

# Notice of Special Interest (NOSI): Reproductive Health, Pregnancy, and Parenting among Women with Disabilities

## Notice Number:

NOT-HD-21-025

## Related Announcements

[PA-20-185](#) NIH Research Project Grant (Parent R01 Clinical Trial Not Allowed)

[PA-20-183](#) NIH Research Project Grant (Parent R01 Clinical Trial Required)

[PA-20-200](#) NIH Small Research Grant Program (Parent R03 Clinical Trial Not Allowed)

[PA-21-221](#) NICHD Small Research Grant Program (R03 Clinical Trial Required)

[PA-21-231](#) NICHD Small Research Grant Program (R03 Basic Experimental Studies with Humans Required)

## Issued by

Eunice Kennedy Shriver National Institute of Child Health and Human Development ([NICHD](#))

## Purpose

The purpose of this Notice of Special Interest (NOSI) is to encourage and support research studies in women with disabilities (WWD) in any of three interconnected areas of high priority to NICHD:

- Gynecologic care and preconception health for women and adolescent girls with disabilities
- Pregnancy in WWD
- Postpartum and parenting needs of WWD

It is not expected or required that all areas will be addressed in one application.

## Background

Fertility in most women with physical, intellectual, or developmental disabilities is not impaired, and pregnancy among women with disabilities is increasingly common. More than 1 million women of childbearing age report needing assistance with activities of daily living because of a disabling condition. Although disabilities vary in their etiology and impact, they can be broadly classified based on common activity limitations. Physical disabilities, such as cerebral palsy and spinal cord injuries are associated with impaired mobility, flexibility, and dexterity; sensory disabilities, include vision and hearing impairments; intellectual and developmental disabilities (IDD), such as Down Syndrome and Autism Spectrum Disorder, are associated with limitations in cognition and adaptive functioning. Improved diagnosis and care of people with disabling conditions are leading to a growing population of WWD who are capable and desirous of becoming pregnant and parenting.

Gynecologic care and preconception health beginning in adolescence are essential precursors of healthy pregnancies. The limited data that exist suggest that women with disabilities are at increased risk for adverse pregnancy outcomes, including preterm delivery, low birth weight, fetal growth restriction, and cesarean delivery. Women with physical disabilities are at risk for urinary tract infections, incontinence,

skin breakdown, decreased mobility and increased risk of falls, as the physical changes that occur as pregnancy progresses affect balance. Women with intellectual disabilities often have limited access to accurate reproductive health information, and have higher rates of delayed or inadequate prenatal care. Women with disabilities of all types are at increased risk for mood and anxiety disorders, chronic stress, domestic violence, and substance use, all of which impact pregnancy outcomes.

Evidence from prior research supported by NICHD and other federal agencies (e.g., Centers for Disease Control and Prevention (CDC) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)) reveals that WWD face individual, interpersonal and socioecological barriers to inclusion in sexual and reproductive health services. WWD encounter obstacles in accessing gynecologic healthcare, receiving optimal obstetric care and obtaining parenting support.

These barriers persist in part due to negative attitudes among practitioners and caregivers towards sexual behavior, pregnancy, and parenting by WWD, and there is a corresponding dearth of training and expertise among healthcare providers in obstetric and gynecologic health in caring for WWD. Additionally, many healthcare providers offices and routine examination infrastructure (e.g., weight measuring stations and communication modes) are inaccessible for WWDs. Postpartum care at home is often limited by equipment (e.g., changing tables) that lacks the physical modifications necessary to be usable by women with physical disabilities.

Disability status intersects with other social determinants of health. Rates of physical disability are highest among non-Hispanic black women, who are also more likely to have severe disabilities compared to other racial/ethnic groups. Compared to women without disabilities, WWD have lower levels of educational attainment, are less likely to be employed, earn lower wages when employed, and are more likely to live in poverty. Difficulty accessing health care is frequently reported by people with disabilities, even when they have insurance. Barriers to obtaining needed care include difficulty with transportation, limited provider availability, and limited physical accessibility to and within health care facilities. The extent to which these factors contribute to adverse reproductive health, pregnancy, and parenting outcomes in women with disabilities is unknown.

## **Research Objectives**

The objectives of this NOSI are to advance knowledge of the gynecologic care, preconception health, pregnancy, and parenting experiences of WWD; to reduce barriers to inclusion in meaningful reproductive health, pregnancy, and parenting experiences among WWD; and to improve outcomes in reproductive health, pregnancy, and parenting for WWD and their children. This NOSI encourages research aimed at elucidating multi-level factors and establishing a strong evidence base for interventions and clinical practice guidelines that will support healthcare access and inclusion, relevant assistive device and technology development, and environmental modifications in this scientific area.

**Topics of interest include but are not limited to:**

### **Gynecologic Care and Preconception Health for WWD**

- Epidemiologic studies of receipt of gynecologic preventive screenings, contraceptive use, and other well-woman care; strategies to translate findings into provision of care.
- Development and provision of disability-appropriate education about sexual and reproductive health.
- Studies of healthcare setting physical and equipment modifications, e.g., examination tables.
- Studies of desires/intentions/planning for pregnancy, facilitators and barriers to attempting pregnancy, and development of appropriate tools for participatory decision-making.
- □Studies on developmentally-appropriate approaches to obtaining and assessing consent to reproductive care.
- Studies of preconception care to optimize conception and pregnancy outcomes.
- Studies of delayed childbearing and infertility.

## Pregnancy in WWD

- Epidemiologic studies to estimate the incidence/prevalence of pregnancy, pregnancy complications, and maternal and infant outcomes.
- Integration of disability identifiers in state and national databases used to study maternal and child health.
- Prenatal care disparities and healthcare providers attitudes, including studies of systemic and physical barriers specific to prenatal care and approaches to overcome these barriers.
- Investigations to identify optimal composition of prenatal care delivery systems and their impact on pregnancy outcomes.
- Development of disability-appropriate education about pregnancy, labor and delivery, and postpartum discharge.
- Studies of healthcare setting physical and equipment modifications, e.g., delivery suites.
- Studies of pregnancy outcomes and comorbidities, including modifiable risk factors (e.g., nutrition, diet, pre-pregnancy weight, morbidity, and gestational weight gain).
- Identification of specific risk factors and mechanisms predicting adverse pregnancy outcomes and translation of findings into prevention strategies.
- Assessment of mental health disorders, substance use, incidence of domestic violence and other forms of abuse, and stress during pregnancy.
- Investigations to identify best practices for disability appropriate management of labor and birth

## Postpartum and Parenting by WWD and their partners

- Identification of barriers and facilitators to postpartum care and interventions to reduce barriers.
- Studies of infant feeding patterns and interventions to reduce barriers to breastfeeding.
- Studies of healthcare setting physical and equipment modifications, e.g., examination tables.
- Design and testing of adaptive equipment, assistive technologies, and support systems to support independence in parenting.
- Interventions to make parenthood more inclusive and accessible, including development of disability-appropriate educational materials for infant and toddler care.

## Application and Submission Information

This notice applies to due dates on or after June 5, 2021 and subsequent receipt dates through May 31, 2024.

Submit applications for this initiative using one of the following funding opportunity announcements (FOAs) or any reissues of these announcement through the expiration date of this notice.

- [PA-20-185](#) NIH Research Project Grant (Parent R01 Clinical Trial Not Allowed)
- [PA-20-183](#) NIH Research Project Grant (Parent R01 Clinical Trial Required)
- [PA-20-200](#) NIH Small Research Grant Program (Parent R03 Clinical Trial Not Allowed)
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All instructions in the [SF424 \(R&R\) Application Guide](#) and the funding opportunity announcement used for submission must be followed, with the following additions:

- For funding consideration, applicants must include NOT-HD-21-025 (without quotation marks) in the Agency Routing Identifier field (box 4B) of the SF424 R&R form. Applications without this information in box 4B will not be considered for this initiative.

Applications nonresponsive to terms of this NOSI will not be considered for the NOSI initiative.

## Inquiries

Please contact the University of South Florida Technology Transfer office representative for submission - Roisin McNally at [rmcnally@usf.edu](mailto:rmcnally@usf.edu).