Introduction to Deaf-Blindness and the Virginia Project for Children and Young Adults with Deaf-Blindness

The Virginia Project for Children & Young Adults with Deaf-Blindness
Agenda

- Overview of Virginia Hands and Voices
- Introduction to Deaf-Blindness
- Virginia Deaf-Blind Project overview
- Early Pre-Linguistic Communication
- Questions and discussion
Virginia Hands & Voices is dedicated to supporting families with children who are DHH without a bias around communication modes or methodology. We're a parent-driven, non-profit organization providing families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. Our outreach activities, parent/professional collaboration, and advocacy efforts are focused on enabling DHH children to reach their highest potential.
What Do We Do Nationally and Locally?

- We provide parents with helpful resources, networks and information
- We offer outreach activities and parent/professional collaboration
- We provide virtual learning opportunities
- Help parents improve communication access and educational outcomes
- We create social opportunities for parents, children and professionals
- We seek out learning opportunities our members may benefit from
Introduction to Deaf-Blindness and Early Pre-linguistic Communication

The Virginia Project for Children & Young Adults with Deaf-Blindness

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“I began to realize how important it was to be an enthusiast in life. If you are interested in something, no matter what it is, go at it full speed ahead. Embrace it with both arms, hug it, love it and above all become passionate about it.”

- Roald Dahl | @projecthappiness_org
Deaf-Blindness

- **Myth**: Deaf-Blind always implies total absence of hearing and vision
- The term deaf-blind includes individuals who have a **wide range of hearing and vision loss**
  - Vision and hearing loss may differ in severity and cause
  - The combined loss occurs when one sense is not able to compensate for the loss of the other
  - Severely limits natural opportunities to learn and communicate
  - 90% of children with deaf-blindness have one or more additional disabilities and/or health concerns
Etiologies in Deaf-Blindness

- Hereditary Syndromes/Disorders
  - CHARGE Syndrome
  - Usher Syndrome (I, II, III)
  - Down Syndrome

- Prenatal/Congenital Complications
  - Cytomegalovirus (CMV)
  - Meningitis
  - Microcephaly
  - Hydrocephaly
  - Congenital Rubella
  - Zika
Impact of Deaf-Blindness

- Communication
- Exploration, Mobility, Engagement, Participation
- Relationships, Social Interactions, Friendships
- Visual and Mental Memory, Concept Development
- Independence
- Incidental Learning
Impact of Deaf-Blindness

Learning for a Typical Child

Direct Learning

Secondary Learning

Incidental Learning

Learning for a Child with Deaf-Blindness

Direct
Hands-on experiences are essential
The best way to learn

Secondary
Is difficult

Incidental
Usually does not occur and is not effective
What We Offer

1. Family support from the Project’s Family Engagement Specialist.

2. Customized on-site and virtual coaching and consultation on deaf-blind specific strategies including communication and engagement strategies.


4. Free Lending Library of books, videos and other resources.

5. Online training modules that focus on a variety of topics that impact a child with deaf-blindness.
Connections to National & State Family Organizations

[Logos for NFADB, CHARGE Syndrome Foundation, USH, and Ana's Voice]
We are federally required to keep a census of individuals in the state under the age of 22 who meet the federal criteria for “deaf-blindness”.
# 2018 State & National Count

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*Our number increased from last year and we couldn’t do it without our partners, like you!*

National Center on Deaf-Blindness, 2017
FAQs

Q: My child has vision loss but does not receive vision services. Can he/she still be on the Child Count?

As long as vision and/or hearing impacts their access to education, they can be eligible to be on our Child Count and receive support from the VDBP.

Q: I think my child has a hearing loss, but it is not diagnosed yet. Can he/she still be on the Child Count?

The child can be on our Child Count under the category of “Further Testing Needed” up to 1 year while the team works on getting a diagnosis. For that year, the family and team can receive support from the VDBP.
“Senses & Census-ability” webinar

Get Connected

Virginia Deaf-Blind Project website:
https://sites.google.com/vcu.edu/vadeafblindproject/home?authuser=0

- Professional development opportunities
- Updated Child Count resources (coming soon)
- Lending Library

Virginia Deaf-Blind Educators Community
Registration: https://forms.gle/SM2b1w2ewTJt3kQ17
- Monthly web conferences
- Online resources
Early Prelinguistic Communication
What do you think of when you hear this phrase?
Assessing Expressive Communication: Form and Function

https://communicationmatrix.org/
Forms of Communication
How we communicate

Forms can be divided into:

- non-symbolic forms (body movements, objects, etc.)
- symbolic forms (arbitrary symbols such as words, visual languages, tactile symbols, etc.)

objects
tactile symbols
Communication Partners

Building Trusting Relationships Through Presence and Availability

During all interactions . . .

• Stays fully present, not engaged in other interactions or activities when interacting with the child
• Stays open and available, waiting calmly and quietly for initiatives or responses
• Waits calmly for as long as the child needs to give a response
• Takes advantage of the here and now as a learning opportunity
• Does not rush through activities

Communication Partners
Processing Time

"Literacy For Us: Developing a Foundation for Literacy in Children with Deaf-Blindness"
Communication Partners
Joint Attention
Communication Partners
Reciprocal Turn-Taking
Communication Partners
Reciprocal Turn-Taking
Thank You!

Any questions?

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