaucratic, and rigid. They administer rather than lead, and far from providing inspiration and positive challenges to the citizenry, they typically are themselves difficult to inspire, resistant to change and dynamism, and often resentful of voluntary citizen self-help action. Indeed, agency sluggishness is one of the major reasons why many self-help groups have sprung up. The reader is invited to review in his mind the number of inspiring, challenging public human service agencies he knows, in contrast to such that are private and voluntary in nature.<sup>5</sup>

Conflicts of interest or loyalty. When a professional person provides protective services as part of his agency-defined duties, it is inevitable that he will experience conflicts of interest or of loyalty. By the very way in which our system works, the interests of the client must be expected occasionally to be at variance with the interests of the agency. This places the professional in the middle, and human nature and our system being what they are, professionals more commonly internalize the interests of the agency than of the client. In contrast

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<sup>5</sup> The remarkably superior performance of private welfare services has recently been documented in an outstanding history of welfare in the United States (Coll, 1969).

to the agency which has many voices and much power, a retarded person's voice and power, for instance, are zero unless someone else speaks for him. Professionals whose career interests, reward systems, and social system ties lie within agencies--as is commonly the case--cannot be expected to provide impaired persons with the loud, loyal, consistent, unwavering voice they need. The difficulties of professionals acting as advocates for individuals are well analyzed by Payne (1970).

Scarcity of options. Because of local legal structures or traditions, a specific protective service provision may come to be used to the virtual exclusion of other alternatives even though the wide range of circumstances in which impaired persons and their families may find themselves calls for a wide range of options. For example, in Minnesota, the existence and tradition of public guardianship has "driven out" the development and utilization of other options.

Scarcity of service. In most states, only a miniscule proportion of persons needing protective services receive them. Even in states with strong provisions, such as Minnesota, many more persons need services than receive them.

Impracticality of arrangements. Some protective service plans sound very good--but they don't work. The Massachusetts Trust for the retarded, though in existence for almost a decade, has served only a miniscule number of persons. The State of Washington has an imaginative "co-custody" law; though in existence since 1955, it has never been used. Only slightly better has fared Washington's parental successor

law, which has been used but a few times in the ten years of its-existence. Generally, such non-functional provisions are either impractical or in conflict with existing value systems.

Critique Conclusion. Some of the shortcomings mentioned above have a tendency to interact. For example, it has been stated (United Cerebral Palsy Association, 1968) that welfare workers in Minnesota, administering public guardianship of the retarded, have tended to pursue the easy course of institutionalization so that public guardianship too often became synonymous with public custody. This may well have been the result of an interaction between the afore-mentioned shortcomings of impersonality and conflicts of interest. Similarly, it is to be expected that uninspired administration interacts with impersonality of service, scarcity of options, etc.

A system may fail because it is cumbersome, because it has an inadequate administrative structure, because it does not reflect prevailing cultural values, because it is uninspired and uninspiring, etc. If, after reasonable time and efforts, a system does not work while the problem it was intended to alleviate persists, something else should be tried, regardless of the reason for the failure. I propose a new schema to supersede and subsume the protective service schema.

## A NEW SCHEMA: CITIZEN ADVOCACY

I will define citizen advocacy as: "a mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention."

Viewing the interests and welfare of the impaired person as if they were his own, the mission of the advocate is to use culturally appropriate means to fulfill the instrumental and expressive needs of such a person, consistent with cultural norms and with the person's impairments and potentials. For lack of a better term, and especially to avoid use of the term "ward," I shall refer to the impaired person in an advocacy relationship as a "protege."

In order to represent someone's interests as one's own, one must pursue a strategy which minimizes potential conflicts of interest. Thus, the advocacy concept demands that advocacy for an impaired person is to be exercised not by agencies, and not by professionals acting in professional roles, but by competent- and suitable citizens. To underline these emphases, one can quote as an example from Article V of the Declaration of General and Specific Rights of the Mentally Retarded adopted in October of 1968 by the International League of Societies for the Mentally Handicapped: "No person rendering direct services to the mentally retarded should also serve as his guardian" (ILSMH, 1969).

Conceivably, advocates can function singly or in groups, and represent the interests of both individual persons as well as groups of persons. However, the heart of the proposed advocacy scheme is individual advocacy, in which one citizen is the advocate for one other citizen. It is primarily with this type of advocacy that this treatise concerns itself.

#### Advocacy Roles and Functions

Students of protective service provisions have often been bewildered by the variety of protective services, the overlap between different provisions and the lack of agreement on the definition of certain protective roles such as trustee, conservator, guardian, etc. I propose that our concepts and service structures can be greatly advanced by imposing the previously mentioned distinction between instrumental and expressive functions upon advocacy roles. This distinction appears to be much more powerful and relevant than the traditional legal distinction between protection of persons and property.

For instance, a marginally independent retarded adult who is capable of economic self-support and who lives in a boarding house in the community may only need occasional instrumental guidance in matters such as transportation, use of leisure time, budgeting, preparation of tax return forms, etc. Another similar person may reside with his family and receive all the necessary instrumental support, but may be unloved and rejected by his family, and emotionally isolated and starved. In order to function adequately, he may need no more than a friend who extends emotional (expressive) support to him.

Similarly, a person may be institutionalized and have all of his instrumental needs met, but may suffer from the lack of a highly personalized expressive relationship that cannot be supplied by the institution employees. A friend who telephones and visits, who sends mail and gifts, and who perhaps invites his protege into his home for visits or special feast days may well fill the need for an expressive relationship. .

Finally, there are instances where both expressive and instrumental needs are unmet. A most striking example is the orphaned or abandoned child needing adoptive or foster parents who will perform all those expressive and instrumental functions ordinarily performed by biological parents.

It is useful to make a distinction between the meaning of various advocacy roles for children on the one hand, and for adults on the other.

#### Advocacy Roles and Functions for Children

Table 1 lists three types of advocacy roles for children: primarily instrumental ones, primarily expressive ones, and those that are both. Some of the listed advocacy types are self-explanatory. For instance, parental successorship as envisioned by the laws of the State of Washington probably would imply both instrumental and expressive functions in most instances. In our culture, the god-parent role has some similarity to the parental successorship. The term "conservator," is used broadly so as to subsume what is sometimes called "guardianship of property" in distinction to "guardianship of the person," refers to no more than the administration of income, property, estates, etc., on behalf of a protege.

Table 1  
 Advocacy Roles for Children  
 Advocacy Needs to be Met

	Primarily Instrumental	Primarily Expressive	Both Instrumental And Expressive
Advocacy Roles	Conservator	Advocate-Friend	Instrumental-Expressive Guide-Advocate
	Instrumental Guide-Advocate		Foster Parent
	Instrumental Guardian		Instrumental-Expressive Guardian Adoptive Parent Parental Successor

Other terms found in Table 1 are novel. In keeping with the instrumental-expressive distinction, a distinction has been made between (primarily) instrumental and instrumental-expressive guardianship. This distinction is one which may well deserve clearer definition in law. An instrumental guardian might be a citizen who plays an active role in making decisions about and solving major practical problems in the life of--let us say--a retarded child or teenager whose expressive needs are being met by warm, accepting, loving, but instrumentally inadequate parents who may themselves be retarded. The instrumental guardian in such a case need not necessarily have a close emotional tie with the child; competence, a sincere interest, and positive attitudes may well be sufficient. In contrast, an example of an instru-

mental-expressive guardian would be one who plays some instrumental and many expressive roles to a child in an institution. This role would be equivalent to that of plenary guardian, as generally recognized by law. Table 1 does not list a purely expressive guardian because such a role does not appear to be legally definable in our type of society.

The term "guide-advocate" refers to advocates who function much like guardians, but unlike guardians, they usually do so informally in situations where legal sanction and powers are not feasible or necessary in order to achieve the desired ends. Of course, without a legal status, guide-advocacy will lack a legal review process, but appropriate review can be achieved by an administrative process to be discussed below in another section. Examples of roles already recognized by law which might fall under the guide-advocacy concept include the "tutorship" in Louisiana law which is a mild form of guardianship, and the "representative payee" role recognized, by the Social Security Administration.

Table 1 also distinguishes between (primarily) instrumental guide-advocates and those who fulfill both instrumental and expressive needs. An example of an instrumental guide-advocate is an adult who helps instrumentally inadequate parents to get medical attention for their child, to get him into the proper class or school, etc. An instrumental-expressive guide-advocate might, for example, assume a de facto parental role to a child in an institution. Such a role is particularly

appropriate where a child in an institution has parents who refuse to relinquish legal but fail to exercise social parenthood.

Table 1 also uses the term "advocate-friend" to refer to a person whose advocacy mission is primarily that of an expressive relationship. The term "advocate-friend" rather than merely "friend" was chosen in order to clarify the intended purpose of the friendship. In practice it is unlikely that a distinction between the two exists.

Foster parenthood is listed in the table as an advocacy that is both instrumental and expressive, but whether foster parenthood should even be considered to constitute advocacy at all is controversial. One important requirement for advocates is freedom of conflicts of interest which, in turn, requires that advocates be unpaid for their services. Foster parents are paid, but they are not agency employees, and they frequently become as effective in their rearing of foster children as natural parents. In other words, they may become the de facto social parents of a child, and the foster payment can be likened to the public subsidies which biological parents might receive under (Social Security) programs such as Aid to Dependent Children.

Usually, a child's need for advocacy precedes measures such as foster placement, and an advocate should be found when needed. This means that typically, a child's first advocate should not be a foster parent. If the child is eventually fostered, and if the foster parents develop into unselfish advocates, the advocacy functions can gradually be transferred to them. However, until this proves timely and feasible, someone else should play the advocacy role.

Generally, it is highly desirable that any child (and many severely impaired adults) who lacks effective parents have not only a citizen advocate, but one who actually becomes a legal guardian. The advantage may not so much be of legal nature, but of a psychological one. When an advocate becomes a guardian, he will almost invariably be more committed; thereby, he is not only apt to do more for his protege, but to require less prompting and back-up by the advocacy office.

#### Advocacy Roles and Functions for Adults

Again utilizing the instrumental-expressive distinction, Table 2 lists advocacy roles and functions for adults. By now, the distinctions between instrumental and instrumental-expressive guardians and guide-advocates is relatively self-explanatory. Note certain additions and deletions when Table 2 is compared to Table 1.

Table 2

#### Advocacy Roles for Adults

#### Advocacy Needs to be Met

	Primarily Instrumental	Primarily Expressive	Both Instrumental And Expressive.
Advocacy Roles	Conservator	Advocate-Friend	Instrumental-Expressive Guide-Advocates
	Instrumental Guide-Advocate		Instrumental-Expressive Guardian
	Instrumental Guardian		Instrumental-Expressive Spouse

A perhaps puzzling addition is that of "instrumentally- and expressively-competent spouse." The implied assumption here is that a spouse can be an effective advocate for an impaired person. For instance, a retarded adult who is economically self-supporting may find fulfillment of expressive needs with a spouse, although the chances for such fulfillment probably vary with the instrumental and expressive, competence of the spouse, and with the likelihood and number of offspring. In regard to the latter point, modern means of contraception and increasing acceptance thereof are making benefits of marital life available to many individuals for whom marriage was at one time unthinkable. However, in regard to the former point, it would appear that marriage as a solution to the advocacy needs of an impaired person is inadvisable unless the impaired person's spouse is instrumentally as well as expressively competent. For many impaired individuals, marriage to a spouse who does not meet these criteria may still be better than no marriage at all, but it may well be that then, outside advocacy will be required for one or possibly even both spouses.

The terms foster parent, adoptive parent, and parental successor are missing from Table 2 on the basis of three assumptions: (1) In practice, natural or adoptive parents ordinarily become the guardians of or guide-advocates for an impaired adult child. (2) Foster parenthood implies the rearing of children; if the relationship continues into adulthood, it usually will assume the form of guardianship or guide-advocacy. (3) Since parents lose legal authority over children who attain their majority unless guardianship-typo provisions are made, co-guardianship of an adult is, in effect, guardianship successorship.

### Some Special Types of Advocacy

As previously emphasized, the heart of advocacy consists of a one-to-one relationship such as detailed in Tables 1 and 2. However, one can also conceive of some other variations on this theme.

#### Generic Advocacy

A person may play an advocacy role for an entire category of persons, such as the poor, the retarded, etc. An example is a person such as Ralph Nader who has acted as a citizen advocate for the consumer.

#### Collective or Corporate Advocacy

We speak of collective or even corporate advocacy when a group of individuals covenant between themselves to represent the interests of an entire category of persons. Examples are the many voluntary citizens' groups such as the Association for Retarded Children, United Cerebral Palsy, etc.

#### Group Advocacy

I define group advocacy as involving a highly specific and circumscribed group of impaired proteges, and a highly specific and circumscribed, but usually informal, group of citizens. Examples are a women's church club which "adopts" the residents of a home for the aged, or of a living unit in an institution for the retarded; a service club which dedicates itself to the role of a citizens' watchdog group over a particular public agency such as an institution; and a legal firm which provides free services to a specific group of persons, such as the poor of a certain neighborhood.

### Multiple Advocacy

One citizen or family may play advocacy roles to more than one protege. For instance, an attorney may act as conservator for several impaired persons, or a citizen may play different advocacy roles to two or three impaired individuals.. As long as only a few proteges are involved, such arrangements can still preserve the sustained one-to-one relationship so crucial to effective, individual advocacy.

### Dispersed Advocacy

It is conceivable that in some instances, several citizens might divide advocacy functions in regard to a protege among themselves. In Table 4 (to be introduced later), situations will be sketched where an impaired person might be best served by having one instrumental guide-advocate and one or several close advocate-friends (i.e., "co-advocates").

In practice, an advocate will rarely function alone. Since advocates will, by definition, be mature citizens, they will generally have spouses and other family, and in practice, an impaired person will enjoy not only the action of his formally sanctioned advocate, but also that of the advocate's spouse and family. In fact, in many cases, it may be found desirable and feasible to define or perceive a couple or a family as constituting a single advocate.

### Crisis Advocacy

An impaired person and/or his family may experience a sudden crisis that requires immediate and extensive attention. During such a crisis there may be no one with the time and calmness to contact the

relevant persons and agencies that may be involved or that may render help; it may be some time before a suitable helping agency is identified; and the agency may be sluggish in its response. In such a crisis situation, an advocate can step in and act as coordinator, legman, and backup. He may provide transportation, attend to certain undone but important functions, and can see to it that the agencies will not play run-about games.

A good example of crisis advocacy is the "pilot parent" system (sometimes also known as an "empathy bureau") described by Standifer (1964). Parents who have a retarded child, who have made an exemplary adjustment, and who are knowledgeable about community resources offer their assistance on a couple-to-couple basis to other, usually younger, parents who just learned that their child is retarded. The pilot parents help the other couple to obtain assessment and other services, and may provide additional practical assistance. They also furnish an empathy and emotional buffer that the other couple may need until they have worked through their shock and possible grief.

Somewhat related to crisis advocacy is advocacy specific to certain missions. For example, the Temple University (Philadelphia) Community Mental Health Center has operated a "patient advocate system" in which three advocates assist consumers through the bureaucratic agency maze. However, the advocacy concept is diluted here by the fact that the advocates are apparently paid, and are paid by the agency serving their proteges.

Crisis advocacy may be a once-in-a-lifetime event for an impaired or disadvantaged person, but can be of major significance at that time. A central advocacy office, such as discussed further below, can be particularly useful not only in providing or mediating crisis advocacy, but in also furnishing needed back-up services to the crisis advocate.

### Youth Advocacy

Basically, advocacy calls for mature advocates. However, one special subvariant of advocacy, which I call "youth advocacy," might involve teenagers. On occasion, a teenager might select another, impaired or disadvantaged, teenager or child as a special friend; or a group of teenagers, such as a youth club, might assume a special socializing or friendship function vis-a-vis a group of impaired children or fellow teenagers. An example here are the social youth clubs in Stockholm which consist half of college students and half of retarded young adults. By means of their social meetings, and retarded youths learn age-appropriate social behavior, dress, speech, grooming, bearing, etc. This club fulfills a very special need because retarded adolescents often lack close contacts with friendly peer models with whom they can identify and whom they can profitably imitate.

Experience with the Nebraska Youth program suggests that it is sometimes desirable that two young people act jointly in a (dispersed) advocacy role to a retarded child or age peers; and that until they grow into full advocacy themselves, youths might be assigned to serve as advocate cadets or apprentices with mature advocates, or as co-advocates with more advanced youth advocates.

Obviously, special relationships between impaired and nonimpaired young people are very desirable, and can serve useful functions. In some cases, however, these functions may no longer fall under the advocacy concept.

#### The Advocate Associate

Many professionals, agency personnel, and other individuals in influential positions are likely to embrace the advocacy concept without, however, actually playing direct, individualized, sustained advocacy roles. Instead, they can act as apostles of the concept, as change agents within their own agencies, and as members of committees for the advocacy office (described later). Whenever the advocate has to deal with the associate's agency, the associate can exert special inside influence in gaining acceptance for the advocate's role and in facilitating the advocate's task.

#### The Determination of Specific Advocacy Needs

In Tables 1 and 2, major needed advocacy roles and functions for children and adults, respectively, were listed. The question now arises as to how the advocacy needs of a specific person might be determined.

A commonly heard cliché, although a true one, states that human service, needs and personal circumstances are so varied that every case must be considered individually. However, this truism has served many clinicians as an excuse for (1) avoiding the demanding process of evolving broad principles and concepts that can govern routine services; and for (2) chaotic and therefore often undisciplined, inefficient, and perhaps even irrational functioning.

A good example is the situation in regard to residential services for the mentally retarded. Here, failure to establish and act in accordance with consistent and reasonable up-to-date principles has resulted in an incredible mess (e.g., Blatt, 1969; Blatt & Kaplan, 1966; Hirje, 1969a; Wolfensberger, 1969a) that has been termed "a disgrace to the nation" by the President's Committee on Mental Retardation (1967). One reason for the mess has been the cliché that individual circumstances differ so much that no general principles can be established and applied in regard to the advisability of institutionalization for specific persons.

Yet it has been shown that rather detailed clinical decision-making systems can be devised, and even automated. For instance, International Business Machines, Inc., (e.g., Moore, 1968) has developed an automated "clinical decision support system" for general medical diagnosis and management. Wolfensberger and Menolascino (1970) have evolved a clinical decision selection scheme applicable to the counseling of parents of the retarded. In regard to the specific example given above (institutionalization of the retarded), a relatively detailed decision support process was evolved by Wolfensberger (1967) from a set of basic assumptions and facts. Despite the variety of individual circumstances, such a decision system appears capable of coming up rather automatically with recommendations in specific cases that would be supported by a majority of experienced clinicians. Such a decision system might well be placed within the context of larger human management decision systems (Wolfensberger, 1969a) toward which our society appears to be moving.

Similarly, it is proposed here that a decision selection system in regard to advocacy needs can be established and can be highly useful in a significant proportion of cases. Obviously, a multiplicity of such systems is conceivable, and only empirical evaluation can reveal their relative effectiveness. However, one such system is presented here on a tentative basis, and summarized in Tables 3 and 4. Again, it appeared important to make a distinction between children and adults, and in a sense, there are actually two decision-making schemes, one for each age group.

To begin with the advocacy needs of children, a series of determinations are called for. The first determination assesses whether the child's condition is such as to require long-term specialized service which is only available in a residential setting. Here, it should be kept in mind that on this level, only the child's condition and needs should be considered, and in a rather technical sense. Thus, typical determinations here are whether the child is so ill as to require prolonged maintenance-of-life type hospital care; whether chronic medical problems indicate the need for long-term residence in a special treatment center; whether behavior problems require extended residence in a corrective or psychiatric facility, etc. Modern considerations regarding residential services should prevail in such determinations (e.g., Dybwad, 1970; Governor's Citizens' Committee, 1968a, 1968b, 1968c; Kugel & Wolfensberger, 1969; Menolascino, Clark, and Wolfensberger, 1968, 1970; Wolfensberger, in press).

The second determination is whether the instrumental competence of the child's parents (or acting parents) is significantly below acceptable societal norms. Most parents, of course, will meet this criterion of adequacy.

The third determination assesses whether parental instrumental or expressive functions are impaired in regard to the specific child in question. Here, it must be kept in mind that while parental instrumental or expressive functions may be adequate in regard to one child, they may be inadequate in regard to another. This discrepancy can result because of characteristics of either the child or the parent, or an interaction between both. For example, in one family, general parental instrumental adequacy may be very high, but may nevertheless be inadequate for the management of a child with spina bifida. In another family, parental expressive functioning may be adequate for all siblings within the family except for the child who appears to be mentally retarded. A clear distinction must be made between a situation where a family with adequate instrumental sources rejects or expels a handicapped child because of a breakdown in expressive processes; a situation where a child's condition and the family's instrumental resources interact in such a way as to cause a breakdown in instrumental functions for the specific child; and a situation where instrumental functioning of the parents is inadequate for child rearing generally.

Table 3

## A Summary Guide to the Advocacy Needs of Children

Does the Child's Condition Call For Long-Term Specialized Residential Service?	Is General Parental Instrumental Competency Significantly Below Societal Norms?	Are Routine Instrumental or Expressive Functions Impaired in Regard to the Child?		Rank Order of Major Typical Advocacy Needs that Can Feasibly be Met									
				None Needed	Primarily Instrumental		Primarily Expressive	Both Instrumental and Expressive					
					Instrumental Guide-Advocate	Instrumental Guardian	Adult Friend	Instrumental-Expressive Guide-Advocate	Foster Parent <sup>a</sup>	Instrumental-Expressive Guardian	Adoptive Parent		
Yes	Yes <sup>b</sup>	Yes	Yes										
			No		2	1		3		1	2		
No	No <sup>c</sup>	Yes	Yes					1					
			No	1									
No	Yes <sup>b</sup>	Yes	Yes							2		1	
			No							1			
	No	Yes	Yes							2		1	
			No	1									
	No	No	Yes	Yes					1				
				No	1								

<sup>a</sup> As discussed in the text, foster parenthood should only be considered as constituting advocacy under certain conditions, and other persons may have to play advocacy roles at least temporarily.

<sup>b</sup> By definition, a "Yes" here also implies, in the next column, a "Yes" in regard to impairment of instrumental functions involving the handicapped child.

<sup>c</sup> If a child requires services that necessitate placement outside the home, parental instrumental functions are by definition inadequate for this particular child. Thus, again, the next column cannot contain a "no."

The third determination can be seen as consisting of two parts, the instrumental and the expressive one. In this determination, and in the preceding (second) one, it is usually sufficient to establish whether at least one parent meets criteria of adequacy. In only rare and extreme circumstances is it likely that a judgment of "No" must be rendered as long as there *is* at least one (acting) parent who meets the criteria.

As Table 3 shows, this series of determinations can yield strong suggestions as to a likely hierarchy of necessary advocacy needs. For instance, if a child has parents who are inadequate not only in regard to his instrumental and expressive needs, but also to those of the other existing or potential children, then this child needs an advocate or advocates who both socially and legally will assume typical parental roles. If this child requires long-term specialized residence, a legally appointed instrumental-expressive guardian is most desirable; since the bio-social parents are still alive and known, an adoptive parent is a less desirable and feasible second choice; and instrumental-expressive guide-advocate is third choice because this arrangement lacks the legal definition that would be desirable here. If the child does not require long-term specialized residential service, an adoptive parent is first choice, and a foster parent (possibly with an additional guide-advocate) is second. In both cases, it is assumed that the adoptive or foster parent will take the child into his home and raise him as his own.

Certain situations have been rated as not requiring special advocacy other than that provided by the parents. Also, there is no column for conservatorship as might be expected under the rubric of primarily instrumental advocacies. This advocacy was omitted from the Table because of three interrelated assumptions:

1. The decision to establish conservatorship is largely independent from the determination of other types of advocacy needs.
2. The advisability of conservatorship has relatively little to do with impairment; theoretically, conservatorship arrangements are advisable for any child whose parents have something to conserve.
3. While other advocacy needs are either mutually exclusive or at least stand in a clear rank-order of desirability to each other, the advisability of conservatorship is almost completely unrelated to the advisability of other advocacy needs.

In regard to adults, Table 4 shows that there is also a series of three determinations, but that they differ in nature, emphasis or nuance.

The first determination involves a rough judgment of the general adequacy of the presumably impaired person along a dependence-independence continuum. The present schema suggest the desirability of a classification into one of three levels of this continuum.

The second determination is where the potential protege lives at the time of the assessment. In Table 4, it is assumed that an essentially dependent person can only live in his parental home or in some group residence such as an institution, hospital, or hostel. However, an independent or marginally independent person might conceivably live in his own home or apartment, or in a rooming house.

A Summary Guide to the Advocacy Needs of Adults

Adult's Degree of Independence	Where Does the Adult Reside?	Are Necessary Instrumental And Expressive Needs Being Met?		Rank-Order of Advocacy Needs <sup>a</sup>
		Instrumental?	Expressive?	
Essentially Dependent	Parental Home	Yes	Yes	1. I-E Guardianship, by Parents if Feasible
			No	1. Parents as I Guardians, plus Advocate-Friend
		No	Yes	Removal of Adult to Group Home, plus (1) Parents as I-E Guardians <sup>c</sup> , (2) Parents as I Guardians, plus Nonparent as Advocate-Friend, (3) Nonparent as I-E Guide-Advocate, (4) Nonparent as I Guide-Advocate, and an Advocate-Friend
			No	Removal of Adult to Group Home, plus (1) Parents as I-E Guardians <sup>c</sup> , (2) Parents as I Guardians, plus Nonparent as Advocate-Friend, (3) Nonparent as I-E Guide-Advocate, (4) Nonparent as I Guide-Advocate, and an Advocate-Friend
	Group Home	Yes	Yes	1. I-E Guardianship, by Parents if Feasible
			No	1. I-E Guardianship, by Parents if Feasible 2. I Guardianship, by Parents, plus Advocate-Friend <sup>c</sup> 3. I-E Guide-Advocate
		No	Yes	1. I Guardianship, by Parents if Feasible <sup>c</sup> 2. I Guide-Advocate
			No	1. I-E Guardianship, by Parents if Feasible <sup>c</sup> 2. I-E Guide-Advocate
Marginally Independent	Parental Home	Yes	Yes	1. I-E Guardianship, by Parents if Feasible
			No	1. Parents as I Guardians, plus Advocate-Friend
		No	Yes	Removal of Adult to Group Home, plus (1) Parents as I-E Guardians <sup>c</sup> , (2) Parents as I Guardians, plus Nonparent as Advocate-Friend. (3) Nonparent as I-E Guide-Advocate, (4) Nonparent as I Guide-Advocate, and an Advocate-Friend
			No	Removal of Adult to Group Home, plus (1) Parents as I-E Guardians <sup>c</sup> , (2) Parents as I Guardians, plus Nonparent as Advocate-Friend. (3) Nonparent as I-E Guide-Advocate, (4) Nonparent as I Guide-Advocate, and an Advocate-Friend
	Group Home	Yes	Yes	1. I Guardianship, by Parents if Feasible
			No	1. I-E Guardianship, by Parents if Feasible <sup>c</sup>
		No	Yes	1. I Guardianship, by Parents if Feasible <sup>c</sup> 2. I Guide-Advocate
			No	1. I-E Guardianship, by Parents if Feasible <sup>c</sup> 2. I-E Guide-Advocate
	Own Home	Yes	Yes	None
			No	1. I-E Competent Spouse 2. Advocate-Friend
		No	Yes	1. I-E Competent Spouse 2. I Guide Advocate
			No	1. I-E Competent Spouse 2. I-E Guide-Advocate
Essentially Independent <sup>b</sup>	Parental Home	Yes	Yes	None
			No	1. I-E Competent Spouse 2. Advocate-Friend
	Group Home	Yes	Yes	None
			No	1. I-E Competent Spouse 2. Advocate-Friend
	Own Home	Yes	Yes	None
			No	1. I-E Competent Spouse 2. Advocate-Friend

<sup>a</sup> Instrumental has been abbreviated as "I," Expressive as "E."

<sup>b</sup> This classification implies that the person must be essentially instrumentally competent, ruling out a "No" category in the third column.

<sup>c</sup> An assumption here is that some parents, who failed at providing the necessary instrumental or expressive roles while the impaired adult lived in the parental home, can succeed at those if their adult child resides elsewhere.

As with children, the third determination for adults also has two parts which are concerned with the question as to whether the person's instrumental and expressive needs, respectively, are being met.

The rank order of advocacy needs suggested by these determinations is written out rather than checklisted as in Table 3. This became necessary because certain situations called for multiple or qualified advocacy types. Also certain assumptions should be noted.

1. While for an impaired adult, residence outside the parental home may be more consistent with normalization principles than residence in the parental home, it was assumed that the latter might still be at least defensible if not optimal.
2. Advocacy needs of adults are apt to change more readily than those of children. For instance, marriage of a protege to an instrumental-expressive spouse may suddenly, completely, and permanently obviate the need for all other types of advocacy.
3. Table 4 only suggests the immediate advocacy needs of an impaired adult. In some cases, it will be desirable to work toward different long-term arrangements than may be indicated for the moment. For instance, while parental guardianship may be indicated at one point in time, it may also be desirable to arrange for a guardian-successor, multiple, or dispersed advocacy.
4. Some categories in the table imply that some satisfactory advocacy arrangement already exists, as in the case of the marginally independent adult who lives in his own home and whose instrumental and expressive needs are being met. This situation would be a contradiction of terms in the absence of a satisfactory advocacy.

5. When children attain their legal majority, parents lose legal parental prerogatives unless these are continued by legal arrangements such as court-appointed guardianship. In many cases where an adult needs a special advocacy relationship, the parent is the person best suited to provide it.

6. Similar assumptions as were made in regard to conservatorship for children also apply here.

#### An Implementive Mechanism

The citizen advocacy concept has been criticized on three counts:

1. Not enough citizens will be motivated and inspired to assume advocacy roles. For instance, it is widely claimed that it is very difficult to secure foster parents, adoptive parents, or even guardians for retarded children.
2. Even if many citizens were motivated to act as advocates, it would be difficult to implement the concept.
3. Even existing advocacy functions which are subject to judicial supervision, such as guardianship and conservatorship, are very poorly supervised. Thus, additional and/or extended advocacies might fare even *worse*.

Some of these criticisms are answered later in this paper. However, one answer here is to propose the establishment, on local and possibly state levels, of citizen advocacy offices. The local office might function best if it is entirely independent, or associated with an independent and probably private body. The state-level office could be part of--but substantially independent from--some existing office of government.

The functions of a local advocacy office would include the following:

1. Planning and budgeting.
2. Dissemination of the advocacy concept, in order to: make it a familiar concept in our society generally; draw attention to new options for citizens in search of a human service role; and spread knowledge about the availability of this service to those who may need it.
3. Further definition of desirable advocacy roles.
4. Clarification of desirable advocate characteristics.
5. Recruitment of citizens for advocacy roles. Such recruitment can often be accomplished during the dissemination process. Thus, talks to church groups, civic and service clubs, college classes, etc., can be coupled with challenges to accept an advocacy role.
6. Screening of potential advocates.
7. Establishment of guidelines for the conduct of advocates.
8. Orientation and education for advocate candidates. However, care should be taken that the professional advocacy office staff--who may come from an agency background--do not yield to the temptation to "professionalize" the advocacy role. Professionalization or formality would probably destroy the heart and guts of advocacy: a citizen acting to protect the interests of another citizen, as if they were his own, utilizing such means and ways which are typical of everyday citizenship functioning, rather than everyday-professional or agency functioning.

9. Arranging specific advocacy relationships. This involves development of a file of names of persons in need of advocacy, a determination of the advocacy needs in each case, selection of suitable advocate candidates for a case, bringing the advocate candidate and the impaired person together, and eventually sanctioning the relationship if it appears to be a well-matched one.
10. Supporting advocacy relationships by means of legal, administrative, and professional assistance. This will be discussed further in the section on staffing of advocacy offices.
11. Conducting periodic reviews of advocacy relationships. Most advocacy relationships that exist in everyday life are either not subject to legal review at all, or only under unusual circumstances. For instance, parenthood is only reviewed after allegations of gross neglect, abuses, or failure. Similarly, many informal advocacies that might be arranged by an advocacy office might lose their cultural meaning if they were subjected to legal or excessive review.

However, there remains the fact that the advocacy concept calls for vigorous protection of the interests of impaired persons, and the mere arrangement of an advocacy relationship is no assurance that this desired goal will be attained. Thus, an advocacy office will have to exercise some review of the arrangements it has mediated.

Here, it may be useful to think in terms of a continuum of formality of review. For instance, for formal arrangements, such as

conservatorships and guardianships, a court may delegate rather formal review procedures to an advocacy office.<sup>6</sup> For certain other types of advocacies, such as guide-advocacy, the office may conduct not legal, but administrative reviews. These might consist of, or include, telephone calls, correspondence and/or visits to the advocate and the protege; discussions among office staff; and consultation between office staff and the special consultants or professionals mentioned in the section below on staffing.

Certain advocacy relationships should probably remain unreviewed unless new evidence of advocacy need reaches the office via requests, referrals, complaints, etc. Advocacies in this category include spousal ones, friendship, and guide-advocacy (for adults) on the part of parents which, during an earlier contact with the office, had been assessed to be satisfactory.

Recruiting advocates and setting up advocacy, arrangements will probably be the most crucial mission of the advocacy office. While supervision and follow-up will be an important function, it can be assumed that the majority of advocacy relationships, once they get going successfully, will require little attention from the office staff. One staff member could probably conduct supervision, review and follow-up for several hundred established relationships.

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<sup>6</sup> This may require special legislation.

An important point to remember is that the advocacy office usually will not exercise any direct advocacy functions, and cannot be held responsible for the actions of the advocates it has "set up in business." Its review of advocacy adequacy should only address itself to the question whether the advocate adequately identifies with and fulfills the needs of the protegee--not with how stridently this is done, or how bothersome the advocate becomes to other professionals and agencies. Like all agencies and facilities, an advocacy service should have an advisory body with representation from consumers and their families, professionals, and concerned citizens from the community *at large*.

In addition to local offices, there could be an advocacy office on the state level in each state. Such a state-level office would not render direct advocacy mediation and support, but would function primarily to back up the local offices, especially in areas of ideology, fund raising, coordination, dissemination, training, legal class action, and legislation. While state-level advocacy offices appear highly desirable, local offices should be able to function regardless whether a state office exists or not. However, to ensure the success of the advocacy schema, advocacy offices should always have at least one full-time paid staff member; otherwise, the pessimistic predictions of the critics of the schema are too apt to come true. This full-time person need not work on advocacy exclusively, but should be available at all times when needed.

### Staffing of the Advocacy Office

A citizen advocacy office should probably be staffed by persons with administrative, casework, and public relations skills. However, it should have access to legal services and to professionals skilled in areas such as behavior management and child development. The needed attorneys and professionals might be either full-time or part-time employees of the office; they might be retained on an ad hoc basis; or they might themselves be volunteers who donate their services as a contribution to the citizen advocacy concept. A major role of attorneys would be to assist with the setting up of guardianships, conservatorships, and adoptive parenthood. Other human service specialists would advise citizen advocates who confront particularly difficult problems in their advocacy work. For example, an expressive guide-advocate to an emotionally disturbed child might require the counsel of a psychologist, psychiatrist, or special educator.

A point here that I consider to be crucial to the successful implementation of the advocacy schema is that citizens must know that in difficult advocacy situations, they will receive certain kinds of back-up that will permit them to be effective, and that will likely prevent their being "wiped out" legally, emotionally, financially, or otherwise.

### Desirable Advocate Characteristics

Among the functions of the advocacy office described above would be recruitment, screening, and selection of advocates. Because our experience with advocacy services are limited, and because different advocacy functions call for different advocate behaviors, there are only a few universal advocate characteristics that appear desirable.

First, it is important that the advocate has the type of community stability which makes it likely that his relationship to the protege can be a sustained one. Mobile business executives and armed forces personnel usually lack the continuity of residence that is almost essential for most advocacy functions.

Second, the advocate must be willing to undergo orientation and preparation. This preparation need not be lengthy or formal; it may consist of a single workshop, or a few interviews. However, it is likely to screen out many persons who volunteered impulsively but lack perseverance.

Third, the advocate needs to understand his specific advocacy mission.

Fourth, the advocate must have competence in whatever advocacy role or task he chooses to assume. Because of the wide range of such roles and tasks, incompetence in one must not be judged to imply incompetence in another, and vice versa.

Fifth, the advocate needs to make a commitment to this mission.

Sixth, whatever mission the advocate selects, he should display what the community would judge to be "good moral character."

These six characteristics appear to be rather basic. In addition it would be highly desirable if the advocate would consider joining the action group in his community that is concerned with his protege's impairment. For a retarded protege, that would be the local association of parents and friends of the retarded; for a cerebral palsied person, it would be the local chapter of United Cerebral Palsy; etc. Membership

in such a group can serve to support the advocate's motivation, to enlighten him regarding the special needs of his protege, and to inform him regarding new developments and resources.

For persons needing long-range advocacy, it will be desirable to select relatively young advocates who are likely to survive them. Some types of advocacy need not be long-term, especially if primarily instrumental functions are involved. While physical separation may necessitate the discontinuance of some advocacy functions, other functions can be continued, and a new advocate can take up the discontinued ones.

#### Advantages of the Advocacy Schema

Most directly, of course, the greatest advantage of the advocacy schema consists of the meeting of the advocacy needs of large numbers of people. However, there are other major benefits.

At present, the unmet advocacy needs of many citizens consume the services of a large number of professionals. Services (of the non-advocacy type) rendered by social workers, psychologists, psychiatrists, etc., are often required because of various crises in human lives. Many of these crises might have been prevented by means of advocacy relationships. Also, many professional services actually constitute attempts to provide the needed advocacy, although such efforts are inherently problematic and of limited success, as pointed out earlier in this paper.

If citizens would assume a major portion of the advocacy burden, it could be expected that they would not only give of their hearts and

minds, but also of their time and material substance. The value of their total investment could be expected to be appreciable and equivalent to the cost of a great many human services that would otherwise have to be rendered by public agencies. For instance, a family that adopts a retarded child might save the public the cost of life-long institutionalization, which has recently been estimated to be between \$100,000 and \$300,000. An instrumental guide-advocate to a handicapped person might render the type of service that might otherwise have called for the intervention of an agency social worker. Friendship and expressive guide-advocacy to adolescents might prevent much aggressive behavior that would inflict material or even personal damage, and result in police and legal action. Indeed, it appears that the citizen advocacy schema fulfills the requirements Allen (1969) had in mind when he called for "an inexpensive, stigma-free guardianship procedure" (p.85).

In other words, at a time when the need for action by human service agencies is increasing while funding for such services is becoming very problematic, citizen advocacy can simultaneously fill the human need as well as reduce costs. I would estimate that the cost of an advocacy office would be multiplied at least twenty-fold in terms of the value of the needed human services it will mediate.

In some cases, the advocate must play the role of an adversary to an agency in order to protect the interest and welfare of his protege. However, there will be many instances where an advocate can provide an agency with support that can make a critical difference in

agency success. For instance, habilitation of institutionalized retarded adults back into the community is very difficult because of the lack of adequate community follow-up and supervision. Agencies have not been too successful in this task because of their cumbersome operations, while citizens appear to be highly suited for one-to-one supervision. Also, they are more suited than agency personnel for absorbing an agency client's emotional shocks upon social or vocational failure experiences. This is the type of situation in which an instrumental-expressive guide-advocate can be highly effective.

Both voluntary citizen action and agency services have their strengths and weaknesses. The schema proposed here promises to capture the strength of both while minimizing the weaknesses of either. Thus, most human services rendered by agencies are now rendered with public support and as a matter of right. From the agencies, citizen advocacy can draw professional services for impaired persons, supervision and mediation, and recognition of advocacy as a right; from its volunteer background, advocacy can draw informality, flexibility, enthusiasm, inspiration, and valuable time and resources. Citizen advocacy is unencumbered, on the one hand, by typical rigidities of public agencies and, on the other hand, by the sometimes undisciplined and incompetent operation of unguided and unsupported volunteers.

Another advantage of the citizen advocacy schema is that in any state, it can certainly be implemented at least partially on the administrative level, without special legislation. At the same time, an advocacy office can utilize all existing laws that are relevant (such

as those pertaining to traditional guardianship, inheritance, trusts, foster care, etc.) while attending to the passage of additional laws which extend the range of options (e.g., laws relevant to co-custody, parental successorship, and so forth). In other words, an advocacy office can function quite effectively without a specific or even unified set of laws, although the latter would probably be advantageous.

Finally, advocacy brings previously uninvolved citizens into human problem fields. For instance, in Lincoln, Nebraska, many advocates for retarded proteges have joined the local Association for Retarded Children. Consumer, special-interest, and voluntary (self-help) action groups may find that citizen advocacy can be a major means for swelling their ranks with citizens whose interest is even nobler than their own. Especially in the parent movement (such as in mental retardation), members can now find intimate support and the kind of action they previously found almost only among themselves.

#### Can the Advocacy Schema Succeed Now?

There are already many programs in operation which constitute or resemble advocacy, but which lack a unifying conceptualization, articulation, terminology, and/or mechanism. I propose that there has never been a more propitious time for attaining these important elements, and for making the advocacy schema work. There are three trends in particular which inspire this confidence.

One of these trends is a new attitude both of and toward the consumer generally, and the consumer of human services specifically. Agency clients are now less apt to be viewed as charity recipients, to be

treated with 'indifference or contempt, and to be given the well-known agency run-about. Human services are increasingly being interpreted as rights rather than privileges, and such service consumers no longer cringe passively before the formerly god-like power and/or posture of the agency hack. In this new atmosphere, citizen advocacy is increasingly seen as a noble and desirable role--even by professionals once apt to view such advocates as useless trouble makers, much as parents of the retarded and other handicapped groups were once viewed. Thus, we see increasing acceptance of consumer action, and--for the first time--even extensive consumer representation within agencies themselves.

A second major trend is citizen volunteerism. Our nation currently appears to be in a phase of reaction to the trends toward centralization and formalization of societal processes. While such centralization and formalization will undoubtedly continue in many areas, citizens are seeking a balance to this trend, and readiness to volunteer for civic action appears to be a manifestation of this search.

Each Presidential Administration or family tends to have a personal, private "theme." The Kennedys had mental retardation, the Johnsons had beautification of the environment. The Nixons have citizen volunteerism as a "theme." This fact is likely to be both a manifestation of the above-mentioned movement, as well as a major boost to it.

The third trend is a disillusion with science and technology as exclusive or even major avenues toward the solution of social problems.

Citizens, especially youths, are turning increasingly toward the world of social thought: and direct human service for solutions. The citizen advocacy concept and schema can offer a highly sanctioned role to innumerable citizens who want to make a meaningful human service contribution, but who have already chosen careers in nonservice areas, who are under-utilized (e.g., housewives), or who aspire to careers of human service but still have many years of training ahead of them (e.g., students).

Earlier in this paper, public and voluntary human service agencies were contrasted in terms of how inspired or inspiring they tend to be. The citizen advocacy schema proposed here may well be capable of capturing the best of both worlds, by harnessing the volunteerism, the need to extend a human service, and the dynamism widely prevalent in our citizenry, while at the same time providing a public agency framework that elevates citizen advocacy to a civil right. However, while I believe that the advocacy schema can work now, I do not doubt that success will hinge upon the conviction, enthusiasm, and inspiration of the advocacy office personnel. An example is of interest here.

In 1968, a special research unit of the University of Nebraska Medical Center was to be discontinued. In this unit were eight mongoloid infants who had been transferred there from the state institution for the mentally retarded. Because of the progress the children had made in the intensive treatment atmosphere of this special unit, the staff dreaded the thought of returning the children to the drab understaffed, and uninspired state institution. It was decided to embark boldly on a search for foster homes.

As might be expected, the first thing that happened was that "experienced" professionals and agencies pontificated on the "proven" impossibility of finding foster or even adoptive homes for handicapped children generally, the retarded specifically, and mongoloids uniquely. Yet with the efforts of primarily two young and inexperienced professionals--both only with bachelor degrees in nursing and general studies, respectively--foster homes for all children were found within nine weeks. Had the children been legally free for adoption, which they were not, several adoptive homes might well have been found. In fact, some of the current foster parents would probably consummate adoption if it were possible. Of course, the placement procedures were highly unorthodox, and circumvented the traditional child placement agencies. For instance, the two young workers recruited foster parents by drumming up publicity, arranging to have several articles in the local newspapers, and appearing on TV spots and appeals. Much was learned by all from this episode.

#### Some Working Models

The citizen advocacy concept has already been embraced to a significant degree in Nebraska. For instance, one of the five principles that underlie the Nebraska plan for services to the retarded (Governor's Citizens' Committee, 1968a, 1968b, 1968c) is: "Each retarded person, particularly if he resides in an institution, should have a special relationship to a competent individual who will act as his personal advocate, vigorously representing his interests and safeguarding his welfare."

The first two citizen advocacy services in the nation were established in Nebraska in early 1970. One of these services was initiated by the Capitol Association for Retarded Children, and is located in Lincoln, the State Capital. This advocacy office, even though it has been operating on a very small budget and for a short period, has had remarkable success in establishing advocacy relationships for the mentally retarded, and in gaining acceptance of the concept in the community. With the help of an advisory committee and several subcommittees, the director performs the functions of an advocacy office as listed earlier, such as recruiting, selecting, orienting, guiding, and reinforcing citizen advocates. The committees mentioned consist of representatives of various agencies and services, as well as interested citizens, advocates, and even proteges.

Initially, this advocacy office has given priority to the establishment of advocacy relationships for retarded persons who are about to return from the institution to the community. In one newly-established community hostel, every retarded resident has an advocate. Many of the retarded persons who have been assisted by this service have changed dramatically after their return to the community. One adult man had resided in the state institution for almost his entire life,

<sup>7</sup> Initially, this service was funded by federal block grant money channelled via the Nebraska Department of Health and the Nebraska Office of Mental Retardation. Funding was continued primarily by the local United Fund (Red Feather) agency. The director of the advocacy office is responsible to the executive director of the Capitol Association for Retarded Children.

and is now being sponsored by a family in the community. After a brief period of confusion and getting used to one another, some remarkable changes took place in everyone involved. The retarded man had never made a telephone call, shopped groceries on his own, selected his own clothing, prepared a meal or cleaned up a kitchen, negotiated through a city atmosphere, or gone on a do-it-yourself family-style picnic. These things we take for granted, and we can really not teach them too well except within the context of normal and individualized interactions and practice. This, advocates can do, and can do infinitely better than agencies. The advocate family mentioned above is teaching these things to their protege, and today it is conceivable that he eventually may become an independent citizen in the community, with assistance from his advocates only as he wants or really needs it. There are many other retarded persons who have undergone similar improvements after being given the opportunity to reenter their community through the help of advocates.

Very similar examples can be drawn from Edgerton's (1967) description of the community lives of retarded adults who had returned from the institution to the community, and whose success or failure often hinged on the presence or absence of persons who played advocacy roles in their lives. However, advocacy is not merely needed as an adjunct to rehabilitation, but for many other social, legal, moral, and emotional reasons as well.

In addition to this advocacy service on the county level, there is also a state-wide youth advocacy service, originally coordinated by the

Nebraska Office of Mental Retardation. This service marshalls the idealism and energy of young people from across the entire state, and encourages one-to-one and two-to-two relationships between them and residents of the same or lower age at the state institution. These young people come in bus loads on weekends, and interact with their proteges who are children and youth who will likely return to their communities as local residential and other services are being implemented. At the institution, the young advocates interact with their proteges, but they also ask probing questions about institutional care and handling, and may campaign for better procedures and conditions.

As the proteges return to their communities, they will find there one or two young citizens who know them, who have an intense interest in them, and who may continue their advocacy for life. In some ways, this youth advocacy resembles the so-called "buday" or "big brother" system, but in its intent and nature, it goes beyond it.

The "Big Brother" movement is a pure example of citizen advocacy, except that it is limited in scope (e.g., proteges are mostly younger adolescents of the same sex who lack at least one parent), in mission (being mostly expressively oriented), and in length (being mostly of moderate duration).

Another working model, this one in the State of Washington goes by the name M-2 (an abbreviation of "man-to-man") and is operated by a non-profit corporation called Job Therapy, Inc. Since 1965, it has arranged advocacy relationships between citizens and imprisoned felons,

with heavy emphasis on facilitating the felon's successful reentry into the community after release from prison. This program has reduced recidivism drastically. It is noteworthy that the program (described in the August 1970 issues of both The Rotarian and the Reader's Digest) demands and elicits long-term commitments on the part of the advocates.

As the above examples show, advocacy services might concern themselves with a specific category of impairment; however, in the long run, it would probably be desirable if they served persons with all kinds of handicaps and needs.

Keen interest has been shown from across the nation and Canada in the Nebraska advocacy program, and establishment of similar services in several other states and provinces appears imminent. In order to facilitate the implementation of the advocacy schema, advocacy training programs for leaders on the state and national levels have been and are being conducted across North America. Generally such programs are addressed to individuals who can play major roles in disseminating the advocacy concept; who can initiate, support, and direct advocacy services; or who might come into massive contact with advocates (e.g., institution superintendents).<sup>8</sup>

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<sup>8</sup> For overheads, brochures, and other materials on the advocacy concept, contact the author.

## Some Words of Warning

1. Protective services of the past have had a tendency to function on an "all-or-nothing" basis. Within the proposed advocacy schema, recognition of the continuity of human needs and a commitment to the maintenance of human dignity imply an avoidance of "protective overkill," and adoption of a strategy of "minimal advocacy."

2. It is more important that citizen advocates be vigorous and dedicated than that they be always right. In balance, and in the long run, it is better that they represent their proteges' interest vociferously even if sometimes also irrationally. The mere fact that a person has a spokesman will often assure adaptive agency responses. Even if the spokesman's demands are neither reasonable nor met. Thus, agency personnel must be extremely cautious in assessing the quality of an advocacy relationship, and in interpreting their own responses. In agency work, a professional may be apt to belittle the advocate who is "a pain in the neck"--yet this advocate may well be the one who is effective.

3. For the very reason that advocates can make a lot of powerful people uncomfortable, the advocacy office should have maximal independence so as to be free from conflicts of interest. Ideally, the office should be funded privately, perhaps by Red Feather monies, private foundations, etc. If publicly funded, the administrative and control distance between the funding source and the office should be as wide as possible, and every means

should be used to maximize the freedom of the advocacy office, to carry out its functions without subverting influence. For instance, if advocacy offices are to be funded by state monies, it may be better to have such offices under the legislative branch than the executive one.

4. The staff of advocacy offices must resist possible temptations to "professionalize" the advocates, i.e., to expect them to function as miniature, quasi-, para-, or junior case workers, to undergo excessive training, to render case studies or extensive written reports, etc. Advocates are citizen volunteers, functioning in typical--though exemplary--citizen activist roles, utilizing normative societal means available to other citizens to achieve their goals.

5. Advocates"generally should not be compensated for their work (foster parenthood and subsidized adoptive parenthood might be an exception). Such compensation almost automatically creates the conditions for conflicts of interest, and destroys the essence of advocacy.

6. Although advocates are volunteers, they must never be viewed by agencies as volunteers to the agency; they are volunteers to specific persons.

7. For understandable reasons, relatives of the handicapped, members of voluntary actions, groups (such as associations of parents and friends of the retarded), and individuals handicapped themselves are particularly apt to volunteer themselves for

advocacy missions. However, many such individuals are already playing collective or other advocacy roles, and generally they should be discouraged from assuming additional advocacy functions (except perhaps committee work). Instead, vigorous efforts should be made to recruit unimpaired and previously uninvolved citizens as advocates, thereby both broadening the support base for advocacy, enhancing its image, and increasing societal understanding and tolerance of differentness,

8. Citizen advocacy should not be confused with the Nordic institution of the Ombudsman system. Our advocate may function as an "ombudsman" (with a small o), i.e., a spokesman; but he not an Ombudsman (with a capital O) who is a public official with powers to investigate citizens' complaints about malfeasance by other public officials. For example, in Sweden, the Ombudsman system consists of a national office with vast powers to investigate grievances, and with considerable moral authority in correcting official malfeasance or unresponsiveness. However, the system is not intended to involve the sustained individual and highly personalized relationships envisioned in the advocacy schema. While the Ombudsman office serves largely as an information center in Denmark, Finland, and Sweden, its presence as a watchdog has been considered to be one of the more important factors in preserving the Swedish people's confidence in democratic government (Rosenthal, 1964).

9. At present, a great deal is being said and written about advocacy. Unfortunately, most current advocacy concepts are very vague, and when advocacy is mentioned in connection with service systems, speakers and writers usually imply the need for advocacy within specific service agencies (Thursz, 1970, p. 33, 40 ff.). Unfortunately, such an approach to advocacy takes much for granted, e.g., that advocacy by an agency or within the service system is potent and effective in safeguarding the rights and welfare of agency clients. The citizen-volunteer advocacy sketched above should not be confused with such agency or professional advocacy, no matter how desirable the latter may be.

#### Conclusion

I see current protective service schemas as having been born at a time when comprehensive local human services were inconceivable to most Americans. Thus, several major protective service schemas involve a combination of advocacy and the rendering of social case work. In the future, however, such case work will increasingly be conducted by professionals in publicly-sponsored service agencies, and by 1980, the vast majority of our population will have available rather comprehensive local or regional services, especially in the fields of developmental disorders. With the increasing availability of such services, it becomes imperative to split the advocacy from the professional and agency service function.

Once operational, an advocacy office may have more demand for its services than it can handle, at least for some time. Also, until more

experience with operational advocacy services becomes available, we must leave open the possibility that some types of public guardianship may be needed. In consequence, I propose that as both advocacy and public comprehensive services develop side-by-side, the following courses of action be pursued.

1. Public guardianship powers should be legally vested in certain local service systems, but should be used as back-up where citizen advocacy proves insufficient.
2. Service agencies and advocacy offices should agree on a set of rules that would govern the liaison between them.
3. In addition, advocacy offices should develop statements of advocacy ideology for which they should seek endorsement from local service agencies. Agencies must learn to look upon citizen advocates not as bothersome nuisances or as adversaries to their identity as professionals or persons, but as adversaries to agency and societal weaknesses; as such, advocates should be viewed as partners in the quest for better human services, just as prosecutors and defenders in a court of law are not enemies of each other or of justice, but adversary partners in a process intended to yield the largest good for the largest number.

## References

- Allen, R.C. Legal rights of the disabled and disadvantaged. Washington: U.S. Department of Health, Education, and Welfare, 1969.
- Blatt, B. Purgatory. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services for the mentally retarded. Washington: President's Committee on Mental Retardation, 1969. Pp. 35-49.
- Blatt, B., & Kaplan, F. Christmas in purgatory: A photographic essay on mental retardation. Boston: Allyn & Bacon, 1966.
- Boggs, E.M. Legal aspects of mental retardation. In I. Philips & M.A. Esser (Eds.), Prevention and treatment of mental retardation. New York: Basic Books, 1966. Pp. 407-428.
- Coll, B.D. Perspectives in public welfare: A history. Washington: U.S. Department of Health, Education, and Welfare, 1969.
- Dybwad, G. Roadblocks to renewal of residential care. In F. Menolascino (Ed.), Psychiatric approaches to mental retardation. New York: Basic Books, 1970. Pp. 552-574.
- Edgerton, R.B. The cloak of competence: Stigma in the lives of the mentally retarded. Berkeley, California: University of California Press, 1967.
- Franklin, D.S. The adoption of children with medical conditions: Part I. Process and outcome. Child Welfare, 1969, 48, 459-467. (a)
- Franklin, D.S. The adoption of children with medical conditions: Part II. The families today. Child Welfare, 1969, 48, 533-539. (b)
- Franklin, D.S. The adoption of children with medical conditions: Part III. Discussion and conclusions. Child Welfare, 1969, 48, 595-601. (c)
- Governor's Citizens' Committee on Mental Retardation. The report of the Nebraska Citizens' Study Committee on Mental Retardation. Vol. 1. Lincoln, Nebraska: State Department of Public Institutions, 1968. (a)
- Governor's Citizens' Committee on Mental Retardation. The report of the Nebraska Citizens' Study Committee on Mental Retardation. Vol. 2. Lincoln, Nebraska: State Department of Public Institutions, 1968.

- Governor's Citizens Committee on Mental Retardation. Into the light. Lincoln, Nebraska: State Department of Public Institutions, 1968. (c)
- Helsel, E.D. Avenues of action for long-term care of the multiply handicapped. Rehabilitation Literature, 1965, 26, 262-278.
- Helsel, E.D. Annotated bibliography on protective services, Mental Retardation, 1967, 5(1), 10-15.
- International League of Societies for the Mentally Handicapped. International League of Societies for the Mentally Handicapped. Brussels: ILSMH, 1969.
- International League of Societies for the Mentally Retarded. Symposium on guardianship of the mentally retarded: Conclusions. (San Sebastian, 29-31 May, 1969) Brussels, Belgium: Author. 1970.
- Kugel, R., & Wolfensberger, W. (Eds.-). Changing patterns in residential services for the mentally retarded. Washington: President's Committee on Mental Retardation, 1969.
- Lehmann, V., & Mathiasen, G. Guardianship and protective services for older people. Albany, N.Y.: National Council on the Aging Press, 1963.
- Levy, R.J. Protecting the mentally retarded: An empirical survey and evaluation of the establishment of state guardianship in Minnesota. Minnesota Law Review, 1965, 49, 821-887.
- Massachusetts Association for Retarded Children. To keep on caring. Auburndale, Massachusetts: MARC, undated.
- Menolascino, F., Clark, R.L., & Wolfensberger, W. (Eds.). The initiation and development of a comprehensive, county-wide system of services for the mentally retarded of Douglas County. (2nd ed.) Vol. 1. Omaha, Nebraska: Greater Omaha Association for Retarded Children, 1968.
- Menolascino, F., Clark, R.L., & Wolfensberger, W. (Eds.). The initiation and development of a comprehensive, county-wide system of services for the mentally retarded of Douglas County. (2nd ed.) Vol. 2. Omaha, Nebraska: Greater Omaha Association for Retarded Children, 1970.
- Minnesota Department of Public Welfare. Looking ahead: Suggestions for parents of mentally retarded children. St. Paul, Minnesota: MDPW, 1956

- Moore, F.J. Development of a clinical decision support system.  
Yorktown Heights, N.Y.: International Business Machines Corporation, 1968.
- Nirje, B. A Scandinavian visitor looks at U.S. institutions. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services for the mentally retarded. Washington: President's Committee on Mental Retardation, 1969. Pp. 51-57. (a)
- Nirje, B. The normalization principle and its human management implications. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services for the mentally retarded. Washington: President's Committee on Mental Retardation, 1969. Pp. 179-195. (b)
- Parsons, T., & Bales, R.F., with Olds, J., Zelditch, M., Jr., & Slater, P. Family, socialization and interaction process. Glencoe, Illinois: Free Press, 1955.
- Payne, J.E. Ombudsman and advocate: New roles for social workers. Unpublished paper, Graduate School of Social Work, University of Texas at Austin, 1969.
- President's Committee on Mental Retardation. MR 67: A first Report to the President on the nation's progress and remaining great needs in the campaign to combat mental retardation. Washington: U.S. Government Printing Office, 1967.
- Rosenthal, A. The ombudsman--Swedish "grievance man." Public Administration Review, 1964, 24, 226-230.
- Standifer, F.R. Pilot parent program: Parents helping parents. Mental Retardation, 1964, 2, 304-307.
- Thomson, M. Prologue: A Minnesota story of mental retardation showing changing attitudes and philosophies prior to September 1, 1959. Minneapolis, Minnesota: Gilbert, 1963.
- Thursz, D. Consumer involvement in rehabilitation. Washington: U.S. Department of Health, Education, & Welfare, 1970.
- United Cerebral Palsy Association. Proceedings of the Conference on Protective Supervision and Services for the Handicapped; New Kensington, Pennsylvania, November 15-17, 1966. New York: UCPA, 1966.

- United Cerebral Palsy Association. Mandate for action in protective services for the handicapped: Report of the Conference on Protective Services. St. Louis, Missouri, September 16-18, 1968. New York, UCPA, 1968.
- White, W. & Wolfensberger, W. The evolution of dehumanization in our institutions. Mental Retardation, 1969, 7(3), 5-9.
- Wolfensberger, W. Counseling the parents of the retarded. In A.A. Baumeister (Ed.), Mental Retardation: Appraisal, education, and rehabilitation. Chicago: Aldine, 1967. Pp. 329-400.
- Wolfensberger, W. A new approach to decision-making in human management services. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services for the mentally retarded. Washington: President's Committee on Mental Retardation, 1969. Pp. 367-381. (a)
- Wolfensberger, W. The origin and nature of our institutional models. In R. Kugel & W. Wolfensberger (Eds.), Changing patterns in residential services for the mentally retarded. Washington: President's Committee on Mental Retardation, 1969. Pp. 59-171. (b)
- Wolfensberger, W. Will there always be an institution? II: The impact of new service models. Mental Retardation, in press.
- Wolfensberger, W., & Menolascino, F. A theoretical framework for the management of parents of the mentally retarded. In F. Menolascino (Ed.), Psychiatric approaches to mental retardation. New York: Basic Books, 1970. Pp. 475-493.