

Enhancing Maternal Care for Women with IDD: A Toolkit for Doulas & Healthcare Providers

Research Team

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Consultants

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Background

- Women with intellectual and developmental disabilities (IDD) have disproportionately **high rates of poor birth outcomes** and **postpartum care**.
- Women with IDD report fewer sources of emotional and social support during pregnancy. They also experience **unique barriers to perinatal care** including a lack of resources and/or educational materials geared toward their learning and cognitive needs.



- **Doulas** support pregnant and postpartum individuals during childbirth and after through emotional, physical, and informational support; this is associated with improved birth and postnatal outcomes.

Current doula practices do not include adaptive strategies for women with IDD.

- A diverse group of stakeholders, including doulas and persons with IDD **will develop a toolkit for doulas and healthcare providers to support the needs of women with IDD**, which will ultimately **enhance labor and delivery doula care** for women with IDD.

Objectives

Over the **2-year study period**, we will

1. Survey doulas, nurses, and allied healthcare providers about knowledge and experience of providing perinatal care to women with IDD.
2. Identify, review and modify doula training materials with the core leadership team.
3. Develop and draft guidelines for doulas, healthcare providers and women with IDD.
4. Engage with wider advisory group to review draft materials, including focus groups and individual interviews.
5. Review, refine and finalize guidelines following advisory group feedback.
6. Disseminate guidelines via the websites of The National Research Center for Parents with Disabilities and The National Center for Disability and Pregnancy Research and with community-based dissemination partners.
7. Publish findings in a peer-reviewed publication.

Research Goal

To develop a toolkit for doulas and healthcare providers to support pregnant and laboring women with IDD.

What is a doula?

“A doula is a trained professional who provides continuous physical, emotional, and informational support to their client before, during, and shortly after childbirth to help them achieve the healthiest, most satisfying experience possible.”

- DONA International

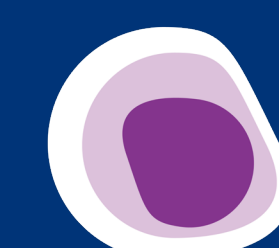
Main Takeaway

Doula care that meets the needs of pregnant women with IDD may help to reduce disparities in care, particularly for low-income families and women of color, and to expand access to equitable perinatal care.



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National Research Center for
Parents with Disabilities
Centro Nacional de Investigación para
Padres con Discapacidades



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Methods

- Core leadership team will meet monthly to

1. **adapt guidelines** for doulas as they support women with IDD during labor and delivery and
2. **provide information to women with IDD** about working with doulas during labor and delivery



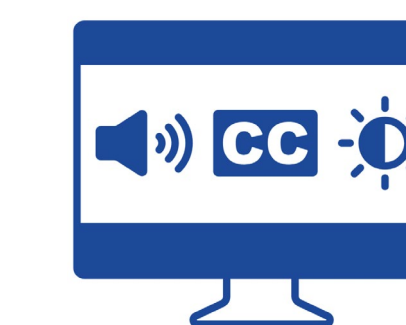
- Engagement team will evaluate the **accessibility** and **acceptability** of the guidelines. The team will include a diverse population of women with IDD, women with diverse disabilities who are pregnant or who have been pregnant, researchers with expertise in addressing IDD- related health disparities, and doulas.
- Adapted doula guidelines will be **relevant** and **accessible** to doulas with no specific training in working with women with IDD.

Lived Experience Input

Individuals with IDD will be involved in all phases of the project.

- In addition to our Lived Experience Expert who is a member of the core research team, this project is supported by the Advisory Boards of the National Centers for Parents with Disabilities and Disability and Pregnancy Research.
- **Both Advisory Boards consist entirely of disabled parents, including parents with IDD.**
- Members of the boards will evaluate the accessibility of the guidelines for women with IDD through focus groups or individual interviews.
- We will seek board input on this project at each of the quarterly meetings (i.e., seek input about the development of the initial guidelines, the protocol for gathering stakeholder feedback, dissemination strategies, etc.) to ensure accessibility and acceptability.

Dissemination



- We will create products (including videos, plain language summaries, Easy Read briefs, etc.) and disseminate them to
 - Women with IDD,
 - Doulas,
 - Program / policy developers, and
 - Community-based healthcare providers to facilitate access to doula care.
- Products will reflect **inclusive design practices**, and ultimately aim to improve delivery of healthcare, specifically doula labor and delivery care, to adults with IDD.



Next Steps

- We will survey the Advisory Board members at the end of Years 1 and 2 to get feedback on the experience of participating in the development of the toolkit. We hope to learn about the members' sense of engagement, comfort, and partnership with the process.
- In the future, we hope to survey doulas to see if they find the adapted training and strategies helpful.



Ultimately, we hope to engage in clinical effectiveness research to evaluate the impact of doula care in reducing existing perinatal disparities in women with IDD and promoting birth equity.