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IABDB  
Annual  
Report

Fiscal Year

2007-

2008



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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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Who are Deaf-Blind

## I. Letter to Governor Quinn



**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**

*DHS/DDD Parent Representative*

**Jody Wolfe**

*DHS/DRS Parent Representative*

**Maria Roeters**

February 20, 2009

The Honorable Pat Quinn  
Governor, State of Illinois  
207 State House  
Springfield, Illinois 62706

Dear Governor Quinn:

We are pleased to present this annual report of the Illinois Advisory Board for Services for Persons Who are Deaf-Blind (IABDB). 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,

J. Michael Parvis, 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 (IABDB) 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 its effect on the information gathering processes. A child or toddler who is deaf-blind faces developmental challenges that include and go 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's recommendations are as follows:

1. The General Assembly should 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.
2. State Agencies should sustain 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.
3. The Department of Human Services (DHS) and all State Agencies should 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.
4. DHS must 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.
5. The Illinois State Board of Education should review state priorities to address the unique and challenging needs of students who are deaf-blind; including the state financial plan, the child identification of students who are deaf-blind, special education services for students who are deaf-blind including transition options. ISBE should also review training needs of personnel who interface with these students.
6. Outcomes and follow-up results from Philip J. Rock Center and the Hearing and Vision Connections statewide trainings should be reviewed.
7. State Agencies and the Governor's Office should 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.

## **V. Major Activities**

### Meeting Dates

During FY08, IABDB convened meetings October 11, 2007, December 6, 2007, February 7, 2008, April 3, 2008, and June 5, 2008. The meeting normally scheduled for August was canceled. Meetings are scheduled for the first Thursday of every second month.

### Summary of Major Activities

1. Sent correspondence to Lilia Teninty, Director, Division of Developmental Disabilities, and DHS, inviting her or her representative to meet with IABDB with regard to the following issues: concerns regarding the PUNS database including a clear understanding of deaf-blindness as a dictate category and representation from DHS/DD on IABDB. Mr. Robert Holladay, Mike Dittmer and Tammy Benjamin, DHD-DD then met with IABDB regarding these concerns at the December 2008 meeting.
2. Coordinated Deaf-Blind Awareness Week 2008 in Illinois which included working with a pro bono Public Relations agency, "Engage Creative" to create an informational YouTube video. The YouTube video featured a young adult woman with deaf-blindness going about her daily life. IABDB emailed information about the IABDB Helen Keller Deaf-Blind Awareness Week campaign to 2,197 email addresses. In addition, IABDB requested and received an official Illinois proclamation from the Governor's office. The proclamation was framed and sent to the Illinois School for the Visually Impaired (ISVI) for the Deaf-Blind Interpreters & Interpreter Training Program Workshop.
3. Expanded the IABDB website, [www.bemyvoice.com](http://www.bemyvoice.com). This website now contains a wealth of information, numerous important links and resources for families and consumers. Our YouTube video may also be accessed from this site.
4. Successfully pursued the filling of long-vacant seats on the IABDB, specifically representatives from ISBE and DHS. As a part of this, IABDB responded to the DHS Audit Findings regarding membership on the Board.
5. Served as an advisory committee for Project Reach: Illinois Deaf-Blind Services and provided input to Hearing and Vision Connections.

## **VI. Closing Comments**

For FY 2007-2008 we have seen budget constraints impact service delivery to persons who are deaf-blind, yet again. Given the current state of the economy in the U.S. as well as our state, we expect even more ominous budget consequences for FY10. However, difficult times call for creative and novel approaches to problem solving. We view these difficult times as an opportunity to examine business as usual and to strike out in new directions and explore new ways of doing things. At a time when a variety of factors have led to an increase in the number of persons in Illinois who are challenged by deaf-blindness, the State's resources have declined dramatically. We view this as a challenge to our Board and indeed to the State to re-examine the current support systems for persons with disabilities and create a better system for persons with deaf-blindness and other disabilities.

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 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 continued work 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. We have expanded our use of technology in this effort by establishing our website, [www.bemyvoice.com](http://www.bemyvoice.com).

The Board recognizes that the 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, Philip J. Rock Center and School, 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 09**

### ***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 2009 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.

Objective 3: Expand the information on IABDB's website, [www.bemyvoice.com](http://www.bemyvoice.com) and increase the number of links to and from relevant websites.

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

Objective 1: Follow-up on recommendations submitted to the Illinois Council on Developmental Disabilities regarding revisions and updates to the PUNS database and process.

Objective 2: Continue to 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.

Objective 3: Contact Illinois Association of Deaf-Blind to identify areas for collaboration and coordination of activities.

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 meetings	# of Members	Appointed by	Current Chair
Services for Persons Who Are Deaf-Blind [Illinois Advisory Board for]			Active	6 per year	11 Sitting Members 4 Guest Members		J. Michael Parvis
<b>Annual cost</b>	<b>Fund source</b>	<b>Agency Contact</b>	<b>Phone #</b>				
\$5000	IDEA	Barbara Sims	217/782-5589				

### MEMBERSHIP INFORMATION

#	Name	Title	Address	Sex	Representing	Length of term	Initial Appt. Date /Date Board Member Began Attending Meetings	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	2003	2008
2	Faith Rosenshein Young	Parent Representative	19W079 Avenue Barbizon Oak Brook IL 60523	F	Governor's Office	3 Years	2004	2011
3	Faye 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	1992	2011
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	J. Michael 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	2011
10	Jody Wolfe	Parent Rep.	3021 Cyprus Court Buffalo Grove, IL 60089	F	Department of Human Services/Division of Rehabilitation Services	3 Years	2008	

## 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	Regional Representative	485 42 <sup>nd</sup> Avenue East Moline, IL 61244	F	Helen Keller National Center	Guest		Ongoing
3	Joann Rushing	Program Manager	1850 W. Roosevelt Rd. Chicago, IL 60608	F	Chicago Lighthouse for the Blind	Guest		Ongoing
4	Julie Somers	Deaf-Blind Consumer	11438 S. Sawyer Ave. Chicago, IL 60655	F	Adult Consumers	Guest		Ongoing