DIVERSITY OF CHILDREN WHO ARE DEAF-BLIND: STRATEGIES FOR EDUCATIONAL SUCCESS

WSDS Joint Outreach Training
January 11, 2019
Objectives for Today

1. Understand the diversity of children and youth who are deaf-blind, ages birth to 21.

2. Learn about effective strategies for children who are deaf-blind.

3. Increase understanding about effective teaming for students who are deaf-blind.

4. Know the services and resources offered in our state, including the Deaf-Blind Project.
1. What did you miss last year? Greg Abell, “Sound Options” Mediation Services

2. Conflict is a natural part of teaming.

3. Greg’s term for “Conflict Resolution” is “Participating in the Work of Others.”

4. We have a job title, but when we show up, we may notice the expectation/need is different! Am I a specialist to share expertise, or a consultant here to listen and facilitate? What does this team need right now to be effective for this student?
Who are we?

Introductions:

Deaf-Blind Project
Presenters

- **Katie Humes, M.Ed.**
  Director, WSDS/Deaf-Blind Project

- **Sarah Godwin, M.Ed.**
  Deaf-Blind Consultant, Transition age Deaf-Blind Project

- **Nancy Hatfield, Ph.D.**
  Early Childhood Consultant, Deaf-Blind Project
Presenters

■ Emma Packard, M.Ed., M.A.
TVI, O&M Specialist
Consultant, Deaf-Blind Project

■ Debra Kahn, B.A.
Deaf-Blind Mentor
Who’s Here?

Introductions:

CDHL Outreach Staff
WSSB Outreach Staff
Some terms: Blind/Visually Impaired (VI)

Roles

▪ Braillist
▪ Teacher of the Visually Impaired (TVI)
▪ Orientation & Mobility (O & M)
▪ Certified O & M Specialist (COMS)
Some terms: Deaf/Hard of Hearing (DHH)

Roles
▪ Audiologist
▪ Language Coach
▪ Teacher of the Deaf (TOD)

Technology
▪ Cochlear Implant
▪ FM system
▪ Hearing Aids

Language/Communication Mode:
▪ American Sign Language (ASL)
▪ Listening /Spoken Language (LSL)
▪ Signing Exact English (SEE)

Also used:
▪ Pidgin Signed English (PSE)
▪ Total Communication
▪ Simultaneous Communication (Sim-Com)
Visual/Auditory Processing: D/HH, B/VI, DB

- Cortical Visual Impairment (CVI)
- Central Auditory Processing Disorder (CAPD)
- Auditory Neuropathy Spectrum Disorder (ANSD)
Some Terms: Deaf-Blind

Role
Deaf-Blind Intervener

Language/Communication Mode:
- ASL (visual, tracking or tactile)
- LSL
- SEE
- Tactile Signs
- Tangible Symbols
- Pro-Tactile (PT)
When you think of a person who is Deaf-Blind, what comes to your mind?

Photo courtesy of National Family Association for Deaf-Blind (NFADB) https://nfadb.org
Breakout: Two Groups

- Birth to Three Providers go with Nancy Hatfield and Emma Packard!
- Consultants with children ages 3-21 years, stay with Katie Humes and Sarah Godwin!

(Meet here for Potato Bar Lunch!)
What do you think are the most common causes of deaf-blindness?
### Reasons for Deaf-Blindness

#### Primary Identified Etiology

<table>
<thead>
<tr>
<th>Etiology</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hereditary Syndromes/Disorders</td>
<td></td>
</tr>
<tr>
<td>CHARGE syndrome</td>
<td>933</td>
</tr>
<tr>
<td>Usher syndrome (I,II,III)</td>
<td>329</td>
</tr>
<tr>
<td>Down syndrome (Trisomy 21 syndrome)</td>
<td>315</td>
</tr>
<tr>
<td>Stickler syndrome</td>
<td>137</td>
</tr>
<tr>
<td>Dandy Walker syndrome</td>
<td>115</td>
</tr>
<tr>
<td>Goldenhar syndrome</td>
<td>101</td>
</tr>
<tr>
<td>OTHER: Hereditary Syndrome/Disorders</td>
<td>2,552</td>
</tr>
<tr>
<td>Prenatal/Congenital Complications</td>
<td></td>
</tr>
<tr>
<td>Cytomegalovirus (CMV)</td>
<td>292</td>
</tr>
<tr>
<td>Hydrocephaly</td>
<td>214</td>
</tr>
<tr>
<td>Microcephaly</td>
<td>206</td>
</tr>
<tr>
<td>OTHER: Pre-Natal/Congenital Complications</td>
<td>679</td>
</tr>
<tr>
<td>Postnatal/Non-Congenital</td>
<td></td>
</tr>
<tr>
<td>Asphyxia</td>
<td>194</td>
</tr>
<tr>
<td>Severe Head Injury</td>
<td>159</td>
</tr>
<tr>
<td>Meningitis</td>
<td>137</td>
</tr>
<tr>
<td>OTHER: Post-Natal/ Non-Congenital</td>
<td>670</td>
</tr>
<tr>
<td>Complication of Prematurity</td>
<td>1,047</td>
</tr>
<tr>
<td>No Determination of Etiology</td>
<td>1,920</td>
</tr>
</tbody>
</table>

Deaf-Blind Child Count: National Center on Deaf-Blindness

How many children/youth “Deaf-Blind” in Washington?

<table>
<thead>
<tr>
<th>Educational Service District (ESD)</th>
<th>0 – 2</th>
<th>3 – 5</th>
<th>6 – 11</th>
<th>12 – 17</th>
<th>18 – 22</th>
<th>ESD TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>ESD 101 (Spokane)</td>
<td>0</td>
<td>3</td>
<td>7</td>
<td>10</td>
<td>8</td>
<td>28</td>
</tr>
<tr>
<td>ESD 105 (Yakima)</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>ESD 112 (Vancouver)</td>
<td>1</td>
<td>2</td>
<td>7</td>
<td>8</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>ESD 113 (Olympia)</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>7</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>ESD 114 (Bremerton)</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>5</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>ESD 121 (Renton)</td>
<td>4</td>
<td>20</td>
<td>31</td>
<td>26</td>
<td>24</td>
<td>105</td>
</tr>
<tr>
<td>ESD 123 (Pasco)</td>
<td>0</td>
<td>2</td>
<td>6</td>
<td>5</td>
<td>5</td>
<td>18</td>
</tr>
<tr>
<td>ESD 171 (Wenatchee)</td>
<td>0</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>ESD 189 (Anacortes)</td>
<td>5</td>
<td>9</td>
<td>12</td>
<td>19</td>
<td>15</td>
<td>60</td>
</tr>
<tr>
<td><strong>TOTAL:</strong></td>
<td>10</td>
<td>39</td>
<td>77</td>
<td>91</td>
<td>72</td>
<td>289</td>
</tr>
</tbody>
</table>

CHILD COUNT: [https://www.wsdsonline.org/db-childcount/](https://www.wsdsonline.org/db-childcount/)
STATE & FEDERAL (IDEA) DEFINITION OF DEAF-BLIND IN EDUCATION
WAC: “Deaf-Blind”

- “Deaf-Blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and developmental and educational needs that they cannot be accommodated in special education programs solely for students with deafness or students with blindness and adversely affect a student’s educational performance.”

- Note that for most of the children we see, their IDEA Category on the IEP is not “deaf-blind.”

- May be multiple disabilities, health-impaired, etc.
From infants to adults, what is our role?
Diversity of Children and Youth who are Deaf-Blind

- Calendar Conversation: https://youtu.be/foN-gLb27jY
- Kathryn Tastes a Grapefruit: https://youtu.be/XdKPk2Dm1cc
- Patsy and Amanda Lunchtime Conversation: https://youtu.be/v-GQc494I1M?t=179
- Charlotte learns Braille: https://youtu.be/pzP7DUZOKZE
Evaluations: What, who, when (sequence), how?

“Deaf-Blindness is a disability of access.”
Alsop, Blaha, & Kloos, 2008
Authentic Assessment Elements for DB Students

- Identify the purpose of this assessment.
- Family involvement is key!
- Comprehensive approach: interviews, observation (formal/informal) and tools.
- Include staff or consultants with specialized training in the communication, development and learning needs of children who are deaf-blind.
Process of Evaluations

- Identify the assessment team based on the reason(s) for evaluating, and the primary language of the child.
- Identify the sequence. Vision is typically first. Co-evaluate to reduce child fatigue.
- Arrange for family involvement (e.g. phone call, email, in person).
- Set up formal and informal observation times across multiple settings.
Who is on my team?
Strategies for Success

- Effective strategies from educators in the field including state deaf-blind projects, over the years, led to our website videos.
- Some of these ways of interacting incorporate deaf-blind etiquette and from the Deaf-Blind Community (adults).
- Effective Teaming is key!
- An Intervener may be determined by the IEP team to be needed.
ALL CHILDREN COMMUNICATE
Hand Under Hand (HUH) Tactile Modeling/ Communication

- Respectful, non-controlling interaction
- Allows child to initiate movement
- Allows child to initiate communication
- Increases opportunities for independence
- Foundation for tactile communication, tactile signing and Pro-Tactile
SIMULATION

Pick a partner
“But, she won’t use her hands.”
Strategies for Success

- Wait Time matters!
- Use child “LIKES” as a bridge to new concepts and vocabulary. See form.
- Consistent Routines matter. Each person who does a routine needs to do it the same way. See form.
What is an Intervener?

- Role of an Intervener
- What does this mean in Washington State?
  - 2017 Deaf-Blind Census (10-15)
  - Some districts have job description
  - No standardization of training, yet
  - Opportunities to learn: OHOA
  - “Path to Formal Training” 2019-2023
Examples of Interveners

“Do with, not for!”

Matt and the Ducks Video:
https://youtu.be/yHsblG_hMa8

Jarvis’ Schedule Video:
https://youtu.be/bMz-xG9gk8k

High School Assignment:
How does this Intervener help this student build concepts?
LUNCH For Your Mind?

- Pull out the handout “Role Comparison for Supporting Students Who are Deaf-Blind in Washington.”
- Read through it.
- Discuss the handout with someone.

“Did you know about interveners before today?”

“What’s your experience with interveners, if you’ve had any?”

What are your questions about interveners?
Interveners

Photos courtesy of National Center on Deaf-Blindness: https://nationaldb.org/
Scenario: Birth to Three

- Our team: Cindy (TVI) and Susan (TOD)
- Infant in rural area, parents from Russia
- Child has rare syndrome with intensive medical needs (g-tube for feeding, tracheostomy)
- Limited volitional movement
- Severe conductive HL – BAHA hearing aids
- Vision: abnormal optic nerves; hyperopia
- How to recognize and support development of communication, active learning
Scenario: Birth to Three

Video #1
https://www.youtube.com/watch?v=5qr8ck3042c

Video #2
https://www.youtube.com/watch?v=vm_S2Xafr6o
Scenario: Transition Age

- 17 year old Junior in a high school Deaf/HH Regional Program.
- Usher Syndrome Type II
- Vision: Retinitis Pigmentosa (Progressive Vision Loss), Peripheral Loss, 20/20 Acuity w/Glasses
- Hearing: Moderate Hearing Loss, Bilateral HA’s
- Upon graduation, student wishes to attend college, (Gallaudet or local college). Interested in studying art. Also wants a part-time job to earn spending money during the summers.
- Annual IEP meeting coming up, to include discussion of preparing for post-school.
Topics for this IEP Meeting:

1. Academic progress
2. Evaluations: Vision and O&M
3. Transition Goals:
   - Identify colleges of interest; application process and deadlines.
   - Identify possible careers related to art
   - Identify Adult Services: e.g. DVR, DDA, Dept. of Services f/t Blind (DSB), Deaf-Blind Service Center (DBSC).
   - Identify Pre-Employment Skills the student would like to develop.
Activity: In Groups of Three

- You are the student’s Teacher of the Deaf.
- One of the school’s paras has recently attended a workshop on Pro-Tactile, provided by the Lighthouse for the Blind for adults in the local Deaf-Blind community. The para approaches you and suggests that the IEP team discuss “teaching the student Pro-Tactile.”
IEP Scenario: Next steps?

A. In IEP meeting, suggest Pro-Tactile as a possible addition to the student’s academic program.

B. Save the topic of Pro-Tactile for another time, considering the topics on the IEP agenda already.

C. Contact the WSDS DB Project Transition Consultant about connecting with Deaf-Blind adult agencies for the student to access, including more about Pro-Tactile and other resources.

- Which option(s) would you pursue and why?
- What other information would you want to gather?
Scenario: School Age

- Child in gen ed middle school, rural district. (HH and VI/Blind, recurring health issues)
- Uses Listening/Spoken Language (LSL)
- Benefits from hearing aids & FM system
- Vision diagnosis: Glaucoma
- “Where is my stuff? Hearing aids, magnifiers, school bag, homework, books.”
- Services: Braille, O & M
- How to carry stuff, arrive on time, access learning, connect w/ peers, fill in gaps?
- Who might/should/could be on her team?
WSDS website: https://www.wsdsonline.org/
Questions?
Contact Us

Katie Humes, Director
khumes@pssed.org

Khanh Huhtala, Program Coordinator
khuhtala@pssed.org
(800) 572-7000

www.wsdsonline.org/
Resources

National Center on Deaf-Blindness (NCDB):
https://nationaldb.org/

Open Hands, Open Access (OHOA) Deaf-Blind Intervener Learning Modules. Washington Cohort (WSDS):
Strategies for Increasing Expressive Communication

- Hand Under Hand
  https://www.wsdsonline.org/hand-under-hand/

- Consistent Routines
  https://www.wsdsonline.org/routines/

- Motivation for Communication: Likes/Dislikes
  https://www.wsdsonline.org/likes-dislikes/
References


Bruce, S., Janssen, M., Bashinski, S. (2016). Individualizing and personalizing communication and literacy instruction for children who are deafblind. Journal of Deafblind Studies on Communication. 2 (1), 73-87

References


Rowland, C. (2009). *Assessing communication and learning in young children who are deaf blind or who have multiple disabilities*. Retrieved June, 2013, from:

