CENTER FOR DEVELOPMENT & DISABILITY

AODD/ OVERVIEW OF DEAFBLINDNESS

A Message from NMPED

"Evidence-based interventions for individuals with deafblindness are not universal. Although these are evidence-based interventions, they should be individualized for a particular student. In the education setting, the IEP team will develop the plan for that student. The IEP team shall review an IEP at least on an annual basis."

Project for New Mexico Children and Youth Who Are Deafblind

DEAF-BLIND NETWORK
TECHNICAL ASSISTANCE ACROSS THE NATION

The contents of this presentation were developed under a grant from the U.S. Department of Education, #H326T180030. However, these contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government.

Overview of Deafblindness

CHILDREN AND YOUTH AGES 0-21

Project for New Mexico Children and Youth Who Are Deafblind

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Outcomes

- You will be able to define deafblindess and identify if an individual is deafblind.
- You will be able to name the most common causes of deafblindness in children and youth ages 0-21.
- You will be able to identify the challenges of being deafblind as a disability and how it impacts learning.
- You will know how deafblindess is tracked in New Mexico and resources for children and youth with deafblindness.

What is Deafblindness?

Definition of Deafblind

Federal definition for students in early childhood special education (3-5) and school aged special education programs (6-21):

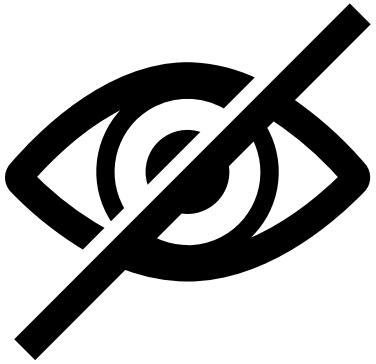
Deafblindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.

For infants and toddlers receiving Part C early intervention services, Deafblindness is defined as:

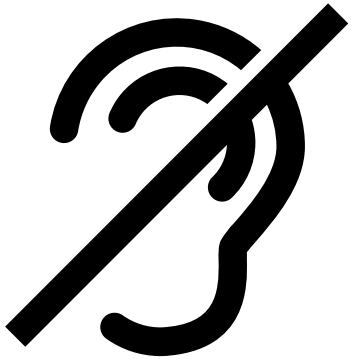
Combined hearing and vision impairments or delays, the combination of which causes such severe communication and other developmental and intervention needs that specialized early intervention services are needed.

Vision Impairment

Normal Vision: Better than 20/70
Low Vision: Vision acuity of 20/70 to 20/200
Legally Blind: Visual Acuity of 20/200 or less
Light Perception Only
Totally Blind
Diagnosed Progressive Loss
Documented Functional Vision Loss



Hearing Impairment



Mild (26-40 dB Loss)
Moderate (41-55 dB Loss)
Severe (71-90 dB Loss)
Profound (91+ dB Loss)
Diagnosed Progressive Loss
Documented Functional Hearing loss

Who is Deafblind?

	Normal Hearing	Hard of Hearing Mild to Moderate	Deaf Severe to Profound	Progressive Loss	Central Auditory Processing Disorder (CAPD)
Normal Vision		Hearing Impaired	Hearing Impaired	Hearing Impaired	Hearing Impaired
Low Vision	Visually Impaired	**Deafblind**	**Deafblind**	**Deafblind**	**Deafblind**
Legally Blind	Visually Impaired	**Deafblind**	**Deafblind**	**Deafblind**	**Deafblind**
Progressive Loss	Visually Impaired	**Deafblind**	**Deafblind**	**Deafblind**	**Deafblind**
Cortical Visual Impairment (CVI)	Visually Impaired	**Deafblind**	**Deafblind**	**Deafblind**	**Deafblind**

*Includes observed or suspected sensory losses

Low Incidence Disability

- Deafblindness is a low incidence disability.
- There are approximately 10,000 children and youth in the United States who have been identified as deafblind.
- In 2021, there were 151 children and youth identified as deafblind in New Mexico.

Other Terms for Deafblindness

Dual Sensory Loss

Dual Sensory Impairment

Multi-Sensory Impairment

Dual Sensory Disability

Combined Vision and Hearing Loss

Acquired Deafblindness

VS

Congenital Deafblindness

Causes of Deafblindness

Causes of Deafblindness

- Hereditary/ Chromosomal Syndromes & Disorders
- Pre-Natal/Congenital Complications
- Post-natal/Non-Congenital Complications
- Prematurity
- No Etiology

Hereditary/Chromosomal Syndromes and Disorders

Aicardi syndrome	Cri du chat syndrome	Kearns-Sayre syndrome	Morquio syndrome	Smith-Lemli-Optiz (SLO) syndrome	Vgot-Koyanagi-Harada syndrome
Alport syndrome	Crigler-Najjar syndrome	Klippel-Feil sequence	NF1 – Neurofibromatosis	Stickler syndrome	Waarrdenburg syndrome
Alstrom syndrome	Crouzon syndrome	Klippel-Trenaunay-Weber syndrome	NF2 – Bilateral Acoustic Neurofibromatosis	Sturge-Weber syndrome	Wildervanck syndrome
Apert syndrome/ Acrocephalosyndactyly, Type1	Dandy Walker syndrome	Kniest Dysplasia	Norrie disease	Treacher Collins syndrome	Wolf-Hirschhorn syndrome
Bardet-Biedl syndrome	Down syndrome	Leber congenital amaurosis	Optico-Cochleo-Dentate Degeneration	Trisomy 13	
Batten Disease	Goldenhar syndrome	Leigh Disease	Pfieffer syndrome	Trisomy 18	
CHARGE Syndrome	Hand-Schuller-Christian	Marfan syndrome	Prader-Willi	Turner syndrome	
Chromosome 18, Ring 18	Hallgren syndrome	Maroteaux-Lany syndrome	Pierre-Robin syndrome	Usher I syndrome	
Cockayne syndrome	Herpes-Zoster	Moebius syndrome	Refsum syndrome	Usher II syndrome	
Cornelia de Lange	Hunter Syndrome (MPS II)	Monosomy 10p	Scheie syndrome (MPS I-S)	Usher III syndrome	

CHARGE Syndrome

An extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. CHARGE syndrome is correlated with genetic mutation to CHD7 and the prevalence of CHARGE syndrome is 1:10,000-1:15,000 live births.

Features of CHARGE syndrome are hearing and vision impairment, low muscle tone, developmental delays, heart defects, kidney abnormalities and growth deficiency.

Charge Syndrome Foundation: https://www.chargesyndrome.org/

Usher Syndrome

Type 1 — Born profoundly deaf and experience progressive vision loss due to retinitis pigmentosa. Vision loss is typically noticed before the age of 10 and continues through adulthood.

Type 2 — Born hard of hearing and gradually lose vision due to retinitis pigmentosa. Vision loss manifests in teen years and progresses throughout life.

Type 3 — Typically born with normal to near-normal hearing. Hearing loss begins during late childhood or adolescence and progresses to profound hear loss. Born with retinitis pigmentosa that manifests in later childhood or early adolescents.

Usher Syndrome Coalition: https://www.usher-syndrome.org/

Down Syndrome (Trisomy 21 Syndrome)

Down syndrome is the most common chromosomal condition in the United States. It occurs in one of every 700 babies born.

Down syndrome has multiple features such as narrow ear canals, congenital heart disease, mild to moderate intellectual disability and low muscle tone. Individuals with Down Syndrome are more likely to have difficulties with eyesight as well as hearing impairments.

National Down Syndrome Society: https://ndss.org/about

Pre-Natal/Congenital Complications

- Congenital Cytomegalovirus (CMV)
- Hydrocephalus
- Microcephaly
- Maternal Drug Use
- Fetal Alcohol Syndrome

Post-Natal/Non-Congenital Complications

- Infection
- Trauma
- Asphyxia
- Stroke
- Severe Head Injury
- Tumors

Complications of Prematurity

1 in 10 babies is born premature

Complications:

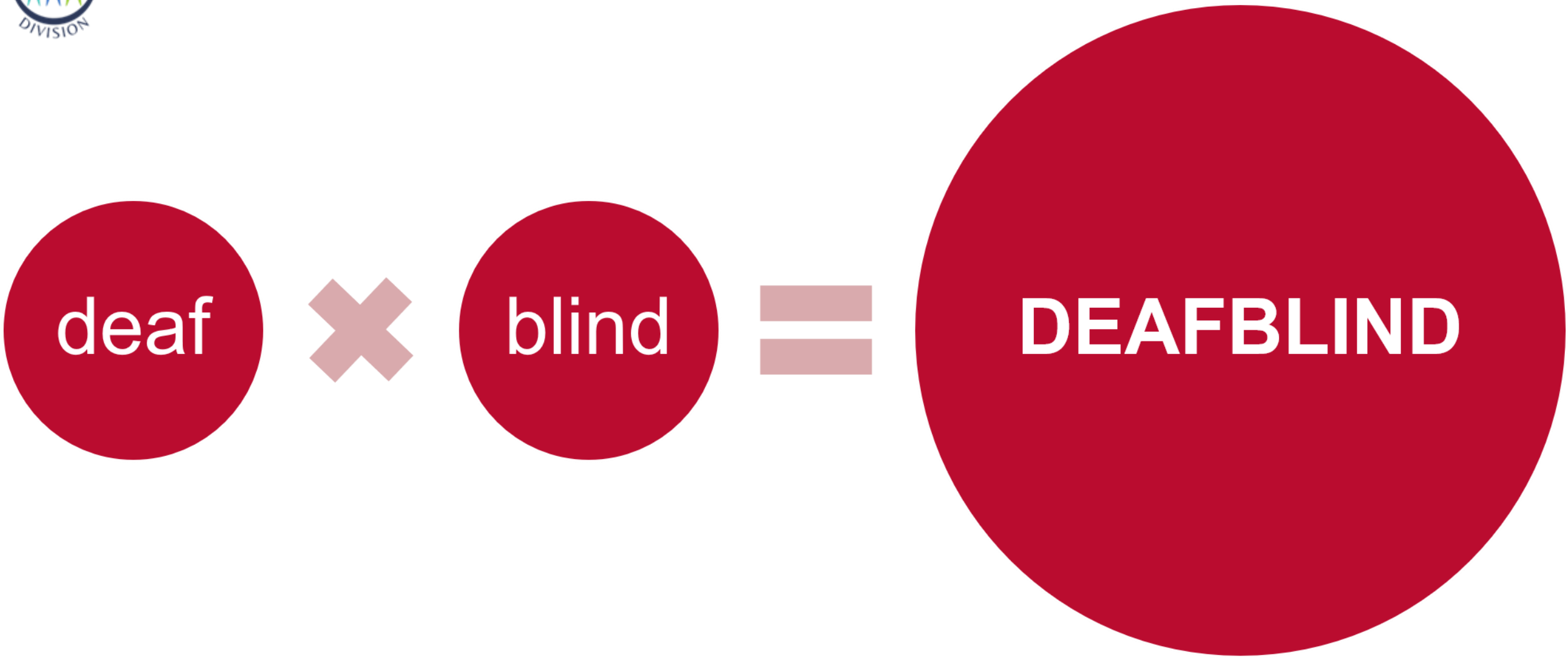
- Breathing problems
- Retinopathy of Prematurity
- Infections or Neonatal Sepsis
- Chronic Lung Disease
- Higher risk of losing some hearing
- Brain bleeds

How is Deafblindness Identified?

Newborns	Hearing is before leaving the hospital after baby is born. Vision should be checked by age 6 months. If there are risk factors, vision will be screened and monitored.
Ages 0-3	Hearing and vision screenings should be completed at well child check-up with the pediatrician and by early intervention agencies.
School Aged	Hearing and vision is screened as part of the process to be tested for special education in public schools. Child's hearing will be screened at the well child check-up with the pediatrician.

CDC Guidelines: https://www.cdc.gov/

Challenges of Deafblindness


deaf
blind
DEAFBLIND

Challenges of Deafblindness

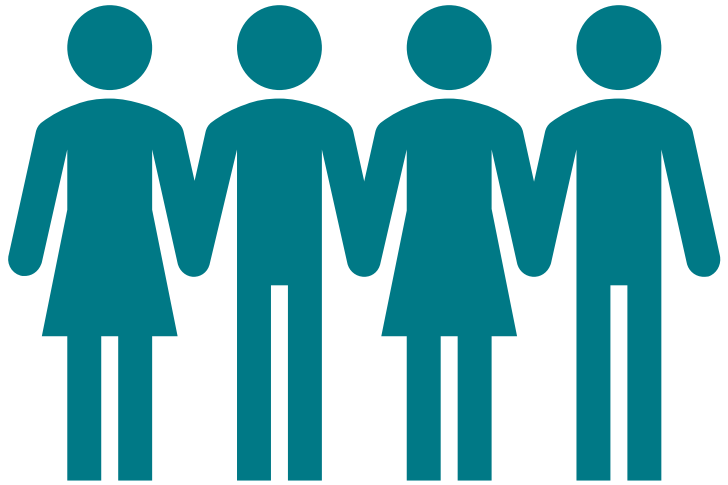
Challenges of Deafblindness

Deaf-blindness impacts all areas of development including social relationships, communication, learning and movement.

Developmental abilities are also impacted by the age the deaf-blindness began, type and degree of loss, and the presence of additional disabilities.

Communication

- Unique modes of communication
- Emerging communication
- Conversations may look different
- Limited opportunities
- Communication may be missed



Isolation

- Light and noise can make communication difficult
- Access to peers can be impacted
- May become withdrawn

Differences in Learning

Incidental Learning:

Learning that occurs by observing our environment, people and activities.

Direct Instruction:

Individuals with deafblindness need direct teaching to learn about their environment, gain information, and to understand concepts.

Concept Development

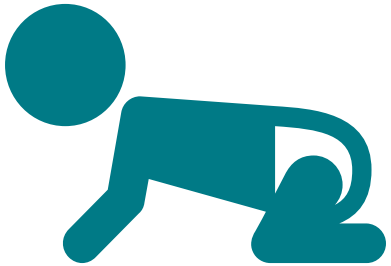
- Direct instruction
- Object permanence
- Characteristics, function, names
- Foster curiosity

Life May Feel Unexpected and Random

- May not have access to cues
- May not understand concepts of a routine
- People may not give an individual who is deafblind needed information

Orientation and Mobility

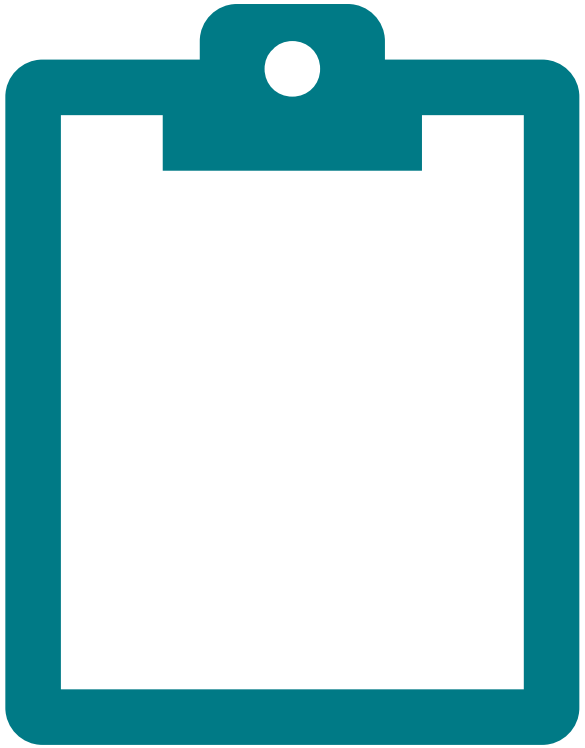
- Delay in motor skills in early childhood
- New environments might be challenging
- May not have the skills to navigate safely
- May not have tools to explore an environment
- May struggle with changes to a familiar environment



Lack of Training

- Educational teams may not have deafblind training
- Parents and family may not understand the impact of deafblindness
- Peers may not understand deafblindness

Identification



- Multiple disabilities
- Intellectual disabilities
- Health problems
- Autism
- Diagnosis overlooked

Let's Review…

- Deafblindness in the combination of a hearing impairment or blindness and a vision impairment or deafness. Most individuals with deafblindness have some hearing and some vision.
- Identifying the cause of deafblindness is important. Some genetic or health conditions may have progressive vision or progressive hearing loss.
- Deafblindness impacts all areas of development.

Let's Review…

- There can be many challenges for individuals with deafblindness. If challenges are not addressed, it can contribute to isolation, dependence on others to navigate a space, a chaotic life, difficulty forming concepts and impacted communication abilities.

- Early identification is important for parents, caregivers and educational teams to ensure that evidence-based interventions are used to give the child access to their environment, peers and learning opportunities.

Project for New Mexico Children and Youth Who Are Deafblind

Project for New Mexico Children and Youth Who Are Deafblind

Deafblindness has its own unique challenges.
It is important that anyone working with an individual with deafblindness have training to understand this rare disability.

Project for New Mexico Children and Youth Who Are Deafblind

Technical assistance (TA) and training — For families, service providers and educators of children and youth who are deaf-blind. Provided through distance technology, in-home, classroom, telephone or email consultation. 3 levels of TA available: Universal, Specialized and Intensive.

Annual trainings/workshops —To increase our state's capacity to meet the unique needs of children and youth who are deaf-blind. Trainings are usually at no, or low cost, to participants.

Project for New Mexico Children and Youth Who Are Deafblind

Early childhood and school-aged transition support and consultation

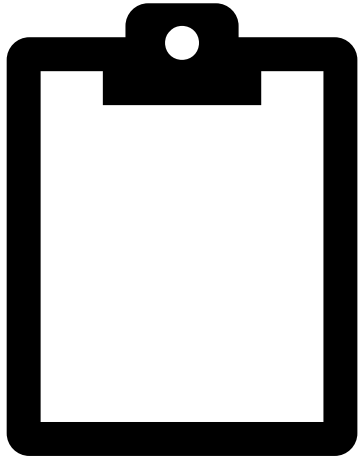
Resource dissemination — On various topics in the field of deaf-blindness including distance-education and online learning opportunities.

Involvement — Local, state and national initiatives and committees to advance the understanding of the needs of children/youth with deaf-blindness.

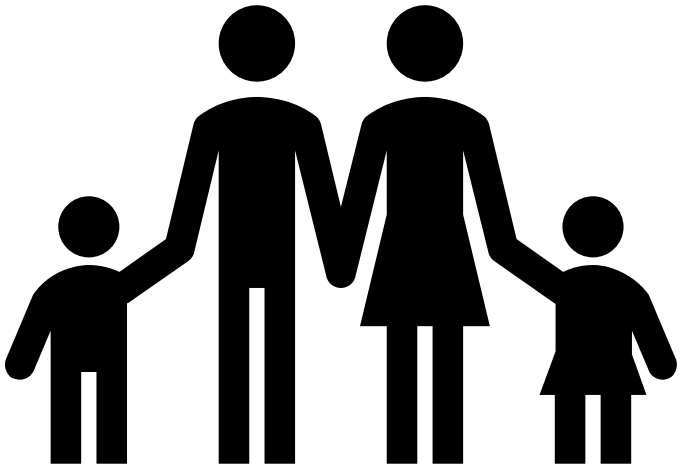
Project for New Mexico Children and Youth Who Are Deafblind

The National Child Count of Children and Youth who are Deaf-Blind provides extensive information on the population of children identified with deaf-blindness in the U.S, aged birth through 21. Data includes state and national information on:

- Population demographics (age, ethnicity, gender)
- Type and severity of vision and hearing loss
- Causes of deaf-blindness
- Presence of additional disabilities
- Educational setting
- Living setting



Project for New Mexico Children and Youth Who Are Deafblind

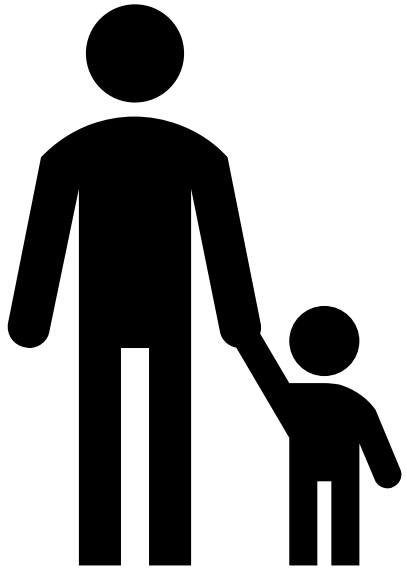


If you know an individual who is deafblind, please reach out to the project to ensure they have access to the resources provided and their information can be included in the annual census.

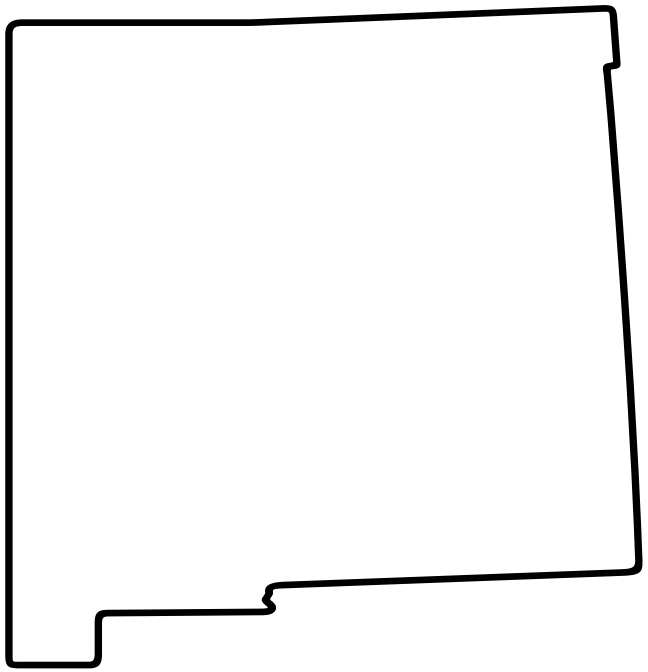
Who Can Refer?

Anyone who knows or works with a child with deaf-blindness, including:

- Families
- Teachers
- Early childhood staff
- Physicians
- Nurses/discharge planners
- Physical/occupational and speech therapists
- Social workers/case managers

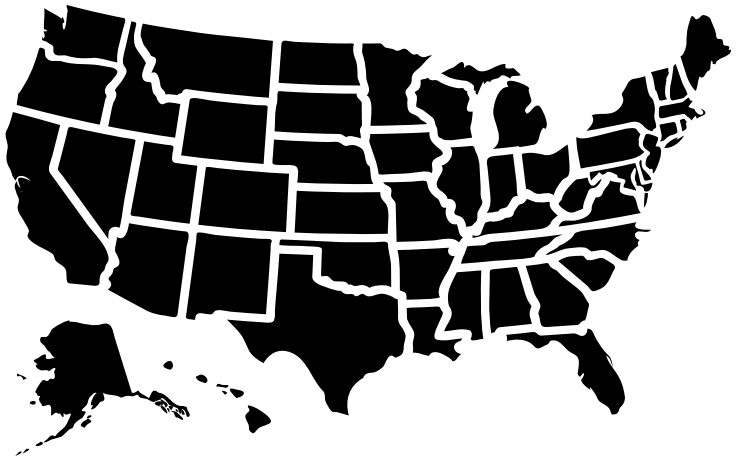


New Mexico Resources



- UNM Project for NM Children and Youth Who Are Deaf-Blind
- NM School for the Blind and Visually Impaired
- NM School for the Deaf
- NM Community Outreach Services for the Deaf/Deaf-Blind
- Hands and Voices
- Parents Reaching Out (PRO)
- NM Commission for the Deaf & Hard of Hearing
- NM Commission for the Blind
- NM Technology Assistance Program (NMTAP)
- NM FINDER

National Resources



- National Center on Deaf-Blindness
- Helen Keller National Center
- Perkins School for the Blind
- National Deaf-Blind Equipment Distribution Program
- National Family Association for Deaf-Blind
- The Paraprofessional Resource and Research Center
- Paths to Literacy
- National Organization for Rare Diseases
- Usher Syndrome Coalition
- National Intervener and Advocate Association
- Design to Learn

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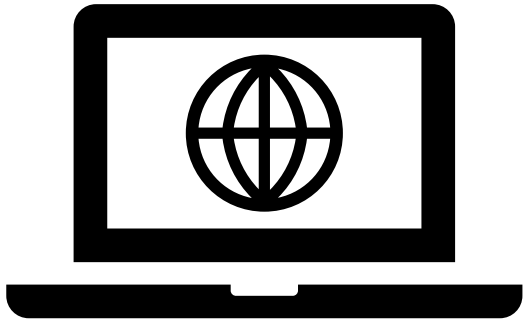
Want More Info?



Project for New Mexico Children and Youth Who Are Deafblind:

https://unmhealth.org/services/development-disabilities/programs/other-disability-programs/deaf-blind.html

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