

# National Center for Disability and Pregnancy Research: Overview

October 2021

## Introduction

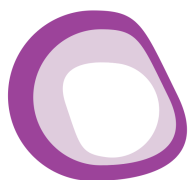
The National Center for Disability and Pregnancy Research (NCDPR), housed at the Lurie Institute for Disability Policy at Brandeis University, will examine pertinent knowledge gaps about the perinatal—including preconception and postpartum—health of people with disabilities.

Policymakers and medical practitioners can use our findings to plan, implement, and deliver services for a diverse and growing population of people with disabilities who desire pregnancy. We are collaborating with partners at research institutions, including the University of Michigan, Oregon Health & Sciences University, the University of Toronto, Cincinnati Children's Hospital, the University of Minnesota, and Magee Woman's Hospital Research Institute & Foundation to conduct cross-disability, multidisciplinary research—and to share our findings with a wide audience. To make sure that our research puts the community's needs first, we will consult the NCDPR community advisory board on all our research and knowledge-translation activities.

The NCDPR includes five research projects that will contribute to our understanding of pregnancy experiences, perinatal risks, complications and outcomes in people with disabilities through rigorous, population-based research.

## Research Projects

***Expanding the Evidence Base on Perinatal Disparities in Disability Populations*** · **Investigators: Horner-Johnson (Co-Principal Investigator), Mitra (Co-Principal Investigator), Akobirshoev, Slaughter-Acey:** We will use national and administrative data to learn more about the perinatal risk factors of pregnant people with disabilities. Specifically, we want to learn how the intersections of race, ethnicity, and disability play a role in perinatal outcomes. Although there is research that documents disparities in maternal and child outcomes for pregnant people of color, as well as people with disabilities, research on perinatal health has directed relatively little attention to how race and disability interact.



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***Developing Preconception Education for Women with Mobility Disabilities · Investigators: Harris (Project Director), Valentine:*** We will develop and test a comprehensive preconception education curriculum geared to the specific needs and concerns of people with mobility disabilities who are considering pregnancy or want to learn more about their reproductive and sexual health.

***Accessible Pregnancy Action Plan · Investigators: Ayers (Project Director), Powell:*** We will develop and test the use of tailored birth plans for people with disabilities to help them communicate their needs and expectations about labor and delivery with their healthcare providers.

***Reimagining Healthcare Design for Maternal and Infant Health for People with Disabilities · Investigators: McKee (Project Director), Ernst:*** This research project examines the use of disability and accommodation “flags” in a pregnant person’s electronic medical record to alert OB/GYN providers to the need for specific accommodations or services for people with physical, sensory, or cognitive disabilities (e.g., adjustable exam tables, large-print post-visit summaries).

***Edinburgh Postnatal Depression Scale for People with Intellectual and Developmental Disabilities · Investigators: Brown (Project Director), Aunos:*** People with intellectual and developmental disabilities, or IDD, are more likely to experience more frequent and severe mental health challenges than people without IDD. To help support this population, we will adapt and test the reliability of a tool to detect postnatal depression in people with IDD. After we adapt this screening tool, social service and healthcare providers will pilot the test in the field.

***Accessibility of dissemination materials and presentations:*** We will translate and share our research findings for a variety of audiences. Our dissemination efforts will include an online portal that includes for people with disabilities, advocates, family members, and professionals interested in pregnancy and disability, as well as a series of webinars geared toward healthcare providers and advocates. We will also seek guidance from our community advisory board, create accessible documents for people with a range of disabilities and knowledge levels, and use multiple delivery methods (e.g., plain-language writing, live captioning, American Sign Language, images and graphs, videos with closed captioning) so that our materials reflect the experiences, accessibility needs, and priorities of the communities we support.

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