

Serving Children with Multiple Disabilities

EHDI April 23, 2024

A little bit about me....

Cindy Friederick, consultant for children with multiple disabilities and deafblindness

Why are are here today?

Topics for the Discussion

Etiology & Physiology

Risk Factors

Leading etiologies vision loss and deafblindness

CVI - incidence and yes, it is a bit of an unknown

Relationships & trust

Communication - I'm talking are you listening?

Impeccable Observer - slow down and watch

Behavior & Hope

Q&A and Resources

Record Review:

High Risk factors DHH



Risk for DeafBlind?

Top Visual Impairments?

- Cortical/Cerebral/Neurological Visual Impairment (CVI)
- Optic Nerve Hypoplasia (ONH)
- Retinopathy Prematurity (ROP)

[2022 Babies Count birth-36 months](#)

Risk Factors		
JCIH risk factors (2019)		
Family history of early, progressive or delayed onset permanent childhood hearing loss	<input type="text"/>	No <input type="button" value="v"/>
Neonatal intensive care > 5 days	<input type="text"/>	Yes <input type="button" value="v"/>
Hyperbilirubinemia with exchange transfusion	<input type="text"/>	No <input type="button" value="v"/>
Aminoglycoside administration > 5 days	<input type="text"/>	No <input type="button" value="v"/>
Asphyxia or Hypoxic Ischemic Encephalopathy	<input type="text"/>	No <input type="button" value="v"/>
Extracorporeal membrane oxygenation (ECMO)	<input type="text"/>	No <input type="button" value="v"/>
In utero infection: such as herpes, rubella, syphilis, toxoplasmosis	<input type="text"/>	No <input type="button" value="v"/>
In utero infection: cytomegalovirus (CMV)	<input type="text"/>	No <input type="button" value="v"/>
Mother + Zika and infant: no laboratory evidence/ no clinical findings	<input type="text"/>	No <input type="button" value="v"/>
Mother + Zika and infant: laboratory evidence of Zika + clinical findings	<input type="text"/>	No <input type="button" value="v"/>
Craniofacial malformations: microtia/atresia	<input type="text"/>	No <input type="button" value="v"/>
Craniofacial malformations: Other (e.g. ear dysplasia, oral facial clefting, white forelock, microphthalmia)	<input type="text"/>	No <input type="button" value="v"/>
Congenital microcephaly, congenital or acquired hydrocephalus	<input type="text"/>	No <input type="button" value="v"/>
Temporal bone abnormalities	<input type="text"/>	No <input type="button" value="v"/>
Syndromes associated with atypical hearing thresholds	<input type="text"/>	No <input type="button" value="v"/>
Culture-positive infections associated with atypical hearing thresholds: bacterial or viral (e.g. herpes, varicella), meningitis or encephalitis	<input type="text"/>	No <input type="button" value="v"/>
Significant head trauma /basal skull/temporal bone fractures	<input type="text"/>	No <input type="button" value="v"/>
Chemotherapy	<input type="text"/>	No <input type="button" value="v"/>
Caregiver concern regarding hearing, speech, language, developmental delay and or developmental regression	<input type="text"/>	No <input type="button" value="v"/>

Leading Causes of Deafblindness

[NCDB Child Count 2022:](#)

Iowa identified 4 children birth-2, 19 children ages 3-5, and 35 children ages 6-11.
What's concerning about that data?

National

- Hereditary: **CHARGE**, **Usher Syndrome**, Down Syndrome,
- Prenatal Complications: **CMV**, **Hydrocephaly** and **Microcephaly**,
- Postnatal: **Asphyxia**, **Severe Head Injury**, Meningitis, **Rubella**
- Overall: **CHARGE**, Prematurity (close 2nd)

Leading Cause of Visual Impairments

1. Cerebral/cortical or neurological visual impairments (CVI) caused by damage to the brain's visual pathways or visual processing areas.
 - Anoxic brain injury associated with premature birth or other Traumatic Brain Injury, such as hypoxic ischemic encephalopathy, periventricular leukomalacia, stroke or seizure or typically associated with genetic syndromes, such as AGS, CDKL5, etc. Infections like meningitis. A wide range of genetic syndromes (Williams, Rhetts, CDKL5, Trisomy 21, West, Pitt Hopkins, Malan, etc.) and genetic variants, Metabolic disorders, Central nervous system developmental defects, Epilepsy/seizure disorders, Abnormal Brain Conditions (i.e. Polymicrogyria, Agenesis of the Corpus Callosum, Microcephaly), Hydrocephalus
2. Optic Nerve Hypoplasia (ONH) the **under-development or absence of the optic nerve combined with possible brain and endocrine abnormalities.**
3. Retinopathy of Prematurity (ROP) **an eye disease that can happen in babies who are premature (born early) – or who weigh less than 3 pounds at birth**

Relationships: *showing you care matters*

Security and attachment - past history and experiences with people

Stress - lack of coherence/access, not know what is happening, who, being hurried, tired, sick, etc.,

Touch - too fast, too much random touch, disappearing and reappearing.

- Always let them know when something is going to happen to them before it happens.
- Used to establish joint attention in the absence of vision
- Hand Under Hand not hand over hand
- Used by the child to learn about their world takes time

Interacting with the hands and body...resist controlling them

Communication

- When is someone available to communicate? Who is it?
- Disappearing people and object, talking about things I don't care about or understand
- Lack of visual access creates a lack of access to information that tells us who is there? What they are talking about? Where communicative partners are? And when the opportunity to communicate may present.
- Joint attention for children with visual impairments - use touch while speaking, use instructional language vs chatter when the circumstance dictates
- Echolalic Speech - form with no function, use [Hand Under Hand](#)
- Communicative Forms - speech, sign, tactile symbols, gestures, touch, touch cues, tactile sign, objects, partial objects, pictures,

Observation

Be an impeccable observer....

- What does he/she like? How do he/she use her senses to learn/interact with preferred objects.
- How are they using their senses to make sense of the world around them? Security? Touch, sight,
- Movers and shakers vs using the slower ones...

Behavior is communication, are you listening?

- Health?
- Physiology? Sleeping, eating (swallowing), pooping, breathing, seizures, some parents are trying to keep their children alive and struggle to feel they have the ability to do that.
- Stress? Safety and predictability,
- Relationships?
- Touch? Be mindful of what you are communicating through touch

I have something to say and no way to say it

Empathy & Relationships Matter

Sometimes doing less but building a relationship matters more in the long run.

Resources - questions?

[Iowa Deafblind Project](#)

[Hand Under Hand](#)

[National Consortium on Deafblindness](#)

[CHARGE Syndrome](#)

[CVI NOW](#)

[Optic Nerve Hypoplasia \(ONH\)](#)

[Texas Deafblind Project](#)