



Women with Intellectual and Developmental Disabilities Are At Higher Risk of Dying and Developing Serious Health Problems During and After Pregnancy, U.S. Research Finds

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The reasons probably lie in certain pre-existing health conditions as well as in social and economic circumstances known to be associated with negative health outcomes, researchers conclude.

Introduction and Background

Women can experience serious negative health outcomes as a result of being pregnant and giving birth, and may sometimes even die. One negative outcome, called *severe maternal morbidity* or SMM, is a serious medical problem like a heart condition or infection that can occur during labor and delivery or after the baby is born. The other negative outcome, called *maternal mortality*, refers to the death of a person during pregnancy, labor, or after the baby is born.

SMM is an outcome that people study in order to improve the safety and well-being of women during pregnancy and after delivery of a baby. In the United States, the risk of SMM is often higher for women from certain ethnic and racial groups, such as Black women. Researchers would like to know why the risk of SMM is increasing in the US and to explain why some people have worse pregnancy outcomes than other people.

In this study, researchers looked at medical records to find out how many women who have intellectual and developmental disabilities (IDD) died

during pregnancy, during delivery of their baby, or after the baby's birth. They also looked at how many experienced SMM. The occurrence of these outcomes among women with IDD has not been well studied. The researchers compared the rate of dying and of SMM for mothers with IDD to the rates for mothers who didn't have IDD. From that, they calculated the risk of both maternal death and SMM that women with IDD have compared to the risk that women who don't have IDD have.

What They Did

The researchers looked at women who had babies in the U.S. between 2004 and 2017. They found the information about babies that were delivered in hospitals in a national database. They compared records of pregnancy outcomes among women who had IDD to records of pregnancy outcomes among women who didn't have IDD.

Researchers also found information in the database records about the mother's overall health at the time of delivery and the mother's access to healthcare.

What They Learned

The researchers learned that women with IDD were much more likely to die when they were delivering their baby than women who did not have IDD. In the study, even after taking into account other factors that might increase negative birth outcomes, **women with IDD were over two times more likely to die during or after childbirth** than women who didn't have IDD.



Women with IDD were over
2X AS LIKELY
 to die during or as a result of childbirth
 than women without IDD

Pregnant women with IDD who gave birth were also much more likely to experience SMM than women who did not have IDD. After the researchers took into account other factors that might increase the risk of SMM, **women with IDD had roughly between twenty and thirty percent higher risk of SMM** than women who didn't have IDD. This means that women with IDD were at a much higher risk of SMM than other women when they are pregnant or deliver their baby.



Women with IDD were
23%–31% MORE
 at risk of SMM than women without IDD

The researchers believe that it is likely the higher risk of maternal death and SMM in women with IDD is partly a result of higher rates of pre-existing health conditions, but that there are also other reasons for these higher rates.

It's also likely that women with IDD may have higher rates of challenging social and economic circumstances and these could increase their risk of SMM and maternal death. The database the researchers used did not record all of this information, so the researchers could not measure this possible explanation directly.

However, the researchers believe that the risk of SMM and death during childbirth for women with IDD was most likely significantly increased by these other things that are known to lead to negative pregnancy outcomes.

These other things include:



- lack of good healthcare for women with IDD during pregnancy;



- problems finding good healthcare due to stereotypes about people with IDD that many medical staff, including doctors, sometimes believe;



- medical staff who don't communicate in ways that are accessible to women with IDD when they speak or give written information or instructions;



- delays in diagnosing conditions in women with IDD and in getting them the medical care they need;



- a lack of pregnancy-related health information or knowledge among women with IDD.

Take-Aways

The researchers' study gives us more information about the experiences with healthcare that women with IDD have during pregnancy and after they have their baby. The study also helps to understand the differences in those experiences compared to women who don't have IDD.

The researchers think that women with IDD are more likely to have negative healthcare experiences that can lead to negative pregnancy outcomes and might even contribute to the mother getting very ill or dying during delivery or after the baby is born. These experiences could even put the mother's baby at risk of getting sick or dying.

What Needs to Change?

1. The researchers concluded that people who work in medicine and healthcare should be better trained so that they know how to provide good healthcare to women with IDD from pregnancy to delivery and the period of time after the birth of the baby.
2. Doctors and other healthcare workers should know how to recognize and treat the health conditions that women with IDD may have that could lead to worse outcomes during pregnancy for the mother or the child.
3. Doctors and other healthcare workers should learn better ways of communicating with pregnant patients with IDD.



4. Doctors and other healthcare workers should have a positive attitude toward people with IDD, and toward women with IDD who are pregnant or may become pregnant.
5. Doctors and other healthcare workers should provide better information about healthcare to patients with IDD and make sure that the information is accessible to people with IDD.



Credit

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