

Article: Quality of life, satisfaction with care, and the experiences of adults with intellectual and developmental disabilities before and during COVID-19

Authors: Hickey, E. J., Caudill, A., Laufenberg, H., Hrabik, L., DaWalt, L., Ausderau, K. K.

Key Points:

- People with IDD should be part of making decisions about their lives.
- Health information, especially about things like vaccines, should be accessible and easy for adults with IDD to understand
- There is a difference between how care partners report quality of life for adults with IDD than how adults with IDD report quality of life themselves
- Quality of life for adults with IDD is connected to how sure they feel that the COVID-19 vaccination is safe

Glossary:

COVID-19: A sickness that started in 2019 which can feel like a cold or the flu. It got many people very sick and caused people to stay away from other people for a while.

COVID-19 Vaccination/Vaccine: A shot to protect people from getting sick with COVID-19.

Barrier: Things that make it hard to do something.

Why this article matters:

COVID-19 had a big impact on people with IDD and their access to healthcare, support services, and daily activities. This article talks about what people with IDD went through before and during COVID-19 in order to help support them in the future.

Description of the Study:

Surveys were sent out across Wisconsin to adults with IDD asking about their support services, choices, independence, and quality of life in 2017 and in 2021. The survey could be done by an adult with IDD or by someone else who could fill it out for them. In 2017, there were more adults with IDD who filled out the survey for themselves and there were more females who filled out the survey than in 2021. The survey in 2021 included extra questions about COVID-19. The extra questions asked about how people felt about vaccinations and their experiences during COVID-19. The researchers then found connections between how people answered the questions and compared the differences between the two years.

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Research Questions:

- What was it like for adults with IDD during COVID-19 and how did they get the COVID-19 vaccination?
- Is there a link between people with IDD's quality of life and how happy they are with the amount of healthcare and daily help they could get before and during COVID-19?
- Does quality of life and how happy people are with the amount and quality of their services connect to their feelings about getting the COVID-19 vaccine, facing problems getting it, and what they think about the shot?

Important Results:

- It is important for people with IDD to easily access trustworthy information about COVID-19, especially how to get vaccinations.
- Many adults with IDD learned about the COVID-19 vaccine from their parents, guardians or support staff. They usually did not decide for themselves whether they got the shot or not.
- The quality of life for adults with IDD might be connected to how safe they felt to get the COVID-19 vaccine.
- Between 2017 and 2021, there was not a meaningful difference in the overall quality of life, but care partners often reported higher quality of life and adults with IDD themselves. Younger people with IDD generally reported higher quality of life.
- There were not any differences in reported happiness with the quality of help received between 2017 and 2021.

How the results will be used:

- This study will inform ways to help and support people with IDD during big health problems in the future.
- Researchers can use this article to understand barriers to adults with IDD getting information about COVID-19 and getting COVID-19 vaccinations and work to remove the barriers.

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