

Contact: [FCHIP@Luriechildrens.org](mailto:FCHIP@Luriechildrens.org) • Website: [luriechildrens.org/FCHIP](https://luriechildrens.org/FCHIP) • Twitter: [@LurieFCHIP](https://twitter.com/LurieFCHIP) • Instagram: [@luriefchip](https://www.instagram.com/luriefchip)

## Disability, Mental Health, Policy, and Motherhood: Mother's Day 2024

In this report, FCHIP highlights images from the Lurie Family Photobook, an ongoing project compiling images of Lurie Children's families in the hospital and in the community.

This May 12<sup>th</sup>, FCHIP celebrates its third annual Mother's Day Report! This report highlights important issues for mothers and families including maternal mental health, disability, and a new focus on policy changes that can impact mothers in 2024. We also highlight innovations in Maternal and Child Health (MCH) initiatives happening across the country.

### MOTHERS WITH DISABILITIES ACROSS THE U.S.

In 2012, the United States National Council on Disability released [\*Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children\*](#). This report brought attention to the discrimination and inequities faced by parents with disabilities. To help reduce disparities, studies have focused on mothers with disabilities and the challenges they face.

Many of these studies use data from the [\*Pregnancy Risk Assessment Monitoring System\*](#) (PRAMS), which has tracked information on women during the time they have a



Our central tenet is "Children Thrive when Families Thrive." Established in 2020, FCHIP is housed at Ann & Robert H. Lurie Children's Hospital of Chicago, in the Stanley Manne Children's Research Institute and the Mary Ann & J. Milburn Smith Child Health Outcomes, Research and Evaluation Center.

Suggested Citation: Candace Jarzombek, Clarissa Simon, and Craig Garfield. 2024. Disability, Mental Health, Policy, and Motherhood. Family and Child Health Innovations Program (FCHIP) Report .

FCHIP is directed by founder [Craig F. Garfield, MD, MAPP](#).

 Ann & Robert H. Lurie  
Children's Hospital of Chicago®

Stanley Manne  
Children's Research Institute™

Smith Child Health Outcomes,  
Research and Evaluation Center

new baby for over three decades. Starting in 2019, PRAMS [added questions](#) that asked participants about if they had a disability. These questions asked people if they had difficulty with:

- Seeing
- Hearing
- Walking or climbing stairs
- Remembering or concentrating
- Self-care (such as washing all over or dressing), and
- Communicating (for example, understanding or being understood).

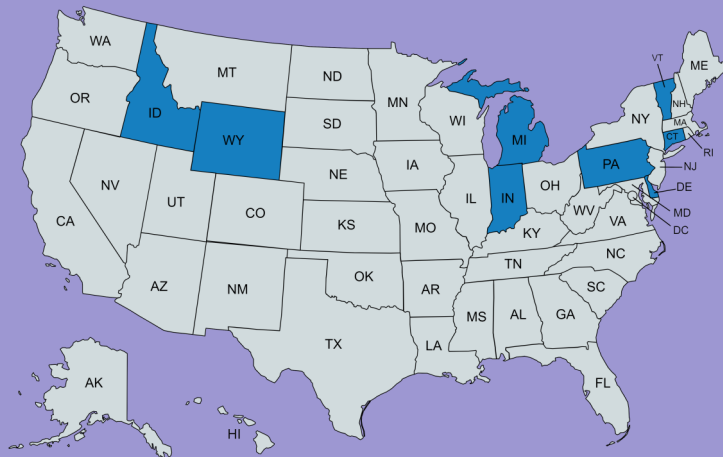


Results from the survey showed that 6 percent of respondents said that they had one or more of these types of disabilities. Although PRAMS started asking questions about disabilities in only 24 states, today all participating states have added these questions to their survey of new parents. This data will help us understand how we can help mothers with disabilities get the resources they need when they are pregnant and have a new baby.

PRAMS data has been used to show that women with disabilities have almost twice the risk of having at least [three or more health risks](#) (e.g. smoking, heavy drinking, high blood pressure, diabetes, obesity) before they became pregnant compared to women without disabilities. Another health risk for women with disabilities is more than twice the rate of [intimate partner violence](#) (i.e. domestic violence) before and during pregnancy. Other risks for women with disabilities include higher risk of [food insecurity](#) during pregnancy and fewer postpartum [social supports](#). For improved outcomes for Americans with disabilities, particularly during pregnancy and postpartum, measures including increased accessibility to health insurance can help; during the height of COVID, women with disabilities saw [increased postpartum contraceptive use and increased rates of health insurance](#), including Medicaid, compared to women without disabilities.

## Protections for the Rights of Parents with Disabilities

As of 2022, only 8 states did not allow for parental disability to be used as grounds for termination of parental rights. These states are shown in blue on the map. All other states have laws that allow for parental rights to be taken away based on a parent's disability status. For more information and to learn more about protections for the rights of disabled parents, visit the [National Research Center for Parents with Disabilities](#).



Adapted from the [National Research Center for Parents with Disabilities](#).

## BREASTFEEDING AMONG PARENTS WITH DISABILITIES

PRAMS data has also been used to examine rates and patterns of breastfeeding among parents with disabilities. Compared to people without disabilities, those with disabilities had [lower breastfeeding rates](#) when their babies were 2 and 3 months old. Disability status meant parents were less likely to receive information about breastfeeding from health care providers like doctors, midwives, and nurses. In sum, healthcare providers can and should make changes to how they talk to patients to better support mothers with disabilities.

Collecting data about parents with disabilities is just the first step to addressing inequities. [Researchers have been working with mothers with disabilities](#) to develop strategies and resources healthcare providers can share with their patients. To support the feeding plans of all parents, especially those with disabilities, providers can:

- Listen to individual concerns and preferences
- Respect patient decisions and autonomy
- Embrace creativity in finding an approach that works for everyone
- Provide multi-mode breastfeeding education, including face-to-face instruction, written resources and videos
- Evaluate easy read resources for clarity and ask for feedback on these resources from individuals who use them
- Support both nursing and pumping choices for mothers
- Ensure that ASL interpreters are available for lactation consultant visits in the hospital

## MENTAL HEALTH AND MOTHERING

Antenatal (before birth) and postpartum (after birth) depression and anxiety are thought to affect [1 in 8](#) American mothers. Poor maternal mental health can exert impacts beyond the mother herself, leading to challenges with caring for a new baby. High levels of

## State Maternal and Child Health Innovations

The [Association of Maternal and Child Health Programs Innovations Database](#) highlights effective programs and policies that support maternal and child health in the United States. The following two practices were recently added to the database.

### *Safer Childbirth Cities—Jackson, Mississippi*

The Safer Childbirth Cities initiative has supported and brought together community-based organizations in 20 cities across the United States. The [Mississippi Public Health Institute](#) leads the [Jackson Safer Childbirth Experience](#) project, which provides community-based doula services with the goal of decreasing unnecessary C-sections and improving birth outcomes among African American women. This project has had many positive impacts for the community, with high rates of women staying in the program and reporting how helpful the program has been.

### *Healthy Mom, Healthy Family*

The [Healthy Mom, Healthy Family project](#) is intended to improve healthcare between pregnancies for mothers across Ohio by providing health screenings for mothers. These screenings ask about depression and anxiety, tobacco use, family planning, and multivitamin use. This program has the potential to help mothers improve their health and reduce risk for pregnancy complications in the future.



Special Note: This *Health Affairs* issue also includes an article on paternal mental health by FCHIP's Dr. Craig Garfield and Tova Walsh, PhD, MSW, MS. Read it [here](#).

stress are linked to unsafe infant sleep practices, while depressed mothers are more likely to report sleeping in the same bed as their baby, both findings indicating that [babies are at risk when mothers are unwell](#) mentally. Attention to maternal mental health has increased as the [number of mothers diagnosed with depression and anxiety has increased](#) substantially since 2008.

Last month, *Health Affairs* released a special issue all about mental health during pregnancy and after having a baby. Articles in the issue highlighted challenges including reduced access to mental health treatment. The issue provided strategies for improving mental health outcomes, like [extending Medicaid coverage](#) for mothers after pregnancy and [using text and telephone](#) to screen new mothers for mental health conditions and refer them to treatment. To support diagnosis and treatment for maternal mental health, the federal government recently provided \$11 million of funding for the [Screening and Treatment for Maternal Mental Health and Substance Use Disorders](#) program.

## National Policy Updates

Congress recently passed two laws to help protect the rights of workers who are pregnant or nursing. These two laws are: Providing Urgent Maternal Protections (PUMP) for Nursing Mothers Act and the Pregnant Workers Fairness Act (PWFA).

The PUMP Act went into effect on December 29, 2022. This law requires employers to give reasonable break time to workers who are breastfeeding so that they can pump. Employers also need to provide a private space to pump that is not in a bathroom. These protections have to be offered until the child's first birthday. The United States Department of Labor provides [several resources](#) to help nursing workers and employers make sure the PUMP Act requirements are met.

The PWFA went into effect on June 27, 2023. This law requires employers to provide reasonable accommodations to workers when they have a limitation that is related to pregnancy, childbirth, or another related medical condition. The [U.S. Equal Employment Opportunity Commission](#) provides resources and guidelines for following the PWFA. They also provide tips for pregnant workers about how to ask for accommodations and what to do if their employer says no to their request.

Both laws provide important protections that prevent discrimination and help pregnant and postpartum workers stay in their jobs during and after their pregnancies.

