Accessible Pregnancy Action Plan (APAP): Welcome

National Center for

Disability & Pregnancy Research

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.







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

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 (disabilityspecific 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

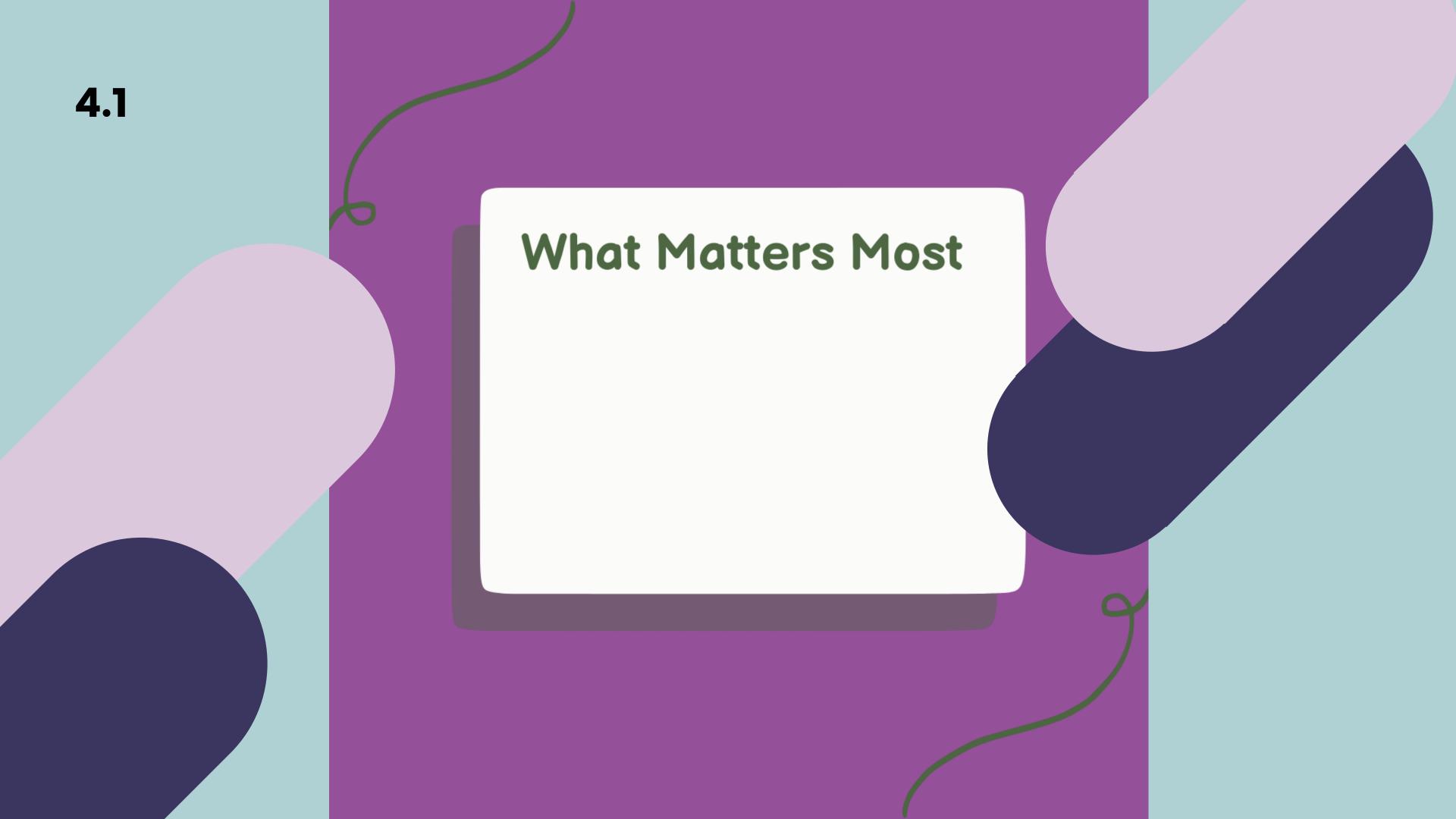
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WHAT IS YOUR PREGNANCY STORY?



At the end of this session, you'll be able to:

- talk about what matters most to you during your pregnancy
- know who and what is needed to support you
- think about ways to communicate your plans



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 after birth:

- 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:

Thank you for sharing your journey with us.

Please let us know when you give birth!

Facilitator's email:

Facilitator's phone or text:

