# Accessible Pregnancy Action Plan

Facilitator's Guide





Brandeis

THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT Lurie Institute for Disability Policy





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#### **Funding Statement**

Research reported in this publication was supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) under grant number 90DPHF0011, awarded to the National Center for Disability and Pregnancy Research (NCDPR) at the Lurie Institute for Disability Policy, Brandeis University. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIDILRR, ACL, or HHS.

#### **About This Guide**

The intervention described in this guide was developed by Dr. Kara Ayers, PhD, Associate Professor of Pediatrics in the College of Medicine at the University of Cincinnati and Cincinnati Children's Hospital Medical Center and Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities.

#### **How to Cite This Guide**

National Center for Disability and Pregnancy Research. (2025). *Accessible Pregnancy Action Plan: Facilitator's Guide*. Brandeis University, Waltham, MA.

# Accessible Pregnancy Action Plan: Facilitator's Guide

#### **Note to the Reader**

This Facilitator's Guide is *not* a semi-structured interview guide. This guide was written for administration by a trained disabled facilitator who has personal experience with pregnancy. The process of developing the participant's Accessible Pregnancy Action Plan is meant to take place through a series of discussions between participant and facilitator, without the use of scripted questions. While each module has a discrete topic and objectives, the participant may identify other pregnancy, labor and delivery, and/or postpartum concerns that they wish to discuss. If you have questions about this intervention or its intended use, please contact <u>Dr. Kara Ayers</u>.

#### **Facilitator Notes**

The Accessible Pregnancy Action Plan (APAP) is based on the Health Empowerment and Self-Determination Theories (Shearer, 2009; Ryan & Deci, 2000). Both theories focus on empowering the individual, particularly in healthcare settings. Many people with disabilities, particularly people considering pregnancy or parenthood, have likely felt disempowered in their past interactions with healthcare providers and others with whom they've talked about sexual and reproductive health or pregnancy. To maintain the fidelity of this intervention, the interview will repeatedly return to the question, "What Matters Most?" to the participant, with the ultimate goal of developing an individualized APAP for the participant to share with their perinatal providers.

There are two components of the APAP: 1) a one-page graphic organizer that a participant can quickly reference and take with them to appointments; and 2) a more detailed text-only version. Some people may not need to use both components.

The APAP intervention is unique because it provides the disabled pregnant woman the opportunity to work with a disabled peer facilitator who has experienced pregnancy and to talk about experiences of stigma and discrimination common to many pregnant women and parents with disabilities. While the burden of stigma and discrimination may come up as early as the first session (i.e., when sharing pregnancy stories), the

intervention will address it in more detail as rapport is established with the participant.

There are slides embedded within this document to guide facilitation of this intervention. Many participants will likely use their smart phones, which minimizes the ability to see slides *and* faces. For this reason, it's advised to stop 'screen share' after sharing a slide to build rapport with the participant as you talk through the material. After each session, complete the debriefing document, documenting any observations or lessons learned from the session.

#### **Resources for Facilitation**

Slides for facilitation<sup>1</sup>: These slides provide visual support to facilitate the sessions. They are *not* intended to guide the entire facilitation; the participant should not feel as if they are attending a lecture. Please consider turning the share screen on and off to provide some visual cues with the slides before returning to a face-to-face discussion using the full screen.

<u>APAP List of Accommodations and Supports</u>: Refer back to this document as you brainstorm what to include in the participant's APAP. This is intended to be a dynamic document; expect that it will develop and change over time.

APAP One-Pager Template: Shortened version of the APAP

<u>APAP Text-Based Longer Version</u>: This document will be individualized for each participant and is intended to provide a place for longer written explanations or details related to proposed supports and plans. Some participants may not wish to plan or document in detail but many will likely have more information to document than what fits on the one-pager.

Evaluation: We encourage facilitators to implement their own evaluation process to demonstrate program impact. Consider measuring:

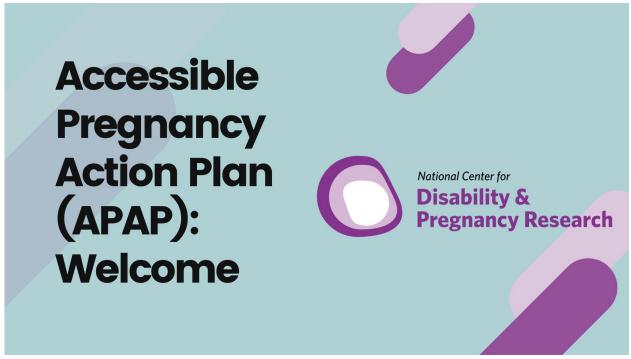
- Participant empowerment and self-efficacy (baseline and follow-up)
- Knowledge and confidence in birth planning

<sup>1</sup> To access the APAP slides, please contact Dr. Ayers at <a href="mailto:kara.ayers@cchmc.org">kara.ayers@cchmc.org</a>.

- Satisfaction with the facilitation process
- Birth experience outcomes (where appropriate)

Design your evaluation using established research instruments appropriate for your setting, population, and available resources. Many instruments are not validated for or inclusive of people with disabilities. Consider this carefully as you select and/or adapt your evaluation instruments.

#### **Module 1: Welcome and Introduction**



Welcome Slide from the Accessible Pregnancy Action Plan (APAP) Facilitation Slides

#### Welcome

**Welcome** the participant and **introduce** the program. **Review** the objectives of the session.

#### **Learning Objectives**

At the end of this session, the participants will be able to:

- Identify how a birth plan may be helpful for them.
- Connect to a peer facilitator to discuss the experience of pregnancy with a disability. Peer facilitators are disabled people who have experienced pregnancy.
- Define stigma as it relates to pregnancy and disability.

# 1.1 What is an Accessible Pregnancy Action Plan (APAP) and How Can It Help Pregnant People and Their Babies?

The APAP is a document that:

- will be developed by the participant with guidance by the peer facilitator.
- is based on each participant's identified needs and preferences during labor, birth, and postpartum.

#### Complete baseline demographic and evaluation measure(s).



"What is your pregnancy story?" Slide from APAP's Facilitation Slides, Module 1

#### 1.2 What is Your Pregnancy Story?

**Share** introductions to facilitate rapport between participant and facilitator:

- Discuss shared experiences (if any) of peer facilitator and participant.
- Inquire about how the participant learned of their pregnancy. What was their initial response? What has their pregnancy been like so far?
- Learn how (if at all) the participant's disability has impacted their pregnancy.

#### 1.3 What is Stigma?

**Define** stigma as it relates to pregnant people and parents with disabilities in order to:

- Discuss the history of ableism in healthcare and the child welfare system.
- Discuss how (if at all) the participant has already experienced or anticipates experiencing stigma or stereotypes about parenting with a disability.
- Identify any coping mechanisms that the participant has used in response to experiences of stigma, discrimination, and ableism.
- Normalize feelings of frustration and concern about stigma, stereotypes, and discrimination as a pregnant person and/or parent with a disability.

Facilitator Note: This module is an introduction to the program. Introduce ideas, like the history of ableism in reproductive healthcare and the child welfare system, with basic information while paying attention to whether this is known or new information to the participant. This will guide how and when to readdress these concerns in later sessions. For participants who are already familiar with and concerned about potential over-involvement or unfair involvement of child welfare workers in the lives of their family, this topic may be appropriate to discuss during each module. For participants unaware of this concern, it may be more appropriate to wait until Module 5 to discuss this issue further so the participant has an opportunity to increase their locus of control and develop their APAP before addressing stigma and discrimination commonly experienced by parents with disabilities.

#### Module 2: What Do You Need for Your Pregnancy?

#### **Review and Connect**

**Welcome** the participant to Module 2 (let the participant know that they are now moving into Module 2 of the program).

**Review:** The goal of this program is to empower the participant while developing an APAP. The APAP will take shape as the participant, along with their support team, thinks about and plans for their pregnancy, labor and delivery, and postpartum time.



"What do you need for your pregnancy?" Slide from APAP's Facilitation Slides, Module 2

#### **Learning Objectives**

At the end of this session, the participants will be able to:

- Identify what matters most to the participant during their pregnancy.
- Know who is needed to support the participant during pregnancy and what they will do.
- Demonstrate ways to communicate clearly about their plans for the pregnancy.

#### 2.1 What Matters Most during Pregnancy?

**Ask** the participant what matters most to them during pregnancy. **Explain** that thinking through this question will be repeated and may be helpful to pregnant women, especially those who experience stigma.

- What Matters Most (WMM) is different for everyone. There are no right or wrong answers.
- Sometimes we may feel pressured by others regarding "What Matters Most" to them. WMM should be the pregnant person's (participant's) choice.

• What Matters Most may or may not be in the participant's control.

# 2.2 What Accommodations and Supports Would Be Most Helpful through Pregnancy?

**Brainstorm and identify** accommodations, supports, and strategies to help the participant during pregnancy.

- Discuss what has already been helpful to the participant during their pregnancy, whether these are formal accommodations, informal supports, or anything else that has helped, whether large or small. Remember informal and formal supports are meaningful. Formal support is often tied to funding or programs such as personal care attendants (PCAs). Informal support may include options in your neighborhood or community. Informal support can come from friends, family, and others in your community.
- Identify what supports and accommodations are missing, if any. Review the
   <u>APAP list of common accommodations and supports</u> for labor, birth, and
   postpartum. Determine what accommodations are needed. Other supports
   and accommodations not listed on the accommodations sheet may be added
   to the APAP.



"How will you communicate your plan?" Slide from APAP's Facilitation Slides, Module 2

## 2.3 How Can the Participant Communicate Their Plan with Their Team?

- **Discuss** who needs to know about the participant's APAP plan and how to communicate the participant's needs effectively with the provider team.
  - Questions for the participant to consider: Who will be with you during labor and delivery? What parts of the plan should they know to best support you? Some people assign different roles to different people in their lives. Who would be best suited to help advocate for each of your needs and wants during this important time?
- Identify people and roles who will support the participant at various stages throughout pregnancy. Support people may change from one stage of pregnancy to the next.
- **Discuss** strategies to communicate about accommodations the participant needs. Practice how to initiate the topic and identify strategies to remember what is discussed (e.g., notetaking, bringing another person to appointments, etc.). It may be helpful to role play how the participant can bring up their plan and what they'd like their provider to know about it.
- Discuss sources of information about pregnancy. The credibility and trustworthiness of sources may vary. Many sources may not include the experience of disability.
- **Discuss** the participant's sense of control.
  - Questions for the participant to consider: How much control do you feel like you have in the way your pregnancy is managed? How much control do you feel like you have in what your delivery will be like? If the participant feels disempowered or not in control, discuss why and how they might be able to exert more power over their own birth experiences.

# HOMEWORK

TALK TO AT LEAST ONE
MEMBER OF YOUR SUPPORT
TEAM ABOUT YOUR
ACCESSIBLE PREGNANCY
ACTION PLAN.

BRAINSTORM OTHER
ACCOMMODATIONS OR
SUPPORTS THAT WOULD BE
HELPFUL TO YOU.

WHEN IS OUR NEXT SESSION?

Homework Slide from the APAP Facilitation Slides

**Homework:** The participant will plan to talk to at least one member of their support team about this session's materials. They will also be encouraged to brainstorm about other accommodations or supports that may help them during pregnancy. The facilitator will document the accommodations and supports identified during this session.

Facilitator Note: While it is possible to complete Modules 1 and 2 together in one session, the homework between Modules 2 and 3 requires a break. During the next session, you will discuss labor and delivery. It may be helpful for the participant to apply skills identified in Modules 1 and 2 to learn from other disabled women what labor and delivery was like with their disability.

#### Module 3: What Do You Need for Labor and Birth?



"What do you need for labor and birth?" Slide from APAP's Facilitation Slides, Module 3

#### **Review and Connect**

Welcome the participant to Module 3.

The facilitator begins by reviewing the homework assignment (see figure above).

**Encourage** the participant to share about the experience of discussing their APAP with a support person. The facilitator will **share** the APAP takeaways about pregnancy. **Ask** the participant if they'd like to make any additions and/or changes to the plan.

#### **Learning Objectives**

At the end of this session, the participants will be able to:

- Identify What Matters Most (WMM) for the participant's labor and birth.
- Know who and what is needed to support their labor and birth and what each support person will do.

 Demonstrate ways to communicate clearly about their plans for labor and birth.

#### 3.1 What Matters Most during Labor and Birth?

**Discuss** what matters most to the participant during the labor and birth experience:

- Consider the differences between planning for pregnancy and labor/birth.
- Identify what information is needed before birth and where the participant can find it. For example, where and how a participant can learn about specific relaxation techniques for labor and delivery, and where they might find information about pain management during labor, etc.
- Plan how the participant will communicate these goals for her labor and birth experience.



"How will you take care of yourself during labor and birth?" Slide from APAP's Facilitation
Slides, Module 3

#### 3.2 What are the Options for Self-Care during Labor and Birth?

**Plan** how, when, and with whom the participant will meet their needs during the labor and birth process:

- Discuss which parts of the plan are flexible since labor and birth are often unpredictable.
- Identify and encourage relationships that make the participant feel supported during labor and birth.
- Find out how the participant's disability may impact labor and birth. This
  may involve seeking information from the healthcare team and from other
  trusted sources.

# 3.3 How Can the Participant Communicate Their Labor and Birth Plan with Their Team?

**Identify** what accommodations and supports are needed during labor and birth and how the participant will try to ensure they are in place:

- Describe how people will gain informed consent from the participant during parts of the birth process where it may be more challenging to communicate.
- Review the <u>APAP accommodations and supports list</u>. Add accommodations and supports for labor and birth to the participant's APAP if new ideas emerge.
- Discuss strategies to communicate about the accommodations the participant needs. Practice how to initiate the topic and identify strategies (e.g., notetaking and/or bringing another person to appointments) to remember what is discussed.
- Discuss sources of information about labor and birth. Credibility of sources can vary. Many sources may not include the experience of disability.

**Facilitator Note:** If the participant completes Modules 3 and 4 together, the facilitator and participant should work together (share screen) to fill in the section on supports needed for labor and birth. If the participant stops after Module 3, the facilitator can complete this section after the session and review it with the participant at the start of Module 4.

#### Module 4: What Do You Need in the Hospital?



"What do you need in the hospital?" Slide from APAP's Facilitation Slides, Module 4

#### **Review and Connect**

**Welcome** the participant to Module 4 (or inform the participant you are now beginning Module 4 materials).

**Ask** the participant if they'd like to make any additions and/or changes to their APAP.

**Facilitator Note:** Most but not all pregnant women give birth in a hospital. This session talks about planning for giving birth outside the home. If the participant plans to give birth in the home, at a birthing center, or somewhere other than a hospital, this session can be adjusted with this change in mind.

#### **Learning Objectives**

At the end of this session, the participants will be able to:

• Feel a sense of control in planning their hospital stay after their baby is born.

- Communicate with their medical team and people who provide support about their plans and priorities for the hospital stay.
- Plan to be proactive in anticipation of any disability-related barriers in the hospital.



"What Matters Most" Slide from APAP's Facilitation Slides, Module 4

#### 4.1 What Matters Most During the Postpartum Hospital Stay?

**Discuss** What Matters Most to the participant during the hospital stay after the baby is born.

- Consider what accessibility challenges and barriers may present during the hospital stay.
- Identify what information is needed before birth about the hospital stay and where the participant can find it.
- Plan how the participant will communicate these goals for the hospital stay and reflect these intentions in the APAP.

# 4.2 What Accommodations and Supports Would Be Most Helpful for the Hospital Stay after the Baby is Born?

**Brainstorm and identify** accommodations, supports, and strategies to help the participant while in the hospital.

- Discuss what has been helpful to date. Remember, both informal *and* formal supports are meaningful.
- Identify what supports and accommodations will be needed during the postpartum hospital stay. Add those to the APAP if needed.

# Module 5: How Can You Cope with Stigma and Barriers by Remembering What Matters Most?



"How can you cope with stigma and barriers by remembering what matters most?" Slide from APAP's Facilitation Slides, Module 5

**Welcome** the participant to Module 5 (or inform the participant you are now beginning Module 5 materials). This is the last session before the participant and facilitator reconnect after the baby's birth.

**Review** the APAP. **Ask** the participant if they'd like to make any additions and/or changes to the plan. If the participant doesn't have access to a printer and wants a hard copy, the facilitator should document their address to mail a copy of the plan.

#### **Learning Objectives**

At the end of this session, the participants will be able to:

- Summarize and communicate with others about their APAP.
- Discuss the benefits of health empowerment in coping with stigma and discrimination.



"What is your pregnancy story?" Slide from APAP's Facilitation Slides, Module 5

#### 5.1 What is Your Pregnancy Story Now?

**Discuss** what plans the participant has made and put into place since starting their APAP:

- Consider what accessibility challenges and barriers remain and how the participant may address them.
- Identify what information is still needed and where/how the participant can find it.

### 5.2 How Will You Stay Empowered in the Face of Stigma and Discrimination?

Experiencing stigma, stereotypes, and discrimination is not uncommon for pregnant people with disabilities. **Discuss** ways the participant will build and/or maintain confidence and belief in their abilities to be "good parents" despite some negative interactions with others.

**Share** knowledge and experiences of myths, stereotypes, and discrimination faced by new parents with disabilities:

- Discuss how parents with disabilities may face discrimination while in the hospital after giving birth to their baby.
- Discuss research indicating health empowerment as an effective strategy in coping with stigma.
- Identify what—if any—experiences with stigma and stereotypes about parenting with a disability the participant has faced or heard about from others.
- Normalize feelings of frustration and concern about stigma, stereotypes, and discrimination as a pregnant person and/or parent with a disability.

# 5.3 What Supports Will You Need during the First Few Weeks Home with Your New Baby?

- **Discuss** what the participant expects for the first few weeks after birth.
- **Identify** what supports they will have available and which needs are currently unmet.
- Include a list of tailored contacts available for support after birth in the APAP.

# 5.4 How Will You Use Your Accessible Pregnancy Action Plan (APAP) to Focus on What Matters Most?

**Summarize** the participant's APAP and plan for its implementation:

• Review strategy for communication and implementation of plan.

- Discuss what roles, needs, and accommodations remain unfilled or unmet and how the participant plans to address these before birth.
- Connect the APAP to what the participant identified as What Matters Most (WMM) during pregnancy, labor, and birth.

This will be the final meeting before the participant gives birth. The facilitator should find out when and how to contact the participant after they've given birth for a follow-up session. The follow-up session can take place between two weeks and three months after birth.



"Thank you for sharing your journey with us." Slide Concluding the APAP Facilitation Slides

#### **Module 6: Follow-Up**

**Reconnect** with the participant in this final, follow-up session. In this session, they'll discuss their experiences with pregnancy, labor, childbirth, and the hospital stay after their baby was born.

# 6.1 What Went as Planned and What Did Not during Labor, Birth, and the Hospital Stay?

**Reflect** on how the participant's experience matched or did not match what they expected:

- Discuss facilitators and barriers to the implementation of the APAP.
- Identify what informal and formal supports were helpful during labor, birth, and the hospital stay.
- Consider how support needs and dynamics have changed over time and through this experience.

#### 6.2 What are Sources of Support for the Next Phases of Parenting?

**Identify** what sources of information, support, and services exist for parents with disabilities:

- Consider further connections with parents with disabilities to address questions and seek information about parenting with a disability.
- Discuss what services are needed and what might be available in the participant's communities.
- Reflect on what accommodations and types of support were most helpful and what might remain or change in the future.

**Conclude** with expressions of appreciation for the participant's willingness to engage in this process. Reflect on the benefits of empowerment discussed throughout this intervention (e.g., identifying needs, planning for the future, connecting to peers).

Refer people interested about learning more about perinatal and parenting research to the <u>National Research Center for Parents with Disabilities</u> and the <u>National Center for Disability and Pregnancy Research</u>.

#### References

Ryan, R. M., & Deci, E. L. (2000). Self-Determination Theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*(1), 68–78. https://doi.org/10.1037/0003-066X.55.1.68

Shearer, N. B. C. (2009). Health empowerment theory as a guide for practice. *Geriatric Nursing*, 30(2 Suppl), 4–10.

https://doi.org/10.1016/j.gerinurse.2009.02.003

#### **Appendices**

Appendix A. Accessible Pregnancy Action Plan: Accommodations and Supports

Appendix B. <u>Accessible Pregnancy Action Plan: 1-Pager Template</u>

Appendix C. Accessible Pregnancy Action Plan: Text-Based Extended Version

#### Appendix A

#### **Accessible Pregnancy Action Plan: Accommodations and Supports**

Let's get started brainstorming accommodations and supports for your pregnancy, labor, birth, and hospital stay after your baby is born. This document is built by and for our disability community. You'll be adding to it alongside other pregnant people with disabilities.

Types of Disability	Accommodations and Supports
Blind/Low Vision	<ul> <li>Private room</li> <li>Lighting preferences</li> <li>Audio descriptions for videos</li> <li>Materials in Braille</li> <li>Large print</li> <li>Access to screen reader</li> <li>Human guide</li> <li>May need accommodations for number of "visitors" as support people are not visitors</li> <li>Lactation support</li> <li>Visual reminders for nurses and doctors to describe what they're doing</li> </ul>









Cognitive, Intellectual, or Developmental Disability	<ul> <li>Assistance completing surveys and patient intake forms</li> <li>Checking for understanding</li> <li>Closed captioning during telehealth or video visits</li> <li>Information in advance</li> <li>A support person to discuss medical decisions with during visits</li> <li>Information in writing to summarize visit</li> <li>Visuals and pictures to explain concepts</li> <li>A doll or model to practice or demonstrate what to expect</li> <li>Reduced sensory input</li> <li>Audio recording of appointments or classes (i.e. birthing classes)</li> <li>Visual aids to describe birthing process</li> </ul>
Deaf, Hard-of-Hearing, DeafBlind	<ul> <li>Assistive Listening Devices         (ALDs)</li> <li>ASL interpreter</li> <li>Closed captioning for telehealth         or video visits</li> <li>Providers wear clear masks</li> <li>Provide directions and follow-up         information in written form</li> <li>Real time captioning</li> <li>Quiet space for communication</li> </ul>

	<ul> <li>Noise canceling headphones if there is noise from equipment</li> <li>Instruction for providers and staff to face patient for lipreading</li> </ul>
Mental Health	<ul> <li>Additional structure and assistance regulating emotions</li> <li>Clear protocols to help me prepare for care</li> <li>Need for reduced sensory input</li> <li>Provide directions/follow-up in writing</li> <li>Modifications to the COVID-19 mask policy</li> </ul>

Mobility Disability and/or Wheelchair Use	<ul> <li>Adjustable tables</li> <li>Assistance with transfers and walking</li> <li>Availability of transfer equipment (e.g., a lift, a transfer board)</li> <li>Human assistance with transfers</li> <li>Larger exam rooms</li> <li>Wheelchair scales</li> <li>Modifications to the COVID-19 mask policy</li> <li>Personal care attendant (PCA) support, including during antenatal recovery</li> <li>Meeting accommodations needs in hospital room</li> </ul>
Respiratory	<ul> <li>Modifications to the COVID-19 mask policy</li> <li>Need for oxygen tank</li> <li>Plug outlet for oxygen concentrator</li> </ul>

Speech/Communication	<ul> <li>Closed captioning during video visits</li> <li>Confirm that I understand</li> <li>Give me additional time to speak</li> <li>Understanding prompts from the provider</li> <li>Whiteboards for communication</li> </ul>
Other Sensory	<ul> <li>Fragrance-free environment</li> <li>Limit touch</li> <li>Placement in room early</li> </ul>
Upper Body and Fine Motor Skill Impairment	<ul> <li>Assistance with clothing management</li> <li>Assistance with completing surveys/patient intake</li> <li>Assistance with transfers</li> <li>Modifications to the COVID-19 mask policy</li> <li>Bladder program and skin breakdown assessments</li> <li>Alternate positions during birthing/exams</li> </ul>
What else?	

#### Appendix B

#### **Accessible Pregnancy Action Plan (1-Pager Template)**

Please see the following page for a printable version of the 1-pager template of the Accessible Pregnancy Action Plan.

# Accessible Pregnancy Action Plan

Plans after Supports after Birth Example: Ask nurse to adjust lighting Plans for Labor Example: Low light levels during labor Supports for Labor Pregnancy Plans for Supports for Pregnancy



Disability & Pregnancy Research







#### **Appendix C**

#### **Accessible Pregnancy Action Plan (Text-Based Extended Version)**

Please see the following page for a printable version of the extended version of the Accessible Pregnancy Action Plan.

My Accessible Pregnancy Action Plan (Extended Version)
Supports for Pregnancy
Plans for Pregnancy
Supports for Labor
Plans for Labor
Supports after Birth
Plans after Birth







