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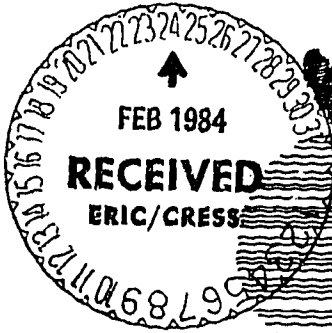
ABSTRACT

The National Rural Independent Living Network, funded to Murray State University (Kentucky) by the National Institute of Handicapped Research, is developing Community Independent Living Service Delivery Systems (CILSDS) for rural people with disabilities which will be housed in over 500 communities by early 1986. The CILSDS, staffed by citizen volunteers and professionals, are currently located in 20 communities and are linked by a network of individual volunteers, existing service and social clubs, libraries, churches, country stores, volunteer fire departments, and numerous other agencies and organizations that wish to help their disabled neighbors lead relatively independent lives. Project staff spend time in each community identifying residents who have disabilities and determining their independent living needs, as well as assessing community volunteer resources. Creating CILSDS is a natural extension of dynamic and community-responsive public school special education programs. Involving trained volunteers in the provision of services to people who have disabilities can reflect positively on schools and human service agencies. The CILSDS can become focal points for total community interdependence across a wide band of services. A diagram showing lay citizenry resource networks and professional resource networks, linked through the central core of the public school, is provided. (MH)

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Should A Special Educator Entertain Volunteers: Interdependence In Rural America

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Abstract

Rural communities have a tradition of helping each other and of shared interdependence. The National Rural Independent Living Network is developing community independent living service delivery systems in over 500 communities by early 1986. Strategies for designing a volunteer program, recruiting and training volunteers and for linking volunteers with people who have disabilities are provided.

SHOULD A SPECIAL EDUCATOR ENTERTAIN VOLUNTEERS:

INTERDEPENDENCE IN RURAL AMERICA

Rural Americans take pride in helping each other solve their own problems. Unlike many of their urban counterparts, rural citizens have not learned to expect vast arrays of services that can be tapped whenever something goes awry. People in rural areas know each other. They are generally aware of needs and resources, and they are willing to share what they have if their neighbor needs it. These characteristics can be observed every day as neighbors help each other with agricultural chores, construction tasks, and even caring for each other in times of illness.

One-third of the nation's population live in rural areas. This percentage is increasing as the movement away from the cities intensifies. (Naisbitt, 1982) Rural people who have disabilities do not have access to the wide variety of services available to their urban counterparts. It is true that most states provide regional offices or some other service delivery mechanism charged with the responsibility for meeting the needs of rural people who have disabilities. However, most rural citizens either don't know about the services for which they are eligible or are too proud to "go on the government dole."

Since the passage of Public Law 94-142, the number of public school handicapped children identified and served has increased by 92% (Helge, 1980). However, even though the percentage increase has been substantial, services in rural school systems has been sporadic. For example, most rural school systems began delivering special education services in elementary grades but neglected to expand these services in secondary

programs. As a consequence, many handicapped youth have no services available as they reach high school age and drop out of school. Also, most rural communities "cannot afford" early childhood handicapped programs. Consequently, these services are not usually provided. Because of cutbacks in federal funding, many states trimmed their special education budgets by altering the formulas with which they calculated reimbursement to local education agencies. Thus, hundreds of school systems across the country either reduced the number of special educators in their programs or did not add previously planned positions.

Concomitant with these retrenchment moves in public schools, social service agencies also were affected by budgetary cuts and were forced to reduce services and field personnel.

How About Doing Something Different?

With the above "gloom and doom" perspective, it seems clear that professionals committed to providing services to people with disabilities must look toward alternative delivery strategies. The National Rural Independent Living Network, funded to Murray State University by the National Institute of Handicapped Research, is doing just that in numerous rural communities across America. This project is capitalizing on inherent attributes of rural communities by creating Community Independent Living Service Delivery Systems (CILSDS) staffed by citizen volunteers and professionals. These are currently being located in 20 sites and will be housed in over 500 rural settings by early 1986.

The project is developing a network of rural communities and establishing communication and sharing systems within and among these communities. This network is composed of individual volunteers, existing

service and social clubs, libraries, churches, country stores, volunteer fire departments, and numerous other organizations and agencies that wish to help their disabled neighbors lead relatively independent lives.

The Process

Twenty rural communities through America were selected to participate in the developmental phase of the project. Project staff spend time in each community identifying residents who have disabilities and determining their independent living needs. Data regarding community volunteer resources are also assessed.

Within each community, a Central Core group is being identified. Staff assist local Central Core members in the development of the Community Independent Living Skills and Services Network for their community. Central Core groups include county libraries, ministerial associations, rural corner stores, public schools, and other sites within the selected communities which can be used to link local resources with people having needs.

A computerized Resource Matching System is installed in each Central Core organization for networking local volunteers and professionals with people who have disabilities and who need services. Additionally, all of the Community Independent Living Service Delivery Systems may be in contact with each other via computer communications for resource sharing purposes.

The following sections of this article describe the development and implementation of a Community Independent Living Service Delivery System which takes advantage of all available volunteer and professional resources in a particular rural community.

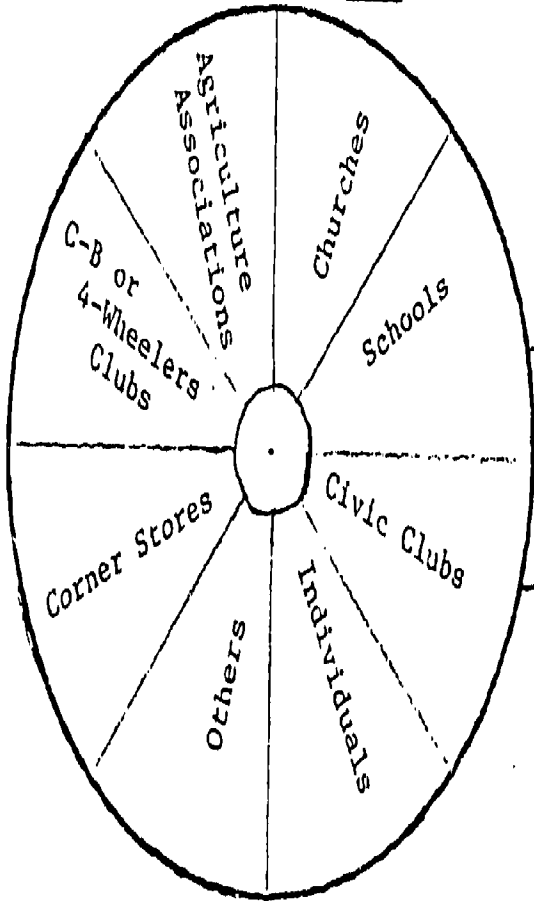
The Model

Figure 1 illustrates the linkage system which incorporates networking concepts allowing lay citizens and professionals in rural areas to provide resources needed by people having disabilities. (This figure illustrates a Community Independent Living Service Delivery System [CILSDS] with the public school as the Central Core. Central Core groups also include ministerial associations, county libraries, and others identified in specific communities as primary resource providers or networking organizations.

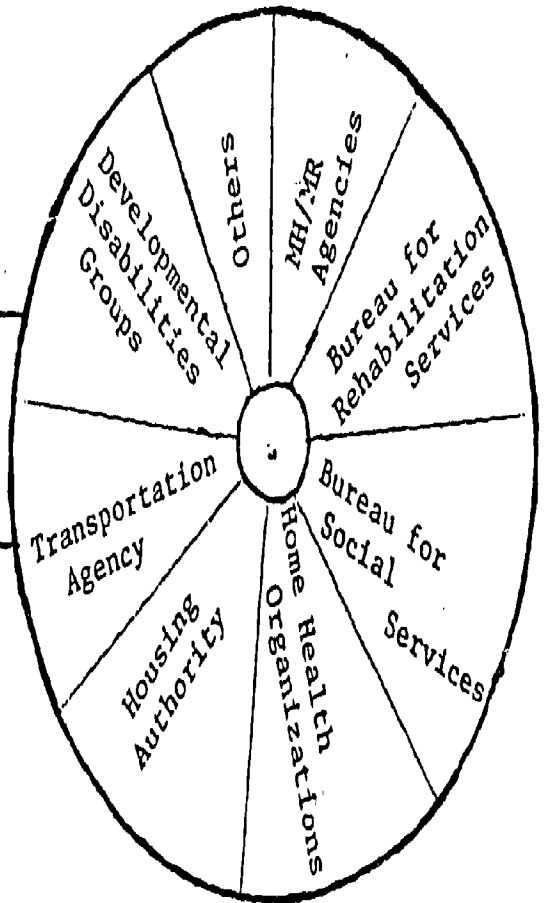
Figure 1

COMMUNITY INDEPENDENT LIVING SERVICE DELIVERY SYSTEM

Lay Citizenry
Resource Networks



Professional
Resource Networks



CENTRAL CORE

Public School

↑
NEED
expressed by
handicapped individual

↓
RESPONSE
with resources
and services

(Public School is one of four Central Core Types included in the project.)

It can be seen that the Community Independent Living Service Delivery System is essentially a vehicle for linking disabled individuals in any given community with the resources that are available in that community. The elements identified within the spokes of the wheels for lay citizens and professionals should be thought of as examples since each community will have many different elements appropriate to its own area. In the example in Figure 1, lay citizens (not professionals normally working with disabled individuals as their primary constituency) are found in churches, schools, civic clubs, corner stores, labor unions, citizens band or fourwheeler clubs, or people participating in the area agricultural association. There is a space left for "others" since most rural areas will have a wide variety of groups that will wish to participate in the CILSDS. The following list of potential participants or strategies could be involved in a CILSDS and was drawn from the archives of exemplary rural programs maintained by the National Rural Project at Murray State University:

- Post Office
- County Stores
- Milk Carriers
- Mail Carriers
- Newspaper Deliverers
- Meter Readers
- Book Mobiles
- Telephone Service Personnel
- Private Pilots
- Lift-Equipped School Buses not being used while children are
are in school
- Volunteer Fire Departments
- CB Radio Clubs
- Ham Operators
- Ministers
- Retired Personnel
- Unemployed Personnel (Unemployment is higher in rural America
than in other areas)
- Vocational Rehabilitation Centers
- Advocacy Groups
- Individuals Who Own Computers

Foster Grandparents
 Disabled and Nondisabled Veterans
 Wranglers Riding Clubs
 Garden Clubs and other Social Organizations
 Civic Clubs including Woodmen of the World, Lions, Rotarians,
 or Jaycees
 Chambers of Commerce
 Home Demonstration or County Extension Agents
 Local TV, Radio and Newspaper
 Electronic Bulletin Boards
 Girl and Boy Scout Organizations
 4-H Clubs
 County Health/Nurses
 Welcome Wagon Volunteers
 Local Businesses
 Golden Age Centers

The examples contained within the spokes of the Professional Resource Networks are only examples of the types of human service agencies which might be present in any specific rural community. Clearly, there would be others, and some would have different titles for the same function (depending upon local and state activity and regulations). The Central Core provides the linkage system. It draws appropriate resources from the Lay Citizenry Resource Networks and from the Professional Resource Networks, depending upon the availability of the resources and the specific needs of individual people who have disabilities. The public school shown in Figure 1 as the Central Core unit of the CILSDS is one of the four models developed by the National Rural Independent Living Network.

Rural public schools exist in almost every local governmental unit and are powerful political units. In fact, schools promote rural community integration and are effective instruments of change in the rural community. Public schools in rural America are still held in high regard. Parents religiously attend back-to-school nights, and the school building is seen as a valuable community resource.

Since the advent of PL 94-142, many children who would previously have been sent to institutions are being educated under the auspices of public school systems. Creating a Community Independent Living Service Delivery System is a natural extension of a dynamic and community responsive public school special education program. Providing services to preschool and to older (out of school) disabled people is a natural step in providing a continuum of services. The presence of a CILSDS ensures that disabled citizens can remain living as independently as possible throughout their life with their family and in their neighborhood.

Contrasting Points of View

Carl Hess (1982) states that, "There's something about volunteerism that is very subversive -- in this century at least. It flies directly in the face of the two major conventional wisdoms of our time -- professionalism and corporatism." Hess argues that early Americans volunteered to help their neighbors on a routine and expected basis. However, in the recent era of massive social change, society began to expect that "professionals" would solve serious problems and that volunteers could deal with necessary tasks that professionals couldn't justify doing or did not want to do. As a result, professional organizations and their media are decrying the infusion of lay citizens into what professionals have recently considered as their professional domain. The hard truth is that many tasks (chores) undertaken by professionals could easily be handled by lay citizens volunteers; particularly with some direction by professionals. Once professional educators and other human service providers understand the reality that the golden era of

professional human service is over, they will begin to search for alternative resources to keep service delivery at pre-budget cut levels. The only way to do this is via the volunteer community.

Involving trained volunteers in the provision of services to people who have disabilities can reflect positively on the school or the human service agency for the following reasons:

(1) Most volunteers are already active, busy individuals. Thus, they frequently participate in extensive communication networks throughout the community. The good will they can generate for an agency or organization will be beneficial at budget time -- or when state or federal headquarters attempt to curtail services in the rural area. Additionally, because of this extensive communication network, additional resources will be offered from community businesses, social and civic clubs, individuals, etc.

(2) Professionals capable of using a trained cadre of volunteers will be able to provide more services to more people with disabilities than if they were simply "one-person shows."

(3) Volunteers can often handle routine activities. This frees the professional to provide more sophisticated or in-depth services needed by disabled citizens.

Frequently stated reasons for not involving volunteers include the extensive time required to train them, concerns about their reliability, fear (on the part of the school personnel), a desire to keep school and community separate, confidentiality issues, etc. All of these can be overcome by the development of an appropriate recruitment, training, and matching system.

Establishing a Community Independent Living Service Delivery System

One reason for the vast potential of rural volunteerism is that it is a highly respected and valued activity. Although most rural citizens won't call themselves "volunteers," they will admit that they helped a neighbor bring in the crops or build a barn, took him or her shopping, or mowed his or her yard. All of these types of assistance are needed by some rural disabled citizens in order that they might continue to live relatively independent lives in their community. Once their rural neighbors are aware of the need, they usually help out with little expectation for recognition or reward.

On the other hand, most rural citizens have not been exposed to many people with disabilities. This is primarily because most visible and serious disabilities are low-incidence conditions.

Some First Thoughts

Good volunteer networks do not happen spontaneously. Many of the planning activities which must be undertaken are foreign to most special educators and other human service personnel. For example, CILSDS planners in rural communities must be knowledgeable of the community power structure and communication networking system. Community leaders including officers of civic clubs, social clubs, church groups, and professionals in human service agencies should be thoroughly briefed on the proposed CILSDS. Their suggestions should be requested, accepted and used. Each visit should elicit other names of people who are important contacts within the community. Only when the elicited names become redundant should the planners determine that they have contacted enough of the community power group to insure appropriate direction for the CILSDS and support for its implementation.

Another group that should be visited during this initial planning stage includes people with disabilities, their families, and existing support systems (both volunteer and professional agencies and organizations). Their advice should be sought and frank discussions of their needs with respect to independence within the community should occur. It is from these discussions with people who have disabilities that CILSDS planners learn which businesses, state and local agencies, churches, etc., are accepting of disabled persons and accessible to them. Additionally, numerous other needs develop through these discussions. (For example, the most frequent need expressed to NRILN staff by elderly people with disabilities was the need for human contact. Many of these folk said they could maintain themselves independently in their homes but felt isolated and had no one with whom to talk.)

Once planners of the CILSDS have determined that such a system would be acceptable to potential volunteers and to local citizens with disabilities, a CILSDS task force should be formed. (A note of caution is injected here: CILSDS planners must insure that another bureaucracy is not created. Rules and structure should be as simple as possible for the specific community.) The task force should consist of people with disabilities, parents or others who provide daily care for people with disabilities, and representatives from schools, business, churches, civic, and social organizations. The purpose of the task force is to formulate community-specific policy for the CILSDS. (The networks formed by the NRILN are diverse. One end of the continuum would be simple service delivery to a handful of disabled persons within the area. At the opposite end are total community networking systems in which any person in the community, disabled or not, can receive the

services of volunteers.) By vesting the task force with this type of decision making authority, a community network involving all elements of the community can be formed successfully.

The Resource Generator depicted in Figure 2 illustrates the interaction of various community organizations involved in a comprehensive Community Independent Living Service Delivery System. Different interactions will occur among agencies based on the specific needs of people who have disabilities (or for other constituent groups as determined by the local CILSDS task force). Because of the diversity in rural America, the types of organizations and agencies included in the Resource Generator will differ. However, the concept of shared interdependence in the provision of services to people with disabilities will remain consistent throughout rural America. It is clear that the CILSDS can become the focal point for total community interdependence across a wide band of services.

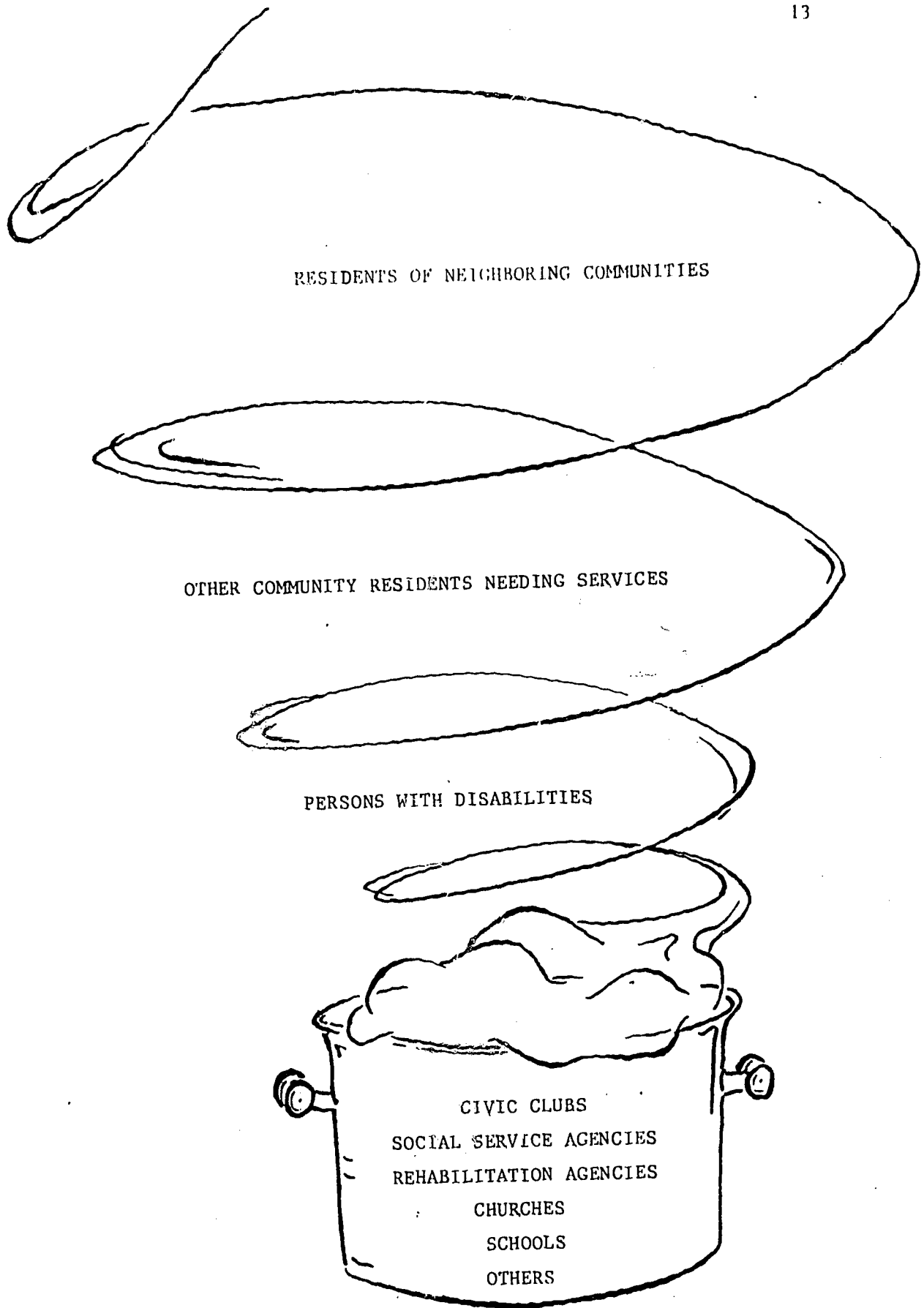


Figure 2
RESOURCE GENERATOR

Recruiting Volunteers

Nearly every person in a rural area can contribute something to the CILSDS. Contributions might include: (1) the provision of services such as yard work, personal care, or home care; (2) use of skills -- constructing ramps, teaching cooking or gardening; or (3) arranging for other resources -- accessing state funds or services for the disabled or applying for federal funds.

The key to involving volunteers in the CILSDS is personal contact. Very few volunteers respond solely to media appeals. Thus, presentations to civic, professional, and other organizations by task force members with subsequent personal telephone calls, face-to-face visits, or letters as follow-up will generate numerous volunteers. The National Rural Independent Living Network uses a total community involvement process to identify volunteers and people needing their services. This process includes distribution of a Resource Assessment Instrument to the total community through churches, schools, businesses, clubs and other organizations, and personal contacts. This procedure for distributing and collecting the Resource Assessment Instruments encourages the participation of a wide spectrum within each rural community. Additionally, identification with the local effort is enhanced by distributing bumper and window stickers for use on cars, businesses, and the windows of homes of those who return completed Resource Assessment Instruments.

Getting the cooperation of local media is not difficult for this type of activity. There is great human interest in a total community joining together to assist people who have disabilities. If the focus of this effort is on a specific weekend or week, an extensive series of articles or news reports can aid the recruitment effort.

People volunteer for a variety of reasons, and CILSDS planners should identify the "hot buttons" of their community residents. The NRILN has identified the following to be motivators:

- Community recognition
- The chance to do something different
- The opportunity to meet others
- Recognition that the CILSDS is doing something important
- Volunteering is part of group or organization mission
- The opportunity to help someone seen as less fortunate
- Important persons ask for volunteers
- It would be something new and a learning experience
- An opportunity to use skills and provide services in a unique manner
- Companionship and friendship

It is a myth that people who volunteer are usually those having time to spare. Most volunteers are already very busy people.

Once the Resource Assessment Instruments are returned, task force members should interview, in person or by phone, each prospective volunteer to clarify any ambiguities on the resource instrument and to determine more specifically the types of volunteer service being offered. This interview should also ascertain the degree of training the volunteer will need to work with people who have specific kinds of disabilities.

Training

The primary training objective for volunteers who will be providing services to people disabilities is to enable the volunteer to overcome his or her fears of the disabled. Feelings of insecurity, uncomfortableness, fear, pity, anxiety, and similar stumbling blocks are present in most would-be volunteers who have never worked with or associated with people having disabilities. The desensitization of the volunteer toward disabling conditions is necessary. This enables the volunteer to understand that the disabled service recipient is a real human being, more like the volunteer than different from him or her.

Involvement of those with disabilities in volunteer training programs is one positive approach to helping overcome this fear of the disabled. Frank discussions between the disabled and the non-disabled regarding, "Does it hurt?", "Will you get better?", "Is it catching?", "How can it help?", "What kinds of things are you capable of?", etc., create an awareness about characteristics of people who have disabilities. Desensitization also demonstrates to those who have disabilities that their rural neighbors care about how they feel but haven't known how to ask the questions.

Part of the training includes the simulation of a disabling condition. This simulation includes an entire day in a wheelchair, with a blindfold, or with arms and/or legs tied to prevent movement. This type of simulation is followed with a discussion of how the "disabled" individual felt when he or she was ignored by others or condescended toward.

Another major type of training used by the CILSDS is related to specific disabilities and based on the specific needs of disabled residents. (For example, professionals in communities participating in the National Rural Independent Living Network volunteer their services to train other volunteers in such activities as helping a nonambulatory neighbor in and out of a wheelchair, guiding a blind person around town, adapting activities to the physical capabilities of elderly people, etc.) School personnel can train volunteers to do routine tutoring, behavior reinforcement, and other activities that occupy a great deal of the special education teacher's time.

Training should be done by local citizens instructing their neighbors in providing services and skills to other neighbors. Instructional modules for assisting in this activity have been developed by the

National Rural Independent Living Network and are provided to each NRILN site for use.

Linking Volunteers To People Needing Services

The linkage system devised by the National Rural Independent Living Network is a computerized Resource Matching System. The Resource Matching System (using Apple IIE computers and PFS: File and PFS: Report software) allows the CILSDS the capacity to search its volunteer skills-bank for one or more volunteers who "fit" the request for services. The volunteer skills bank includes the information provided by community residents who completed the Resource Assessment Instrument discussed above. Additionally, the Resource Matching System includes information about state and federal services and resources which should be available to people who have disabilities. Thus, the CILSDS has the capacity to identify local, state and federal resources in response to expressed needs of rural community residents who are disabled.

Another function of the Resource Matching System is to maintain a record of volunteer use and services requested by specific people. This allows CILSDS personnel to use many volunteers rather than a select few and to forecast the needs of individual recipients of volunteer services based on previous experience.

While the NRILN communities are computerized, it is entirely possible to run the Resource Matching System out of a file cabinet or to use a "cards and stylus" type of sorting system. (The NRILN is designing a non-computerized card-stylus system for communities for which a computer is either undesirable or unnecessary. The principles are the same; that is, to match the most appropriate volunteers available with a person needing service.)

Problems

Recruiting volunteers is not a problem in rural America. The main problem is keeping volunteers busy. It is discouraging for a volunteer to complete the Resource Assessment Instrument, be trained, and then wait for a call that never comes. Volunteer coordinators should contact each volunteer at least monthly with a status report of what is being done and involve him or her in some type of activity. Groups of volunteers could be coordinated through the CILSDS to provide some community service even if it is not at the direct request of a person having a disability. Some communities participating in the NRLIN counter this problem by making theirs a total community networking system wherein any citizen can request services of a volunteer. This keeps more volunteers busy and still meets the needs of those with disabilities.

Another problem area is maintaining the momentum for the CILSDS. Ongoing public relations and media coverage must be provided by the task force. News articles about successful volunteer activities; presentations to social, civic and business organizations about CILSDS functions; and other types of community awareness strategies should be employed. Another problem, even in rural America, is that some "undesirable elements" will seek to participate as volunteers in order to practice unscrupulous behaviors. However, rural community communications and networking systems are so strong that most undesirable individuals are readily identified and excluded. The initial recruitment interview is particularly important for identifying undesirable volunteers when they are not known to the community.

Another problem area is that many professionals feel threatened by having volunteers interfering with their business. This problem can

usually be alleviated, particularly in rural areas where professional staffs are small and overworked, by involving the professionals early in the development of the CILSDS and soliciting their assistance as volunteer trainers of volunteers. Additionally, the advice of these professionals should be sought on an ongoing basis in order to fine tune training and service delivery systems within the CILSDS.

Summary

Rural special educators and others who work with the handicapped and people with disabilities are in a unique position to create a system of interdependence within their communities. Rural areas are excellent arenas for the development of interdisciplinary activities which cut across professional and community lines. People in rural communities are not as accustomed to receiving state and federal largess to the extent that their urban cousins are. Additionally, rural folk have traditions of helping each other and prize personal and community interdependence.

The National Rural Independent Living Network at Murray State University is establishing model rural Community Independent Living Service Delivery Systems across America.

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