

# Link by Link



**A Guide to the Development & Implementation of Services  
for Persons who are Deafblind and Live in Rural Areas**

Lynn Blashaski, M.A.  
and  
Steven R. Sligar, Ed.D.



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Developed by  
Center for Sight & Hearing,  
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This manual is based on a five-year project (project) conducted by the Center for Sight & Hearing (Center). The Center provided two distinct yet overlapping services. First were direct services to individuals who are deafblind<sup>1</sup> (individuals) and second were technical assistance (TA) and training for professionals who worked with persons who had a combined hearing and vision loss. In this dual capacity, the Center identified individuals who needed services, developed a network of service providers and linked them together. The process used by project staff to develop an exportable model of service development is described in this manual. Center staff continue to use this model during ongoing service delivery to persons who are deafblind and live in rural areas.

### **PURPOSE**

This project was designed to improve services for persons who are deafblind and live in rural areas. An individual was considered deafblind when s/he hears only limited speech and often has difficulty understanding what others say in combination with a corrected visual acuity poorer than 20/70 in the better eye or restricted visual field of 20 degrees or less in the better eye. To provide the necessary, and oftentimes very specialized, services individuals who are deafblind require is a challenge for many agencies located in rural areas. As a result, many individuals *fall through the cracks* and are underserved or not served at all. The purpose of this project was to provide services and to

produce a manual or blueprint for agencies to develop services in their local areas.

*Link by Link* can be used, replicated and disseminated to expand the availability of services for the growing population of persons who are deafblind. Users are encouraged to *fill in the blanks* that are unique to their respective service area.

### **Background**

The Rockford (IL) Lions Club originally founded the Center for Sight & Hearing in 1962 as a program for persons who *were* blind or visually impaired. In 1984 services were expanded to include persons who were deaf or hard of hearing. Persons who were deafblind received services based on their preferred communication mode until 1998, when specialized services began. The Center provides a variety of rehabilitation services (Appendix A) for individuals of all ages who have varying degrees of vision and/or hearing loss. Outreach services such as technical assistance and presentations are also available to professionals and community members. The Center staff has background and experience in a variety of fields and utilizes an interdisciplinary approach in service delivery.

In 1997 the Center contracted to serve as an outreach site for the Midwest Center for Postsecondary Outreach (MCPO) at St. Paul College—a community and technical college in St. Paul, MN. MCPO is part of a national consortium, the Postsecondary Education Program Network (PEPNet), which provides technical assistance to facilitate services for persons who are deaf

<sup>1</sup> There are several ways to identify the disability that combines deafness and blindness. At the Center for Sight & Hearing, it is our philosophy that the presence of both conditions is not one disability plus another—it is unique and as such is identified as deafblind. This is the term used throughout the Guide.



or hard of hearing in a postsecondary environment. Specifically, the Center serves other community rehabilitation programs through training and technical assistance. MCPO provided financial support for publication and dissemination of this manual, which is available through the PEPNet Resource Center (<http://prc.csun.edu/>) in both print and online versions.

### **Affiliation with the Helen Keller National Center**

In 1998 the Center began a formal affiliation with the Helen Keller National Center (HKNC), which continues to date. Under the terms of this agreement, the Center was responsible to design, implement and maintain a project that would coordinate a variety of services to individuals who are deafblind and live in rural areas. Services such as technical assistance and in-service training were also made available to community agencies that worked with the target population. In turn, the HKNC financially supported the program for the term of five years with the intention that the project would be self-supporting after the fifth year, which it is.

### **THE CENTER'S PROGRAM**

The overall goal of the Center's project or program for persons who are deafblind was to develop services in the individual's actual environment (e.g., home, job site, school, and/or community). Special emphasis was placed on utilizing a person-centered approach to ensure that the individual had direct input into the needed or required services. The geographic area comprised 13 counties in Northwestern Illinois and Southern Wisconsin; however

occasional requests for services or assistance were met in adjoining counties. Administrative and direct service delivery staff in this catchment area were also served, usually at their respective work sites.

### **DEVELOPMENT OF THE MODEL**

Four key components served as the basis for the Center's service delivery model.

1. It was important to identify service providers with **unique characteristics** to insure the capacity, capability and willingness to work with the target population. Specifically, four characteristics were sought, and these are described in the following.
  - An emphasis to develop and provide services in **non-traditional settings**. Often the obvious service delivery sites were state-operated agencies such as educational agencies and the State Department of Human Services. The Center sought less traditional agencies, e.g., local nursing homes, senior centers and other private vendors.
  - **Person-Centered Planning** was used to develop and guide services. The underlying assumption was that the individual determined needs and desired service outcomes. All services were driven by the individual's wants, needs, and preferences, which were used to develop a plan of action. The individual plan served as the foundation on which to build goals, objectives and desired outcomes for a particular service. (See Appendix B for a sample plan outline).

- Delivery of service in **actual environments**. Unlike traditional models where individuals are brought to an agency to receive training or a particular service, this model focused on conducting outreach in the individual's home, work and/or community. Provision of training in the more natural setting facilitated a successful transfer of learned skills. For example, if an individual learned to grocery shop at a store near the training agency and then returned home, skill transfer was more difficult due to the change in store layout and travel routes. On the other hand, instruction at a site used by the individual not only provided for a direct application but also reinforced the learning.
- An **interdisciplinary team approach** was emphasized in the provision of services. The Center has staff members who represent diverse backgrounds and disciplines. Additionally, community-based professionals were sought to serve as referral agents and to offer their unique skills or information. This type of collaboration allowed for a more successful outcome since no one professional was able to provide everything nor is this a realistic approach. For example, an individual may have received job placement training from one agency, advocacy assistance at the local center for independent living, and medical assistance from a community clinic.

It is important to note that the above components overlapped. For example, the

use of person-centered planning and the ability to provide services in the individual's actual environment were a large part of what made this particular program exemplary. Additionally, the use of an interdisciplinary approach often meant technical assistance was provided to help an outside agency work more effectively with an individual.

## 2. Use of various communication modes.

Several communication modes were used to facilitate the sharing of information across rural boundaries and some examples are:

- Facsimile (fax) machine;
- Accessible telecommunications, for example standard and amplified telephone, text telephone (also referred to as a TTY or TDD), TeleBraille and the relay system (711);
- Teleconferencing/Videoconferencing;
- Internet (E-mail and the World Wide Web) in combination with specialized assistive software and hardware for Braille output, speech output and screen enlargement; and
- Face-to-face meetings, whenever possible, were still the preferred method to communicate information, especially with consumers.

## 3. Identification of characteristics.

Demographics of individuals served in rural areas were compiled via two separate forms. The HKNC National Registry Form documented demographic data on a national level. The Center completed the form and then forwarded it to HKNC for entry into the confidential



registry by HKNC staff. The Center used an Internal Data Sheet (Appendix C) to compile information on individuals served for program monitoring and outcome reporting purposes.

4. **Training and technical assistance** was provided to both individuals and agencies. Topics ranged from general information on deafblindness to specific requests on how to select and use equipment, deliver services, communicate effectively and a host of other subjects. **Trainings** refer to stand-up presentations or skill building exercises and require platform skills. These activities were interactive and covered specific topic areas. **Technical assistance** (TA), on the other hand, was customized for the individual or staff member who requested the assistance. Program development, either development of an individualized plan or specific services were usually covered through technical assistance. An example of TA was a group of service providers who received assistance on how to improve services for an individual in their residential program.

#### **PROCESS**

The task of linking individuals who are deafblind with appropriate agencies often proved to be challenging. Three major components were used to guide a successful connection. These components were:

- Identification of community-based agencies, service providers and resources that provided needed services and/or support (through direct services and outreach);
- Identification of individuals who are deafblind and live in rural communities who were in need of services, resources, and/or support; and
- Orchestration of a match between the individuals who sought services and the agencies/resources that met the needs of the individuals.

The identification of agencies and individuals generally occurred simultaneously. Each time a new agency or individual was identified this link usually led to another agency or individual.

#### **IDENTIFICATION OF COMMUNITY AGENCIES**

The initial (and very important) step to develop a program for individuals who are deafblind was to establish a working contact list. This list served as a referral source for unmet requests for services. It also was a way to link individuals with needed services in their home communities.

Research was done to locate all potential agencies and service providers within the service delivery region. The goal was to become familiar with all community agencies in order to network and share services and resources. Once the agencies were known, *it was important to make a personal connection so that contact was made with a person and not an organization* (in this case, the deafblind specialist and not the Center for Sight & Hearing). There were many different ways to identify agencies in rural areas. It did, however, take more effort and patience since these resources were often scarce and geographically spread out. The following six methods of communication were used to establish an initial contact base.

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### **Telephone Books and Maps**

Some of the most generic resources, such as phone books and accompanying maps proved very helpful in the initial search for service providers. An effort was made to collect these items from each of the counties and cities served in the target area. These tools were used to identify resources in the most rural cities (which were often not included in computerized searches). Maps (county or those located in telephone books) were used to create a comprehensive list of cities served. Once cities were identified, the yellow pages were searched using the keywords (see Internet section) for agencies that served individuals in each respective city or area.

### **The Internet**

The Internet was a helpful tool because it could be accessed virtually anywhere and provided leads to even the smallest of communities. The first step was to browse by city using major search engines such as InfoSeek (now Go.com), Google and Yahoo. The use of keywords for specific types of services helped to narrow the search.

Finally, websites were utilized to search for a particular category, such as a city name. One useful site was [www.hometownusa.com](http://www.hometownusa.com). It provided links to every city in the United States and searches were narrowed according to specific names or types of agencies. For example, a search was made for Lake Geneva, Wisconsin, with the keyword audiologists to obtain a listing of professionals in that Wisconsin community.

### **Letters**

Personal letters were helpful in the initial stages of program development to establish contacts within a community. Once agencies were identified (via the above methods), a letter and Center referral form were sent to each agency. The following points were included in the letter:

- Reason for agency contact, which was the purpose of the project;
- How the agency provided or needed assistance; and
- Contact information for the agency to reach the author of the letter.

Follow-up phone calls were made to agencies within two to three weeks of the mail date. At that time, an inquiry was made to determine if the agency wanted to have a meeting, e.g., to gain more detailed information and/or to discuss how the target agency can further develop services. A sample letter is in Appendix D.

### **Networking**

Another helpful method to identify service providers was to network with other colleagues, professionals and agencies with whom a working relationship already existed. Professionals who had contact with the project through meetings, word of mouth, day-to-day operation of services, and community connections were sought for their feedback and assistance.

Initial contact was made with these professionals by telephone. Meetings were then scheduled to discuss the project's goal(s), identify challenges to find individuals (and the subsequent provision of services), how the professional could be



of assistance to meet the goals, and whether the contact was aware of any additional resources and/or agencies that could help the population. Some examples of contacted agencies are in Appendix E.

### **Resource Directory**

As service providers and agencies were identified, their contact and service delivery information was documented and compiled. A centralized database (or resource directory) helped to make referrals to communities outside the target area and also allowed other staff members access to information as needed. The project's initial directory contained over 200 agencies in 13 counties and was sorted by the agency's geographic service area. For example, agencies that were international or served the entire USA were listed first, followed by those with statewide responsibilities, and finally those that served a specific region, county or township (a sample page is in Appendix E).

The establishment and maintenance of this directory is a time-consuming process that pays nicely when needed.

### **Advisory Council**

Professionals in vision/hearing-related fields were excellent sources of information, support, resources and suggestions that helped to direct the project. Therefore, an advisory council (AC) was developed and the following questions were addressed.

- What purpose will the AC serve?
- How members will be utilized?
- What is the overall goal of the AC?

- What funding is available to support council-related costs, such as lunches, interpreters, etc.?
- Who will sit on the AC? (Which professional backgrounds are sought for feedback and assistance? Which consumers with deafblindness are willing to be involved?)
- How often will the AC meet?
- Where will the meetings be held?
- What objectives/goals will the AC develop?

A combination of twelve professionals and consumers with various backgrounds were selected to sit on the AC. Meetings were scheduled quarterly and were driven by the pre-determined goals of the project as well as an agenda specific to the needs, challenges and issues of the participants.

The delegation of tasks to advisory council members reduced the strain on the facilitator/leader of the group. In addition, the assignment of specific responsibilities to each member increased their sense of purpose and added cohesion among the group members.

Concurrent with the identification of community agencies was the identification of individuals who are deafblind, which is described in the next section.

### **IDENTIFICATION OF INDIVIDUALS WHO ARE DEAFBLIND**

During the identification of community agencies, the question *where are these individuals?* was also addressed. Even with the growth of the senior citizen population, identification was difficult. Two challenges to project development

were the appropriate identification of a dual sensory loss and where the people lived.

Many of the methods used to locate individuals were imbedded in the strategies that identified community service agencies. A survey of agencies was conducted to identify those with interest or need for training, technical assistance or direct service for a specific individual. For example, nursing homes were recognized as primary providers. Staff members in the nursing home environment often requested an assessment of a resident to determine specific need areas. Through this evaluation individuals were identified. Possible collaborations with/between and among agencies were also identified. Print media was also used to inform agencies and individuals about the program.

### **Questionnaires**

Target agencies from the community analysis received a questionnaire to determine the areas (both geographic and within any specific agency) most in need of specialized services. Agencies were selected based on the likelihood that they worked with individuals who have vision and hearing loss. The questionnaire (Appendix F) was developed by the Center's deafblind specialist to collect information regarding the individuals they served and to:

- Determine what services are needed in their community;
- Identify basic training needs of agency staff;
- Find out which services/resources are lacking in the community; and

- Learn more about the targeted agencies and the services they provide.

A cover letter was mailed with the questionnaire to agencies in the 13-county service area. Follow-up phone calls were made to the agencies approximately three weeks after the mailing. At that time, in-service training(s), technical assistance, individual needs assessment(s) and other requested services were scheduled.

### **Training and Technical Assistance**

Discussions with other agency personnel about issues of deafblindness were a great way to educate service providers as well as to identify new individuals who needed services. Many of the agencies contacted through the questionnaire responded and asked that training or TA be scheduled for a staff in-service. Another benefit of the training was an improvement in the skills of staff to identify more appropriately individuals who are deafblind. Presentations on the various topics were given.

It was very important to make the learning interactive and hands-on. Straight lectures did not work because the content was so abstract. The participants needed to have time to process and practice the information or skill.

### **Agency Visits**

There were several benefits that resulted from a direct meeting through either training or TA with an agency. First, face-to-face interaction with service providers opened the doors for future collaboration and networking opportunities. Services to persons who are deafblind took on new meaning when a name, face and



personality were connected with the service.

Secondly, professionals understood more clearly how they could be of assistance when given the opportunity to share information and ask questions in real time with a content expert.

Finally, these meetings helped to locate individuals who needed services and to match the individual with available assistance, sometimes even in their own agency!

Professionals were sought who had the means to meet the needs of the target population (e.g., staff knowledgeable about vision and/or hearing loss, funding, services). Contact was made with the agencies that were identified via the methods listed in the previous section. Face-to-face meetings were arranged at the target agency with professionals who work most frequently with individuals. Generally these professionals were the activities director, social worker, or personnel who ran the program.

When meetings were arranged with more than one agency at the same time and place, then it was important to brainstorm in advance what the agencies could offer each other and to establish methods for follow through. Objectives of the meeting included:

- Discussion regarding number of individuals who are deafblind at each agency;
- Mutual sharing of service/resource information; and

- Identify ways all agencies can collaborate to increase service outcomes based on the individual's needs.

### **Collaborations**

In order to build a network of service providers and identify persons who were deafblind, it was important to facilitate collaboration with and among community agencies and advocates of the individual.

### **State Vocational Rehabilitation Program**

Professionals who traditionally serve persons with a vision and/or hearing loss were able to identify individuals in the target population. The local state vocational rehabilitation (VR) program was a good starting point. In some states a separate office serves individuals who are blind. Either way, these offices generally housed professionals (specialty rehabilitation counselor for the deaf or blind) who were knowledgeable about vision or hearing loss.

A phone contact was made to the specialty rehabilitation counselor to explain the purpose of the Center's program and ask the counselors for assistance to identify individuals who could benefit from services.

State vocational rehabilitation agencies may have funds to purchase services or equipment for individuals who want to work. VR may also provide specific services or equipment through a contract with an agency. One such contract at the Center was the Illinois Bureau of Blind Services Older Adult Services. The Bureau provided funds for technical assistance, various services (e.g., Braille instruction, rehabilitation teaching, and home visits to mark

appliances) and provided equipment such as low-vision aids for individuals who were 55 years or older and who had a significant vision loss.

### **Health Care Provider Groups**

Community-based health care providers helped to form a successful liaison between the Center's program and individuals who needed services. First, a group was sought that existed in the local community and whose purpose was already known. Suggestions were sought as to how the group could help identify and serve individuals who are deafblind. Finally, a formal relationship was established when the Center became a member of the network. An example of a network in Rockford, IL, was ADMIT, which was composed of admissions coordinators from local health care agencies. The goal of ADMIT is to coordinate services for individuals who are in transition from nursing homes or hospitals to their own residences. Through membership as a resource agency, Center staff was able to learn the level of services available, identify persons in need of services and facilitate matches between individuals and agencies.

### **Lions Foundation**

The International Lions Foundation is the World's largest social service organization. Lions Clubs are found in every state of the U.S. and are well known for their work with persons who are blind or have low vision as well as those who experience a hearing loss. Even the smallest of cities generally have access to the Lions Club. Many local clubs host youth camps for children and young adults who have

disabilities including those with a vision and hearing loss. Some clubs have camps specifically for persons who are deafblind. Local Lions Clubs can be a great resource to find individuals who are deafblind and participate in their camps and/or other sponsored activities.

The Center staff collaborated with the local Lions Clubs by doing presentations for Lions members on issues related to deafblindness. The Clubs were also asked for their assistance to identify individuals who needed services in their communities.

One of the ways the Center has utilized the Lions to increase awareness and promote education regarding deafblindness is by the organization of social and educational activities during Helen Keller's birth week. For example, the Center has hosted an annual "Helen Keller Awareness Day" picnic for the deafblind youth and adults who participated in the Lions Camp. A date was selected during the week of Helen Keller's birthday, and invitations were sent to the local Lions camps, area agencies that work with individuals who have a vision and hearing loss, Center board members and other professionals affiliated with the Center.

### **Family and Friends**

Referrals often came from concerned family members and friends of someone who was deafblind. They were unaware of community services available to help their loved one and turned to the Center in hopes of connecting with helpful resources.

It is important to include family members, friends, and significant others



in the service delivery process as much as possible (with the individual's consent) to ensure a successful outcome. Significant other involvement was accomplished through inclusion in staff meetings and individual plan development; specific requests for feedback or concerns; and provision of helpful information and resources.

### **Center Co-Workers**

The collaboration of Center staff members was instrumental to build a base of individuals by utilizing colleague expertise and diverse backgrounds. Center staff who provided outreach had exposure to outside agencies and possible referrals. Staff then brought information back to other staff members who provided the needed services. For example, the Center's case manager made a presentation to a local group of health care workers, who then provided a contact site with an individual who needed a service and direct care staff who also needed training. The case manager would then relay this information to the deafblind specialist who would provide the follow-up.

As new individuals were identified, a weekly meeting was developed for the professional team to compile and share information on individuals whether a new referral or current service recipient. This meeting also allowed for routine updates on progress as well as an opportunity to discuss any scheduling problems or concerns.

### **HKNC Regional Office**

Another source of referrals was from the HKNC Regional office. When this office

received inquiries from individuals, families, employers and others, then referrals were made to the Center. The regional representative also served as a partner in the provision of technical assistance and training for agencies and individuals.

### **Direct Services**

The Center provided direct services both on and off site (see Appendix A for listing of Center services).

### **Low Vision Clinic**

The Center offers a low vision clinic on site as one of the core services. It was the Center's experience that 48 (24%) of the 201 individuals who received a low vision exam during 2001 also had a significant hearing loss. Similar figures were experienced in 2002 when 56 (29%) of 195 individuals presented a hearing loss. Most of these individuals were over the age of 55. Many times a hearing loss became apparent during intake and referral, which was conducted over the telephone. At the time of contact the individual was not able to hear the staff person ask questions or later, during the exam when the individual experienced difficulty understanding instructions or providing basic background information.

When individuals were identified as having a dual vision and hearing loss, the deafblind specialist was notified by the staff member who did the scheduling to provide follow-up as needed. It was helpful to have the specialist on hand during the individual's exam appointment to answer questions and provide information on services or products available.

### Home Assessments

Some individuals with deafblindness reside in assisted living, nursing homes or retirement communities where they are unaware of available services. Staff members who work in these agencies are often eager to have access to resources that will help enhance the lives of the residents. These staff members appreciate on-site consultation and individual or group assessments on residents who are deafblind. On-site evaluations can determine the needs of the individuals and result in recommendations on how to improve the quality of their lives.

When an assessment was requested, the Deafblind Specialist (or other Center staff knowledgeable about vision and hearing loss) arranged a meeting with the individual and others, e.g., family, friends, supervisor, or other service delivery staff. The evaluation usually took place at the person's residence though community sites were also used.

The assessment generally consisted of two distinct components. The first phase was an information gathering interview and observation with the individual and others in the individual's life. The purpose was to collect background and current functioning level information about the individual in the following areas:

- Etiology of the vision/hearing loss;
- Challenges/functional limitations in daily life as result of vision/hearing deterioration;
- Goals of individual (what s/he wants now and why);

- Documentation of any assistive technology, special aids or services currently used;
- Sources of income received by the individual (what funds are available to purchase equipment and/or services?);
- Medical history including any additional health problems;
- What social supports are available to the individual (e.g., transportation or funding);
- Methods of communication used; and
- Any other relevant information as it related to the individual.

The second phase of the assessment consisted of *information sharing*. The individual was provided with information and literature on available services both through the Center and other agencies in the community. This phase included sharing free community resources with the individual, such as Talking Books, radio information service and directory assistance.

Whenever possible, actual products and equipment (e.g., magnifiers, directional microphones, vibrating alarms) were brought to the assessment to provide a hands-on experience with technology.

Once the assessment was completed, recommendations were made to guide any future service delivery. Quite often, one of the results of the information sharing was to match the individual with local services.

The protocol used during the assessment was based on *Assessing Workplace Communication Skills with Traditionally*



*Underserved Persons Who Are Deaf* by Greg Long (1966). Additional information about assessment is available from the Helen Keller National Center and the Center for Sight & Hearing.

### **Newsletters**

Agency publications were used to outreach to the lay community and individuals with disabilities. Information was disseminated on various issues that related to deafblindness (e.g., services, technology available; who to contact for assistance; and other relevant information). The newsletter was available in a variety of formats, i.e. large print, Braille, tape and disk.

### **LINKS BETWEEN AGENCIES AND INDIVIDUALS**

Individuals and agencies were identified as described in the previous sections and linked together through the Center's deafblind specialist. The Specialist served as an information and referral source for individuals who needed services and connected the individual with agencies, resources and supports located in his/her community. This connection was made in person, over the phone, via e-mail or by letter.

The individuals and agencies were responsible to make contact with each other and exchange background information, such as the nature of the vision and hearing loss, what services were needed and what resources the agency had available. The deafblind specialist provided follow-up calls approximately 30-60 days later to ensure that the requested services were provided as well as to offer additional assistance as needed.

### **LESSONS LEARNED/ RECOMMENDATIONS**

As with any completed project, the end generally brings reflection on the development process as well as what could have been done differently to achieve more successful results. This manual was no exception. Looking back, several things happened that could prove helpful to other agencies that wish to emulate a similar program for individuals who are deafblind. These "helpful tips" follow.

#### **Terminology**

How individuals view themselves does not always fit the definition of their disability. For example, the Center encountered less resistance when the wording *individuals who have a vision and hearing loss* was used versus *those who are deafblind*. Although individuals may in fact fit the medical or functional definition of deafblindness, they may not see themselves as a fit with this classification since they still have some residual vision and hearing. Agencies need to be sure that the terminology chosen is all-inclusive and understandable to service providers who are responsible to identify and refer individuals who have a combined vision and hearing loss. This education is an ongoing process.

#### **Advisory Council**

It can be a challenge to recruit and retain qualified professionals and consumers on an advisory council (AC). Depending on the time commitment, it may be helpful to rotate members off the council after a certain period of time, for example, every 2-3 years. A rotation schedule limits the commitment of those already involved as

well as opens spaces for new members to join and contribute a “fresh” perspective on the issues at hand.

Note that the original HKNC Advisory Council continues to date. After initial implementation of the project, the AC merged with the existing Center Council and there is standing representation.

### **Volunteers**

Seek out volunteers whenever possible! These extra hands were invaluable with the day-to-day operation of the program. Oftentimes local colleges and universities have students who need to fulfill practicum or internship requirements. Student volunteers are a great way to recruit future professionals into the field of deafblindness and expose them to service delivery and coordination. Senior citizen organizations also frequently seek opportunities for older adults to become involved with volunteer activities. Completing everyday tasks like paper work, copying, running errands, etc. can free up the professional’s time to focus on the more technical aspects of the job.

### **Staff Development**

Agencies who can afford to provide stipends to staff members to attend trainings, seminars and conferences should do so whenever possible. Although much knowledge can be shared within an interdisciplinary team, outside expertise and experiences from professionals can further assist in staff development. It should also be noted that some organizations offer free seminars and learning opportunities that are accessible to any agency. Field trips and guest lecturers at staff meetings are two excellent sources of information.

### **Group Training**

It has been the Center’s experience that the majority of service providers prefer smaller, more intimate environments for in-service training. Several local agencies were asked about attending a group training session on how to improve deafblind services. Agency feedback strongly preferred customized training that focused on their particular needs, challenges and concerns. Individual site training may not always be possible, given travel costs and limited staff availability. Scheduling multiple stops on each visit was one way to provide more individualized services. Agencies need to work together to see what compromises may be made. The HKNC National Training Team is an excellent resource for suggestions and training.

### **Interpreting**

Communication access continues to be a challenge, especially in rural locations. First, the communication preferences of the individual must be considered, which may or may not involve a sign language interpreter. For those who use a sign language interpreter, availability is often scarce, as well as more costly when travel is involved. Communities that have local colleges and/or universities with interpreter training programs may be able to utilize students-in-training for some of their needs. Additionally, video remote interpreting is another emerging technological option for agencies that cannot afford the travel costs of hiring an on-site interpreter. The Postsecondary Education Program Network ([www.pepnet.org](http://www.pepnet.org)) can be contacted for more information on new technology (Appendix G).



### **Documentation**

Any agency that attempts to develop a deafblind program (in full or in part) should make sure to *Document! Document! Document!* Documenting everything (e.g., contacts made with agencies/individuals, services provided, programs and procedures for service development, etc.) will be much more helpful to have from the beginning than to retrace steps later down the road. With agency changes and staff turnover it can be a challenge to keep abreast of what has been completed, what needs to be done, and a host of other bits of information.

It is recommended that all information pertaining to the program be kept in a centralized database where all staff have access to the information as needed. At the very least, a separate file drawer should be available in a common area to allow for easy access.

### **On The Road**

It is quite likely that travel will be required for agencies. There are three things to keep in mind when plans are made to contact agencies in person.

First, research should be done in advance to determine which agencies will be visited. The Internet can be a very helpful research tool by providing information on which cities are located within the target region, how large the communities are, which organizations are present in a particular city, total travel distance, and other facts.

Second, it is important to plan visits in a time-and cost-efficient manner. Time of

year/weather should be taken into consideration, for example, if travel will occur over rural, country roads. Perhaps the farthest cities can be targeted during the spring and summer months and the closer cities can be visited when the weather is more unpredictable. Care should be taken to group as many cities together in one trip as possible to save on gas and mileage.

Third is to be aware of the stress and strain that accompanies travel. Staff need to have schedules adjusted. For example, it is hard to make an 8:00 AM meeting when the staff person arrived home the evening before at 9:30 PM.

### **Staff Input**

Co-workers are extremely helpful to spread the word about services and to identify individuals who need services. Staff members who provide outreach services and/or give presentations to other community-based agencies can help to make contacts with individuals. When staff encounter individuals in need of services, they can connect them with the deafblind specialist.

### **Cross Generation Request**

One of the biggest surprises to surface during the development of the Center's deafblind program was the number of grandchildren who sought assistance for their grandparents. Apparently, the number of grandparents who are primary caregivers for their grandchildren has sharply risen and as grandchildren notice changes, they seek help. Although many adult children still continue to seek assistance for their elderly parents, a trend to receive inquiries from the third generation was observed.

**ADDITIONAL INFORMATION**

For further explanation about this manual, please contact:

Deafblind Specialist  
Center for Sight & Hearing  
8038 MacIntosh Lane  
Rockford, IL 61107  
815-332-6800 V  
815-332-6810 Fax  
815-332-6820 TTY  
info@rockfordcenter.org

For additional information about deafblindness contact the Center or Helen Keller National Center  
141 Middle Neck Road  
Sands Point, New York 11050-1299  
516-944-8900 ext. 326 V/TTY  
516-767-1738 Fax  
hkncinfo@rcn.com

## **APPENDIX**

- A. Center Services
- B. Individual Plan Outline
- C. Data Sheet
- D. Sample Letter
- E. Resource Directory
- F. Questionnaire
- G. Postsecondary Education Program Network

**Professional Services****Designed to promote personal and social independence****Available for all participants:**

- Daily living skills (cooking, grooming, etc.)
- Functional academics (literacy for work and home, math and study skills)
- Assistive device or adaptive technology training (flashing alarms, low-vision devices, computer screen reading software, etc.)
- Keyboarding and personal typing skills
- Recreation (peer-supported and sponsored activities at the Center or in the community)
- Personal management (budgeting, home and medical areas)
- Adjustment counseling
- Job readiness training (résumé, development, interview skills)

**Customized services for persons who are blind or have low vision:**

- Low vision clinic (evaluation, prescription, fitting and trial of various devices)
- Braille literacy (Grade I or II)
- Orientation and mobility in the home, work site and community
- New Visions (program for persons who are experiencing a recent vision loss)
- Adaptive techniques (money identification, organizing and labeling, etc.)

**Customized services for persons who are deaf or hard of hearing:**

- Communication skills (sign language and speech-reading)
- Intensive developmental training for persons who are deaf

**Community Services****Designed to promote awareness and vocational integration**

- Available for consumers, employers, professionals, civic groups, and others
- Presentations on deafness and/or blindness
- Tours of the Center (technology demonstrations and service consultation)
- Technical assistance (program development, work site assessments and staff training)
- Information about services and referral to appropriate program or agency
- Simple solutions (adaptive technology demonstration, sales and service center)
- Employment services (evaluation, training and job placement assistance)
- Sign language classes in the evening for the community
- Transportation to/from client's home available for Rockford area

**For information or an appointment, please call  
815/332-6800 Voice 815/332-6820 TTY**

## Appendix B

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's Individual Plan

Date

Plan:       New       Renewal       Revised       Closed

My Rehabilitation Team	Relationship
1.	Individual
2.	Case manager
3.	Rehabilitation Instructor
4.	Rehabilitation Manager
5.	VR Counselor

### My Goal(s)

#### Employment Information

The name of the job I want is

My second choice

Work hours I want are

Wage I need to live

Shift or work schedule I want to work is

Benefits I want are

My work restriction(s) is

Reasonable accommodations I need are

Reasons I want to work

My strengths and abilities are

My living situation is       Independent       Dependent       Other (explain)

My transportation needs are       Independent       Public       Center

#### Medical Background

#### Previous Services

##### Services

- |   |   |
|---|---|
| <input type="checkbox"/> Assessment                             | <input type="checkbox"/> Rehabilitation Teaching      |
| <input type="checkbox"/> Job Readiness (seeking & match)        | <input type="checkbox"/> Communication                |
| <input type="checkbox"/> Job Placement (dev., coaching, & ret.) | <input type="checkbox"/> Orientation & Mobility       |
| <input type="checkbox"/> Post Employment Placement Services     | <input type="checkbox"/> Adjustment Counseling        |
| <input type="checkbox"/> Older VI Adult Program                 | <input type="checkbox"/> Technology/Computer Training |
| <input type="checkbox"/> Other                                  |   |

#### Accommodations, Including Tools, Technology Necessary to Meet Goal(s)

**Cultural/Other Considerations**

**My Service Goal(s)**

**My Objective(s)**

**Desired Outcomes**

**Methods** (how goals are accomplished)

**Person(s) Responsible**

**Assessment Criteria**

**Job Retention Provided**     On Site     Off Site

**Materials/Resources Needed**

<b>Voucher</b>	<b>Start</b>	<b>Stop</b>
<b>Timeline</b>	Start date	Estimated end date
	Time/Hours	Completed date
	Review date(s)	

**Impact on my social security or other benefits**

**What I want my ORS Counselor to help me with is**

**My comments are**

**Satisfaction with services**

**IP staffing summary**

<b>Signatures</b>	<b>Date</b>
1.	
2.	
3.	
4.	
5.	

## Appendix C

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### Data Sheet

<b>Name</b> (Include Middle Initial)	<b>SS#</b>	<b>Case #</b>				
<b>Address</b>	<b>Phone</b>					
<b>E-Mail</b>						
<b>City</b>	<b>State</b>	<b>Zip Code</b>				
<b>Case Manager</b>						
<b>DOB</b>	<input type="checkbox"/> < 18	<input type="checkbox"/> 18-21	<input type="checkbox"/> 21-29	<input type="checkbox"/> 30-39	<input type="checkbox"/> 40-49	<input type="checkbox"/> 50-59
	<input type="checkbox"/> 60-69	<input type="checkbox"/> 70-79	<input type="checkbox"/> 80-89	<input type="checkbox"/> 90-99	<input type="checkbox"/> 100 +	
<b>Ethnicity</b>	<input type="checkbox"/> African Am.	<input type="checkbox"/> Asian	<input type="checkbox"/> Caucasian			
	<input type="checkbox"/> Hispanic	<input type="checkbox"/> Native Am.	<input type="checkbox"/> Other			
<b>Gender</b>	<input type="checkbox"/> Female	<input type="checkbox"/> Male				
<b>Marital</b>	<input type="checkbox"/> Married	<input type="checkbox"/> Single				
<b>Primary Disability</b> (Check only one box.)	<input type="checkbox"/> Blind	<input type="checkbox"/> Deaf	<input type="checkbox"/> Deafblind			
	<input type="checkbox"/> Hard of Hearing		<input type="checkbox"/> Low Vision			
<b>Other Disability</b> (Can check more than one box.)	<input type="checkbox"/> Dev. Disabled	<input type="checkbox"/> Diabetes	<input type="checkbox"/> Epilepsy	<input type="checkbox"/> Mental Health		
	<input type="checkbox"/> Cardiac	<input type="checkbox"/> Orthopedic	<input type="checkbox"/> None	<input type="checkbox"/> Other		
<b>Independent Transportation</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No				
<b>Independent Living</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No				
<b>Use Adaptive Technology</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No				
<b>Leisure Mgt.</b>	<input type="checkbox"/> Satisfied	<input type="checkbox"/> Not Satisfied				
<b>Income</b> (Can check more than one box.)	<input type="checkbox"/> Employed	<input type="checkbox"/> SSDI	<input type="checkbox"/> SSI	<input type="checkbox"/> Social Security		
	<input type="checkbox"/> Public Aid	<input type="checkbox"/> None	<input type="checkbox"/> Retirement	<input type="checkbox"/> Investments	<input type="checkbox"/> Other	
<b>Employment Status</b>	<input type="checkbox"/> Part-Time	<input type="checkbox"/> Full-Time	<input type="checkbox"/> Unemployed	<input type="checkbox"/> Retired		
<b>Education</b> (Check highest level completed.)	<input type="checkbox"/> High School Grad.	<input type="checkbox"/> GED	<input type="checkbox"/> Associates	<input type="checkbox"/> Bachelors		
	<input type="checkbox"/> Masters	<input type="checkbox"/> Doctor	<input type="checkbox"/> No Response			
	Years Completed					
<b>Payor Source</b> (Can check more than one box.)	<input type="checkbox"/> ORS	<input type="checkbox"/> Medicare	<input type="checkbox"/> WIDVR			
	<input type="checkbox"/> BBS-Tech	<input type="checkbox"/> Insurance	<input type="checkbox"/> Self Pay	<input type="checkbox"/> Company		
	<input type="checkbox"/> BBS-EBC	<input type="checkbox"/> Medicaid	<input type="checkbox"/> No Pay	<input type="checkbox"/> Other		
<b>Reason of Referral</b> (Can check more than one box.)	<input type="checkbox"/> Assessment	<input type="checkbox"/> EATS	<input type="checkbox"/> Counseling			
	<input type="checkbox"/> Low Vision Exam	<input type="checkbox"/> Computer Training	<input type="checkbox"/> Soc/Rec			
	<input type="checkbox"/> Drivers License Exam	<input type="checkbox"/> New Visions	<input type="checkbox"/> Transportation			
	<input type="checkbox"/> EDS	<input type="checkbox"/> O&M	<input type="checkbox"/> Speechreading			
	<input type="checkbox"/> CES/Vocational Placement	<input type="checkbox"/> Rehab Teaching				



Date

Organization Name

Address

City/State/Zip

Dear

The Center for Sight & Hearing is pleased to announce our new affiliate program with the Helen Keller National Center.

The target area comprises 13 counties in Northwestern Illinois and Southern Wisconsin. The emphasis of this five year project is to reach people who are Deafblind and live in rural areas. If you have contact with a person who is deafblind or would like assistance to serve this population, please contact me at 815/332-6800 V or 332-6820 TTY.

I have enclosed a Center for Sight & Hearing referral form for your convenience.

This is an exciting project and I look forward to working with you to provide the best possible services for persons who are deafblind.

Very best regards,

**Appendix E**

**Resource Directory for Vision and/or Hearing-related Services (Sample page)**

<b>Counties Served</b>	<b>Type of Agency</b>	<b>Agency</b>	<b>County</b>
International	Provides hearing dogs to people with hearing loss.	International Hearing Dogs, Inc. 5901 E. 89th Ave. Henderson, CO 80640-8315 303-287-3277 Voice/TTY (303)287-3425 Fax <a href="http://www.ihdi.org">www.ihdi.org</a>	Henderson, CO
International	Real-time captioning services for people with hearing loss.	Caption First, Inc. P.O. Box 1924 Lombard, IL 60148 1-800-825-5234 national 001-630-576-5325 international 1-888-957-5233 TTY 1-888-957-5234 Fax <a href="mailto:info@captionfirst.com">info@captionfirst.com</a>	DuPage, IL
Entire USA	Free bibles on cassette for people who are blind or have vision loss.	Aurora Ministries P.O. Box 1061 Bradenton, FL 34206 941-748-3031 941-748-2625 Fax <a href="mailto:AudioBibles@auroraministries.org">AudioBibles@auroraministries.org</a> <a href="http://www.audiobiblesfortheblind.org">www.audiobiblesfortheblind.org</a>	Bradenton, FL
Entire USA	Information and referral agency on deafness and rehabilitation. Provides fact sheets on devices and technology.	ABLEDATA 8630 Fenton Street, Suite 930 Silver Spring, MD 20910 Phone: 800/227-0216. Fax: 301/608-8958. TT: 301/608-8912. Email: <a href="mailto:abledata@orcmacro.com">abledata@orcmacro.com</a>	Silver Spring, MD
Midwest USA	Community-based rehabilitation services for people who have vision and/or hearing loss.	Center for Sight & Hearing 8038 Macintosh Lane Rockford, IL 61107 1-800-545-0080 815-332-6800 Voice 815-332-6820 TTY 815-332-6810 Fax <a href="mailto:info@rockfordcenter.org">info@rockfordcenter.org</a>	Winnebago, IL
State of Illinois	Provides vocational rehabilitation services for people who are blind or have vision loss, or who are Deaf, late deafened, hard of hearing, or deafblind.	Illinois Dept. of Human Services/ Division of Rehabilitation Services DHS Main Offices: 100 South Grand Avenue E Springfield, IL 62762 Rehabilitation Services Web Referral: <a href="http://drs.dhs.state.il.us/owr">drs.dhs.state.il.us/owr</a> or call DHS 24 hour hot line 1-800-843-6154 Eng or Span 1-800-447-6404 TTY <a href="mailto:DRS@dhs.state.il.us">DRS@dhs.state.il.us</a>	All Illinois counties
Northwestern Illinois	Comprehensive medical services for uninsured or underinsured individuals including eye examinations, diagnosis of cataracts and glaucoma, glasses and contact lenses, and special programs for those with diabetes.	Crusader Clinic 1200 West State Street Rockford, IL 61102-2112 815-490-1790 815-490-1891 Fax <a href="http://www.crusaderclinic.org">www.crusaderclinic.org</a>	Winnebago, IL

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**Service Provider Questionnaire**

1. What is the name, address and phone number for your agency?
  
2. What services do you provide?
  
3. What areas or counties do you serve?
  
4. Have you served any individuals who have both a vision and hearing loss?  
 Yes             No
5. If yes to #4, was your staff able to provide the needed services?  
 Yes             No  
If no, please explain:
  
6. Would you and your staff be interested in specialized training to improve your services for persons who are visually and hearing impaired?  
 Yes             No
  
7. What difficulties do staff face in providing services to those with both vision and hearing losses?  
 Communication             Lack of resources  
 Lack of technology             Finding meaningful activities for person  
 Other, please list:
  
8. If yes to #6, are there specific areas you would like covered? Please list:
  
9. Would you like statistical information on the number of individuals with vision/hearing loss in your county?  
 Yes             No
  
10. Thank you for your time! Other comments?

By filling out this form you will help us identify more individuals who have a dual sensory impairment and improve services we provide. Your help is greatly appreciated!

If you have any questions or need additional information, please contact

Name

Number

## **Appendix G**

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### **PEPNet**

The Postsecondary Education Programs Network (PEPNet) is the national collaboration of four regional technical assistance centers funded under a contract with the U.S. Department of Education Office of Special Education and Rehabilitative Services. PEPNet's mission is to improve access and quality of postsecondary education for students who are deaf or hard of hearing.

To learn more about PEPNet and to participate in the PEPNet online training, visit the web site at: [www.pepnet.org](http://www.pepnet.org)

The four regional centers on postsecondary education for individuals who are deaf or hard of hearing follow.

#### **Midwest Center for Postsecondary Outreach**

St. Paul College-- A Community & Technical College  
235 Marshall, St. Paul, MN 55102  
651-846-1337 Voice  
651-846-1537 TTY  
651-221-1339 Fax  
e-mail: [dave@mcpo.org](mailto:dave@mcpo.org)

#### **Northeast Technical Assistance Center**

52 Lomb Memorial Drive  
Rochester, NY 14623  
585-475-6433 V/TTY  
585-475-7660 Fax  
e-mail: [netac@rit.edu](mailto:netac@rit.edu)

#### **Postsecondary Education Consortium**

Center on Deafness  
Claxton Complex A239  
University of Tennessee  
Knoxville, TN 37996  
865-974-0607 V/TTY  
865-974-3522 Fax  
e-mail: [pec@utk.edu](mailto:pec@utk.edu)

#### **Western Region Outreach Center & Consortia**

California State University, Northridge  
18111 Nordhoff Street  
Northridge, CA 91330-8267  
888-684-4695 V/TTY (toll-free)  
818-677-2099 V/TTY  
888-677-6270 Fax  
e-mail: [wrocc@csun.edu](mailto:wrocc@csun.edu)



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Lions of Illinois Region 1D

Midwest Center for Postsecondary Outreach