
IABDB
Annual
Report

Fiscal Year

2006-
2007

The Illinois Advisory Board for Services for Persons Who are Deaf-Blind (IABDB) is committed to partnering with key stakeholders to impact positive change for all individuals who are deaf-blind and ensure they are provided equal access to resources and opportunities to lead fulfilling lives.



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I A B D B

Illinois Advisory Board
for Deaf Blind

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Board Members

ISBE Representative

Dr. Laura Frankiewicz

*Governor's Office Senior Citizen
Representative*

Virgil Krone

*Governor's Office Consumer
Representative*

Geraldine Lawhorn

DCFS Parent Representative

Faye Manaster

DCFS Representative

Marsha Northrup

DHS/DDD Representative

Gail Olson

DHS/DRS Representative

Joseph Parvis

ISBE Parent Representative

Roseann Slaght

*Governor's Office Parent
Representative*

Faith Rosenshein Young

January 3, 2008

The Honorable Rod R. Blagojevich
Governor, State of Illinois
207 State House
Springfield, Illinois 62706

Dear Governor Blagojevich:

We are pleased to present this annual report of the Illinois Advisory Board for Services for Persons Who are Deaf-Blind. You will find a summary of the Advisory Board's activities, our recommendations, and goals and objectives for the current year.

This Advisory Board is described in Article 14-11.02 of the School Code of Illinois. One of the duties of the Board is to:

“...provide advice...on all matters pertaining to policy concerning persons who are deaf-blind.”

We respectfully request that you guide the responsible entities to implement the recommendations in this report. These recommendations have been derived directly from those who support the lives of people in Illinois who are Deaf-Blind.

Sincerely,

Faith Rosenshein Young, Chair
On behalf of IABDB Board Members

II. History, Authority and Purpose of the Board

The Illinois Advisory Board for Services for Persons who are Deaf-Blind 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 deaf-blind, including the implementation of legislation enacted on their behalf.

The Board makes recommendations pertaining to, but not limited to, the following matters:

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

III. Introduction

Individuals who are both deaf and blind have varied needs. The term “deaf-blind” 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 mental retardation. Individuals who are deaf-blind 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 deaf-blind comprise a unique group among students who have disabilities, with equally unique educational needs. The major disability of deaf-blindness is information gathering. A child or toddler who is deaf-blind 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 deaf-blind 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 members

and educational peers. The population of children, ages 3 to 21, who are deaf-blind 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. *The education of children with deaf-blindness is at a crisis.* Many of these students never acquire the knowledge and skills essential for a productive life. Several factors contribute to this problem.

1. Students are under identified and geographically dispersed.
2. Direct service and instructional personnel are in crucial need.

IV. General Recommendations for Illinois Services

The Advisory Board recommends the following.

1. Officially appoint all currently sitting members of the Illinois Advisory Board for Services for Persons Who Are Deaf-Blind to new terms of office. In addition, appoint persons from the community or service agencies, as needed to vacant seats, thus bringing the Advisory Board to full approved membership.
2. Propose and pass legislation that will give consumers and their families the ability to self-direct funds for services and make choices for services on an individualized basis much like a child's educational plan is customized for each individual child.
3. Support the work of the Support Service Provider (SSP) Task Force, including recommendations concerning the cost of SSP services. SSPs provide a necessary communication support for persons who are deaf-blind. Unlike other populations, the need for services such as this (along with interpreter and intervener services) does not diminish relative to the level of independence of the person.
4. DHS and all State Agencies use consistent language and definitions of deaf-blindness. This definition should be no more restrictive in limiting the population to access of services than the federal definition.
5. DHS should recognize the validity of including persons who are deaf-blind in the Prioritization of Unmet Needs Survey (PUNS) and make changes to the database to collect pertinent information regarding individuals who are deaf-blind.

V. Major Activities

Meeting Dates

The Illinois Advisory Board for Services for Persons who are Deaf-Blind convened meetings: October 5, 2006, December 7, 2006, February 1, 2007, April 5, 2007, and June 7, 2007. The meeting normally scheduled for August was canceled. Meetings are scheduled for the first Thursday of every second month. In addition to the normal meeting calendar, a special meeting was held May 3, 2007 at the Philip Rock Center and School to work on Illinois Deaf-Blind Awareness Week activities.

Summary of Major Activities

1. Sent a letter to Tony Paulauski, Executive Director, The Arc of Illinois, recommending that the Illinois Medicaid Waivers move to a function based description of developmental disability using Maryland's language as a model. This change to a functional definition would allow many individuals in Illinois who are deaf-blind to be eligible for the waivers. We continued to monitor the status of the Children's and Adult Medicaid Waivers throughout the fiscal year.
2. Contacted individual consumers and deaf-blind consumer groups in an effort to recruit applicants for the Illinois Deaf and Hard of Hearing Commission (IDHHC). We were successful in recruiting two applicants, one of whom is now an IDHHC Commissioner.
3. Planned and implemented activities for 2007 Helen Keller Deaf-Blind Awareness Week in Illinois in conjunction with the Helen Keller National Center, Illinois Deaf and Hard of Hearing Commission, Philip J. Rock Center & School/Project Reach. Events included a Proclamation signed by Governor Rod Blagojevich; a Proclamation Presentation Event on June 7, 2007 at the James R. Thompson Center in Chicago with special guest Philip J. Rock; an email awareness campaign consisting of a series of five .html emails featuring Illinois residents who are deaf-blind and their accomplishments, sent out to members of the General Assembly, state agencies, news media, and the public; a special edition newsletter featuring stories by individuals and families in Illinois touched by deaf-blindness; and an article in the ISBE Superintendent's Bulletin.
4. Solicited and retained the pro bono services of a marketing firm, Engage Creative, to develop a brand image and platform for the Advisory Board. With their help, we have developed an identity, including a logo and letterhead, a vision statement and a mission statement, and focused our efforts to better accomplish our goals. In addition, to better build our identity and support our goals, we have purchased the domain name www.bemyvoice.com.
5. Secured a representative of the SSP Task Force to attend meetings and submit reports.

6. Continued working with State Agencies to secure official appointments for all members of the Advisory Board. Presently, only Virgil Krone and Geraldine Lawhorn have official appointments. We are still awaiting official appointments of the following, as either their initial appointments were never made official or their terms have expired and new appointments have not been made.
 - Joseph Parvis (DHS)
 - Gail Olson (DHS)
 - Laura Frankiewicz (ISBE)
 - Roseanne Slaght (ISBE)
 - Marsha Northrup (DCFS)
 - Faye Manaster (DCSF)
 - Faith Rosenshein Young (Governor's Office)For the second year in a row, a significant amount of time and effort has gone toward getting these appointments made without success.
7. Discussed Interpreter of the Deaf Licensure Act HB1277 and expressed concerns that it did not take into account the unique needs of individuals who are deaf-blind. Action pending.
8. Published the IABDB Annual Report and succeeded in getting the report distributed and posted on the ISBE website.

VI. Closing Comments

For FY 2006-2007 we have seen budget constraints impact service delivery to persons who are deaf-blind, yet again. At the same time, a variety of factors have led to an increase in the number of persons in Illinois who are challenged by deaf-blindness. The Board has continued to explore avenues for consumers to optimize available resources and encouraged state agencies to reach out to consumers and their families to help them take advantage of all the programs and resources available to them. At the same time, we have requested feedback on service barriers, so we can examine the situation and make recommendations to the appropriate parties to remedy the situation(s).

Additionally, we continue to work with state agencies, disability advocates, and disability service providers to ensure open communication regarding the unique needs and challenges facing individuals who are deaf-blind and their families. To help with this awareness goal and our mission in general, we have begun working with a marketing firm, Engage Creative. Engage ensures we consistently reach and deliver a focused message to our target audience, as reaching our target audience has been a challenge in the past.

The Board recognizes that surest method for improving the lives of persons who are deaf-blind in Illinois is to secure for them equal consideration, planning for and access to services. To succeed in this effort, our recommendations must be heard; our advice must be heeded. It is to this end that we strive in all our activities.

The Illinois Advisory Board for Services for Persons who are Deaf-Blind is committed to continue to collaborate with the Governor of Illinois, Illinois State Legislature, Illinois State Board of Education, Department of Human Services, Department of Rehabilitation Services, Philip J. Rock Center, and Department of Children and Family Services to address issues, maintain and improve current service programs and plan for the future.

VII. GOALS and OBJECTIVES FY 08

ILLINOIS ADVISORY BOARD FOR SERVICES FOR PERSONS WHO ARE DEAF-BLIND

1. To increase awareness regarding individuals who are deaf-blind as contributing members of society.

Objective 1: Plan 2008 Illinois Helen Keller Deaf-Blind Awareness Week celebration events and campaign in conjunction with Helen Keller National Center, Illinois Deaf and Hard of Hearing Commission, and Philip J. Rock Center & School/Project Reach.

Objective 2: Secure a Governor's Proclamation for Helen Keller Deaf-Blind Awareness Week 2008 with the assistance of Helen Keller National Center (HKNC) and IDHHC.

Objective 3: Work to bring full-functionality to IABDB's website, www.bemyvoice.com.

2. To ensure all rights and access to health, educational and vocational services, as well as social and residential opportunities.

Objective 1: Submit recommendations to Illinois Council on Developmental Disabilities regarding revisions and updates to the PUNS database and process.

Objective 2: Follow-up on recommendations with Director of DHS, Division of Developmental Disabilities.

3. To ensure that individuals who are deaf-blind are empowered to determine all aspects of their lives.

Objective 1: Contact consumers and services providers who support consumers about opportunities to provide input regarding issues affecting their lives.

Objective 2: Monitor bills in the General Assembly and provide recommendations regarding the impact on persons who are deaf-blind.

4. To ensure families, educators and support personnel are provided with the necessary training and resources to benefit all individuals who are deaf-blind.

Objective 1: Post training, seminar and resource information on IABDB website.

Objective 2: Meet with U.S./IL Legislators to discuss the most effective means of educating and training persons who are deaf-blind, and providing their families the appropriate training and support services.

Objective 3: Monitor bills in the General Assembly and provide recommendations regarding the impact on persons who are deaf-blind.

Objective 4: Serve as the Advisory Committee for Project Reach: Illinois Deaf-Blind Services.

5. To ensure diversity of membership in the Advisory Board and equal representation of the needs of individuals who are deaf-blind.

Objective 1: Board chair will make follow-up written and/or verbal requests to the Governor and State Agencies requesting status of member appointments.

Objective 2: Invite the Director of DHS, Division of Developmental Disabilities to appoint a representative to the Advisory Board.

Appendix A. Members of the Illinois Advisory Board for Services for Persons Who are Deaf-Blind

Name of Group	Purpose	Authorized by	Status and Timeline	#/frequency of mtgs	# of Members	Appointed by	Current Chair
Services for Persons Who Are Deaf-Blind [Illinois Advisory Board for]			Active	6 per year	11 Sitting Members - 2 Guest Members		Faith Rosenshein Young
Annual cost	Fund source	Agency Contact	Phone #				
\$5000	IDEA	Barbara Sims	217/782-5589				

MEMBERSHIP INFORMATION

#	Name	Title	Address	Sex	Representing	Length of term	Initial Appt. Date	Current term end
1	Gail Olson	Employee Rep.	Hearing and Vision Connections 125 Webster Avenue Jacksonville IL 62650	F	Department of Human Services/Division of Developmental Disabilities	3 Years		
2	Faith Rosenshein Young	Parent Representative	19W079 Avenue Barbizon Oak Brook IL 60523	F	Governor's Office	3 Years		
3	Faye Eldar Manaster	Parent Rep.	8331 Kimball Skokie, IL 60076	F	Department of Children and Family Services	3 Years	2001	2004
4	Laura Frankiewicz	Employee Rep.	300 Cleveland Avenue Carpentersville, IL 60110	F	Illinois State Board of Education	3 Years		Ongoing
5	Virgil Krone	Senior Citizen Rep.	402 Sunnycrest Court West Urbana, IL 61801	M	Governor's Office	3 Years	1984	2005
6	Geraldine Lawhorn	Consumer Rep.	3510 South Rhodes, #1403 Chicago, IL 60653	F	Governor's Office	3 Years	1984	2001*
7	Marsha Northrup	Statewide Coordinator	Deaf Services Department 100 West Randolph Suite 6-200 Chicago, IL 60610	F	Department of Children and Family Services	3 Years	1998	2002
8	Mike Parvis	Employee Rep.	100 West Randolph Suite 5-300 Chicago, IL 60601	M	Department of Human Services/Division of Rehabilitation Services	3 Years	2002	2005
9	Roseann Slaght	Parent Rep.	5178 Hutchison Drive South Beloit, IL 61080	F	Illinois State Board of Education	3 Years	1992	2004
10	Vacant	Parent Rep.			Department of Human Services/Division of Rehabilitation Services	3 Years		Ongoing

*Nominated by Board for Reappointment (see memo dated 4/1/02)

Appendix A. Members of the Illinois Advisory Board for Services for Persons Who are Deaf-Blind

Services for Persons Who Are Deaf-Blind [Illinois Advisory Board for] (Continued)

MEMBERSHIP INFORMATION

#	Name	Title	Address	Sex	Representing	Length of term	Initial Appt. Date	Current term end
1	Tina Lechnick	Chief Administrator	818 DuPage Boulevard Glen Ellyn, IL 60137	F	Philip J. Rock Center and School	Guest		Ongoing
2	Laura Thomas		485 42 nd Avenue East Moline, IL 61244	F	HKNC - North Central Region	Guest		Ongoing