



**National Center
on Deaf-Blindness**

Deafblindness, Family Engagement, and Family Empowerment

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Member**

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.

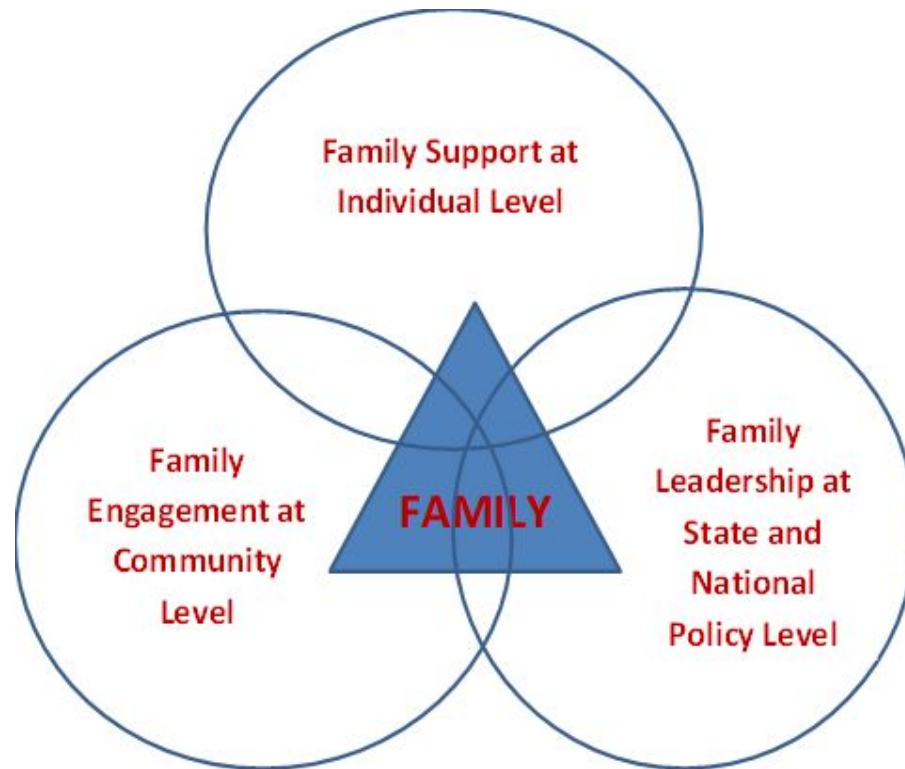
The Value of Family Engagement Priorities

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.

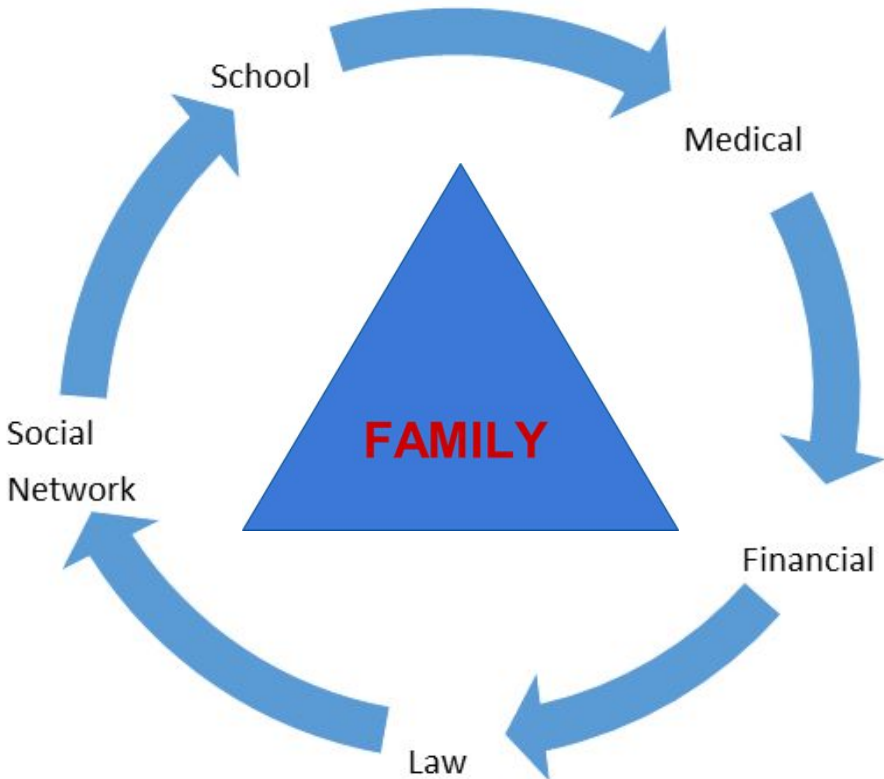
Family Empowerment: Elevating Families in all NCDB Initiatives

- **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**

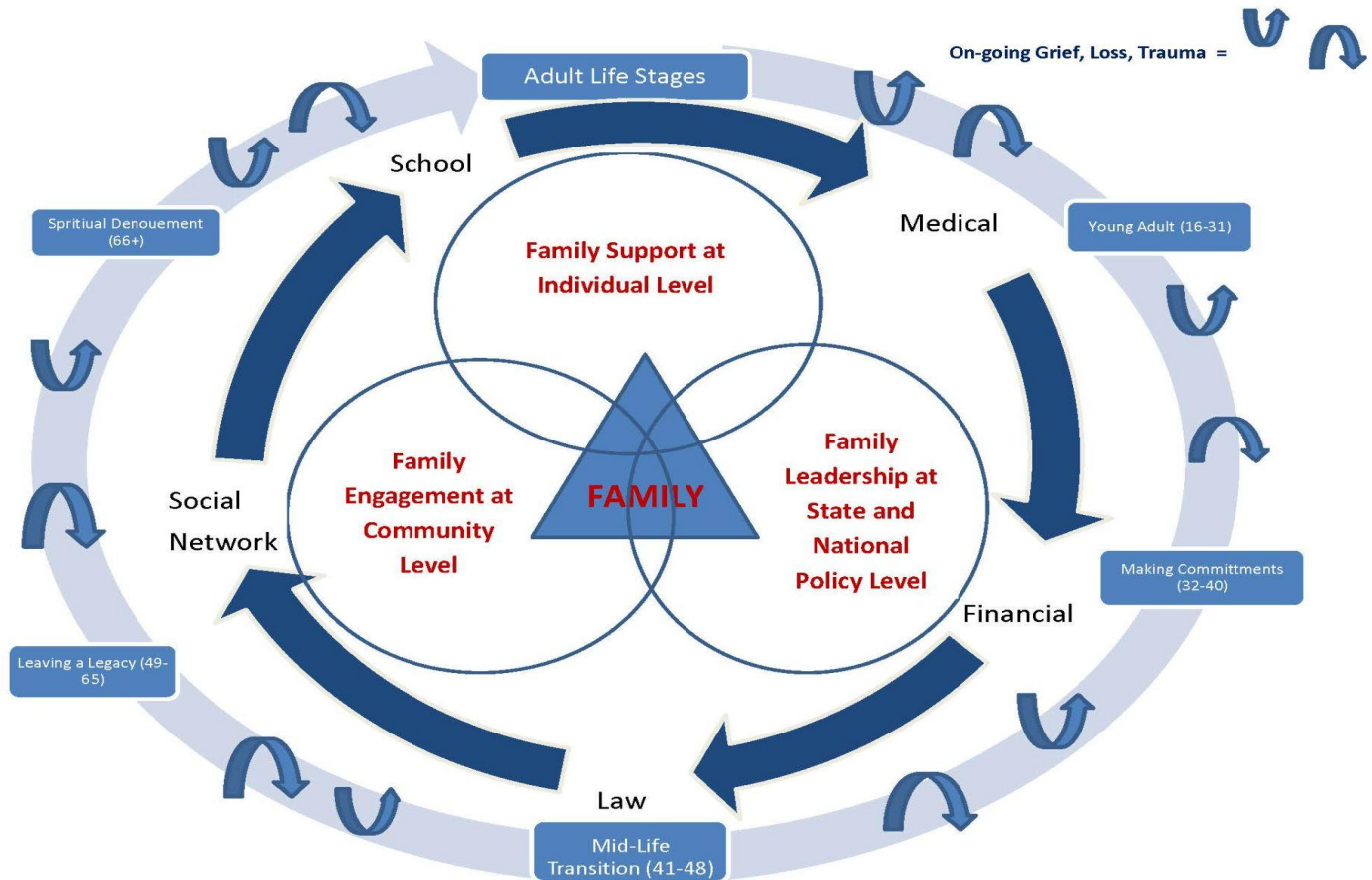
A Family-Centered Approach



Our Families: System Navigation



Meeting Families Where They Are



Forenza, Eileen, Colorado Dept of Public Health and Environment, *Activating Causal Leadership*
Bronfenbrenner, Urie, *Ecological systems theory*. Six theories of child development: Revised formulations and current issues. (pp.187-249). London, England: Kingsley Publishers.

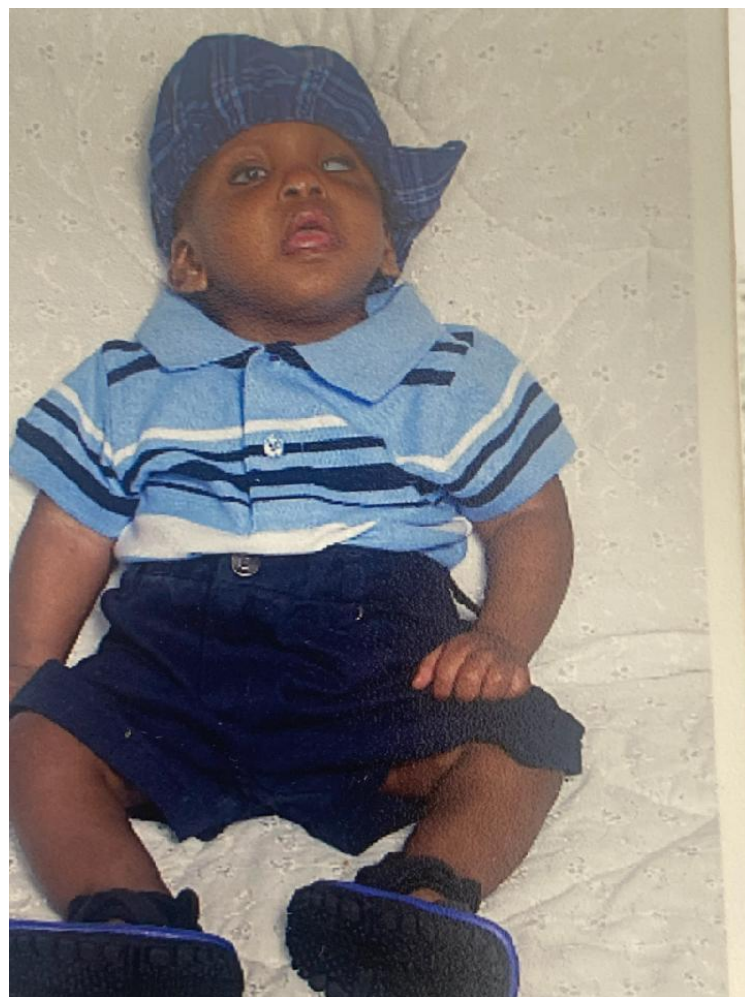
Family Empowerment: Building their Story

- 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

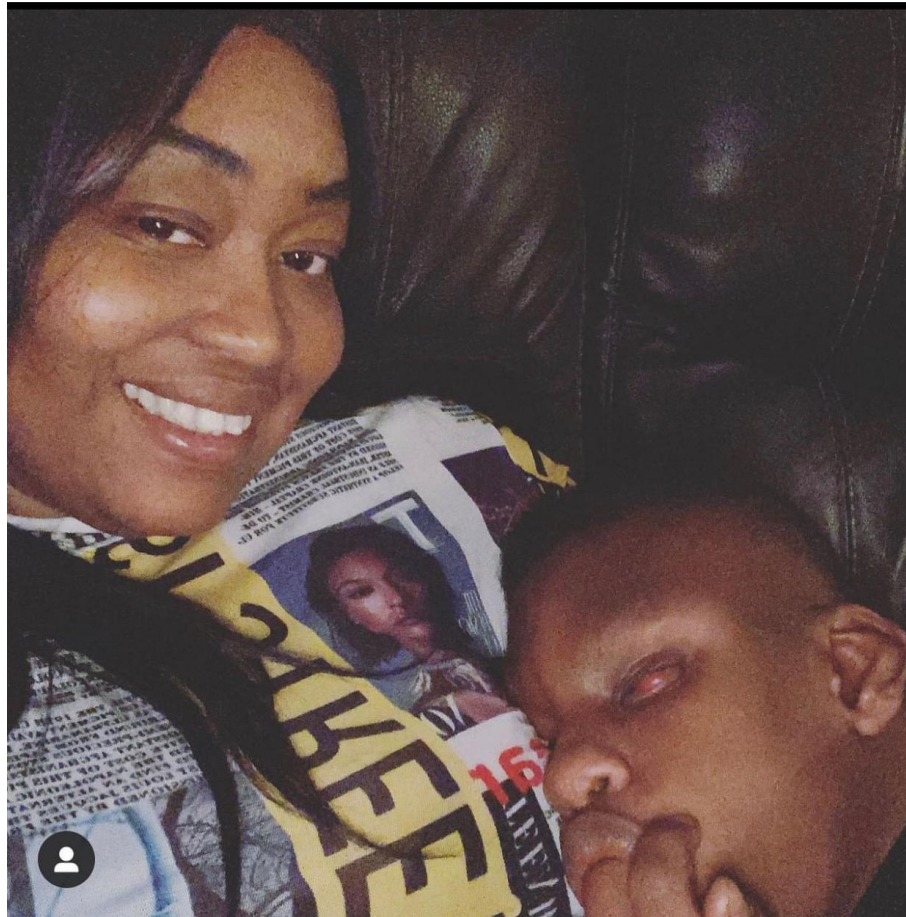


TikTok
@maxjones512

Max was playing kick ball
First clip he was kicking the ball
2nd clip he was going to the bases
3rd clip he was the throwing the ball
so his friend could kick it

max.way1

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](#)

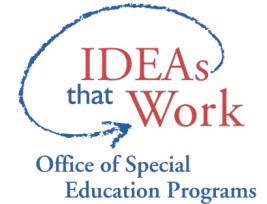
Thank you!

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