

PART

5

**ACTION AND
ADVOCACY**

CHAPTER XIII

NEW DIRECTIONS FOR VOLUNTEERS

by Robert Perske

Not long ago volunteers operated almost all community-based services for mentally retarded persons. Today this is changing. Professional community-based services are beginning to appear. That these services are rapidly increasing stands as a tribute to the volunteer efforts of (first) hard-working parents of retarded citizens, (later) professionals who caught their spark of hope and gave their free time, and (still later) volunteer citizens in the community who were turned on to the cause.

And yet, as professional agencies take over the functions of such "parent groups," one wonders what will become of the countless organized volunteer agencies which dot the American scene—volunteer agencies which, with lots of moxie and little money, provided those first services -on-a-shoestring for retarded citizens in the community. The following possibilities can be conjectured:

1. Some volunteer agencies will diminish to less powerful activities, locally. Some may even die out.
2. Others will welcome their new roles and missions as volunteers.

Locally organized volunteers may choose to take the following directions. In doing so, they would tend to come alive in a new, but just as vital, way. They would operate independently as a volunteer organization. Yet, they could develop interdependent partnerships with service agencies for retarded citizens in the community. Since they will develop their own policies and point of view, at other times they may reactively oppose these service agencies.

SOME NEW DIRECTIONS

Public Attitude Change Task Forces: In some towns, volunteer groups are trying to change public attitudes. Now that retarded citizens are coming out of institutions and rubbing elbows on the streets with others, these volunteers have observed

new forms of negative attitudes on the part of some. They have observed raw prejudice from a few vocal citizens when small group homes are started on certain blocks. Volunteer task forces have organized to counteract exactly these destructive prejudices toward retarded persons. The following examples show some tasks carried out by such forces:

One group of volunteer parents of retarded persons organized as couples and visited with all families on a street where the county agency sought to purchase a small group home for four small mentally retarded children from a local institution.

Another committee methodically surveys newspapers, TV, and radio for helpful statements about retarded citizens as well as negative ones. They respond with grateful letters to those making positive statements. They respond firmly to those making demeaning ones. For example, when a state-employed physician was quoted in the press as alluding to a small group of multi-handicapped children in a community developmental center as "vegetables," this committee sent letters to him, his superior, and even the Governor, requesting him to correct his vocabulary. Happily, this committee makes nine contacts of gratefulness for every confronting one.

Another committee has recognized prejudice on the part of student bodies and teachers now that more retarded children are attending public and parochial schools. They have organized to visit with school boards and faculty groups to clarify the situation and eradicate myths about retarded persons.

Organized volunteers who work at fostering healthy attitudes toward retarded persons in critical situations may find the surrounding service agencies deeply grateful for their actions in the community.

Agency Monitoring Efforts: Some volunteer task forces will monitor specific community agencies according to an orderly plan. One organization has developed separate task forces for each of the following: community residential services, vocational services, developmental centers, public and parochial school education, and nursing homes where retarded citizens reside.

Agency monitoring by volunteer groups is emerging as a skill with its own body of knowledge. The following functions are currently being refined:

1. Regular visits where check lists or written reports are used objectively and respectfully.
2. Procedures for handling grievances from parents about the agency or vice versa.
3. Developing an ability to respond candidly and firmly when they, as an objective outside group, perceive imperfections in the agency.
4. Pointing out and responding gratefully to areas of excellence.
5. Assisting in the celebrations when a new agency unit opens.
6. Holding press conferences to defend an agency unit that has been unfairly attacked.

Volunteer groups can win a new authority as a helpful monitoring force. As they win respect for their service, some agencies will open themselves and welcome such volunteer action. As a result, the agency will undoubtedly be a better one.

Pilot Parents: Some volunteer groups know of certain parents who have successfully worked their own retarded child into their family system. They are singled out, recruited, and trained as Pilot Parents* who are assigned to parents of newly-identified retarded children. The ones who have "been there" help the others to feel they can make it too. Pilot Parents are not counselors, caseworkers, or therapists. They use a powerful development force, "peer group education." They compare notes, discuss common problems, socialize together, and generally help each other achieve healthy development in the human situation which they share. They help parents find the appropriate community agencies for their child.

Actually, Pilot Parents' activities are not new. This sort of activity has been carried on for years. Recognizing this as a valuable service, volunteer groups have organized it into a coordinated effort. As these volunteers are recognized for the service they can render, agencies and professionals tend to make referrals to such organized volunteer groups.

Citizen Advocates: Now that more retarded citizens are struggling to grow, develop, and make it in the community, citizen advocacy programs are emerging as a helpful aid. After careful screening, Citizen Advocate candidates undergo an intensive training program in learning about mentally retarded persons, their human rights, and human needs. If they successfully complete the course, they are each helped to develop an advocate/protege relationship with a mentally retarded person

* In this case I have called them "Pilot Parents." Actually such groups have many names, e.g., "Resource Parents," "Empathy Bureau," "Parent to Parent," etc.

to whom they are assigned. They undergo a continuing period of supervision.

Some voluntary organizations work to inspire ordinary citizens from the community to develop a regular one-to-one relationship so well defined that one can even choose the exact level of relationship: ranging from regularly visiting as a trusting friend, to foster parent, adoptive parent, guardian, or conservator.

Creative Programs to Find Quality Guardianships in the Community: Some voluntary organizations are considering finding qualified citizens who will take on guardianship and conservator responsibilities. Because this avenue is new, little can be said about it yet. However, some organized volunteers appear to be coming up with guardianship models of higher quality and increased responsibility.

Youth Relationships: Some voluntary agencies are now developing organized youth relationships. Some center around community-based facilities; others are organized in high schools, churches, and colleges. Some organize as service clubs. The most successful tend to be small groupings of youth in which one-half of the membership is mentally retarded. Some voluntary agencies seek to develop small groups throughout the city and tie them together through a single board of steering committee.

Government and Legislative Action Forces: In the past organized volunteer agencies have excelled at lobbying, testifying at hearings, personally contacting legislators and government officials, holding community forums, letter writing, and participating in telephone and telegraph campaigns. This will continue. In some instances, organized volunteers may choose to team with community-based professionals to form a creative force for healthy government and legislative change. At other times, if social and legislative change is to be accomplished, they may choose to oppose certain community agency policies.

New legislative action may spur more parents of retarded citizens and more volunteer citizens to speak for themselves. Less and less will local voluntary agencies have professionals speak for them. In one voluntary agency, the executive director refuses any longer to lobby or testify; he trains the volunteers to do it themselves. If professional expertise is needed, it is recruited from the community-based agency. Watching volunteers and professionals stand and testify side by side is exciting.

Action Groups in Low Economic Sectors: Most voluntary agencies had their beginnings in the middle class. Now, some have become aware of retardation problems in low-income areas.

At the same time, they have discovered a creative force of people within low-income areas who are anxious to join the cause. As they join and participate in missions for the retarded, the voluntary agency takes on an added healthy quality. Citizens from low-income sectors have much to contribute to the general cause as well as to their own community.

Often organizations must adjust or waive membership dues in a dignified way. In one organization volunteer members are invited to "sponsor" an active member from the low-economic sector of the city by paying the price of that person's membership. Another group assists low-income persons with bus, cab, or auto transportation to places where they can do valuable work. Babysitting may be needed, as well.

One group has assisted persons from low-income sectors to organize campaigns to fight rubella and lead-paint poisoning. It assisted them in their struggles to obtain community-based services in their area (e.g., vocational training centers, counseling centers, public school education, and child development centers). Also, the group computes the number of useful volunteer hours given to the cause, which to this day is increasing. Now, members from low-income sectors serve on the board of directors and on many all-city task forces.

Human and Legal Rights Task Forces: As voluntary agencies work in partnership with community-based services to insure a richer life for retarded citizens, they perceive one painful thing. They see the many human and legal rights that have heretofore been denied to persons labeled "mentally retarded."

Among these are the rights to education, to treatment, to free choice, to risk-taking, to healthy sexual development, to a life as normal as possible, to community living, to the least amount of restriction possible, and to developing one's highest potential.

Voluntary agencies can develop task forces to face both the general instances of denied rights and the individual critical human situations where the joy of living and growing is being squeezed out of a retarded citizen's life because basic human and legal rights are lacking.

Voluntary associations have already confronted larger statewide and communitywide problems even to the point of going to court. Volunteer task forces will apparently now organize to solve individual problems also.

Because of vested interests, community-based agencies are sometimes unable to become involved in such human and legal rights struggles. But the voluntary agency, free of political

and governmental ties, can be objective and powerfully influential in such struggles.

Program Innovation Task Forces: In a good partnership between a voluntary agency and a community-based service, volunteers can plan and develop innovative programs which eventually will be "spun off" to the direct service agency.

In one low-income area, a committee of mothers wanted to extend the special education or developmental experience into homes. So, with professional advice, they drew up a grant request for an educational toy library. The government agency approved the grant in the amount of toys and equipment. For more than a year, volunteers developed and staffed the toy library. Then, when it was operating, the toy library was turned over by predetermined plan to a community service agency.

A pilot parent group felt a strong need for current books and information on mental retardation which would help in their relationship with "piloted parents." With technical assistance, the volunteers applied for grant money to develop a book lending library. The grant was approved in the amount of the books needed. The volunteers developed a central library area and many satellite library areas throughout the city in the community-based services and schools. Soon this library will be spun off as well.

Such program innovations again illustrate how volunteer service and direct service agencies can dream, plan, develop, and work together according to a common schedule.

The Power of Ad Hoc Task Forces: Any alert voluntary agency soon learns that ad hoc task forces assigned to a specific situation can have a unique creative power as well as a healthy effect on morale. An ad hoc committee can meet and plan and carry out a task; then evaluate and report on it; and finally disband with every member walking away feeling some sense of worth and accomplishment.

One community-based agency asked its volunteer partners to develop a committee of parents to discuss the situation of two young couples who wanted to get married. They spent three sessions discussing the subject of sex, marriage, and mental retardation. In the last session they developed their "awkward and unfinished" guidelines on the subject. But these guidelines, coupled with those developed by a small group of professionals as well as a small group of retarded citizens, gave everybody some new insights and new directions for the community. Such a volunteer action allowed people to look ahead and plan, even when faced with the most difficult questions.

Examples of other ad hoc committees are:

A committee to study aversive punishment in a specific behavior shaping program.

A committee to focus on a particular piece of legislation concerning the right to education.

A committee of both volunteers and professionals to study medication problems in a small group unit of multihandicapped children.

All Volunteers Are Advocates: The above examples are only a few of many now emerging. But all this work has two aspects.

First, *volunteers do the meaningful work.* If the voluntary agency has paid staff, their job is to recruit, train, inspire, enable, and sustain volunteers in doing meaningful jobs. This kind of work is a far cry from envelope stuffing, stamp licking and general "dog-work."

Second, everything the voluntary agency undertakes tends to be group advocacy, individual advocacy, consumer advocacy, citizen advocacy, youth advocacy, or other types of advocacy. Although a mentally retarded citizen may need many supportive services to make it in the community, he may also need a wide array of volunteer advocates.

SOME HARD FACTS THAT MUST BE FACED

Any voluntary agency that successfully emerges with some new directions must confront certain hard situations. A few of them follow.

No Longer "Parents Alone": In the early days of voluntary organizations for retarded persons, the parents banded together, shared in each others' problems, and started the first community services. For the most part, these parents were very much alone.

But, as they succeeded, professionals volunteered their free time. Then, catching the spirit of this new movement on behalf of retarded persons, other citizens chose to join the cause. Today a successful voluntary organization has parents, professionals, and citizens, locking arms and moving forward together.

Parent Loyalties Will Be Divided: Some parents will continue to be thrilled that new community services are coming to their community. They will be willing to work hard and to advocate for them. Other parents may not be so enthusiastic. Some may feel that their son or daughter has all the service he or she needs and will feel no urge to advocate further. Others

will not see community-based services as something their son or daughter should have. Instead, they may tend to see the institution as the only place for their child.

Voluntary Organizations Are Dispensable: Many volunteer groups have worked, thrived, and achieved at certain points in history. Then, when other agencies take over the activity, the volunteers tend to diminish. Voluntary agencies have provided many community services for retarded citizens. Now that others have assumed this responsibility, the voluntary agencies must come alive with another cause and mission or they will eventually be dispensed with. A voluntary organization must be genuinely useful to survive.

Voluntary Agencies Cant Compete with Efficient Comprehensive Community-Based Services: It is quickly becoming impossible for voluntary agencies to do the job of direct service delivery as efficiently as professional agencies with the backing of legislative mandates and government funding. Voluntary agencies must find a new strength and serve as the strong supporters, confronters, and monitors of those services. Furthermore, they must achieve a new cooperative relationship with organized volunteers working for cerebral palsied persons and persons with epilepsy and other developmental disabilities. In a sense, voluntary associations have been hoping for this relationship for many years.

SOME HOPEFUL OPPORTUNITIES

When the problems surrounding change are solved, unusual opportunities seem to arise. The following are a few.

Parents Will Continue as a Vital Force: When parents give birth to a child, they're in for some work. If the child has retardation problems, they'll have some extra work. Those successful in accomplishing the extra work needed to understand, accept, and adjust their child into the family system often find increased growth and development in themselves. Persons like those often become the longtime stabilizing force of a voluntary agency. Since their longtime relationship with their retarded child keeps them involved, they may be more stable. Meanwhile, professionals often shift their loyalties; they may even work for a while in mental retardation and then move to another field.

Parents, Professionals, and Citizens Should Train Together Often: As awkward as it may seem, some of the most creative breakthroughs in our movement resulted from these three types

of persons getting together to carry out a critical task. They didn't always speak the same language. But we are learning that these individual differences help groups to be more creative. Organized parents can have an uncanny way of confronting and provoking new thinking in professionals. Likewise, the professional has much to teach parents. The citizen watching such interchanges can offer some remarkable things from his perspective. The voluntary organization can provide the arena for this fertile three-way creative process.

Community-Based Services Can Thrive When in a Strong Partnership with an Efficient Voluntary Agency: The possibilities of a two-way partnership are numerous. Each has a separate well-defined division of labor. The volunteers can advocate government funding for the community agency. The community agency can advocate donated funds for the voluntary agency. Professionals can leave their agencies in the afternoon and work as volunteers in the evenings. Volunteers and professionals can testify at hearings together. These are only a few of many creative opportunities possible.

A Fertile Body of Knowledge about Volunteers is Emerging: Today we are learning much about understanding volunteers and enabling them to do valuable work. An exciting body of knowledge is emerging. One can learn the way to successfully reinforce and gratify achieving volunteers. One can even direct volunteers so that they neither underachieve nor are exhausted. They can be protected and respected as valuable persons, and they needn't be exploited. People will volunteer for a cause that excites them and helps them to make this a better world. The "age of volunteers" is here; if our cause does not capture the interest of people, other causes will. Paid staff persons in volunteer organizations learn to develop creative skills as "inspirers" and "enablers" of others who do the meaningful work. They learn that in a voluntary agency esprit de corps comes when "success is allowed to build on success." When they feel they want to leave, volunteers can be helped to terminate with dignity. One learns how to help volunteers to feel as if they were part of a family-like task force as well as a member of a large mission. In short, volunteer agencies can be alive. They can be exciting. One can develop a deep sense of achievement in them, while doing a lot of good at the same time.

CONCLUSION

One can look back and marvel at spunky local volunteer associations for retarded citizens who with much energy and

enthusiasm helped our civilization to make a social somersault. Once, those called "mentally retarded" were expected to live out their lives in institutions; today, society expects that they should live in the community. Community-based services are a growing reality.

But, one wonders what will happen to those many local voluntary organizations which worked so well to bring us this far. What will become of them? What's ahead?

Clearly, in this age of volunteerism, the local volunteer associations can thrive in some new ways. They could develop a wide array of thoroughgoing advocacy programs. They could develop a healthy independent partnership with community-based agencies. Frankly, community-based agencies need their volunteer partners: sometimes the volunteers will collaborate with them; sometimes the volunteers will objectively disagree and confront them. But the agencies need these partners all the time.