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.
The Value of Family Engagement Priorities

1. Meet families where they are.
2. Grow family connections.
3. Deepen understanding of the unique experiences of deafblind.
4. Empower families.
5. Strengthen family voice.
6. Provide meaningful and relevant information.
7. Work toward equity for all families.
8. Increase family leadership at all levels.
Family Empowerment: 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
A Family-Centered Approach

- Family Support at Individual Level
- Family Engagement at Community Level
- Family Leadership at State and National Policy Level
Our Families: System Navigation

FAMILY

- School
- Medical
- Social Network
- Financial
- Law
Meeting Families Where They Are

Forenza, Eileen, Colorado Dept of Public Health and Environment, *Activating Causal Leadership*
Family Empowerment: Building their Story

- Start where the family is
- Reflecting on highs and lows in the journey
- Identifying the strengths and what the family has learned
- Celebrating the joy amidst the grief
- Set in the context of being in community with other families
Tiara Jones Story

- FamilyConnect Board Member
- Son is Max, 16 y/o
- Support System
- Values
- Trauma and Grief
Walked by Faith
First Step in Connecting
Grandma’s Walking by Max’s Side
Surgery One Step Forward and Steps Back
Miles Further Along
Many Small Steps Lead to a Big Meeting
Enjoy the Moment on our Walking in Faith
Our Walk Continues Forward
About NCDB

- The National Center on Deaf-Blindness is a Technical Assistance and Information Dissemination Center
- Our goal is to improve services, educational results, and quality of life for children who are deaf-blind
- Work closely with state deaf-blind projects and other partners across the country
- Funded by the U.S. Department of Education’s Office of Special Education Programs
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
Thank you!

Jana Villemez: jvillemez@helenkeller.org
Tiara Jones: maxway1.tj@gmail.com
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