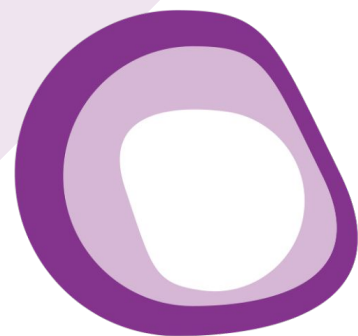


Co-Creating Pregnancy Plans with Disabled People: The APAP Model

Kara Ayers, PhD



National Center for
**Disability &
Pregnancy Research**

Brandeis

THE HELLER SCHOOL
FOR SOCIAL POLICY
AND MANAGEMENT

Lurie Institute for Disability Policy



Cincinnati
Children's®

Closed Captioning & ASL or Spanish Interpretation

A participant has enabled Closed Captioning [Who can see this transcript?](#) X

American Sign Language

Watch:

- Sign Language off
- ✓ American Sign Language

Listen In:

- ✓ Original Audio (Interpretation Off)
- English
- Spanish
- Mute Original Audio

Settings Chat Show Captions Raise Hand Interpretation Leave

The screenshot displays a Zoom meeting interface. At the top, a notification states "A participant has enabled Closed Captioning" with a link to "Who can see this transcript?". The main video feed shows a woman with glasses smiling. A smaller video window on the left shows another participant with the text "American Sign Language" below it. A settings menu is open over the main video, showing options for "Watch:" (Sign Language off, American Sign Language checked) and "Listen In:" (Original Audio checked, English selected, Spanish, Mute Original Audio). Red arrows point from the "Show Captions" button in the bottom toolbar to the "American Sign Language" option in the menu, and from the "Interpretation" button to the "English" option. The bottom toolbar includes buttons for "Settings", "Chat", "Show Captions", "Raise Hand", "Interpretation", and "Leave".



The contents of this presentation were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90DPHF0011). NIDILRR is a Center within the Department of Health and Human Services (HHS). The content is solely the responsibility of the authors and does not necessarily represent the official views of NIDILRR or HHS.



Learning Objectives

1. Learn about the discrimination and health disparities faced by disabled birthing people in the US and their birth outcomes, which highlight the need for an intervention such as APAP.
2. Learn about the Accessible Pregnancy Action Plan (APAP) and how to use it.
3. Apply power-sharing facilitation strategies to guide an accessible birth planning process that centers disabled pregnant people's expertise, preferences, and autonomy while navigating clinical systems.





What we learned from literature

- Barriers in communicating with healthcare providers during pregnancy, labor, and delivery can result in a range of negative outcomes (Biggs et al., 2023)
- Patient-centered communication (PCC) is related to positive outcomes. (Heideveld-Gerritsen, 2021)
- Peer support models and research on birth plans reviewed (Evans et al., 2024)
- Autonomy and empowerment often missing from disabled people's experiences with pregnancy, labor, and delivery (Evans, 2024)

What is an Accessible Pregnancy Action Plan (APAP)?

- The APAP is a process and a document that a pregnant person with a disability can take to their healthcare provider to communicate their needs and preferences:
 - during pregnancy
 - during labor and delivery
 - the first few days after birth
 - if something unexpected happens
- Participants create their APAP through engagement with a peer facilitator focused on health empowerment and patient-centered communication.



How is an Accessible Pregnancy Action Plan (APAP) different from another birth plan?

- The APAP is co-created in 4-6 sessions with a peer facilitator.
- The creation of the APAP includes the recognition that pregnant people with disabilities are not always treated fairly by healthcare providers and others in their lives. Stigma is discussed during sessions.
- An APAP typically includes a pregnant person's disability-related needs as well as their preferences.



The Foundation: Peer Facilitation

- Facilitator qualifications are non-negotiable:
 - Must be a person with a disability
 - Must have personal experience with pregnancy
- Why this matters:
 - Shared lived experience builds trust and reduces stigma
 - You understand the intersection of pregnancy and disability firsthand
- Your role extends beyond the guide:
 - You may need to research between sessions (disability-specific birth considerations, local resources, accommodation options)
 - You're both facilitator and peer—share appropriately from your experience

Core Principle: Individualization

- Areas requiring individualization:
 - Session pacing: Some participants may complete their plan in 4 sessions, others need 6 meetings
 - Sessions 1-2 can combine
 - Sessions 3-4 may flow together
 - Plan format and delivery: Some want printed copies. Others prefer digital documents
 - Content depth: Some participants need extensive accommodation planning; others focus more on communication strategies
 - Disability considerations: Each disability is unique. Don't assume.

Building Momentum: Progress reporting

- Homework between Sessions 2 and 3 is critical
 - Participants must talk to at least one of their support team members
 - This is where the plan moves from theoretical to practical
- At each subsequent session:
 - Ask about conversations
 - Celebrate progress and problem-solve barriers
 - Document what's worked and what didn't
- Encourage ongoing communication:
 - Plans work best when they evolve through dialogue with providers, partners, and support people
 - Each conversation helps refine the APAP
 - Your role includes preparing them for these conversations and debriefing after

The Follow-Up Session: Timing Matters

- Why wait 4-6 weeks:
 - New parents need time to recover and adjust
 - Too early contact can feel intrusive
 - Enough time has passed to reflect meaningfully on the experience
- What if participants want earlier contact
 - You can be flexible but ensure they know that waiting is ok
- Session 6 objectives:
 - Reflect on what went as planned
 - Identify helpful supports and ongoing barriers
 - Connect to resources for parenting
 - Close the loop with appreciation and validation

Remembering the Dual Purpose

- The APAP is both empowering and practical.
 - Practical: Outlines specific accommodations and supports
 - Empowering: Counters stigma and discrimination; builds confidence and agency; Develops communication skills; Creates a sense of control

Summary of Topics to be covered in APAP sessions (via Zoom)

- Introduction and "What Matters Most"
- Planning Pregnancy Accommodations
- Planning Labor and Birth Accommodations
- Planning Accommodations for Hospital Stay
- Coping with Stigma and Refocusing on "What Matters Most"
- Concluding Session

1.2

WHAT IS YOUR PREGNANCY STORY?



What Matters Most?

What Matters Most (WMM) is a research-based approach to honing in on a person's values and what they find most important. In reflecting on pregnancy from your perspective, what matter(ed) most?



2.1

What Matters Most

2.3 How will you communicate your plan?



3.3 How will you communicate your labor and birth plan with your team?



2.2 Brainstorm supports for pregnancy

- Let's look at a list of what has helped others
- Remember formal and informal supports are meaningful.
- What has been helpful in the past?
- What supports are missing?

3.2 How will you take care of yourself during labor and birth?



What do you need in the hospital?

Words matter

When we discuss judgments, misconceptions, or discrimination that pregnant people with disabilities may experience, what words do most people understand and use?

Stigma?

Ableism?

Discrimination?



**How can you cope
with stigma and
barriers by
remembering what
matters most?**

Accessible Pregnancy Action Plan

Plans for Pregnancy

The best environment for me:

- Has the option of an adjustable exam table
- Includes options for comfortable seating
- May include my support person or people
- Is flexible with timing

Providers can help by:

- Talking directly to me
- Providing information in advance
- Providing written summaries
- Limiting touch
- Confirm my consent
- Recognizing and accepting my knowledge about my disability
- Helping me with transitions if needed
- Supporting me to manage stressors
- Understanding my pain changes but can be significant

What matters most to me is:

- Doctors who are informed about OI or willing to look into it.

Plans for Labor and Birth

The best environment for me:

- Includes my support team
- Has options for positioning
- Includes options for massage
- Recognizes my need for pain control
- Includes access to a bath or shower with shower chair
- Includes my personal items

Providers can help by:

- Helping me with transitions if needed
- Writing instructions, timelines, or what to expect on a whiteboard
- Ensuring you have consent before touching me
- Understanding that it's complicated for me to estimate pain based on my history of chronic pain
- Asking about my pain with descriptors instead of numbers
- Being clear about timelines and options for alternative approaches

What matters most to me is:

- that I'm up and moving soon after birth.

Supports and Plans for After Birth


The best environment for me:

- Includes my support team
- Includes my personal items, including clothing
- Recognizes my symptoms are changing and dynamic
- Accepts our decisions about breastfeeding

Providers can help by:

- Ensuring the baby and I have the care we need before going home
- Helping me manage my pain by understanding estimating my pain is complicated
- Respecting my wishes for my child
- Recognizing and accepting my knowledge about my disability
- Helping me with transitions if needed
- Supporting me to manage stressors
- Screening for postpartum mental health concerns
- Communicating a clear plan about recovery from birth and when to resume medications

What matters most to me is:

Participant	Disability
1	Blind
2	Spina Bifida
3	EDS, POTS, psychiatric disability <u>and</u> Long Covid
4	RA, Graves Disease, low vision, and MDD 
5	Long Covid
7	EDS, POTS
8	Permanent connective tissue disorder
9	EDS and RA
10	Osteogenesis imperfecta

2.1

What Matters Most

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>



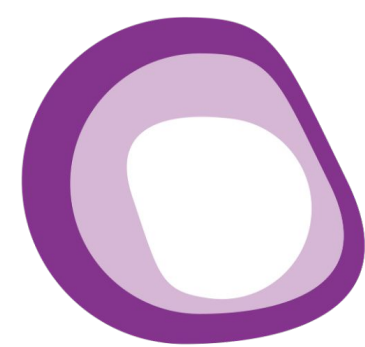


Share your story in our blog about the experiences and needs of pregnant people with disabilities. We publish blog posts in English and Spanish. Blog posts are accepted throughout the year.





Breastfeeding with a Disability: Resources for Nursing Parents



National Center for
**Disability &
Pregnancy Research**

References

Biggs, M. Antonia, Rosalyn Schroeder, M. Tara Casebolt, Bianca I. Laureano, Robin L. Wilson-Beattie, Lauren J. Ralph, Shelly Kaller, Aliza Adler, and Margaret W. Gichane. "Access to reproductive health services among people with disabilities." *JAMA Network Open* 6, no. 11 (2023): e2344877–e2344877.

Evans, M., Tarasoff, L. A., Lunsky, Y., Welsh, K., Proulx, L., Haverkamp, S. M., Parish, S. & Brown, H. K. (2024). Disability justice and collective access to labour and delivery care: a qualitative study. *BMC Pregnancy and Childbirth*, 24(1), 832.

Heideveld-Gerritsen, M., van Vulpen, M., Hollander, M., Oude Maatman, S., Ockhuijsen, H., & van den Hoogen, A. (2021). Maternity care experiences of women with physical disabilities: A systematic review. *Midwifery*, 96, 102938.

How you can reach me:



kara.ayers@cchmc.org



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



[@KaraAyers](https://www.instagram.com/KaraAyers)



My Google Scholar Profile
to read my work.

