

# Family Leadership: Learning from our Families whose Child is Deaf-Blind

Amanda Campbell, Family Leader, SC Deaf-Blind Project Heather Dirks, Family Engagement Coordinator, IA Deaf-Blind Program, EHDI Jana Villemez, Family Engagement Initiative Lead, NCDB

# Family Voice and The Power of Story

- 1) Understanding deaf-blindness as a unique disability.
- 2) Recognize the shared perspectives of families who are here today; and,
- 3) Realize the complexity of family systems, which includes grief and loss associated with the journey, while navigating the unknown for their child who is deafblind.

#### What is Deaf-blindness?

IDEA Regulations, Sec. 300.8 (c) (2)

- "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."
- <u>Etiology Code List for Deaf-Blindness</u>
- <u>Contact your State Deaf-Blind Program</u> for more information on eligibility and support.

# Heather Dirks: Exhale Through the Ordinary



**Husband - Robert** 

Lani (13)

Cambria (11)

Brecken (9)

Emberlynn (6)

#### Lani's Birth



#### **Lani's Early Years**



#### **Diagnosis and Survival**



#### **Rewarding and Exhausting**



#### **Taking a Step Back**



## A "Normal" Teenager



### "Exhale Through the Ordinary"



#### **Amanda Campbell: Finding My Voice**



**Husband - Morgan** 

Ian (14)

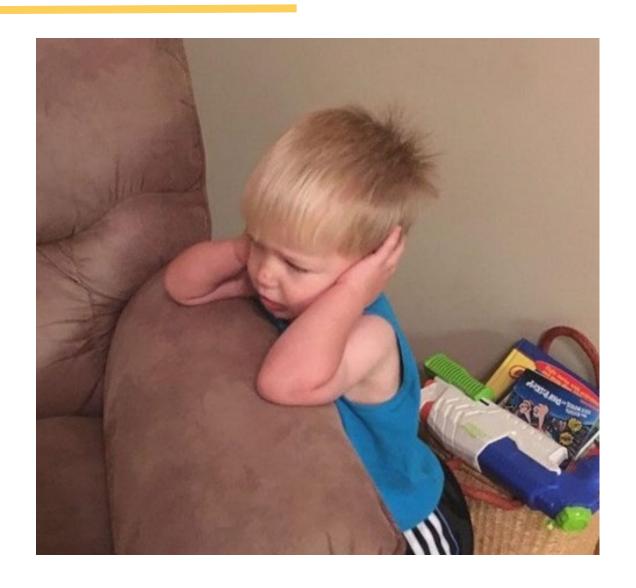
Micah (8)

Mia (5)

#### Micah's Initial Diagnosis



### Micah's Early Years



## Mia's Initial Diagnosis



#### **Usher Syndrome Diagnosis**



#### Acceptance



## Community



#### The Story Continues...



# **Elevating Families in all NCDB Initiatives**

- Family Engagement Helping families partner with service providers and advocate for their children
- Identification and Referral Receiving appropriate services as early as possible and families understanding the impact of deafblindness as early as possible
- Interveners and Qualified Personnel Personnel development and adoption of interveners and teachers of the deaf-blind and engagement with the family, and valuing families as the expert in their child
- Transition Educational opportunities and planning that lead to a meaningful adult life - which includes family engagement and leadership in preparation after high school and beyond

#### **NCDB** Website Features

- Extensive information about deaf-blindness, educational practices, and professional development opportunities
- Details about our initiative-focused work
- The National Deaf-Blind Child Count data on on children and youth who are deaf-blind, including demographics and causes of deaf-blindness
- Contact information for state deaf-blind projects
- Resources to help families learn and connect to agencies and organizations

nationaldb.org

#### Resources

**Etiology Code List for Deaf-Blindness** 

For Families Section of the NCDB website

OHOA Learning Modules in English and Spanish

Parent-professional-relationship

**Telling Your Child's Story** 

The Impact of Deaf-Blindness and Learning

The Impact of Having a Child Who is Deafblind on the Family

<u>The Value of Family Engagement: Identifying Unique Needs and Priorities of Families with Children Who Are Deaf-Blind</u>

<u>Understanding Your Child and Sharing What you Know</u>

Please Contact Us!

Amanda Campbell: <u>amanda.campbell82@gmail.com</u>

Heather Dirks: <a href="mailto:heather.dirks@iaedb.org">heather.dirks@iaedb.org</a>

Jana Villemez: <u>Javillemez@helenkeller.org</u>



## National Center on Deaf-Blindness







The contents of this presentation were developed under a grant from the U.S. Department of Education, #H326T180026. However, those contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Susan Weigert.