The Illinois Advisory Board for Services for Persons Who are DeafBlind (IABDB) is committed to partnering with key stakeholders to impact positive change for all individuals who are DeafBlind and ensure they are provided equal access to resources and opportunities to lead fulfilling lives.
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Dear Governor Quinn:

We are pleased to present a report of the activities of the Illinois DeafBlind Advisory Board from July 1, 2011 to June 30, 2013.

When considering the conglomeration of human and educational services in Illinois, individuals with both vision and hearing loss permeate the entire spectrum of services. Therefore, we have expanded this report to include an overview of major service agencies both state and private efforts to meet the needs of the DeafBlind population in Illinois. The agencies indicated in this report are by no means a comprehensive listing of all service agencies serving the population in Illinois, but do represent those who have had contact with the Board.

Members of the Board have all completed the Open Meetings Act certification provided by the Attorney General and we have completed the first “Members Handbook” for new and current members.

We especially want to thank your Chief of Staff Ryan Croke for his support of our activities and his work with state agencies.

While there are still challenges and issues facing the population in the state, it is an honor as a Board to be able to advocate on behalf of the DeafBlind population in our state.

Sincerely,

Robert E. Griffith, Chair
History, Authority and Purpose of the Board

During the 1960’s there was an outbreak of the Rubella epidemic in Illinois, and other states in the country, which resulted in an increase of infants with both vision and hearing loss. Parents of these children soon found there were limited services, if any, in Illinois designed for children with both vision and hearing losses and as a result a group of parents organized and established the Illinois Parents of DeafBlind which became a strong advocacy group. It is through the efforts of these parents that with the assistance of Phillip J. Rock, a Senator from Oak Park, the Illinois DeafBlind Center and the Illinois Advisory Board came into existence. The Illinois Advisory Board for Services for Persons who are DeafBlind was established in 1975 by Public Act 79-966. The Board provides advice to the State Superintendent of Education, the Governor, and the General Assembly on all matters pertaining to policy concerning persons who are DeafBlind, including the implementation of legislation enacted on their behalf.

Under state statute, the Board makes recommendations pertaining to, but not limited to the following:

- Existing and proposed programs of all state agencies that provide services for persons who are DeafBlind
- The state programs and financial plan for DeafBlind services and the system of priorities to be developed by the State Board of Education
- Standards for services in facilities serving persons who are DeafBlind
- Standards and rates for state payments for any services purchased for persons who are DeafBlind
- Services and research activities in the field of DeafBlindness, including evaluation of services
- Planning of personnel preparation both pre-service and in-service.
Introduction to DeafBlindness*

Individuals who are both deaf and blind have varied needs. The term “DeafBlind” can refer to a student with low vision or no vision, or who has limited hearing or no hearing. Intellectual capabilities also range from above average intelligence to low functioning or severe to profound intellectual disability. Individuals who are DeafBlind have a wide range of communication abilities including oral language, sign language and tactile sign language. Some read large print or Braille, and some are non-readers. Some individuals may have additional physical disabilities and special health care needs. The student may be mainstreamed or be in schools with a deaf or blind program, a program specifically for students with both disabilities, or a program for students with multiple disabilities.

Individuals who are DeafBlind comprise a unique group among students who have disabilities, with equally unique educational needs. The major disability of DeafBlindness is information gathering. A child or toddler who is DeafBlind faces developmental challenges that includes and goes beyond those of children who are developmentally delayed, deaf, or severely visually impaired. Children and youth who become DeafBlind at a later age face challenges such as the need to learn a tactile language, difficulty with self-esteem, and changes in relationships with family member and educational peers. The population of children, ages 3-21, who are DeafBlind represents a highly heterogeneous group. Factors such as severity of the vision and hearing impairments, the age of onset of either sensory loss, and the presence of additional disabilities such as motor, cognitive and medical disabilities, reflect a broad array of needs.

*We recognize that the spelling of the term used for a dual sensory loss is in flux nationally. Many entities use the spelling Deaf-Blind (with a hyphen). The Illinois community of persons with dual sensory loss, prefer the spelling DeafBlind (with no hyphen and capitalizing the “D” and “B”, with no space) For the purposes of this report, we are using the spelling DeafBlind.
Recommendations for the State of Illinois

The Advisory Board recommends the following:

- The Department of Human Services (DHS) now recognizes the validity of including persons who are DeafBlind in the Prioritization of Unmet Needs Survey (PUNS). DHS needs to continue to collect pertinent information regarding individuals who are DeafBlind.

- We recommend that the following human service state agencies appoint (or maintain the appointment) a representative to be the point of contact:
  - DHS/DDD – Department of Human Services/Division of Developmental Disabilities
  - DHS/DRS - Department of Human Services/Division of Rehabilitation Services
  - DHS/DMH – Department of Human Services/Division of Mental Health
  - DHS/ Bureau of Early Intervention
  - ISBE - Illinois State Board of Education
  - DCFS – Department of Children and Family Services
  - Department of Aging
  - IDHHC – Illinois Deaf and Hard of Hearing Commission
  - Illinois Department of Veterans Affairs

- Officially appoint all currently sitting members of the Illinois Advisory Board for Services for Persons Who are DeafBlind to new terms of office, thus bringing the Advisory Board to full approved membership.

- Support annual public awareness campaigns about DeafBlindness.
Major Activities for the Reporting Period

Meetings. The Illinois Advisory Board for Services for Persons who are DeafBlind convened meetings five times a year, generally the first Thursday of the months of February, April, August, October and December. Exact dates/locations of all meetings are available.

Open Meeting Act. The Open Meeting Act Officer provided highlights about the Act. All members completed the Open meeting Act training by Dec 31, 2012. Board members were instructed to complete the required Ethics training. The Board implemented the following recommendations related to the Act

- Meeting dates, times and locations of upcoming meetings are posted every year on ISBE and ABDB websites
- Agenda and items for vote are posted on ISBE and IABDB websites 48 hours in advance of meetings
- Minutes are posted on ISBE and IABDB websites
- Established rules regarding electronic attendance, public comments, taping and filming of meetings are posted on the two websites
- A “review of closed session minutes” is included in the June and December agendas

Prioritization of Unmet Needs Survey (PUNS). The Developmental disabilities agency for the past 10 years has used a document called the PUNS (Prioritization of Unmet Needs) as part of the eligibility for service determination for DD services in the state. Since some individuals who are DeafBlind have the same mannerisms, and behavior characteristics, the Board felt there is a need for a clarification statement in the PUNS document addressing this issue on behalf of DeafBlind individuals who are in need of DD services. We are pleased the Developmental Disabilities Agency has agreed to include a paragraph approved by the Advisory Board in the revised PUNS document.

Department on Aging. The Illinois Department on Aging has made a presentation to the Board. As a result of this presentation, arrangements have been made for a representative from the Helen Keller National Center in New York to make a presentation on “DeafBlindness” at the Department of Aging statewide case coordinators conference. The Department of agency identified their needs in the area of DeafBlindness:

- Accessibility of material in Braille and large print, ASL interpreters and videos in ASL
- Awareness of accommodations that agencies can make to increase or improve access to those who are DeafBlind; information about ADA amendments
- Skill training for staff
- Resources that can be shared when people need more than the Aging network services provide
- Education on auxiliary aids, services and assistive technology

Be My Voice website. ISBE provided approval for a link to the BeMyVoice.com website to be posted on their website. The website is updated on a regular basis. BeMyVoice.com includes interviews and “Person on the Street” responses and public awareness information. The National Usher Syndrome web page was added to BeMyVoice.com
Public Awareness  The primary focus on public awareness has been addressed through the “Be My Voice” web page which was funded and started by a former board member Faith Young. One special series on this web page is a series of interviews with various people asking them “what it means to be DeafBlind?” We finalized arrangements to continue the web page and added a link to the Usher Syndrome foundation home page. The Board also co-sponsored in recognition of the Helen Keller National Center DeafBlind awareness week, an open house which was held at the Illinois DeafBlind Center in Glen Ellyn.

Legislation. The Board received updates on specific legislation impacting people with disabilities. While there were no specific pieces of legislation regarding DeafBlind, we are pleased that the Governor did sign the Illinois Employment First Act.

Illinois DHS/DD Appointment of Staff Person. Several Board Members along with the Helen Keller National Center representative met with Developmental Disabilities Agency representatives to discuss the need to assign a central office staff person to serve as the DeafBlind service representative. We are pleased to report a DeafBlind service representative has been selected. A training program is being developed in conjunction with the Helen Keller National Center in New York.

Board Meetings and Presentations

- 2/2/12 (Board meeting held at Philip Rock) Tour of Philip Rock School
- 4/5/12 (Board meeting held at Philip Rock) “The Changing World of Deafness Coalition on Advocacy, Public Awareness and Funding” presented by Dr. Patricia Scherer, and Illinois Department on Aging, Planning, Research and Development Division presented by Sandra Alexander, Manager
- 6/7/12 (Board meeting held at Philip Rock) No Presentation
- 10/4/12 (Board meeting held at Philip Rock) HKNC presented by Chris Whitefield and Maureen McGowan
- 12/6/12 (Board meeting held at Philip Rock) Division of Developmental Disabilities (DDD) presented by Kevin Bird
- 3/21/13 (Board meeting held at Philip Rock) IL Dept. of Public Health Hearing/Vision presented by Christine Budorick
- 5/23/13 (Board meeting held at Philip Rock) No Presentations
- 8/22/13 (Board meeting held at Philip Rock) Home Service Program presented by Kim Pieczynski
- 10/17/13 (Board meeting held at DRS office, Downers Grove) BBS presented by Jan Sherburne
- 12/05/13 (Board meeting held at DRS office, Downers Grove) ICRE-Wood presented by Derrick Phillips
Illinois DeafBlind Service Summary

The Chicago Lighthouse for People Who Are Blind or Visually Impaired

The Chicago Lighthouse DeafBlind Program provides three core services and programs to adult individuals who have a combined hearing and vision loss:

- **I Can Connect** – provides telecommunication technology equipment for qualified individuals
- **Illinois Telecommunication Access Corporation (ITAC)** - loans Braille phone equipment to individuals who cannot use a regular phone or a TTY
- **Title XX** – provides services to individuals who have open cases with Department of Rehabilitation Services and need assistance with job readiness skills training

The DeafBlind program:

- Hosts the biennial DeafBlind Retreat in Jacksonville, IL held at the Illinois School for the Visually Impaired
- Hosts Le COBDA (The club of Blind Deaf Adults) monthly meetings at The Chicago Lighthouse for social, educational, and entertainment activities for DeafBlind, volunteers, and family members
- Provides information, referrals and resources for individuals who are DeafBlind, family members, friends, and community services
- Works collaboratively with Phillip Rock Center, Project Reach Program, Helen Keller National Center, Department of Rehabilitation Services and other related agencies to identify the needs of individuals who have a combined hearing and vision loss and promote advocacy

Division of Rehabilitation Services (DRS)

DRS send one of its program managers to participate in Board Meetings. We are pleased that DRS in conjunction with Helen Keller National Center has funded and provided training in DeafBlind to selected DRS field staff. DRS have also signed an MOU (Memorandum of Understanding) agreement between DRS, Helen Keller National Center, and the Chicago Lighthouse for the Blind to increase referrals and improve the coordination of services between these three agencies.

DRS is also implementing a unique vocational rehabilitation service to assist DeafBlind individuals who are “employment ready”. This will allow the Agency to employ on a short term basis individuals who can provide direct employment related services to customers who are DeafBlind.

Helen Keller National Center (HKNC)

Mission: To enable each person who is DeafBlind to live and work in his or her community of choice. HKNC is a national rehabilitation program serving youth and adults who are DeafBlind. Support services for youth and adults who are DeafBlind, their families and the professionals who serve them across the country are provided through a system of field services. A HKNC field office (serving Idaho, Illinois, Indiana and Iowa) is located in Illinois and a staff person from that office is a frequent visitor to the IABDB board meetings.
Hearing and Vision Early Intervention Outreach (HVEIO)

Program Mission: To assure that all infants and toddlers in Illinois who are deaf, hard of hearing or visually impaired receive appropriate Early Intervention services.

HVEIO is a statewide training and technical assistance program regarding infants and toddlers who are deaf, hard of hearing or visually impaired (formerly known as Hearing and Vision Connections).

Vision and hearing related highlights include:
- Participation in Sharing a Vision Conference – Springfield
- Parent Advocacy (Individualized Education Plan) training
- Presentations to ISU vision students, including Early Intervention recruitment
- Provision of Functional Vision and Hearing Screening Training Webinars
- Planning for 2014 Opening Doors/ Parent Infant Institute
- Parent Conferences for Parents of Children who are Visually Impaired
- Parent Conferences for Parents of Children who are Deaf or Hard of Hearing
- All Ears Family Fun Walk

Illinois Deaf and Hard of Hearing Commission

This agency has established and funded a task force to address the issue of the state providing SSP services to DeafBlind residents of Illinois. The role of the SSP is to enhance independence and improve the quality of community living.

Illinois State Board of Education
- Currently oversees state DeafBlind grant titled “Project Reach”
- Currently oversees the Philip J. Rock Center and School
- Supports the Illinois Advisory Board for DeafBlind (IABDB)
- Supports the Chicago Light House for People Who Are Blind or Visually Impaired
- Supports Learning Ally (recordings for the blind and dyslexic)
- Supports the Illinois Service Resource Center (ISRC)
- ISBE sends an agency liaison to attend IABDB meetings
- ISBE sends an agency liaison to attend the Illinois School for the Visually Impaired advisory council
- ISBE sends an agency liaison to attend the Illinois School for the Deaf Advisory council
- ISBE provides technical assistance to schools with students who are DeafBlind.

Illinois School for the Deaf and Illinois School for the Visually Impaired

The Board recommended that the two schools implement a program to identify students with Usher Syndrome, a genetic disability. The schools have agreed to provide screening for Usher syndrome to students at both schools.
Philip J. Rock Center

The Philip J. Rock Center and School (PRC) serves two distinct functions in providing services to individuals who are DeafBlind. DeafBlindness does not mean TOTAL deafness plus TOTAL blindness. It means having a combined vision-hearing loss, with most eligible children having some usable vision, hearing, or both. It is the combination of losses that cause developmental and learning challenges.

The Philip J. Rock School, a public residential facility mandated by school code to operate no-reject year-round residential program for students with DeafBlindness (105 ILCS 5/14-11.02) (from Ch. 122, par. 14-11.02) Sec. 14-11.02. It offers a comprehensive residential educational program available for children who are DeafBlind in the 6-22 year age group. The Center provides a wide range of outreach services on a statewide basis at distance and in schools, medical settings, early intervention centers and homes. The combined Center and School concept makes possible a program which provides a continuum of services to children who are DeafBlind and their families. The focus of the Philip J. Rock Center and School is to ensure positive transition outcomes for each student served. All costs are paid for with a line item in the budget of the ISBE – a simple and transparent system for school districts.

Quick Facts about the Philip J. Rock Center and School:

- The school provides an extended day residential school with model classrooms, with state of the art educational services fostering academic and expanded core achievement of students with DeafBlindness and additional disabilities
- The PRC staff members have extensive expertise in the field of DeafBlindness
- Use of the PRC school program to provide a practicum site for University students and future teachers
- Facilitation of family-to-family connections through the activities of two Family Specialists, leading to increased partnerships with schools
- Since its inception, the school has provided residential student services to 52 school districts

Project Reach – Illinois Deaf- Blind Services

Project Reach is the outreach (“center”) component of the Philip J. Rock Center and School. In addition to the in-kind resources provided by the Philip Rock Center, Project Reach uses federal grant funds that were awarded to “Improve Services and Results for Children with Disabilities” (CFDA 84.326T). Project Reach is part of a national network of public and private entities that support this vulnerable, low-incidence population age birth – 21-years. Project Reach was recently awarded a five-year project, and will be providing services from October 1, 2013 – September 30, 2018. Outreach services have been provided to 187 school districts since the service center’s inception.

Quick Facts about Project Reach:

- Project Reach is required to complete an annual child count of eligible children in Illinois.
- On December 1, 2012, Project Reach reported that 436 children were served during the year, and that 410 of those children remained eligible for services.
Project Reach provides a wide array of services for families that have a child with combined vision-hearing loss. Services include:

- Family to family connections upon request based on etiology, medical concerns, educational issues, and other family-driven factors,
- Annual “check in calls” for families of students at critical transitions ages (2 years, 5 years, 11 years, 14 years, 17 years, and 20 years of age),
- Distance technical assistance and home visits driven by student-specific concerns, including opportunities to coach early intervention providers in the home or other natural setting,
- Parent training opportunities in conjunction with the Family Leadership Conference.
- Project Reach provides a wide array of services for schools serving a child with combined vision-hearing loss. Services include:
  - Hosting nationally-created distance learning opportunities on DeafBlindness that provide professional development credits.
  - Dissemination through newsletters and website.
  - Targeted technical assistance, including the development of materials related to transition and other topics.
  - In-class coaching to educational teams focusing on any student with DeafBlindness.
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