

INTRODUCTION TO DEAFBLINDNESS



PROJECT REACH:
Illinois DeafBlind Services

DeafBlind

Deaf-Blind

Dual Sensory Loss

DeafBlind

Combined Vision/Hearing Loss

Deafblind

Dual sensory impairment

Deaf/Blind

deafblind

Dual Sensory Disability

Multi-sensory impairment

Deafblindness Defined

- **IDEA:** Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness. <https://sites.ed.gov/idea/regs/b/a/300.8>
- **Simply put:** Deafblindness is a combined hearing and vision loss that significantly limits an individual's ability to get information from people and their surroundings.

Deafblindness is a disability . . .

- about INFORMATION GATHERING
- which LIMITS ACCESS
- which is EXPONENTIALLY MORE than a hearing loss plus a vision loss (not $3+3=6$, but $3^3=27$)
- which can cause developmental delays, but does NOT necessarily LIMIT LEARNING POTENTIAL

Always PRESUME COMPETENCE

Quick Poll: True or False?

1. DeafBlind means totally deaf and totally blind.
2. All people who are DeafBlind are the same.
3. All people who are DeafBlind use American Sign Language (ASL) to communicate.



Video: DeafBlind Perspectives

Major Causes of Deafblindness

- Hereditary syndrome or disorder (Usher syndrome, CHARGE syndrome, Down syndrome)
- Pre- or post-natal condition
- Prematurity and birth complications
- Infections (cytomegalovirus, meningitis, etc.)
- Injury or stroke
- Family history

Co-Occurring Disabilities

- Some individuals have other disabilities in addition to vision and hearing loss.
- Approximately **85%** of children with deafblindness have **one or more** additional disabilities or health problems; **75%** have **two or more**; **50%** have **three or more**.
- For children with complex needs, hearing and vision loss may not yet be recognized or addressed.
- Classifications other than deafblindness are often listed as a child's primary diagnosis on the Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP).

Project Reach: IL DeafBlind Project

- An IDEA funded project. Illinois State Board of Education contracts with Philip J. Rock Center and School to run the project.
- Provides technical assistance and training to statewide agencies, families, community partners, teachers, and service providers of children and young adults with deafblindness (birth through 21 years of age)
- Part of a network that includes state deafblind projects across the country and the National Center on Deaf-Blindness

Project Reach Services

- Child-specific TA in the home or school
- Statewide and regional presentations, trainings, and conferences
- Technical assistance on specific topics
- Education and awareness of deafblindness
- Family education, support, and connection to other families
- Book, DVD, and DeafBlind 101 Simulation Kit loan

DeafBlind Child Count

- Child Count information (without names or identifying information) is submitted to the US Department of Education
- Assists with funding and planning technical assistance to meet the needs of children
- Any child or youth (ages birth - 21) with a current or suspected combined vision-hearing loss can be referred for services. Eligibility for services is not tied to IEP disability category.

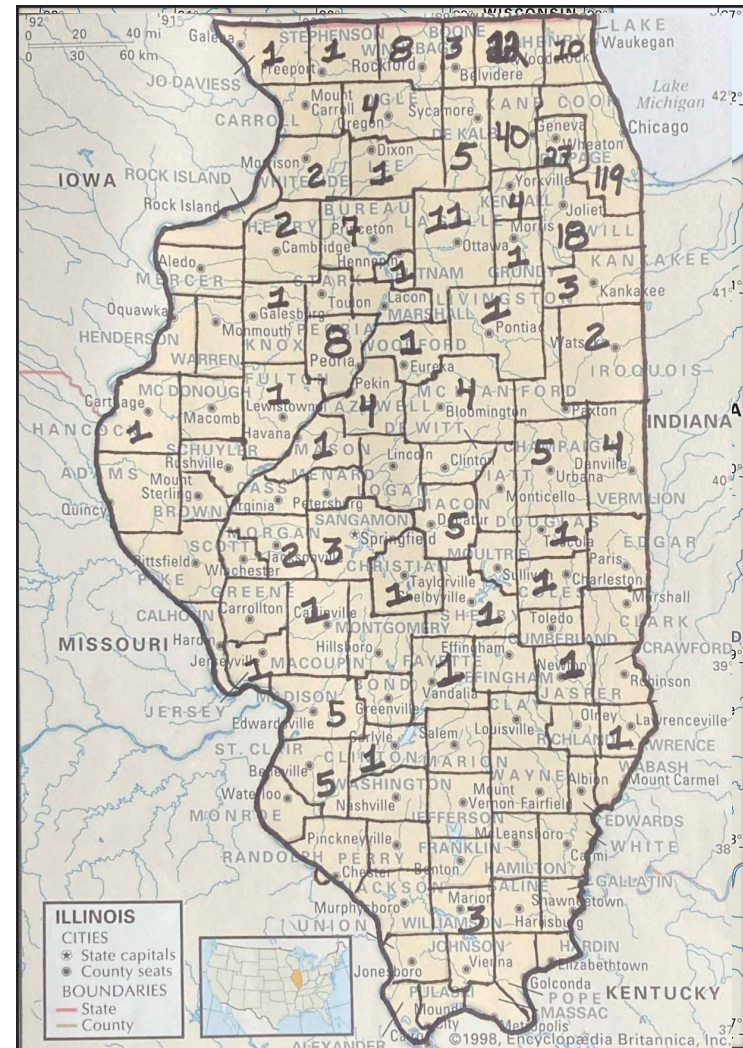
Prevalence of Deafblindness

- Deafblindness is an extremely low incidence disability
- 11,407 children and youth with deafblindness in the United States.¹ Only about **1% experience total deafness and total blindness**. The other 99% have some remaining hearing or vision.
- There are approximately **326** children and youth with deafblindness identified in Illinois²

^{1,2} [2020 National Deaf-Blind Child Count Report \(nationaldb.org\)](https://nationaldb.org/2020-National-Deaf-Blind-Child-Count-Report)

Incidence of Deafblindness

- Children with deaf-blindness are often the **ONLY** one in their school or community with this diagnosis
- Educators and providers have limited, if any, experience working with these children.
- Families are often responsible for educating about deafblindness and their child.



Early Identification and Referral

- It is recommended that children with one diagnosed sensory impairment (hearing or vision) be evaluated in the other area
- Referrals to medical and educational services should be made in a timely manner
- DO NOT “wait and see”

Early Intervention

- The early years are critical, especially in the areas of social-emotional and communication development
- Early intervention services can help families understand their child's sensory impairment and learn how they can support their child's growth and development
- Project Reach provides coaching & TA to families and EI providers

Communication & Connection

Communication is . . .

- Exchanging ideas, thoughts, and feelings
- The way we connect with people
- Often challenging for people with deafblindness

“Not being able to speak is not the same as not having anything to say”

Rosemary Crossley, Australian Educator

Assessment & Planning

- Accurate assessment of communication skills, concept development, and optimal learning modalities is often challenging
- Standardized instruments are not typically appropriate
- A team approach, including the family and education professionals, is optimal

Assessment Resources

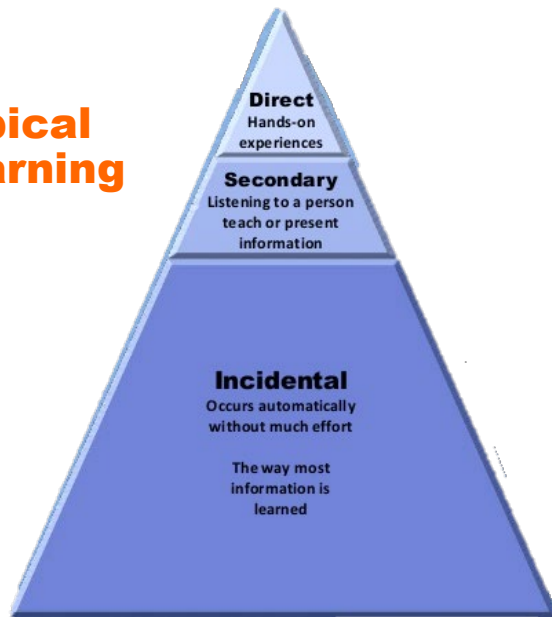
- [Approach to Assessment](#) (NCDB webpage with multiple resources)
- [Assessing Communication and Learning in Young Children Who are DeafBlind or Who Have Multiple Disabilities](#) (free, online)
- [The Communication Matrix](#) (free, online)
- [HomeTalk- A Family Assessment of Children who are Deafblind](#) (free, online)
- [Reach for the Stars, Planning for the Future](#) (purchase from aph.org)

Children who are DeafBlind Learn Differently

Traditional Learners

Learn most information incidentally – just by seeing and listening to what goes on around them

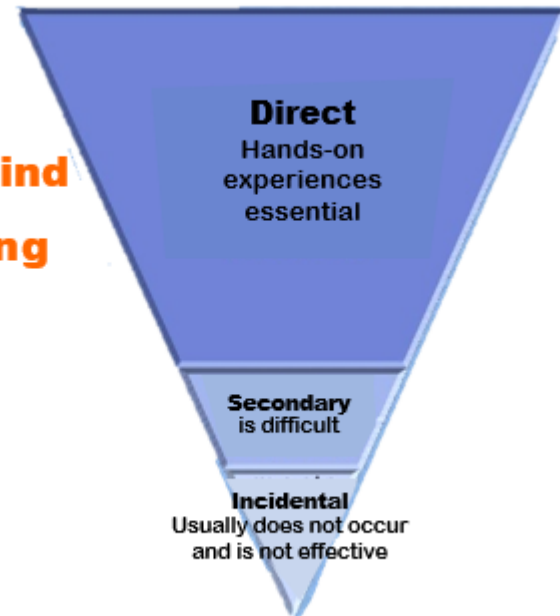
Typical Learning



DeafBlind Learners

Learn by hands-on experience and systematic instruction – this is key for learning. Incidental learning is difficult or does not occur

DeafBlind Learning



Learning Needs of Children Who Are DeafBlind

- Hands-on experiences
- Active movement and exploration of their environment
- Predictable, accessible schedules, consistency
- Use of residual hearing and sight
- High expectations
- Trusting relationships
- Communication, communication, communication

Interveners

- Provide support for social-emotional well-being
- Provide support for development and use of communication
- Provide access to sensory information
- Connect the young learner to the world
- Provide a related educational service in Illinois
(Section 25.560 of Illinois Administrative Code)

Families

- Family-professional partnerships are essential for promoting optimal outcomes for children with deaf-blindness
- Parents should be supported in their role as advocates
- Siblings often experience unique joys and frustrations and may benefit from sibling support programs

Deafblindness & Mental Health

- Limited research
- Sense of Isolation
- Challenges of combined vision/hearing loss can impact emotional and mental well-being¹

¹ [Deafblindness and Mental Health | The Signs of Life](#)

A Few Points to Remember

- Learners who have deafblindness are an incredibly diverse group
- Deafblindness is a disability about information gathering!
- Incidental learning is challenging.
- Purposeful and meaningful activities foster development
- Determining a shared mode of communication is key
- A learner with deafblindness is NOT a "deaf child who cannot see or a "blind child who cannot hear."
Deafblindness is unique and complex disability.

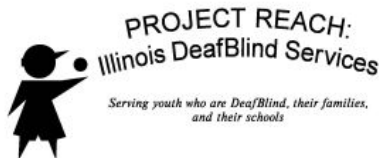
My Contact Information

Faith Rosenshein Young
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www.philiprockcenter.org

[Project Reach: Illinois Deaf-Blind Services | Facebook](#)

The contents of this presentation were developed under a grant from the U.S. Department of Education, #H326T180012. However, those contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Eric Caruso.



**National Center
on Deaf-Blindness**

Mental Health Services

- IL Department of Human Services-
Division of Mental Health
- Statewide Coordinator for Deaf,
Hard of Hearing, DeafBlind, & Late-
Deafened
- My background

My Role

- Provide Information about Mental Health and Access to Services to:
 - Anyone with Hearing Loss
 - Adults and Children
- Hearing Loss includes who?
 - Any Hearing Loss
 - DeafBlind

Contact Information

Jessena Williams, LCSW

Jessena.Williams@illinois.gov

217-786-0023 Voice

217-303-5807 VP

www.dhs.state.il.us/page.aspx?item=30458

Mental Health Services

- In Illinois, mental health services are provided by way of a public system or a private system.
- The type of system is determined by how the provider is paid for these services
 - Public system = Medicaid
 - Private system = private insurance, co-pays, and/or cash pay

Mental Health Services in Illinois

Publicly-Funded System:

Services are billed
through Medicaid

**Private
Practitioners:**
services are billed
through private
insurance and/or
cash pay

Local
Provider(s)
serving your
specific county

Anixter
Center

Advocate

Mt. Sinai

Center on
Deafness

Thresholds

Locate these via:
[http://www.dhs.
state.il.us/page.a
spx?item=27894](http://www.dhs.state.il.us/page.aspx?item=27894)

Mental Health Providers

- There are nearly 200 community providers who provide DMH-funded mental health services statewide.
- Find a provider by using the DHS office locator, and selecting “Mental Health” at the link below

<http://www.dhs.state.il.us/page.aspx?item=27894>

Types of Mental Health Services

- Counseling
- Case Management
- Psychiatric Services
- Supported Employment
- Recovery Services
- Housing
- Crisis

Agencies with Specialized Deaf/DeafBlind Mental Health Services

Advocate (previously known as IL Masonic)

located next to Advocate IL Masonic Hospital

- Outpatient therapy and counseling
- Psychiatry services for medication management

Location and Contact Information

913 West Wellington Avenue , Chicago IL 60657

872-843-0200 Voice-

front desk number

773-904-0126 Video Phone

773-904-0124 Video Phone

Agencies with Specialized Deaf/DeafBlind Mental Health Services

Anixter Center

- Outpatient therapy and counseling
 - Individual and group counseling options

Location and Contact Information

1945 West Wilson St, Chicago IL 60657

773-973-7900 Voice-

front desk number

773-977-4963 Video Phone

LLewis@anixter.org

Agencies with Specialized Deaf/DeafBlind Mental Health Services

Mt. Sinai Psychiatry & Behavioral Health - Chicago

(located next to Mt. Sinai hospital)

- Outpatient therapy and counseling
- Psychiatry services for medication management

Location and Contact Information

2653 West Ogden Ave

Chicago IL 60608

773-257-5300 Voice-front desk

773-321-0094 Video Phone

Agencies with Specialized Deaf/DeafBlind Mental Health Services

Center on Deafness

- Residential placement for adults (age 18 and over)
 - Various locations in Northbrook, IL

Location and Contact Information

2653 West Ogden Ave

Chicago IL 60608

773-257-5300 Voice-front desk

773-321-0094 Video Phone

Agencies with Specialized Deaf/DeafBlind Mental Health Services

Thresholds

- Residential placement for adults (age 18 and over)
 - Kenwood, Logan Square, Bucktown neighborhoods
- Individual Placement and Support (IPS)- Employment Assistance

Location and Contact Information

4101 N Ravenswood Ave

Chicago IL 60613

Deaf Programs Director- Vicki Hall

Voice Phone: 773-537-3341

Video Phone: 773-

Private Providers?

- Contact me to find one in your area
- Private providers can be accessed through an approved request to Medicaid MCO- not always a guaranteed approval
- Call your MCO to request this

Resource- IL Warm Line

FREE Phone Support Available to ANYONE in Illinois

If you or one of you family members has mental health and/or substance use challenges and would like to receive support by phone, call the Illinois Warm Line.

Wellness Support Specialists are professionals who have experienced mental health and/or substance use recovery in their own lives. They are trained in recovery support, mentoring, and advocacy and are ready to listen and support you.

The Warm Line is not a crisis hotline, but is a source of support as you recover or help a family member to recover.

1-866-359-7953

Monday through Friday, 8 am – 8 pm

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