Preparing for Transition of Aging Youth with Complex Medical Conditions and Intellectual Disability

Statement of Problem

With advances in pediatric care, youth with complex medical conditions and/or intellectual disability are increasingly transitioning to adulthood. Families with such youth face increasing challenges of navigating a transition to adult health care and also preparing for long-term care needs as caregivers age. This portfolio examines the challenges around care delivery as youth with complex medical conditions and intellectual disability transition to adulthood.

Description

Through a variety of health services research projects and deeper qualitative interviewing, this team has examined questions ranging from the variability in care delivery between adult and pediatric health systems, as well as the challenges that families face once youth reach adulthood. Illustrating the differences in care delivery between pediatric and adult health systems has required substantial population analysis using health claims datasets across adult and pediatric payers. The team has combined these studies with deeper qualitative interviewing of families to better understand the contextual decisions that they grapple with while preparing for uncertain futures with their aging youth.

Next Steps

The magnitude of variation between adult and pediatric care for youth with disabilities illustrates the need to standardize approaches for care delivery and ensure that all youth can grow into healthy, productive adults. The team intends to disseminate these findings across pediatric and adult health systems in an effort to improve the quality of care for transitioning youth. The emphasis on challenges faced by families caring for youth in community settings will permit strategic work with regional and state leadership to better support families retaining youth at home.

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Suggested Citation

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May 2019

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Aug 2021

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Transitioning From “Sick Kid” to Community Health Worker: Building Better Bridges to Adult Care
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Jun 2018

Transitioning to Adult Care: Supporting Youth With Special Health Care Needs
Evidence to Action Briefs
May 2017

Transitioning to Adulthood: Unique Health Care Challenges for Youth with Intellectual/Developmental Disabilities
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