Providing Accessible Training and Home Support

About the Presenters

Nicole Rambeau, MOTR/L is a pediatric occupational therapist who primarily provides early intervention services to families in Northern Arizona. She is project coordinator of the PATHS program.

Sara Clancey, PhD, MOTR/L, IMH-E is a pediatric occupational therapist who primarily provides early intervention services to families living on the Navajo Nation. She is also the project director for the PATHS program.

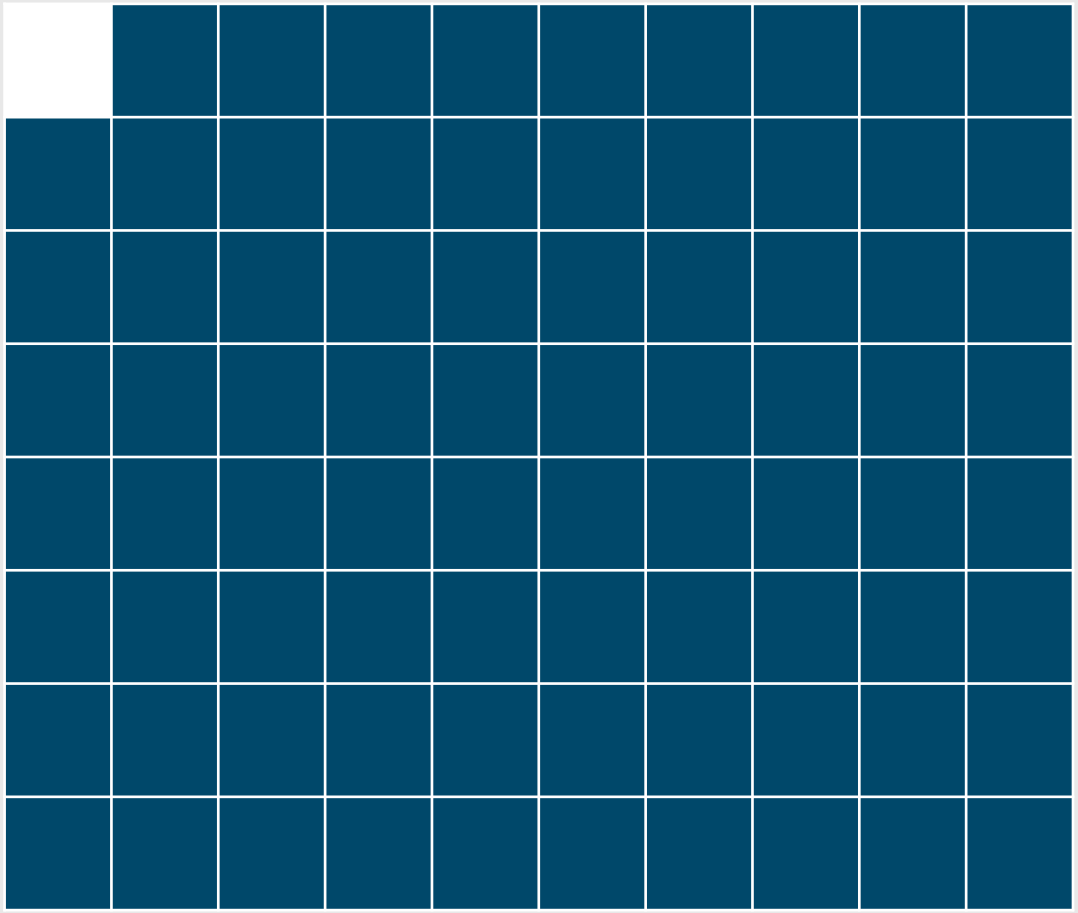
Lindsay Brillhart is a self-advocate, mom of two, a board member for TASP, and a partner with the PATHS project as a member of the parent advisory board & co-presenter for trainings.

Your Turn:

Please share your role & what you are most curious about learning today

Learning Objectives:

- Understand what parents with ID experience & how they respond
- Identify the role of home visiting programs in supporting parents with ID
- Become familiar with the PATHS project & where to access resources
- List important takeaways from interviews with home visitors
- Contribute to a discussion regarding next steps



1 in 100 women have an intellectual disability

Maulik et al., 2011

1.6 million parents have a cognitive disability

Brandeis National Research Center for Parents with Disabilities

How are women with ID impacted?

- Between 60-90% of women with mild ID would like to marry & have children (Brantlinger 1985)
- Fertility rates are similar to women without ID
- More likely to experience poverty, housing instability, social isolation, intimate partner violence, and other forms of abuse
- Significantly higher risk for depression and anxiety (Brown et al. 2022)

How are parents with ID impacted?

- Parents tend to be younger and less likely to be married
- Higher rates of poverty, trauma, stress, and social isolation (West & Dibble, 2022)
- 40-80% of parents with ID experience children being removed from their home (NCD, Rocking the Cradle, 2012)
- Approximately 1/5th of children in foster care have a parent with a disability (DeZelar & Lightfoot, 2019)

How are children of parents with ID impacted?

- At a higher risk for premature birth, low birth weight, stillbirth, and preeclampsia (West & Dibble, 2022)
- At higher risk for developmental delays, behavioral challenges, and speech and language problems (Emerson, 2011)

- Many are excited to be parents and want to be "good" parents
- May feel isolated
- May have difficulties navigating multiple healthcare and support systems
- Are fearful of child welfare involvement
- Often feel judged by professionals
- All contribute to decreased willingness and use of community resources

How do parents with ID respond?

Your Turn:

What would you add to how parents with ID respond?

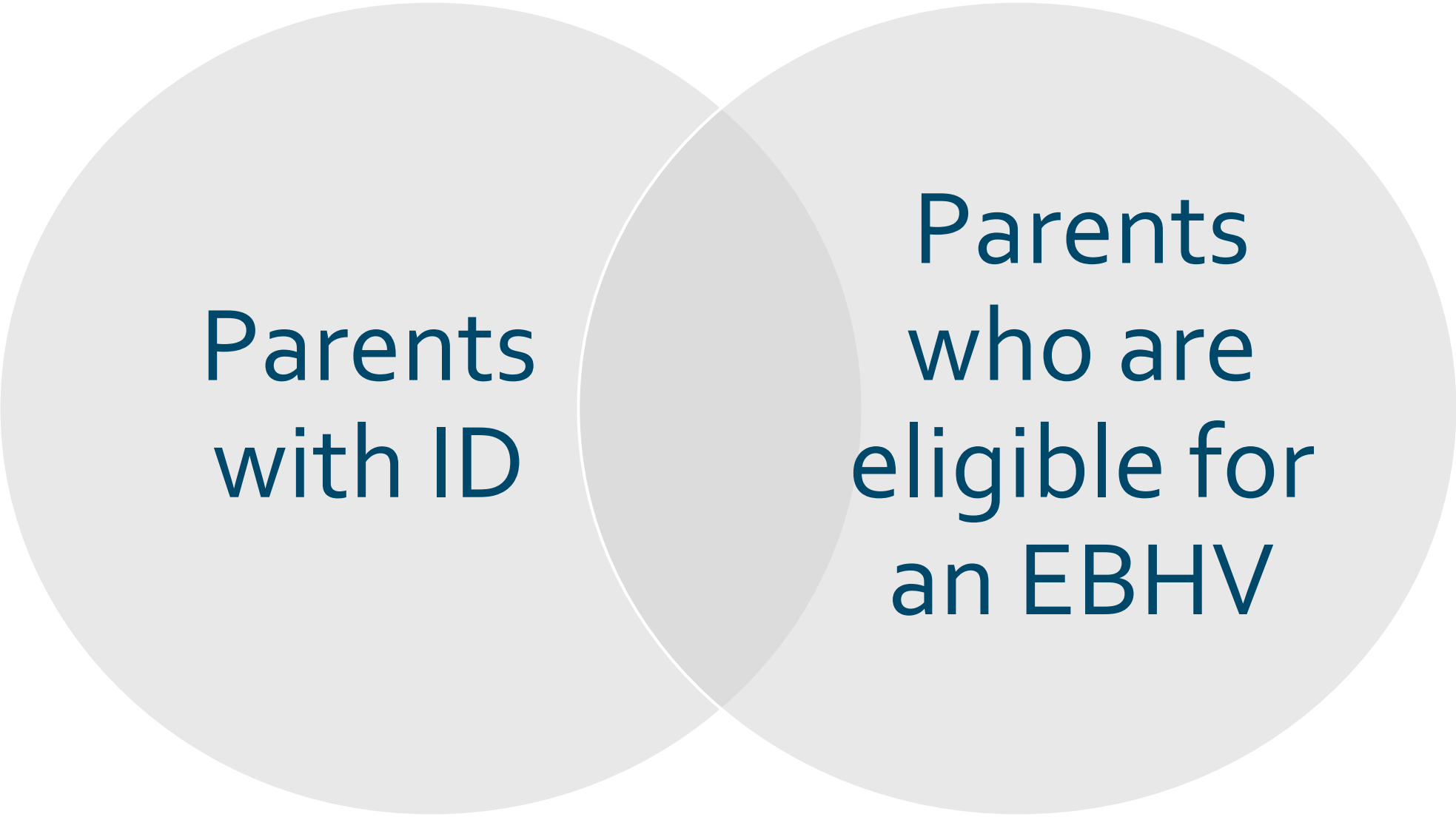
What is the role of home visiting with supporting parents with ID?

Evidence Based Home Visiting (EBHV)

- Federally funded by MIECHV
- Intended to improve health, development, and life course outcomes
- Serve pregnant women and families with children up to 5 years of age
- Mothers and families who are considered vulnerable are eligible
- Specific models have been deemed as effective by HomVEE

For example: Nurse Family Partnerships (NFP)

- Specific model that is deemed as evidence-based
- Designed for pregnant women and their families who are low income and first-time parents
- Registered nurse visits families at their home prior to the birth of their baby and afterwards
- Use a specific curriculum that aligns with their program's values


Parents with ID
Parents who are eligible for an EBHV

The PATHS Project

- Funded by the Arizona Developmental Disabilities Planning Council
- Collaboration of the Institute for Human Development at NAU, home visiting programs, and self-advocates
- Primary goal was to gain understanding of HV perceptions & create trainings to improve awareness of parents with ID

The PATHS Project

- Two advisory boards were created to help guide programing
- A 3-part training series were created and implemented to different groups of home visitors
- Home visitors were interviewed to better understand their experiences and capacity to support parents with ID

https://in.nau.edu/institute-human-development/paths

The PATHS Project key takeaways:

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1. **Attendees of the virtual training series loved being able to hear from parent self-advocates**

The PATHS Project key takeaways:

2. Home visitors expressed their awareness and importance of building relationships with families

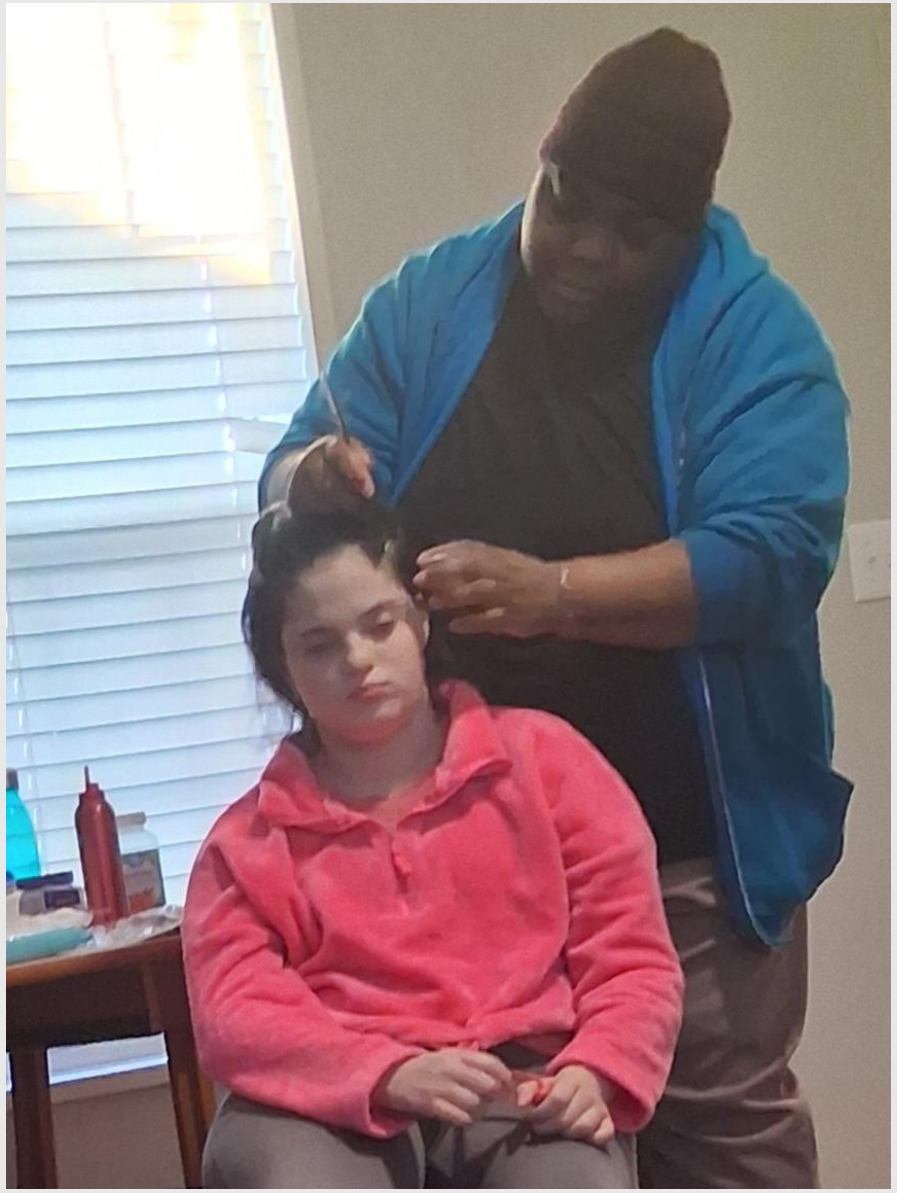
The PATHS Project key takeaways:

3. Home visitors recognized when a parent was having difficulties in learning information and tried to change their services to better fit a family's needs

Discussion & Questions

Your Turn:

Is the term "intellectual disability" easy for everyone to understand?



Your Turn:

Do you think families would feel comfortable having a home visitor ask about a disability?

Your Turn:

How do parents with ID find the right support for their family?

THANK YOU!

Please reach out to Nicole Rambeau at nicole.rambeau@nau.edu or Sara Clancey at sara.clancey@nau.edu for questions & collaboration