



The Sooner the Better:

Effective Strategies for Identifying Infants and Young Children with Combined Vision and Hearing Loss

Presenter: Shelly Voelker, Ed.D., Florida & Virgin Islands Deaf-Blind Collaborative

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OUTCOMES

Increased awareness and knowledge of:

- The diversity of the population of children considered eligible for deaf-blind intervention services
- Behaviors and risk factors associated with identification of young children with combined vision and hearing loss
- *The Florida & Virgin Islands Deaf-Blind Collaborative's* resources, services and referral process

If you suspect that a child may not be able to use his/her hearing and vision effectively to communicate and gain information, please refer the family to the Florida & Virgin Islands Deaf-Blind Collaborative.

1-800-667-4052 352-273-7529

Overview

- Who are these little ones?
- How do we find them?
 - Risk factors
 - Interview Questions
 - Observation & screening

If you suspect that a child may not be able to use his/her hearing and vision effectively to communicate and gain information, please refer the family to the Florida & Virgin Islands Deaf-Blind Collaborative.
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Eligibility

Federal Definition:

“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.”

(IDEA 2004, Section 300.8 (2), 2004)

If you suspect that a child may not be able to use his/her hearing and vision effectively to communicate and gain information, please refer the family to the Florida & Virgin Islands Deaf-Blind Collaborative.

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Eligibility

- You may hear more than one term used to describe eligible children
- The term “deaf-blind” may be frightening to some parents/family members

The FAVI Deaf-Blind Collaborative encourages you to report ANY CHILD you believe to be showing signs of both vision and hearing losses. If you believe that a young child is at risk for combined vision and hearing losses, please let us know. The earlier we receive a referral, the earlier we can help.

<http://deafblind.ufl.edu/welcome/make-a-referral-or-request-assistance/>

Talking about Deaf-Blindness

- **Child with combined vision and hearing loss**
- **Child with deaf-blindness**
- **Child who is deaf-blind**
- **Child with dual sensory loss/losses**
- **Child with dual sensory impairments**
- **Child with deaf-blind intervention needs**

How Do We Find Them?

- Review of medical records
- Interview with parent/guardian
- Observation
- Screening
- Follow-up evaluations

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Risk Factors

- Hereditary Syndrome or Disorder
- Certain prenatal, perinatal and postnatal conditions
- Premature birth
- Severe head injury
- Trauma to the eye and ear
- Multiple disabilities
- Family History of Vision and/or Hearing Loss

Not all individuals with these conditions will qualify as deaf-blind, but when EI professionals read/hear these terms they should automatically think “I’d better be sure that we follow up on vision and hearing evaluations”

Hereditary Syndromes and Disorders

- CHARGE syndrome
- Down syndrome
- Trisomy 13
- Usher syndrome
- Alstrom, Goldenhar, Hurler, Norrie, Waardenburg syndromes

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Primary Etiologies of Deaf-Blindness: Frequency

(from 2015 National Deaf-Blind Child Count)

<https://nationaldb.org/library/page/1944>

| <u>Etiology</u> | <u>Frequency</u> | <u>Etiology</u> | <u>Frequency</u> |
|----------------------------------|-------------------------|-------------------------------|-------------------------|
| No Determination of Etiology | 1755 | Norrie disease | 42 |
| Other: Hereditary | 1557 | Leber congenital amaurosis | 41 |
| Complications of Prematurity | 1039 | Pierre-Robin syndrome | 41 |
| CHARGE syndrome | 926 | Congenital Rubella | 40 |
| Other: Pre-Natal/Congenital | 482 | Infections | 40 |
| Other: Post-Natal/Non-Congenital | 394 | Aicardi syndrome | 37 |
| Cytomegalovirus (CMV) | 304 | Chromosome 18, Ring 18 | 27 |
| Usher syndrome (Types 1-3)) | 295 | Pfeiffer syndrome | 26 |
| Down syndrome (Trisomy 21) | 286 | Alstrom syndrome | 25 |
| Hydrocephaly | 214 | Waardenburg syndrome | 25 |
| Microcephaly | 213 | Marshall syndrome | 24 |
| Asphyxia | 196 | Treacher Collins syndrome | 20 |
| Head Injury | 170 | Cri du chat syndrome | 19 |
| Meningitis | 156 | Fetal Alcohol syndrome | 19 |
| Stickler syndrome | 127 | Refsum syndrome | 18 |
| Dandy Walker syndrome | 120 | Cockayne syndrome | 15 |
| Cornelia de Lange | 101 | Crouzon syndrome | 15 |
| Goldenhar syndrome | 98 | Hurler syndrome (MPS I-H) | 15 |
| Tumors | 86 | Bardet-Biedl syndrome | 12 |
| Maternal Drug Use | 78 | Sturge-Weber syndrome | 12 |
| Wolf-Hirschorn syndrome | 69 | Kniest Dysplasia | 11 |
| Encephalitis | 59 | NF1-Neurofibromatosis | 10 |
| Trisomy 13-15 (Patau syndrome) | 57 | Turner syndrome | 10 |
| Moebius syndrome | 50 | Congenital Toxoplasmosis | 10 |
| Stroke | 46 | NF-2-Neurofibromatosis | 9 |
| Trisomy 18 (Edwards syndrome) | 45 | Neonatal Herpes Simplex (HSV) | 7 |

Prenatal History

- History of maternal infection during pregnancy
 - Rubella
 - CMV (cytomegalovirus)
 - Toxoplasmosis
 - Herpes
 - Syphilis
- Prenatal infant exposure to drugs or alcohol

Not all individuals with these conditions will qualify as deaf-blind, but when EI professionals read/hear these terms they should automatically think “I’d better be sure that we follow up on vision and hearing evaluations”

Perinatal Conditions (check birth history)

- Low Apgar scores
 - 0-4 at 1 minute or 0-6 at 5 minutes
- Hyperbilirubin (jaundice) requiring transfusion
- Mechanical ventilation for longer than 5 days
- Preterm Birth

Not all individuals with these conditions will qualify as deaf-blind, but when EI professionals read/hear these terms they should automatically think “I’d better be sure that we follow up on vision and hearing evaluations”

Prematurity

- Birthweight below 1500 grams (3.3lbs)
- Retinopathy of prematurity
- Exposed to oxygen
- On ventilator longer than 5 days
- Elevated bilirubin requiring transfusion

Complications of prematurity account for a large percentage of the children on the deaf-blind census, so paying attention to this diagnosis is important.

Postnatal Conditions (check health history)

- Syndrome associated with hearing loss and/or visual impairment

<https://com-psychiatry-deafblind.sites.medinfo.ufl.edu/files/2012/06/NATIONAL-DEAF-BLIND-CENSUS-HereditaryChromosomal-2017.pdf>

- Meningitis or encephalitis
- Hydrocephalus/hydrocephaly
- Cerebral palsy or other neurological disorders

EI providers are often more likely than teachers to have birth history information readily available; it's important to pay attention to it and know that these terms signal the need to be on the lookout for vision and/or hearing problems.

Postnatal Conditions (check health history)

- Brain disorders, brain tumors or malformations of the brain
- Loss of oxygen to the brain
- Severe head trauma
- Prolonged fever
- Child received “mycin” or other known ototoxic medications

Neurological disorders are more likely to result in characteristics or diagnoses of **cortical** vision or hearing difficulties than other eye conditions;

so, it's not uncommon for families to have been told that there's nothing wrong with their child's eyes and vision or ears and hearing

“Red Flag” Terms

- Anoxia, asphyxia, hypoxia
- Atresia
- Cerebral hemorrhage
- Cerebral palsy
- Ischemia
- Meningitis
- Periventricular damage
- Fetal Alcohol syndrome

Again, these don't mean for sure that deaf-blindness will be present but that close attention needs to be given to vision and hearing skills and development

Gathering Information from Parents and Caregivers

- Intake Interviews
- Initial Home Visit
- Development or Review of IFSP

DB Project personnel are in a unique position to provide EI providers with tips about what to say and how to get the information that will prove most useful in identifying children with combined vision/hearing loss.

You will often hear this:

Parents have
no concerns
about their
child's vision
or hearing

If you suspect that a child may not be able to use his/her hearing and vision effectively to communicate and gain information, please refer the family to the Florida & Virgin Islands Deaf-Blind Collaborative.

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Parents have
no concerns
about their
child's vision
or hearing

Many EI providers will say "YES"

Unfortunately, that's just not enough!

*These sensory losses may still be present.

*Or children may be at risk for sensory losses due to their syndromes or other medical conditions.

*When both hearing and vision losses are diagnosed or SUSPECTED by the parent or provider, PLEASE report/refer to the FAVI Deaf-Blind Collaborative!

Gathering Information from Parents and Caregivers

- Family history
- Birth History
- Medical/Health History
- Atypical appearance of eyes or ears
- Atypical development of vision or hearing

This slide and the next 6 slides will guide you in strategies for gathering pertinent information related to vision/hearing losses

Each slide provides a setting in which the questions might be used or found most helpful

Information about Hearing

(during intake process)

- Do you feel your child has difficulty hearing?
- Has anyone expressed concerns about your child's hearing?
- Did your child pass the Newborn Hearing Screening?
- Was follow-up recommended? Did you follow up?
- Has your child had a formal Hearing Evaluation?
- Is there any family history of hearing loss?
- Or a history of ear infections?

These questions can be asked by a Service Coordinator,
Social Worker or Family Support Personnel

Information about Vision

(during intake process)

- Is there any family history of eye problems, vision loss or blindness?
- Do you think your child's eyes look typical?
- Do you think your child has difficulty seeing?
- Has your child had a Vision Screening?
- Has your child had a medical eye examination at the hospital or by an ophthalmologist?
- Has your child seen an optometrist?

Information about Vision

(during home visits)

If you've noticed unusual appearance or behaviors, try probing questions such as:

- Did anyone in your family wear thick glasses?
Or an eye patch?
- Does your child wake up with crusty eyes, eyes stuck shut?
Do his/her eyes water a lot?

These questions would be most appropriate when:

- evaluation and/or assessments are taking place in the home
- someone on the team has noticed something new or previously unnoticed that sends up a red flag about vision
- after eligibility has been determined and intervention begun, but vision information was incomplete or service providers notice behaviors that may indicate vision problems

Information about Vision

(during home visits)

- Have you ever been concerned about the way your child's eye(s) move?
- Do their eyes always appear straight (does one eye turn in or out)?
- Is your child afraid to move around or explore?
- Describe how your child behaves around lamps, ceiling lights.
- Does your child seem to notice things more at home or more in a new place?
- What, if anything, have doctors told you about your child's vision?

Sensory Information

- Does your child like or dislike certain kinds of sounds?
- Does your child like or dislike certain kinds of movement?
- Does your child seem hesitant to explore his environment? Afraid? Cautious?
- Does your child respond in unusual ways to her environment?

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Remember your A-B-Cs

- Appearance
- Behaviors
- Conditions

Adapted from: *The Sooner the Better: Effective Strategies for Identifying Infants and Young Children with Combined Vision and Hearing Loss*. National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC), 2006.

Did you Know?

- ❖ Deaf-Blindness is a term that describes children who have both vision and hearing loss
- ❖ Children with Deaf-Blindness have different amounts of usable hearing and vision
- ❖ More than 90% of children with combined vision and hearing loss have additional disabilities or health problems
- ❖ Having multiple disabilities or complex health problems often keeps combined vision and hearing loss from being recognized or addressed



Karlota is 5 years old and living cheerfully with Treacher Collins syndrome, hearing loss and vision loss, among other challenges.



Berneice Ann is 8 years old and living happily with pyruvate dehydrogenase deficiency, hearing loss and vision loss, among other challenges.

“Close attention needs to be given to vision and hearing skills and development. If you suspect that a child may not be able to use his/her hearing and vision effectively to communicate and gain information, please refer the family to the Florida & Virgin Islands Deaf-Blind Collaborative”

Leading Diagnoses Frequently Associated with Deaf-Blindness

1. Complications of prematurity, birth injury, asphyxia
2. Infections/ Meningitis/ Encephalitis
3. Hereditary hearing loss, vision loss
4. Congenital Rubella, Toxoplasmosis, other congenital conditions
5. CHARGE syndrome
6. Down Syndrome and other Trisomy syndromes
7. Usher syndrome
8. Cytomegalovirus
9. Hydrocephaly or Microcephaly
10. Numerous other syndromes



Florida & Virgin Islands
Deaf-Blind
COLLABORATIVE

University of Florida, FAVI-DBC

1600 SW Archer Road
PO Box 100234
Gainesville FL 32610

Phone 800-667-4052

Fax 352-273-8539

info@deafblind.ufl.edu
deafblind.ufl.edu



Assisting families of
children and youth who are

Deaf-Blind

Services

For families:

- ❖ Consultation with early intervention team (via in home visit /phone/email)
- ❖ Family to family connections
- ❖ Access to free training (via phone/computer)
- ❖ Access to Family Specialist for resources and information
- ❖ Access to Deaf-Blind specialists to assist with communication and educational information
- ❖ Limited support for families to attend conferences

For everyone:

- ❖ Provide research-based onsite training, distance learning, information and consultation to individuals and teams
- ❖ Build team capacity to implement evidence-based strategies, accommodations and interventions
- ❖ Refer and connect individuals and teams to relevant organizations, technologies and services

**Services are free of charge.*



Eva is 7 years old living joyfully with Trisomy 13, Cortical Blindness & a mild hearing loss among other challenges.

Who are we & how can we help?

The Florida and Virgin Islands (FAVI) Deaf-Blind Collaborative provide consultation and support to children and youth (ages birth through 21) who have both hearing loss and vision loss (diagnosed or suspected). We consult with families, educators, service providers, agencies and educational teams to support the growth, educational success, communication needs and accessibility for children and young adults concerning their Deaf-Blindness .

Deaf-Blindness is defined as combined hearing and vision losses that may impact communication, mobility, participation and learning. Many people with Deaf-Blindness may also have physical, intellectual and/or additional disabilities. Our goal is to help children and young adults who are deaf-blind participate and experience the same opportunities within our community as others.



William is an 11 year old with Pfeiffer Syndrome Type 2. He wears beautiful blue prosthetic lens and no one can tell they are not his own eyes, he also has conductive hearing loss which since his loss of sight has thankfully improved. He has several girlfriends and LOVES SpongeBob.

Infants and toddlers with some of these behaviors may have combined vision and hearing loss:

- Balance problems, bumping into or tripping over objects
- Inconsistent responses to sounds or visual images
- Light gazing
- Tactile sensitivity
- Overactive startle response
- Communication by biting, hitting self or others, throwing objects, screaming, etc.

Florida & Virgin Islands
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Assisting families of children and youth who are *deaf-blind*

Make a Referral / Request Assistance

<http://deafblind.ufl.edu/welcome/make-a-referral-or-request-assistance>

PLEASE SUBMIT ALL FORMS WITH by FAX or POSTAL MAIL

- **EMAIL IS NOT A HIPAA-COMPLIANT MEANS OF EXCHANGING PROTECTED INFORMATION. *THANK YOU!***

*Once an individual has been reported to the Florida deaf-blind registry, a family, teacher, or educational team may request individualized assistance from the FAVI D-B Collaborative.

**Encourage families to complete a Consent form, so that we can provide information and offer services to children with deaf-blindness, their families, and their educational teams.

Once a family has provided consent, any family member or team member may make a request for Technical Assistance (training, consultation, individualized support) from the FAVI D-B Collaborative.

Make a Referral / Request Assistance

<http://deafblind.ufl.edu/welcome/make-a-referral-or-request-assistance>

**PLEASE SUBMIT ALL FORMS WITH ANY IDENTIFYING INFO
(names, addresses, birth dates, social security numbers, etc.)**

- BY FAX 352-273-8539
- OR POSTAL MAIL: Florida & Virgin Islands Deaf-Blind Collaborative
PO Box 100234, 1600 SW Archer Road, Gainesville, FL 32610
- **EMAIL IS NOT A HIPAA-COMPLIANT MEANS OF EXCHANGING PROTECTED INFORMATION. *THANK YOU!***
- **For Families reporting their child with deaf-blindness**
- **Report a child or young adult to the deaf-blind registry**
- **Consent for the Exchange of Information & Records,**
- **Request for Technical Assistance**