NIMA RISOURCE

VOLUNTEERS

WHO HAPPEN TO BE

DISABLED

PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED WASHINGTON DC 20210

1985?

PREFACE

At the time it seemed natural. As a human services professional I had supervised projects that were dependent upon volunteers, although there had never been any disabled people among them. However, in the interim I had become blind and had worked closely on a number of projects with a whole range of disabled people. When I was asked to coordinate a federally funded volunteer project to address the community needs of older adults and disabled people, I assumed that individuals from both groups were to be included and therefore recruited a team made up equally of disabled, older, and able-bodied volunteers. Only later was I told that this had not been a part of the original plan, but by that time the group was already actively involved in the project.

The team that met the first day in 1979 was varied: it was a mix ethnically and racially, and there was a half century range in age. There was a prim little lady who wore white gloves and a big hat with cherries, a young blind mother who knew little about her community but had dreams in her eyes, and a young

man with severe cerebral palsy who had long hair and a beard and frightened everyone with the speed of his motorized chair. This unlikely trio turned out to collaborate effectively on lobbying efforts at the state capitol.

While the younger and able-bodied volunteers may have originally faced their new colleagues with some discomfort, all discomfort seemed to fade as people concentrated on the best way to address the target of concern: community facilities available for disabled and older citizens. Eventually, friendships were formed across the lines that had previously separated the different "groups," and the whole team worked together efficiently to carry out a successful project.

My positive experience in working with volunteers who happen to be disabled had convinced me of the importance of utilizing this valuable human resource. Disabled people make able volunteers. This brochure is an effort to share with you some tips on low-cost, practical ways of removing barriers to their full participation.

---Mary Jane Owen, MSW

INTRODUCTION

"The volunteer spirit is still alive and well in America."

"We need to make the 1980s years in which disabled individuals achieve the greatest possible access to our society, maximum independence and full opportunity to develop and use their capabilities."

-President Ronald Reagan

This Presidential challenge emphasizes the need to reassess the role of disabled people in our society. He suggests that you, as program administrators, can help to turn a group of people who are often thought of as recipients of services into a strong and vital national resource.

Someone who had never had the opportunity of seeing printed words on paper, when confronted with this new experience, said: "But which do I read—the black part or the white part?" A fresh vision can enable us to look at the same individuals we had classified as "problems" and realize that they are in fact potential assets.

THE EVOLVING PERCEPTION OF VOLUNTEERS WITH DISABILITIES

The following quotations illustrate the evolution of attitudes of program administrators over the past decade toward the use of volunteers who happen to be disabled.

"We always refer such people to the Department of Vocational Rehabilitation. Aren't they the ones who handle such problems?"

"We really don't want our waiting rooms to look too much like a charity ward or the local nursing home lobby. We don't want to discriminate against anyone, but our primary client group are the normal people who happen to have some problems."

"They certainly have to be taken care of but we are not equipped to do it here."

"Oh, no, we do not discriminate against the handicapped. We already serve them."

"I would like to tell you a success story about an agency here in town. I work for a disability office as an information specialist, and I got a call from a crisis center for battered women several years ago. A woman had been referred to the center by the emergency room of the local hospital. Her broken bones and bruises had been treated and she needed a place to go. They had sent her over by cab. The administrator who called me was in a panic because the woman was BLIND. I asked a few questions unrelated to the blindness. It seemed an appropriate referral. The woman had an increasingly abusive husband she wanted to get away from; she needed to get her strength back; and she was wanting to get legal advice as to future options. The administrator, however, kept insisting impatiently that the woman was blind. Finally, I asked her what problems she foresaw with having a blind woman in the shelter. She began to talk about the need for a person to feed the woman, to walk around with her, to help her dress, etc. She was also concerned that there were young children who left toys, and she knew the woman would fall. I asked how the woman had arrived at the shelter. It turned out that she had appeared at the door unaccompanied. 'How do you imagine she managed that if she is really

so helpless?' I asked. 'Have you asked her what assistance she thinks she will need, given the surroundings?' The administrator continued apprehensive. I suddenly realized that I had one more card to play. 'Do you realize that I am blind?' I asked. There was a startled pause and then she said. no. She seemed a little nonplussed. I suggested that she simply tell the blind woman about her concerns and see what they could come up with in terms of practical accommodations. As it turned out, the admission of this woman into the program was a real plus for everybody. She was wonderful with children and took responsibility for entertaining them while she lived at the shelter. Later, she and another woman took an apartment together. She now has a job and continues to serve the shelter as a volunteer counselor."

"I realize that I have put a lot of effort into making our offices as accessible as possible because I wanted to make us a real resource to the community. After going over the material on using disabled volunteers, I realize that I had gone part way. I thought of offering the services. It is really funny now that I think about it that I did not think about opening up the opportunity to disabled people as volunteers. We have several now, and it is working out just fine. Some of the staff were concerned that we would get some negative comments. but all the responses have been positive. And you'd be surprised at how many disabled people are coming 'out of the closet' so to speak. We never realized that there were disabled relatives in some of the families of people we knew quite well. They just never mentioned it, and now they do."

"It was odd, because I thought I was so sensitive to disability issues. I had taken one of those 12-hour training sessions in a wheelchair. But I learned more than ever when a broken leg placed me in a wheelchair for several weeks. People have a different tone of voice they use. I think part of it is just that they physically 'look down' upon someone who is at such a lowered position. It is as though your body suddenly was only three feet tall again and they have a mind set

that a person that close to the ground should be talked to like a child. And more than that were the day-to-day frustrations of just getting around. There are a lot of what I now call 'senseless barriers.' The ideas about accessibility for volunteers who are disabled really give practical advice."

"The material on using disabled volunteers really made me think about things in a different way. I have been concerned about people with disabilities. I became aware that almost all of the families in our community had some friend or actual family member that had some disabling condition. So I decided that we could call together a group of parents of disabled children. It turned out to be one of the best fund-raising tactics I ever used. It wasn't for that reason that I originally did it, but it turned out that so many of these people were on the top of the pile in terms of money and influence. And the parents who didn't necessarily have the personal funds to contribute turned out to have such enthusiasm in helping to make things better in the community for their kids. It has given a vitality to our program that we were lacking before."

"We have been using volunteers who are disabled for some years now. We learned that they make very able volunteers when their special needs are met. We added ramps and some other accommodations. Then we just sort of forgot that there is a difference. I feel good about that and I think our volunteers do, too. We give them all a good orientation and training. We believe in adequate preparation for all our volunteers. We try to be sensitive to any problems that might come up, like vision or hearing needs, but once we let people know we are concerned about helping them be the best possible volunteers, we just kind of let them fade into our pool of resource people."

SOME CURRENT EXAMPLES

The attractive woman behind the reception desk greets newcomers to the mental health clinic. She reassures them and checks their names off the list of expected participants. After they accept her offer of a cup of coffee, she rolls over to the urn in her wheelchair while asking if they want sugar or cream. It is only at this point that they realize she is disabled.

The strong and vibrant voice calls to ask for tax-deductible contributions for the animal rescue unit in a metropolitan area. He obviously has studied the issues and illustrates the cost-benefits to the busy people he is calling. He consults his notes when unusual questions are asked or promises to get back with additional information. He takes down information rapidly and only those used to the sound of a braille writing unit realize the volunteer they have been talking with is blind.

The dramatic poster illustrating the need for expanded library services is seen all over town and the good publicity results in a large turn-out at the town meeting called to discuss the issues. Those who attend the gathering are vaguely aware that an interpreter for the deaf is signing for several of their fellow citizens. It is only as the organizing committee is thanked for their contribution to the success of the meeting that the participants realize that the volunteer in charge of all graphic and written materials is deaf.

Those who had not seen the grounds around the community center are impressed by the colorful flower beds that had been laid out next to the walkway. The colors of the blooms and foliage are artistically arranged and there is not a weed in sight. If anyone

cares to ask, they are told that one of the volunteers has taken over responsibility for the small plots of earth. He had approached the volunteer coordinator with a rather awkward manner and had said he would prefer not to do "paper work". In fact, he had seemed nervous until he was told there were other things that needed to be done. He jumped at the chance to garden and said he'd always enjoyed working out of doors. It was weeks later before he acknowledged that he had great difficulty with verbal directions and did not get along well in structured work situations. He is a glass blower by profession and his work is displayed in many large museums. He has a learning disability.

The guide to city restaurants and recreation facilities is well organized and researched. There is an indication of prices and types of food for a range of restaurants and the hours and admission costs of museums and theatres are included. Many points of historical and cultural interest are described. Maps that illustrate transit routes are included. There are simple line diagrams of the major city regions and all information is cross-referenced in the index. The agency which served as host for a large national conference had suggested to several volunteers that a guide to the city would be appreciated by the out-of-town visitors. A group of friends worked on the project together. They all lived in a half-way home for emotionally disabled adults and had approached the agency as volunteers following a pleasant visit to learn more about community resources. Because the task had sufficient lead time, there was a minimum of stress. The volunteers worked as a team within their own time frame. Everyone associated with the project is pleased.

Local citizens are concerned about how budget cuts will affect community service programs. The Volunteer Clearinghouse has been given the responsibility of

reviewing how volunteers can be used to cut down on budgeted expenditures for a variety of services. A detailed and careful study is presented to the Community Council. Several individuals accompany the clearinghouse administrator, but only when this official turns to a man who has cerebral palsy to ask for clarification on some of the finer statistical formulations does the assemblage realize that the report was developed by a volunteer with speech and mobility difficulties.

The packets of information are neatly stapled and the address labels are perfectly placed. There are pages of names and addresses of legislators and descriptions of a variety of bills that will provide increased protection to elderly citizens. All through the region people review the materials with little thought of the pride felt by a team of mentally retarded volunteers who had carefully followed the precise directions of the agency's legislative director. They had checked the piles of different sheets. One had assembled them in order while another had lined them up neatly before stapling them. A third volunteer placed the address labels. As the pile had grown, the mentally disabled volunteers took pride in their accomplishment. They knew they were helping elderly people and they understood the need for this information to get out in perfect form.

These examples illustrate the reality that disabled people are useful as volunteers in a whole range of agencies and organizations. Sometimes we tend to forget that disabled people are people first—with roles as citizens with many interests and abilities.

THE IMPORTANCE OF VOLUNTEERING

At all levels of American society, we will find folks coming together to volunteer. Our history is based on such groups of good people working together to reach common goals; our present social challenges offer increased opportunity for citizens to meet their own needs, creating self-help and mutual aid efforts that will directly and appropriately address felt needs.

We know that volunteers can humanize social systems: that as they learn about the agencies and organizations into which they pour personal energy and resources, they build bridges of communication and support to the total community.

In late 1982 The President's Task Force on Private Sector Initiatives reported on the year's activities:

"If the involvement of Americans as volunteers insures the survival of our democratic institutions, then those institutions must act to preserve the opportunity and ability of citizens to volunteer."

A June 1981 Gallup Poll was conducted to examine the patterns of volunteerism in America today. It indicated that some of the sterotypes about volunteers are misleading. The facts are:

- Both men and women volunteer
- Volunteers come from all income levels
- College and high school graduates, as well as individuals with less conventional education, find satisfaction in volunteer activities
- All ethnic and racial groups volunteer
- Volunteers come from all age groups

But there are patterns of involvement. The Task Force indicates a reason why some groups don't show up as often as others in the statistics:

"MOSTLY BECAUSE NO ONE ASKED THEM"

Certainly this explanation applies to the range of our citizens with disabling conditions.

The opportunity to participate more fully in the important work that faces us as a nation *must* be made accessible to all citizens. Expression of the moral commitment to care for the needs of our fellow citizens must be balanced by expanding the challenges and opportunities to fully engage in the important work of

creating, with each new day, that vitality that has always marked the dreams and idealism upon which this nation was founded.

SOME PRACTICAL LOW-COST STRATEGIES

In our efforts to recruit volunteers, we may unwittingly be communicating a lack of interest in, or silent rejection of, certain groups of people. For example, heavy doors that require strong muscles are effectively locked against some people. An unramped step may convey the message to others. Unconscious non-attention to the special needs of the blind and deaf may feel to them like rejection. There may be many other examples, even though your intention is to encourage full participation by all citizens.

"I've really been sort of worried about this whole question. Every time we get some federal funds, we have to stipulate that we do not discriminate against disabled people. I know that '504' has something to do with not discriminating and that it is a part of the regulatory system that backs up our receipt of funding. I have been afraid to ask about it because I do not want to stir up any trouble for us. We have such limited resources as it is. If we had to put in an elevator or something like that, we would be out of business tomorrow. Our whole budget for the year would not even begin to cover such a cost."

There are many organizations that have tried using disabled volunteers and found the solutions need not be expensive. The primary ingredient is a change in attitude.

This brochure suggests some low-cost and practical solutions and ways to make disabled volunteers feel at home. Once you have started on this process, you are sure to discover other ideas yourself.

"And so, my fellow Americans, ask not what your country can do for you; ask what you can do for your country."

-President John F. Kennedy

It is important to be sure you really *invite* the people you want to become involved. Talking among ourselves doesn't invite new people into the system. You can send your information and requests to newsletters that go to people with disabilities. Information about both national and local newsletters is available through the independent living projects, rehabilitation and service agencies closest to you. This special effort will be effective in reaching people with

disabilities and will emphasize your desire to include them

We need to remember that deaf people do not often get information from radio and TV and that blind people are usually not aware of your beautiful poster and printed materials. People with problems in mobility need the assurance that your facility is accessible.

Architectural barriers are a terrible bore: they are all around us and we don't even notice them until we try to plan. They become incredibly frustrating when we try to plan for their removal in the abstract. We must think with *real* people toward *real* solutions in *real* situations. Often there are practical alternatives. Some independent living projects have individuals who can build low cost ramps or can give advice on the most economical way to solve problems. You may want to build a ramp or use other strategies, but bring in your local wheelchair expert.

Here are two examples of how organizations dealt with architectural barriers:

"I asked our janitor if he could lessen the pull it takes to open the door. He got so excited about this project that he has gone on to make other changes whenever he sees a problem." "Our Board has taken a real interest in accessibility. It turns out that the Chairman's youngest child is in a wheelchair. When he began to think about accessibility at our facility and that we might use volunteers who are disabled, he got quite excited. He has initiated a special fund effort for us to guarantee that we can make some modifications that would have cost money. We already have a wooden ramp that was constructed by some of our volunteers with contributed supplies from a local hardware store, but we may modify and beautify the whole front of the building while we are making a more attractive ramped entrance. Incidentally, I've noticed that lots of people not in wheelchairs seem to prefer to use that ramp. We hadn't really thought about that."

The only difference between people in wheelchairs and your able-bodied volunteers is that the first group sit down all the time they are in your offices, and they need some way to get into your building while seated. Since you have now solved that problem, you can turn to making efforts to increase the comfort and productivity of your new resource. Push button telephones may be a help. Tables with room for

wheelchairs as well as cleared space around them will be helpful.

Not all people with mobility problems use wheelchairs: slippery floors and rugs that don't lie flat may be real barriers to people with braces, walkers or crutches. Look around for such unexpected and easily modified barriers. If you have a water fountain you may wish to add a cup dispenser.

If your bathroom facilities are not wheelchair accessible you may want to get help in deciding priorities. Common sense will tell you that there has to be sufficient room for a given wheelchair to enter a given door or toilet booth. Standards for new construction and modifications take this into account but in the meantime it is often possible to make minor

alterations to increase ease of entry. For example, stall

doors can be removed and curtains substituted if the

door presents an obstacle. Motorized wheelchairs are

wider than manual chairs, so be sure to consider this.

You may want to replace the sink faucets with levers if they are hard to turn, which will also help many older volunteers. Doors with too high pressure may be modified to allow less effort to open them. It can be helpful to look at your facilities from a sitting position.

One agency with a long mirror did not wish to lower it because most of their people were "standees", but they decided to put a strip of wood under the top edge. This tilted the mirror slightly and allowed both six footers and people in chairs to see themselves.

5 Most people who are blind, particularly those who have lost their sight later in life, do not read braille. They will appreciate receiving your materials on tape. You can contact your local group of blind people to find out the best—and lowest cost—way to make and reproduce these tapes. Someone who uses tapes routinely will probably be your best resource in finding the most cost effective method of reproduction. College programs for the handicapped often are an excellent way to make such contact.

Those volunteers who are blind and do not use braille can read their tapes at home, but you may also be able to secure a tape player from your local library that serves the blind. Such tape players are free to the blind and physically disabled and do not record. Since blind people often wish to speed read their tapes, it is helpful to get the type that allows for variable speed.

When blind individuals read braille, they will want copies of relevant information in that form. Again, you can use your local experts. Once you have gotten the material brailled, you can use the blind version of a Xerox machine—Thermofax. This heat and vacuum process creates multiple thin plastic sheets of the original brailled material. These machines are usually available in agencies that serve the blind and will reproduce your copy at cost. If the brailled materials you develop are to be distributed and stored by sighted people, it saves time to put typed or written notations on them. Confusion can lead to loss of the material!

Braille can be produced in several ways: people who use it carry their own slate and stylus. This consists of a small punch with a rounded wooden grip and two flat hinged pieces of metal that hold the paper while providing a pattern for the brailled characters. Each individual dot is then punched by hand. These two items are popular because they can be tucked into a pocket or purse.

However, for home and office use, a faster method is a braille writer which looks rather like an old fashioned typewriter. These machines speed up the brailling process and cost somewhat over two hundred dollars: less than the average typewriter. There are more expensive electronic devices available but they are not widely used. The investment in a braille writer will increase the comfort and productivity of your blind volunteers.

You may wish to install braille labels in the elevators. Laminating plastic can be brailled and used although since it doesn't last forever, it must be replaced periodically. Laminating plastic can be purchased at your local office supply store. Labels can be put on other areas, such as the rest rooms. If you do not already have raised letters that can be felt on such doors you may want to purchase some at the hardware store. Large numbers and letters are easier for low vision people to read and can be decorative.

If you offer service to the community at large you Owill want to be able to offer it to those who are deaf. In order to be fully accessible, you need to give some thought to your telephone: do you have the capability to receive calls from people using the TTY or TDD system (teletype or telecommunications for the deaf)? There are a number of different telephone systems, but a low cost and efficient method changes any telephone into a TDD when the receiver is placed on a portable device that looks like a typewriter. The messages are typed back and forth rather than spoken and any person who can type can very quickly learn to talk over the telephone with deaf individuals. For less than five hundred dollars one can buy a unit that includes a digital display panel upon which the words appear as typed. There is a TDD operator who will give out information on TDD calls but you will also want to include the information that you can receive such calls in your media releases. You may want a special line or can use the same line for both voice and TDD. When someone is calling from a TDD they can press their spacer bar which will make a unique electronic beeping sound on your phone. That is a signal to use your TDD unit to answer the call.

There is increasing interest in learning sign language. This "second language" is eloquent and graceful; most hearing people are seeing its beauty as it is used in singing and dancing productions or on TV. A basic language class for present staff will allow a minimum "welcome" to a deaf individual. Exchanging written notes is another method of overcoming communication barriers. However, of course the deaf brain works just as fast as any other, and comfortable communication demands an interpreter who can sign rapidly.

Because of the communication problem you may wish to recruit at least two deaf volunteers to provide companionship for each other as you begin the process of bringing that population into your agency, but this should not prevent you from also pushing toward full participation of those individuals in the agency. Local organizations for the deaf may be involved in planning how to best use your resources to expand services. You can also tap the energy and knowledge of our deaf citizens in learning about accessibility for deaf volunteers. This first step may expand your volunteer pool in exciting and unexpected ways.

7 Often people whose speech is difficult to understand find it hard to gain entrance into a variety of activities. We have all experienced some discomfort or embarrassment relating to communication. We may actively fear the challenge presented by such volunteers. Impatience and fear on the part of able-bodied individuals only makes the problem worse. For those with speech difficulties, the stress of trying to speak quickly before being interrupted only intensifies the spasm and increases word distortion. The best communication between any people grows out of patient respect, and nowhere is this more evident than in dealing with people who have speech impairment.

When one first begins to talk with an individual who has a speech disability, such as with severe cerebral palsy or other neurological difficulties, nervousness is natural. There may be fear that one will not be able to understand the other person. If one expects to have trouble, the chances increase that there will be trouble. When we relax and take time to listen, wanting to communicate, barriers to understanding are lessened. It is all right to ask that words and phrases be repeated: the person you are talking with knows he or she has a disability, and it doesn't have to be treated as a secret.

The barriers to full participation for those volunteers who have a learning disability are related to the *form* in which information is given.

"Learning disability" describes a range of physiological conditions which cause problems as individuals process information. One person may be constitutionally unable to gain information that is given verbally while another may be excellent at understanding spoken instructions but have difficulty grasping the meaning of printed words. Because of this variation in where communications barriers intrude, people who want to generalize about this condition may become confused. Several of the more common categories are: **Dyslexia**, which means problems with written information. **Dysphasia**, which means problems with verbal information. **Dyscalculia**, which means there is a problem understanding numbers. **Dysgraphia**, which means a problem in writing.

The barrier for each of these classifications is obviously different. What is a barrier to individuals with one condition can be the open door to understanding for another. Flexibility and creativity in communication are the key to elimination of problems. Again, the expert that can help you solve these problems of communication will be the person who has intimately observed the ways to overcome the particular barriers: the individual who lives with the sensory processing limitation. That individual has

developed techniques that aid in overcoming particular barriers.

Volunteers who have not identified themselves as having a learning disability but who have seemed careless, inattentive or undependable may have had physiological disturbances which prevent them from clearly understanding directions or coordinating activities. You may be able to help such volunteers become more productive by asking how they would prefer to communicate. Since you have already prepared tapes for your blind volunteers, you can offer them to others. A few diagrams or written directions, using the same paper and pencil you carry about to communicate with deaf volunteers when no interpreter is available may be very useful in making your directions more meaningful to some learning disabled volunteers. Remember: the fact that volunteers can see does not necessarily mean they can understand written information, and the fact that volunteers have normal hearing does not mean they can understand auditory information. Your awareness of how to remove the barriers for learning disabled volunteers may increase your skill in better use of those with less obvious information processing difficulties. Most individuals have a preference in the method they use to get information and you will be better equipped to respond to individual choice.

Although the barriers faced by emotionally disabled volunteers are rather vague and diffuse, they feel very real and cannot be dismissed. Most people have felt emotional stress at one time or another. We remember how hard it was to alter our mood when a temporary and unexplainable depression hit us. To some extent, most of us could be called "mentally restored" from temporary and passing disabling emotional storms. In the following discussion of how to overcome the barriers for chronically emotionally disabled people we do not mean to suggest that those individuals who are "restored" need such a structured

experience as is necessary for those emotionally disabled people who live each day with the reality that a variety of factors may bring about a painfully acute reaction that will send them into another episode of psychiatric illness. This chronic condition can mean that the support, encouragement and recognition of worth that are already built into most good volunteer programs may not be sufficient to provide a bridge over the barrier of fear that confronts such individuals.

We are confused about how to best use the positive energy and creative abilities of people in a remission period of their symptoms. We are vaguely aware that many people volunteer out of a personal need but when we know of the psychiatric history of an individual who has had episodes of hospitalization, we may think of them as undependable, nonproductive and possibly erratic. These ideas about people can be a barrier to their full participation and involvement in volunteer activity.

Often the difference between a mutually positive experience for such a volunteer and one that may end painfully for all is as simple as building in "team" support. We can learn from the successful half-way homes that have developed programs that allow persons who have emotional disabilities to become

productive in mutually supportive groups that work on a common task. When this model is used, people who are feeling too much stress can drop out of the activity with no guilt feelings, since their peers will fill in for them. Team members quickly realize when one of the group has neglected to take their medication or needs more rest. The model of several people given shared responsibility to accomplish a given task under flexible and supportive supervision is an ideal situation for many volunteers but is almost a necessity for those who are emotionally disabled. It may be helpful if the group has a psychiatric professional who offers support and assistance upon request.

1 OThere are over six and one half million of our citizens who are mentally retarded. Their mental disability ranges from severe to moderate to mild. Almost ninety per cent of these individuals are minimally to moderately retarded and are very capable of learning many productive skills. They can often be more dependable than volunteers who have more options, because routine tasks can offer an opportunity to prove their worth in a way not always available to them. Their direct approach to assignments can help the morale of a whole office. However, there are barriers to their accommodation.

You will want to think about the steps to be completed as one approaches a particular job or task. This will mean being clear what it is that needs to be done. Much of our language is vague and indirect and we expect others to understand, even when our directions are not clear. Some people will ask: "Would you like to get me some brochures?" when they really mean "I'd like you to get me a packet of brochures with the red cover." The difference between the two "requests" can alert supervisors to the barriers that are set up all around for the mentally disabled volunteer. Language must be concrete. The use of figurative speech and complex concepts only distorts communication. Often those who are retarded have had

fewer chances to learn about normal social interaction than their more mentally able peers. But what they lack in experience they may make up for in their joy of mastery over new challenges. They will need tasks explained and illustrated in specific and concrete fashion.

It may be best to think about how to reach the desired goal or complete the necessary task. As an example:

You may have had the experience of having someone wave in the general direction of a table filled with office materials with the vague directive, "That stuff has to get in the mail." Even with the most eager workers, a routine mailing can be dreary and often other duties or responsibilities will beckon your unpaid staff. If you can carefully illustrate each step of the process, very complex tasks can be completed. Show your volunteers piles of paper to be sorted and stapled. Set up a routine and recognize the importance of this particular process in getting the bigger job done. Do not complicate your directions with too many tasks. Steady and sequential work will get the job done.

With this effort you will have overcome a barrier to a whole range of able volunteers who will invest both their hearts and their energies in your projects.

1 The biggest and most difficult barriers are the internal ones that prevent us from thinking creatively to solve the problems that separate "us" from "those people". Attitudinal barriers result from negative expectations and can be a challenge to overcome. They are often based on myths and fears: myths that new information would dispell and fears that may be based on consciousness of how frail we all are. Preconceptions and negative attitudes short-circuit our thinking into stereotypical traps. Almost all of us are burdened with some negative feelings about disabling conditions but getting to know people who

have a disability illustrates the reality that we are all people first. Such knowledge will ease that discomfort and allow for development of mutual respect. Even the most self sufficient of individuals need recognition of their unique qualities, value and worth. Throughout our history as a nation, volunteer activity has grown and prospered because it allows for the most creative and flexible use of human potential. A little extra effort spent in thinking about common-sense accommodations to help each individual citizen make his or her best contribution to the common good can pay off for the whole community.

12Habits of speech, which reinforce myths and stereotypes about people with disabilities can be powerful barriers. Language reflects a mental picture that develops, in part, out of our attitudes. It is important to evaluate our use of language to avoid phrases that trap people into stereotypes.

The further we get from calling Mrs. Jones and Betty and Joe by their names, the more evident it is that we have placed them into categories. The phrase "Mrs. Jones is weak" may cause us to wonder why she has this condition. We look for explanations: Is it always true and what causes it? Can her condition be improved and how has she organized her life to compensate for physical limitations? Our response tends to be different as we clump people together. "The handicapped are weak". This phrase has removed the concept of a person with unique qualities from our thoughts. This kind of stereotyping language stops us from thinking creatively. A first step to removal of language barriers has been taken when we put the concept of person first.

It is usually best to use the phrases: "a person with a handicap" or "an individual with a disability". Both these words can be used. Preference is based on geographical location. However, there appears to be greater acceptance of the word "disability" among advocates. They tend to associate the word handicap with "cap in hand" as in begging. There is an assertion that any physical or mental condition that limits function can be referred to as a disability and that a person is handicapped only when that condition causes problems. In other words, people are handicapped by a lack of resources available to them.

People with orthopedic disabilities may be handicapped when there is no ramp into a building.

People who are blind are handicapped when only ink printed instructions are offered.

People who are deaf may be handicapped when there is no interpreter available in a court room.

Here is a list of some words that trap people behind stereotypes. You can find additional ones as you develop sensitivity.

"Suffers" This word, used in such phrases as "he suffers from polio" would seem to indicate that someone is in constant pain. This is rarely true. Polio is associated with a lessened sensation. Even when disabling conditions involve certain levels of pain, people are usually able to control its effect by a variety of processes. Don't impose unsolicited pity on anyone, "Invalid" This word has many meanings, all of which are negative. It means nonvalid: not qualified or unfit. This emphasis is inappropriate. Totally paralyzed individuals have a wide range of positive characteristics. "Normal" Sometimes we call non-disabled people "normal" and imply by that usage that anyone else is abnormal. This is inappropriate. Save this word to use when you are talking about numbers or temperatures. "Patient" When people are in the hospital or being treated by a medical professional, it may be appropriate to refer to them as "patients": however, most disabled people do not need that kind of attention any more than able-bodied people do. People who are living in the community and are developing self-reliance are offended when they are called "patients". "Victim" We usually associate this word with the idea of a "dupe", as of a swindler, or of someone sacrificed. Very few of the people you will meet have been "sacrificed". Do not use this word when talking about disabled conditions. "Crippled" The picture this word creates involves a helpless and non-valid person. It

> carries the message of incapability. It has rightly fallen into disuse. Don't

revive it: it deserves to die.

"Afflicted" The phrase "afflicted with a disability" implies continued pain and torment. It suggests a misfortune that is intolerable. Don't inflict this label on people. "Case" Often in social service agencies we find ourselves using this word, but it sounds like something you file away. People resent being filed away.

"Dumb" When used as "deaf and dumb" this word is nonsensical. Deaf people may be verbal or nonverbal in their communication but they are not stupid. This out-of-date phrase should be considered only as historically interesting. The word, used alone, does not describe anyone.

"Unfortunate" The implication of this word involves the idea of bad luck or lack of success. You may think a person was unlucky to have become disabled but you only add to the problem by using a phrase that minimizes personal self-reliance. "Confined"

The phrase "confined to a wheelchair" is used so often it almost seems like one word. The implication is that the chair is an essential part of experiencing the person. In fact, many people make a choice to use this tool of mobility and efficiency. They might be able to get about by other means but would needlessly exhaust themselves. They prefer to use a chair for efficiency. Others may not have the luxury of a choice. They may have to depend upon a chair for their mobility. but it is probably one of several tools they use.

CONCLUSION

This booklet is limited to twelve simple suggestions. There are as many possible solutions as there are people to find them. Do not be afraid to ask for help from your local experts who are living from day to day in your community with their disabilities and have found some practical coping methods for living in that environment. Remember that acknowledgement of a disability allows for the most rapid accommodation to it. In a democracy, all citizens need to be needed and the benefits can escalate.

"A volunteer is a person who can see what others cannot see; who can feel—what most do not feel. Often, such gifted persons do not think of themselves as volunteers, but as citizens—citizens in the fullest sense: partners in civilization."

---White House Task Force on Private Sector Initiatives

A GUIDE TO RESOURCES

This sampling of resources will bring you into contact with a network of information. In addition, you may also want to expand your knowledge of local resources that will be helpful to your organization in serving your community. For example, colleges and universities usually have an office and services for students who are disabled. If your community is fortunate enough to have an Independent Living Program, it can provide you with easy access to disability experts who are aware of local resources.

The Clearinghouse on the Handicapped

Office of Special Education and Rehabilitation Services U.S. Department of Education 330 C Street, S.W. Washington, D.C. 20202 (202) 245-0080

The Clearinghouse will provide direct information about services and agencies serving disabled people. If they do not have specific answers, they can refer you to the organization or individual that will help you get the answers to your questions. They publish guides and directories. Of particular help:

Directory of National Information Sources on Handicapped Conditions and Related Services. (Stock #065-000-00142-0) Priced \$8.00, available

from:

The Superintendent of Documents U.S. Government Printing Office Washington, D.C. 20402 (202) 783-3238

An August, 1982 revision includes an extensive listing of information sources on the whole range of disabling conditions, with addresses and telephone numbers. It can help you locate national organizations which may have branches in your community.

Abledata

National Rehabilitation Information Center The Catholic University of America 4107 Eighth Street, N.E. Washington, D.C. 20017 (202) 635-6090

This data base lists well over 5,000 commercially available aids and equipment that you may wish to purchase for your agency. Requests for data searches may be made directly to the Washington facility. If there is an access center closer to your community, they will refer you there.

The National Center for a Barrier Free Environment

1015 Fifteenth Street, N.W., Suite 700 Washington, D.C. 20005 (202) 466-6896

The Center will respond to direct inquiries for technical and design information and they publish brief papers on a wide range of topics. They have also developed a technical assistance network of approximately 1,000 individuals who can offer advice at the local level. There is a nominal fee to cover staff time; however, arrangements can be worked out to waive or adjust fees if individuals or organizations are unable to pay for services. The Center's list of helpful publications, titled "Tools for Accessibility" is available for \$2.50.

U.S. Architectural and Transportation Barriers Compliance Board

Technical Services Office 330 C Street, S.W. Washington, D.C. 20202 (202) 472-2700

The staff of this Board will respond to public inquiries about national, state and local accessibility codes and provides technical assistance on questions of barrier removal.

Adaptive Environment Center

Massachusetts College of Art Huntington Ave. and Evans Way Boston, Mass. 02115 (617) 739-0088

The staff of the center specializes in adaptive design in many areas. Their office space was designed within an empty factory. Their Hotline information and referral services are free. The Center library includes over 3,000 books and informational tapes. Their focus is to assist others to design their own adaptive spaces and materials.

The Planner's Guide to Barrier Free Meetings Barrier Free Environments, Inc.

P.O. Box 30634 Raleigh, N.C. 27622 (919) 782-7823

Although this guide is specifically targeted for planners of meetings and conferences, it has a much broader application. It provides a quick review of potential needs, problems and solutions. The designs and diagrams are easily figured out and are meaningful to the non-technical reader. There are many practical and low-cost suggestions. Included is a list of resources and product distributors. Copies are available for \$12.95. The BFI may also be a source of other information. Since 1974 its staff has offered design and consulting services and program development for people with disabilities.

The President's Committee on Employment of the Handicapped has developed many helpful brochures and booklets on employment issues. Single copies of all PCEH publications and posters are available free upon request.

Good luck to you as your reference shelf on disability issues grows.

DIGNITY, EQUALITY, INDEPENDENCE FOR DISABLED ADULTS

