

17 normalization via citizen advocacy

Generally, a child in our society has one or two parents 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 children grow up, parents retain deep emotional ties to their children, but the problem-solving oriented aspects of child-rearing become less and less a part of the parental role. As children become adults, our society expects them to function with competent independence, and to solve their own problems. Such functioning is perceived as 'normal'.

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 rather readily provides a substitute for those parental functions that are concerned with clothing, feeding, and housing the child, much less attention is paid to meeting the child's emotional needs.

When a child who does not have a living or functioning parent also happens to be handicapped or impaired, his 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 love him, provide him a home, and to raise him, either on an adoptive or foster basis. Unfortunately, it is much more difficult to meet these needs of a handicapped child who is in such circumstances.

The needs of handicapped and nonhandicapped children 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 both emotional and practical problem-solving support to a degree as is ordinarily extended only 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, a boarding home, or one of the growing number of home-like hostels in the community. Even if a family could be found to take him in, we might prefer some type of group placement. As Nirje (1969) 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, if 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 who could help him meet the practical demands of everyday living –

and hopefully also his relationship needs – it was very likely that human management agencies would enter the case. 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. In many instances, he also became a ward of the state which, in many jurisdictions, meant that the institution superintendent became the legal guardian, even in those cases where the resident still had interested 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 achieving a higher level of functioning in many of the impaired, in keeping a significant proportion of persons out of institutions and nursing homes, 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, 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' mentioned several times in this book, when many of the handicapped were believed to be a major threat to society (*circa* 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 or his family. As this period passed, feeble efforts stirred here and there to re-establish an equilibrium between these interests, 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'.

The concept of protective services covers a wide range of provisions. Among these are trusts, conservatorship, traditional forms of individual adoption and guardianship, and less traditional forms of public guardianship. Of all these, public guardianship has been widely supported as a mainstay of the protective services schema (Helse, in press).

However well-intentioned, protective services (and particularly public guardianship laws and practices) have suffered from a number of major shortcomings. Among these are the unavailability or impracticality of many protective arrangements, the dull rigidity in which they are administered, the fact that conflicts of interest are built into the very structure and functioning of protective service agency personnel, the fact that agencies – again because of their very nature – can rarely provide the sustained individualized relationship so many clients need, and the inability of protective services to match protective measures to protective needs. Characteristically, a person who needed protection received either too little or too much.

Citizen advocacy was conceived in an effort to overcome the above shortcomings by recombining a number of old ideas, methods, and provisions; by adding new ones; and by uniting these into a coherent overall schema.

First of all, in citizen advocacy, competent citizen volunteers represent – as if they were their own – the interests of other individuals who are in some

way impaired, handicapped, or disadvantaged. Secondly, this relationship is structured on an individualized one-to-one, or at least one-to-a-few, basis. Thirdly, many of these relationships will be established on a sustained and often life-long basis. Fourthly, the functions of the advocate will be highly differentiated in order to meet a wide range of 'protégé' needs, while only providing the minimal amount of protection that is needed. Fifthly, the efforts of the volunteer advocates will be coordinated and supported by a citizen advocacy office.

Advocacy roles can range from minor to major, from formal to informal, and from short-term to long-term or even life-long. Formal advocacy roles might include adoptive parenthood, guardianship, and trusteeship for property. Informal roles include friend, guide, and what we have called 'guide-advocacy'. Some advocacy roles emphasize close relationships, and exchange of affection and concern. Others are more involved with practical problem-solving. Many roles fulfill both types of need.

Perhaps the most 'perfect' type of advocacy occurs when a citizen chooses to adopt and perhaps even rear a handicapped and/or neglected child. A less demanding role would be to provide transportation, clothes, counsel, or other practical assistance to the handicapped child of a family who loves and accepts the child, but lacks the means to solve the child's problems. An advocate could make certain that a person gets the education, training, and other services which the community has a responsibility to provide. Advocates could sponsor children without (adequate) family ties by visiting them, giving them gifts, or taking them on trips or to entertainments. Handicapped adults can be assisted in such practical matters as managing money, finding and maintaining living quarters, securing jobs, and learning how to use transportation services. Citizen advocates can give friendship and emotional support to the lonely and neglected by offering companionship, and by sharing worship or the observance of holidays and special occasions.

There is a vast number of persons who are in particular need of individualized citizen advocacy: hundreds of thousands of residents of our mental, penal, and corrective institutions, and of homes for the aged. Many of these persons will also need individualized citizen assistance upon their return to open communities, as will almost all of those who reside in sheltered settings within the community, where even highly dedicated agency personnel must relate to so many persons. For example, an advocate for a young retarded adult or emotionally disturbed person can contribute much to the successful adjustment of his protégé, keeping him out of trouble, teaching him how to use his free time well, and offering advice and support in time of stress and crisis. In some cases, advocates and young persons of the same age who are being rehabilitated could live together in apartments, sharing skills and fellowship, and making more normal, adjusted living possible. (A small program similar to this is currently being operated in Omaha.) Persons once rejected by society for inappropriate action can be assisted to make acceptable social and job contacts in the community by their individual citizen advocates.

Many parents of retarded or physically disabled children look after the interests of their own child as long as they are able, but have great fears and misgivings about their child's future when they are no longer healthy or living. Citizen advocacy could be the means of providing attention to such a

retarded or physically handicapped person, and of preserving the overall type and quality of life that he enjoyed with his real parents.

However, volunteer efforts of the citizen advocacy type will never play a major role unless coordinated and backed-up by a stable administrative mechanism. The advocacy office was therefore 'invented' to be this mechanism. This office attracts, selects, orients, guides, and reinforces citizen advocates; it assesses the needs of a person for advocacy, as well as the abilities of the citizen volunteer to contribute through advocacy. The office conducts advocate training, with emphasis on commitment to the concept; understanding of the protégé's condition; knowledge of laws concerning the rights of handicapped and disadvantaged persons, and of services of potential use to them; and many other areas of action. Furthermore, advocacy offices can provide practical assistance to advocates, and mediate legal and professional services that may be needed by the advocate and his protégé. An important point, though, is that the advocacy office does not conduct advocacy itself, but makes citizen advocacy possible and more effective.

When the advocacy schema was first articulated in 1966, leaders in the field rejected it as too idealistic and unworkable. Idealistic it is – but it is working nevertheless.

The first two advocacy services were initiated in Nebraska in late 1969 and early 1970. One of these is operated, primarily for retarded protégés, by the Capitol Association for Retarded Children in Lincoln, the capital of Nebraska. This office received one of the first presidential citations for volunteerism (January, 1971). It is currently funded jointly by federal social security monies and the Lincoln United Community Services, and was the prime feature of the latter's multi-media presentation which keynoted its 1971 fund-raising efforts.

The second advocacy service is a youth advocacy service which has recruited and guided approximately 180 young people from all over Nebraska to play advocacy roles to residents of similar age, and from their home communities, who reside at the state's institution for the retarded. One goal of this program is to provide continued support to these residents upon their anticipated return to the new community residential services.

Both of these Nebraska services have been widely imitated across North America. As of June, 1972, a total of at least 27 citizen advocacy offices have been initiated, including three state-level ones, 23 local ones, including four in Canada, and one other large youth advocacy service in St. Louis. Efforts to implement are underway in numerous other locations.

The fact that the advocacy schema was implemented first in the field of mental retardation is an historical accident, due probably to the reawakened dynamism in that field which is coming from way behind in setting the pace for certain other fields. From the first, advocacy was intended to be for anyone who needs it. While we can expect to see the development of advocacy offices serving specific groups, we will probably also see the initiation of generic advocacy offices.

On one point, the reader must be specially cautioned. Advocacy as sketched here is not the same as various other types of advocacy concepts and schemas which have recently been developed that imply advocacy by agencies and agency employees rather than by citizen volunteers (who are also free of conflicts of interest), that imply advocacy to groups of individ-

uals rather than specific persons, and that do not rely primarily on sustained and individualized relationships.

The advocate's loyalty is to his protégé, not to an agency or even the advocacy office. Thus, he is a volunteer to the person, not the agency, and a very important part of his mission is implementation of the protégé's rights. Advocates see to it that protégés receive the services to which they are entitled, and are accorded the privileges of their citizenship. Pursuit of a protégé's citizenship rights may include such a basic symbolic act as seeing to it that he can cast his ballot at the polls. Advocate action may necessitate confrontation with agencies, and perhaps even legal action. In some ways, it implies consumer militancy with legal weapons, such as we have seen increasingly of late, and which has resulted in historic court decisions in Pennsylvania, Alabama, and elsewhere. Unfortunately, it was not possible to produce a chapter in this book on this very relevant topic of the role of the organized consumer movement in the implementation of normalization principles.

Because advocates will not always be viewed with favor by agencies, and because they must often become militant, it is of the highest importance that advocacy offices be funded and administered as independently as possible. Preferably, such offices either would be attached to voluntary agencies (such as chapters of voluntary associations in the field of cerebral palsy, mental retardation, *etc.*); be totally independent; be attached to the legislative branch of government, much like ombudsman offices; or be operated by Community Chest (Red Feather) conglomerates.

The citizen advocacy schema has received intense national and even international attention, and implementation is proceeding apace (Zauha & Korn, being published). This sketch here provides only the barest overview. Much like the description of PASS in the next chapter on 'Normalization via agency performance assessment and differential funding', this chapter is only intended to orient the reader to yet another way of implementing the normalization principle, and to entice him to study the advocacy schema in detail in another source (Wolfensberger & Zauha, being published). While advocacy activities can be described and interpreted in many ways, ultimately they imply a normalization of protégé functioning: to obtain for him, as much as possible, an existence comparable to that of other citizens.