

# Healthcare providers have a responsibility to support pregnant autistic people

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## Introduction

In the U.S., there has been very little research on the sexual and reproductive health of autistic people and even less on pregnancy. It also appears that the healthcare system is inadequately prepared to serve the reproductive health needs of autistic patients. We recently learned that less experienced healthcare professionals question whether autistic people have somewhere to go outside of the mainstream system for reproductive health care. They do not.

We must work to improve the care autistic people receive from available systems and providers. Ensuring accessible care, asserting reproductive rights, and increasing knowledge of how best to care for autistic patients are some important steps moving forward.

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## What do we know about pregnancy and barriers to pregnancy care in autistic people?

Barriers to equitable reproductive health start long before autistic people experience pregnancy. Autistic people and students with disabilities are less likely to receive comprehensive sexual and reproductive

health education in school than peers without disabilities. This disparity carries forward into adulthood, where autistic adults may have less access to contraception, have fewer visits to the gynecologist, and less often receive screening for cervical cancer than non-autistic adults.

Historical practices, such as institutionalization, sterilization of women, and custody loss, also contribute to the complexity of this issue and have prevented providers, especially OBGYNs, from better understanding the reproductive health needs of autistic patients.

## Key Points

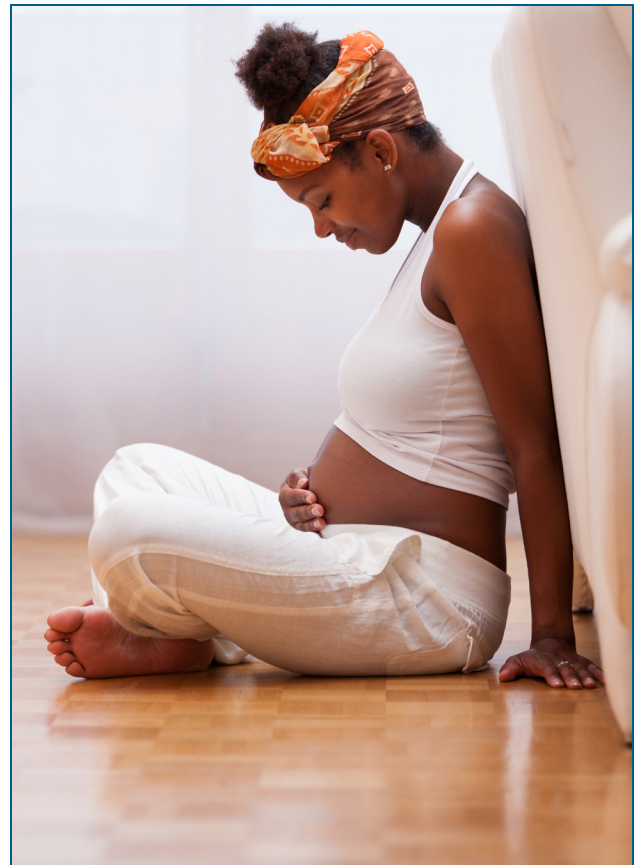
- **Autistic women report that they do not feel fully supported by their healthcare professionals, including OBGYNs.**
- **Many pregnancy-related health conditions are more common in autistic people than in non-autistic people.**
- **Expanded Medicaid coverage allows for the provision of a range of services and supports that autistic people may find helpful during and after pregnancy.**
- **Improving pregnancy care and outcomes for autistic people requires changes in policy, research, and practice.**

Many people in this country face inequities which impact health during pregnancy. One example is the Black maternal health crisis. Black mothers are twice as likely to die or experience complications during pregnancy and delivery than white mothers in the U.S. This is due to many structural barriers (like [redlining](#), Jim Crow laws, and slavery) and [social barriers](#) (access to care, environment, income) faced by minoritized people. People with disabilities often face the same kinds of barriers to health.

Access to reproductive health and planning information, sexual education, and pregnancy-related education is [notably lower among autistic people](#) compared to non-autistic people. Autistic people are [less likely to report](#) receiving explanations about the process of birth.

Many factors may contribute to these differences in knowledge and awareness, including misconceptions about sexuality and infantilization. A common misconception about people with disabilities is that they are not sexually active or have no sexual desire. Infantilization is the treatment of adults with disabilities as if they were dependent children in need of protection.

All of these factors impact the care autistic people receive once they become pregnant. People with intellectual and developmental disabilities (IDD) are less likely to receive timely prenatal health care and are more likely to report inadequate prenatal care [compared to people without IDD](#). Timely prenatal care allows for early screening and monitoring of health conditions and for the delivery of health education. Delays in accessing prenatal care may be associated with [adverse maternal health and pregnancy outcomes](#).



Autistic women report that they do not feel fully supported by their healthcare professionals, including OBGYNs. They feel that healthcare professionals did not communicate clearly during childbirth, and that these professionals did not have sufficient levels of knowledge about autism to [provide quality care and make appropriate adjustments](#). These challenging patient-professional relationships can cause autistic patients to feel unprepared and unheard by their doctors, and to feel a lack of control over their own pregnancy and birthing experiences.

This lack of awareness and experience places additional pressure on the individual to educate the provider about their disability and related needs.

Many pregnancy-related health conditions are more common in autistic people than in non-autistic people, including pre-eclampsia and gestational diabetes. Deliveries are also often riskier in autistic people, including higher rates of pre-term birth, low birth weight babies, and cesarean section. Autistic people may be [twice as likely to die or experience complications during pregnancy and childbirth](#) compared to non-autistic people. Other conditions may be more common but are not well researched, including hyperemesis gravidarum (severe nausea and vomiting during pregnancy) and hypermobility (high levels of flexibility, or ability to move some or all of your joints more than other people can). These should be further explored. Improving pregnancy care and outcomes for autistic people likely involves

improvements across many areas, including policy, research, and practice.

## Improving reproductive health through policy

1 in every 6 people in the U.S. has a disability. Creating and championing policies that improve reproductive health and pregnancy care in all people, and particularly those with autism and/or other disabilities, is a key step to improving population health. Unfortunately, our team recently wrote a blog about policy moving in the opposite direction: the Dobbs decision had [significant impact on the reproductive rights of those who are routinely](#)

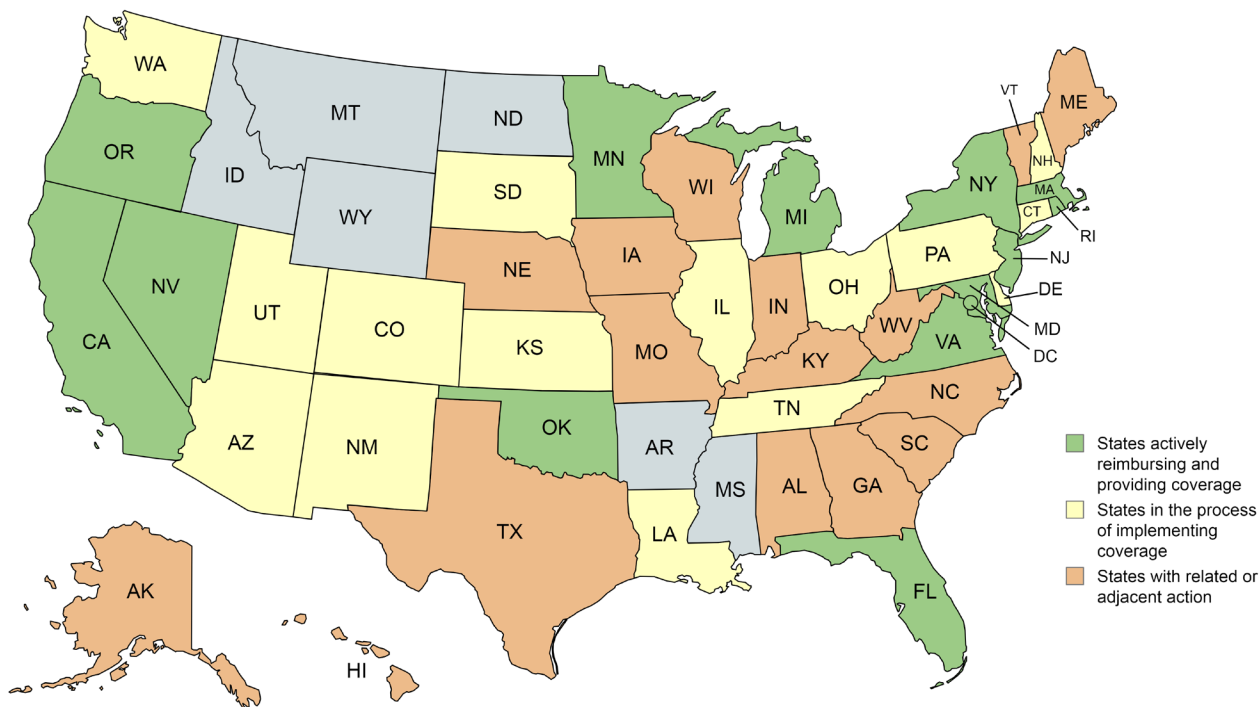


Figure 1: Map of Medicaid Coverage for Doula Services (as of April 2024)

Data for this map were pulled from the [National Health Law Program's Doula Medicaid Project](#). Map created with mapchart.net.

[marginalized](#), including people with disabilities. However, there have been some positive federal policy updates recently.

States now have an option to extend Medicaid postpartum coverage to twelve months after delivery under the American Rescue Plan Act of 2021. Medicaid already covers about half of all births in the U.S. and is an important source of insurance for many people. Public health insurance like Medicaid is vital, because interruptions in employer-based insurance are particularly impactful during pregnancy and the postpartum period.

This extension of coverage, [now implemented in 47 states](#) closes gaps in care and eliminates the financial burden of finding alternative insurance. It allows for the provision of a range of services and supports that autistic people may find helpful in the postpartum period. These may include lactation consultation, breastfeeding supplies, and increased screening opportunities and referrals to mental health professionals, which can support early identification and treatment of mental health conditions that may contribute to postpartum depression and anxiety.

[43 states have taken steps to cover doula services](#) through their Medicaid programs (see Figure 1). [13 states, plus Washington D.C., are actively reimbursing for doula services](#), and several others are proposing some action to support reimbursement (see Figure 1). Doulas are non-medical professionals who provide personalized physical, emotional, and informational support throughout the perinatal period and help advocate for people based on their preferences. By advocating for individuals directly, doulas can ensure patient needs are met and respected, and that the principles of person-centered care are upheld.



We know that doula care can reduce Medicaid costs and [improve birthing experiences and outcomes](#) for people of color, those with low incomes, and people living in underserved communities. The provision of doula services has also been [associated with reduced risk](#) of postpartum anxiety and depression. For autistic people, doulas can address sensory sensitivities and communication needs [that are often present](#) before, during, and after childbirth, and [create a calm and structured environment](#).

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## Improving Reproductive Health through Research

When autistic people are asked about problems they experienced during pregnancy and delivery, they identify a lack of communication, sensory-unfriendly environments, and mental health

concerns. Sometimes these problems are specific to autistic people, like increased rates of certain health conditions and sensory considerations. Sometimes they are just about improving care for everyone, such as improving accessibility to medical information and medical spaces and understanding the importance of reproductive rights. Listening to autistic voices to guide this new research area is key to creating research that addresses prevailing needs and concerns.



## Improving Reproductive Health in Practice

There are clearly gaps in professional training and knowledge on serving autistic patients. There are also gaps in the ability of autistic patients to access health care professionals and the information they need to have an informed pregnancy. These unmet needs contribute to the poor experiences and outcomes of autistic people during pregnancy.

There are clear needs for improvement in medical education, communication, and understanding about the needs of autistic patients within reproductive health practice.

## Improving Supports After Childbirth

While the topic of this brief is pregnancy, we would like to acknowledge that people with disabilities who have children often fear custody loss and issues of parental rights.

Autism has been used as a basis for custody loss, and [parents with IDD](#) are much more likely to have a newborn discharged into state custody than people without IDD. Autistic people should be supported in their desire to be parents, formally (via services and supports) and informally (socially and culturally).

## What's Next?

We are just embarking on this important journey to learn more about pregnancy and autism. As we discover more specific findings about health care utilization and pregnancy experiences among autistic people, we will use those to inform policy solutions. We hope you will stay tuned and in touch! Let us know your experiences and perspectives to guide our research.

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