



**National Center
on Deaf-Blindness**

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

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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.”
- [Etiology Code List for Deaf-Blindness](#)
- [Contact your State Deaf-Blind Program](#) 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



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**](https://nationaldb.org)

Resources

[Contact your State Deaf-Blind Program](#)

[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](#)

[The Value of Family Engagement: Identifying Unique Needs and Priorities of Families with Children Who Are Deaf-Blind](#)

[Understanding Your Child and Sharing What you Know](#)

Please Contact Us!

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DEAFBLIND
PROJECT



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