

Reporting Care Experiences of People with Significant Physical Disability or Serious Mental Illness to Primary Care Clinics

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What was the research about?

Knowing how people view the quality of their care may help doctors improve the care they provide. In this study, the research team wanted to improve care for people with significant physical disability or serious mental illness.

People with disability worked with the research team to create two approaches to convey information about people's perceptions of the quality of their care to doctors:

- **YESHealth.** YESHealth is a program led by disability advocates where those advocates identified concerns people with disability have about their healthcare quality. As part of YESHealth, disability advocates created surveys on different quality concerns. People with disability filled out the surveys every three months. The advocates prepared reports with survey results and recommendations for doctors. The advocates then contacted doctors to try to set up in-person meetings to discuss the results.
- **The Persons with Disabilities Quality Survey, or PDQ-S.** PDQ-S included questions about daily life, independent living, and experiences with primary care doctors. People with disability filled out the PDQ-S. The research team sent the results of the PDQ-S by mail to doctors.

The research team wanted to learn whether either approach would improve experiences of care.

What were the results?

Neither approach improved people's experiences of care.

But YESHealth didn't happen as planned. When the advocates reached out to doctors directly, the doctors didn't agree to meet in person.

Who was in the study?

The study included 27 doctors' offices in Massachusetts. Each office had at least 50 patients enrolled in One Care. One Care is a health insurance program for people with disability ages 21–64 who qualify for both Medicare and Medicaid.

What did the research team do?

The research team assigned doctors' offices to one of three groups by chance. Each group included nine offices. The team sent one of the following to individual doctors at each office:

- YESHealth reports once every three months during the year the study took place and the PDQ-S report at the beginning of the year the study took place. The disability advocates also tried contacting doctors to talk about the results.
- The PDQ-S report only, and only at the beginning of the year
- No reports

The team then compared the results of the PDQ-S survey before YESHealth with results from a second PDQ-S survey after YESHealth ended. The team looked for differences in patients' experiences of care across the three groups.

What were the limits of the study?

Doctors didn't agree to meet with disability advocates. Results of this study might have been different if the advocates and doctors talked about the reports together.

Future research could look at the reasons the disability advocates had trouble getting doctors to be willing to discuss experiences of care directly with them.

How can people use the results?

The approaches in this study didn't improve care for people with significant physical disability or serious mental illness. But the PDQ-S developed for this study may be helpful in other research.

To learn more about this project, visit pcori.org/lezzoni072.