

Perinatal Disabilities Resources

This document provides resources on specific areas of perinatal disabilities focusing on clinical and patient audiences.

Introduction

In United States (US) and Canada, the adult disability population ranges from 16 – 33% of the population.^{i,ii} Approximately 11% of women in their childbearing years are disabled.^{iii,iv} A disability is defined as a physical or mental impairment that substantially limits one or more major life activities, is not regarded as transitory, and is documented in a medical or legal record.^v

Many women, and those capable of becoming pregnant, who are disabled would like to have children.^{vi} Rates of pregnancy among the disabled are similar to those without disabilities.^{vii,viii} However, they have a heightened risk of pregnancy related complications and have issues accessing health care, support before, during, and after their pregnancies, which adds to these health disparities.^{ix,x} They also experience increased societal and environmental stress which can cause pregnancy risks due to the negative attitudes about pregnancy and parenting they encounter from others, including family, friends, health care providers, the general public, etc.^{xi,xii} Women and birthing people living with disabilities struggle with social and environmental barriers related to maintaining health and well-being when compared with women who are not disabled.^{xiii}

Disabled people continue to experience ableism—such as inaccessibility, stigma, and exclusion.^{xiv} Accessible doctors' offices are hard to find, along with accessible equipment such as scales and adjustable tables.^{xv,xvi} Furthermore, health care providers do not have adequate training in the reproductive care of disabled women and birthing people.^{xvii}

Finally, there is a lack of representation in pregnancy and parenting information, books, magazines, resources and educational materials, popular pregnancy and parenting apps.^{xviii}

A note on disability language: The disability communities use a mix of identity-first disability language and person-first disability language (i.e., person with paraplegia). In keeping with the guidelines of the [American Psychological Association \(APA\) guidelines](#), it is important to acknowledge that different members of the disability community may have different choices about how they wish to be referred to and APA (July 2022) offers a discussion on the subject.

Resources

Below are resources divided by subject matter: inclusivity, staff training, and data collection. These resources can be for clinical and/or patient audiences.

Improve accessibility and inclusivity of existing facilities, informational resources, and health promotion programming:

- [Autistic Women and Nonbinary Network \(AWN\)](#): AWN is a non-profit committed to disability justice, gender and race equity, neurodiversity, and trans liberation. This resource includes welcome packages for adults and parents, in English, Spanish, and plain language, that focuses on understanding what it means to be autistic.

- [Autistic Self Advocacy Network \(ASAN\)](#): ASAN seeks to advance the principles of the disability rights movement with regard to autism. ASAN delves into significant social issues by way of reports and policy briefs created to benefit the Autistic and disability communities. One resource includes:
 - [ACCESS, AUTONOMY AND DIGNITY: A Series on Reproductive Rights and Disability Justice](#): The issue briefs in this series explore four important areas of reproductive health, rights, and justice for people with disabilities: access to abortion, access to [contraception](#), healthy sexuality and sex education, and the right to parent.
 - The [resource page](#) is complete with information about working with and supporting people with autism, those who are neuro-divergent, as well as improving sexual health care for people.
- [Center for Research on Women with Disabilities \(Center\)](#): Located at Baylor College of Medicine, the Center promotes, develops, and disseminates information to improve the health and expand the life choices of women with disabilities. The Center includes a [resource page](#) with links to other websites focusing on different topics for women with disabilities.
- [Community Health Inclusion Index \(CHII\) Onsite Assessment](#)- The CHII assessment collects information about healthy living resources in a community and the degree to which they are inclusive. This assessment can be downloaded and used to inform communities and health care providers about resources available for people living with disabilities.
- [National Research Center for Parents with Disabilities | The Heller School at Brandeis University](#) : The center conducts research and provides training and technical assistance to improve the lives of parents with disabilities and their families. The resource page is for parents with disabilities, legal professionals, social workers, and researchers, and cover a variety of topics, including child-welfare law and its effects on parents with disabilities, firsthand narratives from disabled parents about how they raise their children, and advice for professionals working with specific populations of parents with disabilities.
 - The Brandeis University Heller School for Social Policy and Management also houses the [Lurie Institute for Disability Policy](#). This institute leads research that helps shape policies, programs and practices which improve the lives of people with disabilities across the lifespan.
 - Within the Lurie Institute is the [National Center for Disability and Pregnancy Research](#) which conducts multidisciplinary research about reproduction, pregnancy, and disability, including reproductive health, sex education, prenatal health, childbirth, interactions with obstetricians, and support networks.
- [New England ADA Checklist](#): This checklist lists reasonable accommodations to be made for existing facilities like doctor's offices for individuals with disabilities.
- [Strategies for Successfully Including People with Disabilities in Health Department Programs, Plans, and Services](#): This guide developed by the [National Association of County and City Health Officials](#) (NACCHO) highlights specific strategies and tools to help both local and state health departments include people with disabilities in public health programming and planning efforts.



Staff training on the population of people with disabilities:

- [Association of University Centers on Disabilities \(AUCD\)](#): AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary programs that support the care of people with different types of disabilities. The resource page identifies a number of educational resources for working with and caring for people with disabilities.
- [CMS Office of Minority Health Guide for People with Disabilities](#): The CMS Guide explains how people with disabilities generally can make appointments for themselves and what to expect when going to the doctor. This resource comes in several languages.
 - [Arabic / العربية \(PDF\)](#)
 - [Chinese / 中文 \(PDF\)](#)
 - [Haitian Creole / Kreyòl Ayisyen \(PDF\)](#)
 - [Korean / 한국어 \(PDF\)](#)
 - [Russian / Русский \(PDF\)](#)
 - [Spanish / Español \(PDF\)](#)
 - [Vietnamese / TIẾNG VIỆT \(PDF\)](#)
- [Communicating With and About People with Disabilities | CDC](#): CDC's resource on how to communicate with people with disabilities.
- [Docs with Disabilities Initiative](#): This initiative uses research, education, and sharing of stories to drive change in perceptions, disability policy, and procedures in health professions, biomedical and science education. The aim is to build more inclusive educational environments for trainees with disabilities and increase representation of disabled clinicians and scientists in the biomedical workforce.
- [Health and Disability 101 Training for Health Department Employees](#): This instructional video from NACCHO provides basic knowledge about people with disabilities and the health disparities that they experience. The video can help health care employees understand how to reduce some of the stigma brought on by medical providers and the health care system.
- [Hearing Loss Association of America \(HLAA\) Guide for Effective Communication in Health Care](#): This guide was created for patients, families, caregivers, all members of the health care team, administrators, and support staff. It provides information, resources, and tools to help improve communication in medical settings including hospitals, facilities, and private offices. The guide provides information on how to follow the federal, state, and local laws, regulations, and health care standards. It also provides information for patients on what questions to ask to get the services they need.
- [Little People of America Medical Resource Center](#): This is an in-depth reference guide to around 300 different types of dwarfism, intended not just for the lay person, but for medical professionals as well.
- [National Association of the Deaf \(NAD\)](#): This website includes resources, past webinars, and more for the hearing impaired. In addition, there is [information](#) about ensuring pregnant persons have access to interpreters while giving birth.



- [Psychiatric Rehabilitation Association/Psychiatric Rehabilitation Foundation \(PRA/PHF\)](#): This organization grows and train the recovery workforce while promoting wellness and recovery.
 - The [Knowledge Center](#) provides information and resources to improve the practice of psychiatric rehabilitation, including one resource related to [pregnancy](#).

Information about collecting data about pregnancy among women and birthing people with disabilities in your city or county:

- [CDC's Disability Demographic Questions](#): These six sets of questions are the minimum standard for surveys focusing on disabilities. However, other questions focus on addressing pregnancy- and parenting-related services (e.g., family planning, maternal health, WIC, etc.).
- [CDC PRAMS Disability Questions](#): The Centers for Disease Control and Prevention's (CDC) [Pregnancy Risk Assessment Monitoring Survey \(PRAMS\)](#) has a set of supplemental questions that can be added to regular PRAMS. Supplements are used for a short period of time for data collection on topics of emerging concern.
- [National Disability Rights Network Count Everyone, Include Everyone Report](#): This report highlights the importance of accurate data, the availability of data on the disability community today, the limitations that exist and what needs to be improved in federal data collection moving forward.

Articles and Books

Below is literature on disability and/or reproductive care with articles from the Health Service Research database.

- [Black Disability Politics](#): Author Sami Schalk explores how issues of disability have been and continue to be central to Black activism from the 1970s to the present.
- [Special Section on Chronic Conditions and Women's Reproductive Health | HSR](#)
- [Pregnancy, Childbirth & Paralysis](#): This article from United Spinal Association describes what could possibly be expected during pregnancy and childbirth for a woman who has a spinal cord injury.
- [Obstetric Management of Patients with Spinal Cord Injuries \(SCI\)](#): The American College of Obstetricians & Gynecologists (ACOG) has published Committee Opinion Number 808 (May 2020), which replaces Number 275 from September 2002 (and reaffirmed in 2023). The Opinion provides guidance and expertise on care for pregnant persons with SCI.

ⁱStatistics Canada. (2017). A profile of persons with disabilities among Canadians aged 15 years or older. <http://www.statcan.gc.ca>

ⁱⁱVaradaraj, V., Deal, J., Campanile, J., Reed, N., & Swenor, B. (2019). National prevalence of disability and disability types among adults in the US, 2019. *JAMA Network Open*, 4, Article e2130358. <https://doi.org/10.1001/jamanetworkopen.2021.30358>

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ⁱⁱⁱShandra CL, Hogan DP, Short SE. Planning for motherhood: fertility attitudes, desires and intentions among women with disabilities. *Perspect Sex Reprod Health*. 2014 Dec;46(4):203-10. doi: 10.1363/46e2514. Epub 2014 Sep 10. PMID: 25209449; PMCID: PMC4268070.



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Us Centers for Disease Control and Prevention. Disability and Health Overview. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>. Accessed September 27, 2023.
- ^v Americans with Disabilities Act. 1990. <http://www.ada.gov/pubs/adastatute08.htm#12102/>. Accessed January 17, 2016
- ^{vi} Tarasoff LA, Ravindran S, Malik H, Salaeva D, Brown HK. (2020, Jan). Maternal disability and risk for pregnancy, delivery, and postpartum complications: a systematic review and meta-analysis. *Am J Obstet Gynecol*. 2020 Jan;222(1):27.e1-27.e32. doi: 10.1016/j.ajog.2019.07.015. Epub 2019 Jul 12. PMID: 31306650; PMCID:PMC6937395. <https://pubmed.ncbi.nlm.nih.gov/31306650/>
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