

Does a Web-Based Platform for Caregivers Help People with Down Syndrome Get Recommended Health Services?

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What was the research about?

Down syndrome is a genetic condition that affects cognitive ability and physical features. People with Down syndrome often have other health problems. Clinics that specialize in Down syndrome help people get recommended care for these problems, such as eye exams or sleep studies. But not all people with Down syndrome have access to these clinics.

In this study, the research team tested a web-based platform for caregivers to help people with Down syndrome get personal wellness recommendations. The team looked at the use of five services: eye and hearing exams, screenings for sleep apnea and celiac disease, and a thyroid function test. The platform, called Down Syndrome Clinic to You, or DSC2U,

- Collects health history and current symptoms
- Creates personalized checklists for caregivers
- Creates reports of recommended services based on medical guidelines that caregivers can share with their primary care providers, or PCPs

The research team compared caregivers who were offered DSC2U with caregivers who got usual care.

What were the results?

After seven months, compared with usual care, caregivers who were offered DSC2U reported a 1.6-times increase in the number of indicated services completed or recommended. Quality of life for

caregivers of people with Down Syndrome didn't differ between caregivers who were offered DSC2U and those who got usual care.

Caregivers and PCPs reported high satisfaction with DSC2U.

Who was in the study?

The study included 230 caregivers with a child or adult dependent with Down syndrome. Of the caregivers, 91 percent were white, 5 percent were black, 2 percent were more than one race, and 1 percent were Asian; 11 percent were Hispanic or Latino. The average age was 47, and 96 percent were women. Among people with Down syndrome, the average age was 12, and 54 percent were boys. Families lived in areas not served by a Down syndrome clinic.

What did the research team do?

The research team assigned caregivers by chance to use DSC2U or not.

Caregivers completed surveys at the start of the study and two and seven months after a well visit with the local PCP. The survey asked about whether the person with Down syndrome got the indicated recommendations or services. It also asked about quality of life and satisfaction with DSC2U. Two weeks after the well visit, PCPs reported on their satisfaction with DSC2U.

Caregivers, PCPs, and others with expertise in Down syndrome helped plan the study and design DSC2U.

What were the limits of the study?

Most caregivers in the study were white and had college degrees. Findings may differ for caregivers from other backgrounds.

Future research could test DSC2U with people from other backgrounds.

How can people use the results?

Caregivers and PCPs can use the platform to improve health screenings for people with Down syndrome.

To learn more about this project, visit www.pcori.org/Skotko332.