

Early Identification of Children with Deaf-Blindness

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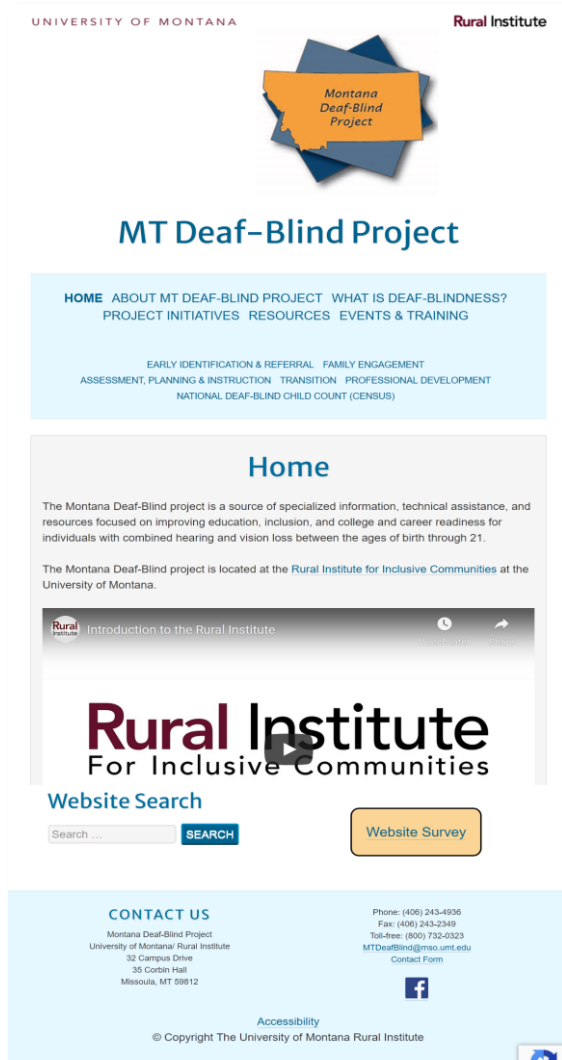
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MTDeafBlind.ruralinstitute.umt.edu



Website Content Areas:

- About the Project
- What is Deaf-Blindness
- Project Initiatives
- Resources
- Events & Trainings
- Early Identification & Referral
- Family Engagement
- Assessment, Planning & Instruction
- Transition
- Professional Development
- National Deaf-Blind Child Count (Census)

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Early Identification of Children with Deaf-Blindness

Susan M. Bashinski

February 3, 2022

**For the Montana Deaf-Blind Project
Rural Institute, University of Montana**

Agenda

- Criticality of early identification—and rationale
- Impact of combined vision and hearing losses on early development & environmental accessibility
- Risk factors associated with certain disability conditions
- Early signs of possible dual sensory loss—what is “typical” to expect?
- Authentic assessment
- Ten areas in which to focus observational assessment
- Formal assessment instruments / procedures
- Review of some key resources

Action Plan

Please record your thoughts, regarding how you *might* incorporate information from today's webinar in your family life / daily practice.

Thank you!

Launch poll #1 – Who is here today?

Remember!

A child with deaf-blindness is **NOT**

- a “deaf child” who cannot see or
- a “blind child” who cannot hear

**Deaf-blindness is a unique
and complex disability!**

Criticality of Early Identification

- Experiences “during the earliest years of life have a profound influence on a child's ability to learn, move, and interact with others”
- This is especially true for young children who experience deaf-blindness because “physical, communication, cognitive, social, and emotional developmental domains are deeply intertwined” (NCDB, 2019)
- Deaf-blindness is especially impactful because of the ways in which these limit accessibility to the environment

Criticality of Early Identification

- In a young child with deaf-blindness, two of her three distance senses (i.e., vision and hearing) are impacted. This means the child must use her contact senses (e.g., taste and touch) to learn about the world!
- Early identification is positively correlated with a reduction in the negative impacts of combined sensory loss on future development, because when combined with early intervention, gathering environmental information can be enhanced.
- **Learning is all about information gathering!**

Identification Statistics

- Ideally, young children who experience deaf-blindness will be identified and referred for support services as early as possible
- For several recent years, approximately only 6.0% of the children on the National DeafBlind Child Count have been ages birth through 2 years of age (NCDB, 2019)
- Approximately 20% of these infants and toddlers are identified as “at risk” and nearly all receive some sort of home-based services

Identification Statistics

- What about Montana?
- During the year 2019, Montana provided support services to 43 individuals, Birth – 21 years of age, and reported an official count of 37 total
- How many of these were young children between the ages of Birth – 2 years?
(launch Poll #2)

Early Development – What's Reasonable to Expect?

Vision

Birth – 1 mo.	1 – 3 mos.	3 – 5 mos.	5 – 7 mos.
<ul style="list-style-type: none"> • Stares at bright sun / walls • Blinks when light is too bright • <u>Briefly</u> looks at person's face OR object in field of vision • Seems to focus best on objects 8-12 inches from face 	<ul style="list-style-type: none"> • Stares at objects within field of vision • Eye contact increases • Begins to shift gaze b/twn objs • Shows some visual tracking and scanning • Focuses best on objects 3" – 5" 	<ul style="list-style-type: none"> • Most objects w/in reach are looked at & put in mouth • Looks for care-giver in a group • Watches objects drop • Reverses direction • Fixates on objects at 3' • Focuses on objects 5" – 20" 	<ul style="list-style-type: none"> • Binocular eye movements well-coordinated • Visually discriminates strangers (w/ emo) • Looks at & responds to variety of facial expressions • Looks in mirror and may respond

Early Development – What's Reasonable to Expect?

Hearing

Birth – 3 mos.	3 – 6 mos.	6 – 12 mos.	12 – 24 mos.
<ul style="list-style-type: none">• Startles or “jumps” when a sudden sound occurs• Awakens or cries when loud noise or talking• Shows recognition and / or comfort by a familiar voice	<ul style="list-style-type: none">• Turns to look for source of an interesting sound• Respond to mother's (or primary care-giver's voice• Turns eyes forward when his / her name is called	<ul style="list-style-type: none">• Turns body toward an interesting sound• Searches when a new sound is present• Demonstrates understanding of common words (e.g., “no,” “bye”)• Experiments with speech & non-speech sounds	<ul style="list-style-type: none">• Speaks one or more “true,” recognizable words• Pairs two words meaningfully together• Demonstrates vocabulary of at least 50 words

Newborn Hearing Screening

- Hearing loss in children is the #1 disability present at birth in the U.S (i.e., AAP estimates that 1 to 3 of every 1,000 babies experiences some degree of hearing loss)
- Ninety-five percent of children are identified at birth, through universal newborn hearing screenings
- A screening takes 5 – 10 minutes
- One to two % of all babies do not pass initial screening
- ID allows fitting with hearing aids early in life or for a family to opt for a cochlear implant

Universal hearing screening is now required by law in ALL 50 US states.

Newborn Hearing Screening

- A universal newborn hearing screening program was established in Montana in 2001
- In 2007, this law was amended to require that all infants must be screened for possible hearing loss within the first month of life (Department of Health is responsible)
- The 2007 amendments require that children referred for further screening receive such screenings and, if necessary, support services within three months of birth
- Protocols, reporting & referral procedures, and audiological assessments are addressed

Newborn Hearing Screening – Method #1

- **Automated Auditory Brainstem Response (AABR)**
- Measures how the hearing nerve and brain respond to sound
- Clicks or tones are played through soft earphones into the baby's ears
- Three electrodes placed on the baby's head measure the hearing nerve and brain's response



Newborn Hearing Screening – Method #2

- **Otoacoustic Emissions (OAE)**
- Measures sound waves produced in the inner ear
- Tiny probe is placed just inside the baby's ear canal
- Probe measures the response (i.e., the echo) when clicks or tones are played into the baby's ears

Launch poll #3



Diagnoses / Conditions Frequently Associated with Dual Sensory Losses

- Extreme prematurity (retinopathy of prematurity)
- CHARGE syndrome
- Cytomegalovirus (CMV)
- Cornelia de Lange syndrome
- "Brain bleed" (intraventricular hemorrhage-IVH)
- Another syndromic condition that many individuals might never have "heard of before"

Some genetic testing might reveal an etiology with which DB is closely associated; the family can, in this case, be more proactive in preparing themselves and setting up supports in advance of the birth.

So....How Do We Find and Identify These Young Children?

CEC's Division for Early Childhood recommends that practitioners:

- work as a team with the family and other professionals to gather assessment information
- support family functioning, promote family confidence and competence, and strengthen family-child relationships by acting in ways that recognize and build on the family's strengths and capacities (i.e., in *knowing their child best!*)

So....How Do We Find and Identify These Young Children?

- Have some knowledge of the milestones for “typical” visual and auditory development
- Review the medical records of a young child who is suspected of possibly experiencing deaf-blindness — *especially results of newborn hearing screening*
- Be generally aware of identifiable syndromes / conditions and other risk factors that are frequently associated with deaf-blindness
- Actively solicit information from family members and key care providers
- Attentively and carefully **OBSERVE** the child!

So....How Do We Find and Identify These Young Children?

- Generally, listen to comments made about the child's birth and early infancy...

EXAMPLES: "He weighed only 2.5 pounds at birth."

"She spent 7 weeks in the NICU."

"Sometimes she seems to see things, but sometimes she doesn't."

"I've never heard of this disorder, have you?"

"He has lots of ear infections, and his ears have an unusual shape, but the doctor says his hearing is fine."

Assessment

- If a family includes older siblings / cousins, *some* degree of comparison is likely OK (remember that each child develops at his / her own rate)
- Looking at developmental milestone checklists, if a range of ages is projected for accomplishment of a task
[NOTE: Calculate true birth age, not “day born” in the case of a little baby born very prematurely]
- Listen to medical professionals—but if you’re a parent, “go with your gut” (if need be) and request an evaluation

Authentic Assessment

- First and foremost, assessment must be **authentic** – *What does this mean—and what does it entail???*
 - Reliable
 - Significant
 - Meaningful
 - Repeated opportunities (to demo skill)
 - Conducted by an individual who is familiar to the child (*If interaction is involved*)

Authentic Assessment

General elements to remember, when completing an assessment with a young child who is suspected of possibly having deaf-blindness:

- **Appearance** of the child's eyes / ears
- General **behaviors** the child routinely demonstrates
- The **contexts** in which the assessment will be conducted—need variety!

Authentic Assessment

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- In the field of deaf-blindness, the “Child-Guided Assessment” approach is one of the most reliable, recommended, authentic practices for completion of an authentic assessment of a child who is suspected of having deaf-blindness
- The “Child-Guided Assessment” approach is based on Jan van Dijk’s framework for assessment and intervention
- This assessment approach was refined and researched by van Dijk, Catherine Nelson, and colleagues as an alternative to “traditional assessment”—in order to yield more valid information *and* reduce the child’s stress.

Authentic Assessment

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The “Child-Guided Assessment” approach:

- relies heavily on concentrated observation
- allows the child to demonstrate his best skills in environments and routines that are non-stressful
- involves the assessor becoming very attuned to the child being assessed, and creating routines *with* him
- involves the child's interests and preferences and incorporates what motivates him
- relies on the assessor “reading” the child's emotions—**and following the child's lead!**

Child-Guided Assessment

- Involves partnering with that child
and
- **INVITING THE CHILD “OUT,”** (of his / her own body) to join you in the world, to interact with the environment, and to build levels of connections

Important Elements of Assessment

During an assessment, it is important to remember that a child suspected of having deaf-blindness:

- is deprived of many of the most basic extrinsic motivations (i.e., curiosity)
- experiences sensory input that is so distorted it might be ineffective as a source of motivation to explore and interact with people / the environment
- will generally not benefit from being left alone with toys / materials
- lacks the ability to anticipate or predict events

Child-Guided Assessment

Child-Guided Assessment Involves 10 Primary Areas for Observation (Bashinski's interpretation)

Biobehavioral State / Behavior State	Orienting Responses
Approach - Withdrawal	Memory
Sensory Learning Channel: Vision	Social Interactions
Sensory Learning Channel: Hearing	Communication
Sensory Learning Channel: Touch	Problem Solving Behaviors

Child-Guided Assessment

Biobehavioral State (Behavior State)

- “Biobehavioral state” is defined as the level of an individual’s general arousal
- Behavior state ranges from deep sleep to actively alert and includes drowsiness and agitation
- Research varies in the number of behavioral states reported (6 – 9)
- Behavior state in newborns is controlled internally, by the needs of the child’s body, and continues to be primarily so in children who experience neurological disability

Child-Guided Assessment

Biobehavioral State (Behavior State)

- ▶ Behavior state can, to some degree, be influenced by external, environment factors

See electronic document, “Learning Environment Characteristics” by Bashinski, et al., 1995

for categories of learning environment variables that *might* be manipulated in an attempt to influence a learner’s behavior state.

Launch poll #4

Child-Guided Assessment

Biobehavioral State (Behavior State)

- To what degree does the child seem to be able to modulate / control his behavioral state?
- How much time does the child spend in a state of quiet or active alertness?
- What is the child's current behavior state?
- What environmental variables appear to possibly affect the child's behavior state?

Child-Guided Assessment

NOTE: Content of questions is credited to van Dijk & Nelson

Approach – Withdrawal

- Does child consistently seem to turn away (if able) from certain people / objects / activities?
- What behaviors are noted that seem to indicate the child wants to engage?
- What behaviors seem to indicate the child wants to terminate an interaction / activity (i.e., disengage)?
- What appears to be motivating to the child?

During Child-Guided Assessment...

It is KEY to work to maximize the learner's sensory access, as the assessor is gathering information re: vision, hearing, and touch.

Child-Guided Assessment

Sensory Learning Channel: **Vision**

- Examine visual engagement *or disengagement*, as well as whether or not the child uses vision in combination with other senses
- How does the child generally relate to visual stimuli?
- Does the child appear to “take in” information through use of his vision?

(See electronic document, “Assessment Overview,” by Utley, Roman, & Nelson, 1998)

Child-Guided Assessment

Sensory Learning Channel: **Hearing**

- Examine auditory engagement or *disengagement*, as well as whether or not the child uses his hearing in combination with other senses
- How does the child generally relate to auditory stimuli?
- Does the child appear to “take in” information through use of his hearing?
- The single most significant impact of a severe to profound hearing loss is its effect on the child’s communication / language development

Child-Guided Assessment

Sensory Learning Channel: **Hearing**

See electronic document, “Functional Auditory Performance Indicators [FAPI]” (Stredler-Brown & Johnson, 2003)

- Integrated approach to auditory skill development
 - Examines seven (7) categories:
 1. Sound Awareness
 2. Sound is Meaningful
 3. Auditory Feedback
 4. Localizing Sound Source (i.e., the ability to localize sound *might* be affected by type of hearing loss)
 5. Auditory Discrimination
 6. Short-term Auditory Memory
 7. Linguistic Auditory Processing
- linked to cognition
what brain does w/ speech

Child-Guided Assessment

Sensory Learning Channel: **Touch**

- Examine tactile engagement or *disengagement*, as well as whether or not the child uses touch in combination with other senses
- How does the child generally relate to tactile stimuli?
- Does the child appear to “take in” information through use of touch?

Early expression of “memories” will likely incorporate tactile and movement aspects of the learner’s experience.

Child-Guided Assessment

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Orienting Responses (involves not only an awareness of a stimulus, but also directing attention to that stimulus in some way)

- In what way(s) does this child exhibit a response that seems to indicate he is orienting to a person, sound, object, etc.? (e.g., more or less activity, various motoric responses)
- What environmental factors have been observed to elicit an orienting response from the child?
- What type(s) of sensory stimuli seem to trigger an orienting response from the child?

Child-Guided Assessment

Memory

What did we discuss previously, that appear(s) to have significant impact on a child's earliest memories?

Launch poll #5

Child-Guided Assessment

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Memory

- Does the child seem to habituate to familiar stimuli?
- How many times does the child need to be exposed to a stimuli to demonstrate habituation?
- Does the child react differently to familiar and unfamiliar people—adults and children?
- Does the child appear to notice if features of a stimulus change?
- Are such reactions differentiated?

Child-Guided Assessment

Memory

- Does the child appear to demonstrate anticipation?
- Does the child seem to associate a preceding event with one that typically follows?
- Does the child react when there is a mismatch to expectations (in #2 here)?
- Does the child demonstrate object permanence?
- Is the child able to learn a simple routine and “remember” how to actively participate in it?

Child-Guided Assessment

Social Interactions

- When another person approaches the child, does she orient to the individual?
- Does the child appear to demonstrate that she has bonded with primary caregivers in her life?
- Does the child engage in turn-taking when another person begins such interaction?
- Does the child ever initiate turn-taking games?
- Approximately how many “turns” does the child take before she disengages?

Communication Reminders!

Everyone communicates!

An assessor and the child's partner in any interactions (during the assessment) need to **EXPECT** the child to communicate.

Child-Guided Assessment

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Communication

- Does the child appear to initiate communication with another person, through the use of idiosyncratic OR conventional sounds, signals, gestures?
- Are any of the above (#1 here) used by the child consistently?
- Does the child appear to use her communication signals differently with different interaction partners?

Child-Guided Assessment

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Communication

- To communicate what possible meanings does the child appear to use communication forms?
- If offered options, does the child make choices?
- Does the child appear able to understand that one item or symbol "stands for" an activity / person / object?

Child-Guided Assessment

Problem Solving Behaviors

- Does the child demonstrate and / or appear to understand cause and effect relationships?
- Does the child appear to understand “means – ends” behavior—that is, the use of an intermediate action to solve a problem?
- Does the child demonstrate appropriate use of the function of common objects?
- Does the child demonstrate task persistence?
- Does the child maintain attention over time?

Formal Assessment Instruments

- ***MacArthur-Bates Communicative Development Inventories***
 - “Words & Gestures” form (8 – 18 months)
documents a child’s understanding and production of early vocabulary items and communicative and symbolic gestures
 - “Words & Sentences” form (16 – 30 months)
documents a child’s production of words and early forms of grammar
 - “CDI-III” (30 – 37 months)
measures a child’s expressive vocabulary and grammar

Formal Assessment Instruments

- ***Ages and Stages Questionnaires—ASQ-3***
 - gold-standard form for developmental screening
 - assesses skills in communication, gross motor, fine motor, problem solving, and personal-social
 - assesses skills across the age range of 1 – 66 months
 - the questionnaire is estimated to require 10 – 15 minutes time for a family to complete; 2 – 3 minutes for a professional to score
 - available in Spanish, French, Chinese, Arabic, & Vietnamese

Resources

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- **Early Identification and Referral Toolbox** (NCDB, 2019)
<https://www.nationaldb.org/products/ei-toolbox/>
- **Part C of IDEA** – “The Program for Infants and Toddlers with Disabilities” (e.g., procedures, partnership info, ideas for addressing ID and referral challenges)
- **EHDI** – Early hearing detection and Intervention programs (e.g., screening by 1 month; intervention services by 6 months, if diagnosed)
- **Hands & Voices** – a parent organization that works in close partnership with EHDI (e.g., partnership info, ideas for addressing ID and referral challenges)
- **Health Care System** - (e.g., organization and information)

Resources

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- ***Early Identification and Referral Self-Assessment Guide*** (NCDB, 2019)
 - https://www.nationaldb.org/media/doc/EIR_SelfAssessmentGuide_041018.pdf
 - 35-page manual
 - Review of data
 - Detailed analysis re: under-identification of infants and toddlers < 2 years of age
 - Detailed analysis re: under-referral of infants and toddlers < 2 years of age
 - Suggestions for developing an action plan

Resources

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➤ H.E.A.R.: Hierarchy of Early Auditory Responses (See electronic document provided, by Lee, Dearman, & Hopkins, 2007)

This document breaks down six categories of auditory skills, according to expected achievement in 3 month intervals (Birth through 18 months of age).

The document also provides EXAMPLES.

Awareness of sound	Comprehension of sound
Sound source localization	Imitation (of sound)
Social responses	Vocalizations / Verbalizations

Resources

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- Numerous state deaf-blind project webpages (*other than from the MT Deaf-Blind Project*) include info:
Washington state
 - “Signs, Symptoms & Risk Factors” that may indicate vision OR hearing loss in young children

Observations: Signs, Symptoms & Risk That May Indicate Visual Impairment in Young Children

Signs & Symptoms	Risk Factors
Atypical Appearance of Eyes: <ul style="list-style-type: none">➤ Drooping eyelid obscuring pupil (<i>ptosis</i>)➤ One eye slightly higher or lower than the other eye➤ Obvious abnormalities in the shape or structure of the eyes➤ Absence of a clear, black pupil➤ Persistent redness of conjunctiva (normally white)➤ Persistent tearing without crying➤ High sensitivity to bright light (observe squinting, closing eyes, or turning away)	Family History: <ul style="list-style-type: none">➤ Family history of visual impairment or hereditary childhood blindness Prenatal History: <ul style="list-style-type: none">➤ Mother has history of toxoplasmosis, rubella, or cytomegalovirus, or other infections during pregnancy➤ Child was exposed to alcohol or drugs prenatally

Observations: Signs, Symptoms & Risk Factors That May Indicate Hearing Loss in Young Children

Associated with Hearing Loss	
Atypical Appearance of Face or Ears: <ul style="list-style-type: none"><input type="checkbox"/> Cleft lip and palate<input type="checkbox"/> Malformations of head or neck<input type="checkbox"/> Malformations of the ears, including lack of earlobes<input type="checkbox"/> Frequent earaches or ear infections (otitis media)<input type="checkbox"/> Discharge from the ears	Atypical Vocal Development <ul style="list-style-type: none"><input type="checkbox"/> Has limited vocalizations<input type="checkbox"/> Has abnormalities in voice, intonation or articulation<input type="checkbox"/> Shows delay in lang. development (e.g., no spoken words at 15 mo; fewer than 50 words at 24 mo)
Atypical Listening Behaviors: <ul style="list-style-type: none"><input type="checkbox"/> Few or inconsistent responses to sounds<input type="checkbox"/> Does not seem to listen<input type="checkbox"/> Does not respond to caregivers calling his/her name<input type="checkbox"/> Shows a preference for certain types of sounds	Other Behaviors <ul style="list-style-type: none"><input type="checkbox"/> Pulls on ears or puts hands over ears<input type="checkbox"/> Breathes through mouth<input type="checkbox"/> Cocks head to one side <p>(Sources: Chen, 1998, 1990; Gatty, 1996; Fewell, 1983; Joint Committee on Infant Hearing, 1991)</p>

Resources

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Washington state (continued)

- A developmental screening checklist for “Functional Vision” (Birth through 5 years) and “Observations: Developmental Skills Related to Hearing in Young Children (Birth though 36 months

Developmental Screening Checklist: Functional Vision

Birth to One Month	
<ul style="list-style-type: none"> Stares at windows and bright walls Blinks when light is too bright When penlight is shone into the eyes, pupils constrict; when light is removed, pupils dilate (pupillary response) Looks at faces briefly Looks briefly at objects placed in field of vision 	<ul style="list-style-type: none"> Eyes turn the opposite direction that the head turns or tilts; this reflex is inhibited after the first few weeks as a child's fixation increases (doll's eye reflex) Grasping, looking, and sucking occur in isolation of each other; hands are usually fisted Seems to focus the best on objects 8-12 inches from face
One to Three Months	
<ul style="list-style-type: none"> Stares at objects within field of vision Eye-to-eye contact increases At one month, looks at outside features of face such as hairline, ears, chin At two months, looks at inside features such as eyes, nose, mouth, eyebrows Eye movements are nearly coordinated and even 	<ul style="list-style-type: none"> Follows movement of person nearby Looks at hand on side favored by tonic neck reflex; may swipe at objects on this side Visually inspects nearby surroundings; may move head and eyes as well as body toward the stimulus Prefers to look at some pictures, people, or toys longer than others; alerts to a favorite object

Observations: Developmental Skills Related to Hearing in Young Children		
HEARING: Does the Child. . .	Y	N
	√	√
BIRTH – 3 MONTHS OLD:		
Startle or jump when there is a sudden loud sound?		
Stir or awaken from sleep, or cry, when someone talks or makes a noise?		
Recognize and get comforted by a familiar voice?		
BY 3 – 6 MONTHS OLD:		
Turn his/her eyes to look for an interesting sound?		
Respond to mother's or caregiver's voice?		
Turn eyes forward when his/her name is called?		
BY 6 – 12 MONTHS OLD:		
Turn toward an interesting sound or toward caregiver when his/her name is called from behind?		
Search or look around when new sounds are		
HEARING: Does the Child. . .		
24 – 30 MONTHS OLD:		
Follow two requests (“Get the ball and put the table”)? (24 mos.)		
Understand conversation easily?		
Identify objects in a book by pointing to them when they are named?		
Hear when you call from another room?		
Produce the following sounds clearly: P,B,M,K,G,W,H,N,T,D ?		
Use three-word sentences?		
Use past tense verbs?		
Name five pictures?		
Answer questions?		
Replace “jargon” with sentences?		
Use 1-2 prepositions (in, on, under)?		

Remember!

Learners who experience deaf-blindness are an incredibly heterogeneous group!

Thank You!

I sincerely appreciate your participation today!
Please feel free to contact me with any
questions:

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