
IABDB
Annual
Report

Fiscal Year

2008-
2009



I A B D B

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. 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*

Catherine Klein

*Governor's Office Consumer
Representative*

Geraldine Lawhorn

DCFS Parent Representative

Faye Manaster

DCFS Representative

Marsha Northrup

DHS/DDD Representative

Gail Olson

DHS/DRS Representative

Robert Griffith

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, 2010

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 Persons who are Deaf-Blind. The report contains a summary of the Advisory Board's activities, our recommendations and our goals and objectives for the current year.

We continue to vigorously pursue our board's charge which includes providing "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." (105 ILCS 5/14-11.02).

We have pursued our charge in the face of many serious challenges including the state's current economic crisis; one that impacts all aspects of support for persons who are deafblind including education, vocational supports and living supports. While we understand the gravity of the economic situation Illinois is in, we cannot fail to be optimistic for the future; a future that includes the necessary supports for persons who are deafblind so that they may pursue a full and rewarding life in the great State of Illinois.

We appreciate your attention to our annual report and we look forward to continuing dialog towards the realization of the recommendation contained herein.

Sincerely,

Laura Frankiewicz, Ed.D.
On behalf of the IABDB

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 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 deaf-blind;
- Standards and rates for State payments for any services purchased for persons who are deafblind;
- 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

While it may seem that deafblindness refers to a total inability to see or hear, in reality deaf-blindness is a condition which can involve a broad range of combined sensory impairments.

A person who is deafblind has a unique experience of the world. For people who can see and hear, the world extends outward as far as his or her eyes and ears can reach. For the individual who is deaf-blind, the world is much narrower. If the individual is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach.

Some individuals who are deafblind are effectively alone if no one is touching them. Their concepts of the world depend upon what or whom they have the opportunity to physically contact. If an individual who is deaf-blind has some usable vision and/or hearing, as many do, her/his world will be enlarged. Many individuals called deaf-blind have enough vision to be able to move about in their environments, recognize familiar people, see sign language at close distances, and perhaps read large print. Others have sufficient hearing to recognize familiar sounds, understand some speech, or develop

speech themselves. The range of sensory impairments included in the term "deaf-blindness" is great. (adapted from National Consortium Deaf-Blindness, "What is Deaf Blindness", www.nationaldb.org)

The Illinois Advisory Board for Services for Persons who are Deaf Blind (IABDB) addresses issues from birth through adulthood. IABDB's charge covers concerns that span Early Intervention services for infants and toddlers, educational services for children and youth as well as all aspects of adult living including those concerns related to senior citizens. In particular, within the adult world, we are confronting issues that relate to the aging Baby Boomers who are experiencing the typical sensory losses associated with aging. We are also confronting the consequences of war in terms of meeting the needs of injured veterans who have returned from war with head injuries and vision/hearing difficulties. Deaf blindness exists across the generational continuum and may touch persons at any stage of life. Issues affecting persons with deafblindness range from the availability of Early Intervention providers and trained teachers in childhood, to available residential, independent living, employment, transportation, recreation and support services in adulthood. Always present are issues related to the unique communication needs of individuals who are deaf blind, such as Braille, sign language and tactile sign though interpreters. Our Board's charge encompasses all of these aspects of deafblindness.

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. Adopt a standard definition of deafblindness for all state agencies and include deafblindness as a separate category on the state PUNS questionnaire (Prioritization of Unmet Needs).

V. Major Activities

Meeting Dates

During the FY09, The Illinois Advisory Board for Services for Persons who are Deaf-

Blind convened meetings October 2, 2008, December 4, 2008, February 5, 2009, April 2, 2009, and June 4, 2009. The meeting normally scheduled for August was canceled. Meetings are scheduled for the first Thursday of every second month.

Summary of Major Activities

1. Coordinated Illinois Deaf-Blind Awareness week 2009. Our efforts included working with a public relations agency, Engage Creative, which has continued to provide pro bono services to IABDB. Engage Creative and board members developed a new YouTube video for 2009 that focused on a younger, school-aged student with deaf-blindness. The video link was sent to over 2,022 email addresses.
2. Worked with representatives from the National CHARGE Foundation to support the 9th International CHARGE Syndrome Conference held in suburban Chicago. There were over 750 attendees from 10 countries and 37 states.
3. Worked collaboratively with Helen Keller National Center –North Central Region and The Chicago Lighthouse for People who are Blind or Visually Impaired. Focus has been on developing plans for Service Support Providers (SSP) including providing input to task force representatives.
4. Expanded the IABDB website, 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 by the site.
5. Successfully pursued the filling of some of long-vacant seats on the IABDB, specifically representatives from the Governor’s Office and DHS. As a part of this, IABDB responded to the DHS Audit Findings regarding membership on the Board. Corresponded with representatives of the Governor’s Office regarding additional vacancies.
6. Served as an advisory committee for Project Reach: Illinois Deaf-Blind Services and provided input to Hearing and Vision Connections.

VI. Closing Comments

In our previous Annual Report we closed by sharing our grave concerns regarding the financial health of the state of Illinois. The events of this year have given us little reason for optimism. We repeat our position that 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 try 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 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 continued work with a marketing firm, Engage Creative. Engage Creative has provided pro bono services to assist us to consistently reach and deliver a focused message to our target audience. We continue to explore the utility of technology in this effort by expanding our website, www.bemyvoice.com. Our on-going public relations campaign will soon include a "call to action" section that will provide the public with suggestions for actions they may take to improve the lives of persons who are deaf-blind. We encourage you, as state leaders to hear our call to action and take bold steps to improve the lives of your citizens who are deaf-blind.

VII. GOALS and OBJECTIVES FY 10

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 2010 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: Develop an effective on-going public relations campaign to include a “Call to Action” regarding deaf-blindness.

Objective 3: Objective 3: Maintain updated website, www.bemyvoice.com.

Objective 4: Create methodology to track outreach efforts.

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

Objective 1: Establish and/or maintain relationships with state and federal agencies that impact the lives of persons who are deaf-blind including Human and Family Services, Illinois Deaf and Hard of Hearing Commission and The Illinois and United States Departments of Veterans Affairs.

Objective 2: Provide model language to appropriate agencies to encourage the adoption of consistent language regarding the definition of deafblindness.

Objective 3: Advocate for the addition of a separate category of “deafblind” on the PUNS questionnaire.

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

Objective 1: Board members will monitor state legislation through individual contacts and as a function of their professional responsibilities.

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: Facilitate communication among agencies and support groups for persons with deafblindness such as the Illinois Association of Deafblind and the Illinois Advocates for the Deafblind.

Objective 2: Support and participate in Chicago Lighthouse deafblind awareness events.

Objective 3: Serve as the Advisory Committee for Project Reach: Illinois Deaf-Blind Services.

5. To ensure diversity of membership in the Advisory Board as representative of the varied needs of individuals who are deaf-blind.

Objective 1: Maintain communication with appropriate state officials to ensure full representation on the board.

Objective 2: Communicate with the Secretary of DHS, Division of Rehabilitation Services to post and fill the position of Deaf-blind specialist.

Appendix A. Current 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] | Makes recommendations to agencies regarding deaf-blindness | Public Act 79-966 105 ILCS 5/14-11.02 | Active | 6 per year | 11 Sitting Members | various | Laura Frankiewicz |
| Annual cost | Fund source | Agency Contact | Phone # | | | | |
| \$5000 | IDEA | Todd Williams & Sarah Sebert | 312-814-5560 | | | | |

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 | 2012 |
| 2 | Faith Rosenshein Young | Parent Representative | 19W079 Avenue Barbizon Oak Brook IL 60523 | F | Governor's Office | 3 Years | 2004 | 2012 |
| 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. | 245 W. Exchange Suite 4 Sycamore, IL 60178 | F | Illinois State Board of Education | 3 Years | 1992 | 2011 |
| 5 | Catherine Klein | Senior Citizen Rep. | 1550 N. Lake Shore Dr. # 29-D Chicago, IL 60610 | F | Governor's Office | 3 Years | 2009 | 2012 |
| 6 | Geraldine Lawhorn | Consumer Rep. | 3510 South Rhodes, #1403 Chicago, IL 60653 | F | Governor's Office | 3 Years | 1984 | 2012 |
| 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 | Bob Griffith | Employee Rep. | 100 West Randolph Suite 5-300 Chicago, IL 60601 | M | Department of Human Services/Division of Rehabilitation Services | 3 Years | 2009 | 2012 |
| 9 | Roseann Slaght | Parent Rep. | 5178 Hutchison Drive South Beloit, IL 61080 | F | Illinois State Board of Education | 3 Years | 1992 | 2011 |

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

| | | | | | | | | |
|-----------|---------------|------------|--|---|--|---------|------|------|
| 10 | Jody Wolfe | Parent Rep | 3021 Cyprus Court Buffalo Grove, IL 60089 | F | Department of Human Services/Division of Rehabilitation Services | 3 Years | 2009 | 2012 |
| 11 | Maria Roeters | Parent Rep | 632 E 161 st Place So. Holland, IL 60473 | F | Department of Human Services/Division of Rehabilitation Services | 3 years | 2009 | 2012 |

Illinois Advisory Board for Persons Who Are Deaf-Blind – Frequent Guests

| # | Name | Title | Address | Sex | Representing |
|----------|----------------|-------------------------|--|-----|--|
| 1 | Michelle Clyne | Project Coordinator | 818 DuPage Boulevard Glen Ellyn, IL 60137 | F | Project Reach IL Deaf-Blind Services |
| 2 | Laura Thomas | Regional Representative | 485 42 nd Avenue East Moline, IL 61244 | F | Helen Keller National Center |
| 3 | Joann Rushing | Program Manager | 1850 W. Roosevelt Rd. Chicago, IL 60608 | F | Chicago Lighthouse for the Blind |
| 4 | John Miller | Director | 1630 South 6th Street Springfield, IL 62703 | M | IL Deaf and Hard of Hearing Commission |