

Empowering Births: The Intersection of Disability Justice and Perinatal Care

Kara Ayers, PhD

kara.ayers@cchmc.org



UCCEDD/LEND

University of Cincinnati Center for
Excellence in Developmental Disabilities
Leadership Education in Neurodevelopmental
and related Disabilities



Kara Ayers, PhD

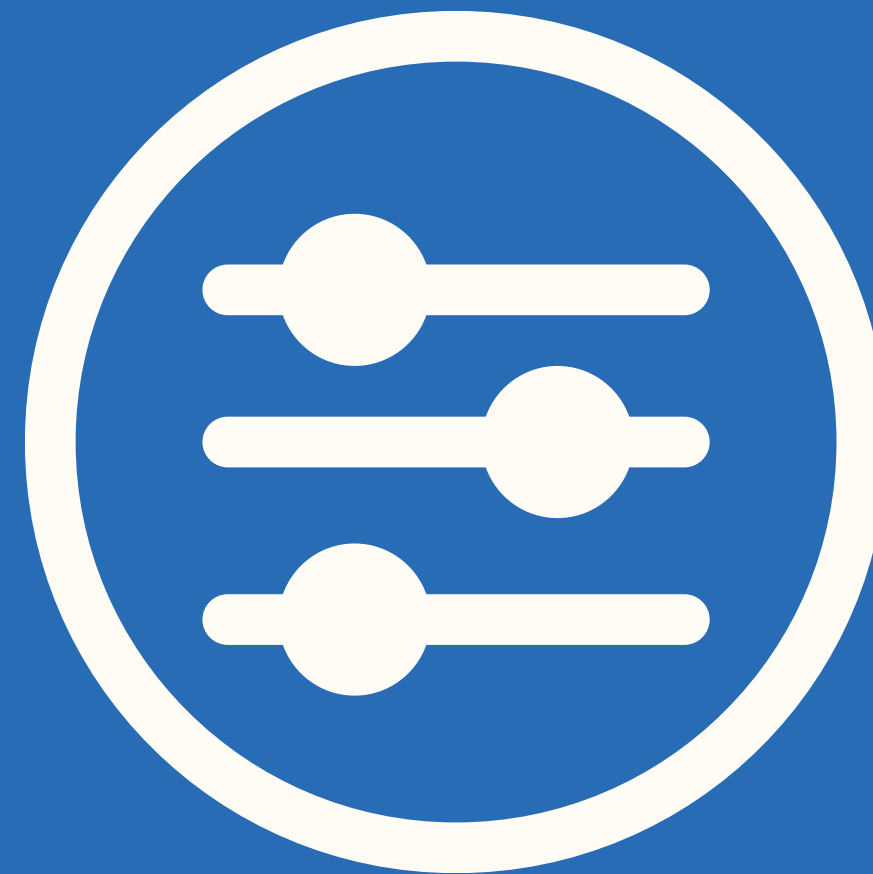
- Professor and researcher
- Trained as a clinical psychologist
- Disabled Parenting Project
- National Research Center for Parents with Disabilities
- National Center for Disability and Pregnancy Research
- No disclosures for this talk



Our Goals:

- Recognize how ableism can manifest in perinatal care and its impact on trauma
- Foster competence in applying anti-ableist, trauma-informed approaches in perinatal care
- Spark a commitment to continue unlearning ableism and practicing disability justice

Level setting with the words we use





Inclusive Language

Person-First Language

Identity-First Language



**Disability or
Disabled.
Say the word.**



**Ableism can be
covert but is
still poisonous.**

A hand-drawn question mark is shown on a light blue, textured background. The word "NORMAL" is written in a bold, black, sans-serif font across the top curve of the question mark. The question mark is drawn with thick, black, textured lines, and a hand is visible at the bottom left, holding the pen that drew it.

NORMAL

Ableism is:

- a false belief that people with disabilities are inferior
- discrimination against people with disabilities
- a set of taught practices and beliefs, which assume nondisabled-ness is the norm .

ABLEISM



A WORKING DEFINITION BY T.L. LEWIS

A system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism, and capitalism.

This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily (re)produce, excel, and "behave."

You do not have to be disabled to experience ableism.

**YOU DO NOT HAVE TO BE
DISABLED TO
EXPERIENCE ABLEISM.**

**Ableism Experienced
by Pregnant People
and Parents with
Disabilities in
Healthcare Settings**

Types of ableism



Internalized




Interpersonal



Systemic or Institutional

MICROAGGRESSIONS EXPERIENCED BY DISABLED PARENTS

Type	Description	Example
Invasion of privacy	People may invade personal space and ask personal questions because you have a disability.	"What happened to you?" "Oh here let me pick her up for you." (Picking up child without asking.)
Helplessness	People may frantically try to help and treat you like a child.	"Oh let me do that for you!" Running to open doors.
Patronization	People praising you for almost anything and finding it surprising you do ordinary things.	"It is so good to see you out and about!"
Denial of disability	Disability is ignored-or claimed to be ignored.	"I don't even think of you as having a disability"
Questioning our children	People may ask children personal questions about their parents or how their family works.	"You are so kind to help your parents." "Who takes out the trash in your house?"



CASE STUDY

Blake Sinnett, Erika Johnson, and Baby Mikaela

May 21, 2010: Mikaela born; Nurse makes hotline report to DFS at 3:15 p.m.

May 24, 2010: Mikaela discharged from hospital and placed in foster care.

May 25, 2010: Petition filed by juvenile officer.

May 26, 2010: Protective Custody Hearing (initial detention hearing); note that caseworker informs Johnson and Sinnett of hearing, but does not inform them of right to be represented by an attorney; court order reflects that attorneys will be appointed for mother and father.

June 16, 2010: Pretrial Hearing; I attended with Johnson and Sinnett; we denied the Petition allegations and requested immediate removal of Mikaela from foster care and placement with parents; no other evidence or testimony allowed for submission; case set for adjudication (trial) on July 20, 2010 (by law, the adjudication must be set within 60 days of when child is removed from parental care; here it was scheduled on the 57th day).

July 20, 2010: Adjudication set for 3:00 p.m.; at 11:00 a.m. the juvenile officer faxed me the Voluntary Dismissal.



**DISABILITY
JUSTICE AS A
PATH FORWARD**

DISABILITY JUSTICE PRINCIPLES (BERNE, 2018)

1. Intersectionality
2. Encouraging leadership by disabled people
3. Resisting normative capitalist production
4. Engaging with cross-movement solidarity
5. Valuing wholeness
6. Pursuing sustainability
7. Fostering cross-disability participation
8. Normalizing interdependence
9. Understanding access as a collective effort
10. Cultivating collective liberation

What does the research tell us?

- Parents with intellectual disabilities CAN learn parenting skills if there is a gap in their knowledge (Feldman & Tahir, 2016).
- Parents with disabilities are OVERrepresented in child protective services despite parental disability not being predictive of abuse or neglect (LaLiberte et al., 2024).
- When last compared (2018), Ohio used “parental disability” more than any other state as reason for termination of parental rights (DeZelar & Lightfoot, 2018).

DeZelar, S., & Lightfoot, E. (2018). Use of parental disability as a removal reason for children in foster care in the US. *Children and Youth Services Review*, 86, 128-134.

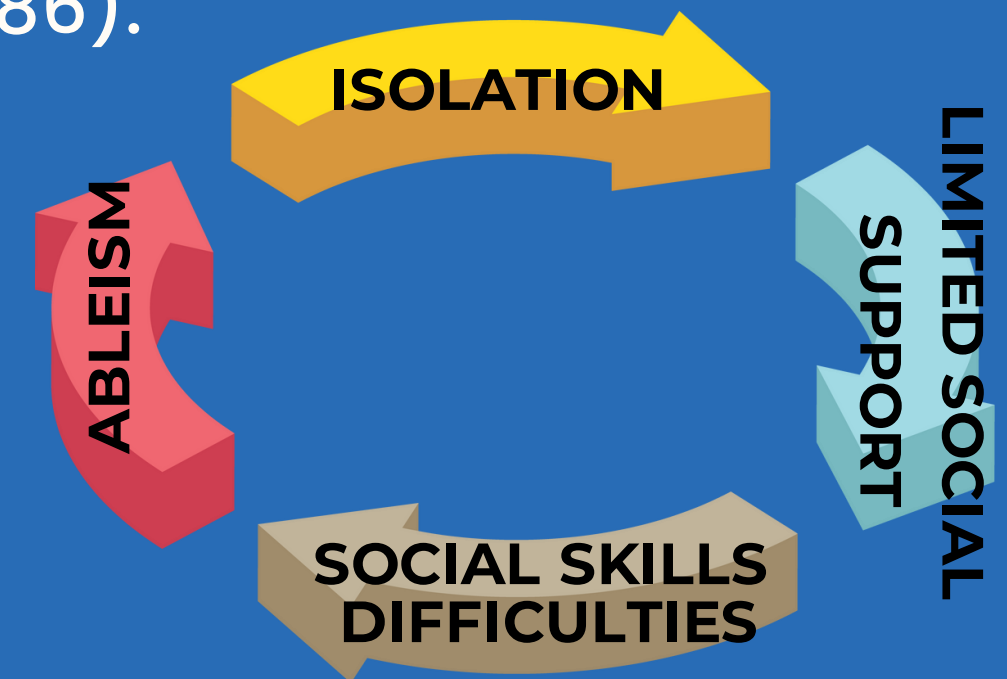
Feldman, M. A., & Tahir, M. (2016). Skills training for parents with intellectual disabilities. *Handbook of evidence-based practices in intellectual and developmental disabilities*, 615-631.

LaLiberte, T., Piescher, K., Mickelson, N., & Lee, M. H. (2024). The overrepresentation of parents with disabilities in child protection. *Children and Youth Services Review*, 158, 107446.

Lightfoot, E., LaLiberte, T., & Cho, M. (2017). A case record review of termination of parental rights cases involving parents with a disability. *Children and Youth Services Review*, 79, 399-407.

What does the research tell us?

- IQ is not an accurate predictor of abuse or neglect (Azar, Stevenson, & Johnson, 2012).
- Parenting risk is better explained and addressed through intervention with other models, including Social Information Processing (Azar, Twentyman, & Kendall, 1986).



Azar, S. T., Stevenson, M. T., & Johnson, D. R. (2012). Intellectual disabilities and neglectful parenting: Preliminary findings on the role of cognition in parenting risk. *Journal of Mental Health Research in Intellectual Disabilities*, 5(2), 94-129.

Azar, S. T., Twentyman, C., & Kendall, P. C. (1986). *Advances in cognitive-behavioral research and therapy*.

What does my research tell us?



- Parents with disabilities have a number of strengths including: acceptance of variations in their children's interests and abilities, adaptability, problem-solving skills, and resilience.
- Parents with disabilities want to partner with their children's health teams. Many have experience navigating healthcare systems.
- Artificial intelligence holds the potential to help AND harm parents with disabilities.

Current research with disabled parents

- Piloting the Accessible Pregnancy Action Plan (APAP) with pregnant people with disabilities
- Piloting the Empowered Disabled Parents Intervention
- Applying health empowerment theory to support healthcare access and utilization by parents with disabilities

Are you a pregnant person with a disability who would like support developing an **Accessible Pregnancy Action Plan** ?

Our research team is working to develop a tool, which we call the **Accessible Pregnancy Action Plan**. This tool would help pregnant people with disabilities think about what they need during pregnancy, during birth, and after having their baby.



We are looking for:

- Pregnant people with disabilities, who are ...
- between 12 and 36 weeks pregnant with their first child, and who ...
- speak English or use ASL to communicate.



Participants will work on their Action Plan with a peer facilitator, who is also a parent with a disability. These meetings will take place over Zoom. There will be between 2 and 4 meetings.

Most participants will complete the intervention in two sessions. They will be paid \$50 per session. Participants who complete the program will also be compensated an additional \$50.



If you have questions, please contact: kara.ayers@cchmc.org



If you'd like to participate, please complete this survey:

<https://redcap.link/caka65t0>



Are you a parent with an intellectual or developmental disability?

We are excited to introduce a new program made for parents like you! Our **Empowering Disabled Parents Intervention (EDPI)** aims to support you in parenting and finding supports and resources for your family. This program will help you think about what matters most to you. You'll work with another parent with a disability to talk about parenting and practice skills.



You and a peer facilitator will meet online through Zoom sessions. The program takes people about 3-4 sessions. For your valuable time and participation, we will compensate you in gift cards worth \$150 if you complete the entire program.



If you're interested in participating or have any questions, please complete this survey. [Insert Survey Link Here]



If you have questions or would like more information, contact Kara Ayers at kara.ayers@cchmc.org.



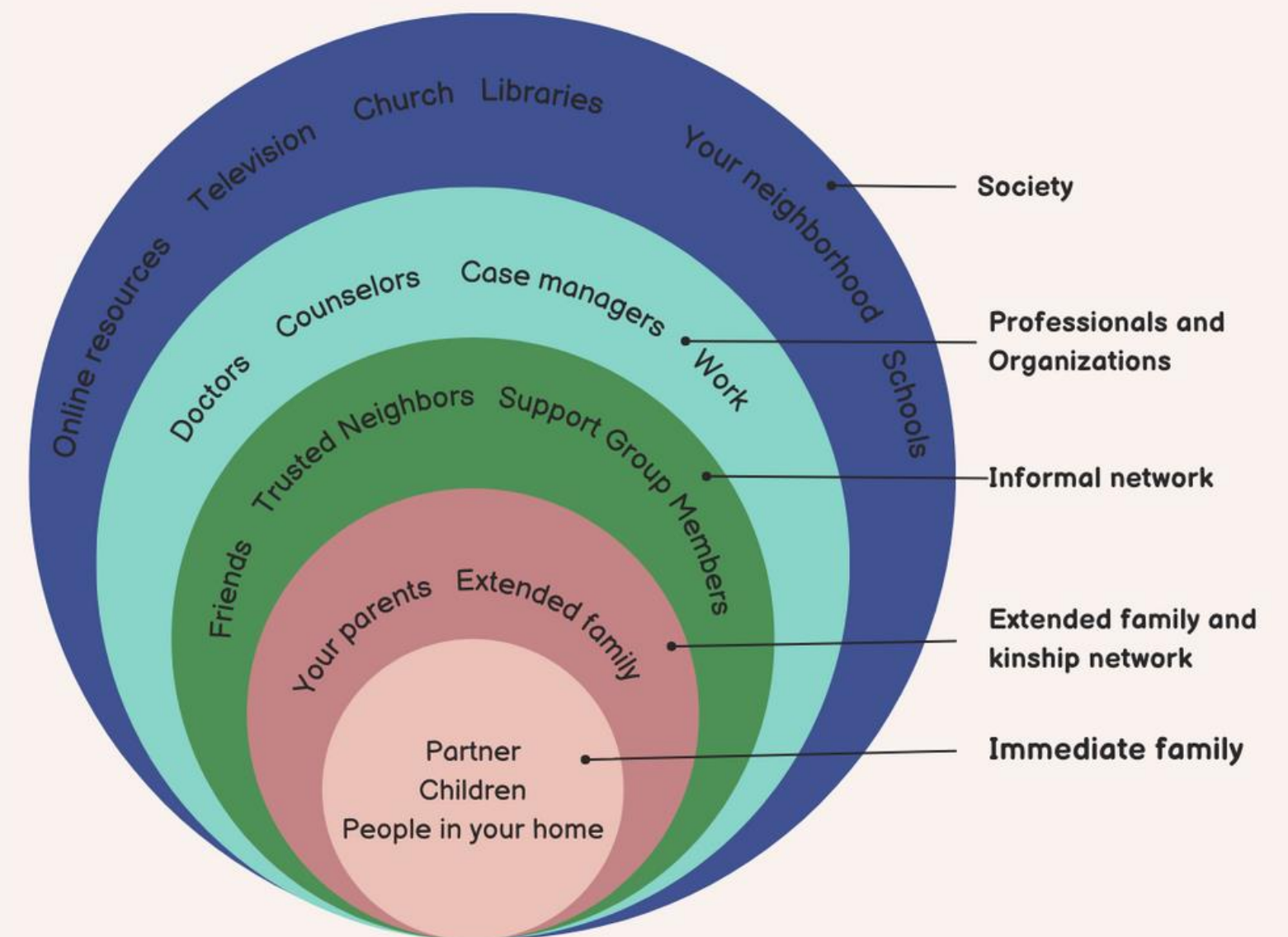
Health Empowerment Theory



What Matters Most

Supporting navigational literacy and health literacy as part of the Empowered Disabled Parenting Intervention

Mapping Family Supports



Adapted from *Enabling & Empowering Families* by Dunst, Trivette, and Deal (1988)

Module 1 (cont.)

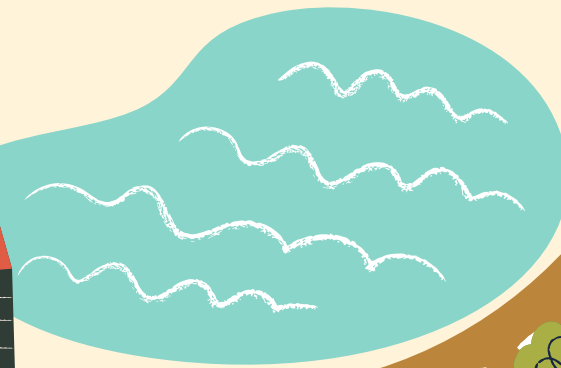
1.3 Pride Practice

Conclude this module by asking the participant to reflect on what makes them most proud about their family. Encourage them to choose a point of pride about their family and also a point of pride about themselves as a parent.





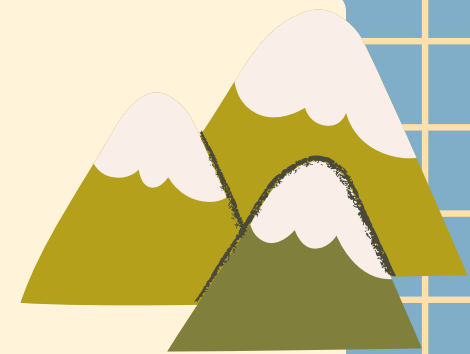
In the home



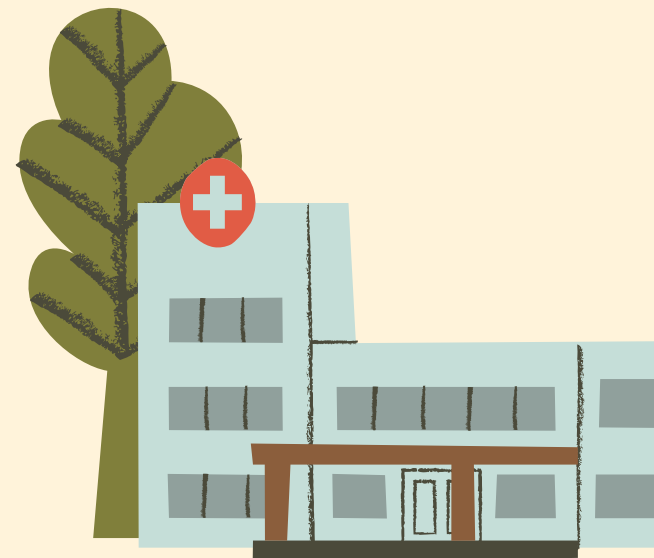
At places to play



At church



Using transportation



At your doctor



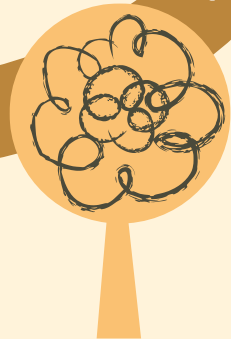
Through your child's school



At the grocery, food banks, and other places for supplies



In our neighborhood



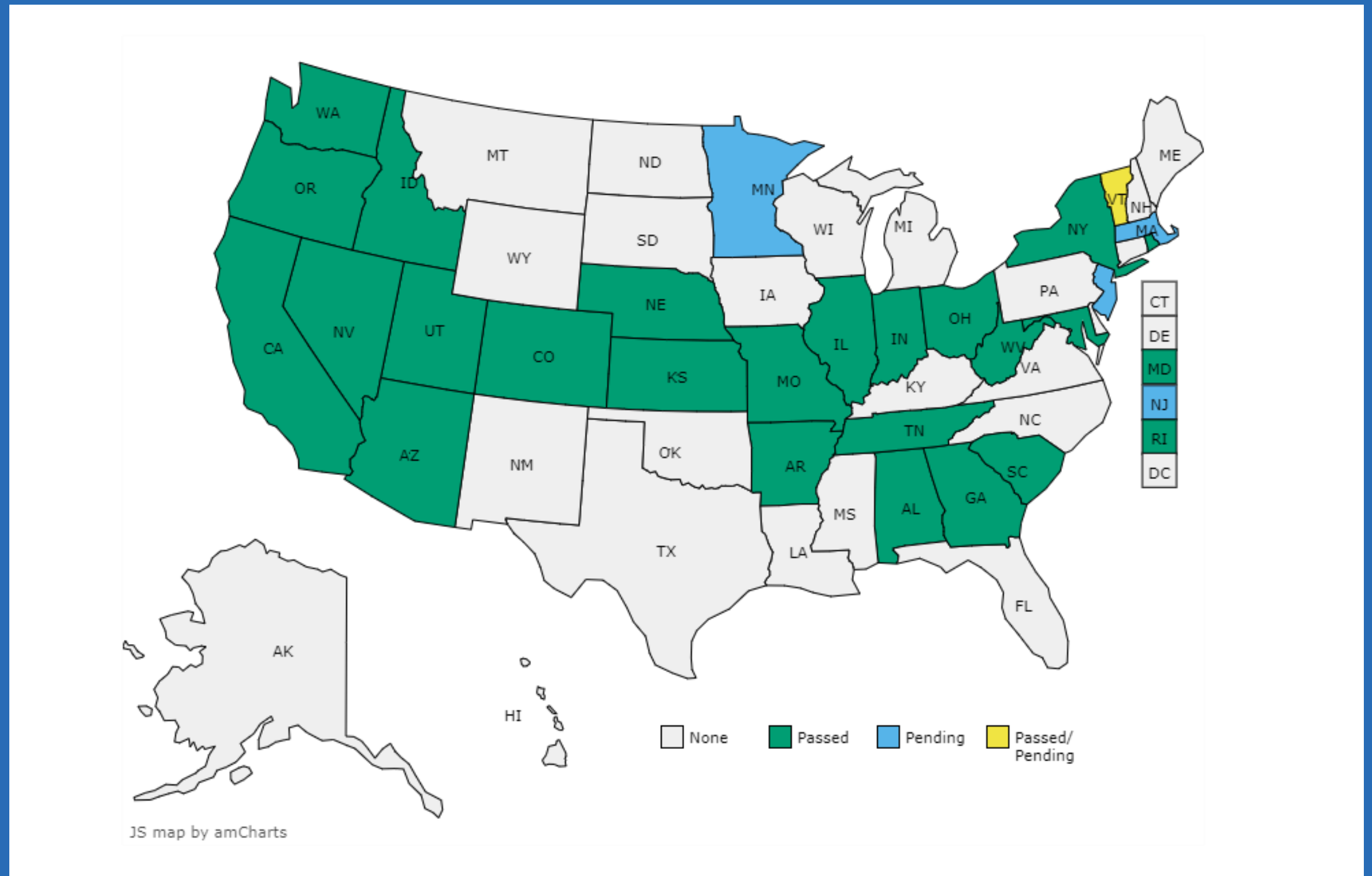
What resources are available in your community?

Many parents with disabilities have significant distrust in systems due to experiences of ableism.

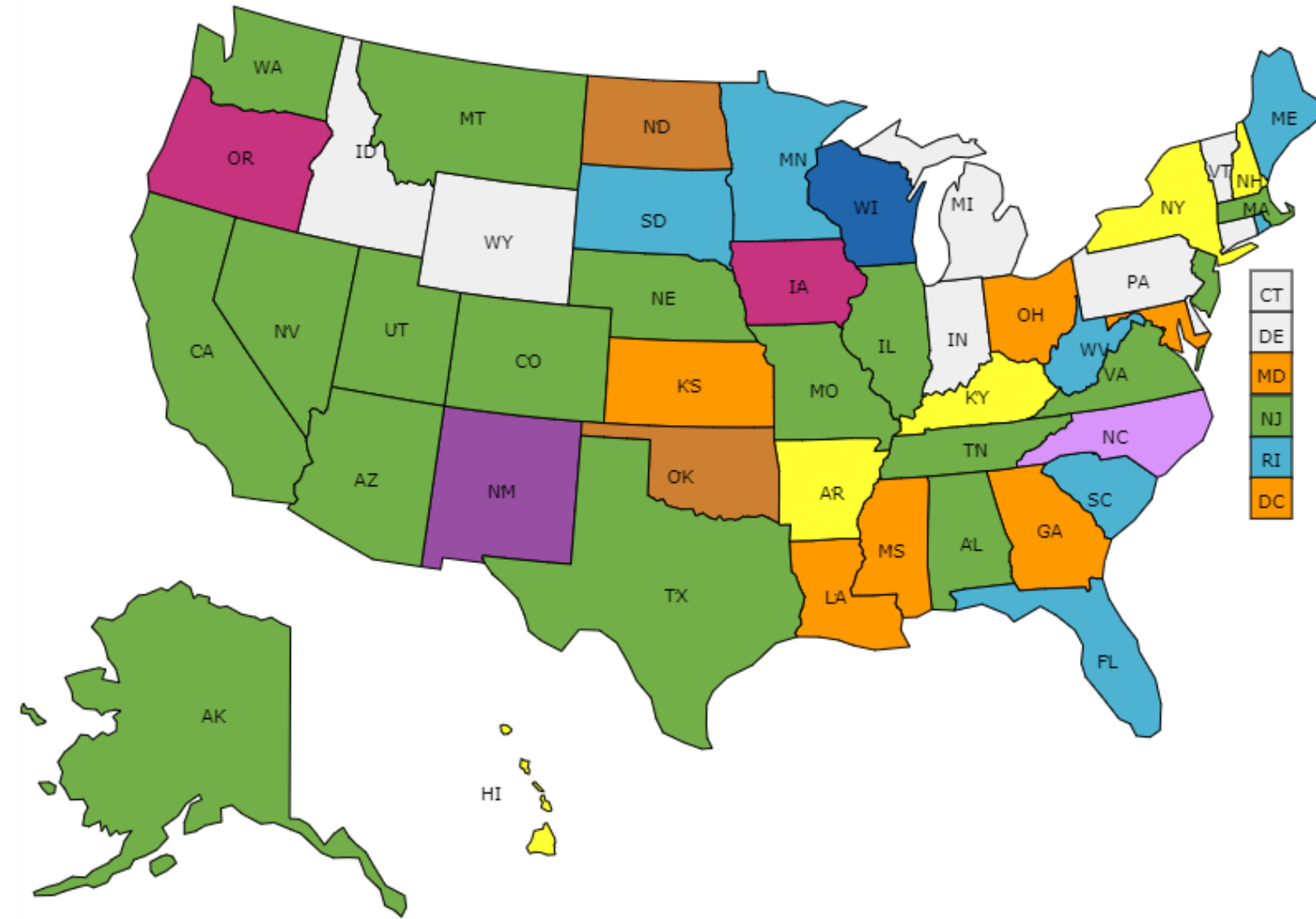
Many states still have laws that allow for direct discrimination in parenting on the basis of disability alone.



**Good news:
There are
more states
with laws to
protect the
rights of
disabled
parents.**



Color legend indicates which states allow discrimination against people with these listed disabilities.



- | | |
|--|-------------------------------------|
| ■ IDD, Psych, Physical/Sensory, SUD, Other | ■ IDD, Psych, Physical/Sensory, SUD |
| ■ IDD, Psych, Physical/Sensory, Other | ■ IDD, Psych, Physical/Sensory |
| ■ IDD, Psych, SUD, Other | ■ IDD, Psych, SUD |
| ■ IDD, Psych | ■ Psych, SUD |
| ■ SUD | ■ None |

(Map data current through October 1, 2022)

A photograph of a red emergency sign with the word "Emergency" in white and a white arrow pointing right. The sign is mounted on a wall, and the background shows a blurred indoor setting with lights.

Emergency



**Ableism
hinders
healthcare
access for all of
us.**

**How can we support
parents with
disabilities?**

Anti-ableist healthcare considers equitable support for disabled parents:



Communication access



Accessible and welcoming spaces



Clarification of expectations for mandated reporting

She can't get into
that building
because she's in a
wheelchair

vs.

She can't get into
that building
because it's not
accessible.



**Reframing barriers
is anti-ableist.**

Case Study Example

She can't feed the baby because she can't mix the formula correctly.

vs.

We are working to get WIC approval for pre-made formula, which will best meet this family's needs.



Reframing barriers is anti-ableist.

**Family-centered care
supports disability-related
needs for parents.**



**Peer supports
are helpful for
many parents
with disabilities.**



**Disabled
Parenting
Project**

- Online and in-person groups can provide emotional support to parents with disabilities.
- Peers frequently share practical strategies that worked for their family while parenting children at different ages.
- Advocacy and empowerment: Many laws to protect the rights of parents with disabilities have been spearheaded by groups of disabled parents.

Key Takeaways



Recognize the history of ableism parents with disabilities have likely experienced (even if they don't label it as such).



IQ is not a predictor for abuse or neglect despite the overreliance on this measure.



Ableism has led to distrust of the healthcare system(s), which can decrease access.



Promising interventions tap into health empowerment, acknowledgement of discrimination, and strengths (often) shared by disabled parents.

**1 IN 10 CHILDREN HAVE A
PARENT WITH A
DISABILITY.**



1 in 10 kids are lucky enough
to have a parent with a
disability 🍀♿️

How you can reach me:



kara.ayers@cchmc.org



[@DrKaraAyers](https://twitter.com/DrKaraAyers)



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[My Google Scholar Profile to read my work.](#)

