

Improving Quality of Life for Young Adults with Sickle Cell Disease as They Transition to Adult Care

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The transition to adult care is a critical and vulnerable period for youth with sickle cell disease, as even small breakdowns in care coordination can have long-term impacts on their health and quality of life. Support during this transition from community health workers (CHWs) and mobile health interventions are among the promising interventions for young adults with special health care needs as they make the transition to adult care.

In this Research at a Glance report, PolicyLab researchers summarize findings from a randomized controlled trial evaluating two support interventions and enhanced usual care impacted the health-related quality of life of young adults with sickle cell disease.

The study found that both the community health worker support and the mobile health intervention modestly improved health-related quality of life after six months. In particular, young adults receiving support from CHWs during this transition had sustained improvements in their health-related quality of life for 18 months after the intervention. Additionally, young adults were highly engaged with CHWs, with frequent and consistent engagement over the course of the study.

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