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ABSTRACT

This final report describes activities and accomplishments of a 3-year federally funded project at the Great Lakes Area Regional Center for Deaf Blind Education to provide technical assistance to service providers and families of children with dual sensory impairments in Ohio, Pennsylvania, and Wisconsin. Individual sections of the report present information on: (1) mission statement/goals and objectives of the Center and of this specific project; (2) meetings of the Regional Advisory Committee; (3) project impact and census (showing a substantially greater number of children identified with deaf blindness); (4) technical assistance contacts (approximately 5000 over the 3-year period); (5) mini-grants and family service awards; (6) the family learning weekends; (7) support to parent groups including a parent leadership weekend; (8) training, including a summer institute each year and SKI*HI training; (9) assessments and evaluations; (10) information dissemination (including a newsletter mailed to over 3,000 people and a toll-free deafblind information hotline); (11) collaboration activities and committees; and (12) sources of further information. (DB)

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FINAL REPORT

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EC 304492

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The Great Lakes Area Regional Center for Deafblind Education

Mission Statement

The mission of the Regional Center is to assess ongoing regional needs affecting parents and service providers of children with dual sensory impairments, and to plan, develop and implement services, information, and training to meet those needs. The Center's efforts are accomplished through inter and intra state collaboration with appropriate programs and services involved in the lives of individuals who have dual sensory impairments and their families.

The role of the Regional Center is to provide leadership and coordination in the areas of innovation, resource functions, provision of technical assistance and dissemination. These functions will enable/empower the states to plan, implement and evaluate multi-level children and family focused services resulting in enhanced outcomes for these constituencies/consumers.

The mission of the Regional Center is to advocate, inform and support change that has an impact on the educational choices offered to children who have dual sensory impairments and their families. This mission involves comprehensive planning, collaboration, preparation and development of innovative materials/resources and dissemination.

The mission of the Regional Center is to support family focused best practices by offering choices and nurturing change through planning, education, advocacy and information in order to improve the lives of children and their families.

The Regional Center's mission is to promote and implement comprehensive best practices that will have an impact on children and families. This will be accomplished through coordination, planning and collaboration of personnel and resources.

The mission of the Regional Center is to facilitate needs-focused change that benefits families and children. Through information sharing, coordination, collaboration and resource utilization, the recipients of Regional Center services are empowered. They are prepared to implement best practices, promote change in their system of delivery, and nurture families in order to maximize independence, increase quality of life and offer large numbers of choices for individuals who have dual sensory impairments.

Goals and Objectives

- I. To develop and provide state of the art early intervention services for infants and toddlers who are deafblind or at risk for deafblindness for whom the states are not mandated to serve. [307.11 (a) (1)]
 - A. Provide transdisciplinary family centered early intervention services for infants and toddlers who are deafblind or at risk for deafblindness in Ohio [307.11 (a) (1) (i) - (iv)]
 - B. Coordinate direct services for infants and toddlers who are deafblind with other service delivery agencies and organizations [307.11 (c) (3)]

- II. To provide technical assistance activities for service providers responsible for providing effective early intervention and special education services for infants, toddlers, children and youth who are deafblind or at risk for deafblindness. [307.11 (a) (2)]
 - A. Identify the technical assistance needs of service providers who are currently serving infants, toddlers, children and youth who are deafblind or at risk for deafblindness [307.11 (a) (2)]
 - B. Provide outreach services to service providers who are currently serving infants, toddlers, children and youth who are deafblind or at risk for deafblindness [307.11 (a) (2)]
 - C. Provide local, state and regional level training for service providers who are currently working with infants, toddlers, children and youth who are deafblind or at risk for deafblindness [307.11 (a) (2)]
 - D. Coordinate technical assistance activities with other key agencies involved in providing state, regional and national technical assistance [307.11 (c) (3)]

- III. To implement pilot projects for supplemental services to expand the capacities of local education agencies to integrate children who are deafblind into neighborhood schools. [307.10 (d) and 307.11 (a) (3)]
 - A. Develop a process for disseminating and reviewing proposals
 - B. Develop and maintain the Pilot Project Sites
 - C. Evaluate the activities of the Pilot Project Sites
 - D. Disseminate information and resources from Pilot Project Sites

- IV. To provide technical assistance activities that will enable families of infants, toddlers, children and youth who are deafblind to assist their child to be part of their family and community. [307.11 (a) (1) (iii)]
 - A. Identify the technical assistance and training needs of families in Ohio, Pennsylvania and Wisconsin who have members who are infants, toddlers, children or youth with deafblindness [307.11 (a) (1) (iii)]
 - B. Provide outreach services to families in Ohio, Pennsylvania and Wisconsin who have members who are infants, toddlers, children or youth with deafblindness [307.11 (a) (1) (iii)]

- C. Provide individual, local, statewide and regional level technical assistance and training to families in Ohio, Pennsylvania and Wisconsin who have members who are infants, toddlers, children or youth with deafblindness [307.11 (a) (1) (iii)]
 - D. Coordinate technical assistance activities with other key agencies in Ohio, Pennsylvania and Wisconsin involved in providing state, regional and national technical assistance to families who have members who are infants, toddlers, children or youth with deafblindness [307.11 (c) (3)]
- V. To promote linkages with institutes of higher education who provide preservice training to personnel who may provide services to infants, toddlers, children and youth who are deafblind. [307.11 (2) (ii)]
- A. To promote collaborative projects focused on increasing preservice education in the area of deafblindness in Ohio, Pennsylvania and Wisconsin [307.11 (2) (ii)]
 - B. To identify and provide technical assistance and training for personnel in institutes of higher education in Ohio, Pennsylvania and Wisconsin [307.11 (2) (ii)]
- VI. To increase the identification of infants, toddlers, children and youth who are deafblind in order to provide direct services and/or technical assistance. [307.11 (a) (2)]
- A. To develop promotional materials and strategies aimed at identifying children who are deafblind
 - B. To compile the census data collected in Ohio, Pennsylvania and Wisconsin for submission to the Office of Special Education Programs
 - C. Maintain and expand linkages with other agencies responsible for identifying children who are deafblind
- VII. To develop and disseminate information and training products for service providers and families of infants, toddlers, children and youth who are deafblind. [307.11 (a) (2)]
- A. Determine local, state and regional needs related to the needs for product development and dissemination
 - B. Develop and disseminate Regional Center informational and resource products
 - C. Develop and disseminate self study and training products
 - D. Develop and disseminate products on best practices and research in deafblindness
- VIII. To evaluate the activities of the project in order to increase accuracy of meeting the needs of the population and to insure ongoing quality of services. [307.11 (c) (1) and (2)]
- A. Evaluate changes in primary recipients of services
 - B. Evaluate changes in secondary recipients of services
 - C. Evaluate results of pilot project sites
 - D. Evaluate materials and product development
 - E. Evaluate accomplishment of goals and objectives
 - F. Evaluate the satisfaction of consumers with services of the Regional Center

IX. Management of project staff and activities. [307.11 (c) (1) and (2)]

- A. Manage direct services function
- B. Manage technical assistance function
- C. Manage the census function
- D. Manage the evaluation plan function
- E. Manage the human resources function
- F. Manage the fiscal resources function
- G. Manage the subcontractual function

Introduction

The mission of the Great Lakes Area Regional Center for Deafblind Education (GLARCDBE) is to facilitate needs focused change that benefits children with dual-sensory impairments in Ohio, Pennsylvania and Wisconsin. Through information sharing, coordination, collaboration and resource utilization, the recipients of Regional Center services are empowered. They are prepared to implement best practices, promote change in their system of service delivery and nurture families in order to maximize the independence, increase the quality of life and offer large numbers of choices for individuals who have dual sensory impairments.

Throughout the project years of 1992-1995, the staff of GLARCDBE attempted to achieve this mission by providing technical assistance, education, training and support to service providers and families of children with dual-sensory impairments. The effectiveness of the project was measured through training evaluations and data on the number of individuals receiving services. However, the impact of the project activities upon families and children with dual-sensory impairments can be best seen through personal stories and letters found at the beginning of each chapter. Barriers that were encountered and overcome during the project included changes in staff, change of fiscal agent and hiring a full staff.

Regional Advisory Committee

The Regional Advisory Committee is comprised of the Project staff, plus selected parent representatives from each state and representatives from the Department of Health (Part H) and the Department of Education (Part B). The full committee meets on an annual basis to discuss Project priorities and obtain an update on the progress of Project activities in each state. The Regional State Representatives also meet formally with the Project leadership on a semi-annual basis. During the grant cycle 1992-1995, the committee met twice.

Project Impact

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Census

Sixteen Year Struggle Has Successful Result

Ohio's observance of National Deafblind Awareness Week, June 25 through July 1, brings not only a proclamation of the week long observance from Governor George Voinovich but it brings hope to the Syler family of Massillon. Hope that this observance will help to educate Ohioans so that other families of people who are deafblind don't have to face the same frustrations they have faced.

Just short of her 18th birthday, Jennifer Syler was finally identified as a member of the deafblind community and eligible for services available through the Great Lakes Area Regional Center for Deafblind Education. Jennifer's mother, Linda, uses the word "finally" when telling her daughter's story because that acknowledgement ended sixteen and a half years of testing for Jennifer and frustration for Linda and the rest of the family.

How could it possibly take all those years to determine blindness and deafness? "One of the problems", explains Linda, "is that when most people think of these disabilities, they think total deafness and total blindness. Jennifer's had hearing aids since she was 6 and though she's legally blind she has slight vision in her right eye. Whatever she has in sight and hearing, she uses to the maximum."

Finally through contact with the Ohio Developmental Disability Planning Council, Linda was put in contact with the Great Lakes Area Regional Center for Deafblind Education. After observing Jennifer and establishing that she qualified for the deafblind program, a team was brought in to work with her in developing a coordinated effort to provide the services she needed. The Center also provided a mini-grant to Jennifer's school system to provide a signing program for fellow students and faculty, special materials needed, and to pay for an aid who is with Jennifer throughout her entire day. But the battle wasn't over yet.

Jennifer then spent 10 weeks at the Helen Keller National Center (HKNC) in New York where she went through a comprehensive rehabilitation and training program designed to make individuals as independent as they can possibly be. Though an extensive report by HKNC was sent to Jennifer's high school, it still took her mother another 6 weeks to get an acceptable Individual Education Plan (IEP) developed for Jennifer. Linda is quick to point out however, "Once we got the plan developed, everyone was great. The administration, staff in special and regular classes, and the Great Lakes Center couldn't be more supportive or involved than they are".

Now Jennifer is fully included in her high school classes. Next year she will be with her classmates in the morning and will spend her afternoons job shadowing. After all of these years, how does Linda feel about the outcome? "I feel like it's too good to be true. It has finally allowed me to continue doing what I'd been doing all along. I have a vision of how things can be for Jennifer. She's a happier child. She's

content. She flies to the school bus in the morning. She just loves school and it's helping her socially too. She's not frustrated anymore."

In addition to full inclusion in school and having her personal aid, Jennifer's program includes community based functional programming: grocery shopping, making up menus, handling her money, living as a fully integrated member of her community. The Great Lakes Area Regional Center will continue with Jennifer until she turns 22. At that time the Columbus Speech and Hearing Center's outreach program for Ohio citizens who are deafblind will take over providing services which Jennifer needs to continue on her road to success.

AXIS Newsletter (Ohio), June 25, 1995

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During each of the project years, the Regional Center reported a Deafblind Census for the states of Ohio, Pennsylvania and Wisconsin. In September of each year, census packets were sent to the contact person for each child on the census in order to update demographic and personal information. In an attempt to identify new children, census packets and GLARCDBE brochures were also sent to school districts, programs serving individuals with mental retardation and developmental disabilities, early intervention contacts and contacts who have previously provided services to identified students. Information was collected for each child on the major cause of deafblindness, degree of hearing and vision loss, other handicapping conditions, IDEA child count category, setting in which educational services are provided and place of residence. In addition, the Regional Center collected information on the types of services that are being provided, opportunities for inclusion and social interactions with non-handicapped peers and parent address (optional). The federally required information for each identified child was then reported to TRACES and the United States Department of Education in February of the following year. Information on the census form which was public record was then disseminated to public health agencies, adult services programs, departments of health, the Division of Vocational Rehabilitation, the Ohio Deafblind Outreach Program and other agencies who requested it.

The total child count for each year of the current project is listed in the table below. These figures demonstrate that our attempts to identify new children in the region have been successful.

NUMBER OF IDENTIFIED CHILDREN WITH DEAFBLINDNESS			
	1992-1993	1993-1994	1994-1995
Ohio	315	357	417
Pennsylvania	410	490	521
Wisconsin	190	170	174

Technical Assistance

4

A Grandmother's Story

11-94

Dear Dr. Stephens,

I am a grandmother left with a deafblind and multiply handicapped child since his mother died. I must say that I feel so great from having the supports and contact with the Regional Center staff in the educational seminars and the contact Charles gets from being with other children. Believe me, it wouldn't happen without them. My load seems so much lighter and needs are being met that were never thought of.

I'm so glad to be a part of this Regional Center and to continue working with them. I look forward to all activities presented and to give the information out to others who have not heard or hold back from being part of these nice things. It's a part of the world that cannot be shut out.

Sincerely,

Julia M. Bell (Ohio)

.....

Regional Center staff spent a large percentage of their time providing technical assistance to families and service providers. Indirect services were provided in the form of on-site program consultation, home consultation for families, training of individual teams to work with a specific student, telephone conversations and loaning of written and audio-visual material. In particular, Regional Center staff provided direction and assistance in the areas of IEP planning, transition and futures planning, strategies for inclusion, team collaboration, early intervention and early childhood curriculum, functional curriculum, arrangement of the classroom and home environment, assessment of functional vision and hearing, behavior management strategies and development of appropriate communication systems. The total number of technical assistance visits are listed in the table below. These figures show that GLARCDBE staff has had contact with a significant number of service providers and parents each year.

NUMBER OF TECHNICAL ASSISTANCE CONTACTS			
	1992-1993	1993-1994	1994-1995
Ohio	175	375	686
Pennsylvania	1123	963	1377
Wisconsin	150	195	277

Mini-Grants and Family Learning Awards

5

Project Leads to Successful Inclusion

Dear Andy,

Thank you for supporting our project through the mini-grant you awarded us. When you read what I have to say, I think you will understand how meaningful the experience was for everyone involved.

The purpose of our project was to provide a female student who is deafblind with more diverse social and recreational opportunities within her school and community, and to further enhance her social relationships with her peers without disabilities. The project involved the participant, her family, her peers, and school and community staff.

A consultant was hired to provide support and training to the participant, peers, family and staff. The consultant assisted us in implementing a textured communication system that will provide the participant with greater opportunities to make choices. Currently, she has been introduced to one texture, a series of raised glue dots that represent ice cream. When the texture is presented to the individual, and she reaches out and touches the texture, she gets a bite of ice cream. Initially the participant needed continuous physical assists. Now after the first physical prompt the participant independently seeks out the texture in order to receive the ice cream. Other motivating items have been identified by her family and peers, and representative textures assigned. These will be slowly introduced throughout the upcoming school year.

The consultant also created a modified billfold that allows the participant greater participation when ordering ice cream and other items from restaurants. With the system, the peer and participant velcro a written and textured request onto the front of the billfold. On the back of the billfold they velcro a written message regarding the location of the money. The participant then hands the billfold to the restaurant employee, who fills the order. Currently the participant needs continuous physical prompts. However, it should be noted that prior to this time the participant had never had an opportunity to participate in the ordering of her food. In the past, the entire process was done for her while she waited at her table.

In addition to spending time at local restaurants, the peers and participant have had increased opportunities to utilize public transportation to get to their destination. They have used both the city bus and medi-van (alternative for the elderly and people with disabilities). The peers and participant have traveled to the malls for shopping and lunch, played games in the video arcades, and visited the Children's Museum.

The peers and participant have also taken a school bus to a water park. They all enjoyed the wave pool and the lazy river. The peers were able to obtain a free intertube for the wave pool, because of their friend with disabilities, and they thought that was pretty cool. They saved five bucks. The peers were also able to take advantage of the water slides. I

would like to say that the participant watched them, but her vision isn't that good. However, she did hear and feel their excitement as they approached her when they came out of the water. She really didn't like their drippings on her but she tolerated it.

We also spent several evenings at the participant's home with her family. While there we planned activities, ate pizza and snacks, and just got to know each other a little bit better.

In the very near future, we are meeting the participant at her family cottage in northern Wisconsin. We have rented a pontoon for the afternoon and hope to enjoy some sunshine and swimming. We also plan on taking a limousine to a Timber Rattler's Game in September.

It should also be noted there were several activities that the peers planned and did independent of the project coordinator. They went to movies, baseball games, fast food restaurants, and just hung out at the participant's house. For the family and project coordinator, this was the ultimate goal of the project: increased independent interactions between the participant and her peers.

So that pretty much describes what we did, but how do I describe to someone what happened? As the saying goes, you had to be there. This was a project targeted for one participant, but it had such a positive impact on so many other people. I've tried to explain the experience to others, as well as take some pictures and videos, but I just can't seem to capture the true outcomes of this project. I saw the participant order food at a fast food restaurant for the first time in her life. The excitement that I shared with a group of her friends when she independently reached out for that texture the very first time. I watched her play video games with one of her friends at the mall. And I saw her relaxed in an intertube with two of her friends perched on each side. It was a great sight.

As we were developing the project, I had a vision of what it was going to be. The project was intended to provide increased participation in community based recreational activities for a student with dual-sensory impairments and a group of her peers. But the project has become so much more than that. The project is not about a series of activities, it's about feelings, and growth, and understanding, and acceptance. Come to think of it, I think that's called friendship.

Needless to say we've come a long way toward increasing the participant's participation in community activities as well as peer interactions. But we've only developed the map. Now we need to follow the directions to get to our final destination.

Sincerely,

Jane Jacobson (Wisconsin), August 22, 1995

.....

The Regional Center sponsored a request for proposals to support the capacity of local education agencies to implement innovative programming for children and youth with deafblindness. The major focus of the funding

was to support projects that expanded existing services or created new services. Projects were to focus on the establishment and implementation of validated effective educational practices in the least restrictive school and community environments for children and youth who are deafblind. The anticipated outcome of each project was the establishment of pilot project sites within each state that demonstrate the use of tested and effective practices in the education of children with deafblindness, leading to an increase in the quality of effective educational practices for this population. Applicants were especially encouraged to apply for a project focusing on the areas of transition from school to community life, early identification and intervention for infants and toddlers with deafblindness, strategies that facilitate inclusion of children and youth with deafblindness into neighborhood schools, acquisition of communication and orientation and mobility skills, nonaversive behavior management and facilitation of family involvement.

During each year, Ohio and Wisconsin offered 3 mini-grants that could be funded for a maximum of \$6000. Requests for proposals were sent to local agencies and early childhood programs that provide direct educational or support services to children with deafblindness. Applications were reviewed by a selection committee comprised of GLARCDBE staff. In Ohio, two mini-grants were funded in the second year of the project, and seven in the third year. In Wisconsin, three mini-grants were funded in the third year of the project. The Director of each funded mini-grant was responsible for submitting a Final Report to GLARCDBE at the end of the project year.

The objectives of the mini-grants that were funded include:

- **Beechcroft High School:** To provide transportation to community sites in order to increase inclusion opportunities and build self-advocacy skills in five students with deafblindness.
- **Cambridge School District:** To train five Birth to Three and twenty school district special education service providers working with students who are both dual-sensory impaired and severely cognitively disabled to use the ABE (Analyzing Behavior State and Learning Environments) assessment process.

- **Cesa #6 Oshkosh, WI:** To provide improved services and educational programming to students who are deafblind, a team of professionals were provided with training, site visits to model deafblind programs and consultation for a year. The team developed resource materials to be used in implementation of several regional workshops for families and staff members involved in the education of students with deafblindness.
- **Cincinnati Public Schools:** To increase the language and communication ability of four students with deafblindness by providing a consistent sign language or communication system for each student that can be used by anyone working with the student at home, at school or in the community.
- **Massillon City Schools:** To provide staff development on inclusion and effective integration techniques for a deafblind student in and outside of school. To inservice interested staff and peers on basic sign language and communication skills. To create and develop simulated environments to support transitioning activities for the workplace and to employ a job trainer.
- **Montgomery County Board of Mental Retardation and Developmental Disabilities:** To determine the feasibility of using equipment to monitor physiological responses of identified students in a school setting. To determine a baseline of the identified student's current level of functioning, profile of biobehavioral states and repertoire of responses to stimulation. To monitor internal physiological responses of identified students, given environmental stimulation. To develop basic communication with the students. This was a two year funded mini-grant.
- **Muskingum County Board of Education:** To provide direct programming strategies that will address visual/hearing impairments for children and families who are not receiving direct services in these areas. To provide direct programming strategies that will address auditory/visual impairments in conjunction with Early Intervention, Preschool-age, School-age, or home-based services that are currently in place. To coordinate training and technical assistance for staff and parent of children with dual-sensory impairments.
- **Neenah School District:** To diversify the social and recreational activities of a deafblind student within her community, while increasing her level of participation and enhancing her relationship with her peers without disabilities.
- **Northmont City School District:** To provide training, consultation, and support to direct service providers so that they develop the skills necessary to teach deafblind students in integrated settings. To assist school staff in identifying appropriate instructional strategies, educational objectives and materials. To provide deafblind students the opportunity to be included in regular education classes so that they may benefit educationally and socially from contact with peers their age who are not deafblind or multiply handicapped.

- **Ohio School for the Deaf:** To provide staff development activities in the areas of career development, development of community living skills, use of technology and selection of appropriate software and materials for students who are deafblind. To assist four students in improving academic performance, development of career skills and making a successful transition to community living.
- **Washington Local Schools:** To create a developmentally appropriate, inclusionary early childhood classroom environment that facilitates the inclusion of a child with deafblindness within his community school. To create a classroom environment where diversity and childhood are celebrated and a rich social interaction between all students is encouraged. To act as a model site that demonstrates innovative early childhood inclusionary strategies, and offers a replicable collection of thematic units.

NUMBER OF MINI-GRANTS FUNDED			
	1992-1993	1993-1994	1994-1995
Ohio	0	2	7
Wisconsin	0	0	3
Pennsylvania	0	0	0

Family Learning Awards

The Family Learning Awards were developed to provide parents in the region with financial assistance to learn more about deafblindness. The awards were available in each state and were for a maximum of \$200 each. Funds were to be used to help defray the costs related to attendance at a conference or workshop about deafblindness (registration fees, travel expenses, childcare expenses), and to purchase books and videotapes about deafblindness. Learning awards helped cover the cost of travel to the national CHARGE Conference, TASH Conference and the Helen Keller National Center Parent Leadership Weekend, and also covered the cost of respite care so parents could attend the Summer Institute.

NUMBER OF FAMILY LEARNING AWARDS FUNDED			
	1993	1994	1995
Ohio	0	2	7
Wisconsin	5	4	5
Pennsylvania	4	3	4

Family Weekend

6

GLARCDBE Services Are Needed

11-23-94

Dear Ms. Warkomski,

As the parents of Nada Ghattas, a six year old severely multiply handicapped daughter, we had gained valuable support from the Family Weekends held in the last three years. Both me and my wife enjoyed the seminars and brought important information home for future use. We also found meeting other families with deafblind children to be very helpful as we exchanged information and experience.

We are looking forward to having more training and workshops to attend. The presence of qualified instructors is of course vital for conducting training of both of us as parents and our handicapped children. We sincerely hope that our state would expand on these programs for the help of children with special needs and their families.

Yours sincerely,

Nasrat Ghattas, M.D. (Pennsylvania)

.....

Fantastic and Fun Family Weekend

8-4-95

To Everyone,

Thank you so very much for the "Family Weekend"! It was fantastic!!! Our kids have never had the chance to have a vacation, let alone even a mini weekend trip. So needless to say they had a blast. On the note of kids, my husband and I appreciate the opportunity you gave them to attend the sibling class.

It was also a great feeling for my husband and I to get away from everything. The classes were superb. I really was amazed to learn what "on-line" was all about. I had absolutely no idea so much information could be accessed. I have discussed this with our PTA as a way to possibly collaborate with other agencies to offer a great resource to parents as well as teachers, agencies, etc. Also, tonight at our PTA board meeting I will discuss the IDEA and promote everyone to write their letters. It was especially nice meeting everyone I've spoken to while on the phone.

Thank you again,

The Moody's (Ohio)

.....

A Celebration of Families

9-25-94

Dear Mary,

I just wanted to tell you how great the weekend "A Celebration of Families" by the Deafblind Project was for myself, Dave, and the rest of the family. I was especially pleased with how "at home" and "part of the family" we were all made to feel. The resources I learned about will help

my son Dave greatly and will - I believe - make him happy, and that is all I want.

Well, thanks so much for making me and Dave and Patrick and Nicole and Jo-Jo (my sitter) feel so very much a part of everything. See you next year in Lancaster!

Ruthann Dunleavy and Family (Pennsylvania)

.....

Family Weekend Provides Needed Support

Family Weekend in Wisconsin is a main attraction for parents and families of the dual-sensory impaired. This is an annual event where parents, siblings and relatives come together to network, hear speakers, and share their most personal thoughts related to their child with dual sensory impairments. One such case was a young 13 year old who was just informed that in addition to a hearing loss, he would be severely visually impaired due to Usher's Syndrome.

Jeff was struggling with the news and venting his frustration to all those around him. Mom, who is a single parent, did not know where to turn. Our specialist in serving the dual-sensory impaired had visited the school where Jeff went and told them about the Family Weekend. Mom was encouraged about the opportunity to attend so that she and Jeff could gain support from other families. Jeff did not want to attend however, and expressed himself in behaviors that were hard for any mother to cope with from a teenager going through difficult times. Mom came with Jeff to the Family Weekend, but he refused to get out of the car. Mom came into the hotel and confided in staff, pouring her thoughts and frustration out as to what she could do to help Jeff. Staff supported her, while the Project Director went to the car and spent some time with Jeff. They talked about what was happening and how the workshop would provide him and his mom with support during these difficult times. That Jeff would meet other kids his age, who in spite of everything, had made it over the rough times and are going ahead with their lives.

The director shared with Jeff that life was not easy, but with support from his mom, sister, and people who cared, he would be okay. Finally, after about 45 minutes, Jeff agreed to come into the hotel and participate with the group. He went swimming and mom was able to attend parent sessions. Jeff stayed for dinner and that evening they checked into the hotel.

Jeff did some mingling with the teenagers in the group, but needed continuous encouragement. A new door was opened for Jeff and his mom. They now know that there is support out there and people who do care. Jeff left on Sunday feeling somewhat better about his situation. The specialist in deafblind would be their ongoing support system for the coming school year. The Family Weekend was a success and each of us learned that people caring is what it is all about.

Andy Papineau (Wisconsin), August 24, 1995

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Family Weekends are major fun and learning events that were held annually in each of the three GLARCDBE states. These weekends provided families with the opportunity to meet and share with other families of children with dual-sensory impairments, express their emotions and frustrations, and discuss issues relating to the organization of parent support groups. All expenses, including lodging, meals, and mileage were covered by the Project. For many, this weekend constituted the only vacation the family was able to take. Workshops were held on Saturday and Sunday for the parents and caretakers, while recreational activities and sibling sessions were arranged for the children. The topics of parent workshops (as determined by needs assessment and parent input) included Issues Facing Siblings of Children with Disabilities, Mother and Father Issues, Advocacy and Leadership, Forming Parent Groups, Futures Planning, Trusts, Adult Services, Adaptive Equipment, Recreation and Leisure Activities, Communication Strategies, Deafblind On-Line: Accessing Information through the Internet and Understanding Anger and Developing Assertiveness Skills. As shown by the earlier "success stories," these weekend have a profound and beneficial impact on the families that attend.

NUMBER OF FAMILIES ATTENDING FAMILY LEARNING WEEKENDS			
	1993	1994	1995
Ohio	12	20	23
Wisconsin	20	17	29
Pennsylvania	17	19	26

Parent Groups

7

Parent Leadership Weekend

Parent Leadership Training is Beneficial

Dear Andy,

Again, I would like to thank you for the opportunity to attend the Parent Leadership Workshop at the Helen Keller Institute in July. I learned a lot on the personal level and as a parent. The presenters were excellent and very knowledgeable.

As a parent of a special needs child, it is nice to go to a seminar where some of our personal needs are addressed. In addition to the much needed time away from our children, the parents got the opportunity to discuss needs and concerns with other parents in the same boat.

From the time my son was diagnosed deaf, we were involved in a very active parents' group in Rockford, Illinois, and I am a firm believer in support groups. Since moving to Wisconsin 4 years ago, there has been a void in that area for us. The annual Deafblind Family Weekend really helps in that respect. This year, Jason met another DB boy the same age from another city, and he talks about him all the time. Although Wisconsin has an annual Family Weekend, I really see a need for a Wisconsin Parent Group, and I hope as a result of the Parent Leadership Workshop, we can get one going.

Thanks again,
Peggy Corning (Wisconsin)

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During the project years 1992-1995, there was a tremendous push by GLARCDDBE staff toward the formation and strengthening of parent groups in each state in the region. For example, many of the Family Weekend topics over the past two years were related to advocacy, leadership, and organizing an effective parent group. In addition, several trainings and a Parent Leadership Weekend were sponsored by GLARCDDBE in order to assist parents in developing the leadership and action plans they need to set a parent group in motion. Within the past year, Ohio families have formed a parent group entitled F.E.E.L., or Families for Encouragement, Empowerment, and Linkages. This group currently has 46 member families divided into 5 regions. Parent Representatives in each region are responsible for organizing gatherings and sharing information. Pennsylvania Parents for the Deafblind have been established for several

years but still benefited from participation in the Parent Leadership Weekend. Wisconsin parents are currently in the process of forming a Parent Group as the result of the Leadership Weekend at Helen Keller National Center.

In July of 1995, 19 parents attended a parent leadership conference in Sands Point, New York entitled "Enhancing the Power of Families With Children Who Are Deafblind." This workshop was sponsored by Helen Keller National Center - Technical Assistance Center and GLARCDDBE, and provided training to enhance advocacy and leadership skills. Topics covered included recent changes in federal and state legislation, communicating with professionals, mobilizing an effective Parent Group and stress management. A total of five parents from Ohio, seven parents from Pennsylvania, and nine parents from Wisconsin participated in this training, which was geared specifically toward the states in our region. In addition, the Outreach Specialists from Ohio and Wisconsin attended the weekend so that they would be able to assist in the formulation of plans of action for the Parent Groups in each state.

Trainings

8

Summer Institute

Stimulating Summer Institute

8-94

Dear Summer Institute Facilitators,

Your efforts in making the 1994 Summer Institute stimulating and worthwhile are very much appreciated. Thank you for the rare opportunity to gather much needed information on deafblind education. We especially appreciate your philosophy that reminded us to accept and to celebrate diversity.

Your warm and exceptionally knowledgeable staff contributed to the quality of our lives by helping our team to contribute to the lives of the families and children we work with. We look forward to working with you very soon.

Sincerely,

Chris Kruse and the Washington Local Team (Ohio)

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Summer Institute is an annual opportunity for parent and services providers to obtain state of the art information on hot topics in deafblindness from experts in the field. The institute is arranged as a three day workshop, with a different topic covered each day. In Ohio and Wisconsin, topics covered during recent Summer Institutes included: Assessing the School-Age Child with Dual-Sensory and Multiple Impairments (June Downing), Assessing the Transition Needs of Young Adults with Dual-Sensory and Multiple Impairments (Jane Everson and Janet Steveley), Understanding Dual-Sensory Impairments: Common Causes and Suggestions for Teaching (Terry Rafalowski-Welch), Strategies for Implementing Inclusionary Practices (Patrick Schwarz), Future's Planning (Sherri Moore), Orientation and Mobility (Brent Bailey), It Begins with Communication (Juli Baumgarner), Making Curriculum Functional (Kevin Arnold), Biobehavior States, Distance Learning, and Accessing Information through the Internet (Mark Stockman). Pennsylvania's topics included Communication, Assessment and Inclusion. The attendance figures for Summer Institutes are listed in the table below.

NUMBER OF INDIVIDUALS ATTENDING SUMMER INSTITUTES			
	1993	1994	1995
Ohio	19	58	119
Pennsylvania	10	9	4
Wisconsin	120	80	87

Regional Center staff also provided many training workshops and inservice sessions to individuals teams, school personnel, and local agencies on issues relating to working with children who are deafblind. Topics covered during these sessions included imbedding I.E.P. goals in everyday activities, understanding deafblindness, strategies for educating children with deafblindness, using communication through touch cues, picture cues, and object cue boxes, person centered planning and futures planning, behavior as communication, sensory stimulation, sign language, establishing communication systems for nonsymbolic learners, functional communication, and principles of orientation and mobility.

SKI*HI TRAINING & PROJECTS

INSITE Makes a Difference to This One

In 1988, my friend Louise, an occupational therapist, told me there was a teaching job opening at the local Easter Seal Society where she worked. Early Intervention? Special needs children? Special Education? I only had a degree in elementary education and early childhood. How could I possibly do that job? She convinced me to apply and interview. I did and they assured me there would be plenty of on the job training.

I took "the job" and teach me they did. I learned more that first year on "the job" than all of my college books ever told me. The scary words I had learned like G-tube, trache, and apnea monitors were all attached to these little precious people and suddenly it wasn't so scary. And "the job" began and evolved a career of caring and sharing with families as a parent advisor over the next four and a half years.

As a youth I was involved heavily with church, school, and community projects that dealt with community service, social work, and helping others so that became my strength and continues to be my strength today in serving families as a parent advisor. That was the easy part! I also believe strongly in sharing information and knowledge

with others as they request and search for it. Being supportive of my families and encouraging them was also easy because I had peers who were so supportive and encouraging to me as a new person in this field. My first year, I can truly say, I learned with the parents of my clients, as if their children were my children, and I was hearing the diagnosis and treatment for the first time, too. Many times my heart sank with theirs, and my eyes swelled with tears like theirs.

As a parent advisor at that Easter Seal agency, I also networked with doctors, children and youth workers, speech therapists, etc. Acting as a liaison with other professionals, I would guide the parents with knowledge and skills that could aid their "total child" and their family. In that process we shared many talks, smiles, laughs, and tears of joy as skills were mastered and tasks were accomplished.

For four years I was a fairly happy parent advisor. The therapists complimented me, the parents praised me, and I felt good about helping these families. Then my supervisor left, the funding systems were changing, laws were changing and I became the coordinator and assistant coordinator of our program. I lasted six months! I was tired of battling MH/MR who fought us for every nickel and dime. I became frustrated turning children over to our local I.U. only to see them lose services. With depression setting in, I quit! I took a new teaching position with Head Start in another county - no more MH/MR. I could still use my skills as a parent advisor - assessing the child's development, supporting parents, acting as a medical liaison, offering specific suggestions and activities, listening to parental concerns and observations, communicating effectively with families, etc. But "the job" just wasn't as rewarding. My heart was missing early intervention.

I applied in this new county with another agency that provided Early Intervention services and I am back to being only an advisor. But after attending INSITE training offered by PennTech, there are several ways my role will change. For example, I am going to go slower and observe more minute changes in my children's behaviors and progress and be more patient with slow progress in my children and their parents. I will plan in smaller steps and always try to better communicate.

Furthermore, with medically fragile children like "my Reid", I will be more tolerant of overly protective parents, continue to be flexible with their schedules because of health, and be overjoyed with the improvements Reid's mother sees because, as she shared with "only me", his extended family doesn't know how to deal with this child that isn't "perfect."

Finally, after INSITE training, this parent advisor knows she has a lot more reading to do. Volumes would describe it better, but I love learning and being able to share it with my families. In conclusion, this parent advisor knows the best way her role can change is to prepare the parents to be the case managers of their child. And, although I am only a parent advisor, let me always remember the words of the frail old man by the deserted beach who continued to throw the stranded starfish back into the sea, "it makes a difference to this one."

Betty Slegowski (Pennsylvania), May 10, 1995

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SKI-HI Institute, a nationally recognized training program, provides specialized training to professionals working with infants and young children with sensory or multiple impairments. It embraces a family centered, home-based approach. SKI*HI Institute training has historically been held in Columbus, Ohio by national trainers and has trained over 150 parent advisors serving in 76 counties. In order to increase local capacity to meet the training and follow-up support needs, a system of state local trainers has been developed. The number of trainers for each of the three SKI*HI Institute training projects are listed below:

- Project INSITE: focus on multiple and dual sensory impairments: 2 trainers
- Project VIISA: focus on visual impairments: 7 trainers
- Project SKI*HI: focus on hearing impairments: 4 trainers

Local state trainers provide training in the various regions in Ohio. Training kits for each of the SKI*HI Institute projects are being developed. The first SKI*HI training by a local trainer was held in the southwestern region with 12 participants serving five counties and impacting more than 40 children with hearing impairments. Comments from participants include, "This is the best training I have attended in years!"; "The trainer was knowledgeable and made the training interesting"; "The materials are easy to follow and provide a wealth of information for families." Parent comments range from "I don't know what I would do with xx; she makes so much sense!"; "I really see the difference in Billy--I feel I am learning a lot to help him."

Pennsylvania has an ongoing training program using State Trainers in INSITE and VIISA. Pennsylvania trained a total of 230 service providers in INSITE during the Project (92-95) and a total of 47 people in VIISA.

A special project with Ohio is the demonstration state for the distance education pilot project for the SKI*HI training for hearing impairments. In

collaboration with five Special Education Regional Resource Centers serving rural, urban and metropolitan regions throughout Ohio, site facilitators have been identified from the pool of past SKI*HI training participants. Three sites will be utilized in the initial phase; the other two sites will be added after feedback and program modifications. On-line computer access is available to trainees participating in the pilot project in collaboration with Deafblind Online sponsored the by Great Lakes Area Regional Center for Deafblind Education.

SKI*HI training activities are co-sponsored by the Ohio Departments of Health, Education, and Mental Retardation and Developmental Disabilities and coordinated by the Great Lakes Area Regional Center for Deafblind Education. Training activities continue to target areas that have limited service options and to provide follow-up services to previously trained persons.

ASSESSMENTS & EVALUATIONS

9

Early Intervention Service Providers

During the summer of 1994, a Needs Assessment Survey was mailed to early intervention contacts from the 1994 Ohio, Pennsylvania, and Wisconsin census. The results of the survey were then used to formulate the focus of the center in terms of early intervention services in 1995. Pennsylvania and Ohio ranked **Assessment of Children with Deafblindness** as their greatest need, while Wisconsin ranked **Early Intervention Strategies** as their highest priority.

Needs Assessment of Families

A mail survey was used to assess the needs of families of children with deafblindness in the three states. In Ohio, the survey was mailed to 152 families from the census, of which 50 (38%) responded. In Pennsylvania, the survey was sent to 267 families, of which 83 (33%) responded. In Wisconsin, the survey was sent to 175 families, of which 79 (45%) responded. The results of the needs assessment were subsequently used to plan inservice and training activities, Family Weekend programs, and topical themes for upcoming issues of the **Perceptions** newsletter. All three states ranked **Developing & Increasing Communication Skills** as their highest priority needs.

Needs Assessment of Direct and Related Educational Service Providers

A similar mail survey was used to assess the technical assistance needs of the direct and related educational service providers who work with the school age children in the three states. In Ohio 112 service providers were sent the survey, of which 86 (75%) were returned. In Pennsylvania, 117 service providers were sent the survey, of which 75 were usable (64%). In Wisconsin, 106 service providers were sent the survey, of which 72 (68%) responded. Highest priority for Ohio was **Intervention Strategies**. For

Pennsylvania and Wisconsin, **Functional Curriculum** was their highest priority.

Assessment Guidelines

Over the project years 1992-1995, a series of Assessment Guidelines were developed in collaboration with Traces, GLARCDDBE's technical support. The purpose of these guidelines is to guide teams composed of educators, service providers, parents and family members in assessing the needs of individuals with dual sensory and multiple impairments between the ages of birth and 21 years of age. The guidelines were written in three sections. Early Childhood, birth to 5 years, written by Ellen Suget Causey, Ph.D. School/Age, 6 - 15 years, written by June E. Downing, Ph.D. Transition, age 16 - 22 years, written by Jane M. Everson, Ph.D.

The guidelines were field tested by service providers in Ohio, Wisconsin and Pennsylvania. Two of the sections are completed and the third section Early Childhood should be completed by January 1996.

These guidelines will be published and sent to every 307.11 project for a resource and will be available to all interested parties for a nominal fee.

Training Evaluations

Following each workshop offered by the Regional Center, participants were asked to complete a standardized evaluation form and rate the effectiveness of the training and the presenter. Participants were also asked ways they would implement the training, the strengths and weakness of the training, and any follow-up needs they could identify. The results for each training were then summarized, distributed to the presenter and others involved in the organization of the workshop and used in the planning of future workshops.

D/B Infoline Evaluations

Following the use of materials provided from the lending library, an evaluation is sent to each library user for their evaluation of materials. This information is then used to update and order new materials for the lending library.

Dissemination of Information

10

PERCEPTIONS Newsletter

Perceptions, the newsletter of GLARCDBE, was sent to over 3,000 parents, service providers, census contacts, and professionals on the Regional Center mailing list on a semi-quarterly basis. This newsletter contained information on topics related to deafblindness (ex: Inclusion, Sibling Issues, Communication), information resources at a local and national level, and a calendar of upcoming events and trainings in the region. In addition, 500-600 copies of the newsletter were sent to each State Coordinator to distribute during trainings and to new contacts.

DB INFOLINE

One of the services offered by GLARCDBE is DB INFOLINE, a toll-free, deafblind information hotline. DB INFOLINE is an information system that allows parents, teachers, and service providers working with the deafblind population to access the information resources of the Regional Center. It contains journal articles, books, videos, catalogs, handouts and other resource material relating to the deafblind and multiply handicapped population. Information is available on topics such as assessment, behavior management, communication, curriculum, early intervention, etiologies, associated syndromes, inclusion, orientation and mobility, recreation and leisure, transition, vocational issues, and many others. Callers are able to get copies, either on paper or disk or electronically, of the information they are requesting, and can borrow books and videotapes through the Regional Center for a one month period. The number of requests for information and referrals received through DB INFOLINE has steadily increased over the past three years of the project showing that the Regional Center is disseminating information on deafblindness to a large number of parent and service providers in the region.

Parent Packets

Twice a year, a Parent Packet was sent to families in Ohio and Wisconsin. This packet contained information on local and national trainings and conferences geared toward deafblindness, family support groups and available resources, legal issues and government actions concerning individuals with disabilities, recent journal articles relating to sensory impairments and multiple handicaps, and sibling issues. The information for each mailing was gathered from the Internet, disability billboards, and journals and newsletters received at the GLARCDBE offices in order to provide the families with the most up to date information on the field of deafblindness.

DB Online

In response to the rapidly growing trend toward electronic communications, the Information Services component of GLARCDBE made a decision to develop a service on the Internet. The popularity of the Internet has been caused in large part by new applications that allow users to access information easily through a graphical, "point and click" or mouse driven interface. In addition to the estimated 15-20 million people with at least some access to the Internet, the major commercial vendors of online services have all begun to integrate their services with the Internet. America Online, CompuServe, and Prodigy have brought an additional 7-8 million people online, and each offers its members a graphical "world wide web" browser application that allows virtually anyone, with minimal training, to access information at thousands of computers connected to the worldwide Internet.

DB Online has just begun to offer GLARCDBE services on the Internet, but after registering the service on several of the popular online clearinghouses that monitor new "web sites," the Project's "home page" was accessed more than 3,000 times since its opening in early August 1995. This high level of

interest was surprising even to our own information services staff members, and confirms the usefulness of making the Project accessible electronically.

At the present time, DB Online is still under construction, but the site does offer easy access to GLARCDBE staff via electronic mail. The project has received many initial inquiries for further information and expressions of appreciation and encouragement to continue developing services. Special hypertext links allow visitors at the site to contact our Project Officer via electronic mail. We have also linked the site via "e-mail" to an international expert in the field, John McInnes, and we anticipate many additional links to experts who can offer assistance through the network.

DB Online currently provides a growing menu of "hypertext pointers" that link the DB Online home page with related services at other web sites. This has been an especially popular service because of the large cluster of related organizations, services, and consumer advocacy groups that are in some way related to the field of deafblindness. For example, we now offer hypertext pointers to the Library for the Blind and Disabled, the Special Education Department at the University of Kansas, the U.S. Department of Education, the Deaf Gopher, and the TRACE Center (Madison, WI). As other deafblind projects and service providers come online, these will be routinely linked as a service to DB Online users. This decentralized model makes it possible to distribute a wide variety of specialized information by simply providing the necessary links that save users the time required to search and locate appropriate resources.

Now that the necessary infrastructure of DB Online has been installed and implemented, many new services are planned. For example:

- The Project plans to begin using DB Online as an alternative medium for publishing and distributing our reports, newsletters, calendar of activities, services, etc. Since these documents are already produced

in-house using a computer, the transfer to the web site for electronic distribution is both time and cost effective.

- Specialized mailing lists will be created for sets of users so that the Project will be able to disseminate updated information to parents, teachers, consultants, and other service providers. The mailing list will be an option for our users and will allow us to post a single message that is automatically distributed to the individual e-mail address of each member of the list. Each member can in turn reply to the whole list with their own message, thus making this an interactive service.
- Online courses on topics of high interest will continue the Project's commitment to providing inservice training and professional development courses for the diverse audiences we serve. A special software program (NovaLink) that supports online computer conferences with a fully graphical interface will be used to provide this service. Initial work with NovaLink has begun through coordination with the SKI*HI Project, which is offering a distance learning program to several Ohio sites on a pilot test basis in 1995-1996.

Other applications will emerge as the Project gains more experience in tapping into this exciting new medium for information dissemination and sharing. The address to access DB Online is
[Http://198.234.201.48/dbonline.html](http://198.234.201.48/dbonline.html).

Special Projects

Ohio Early Intervention Outreach Project

The purpose of this project was to disseminate information about the Regional Center, and identify infants and toddlers, age birth to three, who have dual-sensory impairments and reside in Ohio. During the summer of 1994, we contacted the Health Department in every county in the state, and asked if they would display our Regional Center's brochures in their County Fair booth, health clinics, and any health fairs they may attend. They were also asked to set up a clipboard with a sign-up sheet for us to contact people who wanted more information. Materials, including early intervention brochures, Project brochures, census brochures, and DB INFOLINE request forms were then disseminated to all 88 county Departments of Health by pairs of college students trained to answer questions about the Project and brochures.

We also contacted all County Collaboratives, Children's Hospitals and all hospitals with neonatal units, Special Education Regional Resource Centers (SERRCs), and Family Information Network groups and gave them brochures from the Regional Center. They were asked to disseminate the information to their members and others who accessed their services.

This project resulted in a number of new children being identified as having dual-sensory impairments, as well as several requests for additional information and technical assistance.

Project Promotion

Regional Center staff attempted to increase public awareness of the services we provide through talks at local agency meetings, presentations at conferences such as the Association for the Severely Handicapped (TASH), distribution of project brochures, public service announcements,

announcements in local and regional newsletters, and the production of a project video entitled "See the Dream."

Collaboration and Committees

11

Collaborations

The Regional Center collaborated closely with many state and national agencies in order to broaden and expand the range of services provided to children with deafblind and their families. Examples of such collaborating agencies include the Ohio Interest Group for Individuals with Deafblindness, the Ohio Deafblind Outreach Program, the Ohio Coalition for the Education of Children with Disabilities, the Ohio Department of Education, the Ohio Department of Health, Ohio State School for the Blind, Ohio School for the Deaf, Bureau of Services for Visually Impaired, Ohio Rehabilitation Services Commission, Overbrook School for the Blind, Wisconsin School for the Blind, Wisconsin Department of Health and Human Services, TRACES, the SKI*HI Institute, National Family Association for the Deafblind, Perkins School for the Blind, and Helen Keller National Center - Technical Assistance Center.

Committees

GLARCDDBE staff also represented the Regional Center by serving as members on several planning committees, including Project LIFE, Ohio Governor's Task Force on Early Intervention Personnel Preparation, Ohio Department of Health Low Vision Subcommittee, Ohio Interest Group for Individuals with Deafblindness, Wisconsin Department of Health and Human Services: 0-2 Services, the Wisconsin Division of Vocational Rehabilitation, Pennsylvania Comprehensive System of Personnel Development, Pennsylvania State Transition Team and the Pennsylvania Office of Medical Assistance.

For Further Information

The readers who would like further information concerning the Great Lakes Area Regional Center on Deafblind Education Project can contact:

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GLARCDDBE has established a home page on the Internet and invite all readers to drop by. We also have an electronic bulletin board for those who wish to contact others working with or who have children with Deafblindness.

This report was also sent to Eric at the request of OSEP and can be found under Special Projects.