

## Overview of Deafblindness

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### *Slide 1*

This training is brought to you by the UNM Center for Development and Disability and the New Mexico Public Education Department. My name is Airth McCourt, I am the education consultant for the project for New Mexico children and youth who are Deafblind.

### *Slide 2*

Here is a message from New Mexico Public Education Department:  
“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.”

### *Slide 3*

Project for New Mexico Children and Youth Who Are Deafblind is funded by the Office of Special Education Programs and the New Mexico Public Education Department. Information in this presentation was provided by the deafblind network.

### *Slide 4*

The topic for this training is an *Overview of Deafblindness, Children and Youth Ages 0-21*. This training is beneficial for parents and caregivers of children who are deafblind, educators and early intervention providers, therapists, or anyone who works with an infant, child or youth who is deafblind.

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If you have any questions or would like information or training on deafblindness, please contact the project for New Mexico children and youth who are deafblind. Contact information will be shared again at the end of the training.

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After this training, you will be able to define deafblindness 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 deafblindness is tracked in New Mexico, as well as identify resources for children and youth with deafblindness

### *Slide 7*

In this section, we will cover the definition of deafblindness and how to identify if an individual is deafblind.

### *Slide 8*

How do we define deafblindness? The federal definition of deafblindness is concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that cannot be accommodated in special education programs solely for children with deafness or children with blindness. This definition refers to students in early childhood special education ages 3-5 and school aged children ages 6-21.

For infants and toddlers receiving Early Intervention services ages 0-2, 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. To better understand deafblindness, it is important to have a basic understanding on how visual impairments and hearing impairments are categorized.

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A vision impairment is categorized in many different ways. Visual acuity refers to the ability of the eye to distinguish details of an object at a given distance. Normal vision is typically 20/20 and refers to an individual who see an object clearly that is 20 feet away. Low vision refers visual acuity of 20/70 to 20/200. 20/200 visual acuity means that someone would need to be at least 20 feet from an object to identify it compared to someone with normal vision, who can see it from 200 feet. Legal blindness refers to visual acuity of 20/200 or less, or a field restriction of 20 degrees. Some individuals with vision impairment may have light perception only. If someone is totally blind, they will have no light perception. An individual can be diagnosed as having progressive loss of vision. The last category of vision impairment is functional vision loss, in which the hearing mechanism in the ear function normally, but the brain isn't processing the visual

information effectively. Functional vision loss may refer to a child with a diagnosis Cortical Visual Impairment, commonly known as CVI, in which they may have normal visual function and may even have 20/20 vision, but the brain may have trouble processing and understanding the information.

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Hearing impairment is often measured through decibels, which is a sound's intensity. A person with mild hearing loss may not be able to hear a whisper or the humming of the refrigerator. An individual with moderate hearing impairment at 41-55 decibels may not be able to hear rainfall outside or a conversation. Someone with severe hearing impairment at 71-90 decibels may not hear traffic or a large truck drive by. At profound hearing impairment, which is more than 90 decibels, an individual may not hear a helicopter or a trombone playing. An individual may be diagnosed as having progressive hearing loss, which can occur over a few years or over a lifetime.

Functional hearing loss refers to hearing impairment in which the ear is functioning normally, but there continues to be a hearing impairment. An example of functional hearing loss is Central Auditory Processing Disorder, in which the brain has deficits in the ways it processes auditory information. Hearing impairment can also be related to the frequency of the sound. Individuals with this type of loss may not be able to hear high pitched sounds, which can impact the ability to hear certain sounds in words or voices. Extended exposure to loud sounds can cause hearing loss related to frequency.

### *Slide 11*

So how do you know if an individual is deafblind? Deafblindness refers to any combination of hearing and visual impairment. Someone who is deafblind may have CVI and severe deafness. Another individual with deafblindness may have progressive hearing loss and be legally blind. Deafblindness refers to individuals with *varying* degrees of vision and hearing impairments. Most individuals who are deafblind have some vision and some hearing.

### *Slide 12*

Vision impairments and hearing impairments are both considered a low incidence disability. Deafblindness is also a low-incidence disability, but it is significantly less common. There are approximately 10,000 children and

youth in the United States who have been identified as deafblind. In New Mexico, there are approximately 150 children and youth with deafblindness.

### *Slide 13*

Deafblind is a commonly used term to describe individuals with combined vision and hearing impairments, but there are many terms currently being used to describe this disability. Someone who is deafblind may be described as having Dual Sensory Loss, Dual Sensory Impairment, Multi-Sensory Impairment, Dual Sensory Disability, or Combined Vision and Hearing Loss. These terms are used interchangeably.

### *Slide 14*

There are two types of deafblindness. Acquired deafblindness refers to individuals who become deafblind after they born, typically referring to someone who becomes deafblind after they have acquired language. This can occur from illness, a trauma, or a progressive hearing or vision loss. Some individuals may be born deaf, and then later lose vision and acquire deafblindness.

Congenital deafblindness occurs when an infant is identified as deafblind under the age of two. It is not always immediately apparent that a child is deafblind at birth. Deafblindness can be caused by infections during the pregnancy, premature birth, birth trauma, or a rare genetic condition.

### *Slide 15:*

In this section, we will cover the many causes of deafblindness. The focus of this training will cover the causes specific to individuals ages 0-21.

### *Slide 16*

Causes of deafblindness are categorized in five different ways, Hereditary/ Chromosomal Syndromes & Disorders, Pre-Natal/Congenital Complications, Post-natal/ Non-Congenital Complications, Prematurity, No Etiology. For some individuals, it can take years to receive a diagnosis that would identify the cause of deafblindness. When the cause is not determined, it is considered “no etiology.”

### *Slide 17*

There are many hereditary or chromosomal syndromes and disorders that are associated with deafblindness. Having one of these diagnoses doesn't automatically mean the person is deafblind, but hearing and vision

impairments are common with the condition. We will review some of the more common diagnoses associated with deafblindness in the next slides.

### *Slide 18*

CHARGE syndrome is the leading cause of deafblindness in individuals ages 0-21. CHARGE syndrome is an extremely complex syndrome involving extensive medical and physical difficulties that differ from child to child. CHARGE syndrome is correlated with the genetic mutation to CHD7. 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. One of the hidden features of CHARGE syndrome is the determination and strong character these children display. You can find more information on CHARGE syndrome at the Charge syndrome foundation website.

### *Slide 19*

Another syndrome associated with deafblindness is Usher syndrome. Usher syndrome impacts both hearing and vision. Genetic testing is used to identify which type of Ushers syndrome an individual has to determine what their vision and hearing outcome is. Individuals with Type 1 are Born profoundly deaf and experience progressive vision loss due to retinitis pigmentosa. Retinitis pigmentosa is a disease of the retina cells in the eye and affect light sensitivity. Retinitis pigmentosa can result in night blindness and tunnel vision. Type 1 vision loss is typically noticed before the age of 10 and continues through adulthood. Individuals with Type 2 are born hard of hearing and gradually lose vision due to retinitis pigmentosa. Vision loss manifests in teen years and progresses throughout life. Individuals with Type 3 are typically born with normal to near-normal hearing. Hearing loss begins during late childhood or adolescence and progresses to profound hear loss. They are born with retinitis pigmentosa, which progressively affects vision in the late teens or early adult years. You can find more information on Usher syndrome at the Usher Syndrome Coalition foundation website.

### *Slide 20*

Trisomy 21 Syndrome, commonly known as down syndrome, is also associated with deafblindness. Down syndrome is the most common chromosomal condition in the United States. It occurs in 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. 60-80% of individuals with down syndrome have hearing aids and up to half will need to wear glasses. You can find more information on the National Down Syndrome Society website.

#### *Slide 21*

Prenatal or congenital complications are also a cause of deafblindness. Some Examples are congenital cytomegalovirus, hydrocephalus, microcephaly, maternal drug use and fetal alcohol syndrome.

#### *Slide 22*

Post-natal and non-congenital complications can cause deafblindness. Some examples are infection, trauma, asphyxia, stroke, severe head injury and tumors.

#### *Slide 23*

There can be many complications when a baby is born prematurely. 1 in 10 babies is born premature. Preterm refers to child born before 37 weeks gestation. The earlier in the pregnancy a baby is born, the more likely they are to have health problems. Some complications are Breathing problems, Retinopathy of Prematurity, Infections or Neonatal Sepsis, Chronic Lung Disease, Higher risk of losing some hearing, and Brain bleeds. Very premature infants are at high risk for hearing loss and vision loss.

#### *Slide 24*

In New Mexico, hearing and vision screenings are recommended throughout a child's life through the pediatrician, schools or early intervention providers.

Newborns are screened for hearing impairments using an OAE before leaving the hospital. When a baby is born early and is at risk for developing retinopathy of prematurity, they will have their vision screened. If a child is receiving early intervention services, which occurs at ages 0-2, they will have their hearing and vision screened annually. When children enter special education programs, vision and hearing is screened as a part of the IEP process. If there are no concerns identified, no further screening occurs after the initial assessment to qualify for services.

It is important that parents and caregivers of children who get a referral due to a hearing screening...follow-up with an audiologist to determine if a child has a hearing impairment. Even mild hearing impairments can impact communication at a young age. Parents and caregivers also need to follow up on referrals due to vision screenings with their pediatric ophthalmologist.

Parents and caregivers should discuss family history or risk factors for hearing and vision impairment with their pediatrician to determine if hearing screenings need to be completed more often. Children with multiple disabilities are at a higher risk of having hearing or vision impairments. When combined hearing and vision impairments are identified, that individual now meets the definition of having deafblindness.

### *Slide 25*

In this section, you will learn about the challenges that individuals ages 0-21 with deafblindness face.

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Because of the combined hearing and visual impairments, the dual sensory loss has an exponential impact. Deafblindness is not Deaf plus blind, it is deaf times blind. Typical learners gather information primarily through senses of hearing and vision. It is estimated that more than 80% of learning happens through vision. Individuals with visual impairment or blindness can use hearing to help compensate for loss of vision. Individuals who are D/HH can use sight to help compensate for hearing impairment. When someone is deafblind, they may have some hearing or some vision, but it may be limited or not a reliable source of information. Individuals may have to rely on senses such as touch to get consistent information.

### *Slide 27*

Deafblindness is a disability of access. Access to visual and auditory information about people and things in the environment necessary for learning, communication, and development.

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Because deafblindness is a disability of access, all areas of development are impacted including social relationships, communication, learning and movement. Developmental abilities are also impacted by the age the deafblindness began, type and degree of loss, and the presence of additional

disabilities. For example, someone who had vision prior to becoming blind may have a lot easier time understanding concepts because they understand the information available visually in the environment. There are many challenges that individuals with deafblindness may face at home and in the community.

### *Slide 29*

Communication is a commonly impacted area for individuals with deafblindness. When both vision and hearing is impaired, a child may have delays in speech or delays in signing. An individual with deafblindness may have Unique modes of communication. Communication may be a combination of gestures, reactions, using objects or pictures, or behavior. A child with emerging communication skills might have a conversation by exploring toys together or taking turns playing with an object. Individuals with deafblindness may also use sign language, tactile communication, braille, fingerspelling, and other modes of communication that may be a barrier to those who do not use this form.

### *Slide 30*

Because deafblindness impacts communication, individuals can become isolated. When being in certain environments, light and noise may impact how much someone with deafblindness understand what is being shared with them, whether it is visual or auditory. Peers may not understand the challenges, for example if a friend can hear them well when it is in a quiet room, but during a PE class when it is loud and echoes in the gym, that friend can no longer hear them. Individuals with deafblindness can often be withdrawn when they do not have input from peers or from adults.

### *Slide 31*

Deafblindness greatly impacts incidental learning. Incidental learning occurs by observing the environment, people and activities. When vision and hearing is not a reliable source of information, direct instruction is very important in learning about concepts. Individuals with deafblindness need direct teaching to learn about their environment, gain information, and to understand concepts. They may also need more time and repetition to learn a concept or skill.

### *Slide 32*

Concepts are directly taught, such as object permanence. Individuals with deafblindness may not know to look for an item when it is no longer in



reach. Characteristics are directly taught such as the function of an item and the name of the item. Individuals with deafblindness may need to be taught routines directly, for example if they spilled milk, they may not know that you need to clean it up after. If they do not have the information to know that you wipe up the spilled milk, it would likely be left spilled. Fostering curiosity is important when teaching individuals with deafblindness so that they feel comfortable exploring things using their strengths and abilities.

### *Slide 33*

Another challenge that impacts individuals with deafblindness is how life may feel unexpected and random. Information may be missed that cues for upcoming transitions. For example, a teacher may flick lights on and off to signal it is time to clean up and tell the class that they will go outside after clean up. An individual with deafblindness may miss these cues and not know what is coming up next. An individual with deafblindness may not understand why a routine is occurring. For example, why do we put clothes in a basket? Concepts such as clean and dirty laundry may need to be directly taught to make sense of the routine. Sometimes individuals with deafblindness just aren't given the information for the daily schedule or upcoming transition. It might be confusing when the child suddenly isn't going to school anymore during spring break.

### *Slide 34*

Infants and toddlers with deafblindness may have moderate to significant motor delays. For example, rolling over, crawling and walking may occur much later than typical peers. For individuals with deafblindness, new environments may be challenging. Starting a new classroom or going to an unfamiliar playground may be difficult. Individuals with deafblindness may not know how to navigate new spaces safely. Orientation and mobility specialist work with students with vision impairments to navigate their environment using sounds, landmarks and cane techniques. Some students may not have the tools to navigate a new or familiar space. It can take time to identify what works best for a child, especially when working with young children. Individuals with deafblindness may struggle with changes in a familiar environment. Classrooms get rearranged, home environments get rearranged, outdoor spaces may get rearranged. With

these changes, the individual with deafblindness need to relearn the space to navigate it effectively.

### *Slide 35*

Remember how we talked about how deafblindness is low incidence? That can directly impact a student whose teachers, therapists or paraprofessionals may not have experience with deafblindness or training in deafblindness. Typically, training is focused on hearing impairments or vision impairment. When a student has both impairments, they require unique interventions that are specific to deafblindness. And just like educational teams may be new to deafblindness, parents, caregivers and family of a child who is deafblind may have to learn strategies to support the child with deafblindness. It is important to teach children or peers in ways to interact with a child that is deafblind. Young children who want to play with their sibling with deafblindness may need support to learn to use touch instead of vocal requests to get the child's attention before playing together.

### *Slide 36*

It is common for individuals with deafblindness to also have multiple disabilities and health problems. Many behaviors associated with deafblindness can be missed or attributed to other factors. Individuals with deafblindness may not respond to their name, or use eye contact consistently. They may exhibit self-stimulatory behaviors, such rocking or head shaking. They may not engage in activities and may fatigue quickly. Many of these behaviors could be misattributed to diagnoses and disabilities that the individual already has.

A child may be identified as having a hearing impairment and a vision impairment, but not be labelled as deafblind and therefore not provided with specific evidence-based interventions that could benefit them. When there is early identification of deafblindness, adaptations and interventions can be implemented to ensure that the individuals' strengths and abilities are fully utilized in the home and in the classroom.

### *Slide 37*

Let's review what you have learned so far. Deafblindness is the combination of a hearing impairment and a vision impairment. Most individuals with deafblindness have some hearing and some vision. Identifying the cause of deafblindness is important, some genetic or health

conditions may cause progressive vision loss or progressive hearing loss. Deafblindness impacts all areas of development.

### *Slide 38*

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. In order to make certain that individuals with deafblindness receive support from qualified personnel, the first step is to identify the state deafblind project for resources and training opportunities.

### *Slide 39*

In New Mexico, that project is The Project for New Mexico Children and Youth Who Are Deafblind. This project provides technical assistance for families, service providers and educators of children and youth who are deafblind. Please contact the project if you are interested in resources, trainings, or support for an individual with deafblindness.

### *Slide 40*

Deafblindness has such unique challenges, it is important that anyone working with an individual with deafblindness in New Mexico have training to understand this rare disability. It is important to utilize the individual's strengths and abilities to create an individualized learning program. In New Mexico, there are approximately one hundred and fifty individuals identified as deafblind from the ages of 0-21. These individuals may have early intervention providers, speech and language pathologists, physical therapists, special education teachers, occupational therapist, O&M Specialists, counselors and paraprofessionals. There are free trainings and resources available to ensure that therapists and educators have the appropriate training to support individuals with deafblindness.

### *Slide 41*

The Project for New Mexico Children and Youth Who Are Deafblind provides technical assistance and training for families, service providers and educators of children and youth who are deafblind. It is provided through distance technology, in-home, classroom, telephone or email consultation. The project provides annual trainings/workshops to increase

our state's capacity to meet the unique needs of children and youth who are deaf-blind, training can be requested to support staff and parents. Trainings are usually at no, or low cost, to participants.

#### *Slide 42*

The project can also participate in early childhood and school-aged transition support and consultation. The project disseminates resources on various topics in the field of deafblindness including distance-education, and online learning opportunities. The project is also involved in local, state and national initiatives and committees to advance the understanding of the needs of children/youth with deafblindness.

#### *Slide 43*

The Project for New Mexico Children and Youth Who Are Deafblind also completes the National Child Count of Children and Youth Who Are Deaf-Blind. This census provides extensive information on the population of children identified with deaf-blindness in the U.S, ages birth through 21. Data includes state and national information on population demographics, type and severity of vision and hearing loss, causes of deafblindness, presence of additional disabilities, educational setting and living setting.

Accurate census reporting ensures that our state receives the appropriate funding to meet the specialized needs of the service providers, educators and families of children with deafblindness.

#### *Slide 44*

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.

#### *Slide 45*

Anyone who knows or works with a child with deaf-blindness can refer someone to the project. Often, referrals come from families, teachers, early childhood staff, physicians, nurses and discharge planners, physical therapists, occupational therapists, and speech therapists, social workers and case managers.

#### *Slide 46*

There are many resources available to support individuals with deafblindness such as The Project for New Mexico Children and Youth

Who Are Deaf-Blind, New Mexico School for the Blind and Visually Impaired, New Mexico School for the Deaf, New Mexico Community Outreach Services for the Deaf and Deaf-Blind, Hands and Voices, Parents Reaching Out (PRO), New Mexico Commission for the Deaf & Hard of Hearing, New Mexico Commission for the Blind and the New Mexico Technology Assistance Program.

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There are also national resources to support individuals with deafblindness such as 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 and Design to Learn.

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For information or support for deafblindness, please visit the project for New Mexico Children and Youth Who are Deafblind website.

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To contact the Project for New Mexico Children and Youth Who Are Deafblind, please call 505-272-0321 or toll free 877-614-4051. Or you can send an email to [hsc-NMDB@salud.unm.edu](mailto:hsc-NMDB@salud.unm.edu). The UNM Center for Development and Disability has many resources available through the CDD Library and the CDD Information Network.